Social Influences of Help-Seeking Behaviour Among Patients With Type 2 Diabetes Mellitus in Malaysia

Lee Lan Low, MA¹,², Seng Fah Tong, MBBS, PhD³, and Wah Yun Low, PhD¹

Abstract
This qualitative study aimed to explore the influence of social networks such as family members, friends, peers, and health care providers toward the help-seeking behaviour (HSB) of patients with type 2 diabetes mellitus in the public and private primary care settings. In-depth interviews of 12 patients, 9 family members, and 5 health care providers, as well as 3 focus groups among 13 health care providers were conducted. All interviews were audio-taped and transcribed verbatim for qualitative analysis. Social influences play a significant role in the help-seeking process; once diagnosed, patients source information from people around them to make decisions. This significant influence depends on the relationship between patients and social networks or the level of trust, support, and comforting feeling. Thus, the impacts on patients’ help-seeking behavior are varied. However, the help-seeking process is not solely an individual’s concern but a dynamic process interacting with the social networks within the health care system.

Keywords
type 2 diabetes mellitus, family members, peers, health care providers, social media, primary care setting, qualitative study, Malaysia

Introduction
In the absence of cure, type 2 diabetes mellitus (T2DM) is a chronic disease that requires good glycemic control with medication and lifelong lifestyle adjustments.¹ The ultimate goal of diabetes management is to maximise comfort, reduce symptoms, and thereby avoid complications while preserving quality of life. Diabetes does not only affect patients, it also affects their family and care givers.² Help-seeking of patients is an essential part of the lives of the patients and their family members. Thus, the sociocultural background and patients’ experiences and personal

¹University of Malaya, Kuala Lumpur, Malaysia
²Institute for Health Systems Research, Ministry of Health Malaysia, Kuala Lumpur, Malaysia
³Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia

Corresponding Author:
Lee Lan Low, Institute for Health Systems Research, Ministry of Health Malaysia, 55-1 Setia Avenue, No. 2 Jalan Setia Prima S U13/S, Seksyen U13 Setia Alam, 40170 Shah Alam, Selangor, Malaysia.
Email: lowleelan@yahoo.com
beliefs have a huge impact on diabetes management. Successful management of diabetes requires teamwork involving patients, family members, and health care providers (HCPs).

The behaviour of those who are close to patients will affect the way patients take care of their illness or determine their choice of treatment modalities. The influence of society toward managing a person’s illness is thus understandable. The social network including family members, friends, peers, HCPs, and Internet or social media that patients have social interaction which are part of social influences. The social influences are also the sources of information related to diabetes care, which are part of the patient’s help-seeking process.

Help-seeking behaviour (HSB) is a dynamic and iterative process involving the concept of experimentation with different treatment modalities in order to achieve better quality of life and reduced diabetes symptoms. Understanding this dynamic process will help in planning effective support services for diabetes patients. Many studies have examined the effects of family and social supports on diabetes management, such as self-care, physical activity, adherence to medical regimes, and glycemic control. Previous studies have explored the perspectives or experiences of family members living with diabetic patients as well as patients’ perspective of getting support from HCPs. However, to date, few studies have explored the influence of social network and the impact it has on patients’ decision regarding their help-seeking in Malaysia. Using a qualitative thematic approach, this article aims to describe the social influences on patient’s decision-making in choosing the type of treatment.

**Methods**

**Participant Recruitment**

Twelve Malaysians aged 30 years and older diagnosed with T2DM for more than 2 years were recruited: 7 (3 men, 4 women) were from public primary care clinics and 5 (2 men, 3 women) were from private clinics. Additionally, 9 family members and 18 HCPs were also included. Purposive sampling was used, which included a variation of sociodemography, clinic settings, and duration of illness experience. The study centres were 2 public primary care centres and 5 private general practitioners’ clinics in the urban and rural areas of the state of Selangor, Malaysia.

**Data Collection and Analysis**

In-depth interviews (IDIs) among 12 patients, 9 family members, and 5 HCPs and 3 focus group discussions (FGD) among 13 HCPs from public primary care were conducted from September 2012 to May 2013. Interview and FGD guides were used to facilitate the gathering of information. Questions were focused on “management of diabetes,” “experience with seeking diabetic treatment,” and “support of family members and friends.” Two primary questions were asked for family members: “experiences of living with a diabetic patient” and “their roles in the patient’s diabetic management,” whereas for HCPs, their experiences and perceptions on patients’ behaviour and attitude toward diabetic management were discussed and further explored. The data collection was stopped after saturation was reached during the analysis whereby no new categories were found.

All IDIs and FGDs were audio-recorded and transcribed verbatim with all personal identities removed. Interviews and FGDs were conducted in participants’ choice of language: Malay, Chinese, or English. All transcripts were coded using NVivo 10, a qualitative data management software to aid analysis. Data analysis and data collection were done concurrently after the first interview session. Data were coded thematically and constant comparisons were used to identify common themes. Verbatim quotations in the Malay and Chinese languages were translated to English by bilingual medical student graduates. The codes and constructed categories were reviewed and
discussed among 3 peer researchers throughout the period of analysis. All participants were invited to attend feedback sessions of our preliminary findings. Five participants attended the sessions and their feedback helped confirm our analysis.

**Ethical Consideration**

The Institutional Review Board at the Institute for Health Systems Research, Ministry of Health Malaysia, and the Medical Research and Ethical Committee, Ministry of Health Malaysia (NMRR-12-457-12193), approved the study. Written informed consent was obtained from each participant before the IDIs and FGDs.

**Results**

A total of 39 participants consisting of patients with T2DM, their family members, and HCPs who had been treating the patients were interviewed. Details of the participants’ characteristics are shown in Table 1.

Social influences played a significant role in determining patients’ HSB. They provided the main source of information that supported patients’ decision-making in choosing the type of treatment on diagnosis. Some patients took passive roles, as part of expressing their sick roles, and depended on input from their family members, friends, peers, HCPs, and mass media for information. Some took active roles in sourcing for information. However, besides being the sources of information, the impact of these social influences on their decision-making varied depending on their relationships with them.

**Sources of Social Influences on Diabetes Treatment**

**Family Members.** Partners, parents, children, and siblings or even the relatives actively influenced and provide information related to diabetes. The male patients shared how the wife supported them in terms of food or preparing traditional medicines. However, the family members’ influences on treatment varied depending on who had greater power on patients’ decision-making. An
excerpt below shows how a patient’s decision-making was influenced by family members.

Normally, my wife is the one who goes to ask [seek information]. She is the one who plans for me. (Male, 52 years old, diagnosed with T2DM 4 years ago)

**Friends and Peers.** Besides family members, friends and peers also played an important role in influencing the patient’s decision-making process. Since peers had gone through the same experiences and experimented different types of treatments, the patients looked up to them for advice. Friends and peers may recommend alternative treatments and may even bring them to consult alternative treatment practitioners. Patients also spoke about sharing and exchanging information among peers.

Usually I get the information from others, sometimes when we happen to meet at the gathering of a function or feast. Yesterday I heard from my friend, she also has diabetes. She drinks bitter gourd tea, says it is good, I want to try. (Female, 55 years old, diagnosed with T2DM 3 years ago)

HCPs were also aware of peer influence on patients’ choice of treatment, as shared below by one HCP.

They see others doing okay [trying alternative treatment] . . . friend approaches them and tells them: “I took this [medicine or alternative treatment] and my sugar level went down!” So, they also want to try. (HCP, Female, public primary care clinic)

**Health Care Providers.** The HCPs such as primary care physicians, nurses, and others were also important sources of information. Patients usually filtered the health information received from the different sources, including those from the HCPs and chose to follow the best ones. These depended on their trust on their HCPs. Trust was difficult to establish with unconcerned HCPs. The excerpts below show how patients or their family members have faith in their doctor’s treatment and advice.

My wife was worried. She said you need to continue to seek care from that [this] clinic. My wife told me, “You should not try other treatments or try to seek care from other place, since you have been seeking treatment from the clinic, so better stick to this clinic . . . the doctor gave you advice, so you need to just take the medicine.” (Male, 52 years old, diagnosed with T2DM 4 years ago)

Doctor reminds us [is important] . . . there are doctors who just keep quiet, and straightaway write down diabetes is severe and need to increase the dosage. Never explain anything. That’s not good. (Patient’s wife, 43 years old)

It can be confusing when patients need to decide between oral medication and insulin therapy for their diabetes management, particularly when the information received from family members or friends varied or contradicted. In this case the professional advice from their HCPs was sought.

When doctor suggested starting insulin, I went to ask my friend and siblings. Some said oral medication had side-effects, which is not good. Insulin is good and better. After that, I was so scared for a week. I always came here, to ask nurse. She advised me not to be scared, insulin is better, should chose for insulin treatment. (Female, 52 years old, diagnosed with T2DM 3 years old)

**Books and Electronic Materials.** Patients mentioned that they gained knowledge and information related to diabetes care from books, pamphlets, and electronic materials, including sources from the Internet and social media. The source of media could be a recommendation from other sources or just surfing websites.
The nurse gave me a book . . . said to me, “This one is good for you to read.” (Female, 55 years old, diagnosed with T2DM 8 years old)

The increasing availability of health information on the Internet and the ease of sharing information in social media have made the Internet and social media important resources for patients to refer to when making decisions on the management of their illnesses. One participant shared that he preferred to access information related to diabetes from some reliable websites.

Thanks to the Internet, I keep on reading about diabetes in the Internet. The American Association of Diabetic, you know, they have a good website. (Male, 53 years old, diagnosed with T2DM 13 years ago)

**The Strength of Influence and Impact on Decision-Making Process**

Although patients received advice and recommendations from various sources, the strength of influence on the patients’ decisions and choices of treatment depended on several factors such as the closeness of the relationship with the source of influence, the level of trust, and perception of whether they were being cared for. Patients are more open to suggestions and accept advice from those with whom they have good relationships.

**The Strength of Relationship.** Not all advice and suggestions could influence patients’ choices of diabetic treatment. Patients tended to accept the information given by those who were close to them. Thus, a closer or stronger relationship would have a greater impact and influence on patients’ decision-making in treatment options. Besides spouses, other family members such as sons, daughters, or siblings could have the same effect. The advice from a person with whom the patient has a close relationship can motivate patients to stay positive.

My wife was sad. She told me it was better I went [to seek treatment]. She said, “Don’t be stingy on money. This is a life. Money can be earned.” So my wife asked me to go to hospital. (Male, 52 years old, diagnosed with T2DM 4 years ago)

Similarly, the provider–patient relationship can have an impact on a patient’s choice of treatment and adherence to treatment regimes. Good communication between HCP and patient is important in developing a good relationship. Consequently, the patient would feel satisfied with the service and treatment received. The excerpt below illustrates that a patient sought medical care from a private clinic because she was unsatisfied with the services from the public primary care clinic.

I told them [public HCPs], but it seems that what I had said had fallen on deaf ears. That’s the reason why, sometime I would rather go to the private. (Female, 61 years old, diagnosed with T2DM 10 years ago).

**Level of Trust.** The level of trust between patients and their social network also played a role in the patient accepting suggestions given to them. Trust in human relationships gives the sense of confidence that could drive patients to believe, accept, and follow-up on the advice and suggestion given to them.17 This is especially so if the recommendation came from a peer who had a similar experience.

Sometimes it’s those people suffering from diabetes who tell us: “I eat this, I buy this, I buy that.” So, we also give them a try. (Female, 55 years old, diagnosed with T2DM 3 years ago)
Friendship tends to generate trust and belief; thus, the influence is very strong when patients have faith in their peers’ recommendation. The level of trust could undermine the cost of treatment.

You know the influence from their peers, is what matters. The peer will say my diabetes was cured by this fellow, so they go. You know nobody says the diabetes is cured here [clinic] because you tell them [patients] cannot be cured. Having to pay one Ringgit Malaysia is a problem, but you can see the amount of supplements they are taking, is not cheap. (HCP, Female, public primary care clinic)

Conversely, if a person had no confidence with the health information or service given by the HCPs, they would not accept the advice given by the HCPs. For example, one of the patients shared his experience of receiving a wrong prescription from a clinic. After that incident, he no longer trusted the doctor and would always have his wife to double check the medication.

I do not trust the doctor. I really do not trust the doctor . . . now my doctor is her [patient’s wife] . . . I have to depend on her. (Male, 52 years old, diagnosed with T2DM 21 years ago)

Perception of Being Cared For. Patients with T2DM often experience high level of emotional distress because of fluctuating blood sugar. Thus, receiving support from a caring person would result in a positive feeling, which would lead to a sense of security and would further motivate patients to readily accept advice on treatment options.

As for me, I’m not depressed since I got an early warning, like my mother told me that usually it is hereditary, therefore I’m kind of getting ready, I think I’ve got a lot of support. Also support among friends. (Male, 53 years old, diagnosed with T2DM 13 years ago)

The strong support produced an emotional encouragement, such that patients could rely on family members for decision-making. One family member described how the great support developed between spouses led them to help each other in the management of diabetes.

Teamwork, because we both have [diabetes], and of course I am also concerned for my wife so I will always tell her don’t take that, don’t take this, but once in a while I will give in. I don’t want what happened to me to happen to her. She also mixes with traditional medicine. I told her from my experience, I told that don’t stop taking the clinic medicine. I want her to have the best. (Patient’s husband, 53 years old)

Discussion

This study revealed that social networks had significant impact on how patients choose their diabetes treatment. They were the source of information and had a great influence on patients’ HSB. Treatment characteristics were key information which patients sought from people surrounding them. However, not all information and recommendations provided by the individual’s social networks could influence the choice. The impact varied, depending on its relationship, the level of trust, and perception on how they were cared for.

Previous studies showed that social support and relationships could benefit health, especially for patients with chronic illnesses. Thus, this was consistent with previous studies related to influence from family members, friends and peers, HCPs, and the Internet and social media toward patients’ management of diabetes.

The effect of good provider–patient communication on patients’ HSB was established. Patients were easily convinced by information gathered from the person who had a good relationship with them and with whom they felt comfortable. This study affirms the observation in the past. Thus, good HCP–patient relationship in diabetes care should be emphasised.
Beside relationship, trust and feeling confident with the source of information were other factors that influences patients’ help-seeking. In our study, patients felt confident with suggestions from those who had had the same experience of dealing with diabetes problems, from professionals as well as from reliable websites. Previous studies had indicated that trust and distrust in physicians had an impact on care-seeking and nonadherence behaviours among patients. Thus, HCPs are encouraged to be more sensitive to patients’ unmet needs. They should develop good interpersonal skills to gain patients’ trust.

Many studies have examined the impact of peer support groups on treatment outcomes. However, this study showed that influence of peers and friends were common, but only persons with whom they are strongly attached or with whom they had a good relationship could affect patients’ diabetic management. Thus, a formal peer support group program might not be beneficial unless some positive group dynamics are developed.

**Strengths and Limitations**

The strength of this exploratory qualitative study lies in its ability to provide insight into patients’ diabetes management including influence or support received in their help-seeking process. A good rapport was developed through interaction between interviewer and participants of the study and a more open and candid discussion was possible. The triangulation of methods (interview and FGD) and data sources (from patients, family members, and HCPs) gave a diverse viewpoint. However, the current results should be interpreted within the context of relevant limitations. The study emphasised as sized on an in-depth exploration; thus, its finding cannot be generalised.

**Conclusion**

In summary, our findings revealed that social network was the source of information that patients actively sought in their process of making decisions on treatment; and more importantly, the influence by social networks depended on the strength of relationship, the level of trust, support, and the perceived care rendered. The source of support groups then needs to be considered when forming social support groups for diabetic patients.

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**Authors’ Note**

The contents of this publication are solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the ASCEND Research Network.

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