Barriers to Optimal Control of Type 2 Diabetes

in Malaysian Malay Patients

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Abstract

There are a growing number of people diagnosed with diabetes. But, with the growing number of people diagnosed with diabetes, Malaysia is not spared of this phenomenon, as prevalence stands at 14.9% of adult population. Adequate blood glucose control is vital in diabetes management to prevent complications. Even so there is a lack of diabetic control among people with diabetes in Malaysia and we need to understand why this is. This study set out to explore the perspectives and experiences of Malay patients in managing Type 2 diabetes as a chronic illness and provide recommendations that aim to enhance adherence to treatment and help patients to improve their self-management skills. In-depth interviews were carried out on a purposeful sample of patients and their health care professional (HCPs). Interviews were recorded, transcribed and audiotapes were analysed using NVivo software to identify emerging themes and code according to categories. Interviews were conducted in an Endocrinology clinic in Malaysia with 18 Malay patients (15-75 years, 9 males and 9 females) and 13 HCPs. Results indicated that themes that emerged from interviews with the patients included problems with integrating the treatment regimen and difficulty developing coping skills to achieve the desired blood glucose level. Most patients lacked understanding of diabetes and management of diabetes, nature of diabetes, awareness of having diabetes, diabetic education, knowledge of diabetes, duration of illness, patients' understanding of diabetes, physical effects of treatment, severity of symptoms and disease. Patients believed that they needed to integrate many treatment requirements such as diet, medications, blood glucose monitoring and exercise into their daily routine. However, barriers to achieving good control of diabetes were found to be the constraints in their ability to control diabetes. Education and knowledge related to diabetes that influenced understanding of the disease were also reasons for non-adherence to treatment regimen. Their beliefs and ability to minimise these barriers shaped their attitudes towards disease management. Patients were willing to discuss their problems about self-managing diabetes if some of these barriers were addressed during consultations. It can be concluded that more positive approaches are needed in self-management of diabetes and health care professionals involved in the management of diabetes need to understand their patients' beliefs about their diabetes and constraints faced by their patients to promote more awareness and to foster greater control of diabetes and improve health outcomes.

Keywords: Type 2 diabetes, Malay patients, Control, Barriers, Qualitative, Personal interview

1. Introduction

WHO estimated the number will increase to 300 million by year 2025 (Cockram, 2000a). Total health care spending on the disease worldwide is estimated to be US$ 213 billion and US$ 396 billion by year 2025 (IDF, 2003). It was predicted that 75% to be from developing countries because of rapid cultural and social changes and also increasing urbanisation (Ma et al, 2003 & Chuang, 2003). With this scenario, diabetes will burden the health care system, which is already strained with other chronic diseases such as coronary heart disease, asthma, hypertension, and kidney failure (New Straits Times Press, 2006). Adequate blood glucose control is vital in diabetes management to prevent complications. Yet, despite the various interventions, diabetes control remains a global problem to health care professionals (HCPs). As more people suffer from diabetes due to the increase in the level of obesity worldwide.

Uncontrolled diabetes has led to an increase in complications and thus has doubled the cost of treating these patients. With rapid changes and faced with the prospect of a changing health scenario, Malaysians are already affected by western health problems (Ma et al, 2003 & Ismail, et al, 2002). As 2001 study noted that 10% of the population was diagnosed with diabetes (Ismail, 2001). But, with the growing number of people diagnosed with diabetes, Malaysia is not spared of this phenomenon, as prevalence stands at 14.9% of adult population (National Diabetes Study III, 2006).

Studies also found that the majority of diabetes patients did not have their disease under control[4] where 61.1% of patients had HbA_{1c} greater than 8.0% (Ismail, 2001). The studies found that 87.1% were hypertensive, 63.5% had a family history of diabetes, 51.6% were not on any hypertensive medications, and 37.2% had microalbuminuria (MAU) were also hypertensive. Complications of diabetes have caused Malaysia to be ranked as number one in kidney failure due to diabetes (New Straits Times Press, 2005). A great concern as it implied that diabetes was not well controlled in Malaysia. These statistics also indicated Malaysians suffering from end-stage renal failure was 43 in 1980, increasing 56-fold to 12,000 in 2005. There could also be more unregistered cases. To tackle this problem the Ministry of Health (MoH) has embarked on a new strategy to reduce these alarming figures through education, counselling and getting doctors' cooperation. Among these measures are applying new knowledge and innovations gained from multiple sources and disciplines to ensure much needed changes in the health care system for example, the use of genetic informatics and role of genetic markers in risk of chronic diseases of diabetes and cardiovascular diseases. Implementing new strategies and understanding behaviour of patients to achieve better health (Merican, 2008).

Despite various measures taken, there is still lacked of diabetic control among people with diabetes in Malaysia and there is a need to understand why this is. This study hoped to explore and understand the patients' perspectives as to why the problem of uncontrolled diabetes which contributed to alarming kidney failures due to diabetes in Malaysia and that this paper presents the results of part of the study. The purpose of this study was to explore Malay patient's perspectives on why the lack of control of diabetes and to understand the barriers they faced to prevent complications using interview qualitative methodology. A pilot study was done to determine the suitability and clarity of the interview questions and the data obtained was not used and not as part of the main study. The study hopes to provide recommendations to enhance adherence to treatment and help patients to improve their self-management skills.

2. Methods

2.1 Location and design of study

Once the ethics approval from the study site was obtained, interviews were conducted in the endocrinology clinic of a teaching hospital in Kuala Lumpur. Participants (N = 18) were briefed about the study as in the information leaflets and given their oral and written consent to take part in the study. Qualitative methods was used to research doctor-patient communication about drugs and insights into how such studies are actually carried out to stimulate others to embark on similar studies in this relatively unexplored area was pointed out by Stevenson (2000). A qualitative approach using in-depth interviews was used and following grounded theory approached, when major trends begin to recur, and outlying or secondary themes have already emerged, the qualitative research data is said to reach a saturation point. At that point, researchers can stop adding new informants to their sample (Glaser and Strauss, 1967). The sample selection in this current study includes informants with a range of views of the topic and from a range of different backgrounds as in cross-cultural research as mention by Twinn, (1997) which emphasized that the selection of informants for the study provides a check on the validity of the study.

In qualitative studies, sample sizes are necessarily small because of the complexity of the data, which are expensive and time-consuming to analyse (Bowling, 2002), is not based on quantity of the sample (Kelle and Laurie, 1995), but more on the quality and purposeful sampling to ensure that the investigated cases display theoretical relevant aspects of the empirical domain under study. The data are aimed to provide rich insights in order to understand social phenomena rather than statistical information. A sample size of 'one' however, obviously could not give any generalisations, but there was no clear guideline about what constitutes an appropriate cut-off point. The 'rule of thumb' applied most frequently was that when the same stories, themes, issues and topics emerged from the study subjects, then a sufficient sample size had been reached (Bowling, 2002).

2.2 Selection of respondents

Purposeful sampling of 18 Malay patients (9 males and 9 females) was used ranging from 15-75 years to ensure broad representation of all patients that met the study criteria such as duration of illness, age, complications, medications and who had drug-related problems with their medicines to enhance the trustworthiness of the data after reviewing their medical records. When approached, the patients agreed to take part in the study while they waited between 2-3 hours to see the doctor and they found it convenient to be interviewed in an allocated room near the clinic than in their homes (Stevenson et al, 2000).

The Hawthorne effect was minimised by ensuring that the patients understood that the researcher is not to influence them on their responses. Richards & Emslie (2000) discussed the importance of the professional identity of researcher.

To minimise the effect, the research process must be as unobtrusive as possible by using a small tape recorder with built in microphones. Participants were asked to relax and they were reassured that their responses would be used anonymously.

2.3 Open-ended interview

The interview schedule for patients comprised data regarding their medication which was obtained from their records. The data included were their demographic data (patient id, age, gender, years of being diagnosed, prescribed medicines, HBA1c data, fasting blood glucose data. Additional interview schedule included the patients' knowledge of use and side effects of their medicines, compliance and systems of taking medications, information adequacy and problems related to their diabetes. These interviews conducted by SMA were audio taped and common pitfalls of the interviewing and transcribing processes were avoided (Easton et al., 2000). Durations of interviews varies from 60 minutes to 30 minutes as some patients were willing to share their experiences while some patients needed prompts and encouragement to share their views. Thirteen health care professionals out of 16 (nine doctors, three pharmacists and one diabetic nurse educator) were interviewed to explore their views on diabetes management among patients as they were available during the data collection and agreed to participate in the study. Three HCPs (two dieticians and one diabetic nurse educator) were not available during the data collection. The interview schedule for HCPs were similar to the patients with some criteria added such as their perceptions on patients' ability to control their diabetes, psychosocial and cultural factors that may be contributory to non-adherence to diabetes management. Grounded theory based on iterative and inductive processes where data "collected, theories, potential concepts and categories were developed during the process repeated, until and understanding of the phenomena is achieved" (Bowling, 2002). The interview schedules were developed from the literature review and from previous research and feedback on the suitability of questions after pilot study was done, and during the interviews, the participants were asked the questions that allowed them to share their experiences of having diabetes and their concerns. Questions were particularly directed at how they perceived their diabetes, their knowledge of the disease, their self-management approaches, and their relationships with their health care providers and what they thought they should do to manage their diabetes. The sample size was determined when no new themes were observed and a saturation point was reached (Glaser and Strauss, 1967)

2.4 Data analysis

The transcripts were coded, then analysed for emerging themes and trends by SMA and crosschecked to ensure the categories were agreed by other two researchers (CA and NAK) and to minimise biases. Other concepts have been used to meet various aspects of trustworthiness (Graneheim & Lundman, 2004).

Following methods described by many authors in qualitative research as a guide, (Glaser and Strauss, 1967; Bowling, 2002; Pope and Mays, 1995; Pope and Mays, 2000a; Pope and Mays, 2000b; Miles and Huberman, 1994; Burns, 1989; Burns, 2000; Morse, 1994); Morse, 1999); Morse and Field, 2002; Silverman*, 2000;* Silverman, 2001; Silverman, 2004); initial work of data analysis started as the audiotapes interviews were transcribed as this helped to be familiar with the data. In qualitative research, the analytical process occurs during the data collection phase using sequential analysis or interim analysis (Huberman & Miles, 2002). However, once the data collection has ceased, data analysis would continue in the form of texts as interviews produced transcripts or texts.

The need to validate qualitative research arises from positivist paradigm and it does not fit well in qualitative research due to different epistemological approach in this type of study. One approach to ensuring rigour of qualitative research is to use a method of triangulation. Thurmond (2001) who described the various triangulation methodologies has also cautioned the disadvantages of triangulation such as increased time needed, difficulty in handling a vast amount of data, disharmony due to researchers' biases, conflicts of theoretical framework and lack of understanding of why triangulation strategies were used. Thus, reliability, validity, and generalisation may not be appropriate tools for demonstration of robustness in qualitative inquiry. The concept of crystallisation suggested by Tobin and Begley (2004), which allows for various angles of approach, was more suitable as a means of establishing completeness in naturalistic inquiry rather than confirmation. Caelli (2001), suggested that if qualitative research is to become part of a playing field of equal opportunity with more traditional research and be a viable choice for researchers, it must be made more open, more "user friendly," and less daunting for researchers who wish to engage in it. With that in mind, the researchers in this study addressed this issue collectively to ensure the robustness of this type of naturalistic research. The concept of crystallisation, which allows for various angles of approaches were more suitable as a means of establishing completeness in naturalistic inquiry rather than confirmation.

Data collection was done properly, systematically and rigorously (Pope and Mays, 2000b) through researcher's skill, vision, and integrity to ensure a good data analysis in qualitative research. The ongoing reflections and inductive steps taken during the process would add to the quality of qualitative research.

All relevant data to each category were identified and examined using constant comparison, in which each item is checked or compared with the rest of the data to establish analytical categories. Once all the interviews were

transcribed, coding of the themes was done using the data management software NVivo 2.0, to assist in the data analysis (Kelle & Laurie, 1995); Lee & Fielding, 1995; Lee & Esterhuizen, 2000; Gibbs, 2002). The transcribed interviews were analysed thematically and revised with ease using the software until all the transcripts were coded. Letter R was used to code patient's responses and H was used for health care professionals.

3. Results and discussion

The patients' demographics data is summarised in Table 1. Themes identified were categorised in terms of their beliefs and contributory factors raised during interviews. Themes that emerged included problems with integrating the treatment regimen and difficulty in coping to achieve the desired blood glucose level.

3.1 Understanding of diabetes and management of diabetes

Participants' gave varied responses regarding the management of their diabetes. SMA coded the themes according to their occurrences such as patients' understanding of diabetes as a disease, education and knowledge about diabetes and complexities of the disease. The patients believed that many factors influenced their control of diabetes. For diabetics to be able to self-manage their disease, they must understand the treatment and disease characteristics which include various factors that influence adherence to treatment and hence the control of their diabetes. It is important to see this through the eyes of the patients and their health care professionals in order to achieve high quality of care. Overcoming some of the barriers would be a start to achieve this objective. Personal barriers to optimal diabetes care by Simmons (2001) were among themes that were mentioned by the patients in this current study (Salmiah, 2006). The barriers were summarised in Figure 1.

3.2 Nature of diabetes

Nature of diabetes contributed to one of the barriers to diabetes control as no symptoms or signs during early stage of diabetes. Diabetic patients said that diabetes is a silent disease because diabetes does not manifest itself long after it has been diagnosed. Patients were unaware that they had diabetes until they suffered the complication of the disease or were hospitalised due to diabetes hyperglycaemia (e.g. R01, R06 and R18). A survey found that 36% new diabetics admitted to having the classical symptoms of diabetes (Zaini, 2000). Some were hospitalised due to severe complications. Thus, this led to problems in the treatment of diabetes (Standl, 1998).

R01, (had diabetes for 17 years) was not aware of the disease until he was diagnosed, shared his experience: "*You don't feel sick… that's why you don't go for check up or go for treatment… what is diabetes. Diabetes is not like gonorrhoea or something... why are you worried about ...[….] and you don't suffer, this is the problem… being diabetes…. you don't suffer…. you don't for example…. like other illness…. where you have fever…. diabetes no… you suffer maybe later…. like your heart…. your leg get amputated…. "*

Patients usually blamed themselves for the disease (Hampson, 1997) and for not seeking treatment earlier. Patients like R03, R08 and R19 did not know what diabetes could do to their bodies. They understood the symptoms of the disease but were unable to understand that the disease could progress into something more serious. In the case of R11, he was not aware that diabetes could cause "extreme thirst" and this led to him wanting to drink more sweet drinks to compensate the thirst.

3.3 Awareness of having diabetes

Most patients interviewed were not aware they had diabetes until they experienced the signs and symptoms of the disease like blurred vision, micturition, extreme thirst, and other signs. These signs prompted them to seek treatment at the private clinic or they were hospitalised. R08 attended the clinic for the first time when interviewed. He had eye problems (more than six months), "*like not able to see…. like there is a shadow… then it disappears…. then it occurs again…"* which were due to retinopathy (Younis et al, 2003) [42]. He was not aware that his eye problem was due to the progression of the disease to severe complications. Other patients like R11, R12, and R20 were not aware they had diabetes until they experienced complications and faced the consequences of severe diabetes: "micturition" and extreme thirst "*I woke up at night…. I experience extreme thirst… I drink a lot of canned (soda) drinks… It's planted in my mind that if thirsty…I must have soda drinks. Can relieve my thirst…every 2 weeks I must drink (soda) (R11).* Some experienced *(*R13, R18, R19) extreme tiredness, a common symptom for diabetes, was not suspected among patients, and they dismissed it as work stress and they merely ignored it until complications were visible or they were hospitalised as recounted by R13.

Health care professional, (H01), agreed that most patients were not aware that they had diabetes. "*That is very important because…. From our own diabetes study about half of the patients are not aware that they have diabetes*".

Some patients were aware that they have diabetes because of their lifestyles and dietary habits while some were due to hereditary factors. R01 believed that his diabetes could be due to food as "*you work in the studio…. you drink a lot of coffee…. drink tea… I think that's the cause…. I'm not sure…".* However, most patients believed that hereditary was the main cause of their diabetes similar to a study where 80% of patients believed that hereditary was the cause of their

diabetes (Hunt, Valenzuela and Pugh, 1998)[43]. R02 said both his parents had diabetes and "*it was not surprising anyway*" and R18 had a family history and had diabetes with hypertension. "*I couldn't get up… I felt dizzy… All my family members… my siblings… me… all had diabetes*'" (R18). While R23 said her mother had diabetes that diabetes runs in the family (R06). Having family members or relatives with diabetes helped the patients to understand the disease better. H09 believed that the awareness of diabetes among patients was of an 'acceptable level' and that 'a lot of patients understand, comply, and try to meet diet, exercise, and medication'.

3.4 Diabetic education

The patients also said that they were not given information about the disease and its complication. Some patients were not informed because some doctors did not think that their disease was at a critical level. But, some patients had received diabetic education from the diabetic nurses when they were diagnosed with diabetes. *R01"read a lot of materials about diabetes" and "discuss about diabetes"* with his doctor, while R11 used the Internet to get his information. R19 (a student) "relied on his mother", who was also a diabetic, for information and support. Beliefs, attitudes, and behaviour already existed in the culture that promote good diabetes control, prevent complications, and improve quality of life (Greenhalgh et al., 1998). When asked what diabetes could do to their bodies, not many patients could give a simple account of the disease. H01 commented that there was still a lot to be done in diabetes education where only a small proportion of patients had benefited from the programmes and were motivated to control their diabetes but a greater proportion of the diabetic population needed an approach that is more aggressive to *"educate and motivate patients."*

Besides health care professionals, non-governmental organizations (NGOs) took up diabetic education actively. He added that the implementation of the diabetes education programmes must be looked at so that it would help more patients to benefit from it. Like other chronic diseases, diabetes treatment involved many types of drugs being prescribed; this could lead to non-compliance. H01 was concerned that "g*enerally, most of the patients…sad to say … they don't ask about (disease or medication)… they took for granted."* Medical officer (H06) believed that diabetes is an "epidemic" that patients needed to be educated in to prevent complications of the disease later.

3.5 Knowledge of diabetes

Some patients acquired knowledge about diabetes on their own initiatives (R11) to help with management of their disease. They stressed that they would be grateful if there were more information given by health care professionals. R01 was concerned if patients were not able to read about diabetes to understand the disease as he believed patients "*must be told what to control and how to control*" and which he *thought was "lacking"*. From his experiences, he explained that there was lack of education among diabetic patients. This could enhance management of their chronic disease if they are expert patients (Department of Health, 2001).

H04 believed that patients' constant denial was a barrier to successful diabetes treatment among patients, and "*think the patients are very well aware of the complications… they know that… because I think …they took supplements, they have family members, amputation, heart disease, kidney disease…. they know all that…but I think sometimes they'd rather not know (pause)... and just hope for the best… that kind of attitude."*

3.6 Duration of illness

Most patients were given diabetic education during their early diagnosis to care for their bodies (Mensing, et al, 2004). But, according to R01, it was inadequate, and '*think there must be a lot more information…to diabetic patients'. He suggested that ' … the doctors talk to the patients …what it is. … What's wrong with them…. they come here, I think …they see the doctor… they get the medication… whether they use the medicines…. do they know what's wrong with them… when they have diabetes…. what's strong with them... why is it they become diabetic… I think there is no (enough knowledge)'.*

However, balancing the hypoglycaemia and hyperglycaemia was difficult for most patients interviewed. Some patients almost "gave up" (R22) caring for themselves when they have to control their diet and face problems to maintain it to the reasonable levels *pressure, you blood pressure still goes up…sometimes my blood sugar goes down to 3.6. It becomes very unpredictable/erratic…*H14 found that elderly patients were difficult to educate as "*they may not listen… because it is very long time… there are complications… so it's difficult… there are problems…"*

3.7 Patients' understanding of diabetes

From the interviews with health care professionals, they said that most patients wanted to know more about their disease (H02, female doctor). They needed to know about the progression of the disease, the tests and the levels of their cholesterol. She added that some patients thought their diabetes was due to obesity, lifestyles or other factors. Thus, she stressed that education was essential. H03 (specialist, Chinese female), felt that patients sometimes did not bother to understand the disease better. The patients' perceptions were that they did not suffer from diabetes in the early stages until they suffered from the complications, "*they don't see the problems. Diabetes is a chronic disease so they don't see*

the outright complications for now… it will only develop five to 10 years later. They don't see that…. They feel proud… they feel why should I be bothered with it now…they don't see it. Until the heart attack comes…. blindness comes…". Patients knew of the need to control their sugar levels. However, she explained that patients' knowledge was lacking in certain areas, like "*how good is good or how bad is bad... the HbA$_{1c}$, what is defined as good control also keep changing, so sometimes we don't update our patients*" (H04, A doctor).

On the other hand, pharmacists H10 and H11 felt that patients only knew of complications and did not know how diabetes affected their bodies. H11 believed that the patients' education level played an important role in understanding the disease. "*it's not more of ethnic. It's more of level of education. You can see in educated Malays, they care. You tell them and they say 'thank you' and they follow. Next time when they come back, they tell you 'yes, I did what you said'. … and for the older ones are not educated, the Malays, the kampong folks, they believe in traditional medications, many times what you said they cannot really accept.*" To make a point, she stressed the importance of patients' 'education level' to understand the disease. H11 also pointed that patients believed diabetes "could be cured" and they also thought that they could eat anything if they took their insulin. Patients' mistaken belief that their condition has been cured should also be addressed (Parry et al, 2006).

3.8 Physical effects of treatment

Another condition related factor that posed a problem to some patients was poly-pharmacy. One patient, who had a brain tumour operation, had 12 types of drugs to take, also had diabetes and hypertension. Compliance can be aided by sensible use of drug combinations that are already available (particularly for blood pressure), the use of once daily preparations (for example, glimepiride, sustained release gliclazide, or even glibenclamide) and careful explanation to patients of the reason for prescribing drugs. This action was actively taken by the doctors and patients were informed of the results of their glycated haemoglobin, cholesterol, and blood pressure, along with an explanation of the targets to be achieved, to help them with compliance with their medication (Chowdhury & Lasker, 2002).

Patients also brought up the problem of multiple medication/treatment regimens that they have to perform. Some said they forgot to take their medications when they were to be taken more than twice a day and more than one type. R13 could not remember taking medications due to the many types of medicines. Contrary to findings by Billups et al (2000), H01 added that poly-pharmacy contributed to non-compliance among some patients, as "*In terms of acceptance, we have to look at the implementation…. We give them many drugs that end up with poly-pharmacy…. A few of them complain but they very well know the need for the medication… that can lead to compliance… becomes a big issue*".

3.9 Severity of symptoms and disease

As a diabetic, patients should be able to tell the signs and symptoms of hyperglycaemia and hypoglycaemia in order for them to self-manage their disease. According to Dowell (2002)[50], patients' experiences help to build their beliefs. Some patients explained through their experiences: R01 said *"I think, it is important for the diabetic to understand the systems… you are shaking…your eyes blur…. and sweat…and you know…. the problem is you don't know whether it's low or high ….so you need to test…if it's low you can always sort it out by taking some sugar or sweets, but if it is high you can't take anything…"* Some of the patients said 'you will have gangrene…all that stuff…' (R11), and 'I know that…if you have diabetes…you must be amputated…. If you cut yourself…. it is difficult to heal… that's all' (R12 and R21). Some patients were aware of the severity of the diabetes when they have *heart failure* (R06 and R31). H11 believed some patients lacked the knowledge of diabetes and its complications "*sometimes they don't know why the family got kidney failure…until you explain…diabetes can cause kidney failure, or blind or get their leg amputated… they don't really connect it.*" The complex nature of the disease [51] has caused R06 to postpone other treatments so that he would not risk the complications where doctors need to consider patients' values and choice.

Anderson et al (1995) stressed the complexities of the disease. Patients were asked if they knew the complex nature of the disease that they had to manage. Some patients said their health care professionals did inform them but some were not able to explain the complications of the disease. R02 expressed her worries when she was diagnosed with diabetes like "*that are emotions…. once you know you have diabetes…you start thinking all sort of things related to it*" and the complexities that she had to manage. Some patients mentioned that due to complications such as retinopathy, they could not read the markings on the syringe because they were too small. R06 did not take his insulin when his wife was away and no one could help with his injection. One patient (with a pacemaker implanted) said the severity of disease prevented her from exercising. Level of disability (R06 who had a stroke) and complications of diabetes (R06 and R08) who had cardiovascular complications) also contributed to non-adherence to treatment. Some patients thought that they would not suffer from the complications because of their beliefs that they would occur later in their lives. They would need constant reminders about diabetes complications. Even so, they might have attitude problems. As mentioned by H02: *"Yes, we talk to the patients. There is communication among the doctors and patients. We ask them their problems and advise them of their cooking for their family. We face patients who can't accept our suggestion".*

Patients were willing to discuss their problems in managing diabetes. Many factors contribute to personal barriers to optimal diabetes care (Fig.1). Patients lacked coping strategies and difficulties in integrating the treatment regimen into their lifestyles were contributed to their beliefs and their experiences. Diabetes being a silent disease, caused problems for patients to manage it in the earlier stages of the disease as compared with other diseases (Zaini, 2000). Some patients believed that diabetes showed 'no symptoms, no problem' (Murphy & Kinmonth, 1995) to them initially. Help were sought after they suffered from severe complications like blurred vision, nicturation, polyuria, and extreme thirst. "Veterans" patients (Lawton et al, 2005a) due to long *duration of illness* were more experienced in controlling their diabetes but some recently diagnosed were initially able to control it but had lost interest and cited reasons such as social obligations and external factors which prevented them to be more adherent to treatment requirement of diabetes (Schoenberg et al., 1998). The web of complications due to many patho-physiology changes caused poorly managed diabetics (Standl, 1998) which they are required to take greater initiatives in managing their disease to prevent complications later. Experience and duration of illness could affect the control of diabetes (MacLean, 1991) [56]. Participants who were diagnosed some years ago could explain very well what happened to their bodies when they had diabetes. As compared to young diabetics or recently diagnosed participants. They did not realise that diabetes is a silent disease, which will not manifest its effects long after it is diagnosed. Diabetes is an intriguing disease with its complexities of treatment, management, and complications. The patients were not aware or did not show much experience during the early stages of the disease for them to take early preventive measures. As they become aware of the disease through their experiences down the years or had suffered from the disease for some time, the disease had progressed into severe complications. At this stage, all the patients could do was to prevent further progression of the disease. This could be seen in some of the patients who failed to realise that when they were recently diagnosed with diabetes.

Diabetic education and health literacy is important to diabetics in order for them to understand what is happening to their bodies when they have hypo- or hyperglycaemia (Lawrence & Cheely, 1980). Patients with diabetes must acquire knowledge about the disease to help them to manage it. Some patients showed they had good knowledge about the disease as they took their own initiatives to find out more about it.

Many patients said they understood what diabetes is and its complications. But in-depth interviews, they showed lack of understanding and were unable to explain the disease. This could be one of the reasons why some patients could not control their diabetes. Consistent with Anderson's et al study (1995), on Euro-Canadian women with diabetes, a significant association was found between knowledge and the management of diabetes. However, there was no significant association between knowledge and medication, exercise or diet management. As Johnson (1984) commented, "While knowledge may be a necessary condition for adequate health care, it is not a sufficient condition as the patient may know what to do, but not do it" (pg 509). According to H07, most of the patients knew that the medicines prescribed were to reduce their blood sugar levels. Due to rotation basis at the Endocrinology Clinic, when asked about the education programmes most medical officers were not aware of diabetes education (H07)and even if there is the programmes "*can do a bit more because we are short handed...(lack of educators)*". Thus, the health care professionals were aware that diabetic education is important to the control of diabetes. Muhlhauser (2002) & Berger et al (2002) stressed that diabetes education or self-management programmes are complex interventions. Their evaluation is difficult because of problems in identifying and separately assessing the effect of the various components of the intervention. Their evaluation has presented for discussion a new system for reporting the evaluation of complex interventions such as diabetes treatment and teaching programmes. Patients should be informed of the risk in diabetes complications so that they will be able to share their experiences with their health care professionals.

Cooper et al (2003) in their purely quantitative perspective study showed that patient education appears to have short-term clinical effects, long-term psychological effects and no effects on lifestyle behaviours (pg. 51). Their findings suggest that patient misperceptions of understanding, lack of formal knowledge testing, and the neurological consequences of aging might be more important causes for poor performance than the educational system itself. The findings are clearly disappointing as insulin-treated veterans with stable Type 2 diabetes have major deficits in diabetes knowledge. The degree of deficiency is not strongly correlated with attitudes but is highly influenced by demographic and clinical factors, depression, years of schooling and cognitive function. The study reinforces the ADA recommendations for periodic re-assessment of patient's knowledge and the use of educational strategies that are matched to the patients' abilities (Murata et al, 2003). Interviews with R23 indicated that she took normal foods like the rest of her family members who did not 'suffer from the disease'. She found this difficult as she 'couldn't plan a good diet and couldn't do more exercise'. This was not possible 'because she prepared food for her family'. R21 was a former nurse who was diagnosed with diabetes after the birth of her youngest child. Being in the medical profession, she was able to give an account of her experiences. She described her experiences as an "active" diabetic as she preferred to do housework to maintain physical activity. She also believed that her diabetes was predisposed as her "*parents...had diabetes...at that time... and her "favourite drink was coca-cola..."*

Family support is another personal barrier to diabetics. Interviews with R23 indicated that she took normal foods like the rest of her family members who did not 'suffer from the disease'. She found this difficult as she 'couldn't plan a good diet and couldn't do more exercise'. This was not possible 'because she prepared food for her family'. Educational and psychosocial interventions studies showed beneficial effects on various diabetes management outcomes and is effective if there is relatedness of the various aspects of management (Younis et al, 2003). Davies et al (2001) in their study concluded that diabetes specialist nurses were potentially cost saving by reducing hospital length of stay (LOS). However, there was no evidence of an adverse effect of reduced LOS on re-admissions, use of community resources, or patient perception of quality of care. Thus, the services of diabetic nurse educator would help patients in managing their diabetes. In Lawton et al's (2005a) studies, some patients said that knowing too much would worry them more. Thus, the constant denial acted as a barrier to the uptake services offered by the hospital. Some patients might want to dissociate from diabetic identity, where they constantly deny of having the disease. Reinforcement of education was found to be positive towards diabetes education (Bruttomesso et al, 2003). H02 (medical doctor) and H14 (nurse educator) emphasised that "the traditional educational approach might not be sufficient and patients need to be addressed on an individual basis". Simmons (2001) stressed that diabetes education is not the only factor that influences treatment success but is determined by other barriers but Snoek, (2003) differed on this and insisted, "Education is considered the corner stone of overall diabetes management".

At another point, the doctor (H03) said that some patients had difficulty in understanding what the doctors were trying to say about the disease due to their socioeconomic background. The problem was to convince them about the risks of the disease, if it was left unchecked. They must be convinced that they have a 'potentially life-threatening disease for which rigorous self-management is necessary' (Lawton et al, 2005a). Some patients lacked knowledge of diabetic complications and perceived the seriousness of their disease when other family members suffered the same disease. They were the ones who would be taking positive initiatives in the self-management of their disease. But those who did not know the seriousness of the disease were less likely to take steps to control their blood glucose levels. They were not aware of the complications that could set in if their glucose levels were not controlled to acceptable levels. Most patients suffered from other diseases and diabetic complications. The patients also said that they were not informed of the diabetes and its complication. Frijling et al (2003) found that patients showed inadequate perceptions of their risk of cardiovascular disease. Perceptions by some patients showed that their worries and concerns when complications were evident in later stages of the disease and being hospitalised or referred to hospital signalled that their health is deteriorating (Lawton et al, 2005c). These were perceived by some patients who had difficulty in taking care of their bodies; they did not see the risks involved in having high blood glucose in the body.

4. Conclusion

By reducing some of the barriers, some patients reported better ability to practice diabetes care. Diabetes care is complex and requires great effort on the part of patients in controlling their blood glucose to acceptable levels. Factors that contributed to the control of diabetes needed to be identified in patients as treatment requirement is individualized in caring of diabetes patients. This study has uncovered the perceived beliefs of Malay Type 2 diabetes patients and their coping strategies and illness stress. Understanding patients' experience and beliefs would help both the patients and HCPs to identify areas of concerns and make recommendations for future treatment to enhance adherence to treatment of diabetes. Patients were willing to discuss their problems about self-managing diabetes if some of these barriers were addressed during consultations. Therefore more efforts should be generated to implement the forwarded recommendations in order to achieve more desirable diabetes control in Malaysia.

Patients reported better ability to practice diabetes care when they understood their disease better. The complexity of diabetes requires patients to be aware of their disease and they must be educated to enhance their coping strategies and overcoming their stress of having the illness. Factors that contributed to the control of diabetes once identified could be used in management of diabetes and enhance treatment outcomes. Balancing hypoglycemia and hyperglycemia is a difficult task for most patients and health care professionals need to address the factors and treatment outcomes should be individualised. Health care professionals need to understand the problems patients had in controlling their diabetes especially their ability to balance the contributing factors and adherence to treatment requirement.

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Table 1. Demographics of patients' sample

RESPONDENT NO.	AGE (Years)	GENDER	BACKGROUND	COMMENTS
R01	75	M	Retired	17 years as diabetic
R02	35	F	Teacher	Pregnant
R03	15	F	Student	Overweight, two years as diabetic
R06	58	M	Ex-army	CVS-stroke, 20 years as diabetic.
R08	47	M	Postman	6 months diagnosed
R11	40	M	Ex-army and part-time tour guide	10 years as diabetic
R12	46	M	-	Operated for brain tumour and on 7 types of drugs
R13	31	M	Food business	3 years as diabetic
R14	48	M	International relations	3 types of drugs
R18	50	F	Staff nurse	Hypertension and IHD, Diabetes
R19	18	M	Student	5 years diagnosed
R20	47	F	Housewife	
R21	50	F	Housewife	15 years as diabetic, retired nurse
R22	50	F	Part-time work	Coronary by-pass (use pacemaker) and diabetic
R23	39	F	Teacher	8 years as diabetic
R24	47	M	Government sector	17 years as diabetic, diagnosed when 30 years old
R28	39	F	Clerk in government office	Recently diagnosed
R31	46	F	Housewife	4 years as diabetic, during pregnancy

(Gender: (M=male, F=Female)

Demographic data for health care professional were not presented to protect their identities and confidentiality due to the small number; they could be identified through the dialogues.
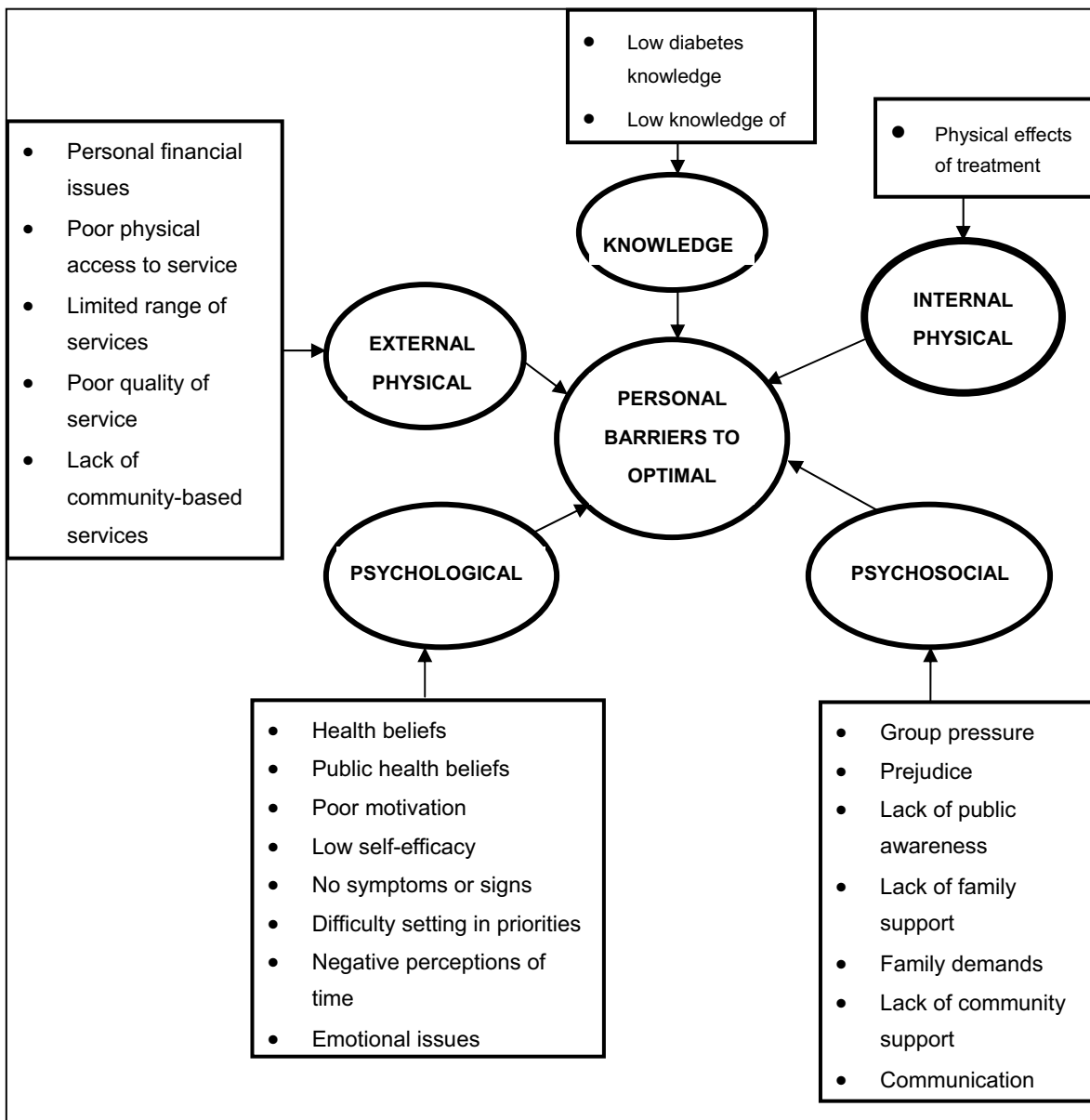
Figure 1. Personal Barriers to diabetes care (Adapted and Modified from Simmons, 2003).