

**DETERMINING TYPES OF TREATMENT TO BE  
ADOPTED BY PATIENTS WITH TYPE 2 DIABETES  
MELLITUS IN A PRIMARY CARE SETTING:  
A GROUNDED THEORY APPROACH**

**LOW LEE LAN**

**FACULTY OF MEDICINE  
UNIVERSITY OF MALAYA  
KUALA LUMPUR**

**2016**

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**LOW LEE LAN**

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Name of Candidate: Low Lee Lan

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## ABSTRACT

Diabetes mellitus is a multi-faceted chronic illness which involves a life-long treatment process that requires patients to continuously engage with the healthcare system. Understanding how patients with diabetes manoeuvre through the current healthcare system for treatment is critical in assisting patients in disease management optimisation. This study aims to explore the issues that determine type 2 diabetic patient's decision in selecting treatment strategy and the decision-making process in deciding upon their treatment options. The ultimate goal of this study is to develop a substantive theoretical model which explains the treatment strategy adopted by patients with type 2 diabetes mellitus in a primary care setting. A grounded theory approach was used to answer the research questions. Twelve patients diagnosed with type 2 diabetes mellitus, nine family members of some of the patients and five healthcare providers from the primary care clinics were interviewed using a semi-structured interview guide. Three focus group discussions were conducted among thirteen healthcare providers from public primary care clinics. The concept of "experimentation" was observed in patient's decision-making for adopting their treatment strategy. This "experimentation" process required triggers followed by information-seeking related to treatment characteristics from entrusted family members, friends, and healthcare providers to enable decision-making related to the choice of treatment modalities. The entire process was dynamic and iterative through interactions with the healthcare system. The decision-making process related to choosing treatment types was complex and exhibited a trial-and-error approach. The purpose of this process was to fulfil a patient's expected outcome or personal goal. The determinant factors illustrated in this model are more diverse than earlier health-seeking behaviour models. This study suggests that an element of uniqueness exists in patients, since individual experiences with regard to symptoms and complications are unique to each patient. The experimentation process is

seen as one that reflects the experiential learning element where learning is accomplished through the action of testing one new treatment with a strategy and this phenomenon is reflective of the concept of adult learning. This model underlines the importance of providing diabetic patients with a safe environment to experiment different treatments within the current healthcare system. Denying patients this experimental trial-and-error process could potentially produce negative consequences such as patients experiencing unmet needs, which could result in patients turning to alternative treatment modalities or switching healthcare providers. Patients should be encouraged to share their treatment strategy with their healthcare providers. Simultaneously, healthcare providers could encourage patients to verify any new information received from sources other than medical experts. This would avoid the perception of risk and subsequently prevent risky behaviour in diabetes management by patients. In conclusion, the substantive theoretical model generated from this study is abstract and believed to possess broader applicability to other diseases.

## ABSTRAK

Diabetes melitus ialah penyakit kronik yang memiliki pelbagai aspek, melibatkan proses rawatan sepanjang hayat dan memerlukan pesakit untuk sentiasa berinteraksi dengan sistem perkhidmatan penjagaan kesihatan. Memahami bagaimana pesakit diabetes mengharungi sistem perkhidmatan penjagaan kesihatan adalah kritikal bagi membantu mengoptimalkan pengurusan penyakit mereka mereka. Kajian ini bertujuan untuk menerokai isu-isu yang menentukan keputusan pesakit diabetes dalam pemilihan strategi rawatan dan proses yang dilalui oleh pesakit dalam membuat keputusan berkenaan pilihan rawatan mereka. Matlamat utama kajian ini ialah bagi membangunkan teori model substantif yang dapat menerangkan strategi rawatan yang diaplikasi oleh pesakit diabetes jenis 2 dalam persekitaran penjagaan kesihatan primer. Pendekatan *grounded theory* telah digunakan bagi menjawab soalan kajian. Seramai dua belas pesakit diabetes melitus jenis 2, sembilan orang ahli keluarga di kalangan beberapa pesakit dan lima penyedia perkhidmatan penjagaan kesihatan dari klinik-klinik penjagaan kesihatan primer telah ditemu bual menggunakan garis panduan temu bual separa-berstruktur. Tiga perbincangan berfokus secara kumpulan telah dilakukan dengan melibatkan tiga belas penyedia perkhidmatan penjagaan kesihatan dari klinik-klinik penjagaan kesihatan primer. Konsep “bereksperimen” dilihat sebagai strategi dalam penentuan keputusan bagi pesakit menerima jenis rawatan yang dipilih. Proses “bereksperimen” ini memerlukan dorongan, diikuti oleh pencarian maklumat berkenaan ciri-ciri rawatan daripada ahli keluarga yang dipercayai, rakan-rakan dan penyedia perkhidmatan penjagaan kesihatan bagi membolehkan penentuan keputusan dibuat berkenaan pilihan modaliti rawatan. Keseluruhan proses adalah dinamik dan berulang melalui interaksi dengan sistem perkhidmatan penjagaan kesihatan. Proses membuat keputusan bagi memilih jenis rawatan adalah kompleks, dan memperlihatkan pendekatan cuba-ralat. Tujuan proses ini adalah bagi memenuhi jangkaan atau matlamat

yang diharapkan oleh seorang pesakit. Faktor penentu yang ditunjukkan dalam model ini adalah lebih pelbagai berbanding model “*health-seeking behaviour*” sebelum ini. Kajian ini mendapati wujudnya elemen unik pada para pesakit, tambahan pula pengalaman individu berkaitan simptom dan komplikasi adalah tersendiri bagi setiap pesakit. Proses bereksperimen dilihat sebagai elemen pembelajaran melalui pengalaman yang mana pembelajaran dicapai melalui tindakan menguji satu rawatan baru dengan satu strategi dan fenomena ini menggambarkan konsep pembelajaran dewasa. Model ini menekankan kepentingan menyediakan persekitaran yang selamat bagi membolehkan percubaan ke atas rawatan yang berbeza dilaksanakan dalam sistem perkhidmatan penjagaan kesihatan semasa. Menafikan pesakit daripada melakukan proses cuba-ralat ini boleh menyumbang kepada kesan negatif seperti kehendak yang tidak dipenuhi, di mana ia boleh mengakibatkan pesakit bertukar kepada mendapatkan rawatan alternatif atau bertukar kepada penyedia penjagaan kesihatan yang lain. Pesakit sewajarnya digalakkan berkongsi maklumat tentang strategi rawatan mereka dengan penyedia penjagaan kesihatan mereka. Pada masa yang sama, penyedia penjagaan kesihatan mesti menggalakkan pesakit untuk mengesahkan maklumat baru yang diterima daripada sumber-sumber selain daripada pakar perubatan. Ini akan menghindarkan sebarang persepsi berisiko dan mengelakkan tingkah laku berisiko dalam pengurusan diabetes oleh pesakit. Kesimpulannya, model teori substantif yang dijana daripada kajian ini adalah abstrak dan dipercayai boleh diterapkan secara lebih meluas untuk penyakit-penyakit lain.

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## LIST OF SYMBOLS AND ABBREVIATIONS

FGD	:	Focus Group Discussion
NHMS	:	National Health and Mobility Survey
GP	:	General Practitioners
GT	:	Grounded Theory
HCP	:	Healthcare Provider
IDF	:	International Diabetes Federation
IDI	:	In-depth Interview
MOH	:	Ministry of Health
QOL	:	Quality of Life
RM	:	Ringgit Malaysia
T/CM	:	Traditional and Complementary Medicine
T2DM	:	Type 2 Diabetes Mellitus
WHO	:	World Health Organization

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## GLOSSARY

**Healthcare provider (HCP)** – refers to medical personnel (e.g. doctor, pharmacist, dietician, nutritionist, registered nurse, assistant medical officer) working in study facilities and involved in the care of patients with type 2 diabetes mellitus (T2DM).

**Self-care** – refers to a participant who is engaged in the self-management his or her illness. Self-care includes the administration of self-management actions such as taking medication, monitoring blood sugar level, managing symptoms, adhering to dietary intake, and performing physical activities and other activities related to the management of diabetes.

**Modern medicine** – refers to Western or allopathic medicine. The system of modern healthcare in Malaysia is a dual parallel system consisting of both public and private facilities. However, the majority of public primary healthcare facilities are under the jurisdiction of the Ministry of Health, while private facilities are operated by single-owner general practitioners. In the public healthcare sector, a nominal fee of RM 1.00 (Ringgit Malaysia) or USD\$0.27 (1USD = RM3.6; rate based on May 2015) is imposed for each medical consultation. In contrast, the private healthcare sector, which is profit orientated, commands diverse treatment costs. In most cases, the majority of patients seeking treatment must bear this cost themselves, although some may be entitled to free medical benefits provided by their respective employers. The benefits provided by employers occur in situations when patients receive treatment in appointed panel clinics. Treatment costs may also be covered by an individual patient's private health insurance.

**Traditional and complementary medicine (T/CM)** – defined by the World Health Organization as the sum total of the knowledge, skills, and practices based on the

theories, beliefs and experiences indigenous to different cultures, whether explicable or not used in the maintenance of health as well as the prevention, diagnosis improvement or treatment of physical and mental illness. In this study, traditional and complementary medicine includes any concoction prepared by patients involving remedies from natural herbs, and may also include a spiritual health component. The notion of complementary medicine is sometimes considered as alternative medicine, and includes various types of modern complementary medicine such as blood chelation.

**Healthcare system**– defined by the World Health Organization as all the organisations, institutions, and resources whose primary intent is to promote, restore or maintain health (World Health Organization, 2000). This definition also encompasses the full range of players engaged in the provision and financing of health services including public, private, voluntary and not-for-profit organisations.

## CHAPTER 1: INTRODUCTION

### 1.1 Background of Study

This chapter contains background information related to the issues with which this study is concerned, including background research, study rationale, problem statement, research objectives and questions, study scope, and limitations. This is followed by an overview of the study design. The chapter concludes with an outline of the thesis.

This thesis project arose from several discussions with policy makers working on the diabetes programme at the Malaysian Ministry of Health, as well as at the state level. Feedback related to diabetes management and problems encountered were obtained from clinicians serving at public hospitals and primary care facilities. The primary concern of this thesis was to understand why diabetes complications have been exhibiting an upward trend in Malaysia (International Diabetes Federation, 2013). Despite the numerous initiatives that have been conducted throughout the nation, ranging from health promotions by creating awareness of the disease to the availability of new drugs for disease management, the number of patients with diabetes suffering from complications and poor glycaemic control continues to increase (Mafauzy, Hussein, & Chan, 2011; Sazlina, Zailinawati, Zaiton, & Ong, 2010).

The issues and concerns raised during meetings with relevant stakeholders included help-seeking behaviour and treatment-seeking strategy among patients with type 2 diabetes mellitus (T2DM). It became evident that the underpinning issues have yet to be explored: how patients interact with the healthcare system when seeking diabetes treatment, the process of deciding which treatment is best for their illness, and the determinants of treatment decisions. A number of clinical and quantitative studies (Clinical Research Centre Malaysia, 2015) related to diabetes have been conducted in Malaysia, though a lack of study research exists which focuses on the treatment strategy

and decision-making process among patients with T2DM. Such studies could explain the process of help-seeking endeavours and explore how patients engage with the healthcare system when receiving diabetes care.

Since the processes involved in seeking diabetes treatment involve the current Malaysian healthcare system, an understanding of the healthcare system - particularly the primary care setting - is essential. The following section provides a brief contextual background of both the Malaysian healthcare system and the diabetes programme.

## **1.2 Contextual Background**

The purpose of this section is to provide a brief overview of the context and setting of the study being conducted. In addition, an overview of Malaysian diabetes care programme provided in the primary care setting is also included. This information, gathered as evidence for this study, provides valuable insight for both the medical experts treating patients with diabetes and the policy makers responsible for non-communicable disease and the development of the national diabetes programme.

Health systems worldwide have multiple goals. The World Health Report 2000 (World Health Organization, 2000) defined the overall health system outcomes or goals are to “improve health and health equity, in ways that are responsive, financially fair, and make the best, or most efficient, use of available resources”. Important intermediate goals also exist; for example, the route from inputs to health outcomes can be accomplished by achieving greater access to and coverage for effective health interventions without compromising any efforts in order to ensure provider quality and safety. Thus, seeking treatment is a process involving patient interaction with a healthcare system and the environment it encompasses.

Previous studies from other countries have investigated health-seeking behaviour among patients with T2DM, particularly in developing countries (these studies are discussed further in Chapter 2). However, the healthcare systems and context of these countries differ from the Malaysian healthcare environment. Hence, this chapter begins with an overview of the healthcare system in Malaysia, its implementation of diabetes care programme and the overall diabetes care system in Malaysia.

### **1.2.1 Types of healthcare delivery systems**

The Malaysian healthcare delivery system consists of three components, which are similar to the explanatory model proposed by Kleinmen (1980) and also by Helman (2007). The model described the characterization of the three sectors: the professional health sector, traditional and complementary medicine, and the popular health sector. The professional health sector, also known as modern medicine, includes a wide range of medical and paramedical professionals which encompass the modern healthcare system, and includes public and private health facilities.

The traditional and complementary medicine sector involves using traditional knowledge and experiences such as spiritual healers (e.g. *bomoh* – a Malay traditional practitioner or shaman) and herbal remedies or medicinal plants. Although traditional and complementary medicine is not commonly viewed as a popular choice for regular treatment of diabetes, it represents one type of diabetes care modality with which some patients continue to experiment (Ching, Zakaria, Paimin, & Jalalian, 2013; Remli & Chan, 2003).

The popular health sector, commonly referred to as “self-care”, represents the lay, non-professional, or non-specialist method, and involves a process of self-management in which people manage illnesses themselves by receiving advice from family members, relatives, neighbours, and peers who have experienced the same illness. Self-medication

and self-monitoring of an illness, as well as self-modification of diet intake and physical activities, are all included in the notion of self-care.

The following section will further explain these three sectors in relation to the Malaysian healthcare system. These three types of treatment modalities were explored among patients with T2DM through referencing their experiences and utilisation of diabetes treatments. Details regarding diabetes treatment experiences are further explored and discussed in Chapter 4 (Results).

### **1.2.2 Overview of Malaysia healthcare system**

Malaysia is geographically divided into two parts: Peninsular Malaysia and East Malaysia (Sabah and Sarawak). Peninsular Malaysia is located in the Asia Pacific Region, bordering Thailand to the north and Singapore to the south, whilst the states of Sabah and Sarawak are separated by the South China Sea and located on Borneo Island, bordering Kalimantan, Indonesia and Brunei Darussalam as shown in Figure 1.1. ("World Map"). Malaysia consists of thirteen states and three federal territories, with a total land area of approximately 329,959 sq. km. Based on population projections provided by the Malaysian Department of Statistics, the population for 2010 was 28.6 million people of different ethnic and cultural backgrounds; the largest group is Malay (50.1%), followed by Chinese (22.5%) and Indian (6.7%). The remainder of population is comprised of indigenous tribes (11.7%), other ethnic groups (0.8%) and non-Malaysian citizens (8.2%) (Department of Statistics Malaysia, 2012).





**Figure 1.1: Location of Malaysia in the world map**

(Source: <http://geology.com/world/world-map.shtml>, retrieved 1/3/2015)

Malaysian economic development and living standards have improved over the past 20 years, particularly with regard to social infrastructure, which includes the healthcare facilities. Overall, the health status and life expectancy rate of the population had improved greatly between 1970 and 2010. The life expectancy of women increased from 66 to 77 years, and for men from 62 to 72 years (Ministry of Health Malaysia, 2012; World Health Organization, 2012). The increase in healthcare facilities in both the public and private healthcare systems was tremendous, particularly with regard to the number of hospitals built under the Malaysian Ministry of Health, as shown in Table 1.1. This increase resulted in a higher access rate for healthcare facilities (88%) for the populations living within 5 km of a healthcare.

**Table 1.1 Ministry of Health primary healthcare facilities, 1995 to 2014**

	1995		2000		2010		2014	
	public	private	public	private	public	private	public	private
Hospital	111	197*	114	224*	131	217	141	214
Health Clinic	772	-	843	-	2833	6,442	2,860	6,801

\* including maternity/nursing homes - data not available

(Source: Health Fact 1995, 2000, 2010 and 2014)

The National Health and Mobility Survey of 1996 (Institute for Public Health Malaysia, 1996) reported that urban areas tend to have greater accessibility compared to rural areas, whereas approximately 40.2% of the population was living less than 5 km from the health facilities in National Health and Mobility Survey 2011 (Institute for Public Health Malaysia, 2012). Improvements in the Malaysian healthcare system have been internationally acknowledged, particularly for its effective health services (Bloom & Standing, 2008).

In the context of modern medicine, the healthcare system in Malaysia has a dual parallel system consisting of both public and private sectors. Generally, the healthcare system in Malaysia involves many different organisations such as the Ministry of Health, the Ministry of Defence (providing health services for military personnel), the Ministry of Education (mainly for teaching hospitals), the state government, and local authorities (providing public health related functions such as environmental sanitation and enforcement of food hygiene laws). However, the Ministry of Health represents the lead government agency taking a stewardship role in health, and also represents the custodian of medical care, which includes hospitals and clinics, and maternal and child health services. On the other hand, the private sector mainly provides curative care services such as general practitioner clinics and private hospitals.

Nevertheless, as far as preference for seeking care at public or private facilities is concerned, the 3rd National Health and Morbidity Survey of 2006 (Institute for Public Health Malaysia, 2008) shows that the pattern is clearly income-dependent (Table 1.2). This suggests that where there is an increase in income, there is an increase in citizens switching from public to private healthcare. In terms of treatment cost, the public healthcare sector provides free or with minimal cost treatments, especially at primary care clinics. Conversely, the private sector primarily provides fee-driven services, and patients must typically pay for treatment themselves. Occasionally, payments can be made by employers, known as employer panel, or it could be subsumed under the coverage of private or personal healthcare (Ministry of Health Malaysia, 2011b).

**Table 1.2: Distribution of household income and utilisation pattern of health clinic, data from 3<sup>rd</sup> National Health and Morbidity Survey (NHMS), Malaysia, 2006**

Household income (RM/month)	Places where treatment were sought (%)	
	Public Health Clinic	Private Health Clinic
<RM400	40.6	13.6
400 – 699	35.6	15.6
799 – 999	31.6	18.6
1000 – 1999	28.9	22.9
2000 – 2999	23.0	29.1
3000 – 3999	19.3	37.1
4000 – 4999	18.2	38.3
> 5000	13.4	41.0

*Source: 3rd National Health and Morbidity Survey, 2006 (1 USD = 3.67 Ringgit Malaysia based on the 2006 rate)*

Traditional and complementary medicine is quite common among Malaysians. As previously mentioned, traditional medicine is sometimes referred to as folk medicine, is usually practiced among lay persons and includes a diversity of health practices, traditional knowledge, and experiences with different approaches and beliefs. The treatment may involve spiritual therapies by faith healers (*bomoh*), the use of herbal

remedies and acupuncture by traditional practitioners (*sin seh* in Chinese) or *ayurvedic*, a form of traditional Indian treatment. Some traditional treatments may include traditional methods of healing that have been passed down from generation to generation.

Although the utilisation of traditional and complementary medicine has a long history and represents a new trend in certain developed countries, its recognition as a healing procedure in many countries has yet to become official. Nevertheless, traditional and complementary medicine has been integrated into many healthcare systems. Some Asian countries, such as China and Vietnam, had already integrated such practices into their healthcare systems decades ago. In Malaysia, the Ministry of Health conducted a nationwide survey in 2004 to identify the prevalence of various traditional and complementary medicine used among its general population. The survey indicates that nearly 69% of Malaysians had used traditional and complementary medicine or treatment at least once in their lifetime (Siti et al., 2009)

The Malaysia healthcare system is gradually recognising the use of traditional and complementary medicine within its public healthcare facilities, with certain modalities being integrated as part of hospital services (Abuduli, Sharifa Ezat, & Syed Aljunid, 2011; Ministry of Health Malaysia, 2011c). Unfortunately, many, if not all healthcare insurance or private insurance companies do not cover the cost of seeking traditional treatment in Malaysia (World Health Organization, 2001). Traditional and complementary medicine has also been practised in the private sector, either legally or illegally, by individuals as a form of traditional practices such as shamanistic spiritual treatments.

Self-care represents another healthcare sector or treatment modality that is quite commonly practised. Data from the National Health and Mobility Survey 2011 indicates

that the percentage of people who had reported illness in the two weeks preceding the survey and self-medicated or administered self-care was high (38.4%). Those who had self-purchased medicine after getting advice from a pharmacist was 14.6% and those seeking advice from healthcare providers, including those from traditional healers represented 37.1%. Some respondents also obtained advice from someone other than healthcare providers (6.4%) (Institute for Public Health Malaysia, 2012). In terms of promoting healthy lifestyles, which promoted included a healthy diet and carrying out physical activities under the Healthy Lifestyle Campaign 1991 (Ministry of Health Malaysia, 2010a).

### **1.2.2.1 Primary care in Malaysia**

Primary care is one of the components within primary healthcare. It is common for these two terms, primary care and primary healthcare, to be used interchangeably. While primary healthcare refers to the system level, primary care focuses on healthcare services (Kamaliah, 2011; Keleher, 2001; Muldoon, Hogg, & Levitt, 2006). Here, the term primary care refers to healthcare services provided at public health clinics or by private general practitioners. The primary care setting in Malaysia consists of public and private settings, as previously mentioned. Public primary care clinics consist of a multi-disciplinary team encompassing family medicine specialists (at selected clinics), general medical practitioners, physiotherapists, occupational therapists, nurses, assistant medical officers, nutritionists, and dieticians. In contrast, private primary care clinics generally consist of a single practitioner or a few practitioners with small group arrangements, and the clinics are primarily located in urban areas (Mustapha et al., 2014).

In terms of treatment costs, a consultation in public primary care clinics costs patients only one Ringgit Malaysia (RM) and senior citizens (over age 60) are exempted

from payment when seeking treatment at the Ministry of Health clinics. However, in private primary care clinics, patients are required to pay for services (Safurah, Kamaliah, Khairiyah, Nour Hanah, & Healy, 2013). Thus, the choice of seeking treatment at public or private clinic depends on the individual's ability to pay. Nonetheless, in terms of provider choice, patients in public care clinics have little choice of their specific doctor when compared to private clinics. In private clinics, patients can choose both the clinic to which they go as well as their general practitioners. In terms of the number of patients seeking treatment at primary care clinics, it appears that patients seeking treatment in public primary care is many times that of those seeking treatment in private primary care (Table 1.3).

**Table 1.3: Total patients attendance at public and private primary care clinics**

primary care clinic	2009	2011	2013
Public	27,041,812	28,656,444	33,379,603
Private	3,174,124	3,505,591	3,867,668

*Source: Health fact 2010, 2012 & 2014*

The Ministry of Health Malaysia provides a number of healthcare services to the population, and one of them is diabetes care programme.

#### **1.2.2.2 Diabetes care programme in Malaysia**

The rising epidemic of diabetes is a global phenomenon, and poses a real threat to the healthcare system of Malaysia and the individuals where its prevalence continues to rise. The National Health and Mobility Survey of 2011 data indicates that 2.6 million Malaysian adults have been diagnosed with diabetes (Institute for Public Health Malaysia, 2011)

Increasing attention has been given to this rise at the global level, to the point where it has become an important national agenda of discussion at various meetings involving

many stakeholders nation-wide, such as other ministries, universities, non-governmental organisations, as well as private societies concerned with this life-threatening disease. As a result of increased concern, various programmes and activities have been initiated by the government including the Clinical Practice Guidelines on the Management of T2DM (Ministry of Health Malaysia, 2009), the Screening of Diabetic Retinopathy (Ministry of Health Malaysia, 2011a), and the approved framework for strengthening non-communicable diseases and control programmes. The Diabetes Registry programme, supported by various diabetes-related research, programmes and activities includes various activities such as intersectoral cooperation, health promotion, and healthy lifestyle programmes as a method of raising awareness (Mustapha et al., 2014).

In relating this section to diabetes treatment, the National Health and Mobility Survey of 2011 data indicates that out of all respondents (N=17,783) diagnosed with diabetes aged 18 years old and above, 56.0% had received treatment from public primary care clinics, compared to 15.0% having received treatment from private clinics, 24.6% having received tertiary care from Ministry of health's hospitals, and 2.5% having received care from private hospitals. However, 1.6% resorted to self-medication by purchasing medicines directly from pharmacies and approximately 0.2% claimed to seek traditional and complementary.

The following sections discuss the rationale of this study, research objectives, and research questions formulated.

### **1.3 Study Rationale**

T2DM and its complications represent a rapidly expanding public health concern that is expected to affect 552 million people by 2030 globally, with devastating health and economic consequences (Guariguata, Whiting, Weil, & Unwin, 2011; Shaw, Sicree, & Zimmet, 2010). In Malaysia, the situation is equally alarming, with one in every five

adults aged above 30 years suffering from T2DM (Institute for Public Health Malaysia, 2011). The situation deserves serious attention and effective efforts should be taken to reduce the prevalence and complications of diabetes which, in turn could save Malaysia from its socio-economic burden. However, with advances in technology and the availability of modern medicine, it appears that metabolic control among patients with T2DM is far from the desired outcome (International Diabetes Federation, 2013; World Health Organization, 2011a). When a person is diagnosed with T2DM, he/she is warranted in adopting a particular set of help-seeking behaviour with the aim of developing a more controlled blood sugar level, reducing diabetic symptoms, and preventing further diabetic complications while restoring quality of life (Chen, Baumgardner, & Rice, 2011; Cornally & McCarthy, 2011).

Although studies related to help-seeking and diabetes treatment have been conducted in many settings, most of these studies do not provide a comprehensive picture. They explored the treatments types (Atwine, Hultsjö, Albin, & Hjelm, 2015; Sheleaswani Inche, Rosnah, & Khadijah, 2014) that patients engaged in, or where they would seek care (Hjelm & Atwine, 2011; Nguma, 2010), including the barriers and facilitators of access to diabetes treatment (Hale, Bennett, & Probst, 2010; Men, Meessen, van Pelt, van Damme, & Lucas, 2012). However, help-seeking is a complex process involving a complex interplay of many inter-linked variables such as predisposing factors, illness condition, the social and economic contexts, and the healthcare system, among other variables (Kolling, Winkley, & von Deden, 2010; Shajahan, Chan, Reidpath, & Allotey, 2012). Each variable that determines help-seeking has a different influencing factor on a patient's decision-making process. Hence, an understanding of how these factors interact and how patients with T2DM manoeuvre through the healthcare system for their diabetes treatment can provide a more comprehensive picture of a patient's help-seeking behaviour.



Diabetes is a chronic illness that is commonly and regularly discussed, and policy makers are evidently concerned about the drastic increase in this illness over the past ten years (Letchuman et al., 2010). This trend is worrisome for healthcare providers, who not only fear the rise of diabetes cases but also fear the increase in patients and family members dealing with complications resulting from the illness. Additionally, various studies also have explored the barriers to optimal diabetes care, such as diabetes treatment with insulin (Lee et al., 2013; Polinski et al., 2013), factors and barriers involving poor glycaemic control (Ismail, Winkley, & Rabe-Hesketh, 2004; Khattab, Khader, Al-Khawaldeh, & Ajlouni, 2010; Sanal, Nair, & Adhikari, 2011). Extensive research has also investigated various interventions for diabetes management (Glazier, Bajcar, Kennie, & Willson, 2006 ; Renders et al., 2001; Saxena et al., 2007); however, this illness remains a critical problem and challenge for all concerned. In this regard, it appears that the determinants enabling treatment management of diabetes are still crucial areas which need to be further explored to better understand the underlying behaviours and patterns practiced by patients with T2DM.

A list of diabetes mellitus studies and related information was compiled (Clinical Research Centre Malaysia, 2015), with a total of 14 books, and including book chapters, guidelines, reports and proceedings, 93 dissertations and theses by Malaysian students, 46 review papers, editorials and commentaries, and 388 original research papers - of which 97 were focused on the primary care setting, and 19 of which were case reports. Although these studies described the prevalence of health-seeking behaviour among patients with diabetes, they primarily used quantitative approaches with pre-identified variables. None of the studies explored an in-depth understanding of the help-seeking processes and how patients with T2DM make decisions regarding the type of treatment they pursued. In addition, no substantive theory or model currently exists to describe the process for selection of diabetes treatment among patients with T2DM in Malaysia,

particularly with regard to how treatment strategy and decision-making processes affect the type of treatment chosen by patients with T2DM. Thus, the theory derived from the emerging exploratory data of this study will aid in explaining how the model functions in Malaysia. This information can further inform policy changes regarding diabetes programmes offered by the Malaysian government.

#### **1.4 Research Objectives**

This study addresses the following objectives:

- a. To explore issues that determines patient treatment strategy.
- b. To explore the process of patients manoeuvre through the current healthcare system and selecting a T2DM treatment method.
- c. To develop a substantive theoretical model that can explains the type of treatment to be adopted by patients with T2DM in a primary care setting.

#### **1.5 Research Questions**

To meet the research objectives, two questions were formulated to understand the type of treatment to be adopted by patients with T2DM in a primary care setting in Malaysia. The term ‘treatment strategy’ is strategy or approach adopted by patients when deciding the type of treatment for diabetes.

- a. What are the underpinning issues that determine patient treatment strategy?
- b. How do these determinants interact and influence each other in selecting and deciding on treatment options in the current Malaysian primary healthcare system?

#### **1.6 Study Scope**

This study was confined to the primary care setting in Malaysia, and the study participants were patients with T2DM that were seeking treatment at primary care

clinics (in both public and private settings). The purpose of selecting patients with T2DM was based on the fact that T2DM accounts for over 90% of all patients suffering from diabetes mellitus in Malaysia (Ministry of Health Malaysia, 2013). Primary care was chosen as a focus due to the fact that nearly 71% of patients with T2DM had sought diabetes treatment at primary care clinics as compared to 27.1% seeking treatment at tertiary care clinics. Based on this rationale, it was deduced an urgent need exists to explore the treatment strategy and its process for patients with T2DM.

## **1.7 Thesis outline**

This chapter has provided the background information dealing with the concern of this study and it also provided a brief overview of the Malaysia healthcare system. The chapter was also followed by the rationale of the research, research objectives, research questions and scope of the study.

Chapter 2 includes a literature review through an overview of existing empirical studies related to issues related to this study. In particular, it provides a review of literature related to diabetes mellitus, including background information on diabetes and treatment management as well as access to diabetes care. This is followed by a discussion of studies related to help-seeking behaviour. The final section highlights the information gap which results in the need for this study and development of a substantive theoretical model which helps to explain how patients with T2DM interact with the Malaysian healthcare system when seeking treatment, with a focus on the primary care setting.

The Methodology section in Chapter 3 is divided into two parts; the first part explains the justification of the research methods, while the second part provides details regarding sampling strategies, data collection processes, data analyses, and discuss of data rigours.

Chapter 4 presents the findings of the empirical data, which applies the grounded theory approach. The results are organised based on an emerging substantive theoretical model which focuses on the “core category” (i.e. the main category that explains the model). The subcategories forming the entire process of the treatment strategy will be explained in greater detail by providing data (excerpts) from the participants.

Chapter 5 entails the discussion section, which illustrates key findings as well as the emerging theoretical model, subcategories, and the overall process of the model which explains the treatment strategy used by patients with T2DM in managing their illness. The emergent theory will be discussed in relation to existing theories and models. Here, the strengths and limitations of the findings will also be discussed.

Chapter 6 concludes with the implications of the practice, recommendations, and future directions for this area of research.

## CHAPTER 2: LITERATURE REVIEW

### 2.1 Introduction

A literature review that is relevant to the topic of this study is important to address the process of fulfilling the thesis. In particular, this chapter aims to identify the knowledge gap which has been explored through past studies. As stated in Chapter 1, the primary aim of this study is to develop a substantive theoretical model that can be used to explain the process of treatment strategy made by patients with T2DM. Constructivist grounded theory was adopted for this study. An initial review of relevant literature is essential, as it explores the information gap related to the management of diabetes, treatment strategy, and help-seeking behaviours. For the purpose of understanding patients' treatment-seeking behaviours, it is crucial to consider the following key elements.

- A basic understanding of diabetes and its symptoms, risk factors, and complications.
- The severity of diabetes, its prevalence, and its burden to the Malaysian healthcare system.
- The influence of social networking on diabetes management.
- How patients with T2DM access and utilise diabetes treatment.
- Areas of help-seeking behaviour being studied in relation to diabetes.
- Existing models for understanding patients' behaviour in seeking diabetes care.

Following these six key elements, this chapter is divided into five sections. The first section introduces and revisits the aim of this study. The second section (2.2) describes diabetes-related information by providing an overview of diabetes mellitus and its management, followed by an overview of diabetes epidemiology in a global context as well as in the Malaysian context. This section also explores the utilisation of diabetes

care. The third section (2.3) further explains health-related help-seeking behaviour and also examines previous studies related to help-seeking behaviours. The fourth section (2.4) discusses relevant theories, and a review of various models used in previous studies to explain help-seeking behaviours is also included. Section five (2.5) reviews the knowledge gaps identified in previous studies and leads into the rationale for conducting this study. Finally, this chapter ends with a summary (2.6).

## **2.2 Diabetes Mellitus**

### **2.2.1 Type of Diabetes Mellitus**

Diabetes mellitus, commonly known as diabetes, is a very common disorder among non-communicable diseases. Essentially, it is a condition in which blood glucose levels are above the normal limit (Fasting plasma glucose  $\geq 7.0$ mmol/l (126mg/dl))(World Health Organization, 2006). This condition could be due to insulin resistance (where the body does not react well to insulin) or decreased insulin production by the pancreas, as without insulin, glucose is unable to enter cells for the provision of energy (International Diabetes Federation, 2013; World Health Organization, 1999).

There are three main types of diabetes: Type 1 diabetes mellitus, T2DM, and gestational diabetes. Type 1 diabetes mellitus is also known as juvenile-onset diabetes and typically occurs among young adults or children, requiring long term treatment with daily insulin injections. T2DM is also known as adult-onset diabetes, and is more common among adults. T2DM can occur at any age and detection or diagnosis of T2DM is typically made when a person experiences symptoms or complications, during a routine blood glucose test, or when seeking treatment for other health problem. The third type of diabetes is called gestational diabetes, and is a condition which develops during pregnancy and is normally diagnosed through antenatal screening. Gestational diabetes usually disappears after pregnancy; however, women who experienced

gestational diabetes have a higher potential for developing T2DM (International Diabetes Federation, 2013).

The common symptoms experienced by patients with diabetes include fatigue, increased thirst, frequent urination, increased hunger, and loss of weight. Diabetes is a risk factor for cardiovascular disease and other chronic complications. Diabetes complications include diabetic retinopathy (damage to eyes leading to blindness), diabetic nephropathy (damage to kidneys leading to renal failure), diabetic neuropathy, coronary heart disease, cerebrovascular disease, diabetic foot (leading to amputation), erectile dysfunction, and periodontal diseases. Although some complications may not result in death, they certainly result in poor quality of life (Kamarul Imran, Ismail, Naing, & Wan Mohamad, 2010; Mazlina, Shamsul, & Saini Jeffery, 2011; Papadopoulos, Kontodimopoulos, Frydas, Ikonomakis, & Niakas, 2007). The differing prevalence of diabetes types and their complications in different parts of the world reflect the underlying differences noted in behavioural, environmental, and social risk factors such as diet, level of obesity, and physical activity (Zimmet, Alberti, & Shaw, 2001; Zimmet, McCarty, & de Courten, 1997) as well as the healthcare delivery system (World Health Organization, 2011b).

This study focuses on patients with T2DM, which constitute more than 90% of diabetes cases. Aside from genetic factors, T2DM is strongly associated with diet and lifestyle. The most common risk factors for developing T2DM include advancing age, family history of diabetes, ethnicity, obesity, unhealthy diet, physical inactivity, and the presence of high blood glucose levels during pregnancy (International Diabetes Federation, 2013). Currently, no known cure for diabetes exists, though the disease can be controlled by taking proper medication and having a healthy lifestyle which includes dietary modification (American Diabetes Association, 2012). T2DM, like many other

chronic diseases, requires strong patient commitment and continuous adherence to treatment plans due to the complexity of treatment and self-management schemes.

### **2.2.2 The prevalence and burden of diabetes**

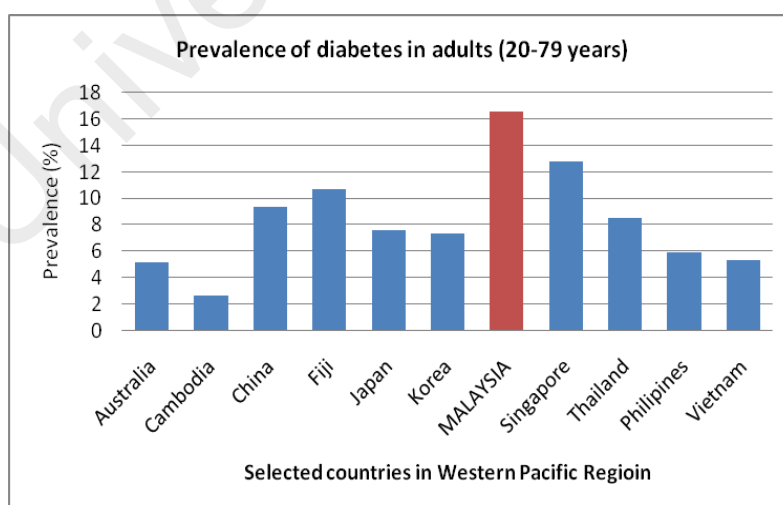
T2DM is a chronic disease affecting millions of adults globally, and the prevalence of the disease is rising. The International Diabetes Federation (IDF) states that the prevalence of diabetes among adults (aged 20 – 79 years) was 6.4% and is predicted to increase to 7.7% by the year 2030. Therefore, between the years 2010 and 2030, there would be a 69% increase in the number of adults living in developing countries with diabetes and a 20% increase among adults living in developed countries (Guariguata et al., 2011; Shaw et al., 2010). The prevalence of this disease is becoming a major burden to the healthcare systems of many countries (International Diabetes Federation, 2013). In addition, this rising diabetes trend is concerning, since it represents a major contributor not only to unhealthy nations, but is also resulting in the rapid rise of healthcare cost and expenditure. This is more prevalent in developing countries, where those who are most heavily affected by T2DM are adults aged 30 years old and above. This represents the core of the working population and contributes to the development of a nations' economy.

In the local context, T2DM represents a major concern in Malaysia as its prevalence among adults aged 30 years and above had increased from 14.9% in 2006 to 20.8% in 2011 (Institute for Public Health Malaysia, 2011; Letchuman et al., 2010). This cause for concern becomes even more crucial when societies similar to Malaysia's are also on the brink of leading an unhealthy and sedentary lifestyle. Among many Malaysians, there is a noticeable trend of many not participating in physical activities while consuming unhealthy diets. Statistics indicate that an increase of convenient food (fast food) intake combined with busy working lives. All of these factors can lead to an



increased risk of developing T2DM, obesity, and cardiovascular disease (Ahmed Al-Naggar, Bobryshev, & Nor Aini, 2013; Johari & Shahar, 2014; Moy & Bulgiba, 2011; Norris et al., 2014).

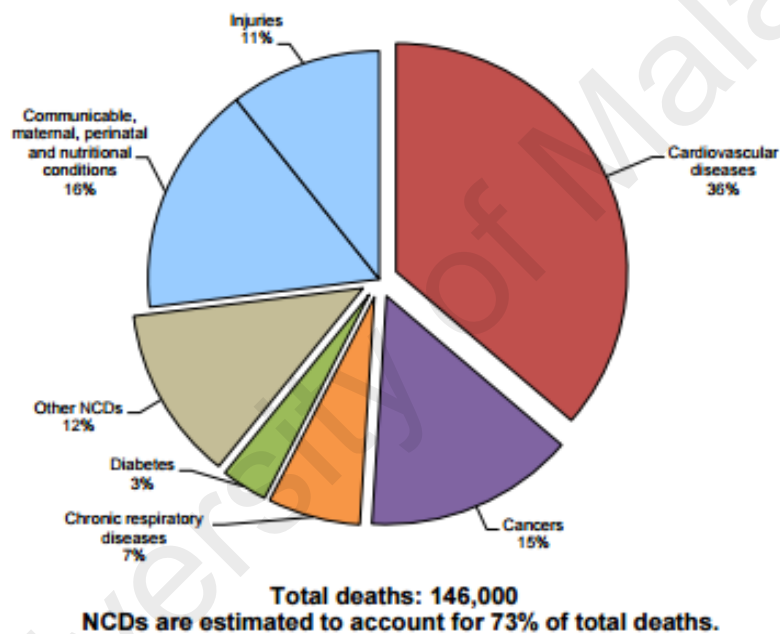
Compared to other countries in the region, data acquired from the International Diabetes Federation (International Diabetes Federation, 2015) showed a concerning increasing in diabetes prevalence among adults in Malaysia when compared to other countries in the Western Pacific region (Figure 2.1). Furthermore, an increase in diabetes complications occurred due to uncontrolled blood sugar levels, which represents a more alarming situation. This condition might partly be due to patients' help-seeking behaviour, where only a small percentage of those with T2DM had received modern treatment at public health centers. Patients exhibited poor performance in controlling their HbA1c, as evidenced by a nationwide study conducted among public primary health clinics and hospitals (Mastura et al., 2011). Due to these inadequacies, it is timely to investigate how patients with T2DM manoeuvre through the Malaysian healthcare system. This includes an investigation of how patients seek alternative and complementary treatments for their illness.



**Figure 2.1: Prevalence of diabetes in adults (20 to 79 years old) in the Western Pacific region**

*Source: IDF, 2014 (WP – Western Pacific)*

In 2013, the International Diabetes Federation reported that the death of 5.1 million people globally was caused by diabetes. In Malaysia, diabetes is among the top 10 diseases, especially among females. Diabetes was ranked 5<sup>th</sup> among 111 diseases in the year 2000 and it was estimated that 2,261 deaths were attributed to diabetes alone (Institute for Public Health Malaysia, 2004). The World Health Organization's country profile for Malaysia (World Health Organization, 2014) indicates that diabetes contributed to 3% of deaths in 2014, representing 73% of the total deaths occurring due to non-communicable diseases (NCD) in Malaysia (Figure 2.2).



**Figure 2.2: Proportional mortality, Malaysia (% of total deaths, all ages, both sexes)**

*Source: World Health Organization - NCD Country Profiles, Malaysia, 2014*

In terms of financial burden, the lifelong process of T2DM treatment is expensive and burdensome to both patients and the country. The International Diabetes Federation estimated that at least USD548 billion was spent worldwide on health expenditures related to diabetes in 2013 (International Diabetes Federation, 2013). In Malaysia,

several studies were conducted at isolated localities which measured the economic burden that this T2DM puts on patients, including the cost of outpatient and inpatient treatments. It cannot be denied that the economic burden of diabetes treatment is substantial. The costing study had reported that patients had spent even more on alternative and complementary medicines for diabetes treatment (Wan Norlida et al., 2014). Another study compared diabetes to other chronic diseases, and discovered that the cost for diabetes treatment can be 66% more than the treatment for a fever (Mazura et al., 2011).

Addressing the increasing prevalence and burden of diabetes represents a major challenge faced by many countries, including Malaysia. Various organisations have worked together in attempting to develop some intervention strategies and treatments to improve the conditions and complications of diabetes. The Chronic Care Model (CCM) is a conceptual framework which was introduced over a decade ago for the purpose of providing a method of chronic disease management (Bodenheimer, Wagner, & Grumbach, 2002; Wagner et al., 2001). Extensive reviews regarding barriers and facilitators of adapting this model in local setting have been published (Kadu & Stolee, 2015). The World Health Organization further modified this model, creating the Innovative Care for Chronic Conditions model (World Health Organization, 2002), which has been adopted by many countries with the aim of improving diabetes management. However, the outcome of such interventions has not been satisfactory. This is due to the inherent barriers and challenges present in the application of this model to the real world (Bodenheimer et al., 2002; Chia, 2013).

In the management of diabetes, patients are expected to adhere to a complex set of behavioural modifications to manage their illness on a daily basis. Certainly, this imposition on patients can increase their personal burden not only for treatment cost,

but also in their personal lives through modifying their lifestyles and maintaining a healthy diet. These adjustments, whether big or small, can incur extra expenses for patients with T2DM. Therefore, it is evident that the management of diabetes as an illness requires not only just drug therapy, but also the need to address other social determining factors. Patients must also find a balance between accommodating both the treatment plan and their desired quality of life (Pera, 2011). Even if patients were successful managing their blood sugar level, there are always dilemmas to face when the recurrence of symptoms or the required adherence to a management plan disrupts patients' daily routine. In this regard, it cannot be dismissed that understanding the management of diabetes is an area of concern for many health experts, health researchers as well as policy makers in the non-communicable disease field. The following sections discuss issues related to the management of diabetes and previous studies in this field.

### **2.2.3 The challenge of managing diabetes**

In the absence of a cure, T2DM requires proper glycaemia control with medication and long-term lifestyle adjustments (Centers for Disease Control and Prevention, 2011). The management of diabetes very much depends on the patient's own effort and responsibility in self-management, which ranges from dietary modification (eating healthy foods), engaging in appropriate physical activities, adhering to treatment regimes, and monitoring of glycaemic control and diabetes condition (Peel, Douglas, & Lawton, 2007; Shrivastava, Shrivastava, & Ramasamy, 2013). The ultimate goal of diabetes management is to maximise comfort, reduce symptoms, and prevent the progression of complications while preserving quality of life. Thus, the treatment strategy applied by patients with T2DM is part of the help-seeking behaviour process.

Moreover, diabetes not only affects patients but also their family members and caregivers (Rosland, 2009). The help-seeking strategy applied by patients represents an essential part of the lives of these patients and their families. A patient's socio-cultural background, experiences, and personal beliefs have a sizeable impact on diabetes management (Mani, Caiola, & Fortuna, 2011). It is evident that diabetes affects not only the individual but also the society and nation, a topic which previous studies have explored extensively (House, Umberson, & Landis, 1988). Social support plays important role in diabetes management (Kadirvelu, Sadasivan, & Ng, 2012; Miller & DiMatteo, 2013; Rintala, Jaatinen, Paavilainen, & Åstedt-Kurki, 2013). Therefore, successful management of diabetes requires teamwork involving the patients, their family members, and healthcare providers (HCPs) (Samuel-Hodge et al., 2000).

As mentioned in Chapter 1, the information provided by the various bodies such as the Ministry of Health, mass media, and other diabetes related non-government organisations have always imparted a strong message to the public about the growing prevalence of diabetes in Malaysia. Various programmes related to diabetes awareness and the nature of diabetes, its symptoms and complications, the risk factors involved, diabetes prevention as well as self-management skills had also been emphasised (Ministry of Health Malaysia, 2010b). In spite of this type of health promotion aimed at raising awareness and knowledge about diabetes and its management, the percentage of diabetes complications continues in an upward trend (Hooi et al., 2013; Ministry of Health Malaysia, 2013; National Renal Registry Malaysia, 2004). This implies that such promotions and programmes have failed to create a direct positive change of attitude and behaviour among the general public as well as diabetes patients. Why have these efforts not directly translated into positive change? Is it due to patients' help-seeking behaviours? Hence, it is timely to possess an in-depth understanding of patients' treatment-seeking behaviour and how they interact with the healthcare system.

A study conducted of people with diabetes in 2004 (Rampal et al., 2010) and a recent nationwide survey in 2011 (Ho et al., 2015; Mastura et al., 2011) have indicated that among those who had been diagnosed with diabetes, only a small proportion had sought treatment and were in control of the disease. This scenario had puzzled many medical experts and stakeholders, and it has not been determined whether this is due to a failure of the healthcare system, the social issues, or whether it is related to the help-seeking behaviours of patients with diabetes.

Essentially, a good healthcare system must provide better access to affordable diabetes treatment to their patients. The goal of many countries includes an aim towards providing a better healthcare system and a reduction in barriers to utilisation of diabetes care. In this regard, it appears that access and utilisation of diabetes care should become important areas of healthcare research.

#### **2.2.4 Access and utilisation of diabetes care**

Access to diabetes care is an on-going topic of discussion, particularly when faced with the issue of barriers to appropriate diabetes care. Thus, this subsection will further discuss barriers to diabetes care. Two main factors contribute to barriers to access and utilisation of diabetes care: healthcare system factors and personal factors. Factors related to healthcare systems include the accessibility, affordability, and availability of diabetes care. Personal factors include a patient's knowledge and perceptions of the illness and their disease progression.

##### **2.2.4.1 Healthcare system factors**

Despite advances in medical technology and diabetes treatment, it appears that accessibility to quality diabetes care, especially in modern medicine, still poses a challenge to many patients worldwide. To understand these barriers, many studies have been conducted in developing and developed countries. It was discovered that common

barriers included financial constraints, accessibility, as well as the lack of social and family support among the illiterate (Abdullah et al., 2009; Gary, Narayan, Gregg, Beckles, & Saaddine, 2003; Gonzalez, 2008; Rhee et al., 2005). Studies have determined that patients living in poor neighbourhoods with poor resources in developing countries often face more barriers compared to those in developed countries. Even in developed countries, where advancements in healthcare systems are good, it appears that such healthcare systems may not be fully utilised by certain populations, such as minority groups, due to financial issues in countries without universal health coverage. Furthermore, since healthcare systems differ between countries, some patients are financially constrained due to lack of free medical care, which prevents accessibility (International Diabetes Federation, 2014) especially among minority populations (Gary et al., 2003; Hippisley-Cox, Yates, Pringle, Coupland, & Hammersley, 2006; Miller et al., 2004; Rhodes, Nocon, & Wright, 2003). From this perspective, it is evident that healthcare disparities among countries may also compound the issue by impeding healthcare access. Furthermore, the lack of access to high quality care by the majority of patients with diabetes contributes to a high percentage of poor outcomes, with many facing uncontrolled disease complications (Saydah, Fradkin, & Cowie, 2004). Moreover, even with healthcare provision, travel time may also create burdens related to costs and transportation, (Littenberg, Strauss, MacLean, & Troy, 2006; Probst, Laditka, Wang, & Johnson, 2007) and represents a barrier for patients travelling long distances to their respective health centres (Mattson, 2010; Strauss, MacLean, Troy, & Littenberg, 2006).

As previously mentioned, affordability and accessibility are two important components related to patient access or utilisation of healthcare. Patients make their own decisions regarding the type of care, the place of treatment, and the time of treatment, depending on their financial capabilities and the accessibility of healthcare

facilities. Although countries such as the USA and Canada have advanced diabetes treatment, their healthcare systems can still be challenging for patients due to increased healthcare costs, resulting in many people becoming dependent on their limited health insurance (Kinney, 2009; Mackey et al., 2012). The lack of health insurance, whether at the level of private health insurance, drug benefit care, or Medicaid, represents a healthcare access barrier for many (Driscoll & Bernstein, 2012; Goudge, Gilson, Russell, Gumede, & Mills, 2009; Kullgren & McLaughlin, 2010). It is obvious that without health insurance, especially for private healthcare, many patients would be financially burdened since diabetes is a costly disease to treat. Therefore, without insurance, many would be unable to gain any access to healthcare. This issue is further compounded in many developing countries where free access to public healthcare facilities does not exist (Brown & McBride, 2015).

Aside from affordability and accessibility, availability also represents another important factor contributing to the impact of healthcare utilisation. The availability of services and types of treatment, as perceived by patients, may include the adequacy of clinical resources. Healthcare systems vary from country to country and the “perfect healthcare system” simply does not exist. Due to this, it was determined that the main barrier preventing patients from seeking healthcare is their socio-economic status (Sohal, Sohal, King-Shier, & Khan, 2015). For instance, even if diabetes care services were made physically accessible by locating them closer to the patient, the fact that different types of healthcare are needed for treatment becomes the issue, which is difficult to address due to resource shortages, which remains a challenge for many countries (Beran & Yudkin, 2010; Larme & Pugh, 2001). Although accessibility to health facilities could be resolved, a lack of availability can also impede patients from receiving the best possible treatment. Patients with diabetes are at risk of developing complications (Ministry of Health Malaysia, 2009; World Health Organization, 1999).



Although some of these complications may not result in death, they can lead to a reduced quality of life and incur high long-term care costs. Therefore, patients are encouraged to seek proper medical treatment and to access appropriate health care service. In doing so, the continuity of their treatment can be ensured and compliance to treatment regimes adhered to, which is crucial for successful disease management.

Accessibility and affordability challenges represent barriers to diabetes treatment, and can result in poor patient adherence to medication (Chia, 2008), missed appointments, and loss of specialist care privileges due to an inability to keep clinic appointments (Karte et al., 2004; Nguyen, Dejesus, & Wieland, 2011). Additional issues relate to convenience and flexibility, including flexible opening hours of healthcare facilities and accommodation of individual patient needs to ensure proper treatment management (Miller et al., 2004) can be practised, and non-compliance to treatment regimes can be reduced where medical supplies are always accessible.

#### **2.2.4.2 Personal factors**

In countries with good healthcare accessibility, diabetes management, particularly treatment adherence and control continues to pose a challenge; hence, barriers go beyond accessibility. Personal factors also play a major role in accessibility; a patient's self-competency in seeking reliable and appropriate information on diabetes and its treatment is crucial. It is equally important for patients to be able to access and evaluate information received from various sources. With advances in technology, seeking health and diabetes information from the internet and social media has become a new trend (Cooper & Kar, 2014; Men et al., 2012). Patients with adequate and appropriate health information concerning their illnesses are more empowered and have a greater understanding of their illness and treatment information. Therefore, such patients are more competent and confident in dealing with their illnesses (Nam, Chesla, Stotts,

Kroon, & Janson, 2011). However, ensuring that these patients seek or receive appropriate information from reliable sources is a challenging task, especially with a growing wealth of information from the internet and social media - which is often unfiltered and unverified. As a result, inappropriate health information may generate misconceptions regarding diabetes treatment which creates higher-risk behaviour among patients.

Diabetes is also known as a “silent killer” because it shows no significant symptoms until patients exhibit a more advanced stage. Hence, many people unknowingly ignore diabetes and its complications. The disease is so insidious that some people with diabetes may often feel perfectly fine until the disease has reached a serious stage, which tends to make people think that no problem exists until it is too late. There are cases where people, though knowing or suspecting that they have diabetes, deliberately delay seeking care. This affects their condition, while some completely ignore their illness in a state of denial. Such attitudes represent obstacles to diabetes treatment, and such patients would be more likely delay seeking care (Rhodes et al., 2003) or discontinue treatment (Kolling et al., 2010) altogether.

Patients’ behaviour in seeking care is complex and varies greatly among individuals. The decision to seek care encompasses various reasons such as when, where, and what type of treatment. Other factors include patients or their family members’ culture and beliefs (Nguma, 2010; Ward, Mertens, & Thomas, 1997), aside from the healthcare system itself (Zgibor & Songer, 2001). Ideally, if the views of family members and healthcare providers on patients’ treatment management could be further explored, it would be possible to determine the factors influencing help-seeking behaviour in patients. These factors could then be addressed in order to improve healthcare systems.

An exploratory study conducted in Uganda determined that many patients with diabetes switched from modern healthcare to traditional medicine as a result of their failure to access healthcare (Hjelm & Atwine, 2011). However, this study did not heavily explore the type of healthcare failure, but simply determined that financial burden was cited by patients with T2DM as the main cause for turning to traditional medicine. Interestingly, other studies found that patients with T2DM turned to traditional and complementary medicines for a variety of reasons, including affordability, perceived effectiveness, easy accessibility and availability, common use by others, convenience to take, the patients' educational background, and the patients' dissatisfaction with modern medicine (Hasniza, Tan, Samsinah, Rokiah, & Riyanto, 2009; Niswah, Chinnawong, & Manasurakarn, 2014; Robinson, Lorenc, & Blair, 2009; Rutebemberwa et al., 2013; Thorsen & Pouliot, 2015). Thus, variation existed in the patients' choice of modern medicine as well as traditional medicine for diabetes treatment. An in-depth understanding of patients' choice of treatment and the different strategies in their decision-making process would prove valuable. Therefore, the aforementioned issues are critical and warrant further exploration.

Understanding patients' treatment strategy and how patients interact with healthcare systems when managing diabetes can provide information which can aid the relevant authorities in designing an improved diabetes prevention programme while developing a system of appropriate treatment management schemes. A comprehensive approach is needed to investigate factors underpinning the choice of treatment strategy and the process of making the choices in patients with T2DM instead of simply focusing on the factors influencing patient choices. To explore patients' treatment strategy processes, an understanding of the existing knowledge related to help-seeking behaviour among patients with T2DM is essential. The following subsections outline previously studied

issues. It will also further explore the concepts and models used by previous studies in explaining help-seeking behaviour.

### **2.3 Help seeking and health-seeking behavior**

The terms “help-seeking behaviour” and “health-seeking behaviour” are sometimes used interchangeably. The definition of help-seeking behaviour is often considered to be difficult and vague to differentiate, thus the same definition may differ in meaning between studies (Rickwood, Thomas, & Bradford, 2012). It is difficult to define help-seeking behaviour in an operational term or in any simple manner since the concept is multi-dimensional. Nursing researchers have tried to outline the concept of help-seeking behaviour by defining it as *“a problem-focused, planned behaviour which involves interpersonal interaction with a selected healthcare professional”* (Cornally & McCarthy, 2011). However, previous studies have defined it as an activity undertaken by someone who needs care for his or her own health problems (Rahman, Islam, Islam, Sadhya, & Latif, 2011; Ward et al., 1997).

Other studies have used the term “health-seeking behaviours” which addresses the process of healthcare-seeking. This involves the process of seeking care, including self-care, self-medication, traditional healing, as well as modern or western treatment and factors which either assist or prevent people from making decisions regarding their own healthcare (Mackian, 2003). This health-seeking behaviour is preceded by a decision-making process that is further governed by individual and/or household behaviour, community norms and expectations as well as provider-related characteristics and behaviours. The interplay of certain factors is central in the final choice of a care-seeking option. This complex behaviour is part and parcel of illness management by patients, and involves various treatment-seeking strategies and coping behaviours in order to cure or restore their quality of life. Additional studies have focused on

healthcare-seeking behaviours or the utilisation of healthcare. Here, the healthcare-seeking behaviours emphasise the “end point” which investigates the utilisation of the formal healthcare system provided. These studies also included an investigation of barriers to healthcare. However, for this thesis, the term “help-seeking behaviour” will be used.

Although the list of literature reviewed is not exhaustive, it nevertheless provides a brief overview of the area of study across regions, while investigating the prevalence of various illnesses through diverse methodologies and approaches. Many of these studies also explored descriptive or specific reasons for health-seeking behaviour, such as patterns of health-seeking behaviour including choices of treatment facilities or services (Amal, Paramesarvathy, Tee, Gurpreet, & Karuthan, 2011; Bhojani et al., 2013; Bourne, 2009; Ngugi, 1999; Shaikh & Hatcher, 2004; Waweru, Kabiru, Mbithi, & Some, 2003), when to seek care or delay in diagnosis or treatment (Pronyk, Makhubele, Hargreaves, Tollman, & Hausler, 2001; Smith, Pope, & Botha, 2005; Yardimci & Mert, 2014), barriers to seeking healthcare (Andersson et al., 2013; Gotsadze, Bennett, Ranson, & Gzirishvili, 2005; Ladha et al., 2009; C. Shaw, Tansey, Jackson, Hyde, & Allan, 2001) as well as health information seeking norms (Manafu & Wong, 2012; Mayer et al., 2007; Riiskjær, Ammentorp, Nielsen, & Kofoed, 2014) and the influence of family members or society in decision-making (Abubakar et al., 2013; Al-Mandhari, Al-Adawi, Al-Zakwani, Al-Shafae, & Eloul, 2009; Jain, Nandan, & Misra, 2006). While these factors were detected among patients suffering from certain illnesses, patients’ behaviours can change over time. Human behaviour is modifiable and therefore a patient’s experience and the strategy they use in deciding or selecting the best treatment for them is not a one-off process, but rather an iterative process. Each illness experience is unique, and the experience of each episode of symptom and complication also varies. Thus, when exploring help-seeking behaviour and what could make patients select

certain types of treatments, the process patients experience and how they interact with the healthcare system should be considered.

Nevertheless, patient choice of healthcare services and type of preferred treatment varies depending on the individual's priorities. Although financial constraint is often an important factor affecting choice, priorities might change if family members consider treatment as important. This priority may also change if the parties involved have more confidence in the expertise of the medical profession, especially when private healthcare services are available – despite the high expenses incurred. For example, those who prefer private healthcare services as opposed to public healthcare services believe that the former is more capable of providing better quality care in terms of convenience and accessibility through reduced waiting times and provision of better quality services (Jain et al., 2006; Nurul Alam, Khanam, & Hossain, 2000).

Moreover, treatment options may also vary depending on a patients' socioeconomic (Ahmed, Tomson, Petzold, & Kabir, 2005; Mushtaq, Gull, Ahmad Shad, & Akram, 2011 ), type of illness (Ezeoke, Onwujekwe, & Uzochukwu, 2012), severity of illness (Pourreza et al., 2011; Watson et al., 2015), healthcare system, and other factors (Chomi, Mujinja, Enemark, Hansen, & Kiwara, 2014; Shaikh & Hatcher, 2004). The preference of patients seeking traditional treatment is common across many countries including in developed nations. Some may also seek traditional treatment which they perceive to be safer and more effective than conventional methods or modern medicine and that traditional medicine is without dangerous side effects (Rogers, 2010). Seeking alternative treatment can also see among patients with a chronic illness such as diabetes. Much has been described about these factors including their help-seeking. However, among these factors, what is the main factor that governs their help-seeking and how this factor interacts with health system and personal factors remain understudied.

Studies investigating help-seeking behaviours have been of interest to researchers of different disciplines, such as sociologists, psychologists as well as medical experts (Poortaghi, 2015, Anwar, 2012). Their interests may diverge based on their disciplines, though the focus remains the same: human beings and their behavioural patterns. The following section discusses the available models being adopted by other researchers seeking to examine help-seeking behaviours among patients with diabetes.

#### **2.4 Theory of help-seeking behavior and related models**

There are a number of theories and models which have been developed or adapted to investigate what causes a person to behave the way he or she does when faced with health related problems (Mackian, 2003). These were established for the purpose of determining and understanding the how, where, and why of patients' help-seeking behaviours. These models were identified from various disciplines including social (or health) psychology, medical anthropology, and sociology, and they have been applied and used in many studies in areas such as public health, nursing research, and chronic diseases (Hausmann-Muela, Ribera, Toomer, & Grietens, 2012). Each of these models involves a list of domains (variables) and factors that help to explain help-seeking behaviours. Some of the models are specifically for healthcare utilisation while other domains may overlap. Table 2.1 provides a list of domains identified from various models (Brannon & Feist, 2007; Hausmann-Muela, Ribera, & Nyamongo, 2003; Penchansky & Thomas, 1981). It appears that some help-seeking behaviour models share common domains and contain overlapping variables (e.g. patient attitudes and perceptions).

**Table 2.1: Help-seeking behaviour models and list of domains**

<b>Models</b>	<b>Domains / variables</b>
Health belief model (Rosenstock, 1988)	<ul style="list-style-type: none"> <li>• Beliefs about impact of illness (perceived susceptibility &amp; severity)</li> <li>• Beliefs about the consequences of health practices (perceived benefits &amp; barrier)</li> <li>• Health motivation</li> <li>• Cue to action</li> <li>• Socio-demographic and psychological characteristics</li> </ul>
Theory of planned behaviour (Ajzen, 1991)	<ul style="list-style-type: none"> <li>• Attitudes towards behaviour</li> <li>• Subjective norm (socio-demographic)</li> <li>• Perceived behavioural control (personality traits)</li> <li>• Intention</li> </ul>
Health care utilisation model (Andersen & Newman, 1973)	<ul style="list-style-type: none"> <li>• Predisposing factors<sup>1</sup></li> <li>• Enabling factors:               <ul style="list-style-type: none"> <li>- Availability of service</li> <li>- Financial resources</li> <li>- Health insurance</li> <li>- Social network</li> </ul> </li> <li>• Need factors:               <ul style="list-style-type: none"> <li>- Perception of severity</li> </ul> </li> </ul>
Kroeger's model (1983)	<ul style="list-style-type: none"> <li>• Predisposing factors</li> <li>• Perceived morbidity</li> <li>• Characteristics and perception of the disorder</li> <li>• Characteristics of the service and enabling factors</li> </ul>
Penchansky and Thomas model (1981)	<ul style="list-style-type: none"> <li>• Availability</li> <li>• Accessibility</li> <li>• Affordability</li> <li>• Accommodation</li> <li>• Acceptability</li> </ul>

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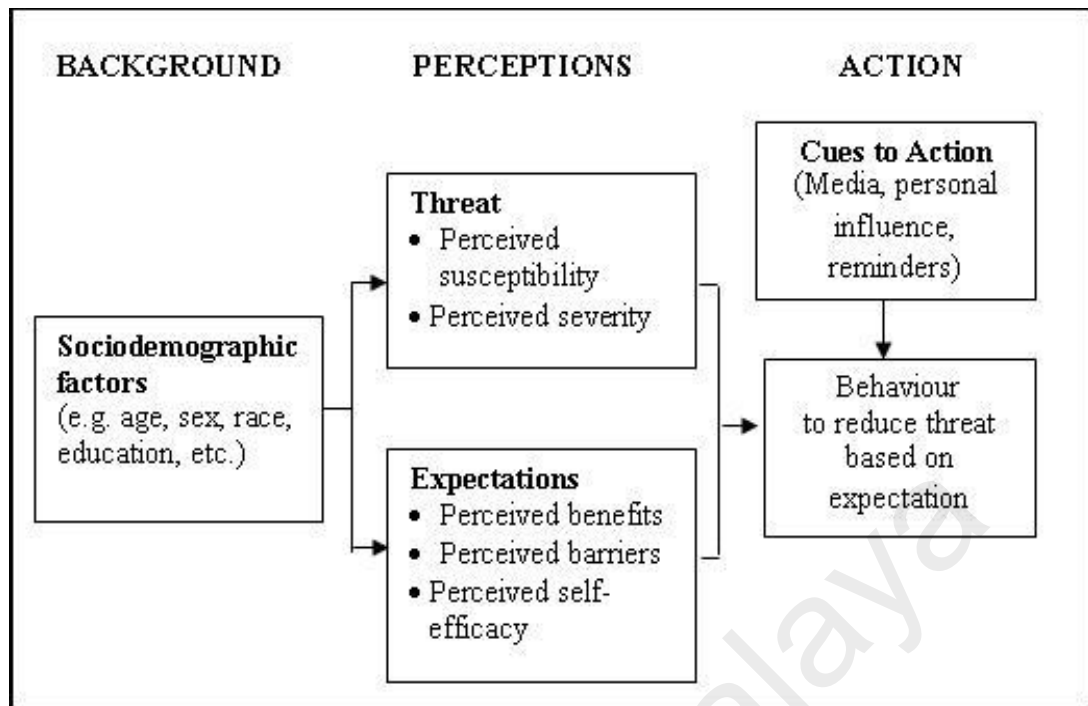
<sup>1</sup> Predisposing factors: age, gender, religions, global health assessment, prior experiences, formal education, attitude towards health services and knowledge about illness



With the many models available, choosing the appropriate ones to explain patients' treatment strategy and decision-making processes with regard to deciding treatment options can be difficult, particularly in attempting to determine which would be the most influential or adaptable. The complexity of understating a patient's help-seeking behaviours and healthcare utilisation is another factor to consider. Therefore, one must focus on the issue being studied, the research questions formulated, and the objectives identified. In the following section, a brief understanding of relevant theories and models most often utilised as research frameworks are presented.

#### **2.4.1 Health belief model (HBM)**

The HBM has been applied in many health-related behaviour studies which aimed at predicting health behaviours, preventive health behaviours, sick role behaviours and utilisation of healthcare facilities (Ghaffari, Tavassoli, Esmailzadeh, & Hassanzadeh, 2012; Turner, Kivlahan, Sloan, & Haselkorn, 2007). The concept was developed by a group of social psychologist in the 1950s with the aim of explaining why groups of people do not utilise healthcare services such as preventative immunisations (Janz & Becker, 1984). Figure 2.3 outlines the basic elements of HBM, which has several constructs based on a person's experience and characteristics, including: "perceived susceptibility" or vulnerability to disease which an individual perceives as the risk of being infected by the illness; "perceived severity", or the seriousness of the disease which a person believes as the impact of the disease and its consequences (threat perception); "perceived benefits", which an individual believes as an advantage gained by taking an action that could provide a positive outcome; "perceived barriers", which refers to perception or awareness of the disadvantages of taking an action or the obstacles that may prevent a successful outcome; "cues to action", which could trigger behavioural change or influence the action; and "self-efficacy", which refers to an individual's sense of self-confidence and ability to take action (Janz & Becker, 1984).



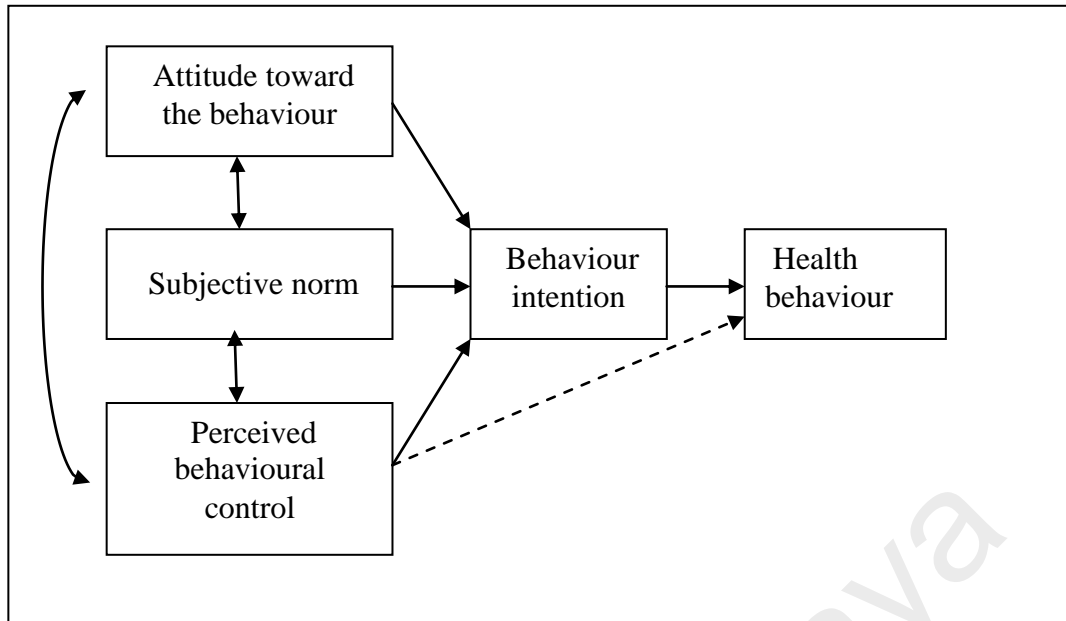
**Figure 2.3: The Health Belief Model (Becker and Janz, 1985)**

Although HBM has been widely applied and adapted to various health behaviour studies, particularly in the areas of exploring psychological dimensions, the flexibility of the model and its variables has made it an adaptable model since it could be used on a variety of behaviours among a diverse population or illness. Thus, this model has been widely applied in diabetes behavioural studies (Rosenstock, Strecher, & Becker, 1988; Zareban et al., 2013), including predicting patient behaviour, the prevention of illness, health-seeking behaviour, and informing health intervention designs in experimental studies (Ahmad, Ramadas, Quek, & Anuar Zaini, 2014). However, this model has also been criticised for its various limitations and its lack of structure. This model has been said to be more of descriptive in nature rather than explanatory, and that it may not be able to predict social influence or environmental, economic, and health system factors that may determine or inform patients' decision-making processes (Denison, 1996). Furthermore, the generalisation of individual behaviours also takes on the assumption that everyone has access to an equal amount of information on an illness, while it

cannot be denied that there is always variation in human behaviours (Harrison, Mullen, & Green, 1992; Norman & Brain, 2005; Orji, Vassileva, & Mandryk, 2012).

#### **2.4.2 Theory of planned behavior**

The Theory of Planned Behavior (TPB) is a theory which links people's attitudes with their behaviours, and represents an improvement from the previous Theory of reasoned Action (TRA). The TPB is commonly used to determine whether an individual's attitude is affected by his or her behaviour and beliefs (Ajzen, 1991). Figure 2.4 outlines the concept of TPB with related variables including attitude towards behaviour (belief and evaluation of the outcome of behaviour), subjective norms (with regard to actions, which believes others supporting the action and motivation will comply), perceived behavioural control, and intentions (intending to take action). The concept of "perceived behavioural control" was added to the TRA to form the TPB (the TRA does not have this variable) with the belief that an individual's intention or behavioural change are not only shaped by a person's perception toward the behaviour and perceived social pressure (subjective norm which a person perceives as the expectation of others) but also involves control belief and self-efficacy. As Ajzen (1986) explained, many other factors can interfere with a person's control over another person's intended behaviour, be it internal or self-efficacy (e.g. a person's skill, abilities, knowledge, and adequate planning) or external factors (e.g. time, cost, opportunity, and the relationship with or cooperation of other people). Thus, a change in a person's behaviour or action taken can be heavily influenced by the positive with which something is evaluated, and how important the person deems the matter to be; for example, how others think they should perform an action.



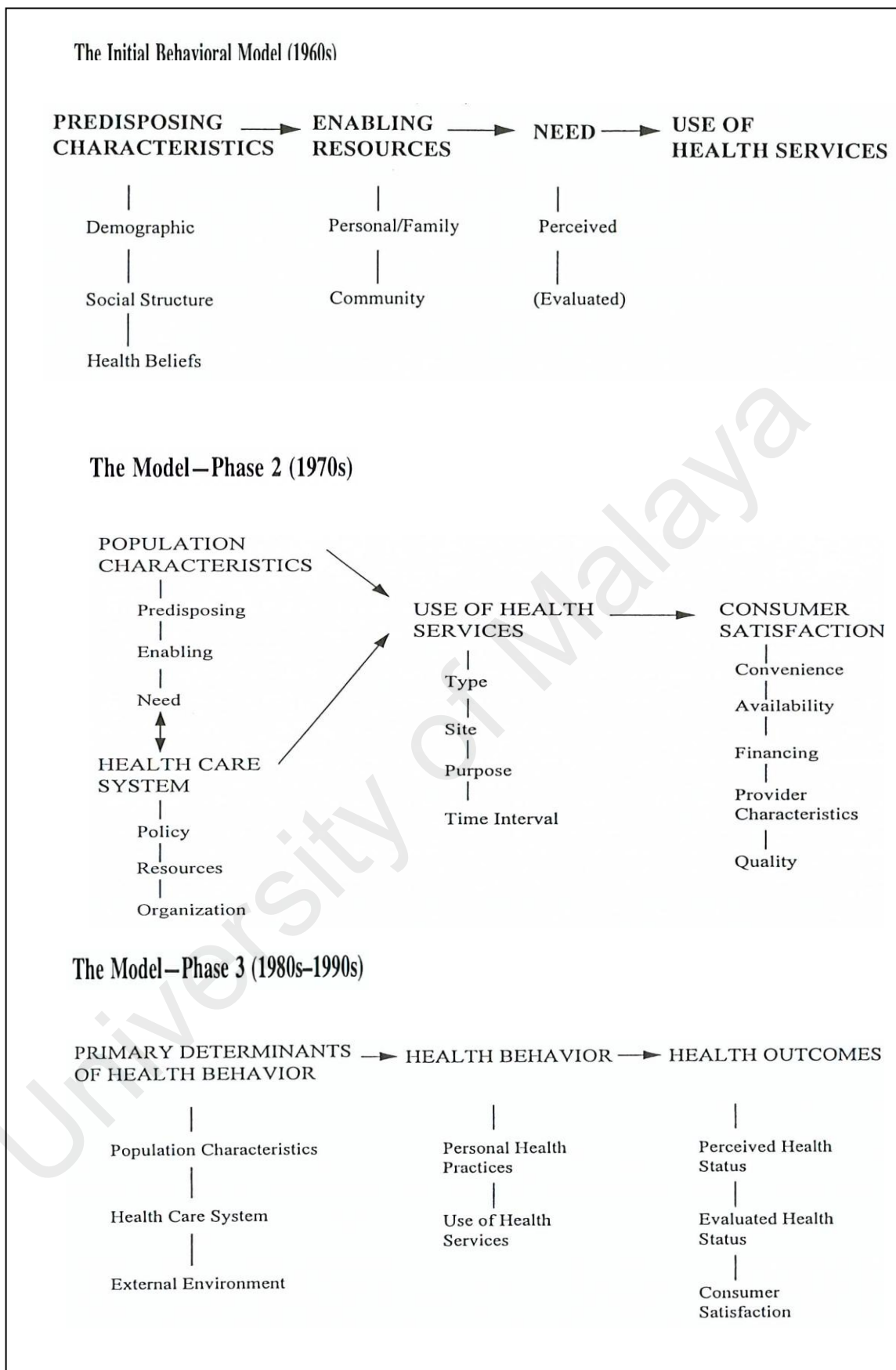
**Figure 2.4: The theory of Planned Behaviour (Ajzen, 1991)**

This behavioural theory has been adopted by studies investigating patients with diabetes which usually investigated patients' attitudes and behaviours. The key element of this model is the encouragement of self-control, which emphasises motivational aspects and the influence of social networks. However, the most common utilisation of TPB in diabetes studies is related to investigating the modification of healthy lifestyles and physical activities (Baker, Simpson, Lloyd, Bauman, & Fiatarone Singh, 2011; Blue, 2007; Boudreau & Godin, 2009; Plotnikoff, Courneya, Trinh, Karunamuni, & Sigal, 2008; White et al., 2012) or medication intake (Farmer, Kinmonth, & Sutton, 2006; Jannuzzi, Rodrigues, Cornélio, São-João, & Gallani, 2014) rather than on care-seeking behaviours or healthcare utilisation. Despite the ability of this theory to link a person's beliefs to their ability to modify health habits, the attitudinal approaches contained in it may not be able to explain long-term behavioural change very well (Taylor, 2009). Particularly for patients with chronic illness, their perceptions regarding the illness often vary, and the risk-perception they acquire may be influenced by their past experiences as well as their environmental and economic factors.

### 2.4.3 Health care utilisation model (Anderson behavioural model)

The Andersen's behavioural model of healthcare utilisation is sometimes called the health services utilisation model. It was initially developed in the 1960s (Andersen & Newman, 1973) with the aim, as quoted from Andersen (1995) *"to assist the understanding of why families use health services; to define and measure equitable access to health care; to assist in developing policies to promote equitable access."* This model is comprised of three categories of determinants: predisposing characteristics (demographics, social structure, and health beliefs), enabling characteristics (availability of services, financial resources, and social network support) and need-based characteristics (perception of severity, perceived needs and clinically-evaluated needs). The model (Phase 2) has been reviewed and refined to include the healthcare system, which consists of health policy, resources, and organisation structure. The incorporation of the healthcare system allows for the inclusion of important components such as the availability of healthcare service types and their categories (e.g. primary or secondary care) which will determine the type of service and when it would be utilised. The model (Phase 3) was further revised to comprise three additional determinants, including primary determinants, health behaviour, and health outcome. The model contains a linear relationship which suggests that primary determinants (patient characteristics or demographics, healthcare system, and external environment) directly cause health behaviour (personal health practices and use of health services) which leads to the determination of patients' health outcome (perceived and evaluated health status and satisfaction) (Andersen, 1995). The three phases of Andersen's behavioural model are shown in Figure 2.5. Andersen's behavioural model has been used and adapted extensively for various health studies, particularly in exploring the utilisation of health services in different diseases (Babitsch, Gohl, & von Lengerke, 2012; Weller, Ruebush, & Klein, 1997) including diabetes (Chen, Popoola,

Radhakrishnan, Suzuki, & Homan, 2015; Gonzalez, Vega, Rodriguez, Tarraf, & Sribney, 2009; Gucciardi, DeMelo, Offenheim, & Stewart, 2008). The review by Babitsch and colleagues (Babitsch et al., 2012) found the revised model of 1995 (Phase 3) to be the model most frequently applied in various studies from 1998 to 2011, with a range of variables being used. However, all of the reviewed studies used quantitative analysis except for one, which developed its own questionnaire that was administered on a focus group. Identifying variables could be added as additional information if the study was more in-depth in exploring the behaviour of patients interacting with the healthcare system and utilisation patterns. Although, the model emphasised the importance of personal and environmental determinants in accessing healthcare services, patients with chronic illness might seek treatment beyond modern medicine, particularly in the many national healthcare systems where complementary and alternative treatments is rapidly growing in popularity. This too could represent another pattern of treatment-seeking behaviours. Thus, recommendations were made for the model to include the category of complementary and alternative treatments utilisation (Fouladbakhsh & Stommel, 2007).



**Figure 2.5: Further refinement of Andersen’s behaviour model of healthcare utilisation from phase 2 to phase 3 (Andersen, 1995)**

#### **2.4.4 Kroeger's model**

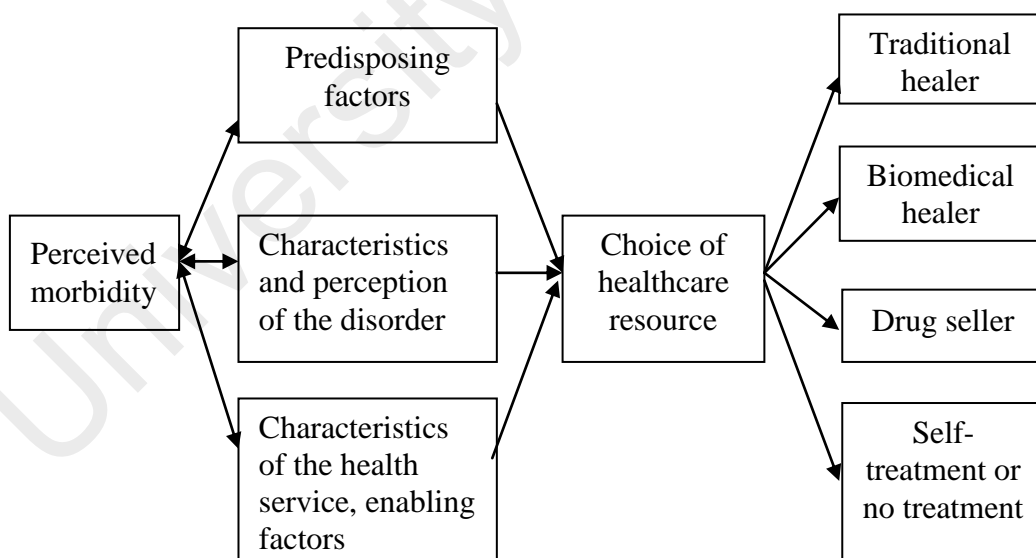
Kroeger's model (Kroeger, 1983) was developed as an extension of Andersen's behavioural model of healthcare utilisation, and proposed interrelated explanatory variables that are affected by the perceived morbidity (Hausmann-Muela et al., 2003) of an individual with different health conditions. Thus, apart from Andersen's predisposing variables/factors, enabling and need characteristics, the additional determinant factor is choice of healthcare options. This model describes the health-seeking behaviour of those who begin to feel or perceive health symptoms and subsequently make choices to either seek treatment or utilise the health services provided, including traditional treatments. Thus, a person's decision to seek healthcare is based on three determinant factors.

The proposed factors, as shown in Figure 2.6, consist of three determinants with different variables. Predisposing factors consist of an individual's characteristics, such as socio-demography, status in the household, household size, degree of cultural adaptation, assets (land, livestock, cash and income), and social network interactions. Other factors include the characteristics of disorder and patients' perception, such as chronic or acute illness, illness severity, aetiological model, expected benefits of treatment (modern versus traditional), and psychosomatic versus somatic disorders. The third factor relates to characteristics of the health service and enabling characteristics, which include accessibility, appeal (opinions and attitudes towards traditional and modern healers), acceptability, quality, communication, and costs.

This model is well-accepted within health-seeking behaviour studies, particularly studies exploring the decision-making process and choice of treatment types (Seeberg et al., 2014; Thorsen & Pouliot, 2015). This model provides a variety of factors that determine a person's choice of treatment within the healthcare system as well as the



treatment option, including self-care and traditional and complementary treatment (Stekelenburg et al., 2005; Webair & Bin-Gouth, 2013). However, the majority of studies on health-seeking behaviour or healthcare utilisation have focused on healthy populations (Chenge et al., 2014; Majumder, 2006). The lack of research conducted regarding the chronically ill or diabetics utilising health services using this model could be due to disease characteristics. Although perception of the disorder is one of the variables, it may not accurately explain the chronic condition of diabetes where patients may not experience serious complications but where diabetes symptoms might affect their quality of life and emotional well-being (Hjelm & Atwine, 2011). A limitation of this model was highlighted by Nguma (2010), who stated that there was a lack of possible explanations to indicate the “why” factor among patients with similar illness severity where some sought immediate treatment and others did not respond at all to seeking care or even delayed seeking care.



**Figure 2.6: Kroeger’s model, 1983**

#### **2.4.5 Perchansky and Thomas's model (access to care)**

Perchansky and Thomas' model shows access to care as a framework that can be used for exploring subjective experiences with healthcare accessibility, as it describes access issues at the interface of patient interactions and encounters with the healthcare system. According to this framework, access to healthcare consists of five distinct dimensions, namely availability, accessibility, accommodation, affordability, and acceptability (Perchansky & Thomas, 1981; Thomas & Perchansky, 1984). The descriptions of these dimensions are presented in Figure 2.7. The model explicitly conceptualises access within a complex healthcare system when provided with the characteristics of healthcare services, the health provider as well as patients' characteristics. In other words, access or accessibility reflects the fit between characteristics and expectations of providers and patients.

- **Availability**  
This is the relationship between the volume and type of existing services (and resources) and the clients' volume and types of needs. It refers to the supply of physicians, dentists and other providers or facilities, such as clinics and hospitals, and of specialised programmes and services.
- **Accessibility**  
This refers to the relationship between the location of supply and the location of clients, taking into account client transportation, resources for travel time, distance and cost.
- **Accommodation**  
This is the relationship between the manner in which the supply resources are organised to accept clients (including appointment systems, hours of operation, walk-in facilities, and telephone services) and the clients' ability to accommodate these factors.
- **Affordability**  
The relationship between prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health insurance. Client perception of worth relative to total cost is a concern, as is clients' knowledge of prices, total cost and possible credit arrangements.
- **Acceptability**  
The relationship between clients' attitudes about personal and practice characteristics of existing providers including age, sex, location and type of facility or religious affiliation of provider or facility, as well as provider attitudes about acceptable personal characteristics of clients, including ethnicity and patient payment source.

**Figure 2.7: Dimensions of access based on Penchansky and Thomas' model on access to care**

The application of Penchansky and Thomas' Model can be useful for describing healthcare utilisation and access, which is one of the main concerns in the healthcare systems of many countries. In this regard, this model presents a complete set of variables that has been used in a number of studies related to healthcare utilisation, particularly in public health studies aimed at exploring the barriers and facilitators of health services. It is a particularly useful indicator for gauging the access to healthcare among chronic disease populations where the condition of the disease requires many needs and long-term treatment. Thus, having access to adequate healthcare is an important indicator for successful treatment management (Elizabeth, Christine, & Bryant, 2015; Kyriopoulos et al., 2014; Metta et al., 2015).

However, despite the commonly-adopted model of the 5As concept (availability, accessibility, accommodation, affordability, and acceptability), there were limitations, including failure to recognise the interdependence between the different dimensions of access, that improvement in the affordability condition is not reflected in the utilisation of care if the other four dimensions are not addressed, and that patients might have other barriers due to other factors (DiGiacomo et al., 2013; Wyszewianski, 2002).

Overall, the theories and models highlighted in this section describe a variety of determinants or factors in health-seeking behaviour, with each model having unique aspects. The interesting feature of all the models discussed is that they present three wide stages in the process of health-seeking or help-seeking behaviour: (i) problem recognition; (ii) the decision to seek help (including what had "triggered" a person's decision to seek medical care, which may include lay referral as well social influence); and (iii) service selection and utilisation, which consists of many variables such as choice of health services or treatment type, where and when to seek treatment, how and under the influence of who to seek care, barriers, and facilitation of access (Zola, 1973).

However, the variables or factors influencing each stage vary depending on the healthcare system, the socio-cultural and economic structure, and the geographical differences (Mackian, 2003). Nevertheless, disease characteristics and the quality of life might propel patients towards a particular treatment-seeking behaviour (Punamaki & Kokko, 1995) which had not been given emphasis. Although Kroeger's model includes the severity of the disease, which may be acute or chronic, as one of the variables that can influence patients' choices of healthcare, nonetheless, even among chronic illnesses such as cancer and diabetes, the treatment-seeking strategy might still differ among patients. Although these established models have been utilised in previous studies, the selection of suitable models for use in explaining the treatment strategy process among patients with T2DM represents a challenge due to the linear relationship process which may not show the iterative process of decision-making among patients selecting their type of treatment. Furthermore, the chronic nature of diabetes, in which the treatment-seeking process is not a one-off event, and requires long-term monitoring of blood sugar level and on-going treatment.

## **2.5 Observed knowledge gap in the reviewed studies**

The complexity of a chronic disease such as diabetes cannot be overlooked as a simple occurrence. An improved understanding of an individual's perception and experience, including his or her treatment strategy process, is needed. A review of previous studies related to help-seeking behaviour occurring in various diseases had shown that a need exists for an in-depth exploration of the emic perspective of people living with diabetes, their family members, and how the healthcare provider's experience and perspective influences patients' decisions in diabetes management. Although the literature review is not exhaustive, a strong dependence on help-seeking behaviour studies conducted in developing countries or on minority groups in developed countries should be avoided. Caution must be exercised in order to be more vigilant in

adopting the available models mentioned. This is due to cultural, political, and economic characteristics being very diverse among both developed and developing countries

The availability of various theories and models for health behaviour as well as healthcare utilisation, particularly for chronic illnesses, is provided with the aim of understanding the various determinants affecting healthcare-seeking behaviours and the process of how this changes. Each model consists of a number of components and various variables contained in each component, some of them exhibiting overlap across models (Noar & Zimmerman, 2005). Furthermore, Hausmann-Muela (2003) criticised the limitations that health-seeking behaviour models had proposed; several issues such as the lack of models emphasising on healthcare providers and the impact of social relation are components that must be addressed. Perhaps a more urgent need exists to explore how patients with diabetes engage in or manoeuvre through the current healthcare system, rather than simply exploring the factors influencing patients' treatment-seeking behaviours – an area which had been extensively studied over the past decade.

Health-seeking or help-seeking behaviour studies focused on the areas of non-communicable disease are relatively new in Malaysia, especially studies using a qualitative approach. The majority of findings were extracted from national health survey data or from disease-specific data (Siti Waringin et al., 2011; Tee, Kaur, Ramanathan, Amal, & Chinna, 2011). However, to the best of my knowledge, to date, no exploratory studies in Malaysia have focused on treatment strategy among patients with T2DM. Though studies focusing on help-seeking behaviour have been conducted elsewhere, Malaysia has a number of undeniably distinct differences when compared to other nations, including a unique healthcare system, demography, culture, and set of

beliefs. Hence, the behaviours described in studies of foreign countries may not be applicable in a local context, nor can the same findings be reflected in Malaysia or its culture. Insight gained from studies of developing countries may not be easily adapted in Malaysia due to such distinctions. It is well-known that diabetes is one of the social determinants of illnesses. Rapid modernisation and globalisation had led to many changes occurring in Malaysian lifestyle, food intake, physical activity and stress level. As a result, certain behavioural changes have been linked to obesity, known as one of the risk factors for developing T2DM. In addition, studies conducted within a pre-determined framework or theory may also be unsuitable for the Malaysian context, as they may limit the exploratory of Malaysian's unique situation, especially for diabetes as an illness.

Grounded theory methodology is known as an approach for theory building (Glaser, 2009). In this regard, using grounded theory methodology would allow this study to embrace the complexity of human behaviours which may be shaped on their own or interact through other experiences and perceptions, as well as the culture, social environment and context of the healthcare system. Thus, the grounded theory approach represents a suitable mechanism to apply for this exploratory study, which explores the subjective and social meaning of illnesses and the decision-making process related to patients' treatment strategy in Malaysia. The grounded theory approach allows theories to be derived from emerging empirical data that can help to explain the treatment-seeking strategy model in the Malaysian context. Additionally, it can provide programme managers with rich and abundant information for developing appropriate future interventions which may also lead to policy changes in diabetes programmes.

## 2.6 Summary

This chapter has reviewed relevant literature related to diabetes, access to diabetes care, health-seeking behaviours studies, and the theories or models that various studies have used in explaining health-seeking behaviours. Diabetes mellitus is a major public health burden that it has become an increasing trend in many countries. Various efforts have been carried out by stakeholders and medical experts to reduce the prevalence of diabetes, its complications, and other risk factors. Since T2DM is a chronic illness with no cure, the patient's own responsibility in self-management and compliance to treatment regimes plays a vital role in keeping their diabetes under control and preventing complications. In this regard, exploring patients' treatment-seeking strategy is a necessary component in understanding overall diabetes management. Various theory-based approaches to health-seeking behaviours have been explored; however, there remains a lack of in-depth understanding regarding the health-seeking process and its patterns.

There is thus a need to gain an in-depth understanding of the decision-making process and underlying issues influencing the selection of treatment strategy among patients with T2DM. The following chapter provides details on the methodology and method used to fulfil the aims of this study.



## **CHAPTER 3: METHODOLOGY**

### **3.1 Introduction**

This chapter discusses the research methodology applied in this study. In section 3.2, the research questions are revisited and discussed. Section 3.3 provides the framework used in this study. Section 3.4 covers the method justifications, while Section 3.5 discusses the research methods used in detail. Section 3.6 provides a narrative outline of reflections of the researcher in relation to the data collection and analysis process of this study. Section 3.7 involves a summary of this chapter.

### **3.2 Revisiting the research objective and research questions**

As mentioned in Chapter 1, this study aims to understand how patients manoeuvre through the Malaysian healthcare system, particularly primary care settings when obtaining diabetic care. The aims include exploring the experiences patients went through in obtaining diabetic care, and subsequently, to develop a substantive theory which can help to explain the process of how patients choose the type of treatment option. Thus, two research questions were forwarded:

- a. What are the underpinning issues that determine patient treatment strategy?
- b. How do these determinants interact and influence each other in selecting and deciding on treatment options in the current Malaysian healthcare system?

These two questions address the rationale of patients choosing among various types of treatment modalities, as well as their treatment strategy process.

### **3.3 Research conceptual framework**

In this chapter, I will use the personal pronoun “I” to refer to myself as the researcher because I believe I am part of every stage of this study, including data collection and analysis. I will describe how I approached the research questions. Then, I will briefly

describe the overall structure of the research. As mentioned in Chapter 1, the research questions were identified based on issues raised by various stakeholders and medical professionals in the field of non-communicable disease. An initial review of relevant literature was undertaken to explore the information gap related to the identified health issues – how patients interact with the healthcare system to obtain care.

The initial literature review also aimed to inform me on the current healthcare system, particularly regarding the function of primary care, while exposing me to how patients managed their illness as well as their help-seeking behaviour. I discovered that interacting with the healthcare system was closely related to the help-seeking behaviour of patients dealing with T2DM. The review of literature in a similar research area provided the insight necessary to narrow down the topic of this research project (Dunne, 2011; Hallberg, 2010) which was initially aimed at exploring the help-seeking behaviours of patients with T2DM. However, it was noted that help-seeking behaviour was too broad for a single study to explore in its entirety. Thus, it was further narrowed down to explore how patients selected particular treatment options and the treatment strategy they used in the process of making their respective decisions.

Although conducting an *a priori* literature review potentially influenced my interpretation of subsequent data, it also rendered my analysis sharper because of my exposure to the vocabulary and culture of patients with T2DM.

The initial literature review revealed a lack of exploratory studies focussing on why and how patients with T2DM decide on the type of diabetic treatment and strategy they prefer. This led me to the research questions and objectives; the nature of the two research questions necessitated an inductive exploratory qualitative approach. Exploring the determinants and how they interact with each other to arrive at the decision on choice of treatment as well as the process of strategy choice would not be possible

through a questionnaire survey – a deductive approach – for two reasons. First, constructing questionnaires to measure the determinants would require constructing a large set of items to ensure coverage of all possible determinants and to ensure that no important determinants are missed. Secondly, using statistical methods to explore the interactions and relationships between these determinants would also be less effective. This is due to the statistical methods required necessitating *a priori* hypotheses, which were not available during the research period. Using generic theories to generate hypothesis would represent an inefficient method – testing many theories to identify the correct one. Hence, an inductive, qualitative approach – which is better suited – was adopted, allowing patients or their mental process of decision-making to be thoroughly explored.

The initial literature review also allowed me to identify the optimal research methods which could be used to explore the process involved in patients deciding on their choice of diabetic treatment. I have chosen grounded theory methodology because it best fits the research questions in this study.

In this research, I have adopted symbolic interactionism as the overarching methodological framework to guide data collection and analysis. Further elaboration of symbolic interactionism and the analysis process will be discussed in the methods section. The final goal of this study is a substantive theory explaining the process of how patients with T2DM choose the type of treatment and their treatment strategy in the current healthcare system. In order to minimise unjustified researcher influence in data collection and analysis, I constantly checked on my stance and participants' stances through self-reflection. I also undertook a member check on my findings to optimise the internal validity of the study. Member checking is the process of finding out whether the data analysis is congruent with the participant's view (Creswell, 2007), section 3.5.9.2

explaining the process. Grounded theory also provided methods for rigour optimisation, which is discussed in detail in section 3.6.

### **3.4 Justification of method**

Viewing knowledge from patients' perspective spans from objectivist on one end to constructivist on the other. The objectivist view of knowledge suggests that meaning is independent of the individual mind and that the view of what it means to know and value are considered to be objectified in the research participants, as seen in a quantitative inquiry. The constructivist view, on the other hand, is based on the assumption that knowledge is constructed by people who are engaged in the world, and meaning is based on their interpretations. Thus, meanings are constructed rather than discovered (Crotty, 1998).

The design of this research involves a constructivist view which regards knowledge as being constructed through interactions between researchers, participants, and the objects around them. I believe that patients' help-seeking behaviour is a result of the meanings they construct from their interactions with the society and the healthcare system in which they engage. Learning to manoeuvre through and interact with a health system is an active and constructive process in which patients with T2DM actively construct meanings and knowledge.

Given that the focus of this study is on the rationale of patients' help-seeking and treatment strategy process, the meanings of their actions will be the underlying focus. I also therefore adopted symbolic interactionism as my overarching methodological framework to guide the data collection and analysis. Symbolic interaction helps to explain how patients with T2DM interact with the current healthcare system in search of diabetic treatment. Symbolic interactionism studies how human beings behave in society and how they act on meanings to generate meanings (Charmaz, 2006; Crotty,

1998). This approach allows for an in-depth understanding of how patients actively interact with people around them and seek information related to diabetes when prioritising and deciding on their treatment type. Furthermore, this approach is optimal in exploring the meaning to the actions taken by patients in making certain decisions as well as in creating meaning as an outcome of their actions, for example, how patients actively select different types of treatment which enable them to achieve a better quality of life.

In line with symbolic interactionism, the study explores how patients make decisions regarding their treatment and treatment strategy process, while grounded theory provides a systematic approach to inductively examine the patterns and rationale of their actions. Also, in line with the purpose of this research, grounded theory enables the development of a substantive theory to explain the underpinning of patients' decisions on their choice of treatment.

Apart from enabling the development of a suitable theory based on empirical data (as opposed to merely testing an existing theory), grounded theory represents a “process” theory (Charmaz, 2006; Glaser & Strauss, 1967) which provides a rich description that goes beyond the experiences and perceptions of any investigation context. Grounded theory also provides a rationale for people to improve their understanding of the entire process of a particular phenomenon or event being studied. This is especially appropriate when there is no model available to explain how a certain phenomenon works. In this case, there is no existing model can be used to understand how patients with T2DM select the treatment strategy when enveloped in a particular healthcare system within a primary care setting – particularly in Malaysia.

### 3.4.1 Brief history of grounded theory

This methodology was first developed by two sociologists, Barney G. Glaser and the late Anselm L. Strauss in the late 1960s. They produced their first book, *The Discovery of Grounded Theory* in 1967 (Glaser & Strauss, 1967). Over the past decade, grounded theory methodology has since ventured into new perspectives and moved from the objectivist grounded theory (by Glaser) to one that is adapted to constructivism by Charmaz (2006).

Charmaz generated a constructivist grounded theory approach which suggests that a grounded theorist should construct the story from the research of participants' voices, views, perceptions, and beliefs based on their personal experiences. This implies that participants' views and the way they construct their world are important features of their experiences, as does how researchers co-construct with participants the process and meaning of actions under investigation. Therefore, when exploring the T2DM patients' insights into how they create meanings out of their actions based on their experiences, we can construct an in-depth understanding of these patients' decisions in selecting their respective treatment strategies.

Charmaz's previous work focused on interviewing patients with chronic illnesses. Thus, her work was applied for the purpose of this research, which explores the behavioural patterns of patients with T2DM by using in-depth interviews (IDI) and focus group discussion (FGD) methods. This method enables the researcher to have an in-depth understanding of the individual actions and perceptions of each research participant during field work (Charmaz, 1990). Each individual's perception and experience, coupled with the respective decision made in selecting the type of treatment, is unique since no one individual shares the exact same experiences. However, the process of arriving at this decision is likely the same. By exploring the patients'

experiences and their actions, it becomes possible to construct a process linking the meaning patients attached to the determinants which subsequently affect the actions they take during the diabetes treatment strategy process.

### **3.4.2 The role of initial literature review in the grounded theory approach**

Review of literature in the grounded theory approach had been debated for over a decade (Hallberg, 2010; Mc Callin, 2006). A discussion regarding the timing involved to undertake the literature review and to what extent literature review should be regarded as adequate before field study (Giles, King, & de Lacey, 2013). According to Glaser's approach to the grounded theory, literature should not be reviewed before entering into field work. Glaser proposed that this would avoid any misconceived assumptions a researcher carries with him/her regarding the issue being studied. However, from the constructivist point of view, a review of some literature is necessary to provide a background for the researcher's theoretical sensitivity, and the process would help the researcher to identify information gaps and clarify any specific ideas to make comparisons (Charmaz, 2006; Giles et al., 2013). This notion is congruent with my approach to constructivist grounded theory, which holds the assumption that data and theory are constructed by both the participant and the researchers. I have thus taken the step of conducting a preliminary literature review to allow me to locate information gaps, to identify recent research approaches, and to become familiarised with the background of the topic and participants of this study. It is important to be open to new information and data from the field and remain cautious of potential differences between background knowledge and the data being observed.

The following section on research methods will discuss data collection, data analysis, and data management. It includes the steps taken by the researcher to minimise bias while ensuring quality and data rigor.

### **3.5 Research methods**

This section explains the research methods adopted in this study, encompassing an overview of ethical considerations, sampling techniques, inclusion and exclusion criteria, data collection, data analysis (including theory development), and data management. The methods chosen for this study are based on the nature of the research questions and methodology as explained in the previous section. Thus, identifying the appropriate data collection methods is essential, which could provide an in-depth understanding and facilitate discussion or interaction between the researcher and participants. As a part of qualitative research procedure, the semi-structured interview approach was deemed more appropriate for this exploratory study rather than structured interviews. It is thus regarded that two methods (IDI and FGD) could provide a good data set compared to other methods of data collection, such as observations, which do not allow a researcher to observe people's thoughts. Moreover, it may not be cost effective to observe patients' behaviours and decision-making processes. Furthermore, the knowledge and experience gained from my previous involvement in qualitative studies had facilitated the field work and data collection for the purpose of qualitative data analysis. With my background as a medical anthropologist, which involved many years in health behaviour studies, this resulted in the development of relevant skills and approaches with regard to interacting with study participants.

#### **3.5.1 Ethical consideration**

Ethical approval was obtained from the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (see Appendix A). In addition, a letter of permission was also obtained from the director of the State Health Department, Selangor, as the study was conducted at two public primary health clinics in State of Selangor (see Appendix B). Prior to the IDIs and FGD sessions, all eligible participants were approached and briefed about the purpose of the study, the data collection process,

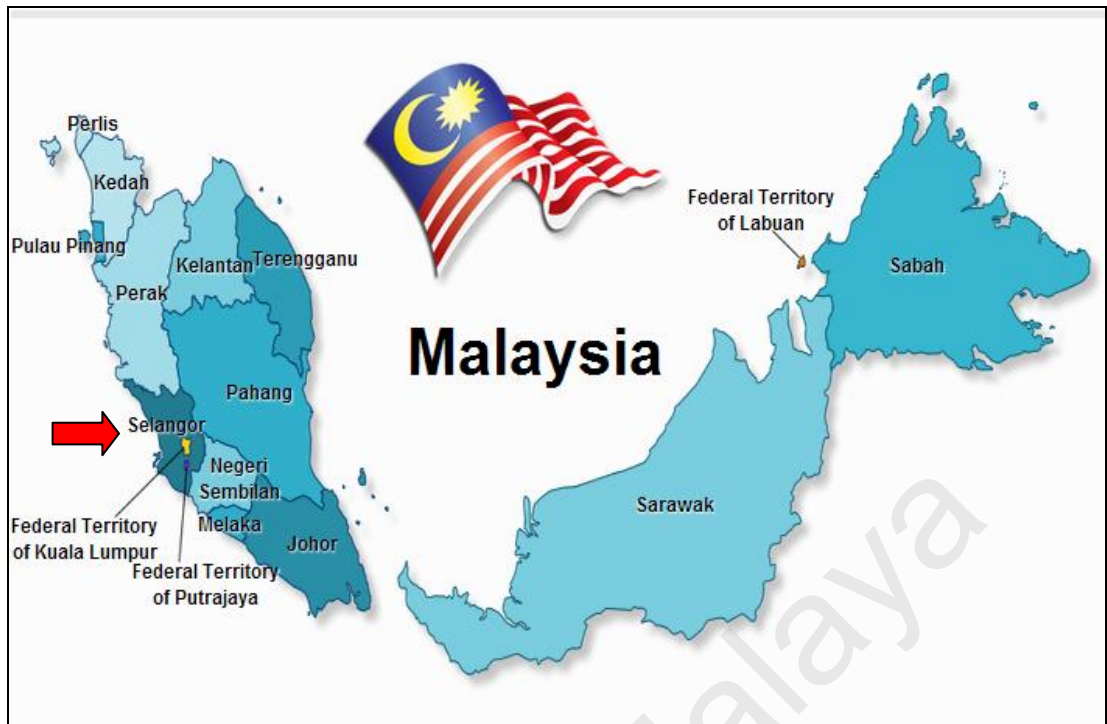


their confidentiality, the use of data solely for the purpose of this project, and to inform them about the policy for improvement of diabetes programmes in Malaysia. They were provided the chance to ask questions and were informed about the voluntary nature of their participation as well as their freedom to withdraw from the study at any time. The information sheets for research participants (see Appendices C and D), provided in two languages (English and Malay), were given to those who agreed to be interviewed. Informed consent (see Appendices E and F) was written in both languages, and the permission to audio-record the interview sessions was obtained from all participants. Participant demographics were acquired from patients, family members, and healthcare providers (see Appendices G, H and I).

The nature of qualitative method which applied to the conversation style communication where sharing of information during the IDI and FGD session was free flowing, with no right or wrong answers. However, sensitivity issues were noted and addressed accordingly in order to avoid any uncomfortable or unpleasant feelings during the interviews. Although the participants' names were used during the interview, all identifying information was concealed in the text, this thesis, presentations, and journal articles for confidentiality and privacy reasons.

### **3.5.2 Study centre**

The study centres included two public (government) primary care centres and five clinics of private general practitioners in two districts in the state of Selangor - one of the thirteen states in Malaysia, as shown in Figure 3.1.



**Figure 3.1: Map of Malaysia and study areas**

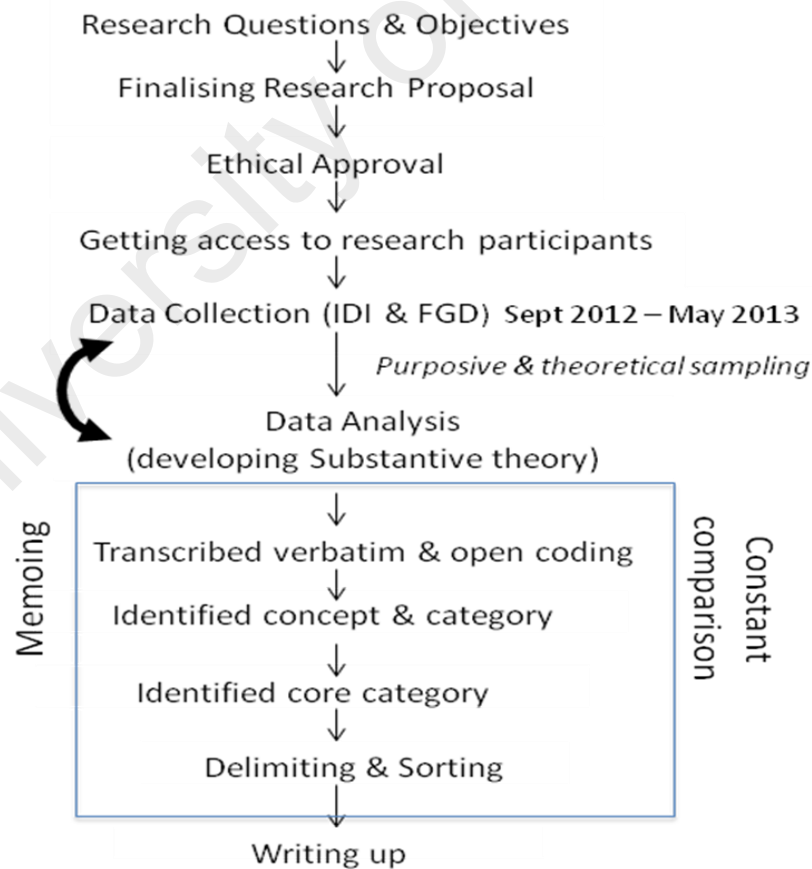
(Source: [https://www.statistics.gov.my/index.php?r=column/cone&menu\\_id=ZmVrN2FoYnBvZE05T1AzK0RLcEtiZz09](https://www.statistics.gov.my/index.php?r=column/cone&menu_id=ZmVrN2FoYnBvZE05T1AzK0RLcEtiZz09), retrieved 1/3/2015)

These two districts were purposively selected with the intention of covering both urban and rural health care facility settings. A rural area is defined as a non-metropolitan area by the National Statistics Department (Department of Statistics Malaysia, 2011). Purposive sampling was used to select the study centre and primary care clinics in these two districts. The two public primary care clinics were chosen based on their geographical locations: one is located in an urban area, while the other is located in a rural area with a mixture in the socio-economic backgrounds of patients. Clinics were identified from a list all public primary care clinic in the state, with both clinics exhibiting the highest number of patients with T2DM in urban and rural settings, respectively. The participation of these private primary care clinics in the study was based on the willingness of the general practitioners. Several general practitioners were approached in both urban and rural areas until a sufficient number of participants were

recruited. There were general practitioners who were reluctant to be interviewed or would not allow patients to be recruited in the study for reasons such as not having patients with T2DM, not having time, their patients being unwilling to be interviewed, concerns about their patients' privacy, and not being interested in research.

### 3.5.3 Overview of research design

As with other qualitative approaches, the steps in grounded theory methods adopted in this study were iterative, as shown in Figure 3.2. Analysis began as soon as data collection started. Data analysis involved coding, categorising, delimiting, and sorting. These analytical steps were conducted alongside constant comparison and memoing. The data collection and field work was conducted over nine months, from September 2012 to May 2013. Research steps are outlined in Figure 3.2.



**Figure 3.2: Overview of research process**

#### **3.5.4 Sampling process (purposive & theoretical sampling)**

Two sampling methods were employed for selection of study participants: purposive and theoretical sampling. Purposive sampling is widely used in qualitative research; it involves the deliberate choice of study participants who fulfil the criteria relevant to research objectives (Creswell, 2007). The purpose of theoretical sampling was to collect data from a specific group of people or place which would maximise opportunities to develop concepts in terms of their properties and dimension, uncover variations, and identify relationships between concepts (Corbin & Strauss, 2008).

Prior to data collection, participants were selected purposively to ensure patients undertaking diabetic treatment from the healthcare system were recruited. A desirable balance of gender and patients with different treatment modalities was selected at this initial stage. Patients seeking treatment at public and private primary care clinics in urban and rural settings were included, as the criteria for exploring the different processes and expectations in receiving treatment regarding clinic and payment methods may differ in these settings.

Therefore, the initial purposive sampling included patients with T2DM were based on the following inclusion criteria:

- Malaysian
- Aged 30 years and above
- Diagnosed with T2DM for more than two years, with or without complications
- Seeking treatment from a primary care clinic (during data collection period)
- Able to communicate in English, Malay, or Chinese (Mandarin)

The rationale for selecting patients diagnosed for more than two years was to ensure that they had engaged in certain treatment strategies. Thus, they were able to

provide an account of their experiences with regard to various treatment-seeking approaches and how they decided on the type of treatment sought. Participants from three ethnic groups (Malay, Chinese, and Indian) were selected because I postulated that different cultures could have different determinants of treatment strategy processes.

I started to approach potential patients at one of public primary care clinics in an urban setting based on the inclusion criteria. The recruitment process was rather smooth due to support from the nurses overseeing the diabetes program at the clinic. Firstly, patients were approached while waiting to see their doctors at the public primary care clinics when seeking on-going diabetes treatment. They were briefed on the objectives of this study, and relevant information regarding the data collection process and participant information sheet was provided to those who have agreed to take part. Patients that had time for the interview were recruited. Willingness to participate was crucial, as the emphasis was on the quality of information shared rather than the number of participants. Once participants agreed to be interviewed, appointments were made and venues were chosen, primarily by the participants. The date, time, and venue for the interviews were decided based on convenience and preference for each patient.

Access to the private primary care clinic in an urban setting was not as smooth as in the public primary care clinics. At the first private clinic I approached, the general practitioner did not allow me to meet or brief him for the objective of my visit. The message was relayed to him by the clinic nurse. The second and the third private clinics agreed to listen to my explanation; however, both were reluctant to allow me to interview their patients, citing that they were not interested. The next clinic I approached was quite positive, and agreed for me to recruit his patients; he provided a list of patients with T2DM and their contact numbers. However, all four eligible

patients refused participation when contacted by telephone. Nevertheless, throughout the long process of recruiting patients from private clinics, I had three private general practitioners who were friendly and positive about the research. They helped me contact the patients and sought their approval for me to interview them. I then followed through and managed to arrange an interview date, time, and venue for/with each patient.

As in rural settings, access to both public and private primary care clinics was quite smooth with good support. Following a briefing session with the doctor in-charge at the District Health Office (district where the rural primary care clinic was located), I was introduced to the nurse in-charge of the diabetes programme at the public primary care facility. The nurse was very helpful and facilitated the participant recruitment process. As for the private clinics in rural settings, the two private clinics that were approached provided their full cooperation. The doctors also managed to receive permission from their patients for me to interview them.

As the study progressed, more specific criteria were used for sampling in order to target patients which could provide data to address any gaps in the emerging analytic theory. As the coding evolved, the theoretical direction became more focused and clear. During the process of analysis, I noted that people around patients were a significant source of information and support in their process of deciding on treatment options and their treatment strategy process, particularly their family members or people close to them. *“My wife gave lots of support, including food preparation. She cooked separately cooked different types of rice... everything is controlled by her” (Ali, 52 year-old, diagnosed with T2DM 4 years ago).* Therefore, caregivers and patients’ spouses were recruited for subsequent interviews. The healthcare providers were also selected from those who had experience in treating patients at the study centres, since patients’ decisions on treatment options were significantly influenced by input from healthcare

providers. The healthcare providers' behaviour could either impede or enhance patients' treatment management and type of treatment (Chin et al., 2001; Yen et al., 2011). Thus, selection of healthcare providers and family members helped in saturating the theoretical framework, explaining the process of treatment strategy, and deciding on type of treatment among patients with T2DM.

The recruitment process for family members and relatives was more straightforward, because all family members and relatives were recommended by the participants (patients). I was given their contact information to further explain the objective of the interviews and to make arrangements for interview sessions. However, three patients did not recommend their family members to be interviewed, citing inconvenience and lack of time.

Sampling ceased when theoretical saturation was reached, i.e. when all categories (themes) were well developed in terms of properties, dimensions and variations, and the core category was well defined (Corbin & Strauss, 2008). It was important for the saturation process to be achieved gradually, as this was part of the crucial process of developing a substantive theory from empirical data. Theoretical saturation was observed after twenty-nine transcripts consisting of 26 IDIs and 3 FGDs, after which no new categories were added to further the understand patient treatment strategy and the decision-making process regarding treatment type.

### **3.5.5 Data collection process**

In order to promote a smooth interaction between myself and the patients, they were given the option of language in which they were comfortable expressing their thoughts freely during the interview process. The interviews took place at the participants' workplaces, houses, or at clinics. Arrangements were made with the nurses

in charge of diabetes at both clinics to use the diabetes counselling room, which was conducive for the interview and audio-recording of sessions.

### 3.5.5.1 Conducting in-depth interview (IDI)

A total of twelve patients with T2DM were interviewed. The semi-structured guides were used to facilitate the conversations and eased the interview process. This was to provide more structure whilst maintaining flexibility. I modified some of the questions to clarify certain issues emerging from previous interviews. This helped in gaining a more in-depth understanding.

For example, one of the participants claimed that the traditional treatments were good and reduced his blood sugar level. However, he was hesitant to take it on a regular basis. This prompted me to ask myself why he did not take the tradition medicine (e.g. *Kratum* leaves or Indian herb), which he perceived as being two natural remedies – especially the Indian herbs, which were effective, cheap, easy to prepare, and easily accessible. After several probes and asking direct questions of why he did not take it regularly, his answer was “*this herb has side-effects as well*”. Side-effects of treatment were one of the sub-categories coded under the category of “treatment characteristics” that lead to a patient’s decision-making process.

Similarly, in another example, at the beginning of an interview with one participant, she was reluctant to elaborate further regarding her experiences with traditional and complementary medicine. I had to rephrase the question as “*What made you try traditional treatment?*” instead of asking the question directly as, “*Why did you chose to seek traditional treatment?*” As the study progressed, the interviews became more focused and structured as the concept emerged. Thus, the questions related to “experimentation”, information seeking, and which factors patients considered when deciding on a treatment option.



The interview process with nine family members was similar to the patient group. Upon receiving their contact numbers, I called to brief them regarding my intention to include them in my study and sought their permissions. As for healthcare providers, the IDIs were conducted with three general practitioners and two senior medical officers from the public primary care clinic. The interview sessions with the healthcare providers from both public and private clinics were conducted at their respective clinics.

The IDIs were audio-taped with the permission of participants. All participants were assured that the data would be kept anonymous and confidential. The digital recorders had a large memory capacity which could last for many hours throughout the long IDIs without any interruption. The digital recorders were also small enough to remain inconspicuous so as not to affect the participant's concentration during the interviews. The interviews among patients, their family members, and healthcare providers ranged from 30 minutes to 1.5 hours. The language used in an interview was dependent on the participant's comfort and preference.

All participants were given a small gift as a token of appreciation after the interview session. A good rapport was developed with all the participants, and they felt comfortable sharing their experiences and were able to relate to the questions asked. A significant level of trustworthiness in the data was achieved because of this rapport and the information provided by participants. Details regarding good rapport are described in the self-reflection section.

#### **3.5.5.2 Conducting focus group discussion (FGD)**

Similarly, the semi-structure topic guide was used to aid the discussion and further rephrase the probing questions to stimulate the discussion to further understand the topic or issue being discussed. Three FGD sessions among healthcare providers from two public primary care clinics were held at the meeting room at their respective clinics.

FGDs were considered to be more appropriate for data collection from healthcare providers, since these allowed them to generate robust discussions. The aim of the FGD sessions was to further explore specific issues, given the range of services provided at the public primary care setting such as those provided by pharmacists, nutritionists, diabetes nurses, and other paramedic groups. Their experiences in interacting with patients and their views on patients' service utilisation were essential areas for exploration during group discussions. Unfortunately, it was not possible to conduct any FGDs among healthcare providers from private clinics because of the small number of participants and inherent difficulty in getting all participants together in one session. Therefore, those were only conducted as IDIs among doctors at each private clinic. Similarly to IDIs, all FGD sessions were digitally recorded with the permission of participants. The three FGDs conducted lasted between one hour and one and half hours. The discussion was facilitated by myself with assistance from a graduate student which acted as note-taker.

### **3.5.5.3 Topic guide for in-depth interview and focus group discussion**

In terms of the IDI and FGD guides mentioned in the previous section (see Appendix J for the topic guides), these were developed and consisted of semi-structured questions along with many probing questions to clarify and elicit detailed information. The topics covered for patients included: how their T2DM was diagnosed, their experiences and perceptions towards T2DM, how patients chose their treatment for T2DM, and how T2DM affected their daily life. Family members were asked about their experiences living with the patients, their perceptions, and their roles in the management of diabetes in the patients. The healthcare providers were interviewed on their experiences and perceptions in treating patients with T2DM and patients' attitudes and behaviours towards the treatment and management of diabetes.

### 3.5.6 Transcribing

The interviews conducted in the Malay language were transcribed without translation for analysis; however the interviews in the Chinese language were transcribed and translated into English for analysis. The meaning of the original conversation was maintained in the translated versions of the conversations in English. All efforts were taken to ensure the quality of translation. The interviews in Malay language were not translated because both of my supervisors and myself were familiar with language. The Chinese (Mandarin) language versions were translated as one of supervisor was not familiar with Chinese language. This was to ensure the mutual understanding and standardisation of meaning among the three of us. The decision was made with aim of maintaining the quality of data and minimising the lost of meaning in translation (Birbili, 2000). To ensure the accuracy of the transcription and translation (for Chinese language interviews), transcripts were read through and the recordings were listened to again prior to analysis. Field notes were also read through to get an overall impression within the context of the interview. Interviews were transcribed verbatim with all personal identities removed. Transcripts were saved in Microsoft Word format and subsequently transferred to Nvivo version 10. However, the first three transcripts of coding were done in Microsoft Word format, and the identified concepts were labelled and notes were made in the “comment” box (a feature of Microsoft Word). The short memos were also jotted down in the left margin, as highlighted in Figure 3.3.

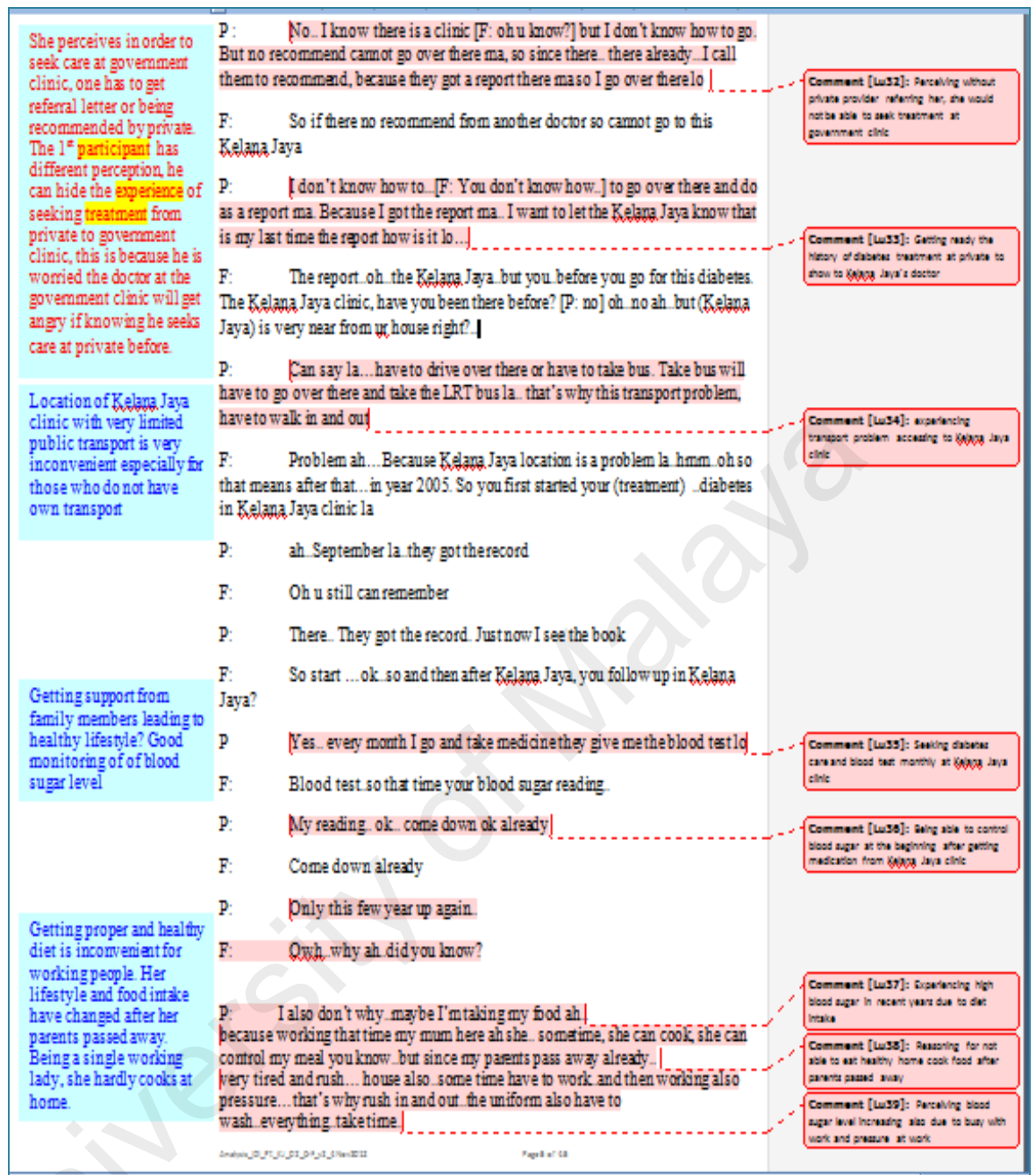


Figure 3.3: Example of open coding with brief memo writing on the left margin

### 3.5.7 Data analysis

Data analysis began soon after the first interview (Liamputtong, 2013). The analysis process involved various stages of coding, categorisation, constant comparison, memoing, and sketching. Coding began with open coding followed by focused coding, with the final stage being theoretical coding (Hallberg, 2006). The texts were read a few

times before coding began. Coding is a method of qualitative data analysis, which is an integral aspect of grounded theory approach. Data were coded with symbolic interactionism as an underpinning theory. Hence, the focus of coding was on the meaning patients with T2DM associated with their interactions with society and the healthcare system when in search of their treatment. Open coding is the process of breaking down the data into distinct units of meaning, which involves line-by-line coding. The line-by-line code could be from a single word, an incident, a phrase, or a statement which may span many lines. Examples of open coding and the segments of verbatim are shown in Table 3.1.

**Table 3.1: Example of coding process**

<b>Verbatim (IDI)</b>	<b>Code (open coding, with gerund)</b>	<b>Category (focus coding)</b>
<i>When I came to this clinic [public primary care clinic], they [doctors] said your blood sugar levels is high [diagnosed with T2DM].</i>	Attending public clinic Being diagnosed with diabetes	Identifying a trigger for action
<i>Then I followed up by monitoring my blood sugar levels and whenever I reduced sweet food on the whole...sweet food, I went to the pharmacy [private], paid RM5, checked my blood sugar, the levels were up and down ...up and down, When I reduced eating sweet food, the blood sugar levels reduced... Ok, I can feel the effect</i>	Monitoring the blood sugar frequently  Reducing sweet foods	Experimenting with self-care
<i>Not that I like it, but I get satisfaction if I do it myself, based on my own ability, my knowledge.</i>	Testing blood at the private pharmacy and paying RM5 per test Realising blood sugar level decreases once intake of sweet food is reduced	Learning from outcome of experimentation
	Feeling satisfied for being able to monitor and control blood sugar level	

During the open coding process, a few questions or queries were used to explore further meanings from the data, by asking questions such as: “Why did this particular

phenomenon happen?”, “What is actually happening in this statement?”, “What is the main concern being faced by this participant and why?”. Applying this set of questions facilitated more analytical thoughts and made me more sensitive to the meanings and concepts.

In line with the symbolic interactionism approach, which analyses people’s actions and the meanings behind their actions, the action code (gerunds) was used as labels (words ending with “-ing”). Codes with similar concepts were reviewed and clustered into sub-categories and categories (examples shown in Appendix K). Together with both of my supervisors, we continuously deliberated, reflected, modified, and adjusted the categories and sub-categories in order to identify the best fitting categories. The advantage of initial coding is the careful manner by which identifying, labelling, and coding word-by-word, line-by-line, or incident-by-incident fulfilled two criteria for completing a grounded theory quality check for analysis, which relates to “fit” and “relevance” (Charmaz, 2006). The identified categories and themes were further defined, and subsequent verbatim texts were analysed using the initial categories as guides. The first and second transcripts generated 213 and 231 concepts, respectively.

#### **3.5.7.1 Focus coding**

Focus coding was the next stage of analysis following open coding; the process is outlined in Table 3.1. Focus coding allows for the generation of a “core category” that forms a substantive theory by integration of all other categories and sub-categories. Focus coding was conducted when a code was found and perceived to be in an analytical direction through the open coding process.

At this stage of coding, the meaning of what participants had said becomes clearer. I constantly sketched through papers in an attempt to understand the flow or process of their treatment-seeking behaviour. The whole analysis is an evolving process, with

unexpected ideas and issues regularly emerging. The most significant or frequent codes in open coding were used as categories for focus coding. For example, with the focus code “*triggering for experimentation*” I checked through the data to see how well it fit with the meaning in the data.

Although open coding did not directly generate some of the focus codes, it helped the progression of analysis toward the level of focus coding. Some of the codes or concepts from the initial coding were refined and reworded during focus coding, whilst certain concepts were omitted when forming the categories at the focus coding stage. The focus codes were more abstract and possessed properties with dimensions that explained the meaning of data and carried substantive meaning. For example, in “*influence of family members, friends, peers, and healthcare providers*”, the category “*influencing*” with properties such as “*significance of influence*” and “*varying impact of influence*” with a dimensional ranged from a weak to a strong impact or influence on the patients’ choice of treatment. The “*significance of influence*” was split into specific properties, such as types of influence, the “*comforting feeling*” which can be dimensionalised as ranging from very comfortable to uncomfortable. Another property was “*level of trust*” which could impact influences towards patients’ decision-making processes.

#### **3.5.7.2 Selective coding (identified core category)**

At the stage of selective coding, the process of delimiting was done carefully by selecting variables related to the core category (Glaser & Holton, 2004). The subsequent interviews, based on theoretical sampling and the coding of transcripts, were focussed heavily around the core category. Although the selective coding process was much easier and more focussed compared to open coding, it required analytical thinking to select the concepts which are relevant to the core category. Nevertheless, the process was facilitated by constant comparison. Reviewing the memos and sketched notes,

combined with further comparisons with the identified categories produced the emerging of concept of “*experimentation*” in patient treatment strategy. The underlying issue of how patients with T2DM manoeuvre through the healthcare system to manage their diabetes emerged through this concept.

Grounded theory is the process and action; the word “*experimentation*” was chosen as the core category, as it was relevant and fit into the emerging theory to explain the entire process. The term “*Experimenting*” was an *in vivo* code, a word used by study participants to describe their treatment strategy process. “*Yes, I am testing! Actually, I am experimenting, experiment! Yes, to tell you the truth, I am not the clever type but I am experimenting with my own knowledge.*” (Hassan, 58 year-old, diagnosed with T2DM 7 years ago). This core category was frequently observed, and was related to the other categories in the data, which also fit well into the phenomenon of study. The concept of “*experimentation*” reflected the diversity of actions by patients and their interactions with the people around them in search for information related to diabetes treatments. The experimentation reflected the conceptual theory which relates meaningfully and was easily linked with other components within the experimentation, such as “*triggering to start the experiment and deciding on the type of treatment*”. It showed that both the action and the process were key features of the theory which emerged from the grounded theory approach.

### **3.5.7.3 Constant comparative method**

The constant comparison was used in generating and refining codes, themes, categories, and the theoretical framework. Thus, during the coding process, I constantly compared the findings within and between categories, and between categories and texts subsumed under the same categories by applying aforementioned questions during the process of identifying categories and subcategories. The codes from transcripts were



constantly compared against the codes from other transcripts. Also, the transcripts coded under a specific code were constantly checked for consistency. Subsequently, categories and subcategories were compared to check for their ability to subsume the subcategories. I also constantly revisited the earlier data and transcripts, and even listened to audio recordings to study the data anew. Later, a similar process of comparison was completed between theoretical codes and framework with the categories and transcripts. Through the process of comparison, differences and similarities were sorted out. This process of constant comparison continued for the subsequent interviews, and was performed throughout the entire process from open coding to focus coding. It also allowed me to visualise patterns emerging from the data, along with the process of constant comparison within each category. The information gathered was capable of producing the theoretical model.

#### **3.5.7.4 Memoing process**

The analysis process was also facilitated by memoing. Memos were written to capture thoughts in the moment. The ideas, curiosity, and flow emerged during the analytical interpretation of data being captured in the memo through the sketching and sorting processes (see Appendix L), particularly during attempts to capture the patients' treatment-seeking strategy and the process of deciding on the type of treatment. Memoing also acted as a reminder, especially during the analysis stage, during which I recalled specific phenomena or reactions when certain issues were raised by participants during the interviews. Ideas and curiosities were jotted down as they emerged alongside the progression from fieldwork to data analysis. Writing memos was done concurrently throughout the fieldwork, and continued until analysis, to capture all ideas and interpretations that emerged, particularly when identifying theoretical codes and categories. Memoing was part of the reflective process that allowed me to question observed issues during the data collection and analysis stages.

### **3.5.7.5 Substantive theory generation and modelling process**

The process of theoretical coding in grounded theory method was aimed at linking the different codes together with a comprehensible meaning and logic. It did not involve simply grouping the categories together; instead, it involved connecting the categories and concepts with each other and identifying the properties and dimensions to provide a sense of understanding. This was accomplished by abstracting the data and moving from concepts towards generating a substantive theory. Throughout the entire process, I refrained from imposing a forced framework. The frequent discussions with my supervisors and feedback on the emerging concepts and categories proved helpful. During this stage, further literature review was also being conducted to compare the emerging theoretical model of this study with existing theories.

In developing the theory through the grounded theory approach, the systematic process of coding, memoing, and constant comparison, I was able to observe the link between the categories, which appeared logical. These questions were helpful in guiding me to reflect on the following points during theory development:

- Does experiencing symptoms lead patients to seek treatment and confirm the diagnosis?
- How would experiencing T2DM diagnosis and treatment lead to further action?
- What triggered patients to try alternative treatment apart from regular follow ups at primary care clinics?
- When and how do patients receive support from family members or people around them, including peers and friends? What are the influences from these people?
- What was/were the action(s) taken after exploring different types of treatments and receiving information related to treatment characteristics from their respective social networks?

- Were there any barriers in seeking treatment from their preferred choice? If so, what were the actions taken?
- What were the consequences of seeking treatment?

The process of data analysis and generation of the theoretical model were not linear, but iterative. The modelling process within the analysis (Appendix M) reflected the extent of the process with careful analysis of the data, and demonstrated the complexity of treatment-seeking strategy and decision-making processes among patients with T2DM. The sorting process took place several times until an integrated idea was formed and theoretical saturation was achieved, at which point a model was subsequently developed.

### **3.5.8 Data management**

After each of the IDI or FGD sessions, recordings were listened to repeatedly to ensure that any unclear voices were immediately jotted down. It is often difficult to control the participants from talking or reacting simultaneously to the topic of discussions when everybody is excited or interested in the conversation. Thus, in order to avoid unclear or overlapping conversations, or if anything was deemed unclear, I made an effort to seek clarification and ask participant regarding any confusing answers or whenever I had doubts.

Data management was facilitated by Nvivo 10(QSR International Pty Ltd, 1999-2014), a type of qualitative data management software. Initially, analysis by manual coding was completed in Microsoft Word format, as it enabled me to immerse myself in the data. Manual coding was completed for the first three transcripts. The subsequent processes of focus coding and selective coding were completed using Nvivo 10 software.

### **3.5.9 Data verification and trustworthiness**

A grounded theory approach is based on four criteria which are used to assess the quality of a grounded theory study: fit, work, relevance and modifiability (Elliott & Lazenbat, 2005; Glaser, 1978). As with any research, assessing the quality of data is critical to ensuring that data is reliable and trustworthy. The credibility of qualitative analysis included rigorous techniques and methods for gathering quality data, and a credibility of the researcher. Hence, I ensured that all of the aforementioned steps were adhered to as closely as possible. In qualitative research, the researcher is the tool used to gather the perspectives and experiences of participants in order to explore a phenomenon (Creswell, 2007). Thus, being a medical anthropologist with the advantage of working in the field of health systems research for more than ten years proved to be beneficial. Moreover, the vast experience of my two supervisors, who are grounded theory experts in a multi-disciplinary field (i.e. psychology and primary care), further added to my list of advantages.

#### **3.5.9.1 Rigour in methods**

Rigour refers to the correct use of research methods, and represents an important aspect of high quality research processes and outcomes (Fossey, Harvey, McDermott, & Davidson, 2002). The methods used in this study were face-to-face IDIs and FGDs which are both suitable for exploring people's perceptions and understanding their actions or activities for certain behaviours. Triangulation strategies involved different methods of data collection, and theoretical sampling led to the inclusion of different groups of study participants based on findings of earlier analysis, which added to the variety of information sources. The inclusion of both public and private primary care, as well as rural and urban settings, also provided different perspectives with varying environmental conditions. In terms of analysis, the different backgrounds of researchers provided a broader view and deeper understanding of the issue under study. Although

triangulation may not be necessary to the extent of finding consensus, it allows for the exploration of different views and comprehensively illuminates the important information and understanding of the processes being studied. The debriefing was completed where the preliminary results and model were presented to study participants in order to gain feedback and check the validity of data analysis.

### **3.5.9.2 Member checking**

The preliminary findings and model were presented to the participants in order to gather their feedback and check the validity of data analysis. Their feedback and comments helped to refine explanations and revised the model. Only five participants from the healthcare providers group were able to attend the feedback session. They were agreeable to the model and concurred that “experimenting” as the core category fits well with the patients’ treatment strategy process. The feedback sessions with the patients and their family members were done with only one patient and his family member. They agreed with the identified categories and the process of deciding treatment modalities as demonstrated by model. Feedback could not be collected from other participants due to inconvenient timing and the availability of study participants.

Presentations and discussions of the findings with policy makers and non-communicable disease experts from Ministry of Health were done to receive feedback from various stakeholders as part of the peer review process, which incited critical comments from a variety of perspectives. The in-depth opinions from experts in non-communicable disease helped to enrich the analysis process.

Preliminary findings were also presented at several meetings and conferences with participants and audiences from diverse backgrounds including diabetes and non-communicable disease, behaviour and anthropology, public health, and primary care.

### **3.6 Self-reflection**

Researcher reflexivity must be taken into account in a constructivist grounded theory approach. My theoretical perspective and experience certainly shaped the research questions and analysis of this study. Since the process of using the grounded theory approach began upon entering the field, the experiences and skills gained throughout the whole process are invaluable. However, with the help of memoing and self reflection, I maintained openness to ideas and concepts generated from the data.

Having over a decade of experience as a medical anthropologist working in the field of health systems research at the Ministry of Health Malaysia equipped me with the familiarity of the current healthcare system in Malaysia. Sensitising myself to the Malaysian healthcare system is helpful and essential in order to truly understand the study participants' sentiments regarding their treatment process and their decision to selecting certain treatment types. Furthermore, my experience also allowed me to be sensitised to the jargon used among healthcare providers. Being a Malaysian conducting an exploratory study of local Malaysian patients was an added advantage. My experience allowed me to better understand the participants' impediments which had been compounded by their cultural and language barriers. Additionally, it provided me with the opportunity to appreciate their stories as patients, thus facilitating the research procedure while exploring their treatment processes, the actions they took, and their particular decisions in selecting a treatment type and treatment strategy process.

#### **3.6.1 Data gathering process**

As a researcher, I explored the decision-making and treatment strategy processes among patients with T2DM. This was very important, as the researcher-participant relationship is paramount in understanding a person's life (Charmaz, 2006). A study on patients' decision-making and strategies for managing their illness requires one to enter

the patients' world, learn their actions and perceptions, and listen to their stories (Charmaz, 2004). My interest and curiosity in exploring their underlying issues and discovering how they interact with current healthcare system for diabetes care encouraged them to share their concerns with me. As one participant told me: *"I am actually very happy to be able to share my experience with you, because you then can use [this information] to share with others."* (Hassan, 58 year-old, diagnosed with T2DM 7 years ago). This demonstrates that participants were open to share their experiences and their strategy for seeking treatment for diabetes. They were willing to explain the various treatment strategy approaches with the hope of their experiences being useful to others experiencing similar illnesses.

The advantages of the IDI method are that it provides a platform for patients to voice their experiences and concerns or vent their frustrations with regard to the healthcare delivery system. They share and place their trust in me without worrying about information which they had hidden from their healthcare providers. Hence, the information shared by the research participants was based on their actual experiences and perceptions, thereby considered trustworthy. When certain information was considered very personal to patients, such as erectile dysfunction, or if it was perceived by the patient to have been caused by diabetes medication, he or she was more willing to share this information with me as a researcher rather than with his or her doctor. For example, one participant mentioned: *"It is because of you...for the purpose of research and your knowledge, that's why I am sharing with you."* (Hassan, 58 year-old, diagnosed with T2DM 7 years ago). Patients also noted their unhappiness with the unfriendly attitude and rude behaviour of healthcare providers, as voiced by one participant: *"I had to bear with the staff's attitude here, as the medicine here is suitable for my diabetes treatment."* (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago). One of the participants suggested that I can conduct a study on traditional herbs, and

described how to prepare the herbs he was taking: *“If you want to do a study on this [traditional herbs], let me explain it to you. Take this herb, just a small portion, one teaspoon, put it into a cup and then you wash it. After that, you have to soak with warm water...”* (Ali, 52 year-old, diagnosed with T2DM 4 years ago).

This close relationship between the researcher and participants, in which participants were willing to confide their personal information with me, was an indicator of a good rapport and hence higher data quality. Furthermore, my fieldwork with the anthropological experience in field and skill proved to be a good qualitative tool, at least during the interview sessions.

I valued this researcher-participant relationship with my commitment in maintaining the trust of participants and ensuring the confidentiality of all information obtained from the interviews. The rich and useful information provided by participants allowed for the creation of the substantive model for treatment strategy processes among patients with T2DM in this study.

### **3.6.2 Handling overwhelming data**

Following a series of IDIs among patients, family members/relatives and healthcare providers, and FGD sessions among healthcare providers at public primary care clinics, I obtained a plethora of data gathered from my field work. Fortunately, with the help of a systematic process, whereby I spent more time with my first interview transcript and carefully coded line-by-line to maintain focus, I was able to move onto focus coding for the three initial transcripts. However, such a large amount of information can be overwhelming. Memo writing exercises and frequent discussions with supervisors allowed for increased focus during the analysis. Throughout the entire data analysis process, it was critical to involve perspectives of others in order to reduce my personal influence on the analysis and ensure the validity of the data process.



### **3.6.3 Experience of coding**

Strauss and Corbin write (1998): “*Analysis is the interplay between researchers and data. It is both science and art.*” As human beings, we are prone to inherent bias which is selectively based on our individual interests. Constantly reminding myself of the research questions during the analysis allowed me to focus on the study objectives. Consequently, the data was coded analytically, without forcing the data, by simply letting the data generate the model, leading to the emergence of a theory by repeating the steps in grounded theory methodology.

### **3.7 Summary**

The method chosen for this study considered the methodological decision to use a grounded theory. Patients with T2DM were active agents in their own lives, and their worlds encompassed the monitoring of blood sugar levels and diets, management of illness, and making life adjustments to improve their quality of life. These findings generated a new substantive theoretical model on the treatment strategy process among patients with T2DM based on empirical data. This piece of information is important for stakeholders for the development of a holistic approach to the care of diabetes, and for planning effective programmes for diabetes management.

## CHAPTER 4: RESULTS

### 4.1 Introduction

As stated in Chapter 1, the objective of this study was to explore how patients with T2DM manoeuvre through the current healthcare system when obtaining treatments for diabetes. This process is presented in a substantive theoretical model that explains the decision-making process of patients in obtaining treatment in primary care setting. Data was sourced from IDIs with twelve patients with T2DM seeking diabetes care from primary care facilities, nine family members of some of these patients, and five primary care doctors from the primary care facilities at which the patients obtained treatment. Another data source included three FGDs from thirteen healthcare providers consisting of doctors, pharmacists, dieticians, nurses, and medical assistants. The details of the participants' social demographic information are shown in Table 4.1, Table 4.2, and Table 4.3. Although the participants of the study represented patients with T2DM in urban and rural settings within both private and public healthcare settings, they consisted of different ethnic and social demographic backgrounds. However, their approaches to illness management and treatment strategy did not differ greatly. The family members also shared their experiences in supporting patients with treatment management, and no major differences were observed in their approaches and influence. Healthcare providers from both private and public primary care expressed similar opinions and experiences regarding the management of patients with T2DM.

**Table 4.1: Socio-demographics of patients with T2DM**

Patient <sup>#</sup>	Sex <sup>^</sup>	Age (year)	Ethnic <sup>*</sup>	Education level	Occupation	Marital Status	Duration of T2DM (years)
Ali	M	52	M	Secondary School	Public Employee	Married	4
Su Lin	F	55	C	Secondary School	Private Employee	Single	8
Raja	M	52	I	Secondary School	Unemployed	Married	21
Devi	F	50	I	Secondary School	Housewife	Married	18
Geeta	F	52	I	Secondary School	Private Employee	Married	2.5
Chong	M	58	C	Tertiary	Private Employee	Married	10
Jamal	M	53	M	Tertiary	Private Employee	Married	13
Hassan	M	58	M	Tertiary	Retired	Married	7
Yi Moi	F	61	C	Primary school	Housewife	Widow	10
Selvi	F	52	I	Secondary School	Public Employee	Widow	3
Fatima	F	55	M	Secondary School	Housewife	Married	3
Ah Hua	F	62	C	No Formal School	Housewife	Married	5

<sup>#</sup> pseudonym, <sup>^</sup>M=Male, F=Female, <sup>\*</sup>M=Malay, C=Chinese, I=Indian

**Table 4.2: Socio-demographics of family members**

Characteristics	Family members (n = 9)
Mean age (range)	46 (24–67)
Sex	
Male	2
Female	7
Ethnic group	
Malay	2
Chinese	3
India	4
Education level	
No formal education	1
Primary school	2
Secondary school	5
Tertiary (college/university)	1
Employment	
Public employee	1
Private employee	3
Self employed	1
Unemployed	1
Housewife	3
Participant's relationship with patient	
Husband	2
Wife	3
Daughter	2
Sister	1
Cousin	1

**Table 4.3: Socio-demographics of healthcare providers**

Characteristics	Healthcare providers (n=18)
Age (range in years)	23 - 65
Sex	
Male	5
Female	13
Ethnic group	
Malay	1
Chinese	2
India	2
Education Level	
Tertiary (college/university)	18
Occupation	
Doctor	8
Pharmacist	1
Nutritionist	1
Nurse	5
Medical assistant	1
Pharmacist assistant	2
Employment	
Public employee	15
Private (general practitioners)	3
Mean number of months working in the clinic (range)	78.8 (1 – 360)
Mean number of months of experience in treating patients with T2DM (range)	133.4 (2– 432)

The following section provides an overview of the substantive theoretical model, followed by a detailed description for each of the four main elements constituting the model. The core category of the model is experimenting of diabetes care (Section 4.3). The remaining four main elements of experimentation were: triggering for experimentation (Section 4.4) and searching for information and knowledge prior to experimentation (Section 4.5), and the results of experimentation: evaluating the outcome of experimentation (Section 4.6), and the undertaking of experiments or how the decision-making approach affects the type of treatment selected (Section 4.7). Section 4.8 presents a summary of overall findings.

#### **4.2 Overview of theoretical model for treatment strategy among patients with T2DM<sup>2</sup>**

In sourcing treatments for diabetes, patients adopted a loop of “trial and error” approach in manoeuvre through the healthcare system. The approach began with a trigger to try a particular type of treatment in order to eliminate the symptom(s) or to fulfil their personal goal, followed by seeking information in order to decide on their options of treatment. Having decided on and undertaking their treatment option, they would assess the treatment outcomes and finally closing the loop by a decision to keep their current option or to readjust their strategy on different types of treatments. Hence, this approach was best seen as a process of experimentation, as shown in Figure 4.1. Each of these stages will be elaborated in the subsequent sections.

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<sup>2</sup> Part of this has been published in Lee Lan Low, Seng Fah Tong, Wah Yun Low (2016) Selection of Treatment Strategies among Patients with Type 2 Diabetes Mellitus in Malaysia: A Grounded Theory Approach. PLOS One (DOI 10.1371/journal.pone.0147127)

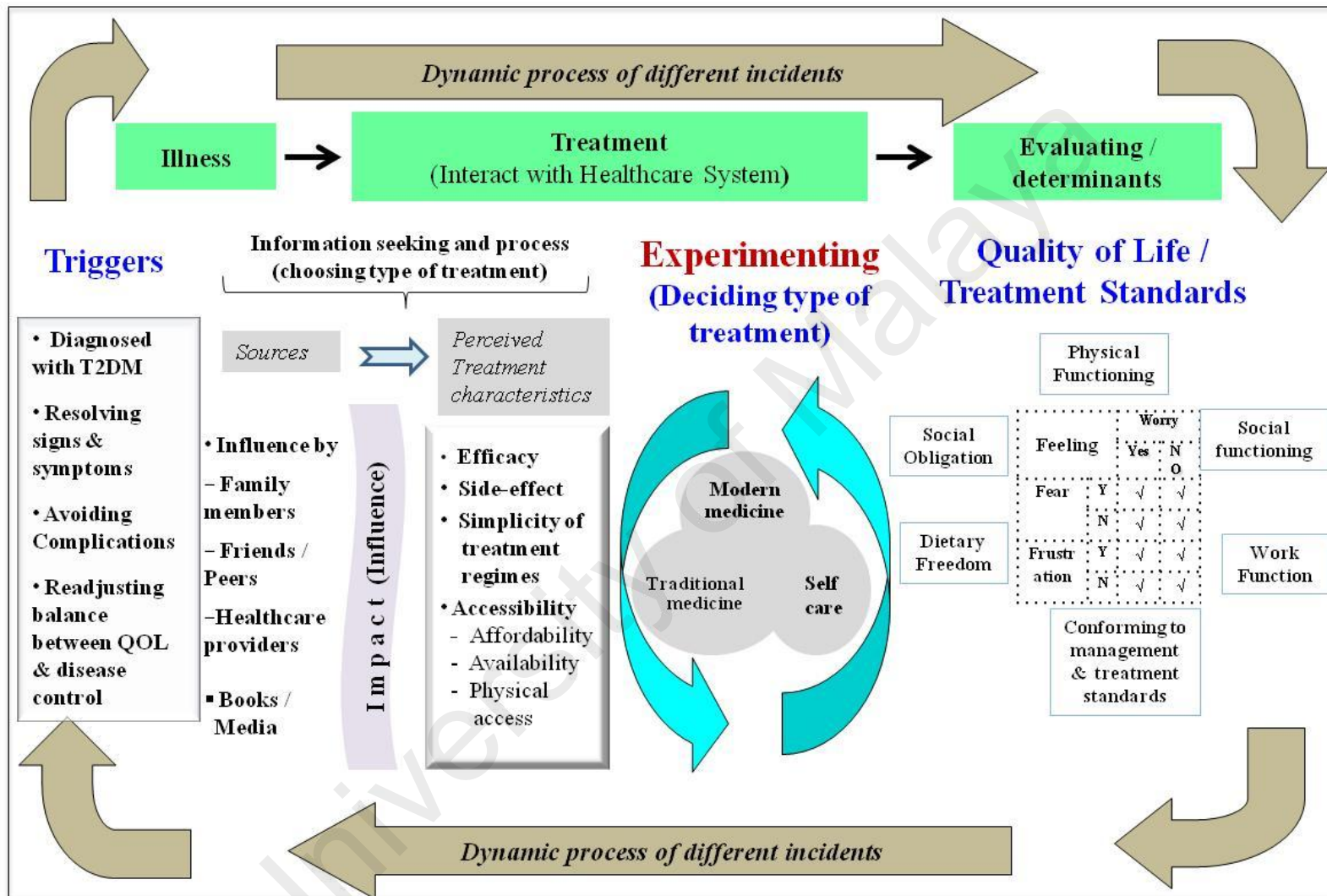


Figure 4.1: Model for treatment strategy among patients with Type 2 diabetes mellitus in a primary care setting

The entire decision-making process involved in choosing a particular treatment type is dynamic and iterative until the outcome of a particular strategy becomes stable and meets the expectations of the patients. The process is restarted and repeated if a new factor emerges, which acted as a new trigger and tips the balance between treatment strategy and goal.

Patients being engaged in their treatment modalities while attempting to achieve the desired goal is evident in the model. These treatment modalities include: 1) Modern medicine, 2) Traditional and complementary medicine, which falls outside the spectrum of modern medicine, and 3) self-care. These treatments are present within the Malaysian healthcare system, as described in Chapter 1. These treatment modalities were practised concurrently, consecutively, or as a mixture of any two or three combinations at different time intervals, such as taking a treatment from modern and traditional medicine, after a gap of one to two hours, for example. Such examples were shared by participants' experiences in using both modern and traditional medicine:

*“Usually I take it. I say, not together. I take the diabetic medication first, then, maybe, one hour later, I take that one [traditional herbs]” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

*“I was treated with medicine and insulin injections. I also took Chinese traditional medicine, [herbs]. I [also] went to see a ‘sin seh’ [Chinese traditional practitioner].” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

Treatment modalities also varied; for example, within the modern medicine there were experimentations using different regimes such as oral anti-diabetic medicine or insulin injection. Traditional medicine and self-care also exhibited had a range of



diverse methods. In this thesis, self-care refers to the patients' management of their T2DM and the illness related activities, such as monitoring of blood sugar level, taking of medication, dietary control, physical activities or exercising, weight management, foot care, monitoring, and recognising the signs and symptoms of diabetes (Ministry of Health Malaysia, 2009).

*“I follow up with self-monitoring of blood sugar. I went to the pharmacy and paid RM5 to check my blood sugar level to see if it was up or down. Sometimes within a day I have experienced going to the pharmacy twice to have my blood tested – in the morning with fasting, and another time after lunch. This was just for my own satisfaction. I can monitor it myself... based on my own knowledge.”*  
(Hassan, 58 year-old, diagnosed with T2DM 7 years ago)

For those who owned monitoring devices, being able to monitor their blood glucose level at their convenience was very encouraging for self-monitoring of their dietary intake. This made it convenient for patients to observe the outcome of their experimentation with different treatment regimes.

*“I checked my blood sugar level; I have my own blood glucose meter. I bought the meter. If I went for any function and had over-eaten, we could feel it. After that, the next morning, we checked the blood sugar level.”* (Selvi, 52 year-old, diagnosed with T2DM 3 years ago)

#### **4.3 Experimentation with diabetes care – the core category**

The term “experimenting” was coined by a participant when he described his rationale for adopting a particular treatment strategy process. *“Yes, I am testing! Actually, I am **experimenting**, experiment. Yes, to tell you the truth, I am not a clever type but I am experimenting with my own knowledge.”* (Hassan, 58 year-old, diagnosed

with T2DM 7 years ago). The term appears to explain how patients deal with the current healthcare system and choose treatment options for diabetes.

The following excerpt indicates how this particular patient experimented with different herbal drinks with the hope that the complementary treatment could improve blood sugar levels:

*“Stevia leaves for diabetes. It is like a sugar, tastes sweet and is easy to drink. I have finished one off, and now I am trying this new one [herbal drink]. I keep changing; I want to see if the blood sugar [level] reduces or not.” (Fatima, 55 year-old, diagnosed with T2DM 3 years ago)*

Experimentation could represent self-care or interest in alternative complementary treatments that could be carried out at any time, depending on patients’ needs and the availability of treatment modalities. Similarly, the following patient shared her experience with diabetes management in an example of outcome-orientated experimentation:

*“We can’t see what is happening inside our body, so, blood tests must be done. If the clinic here does not perform a blood test on me, I will go to other place to do the blood test myself.” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago).*

The following excerpt represents feedback from one of the healthcare providers with regard to patients’ experimentation processes in trying out alternative treatments. This healthcare provider normally encourages patients to have a proper monitoring mechanism in order to claim the traditional medicine is effective:

*“I used to tell my patients... ‘okay, if you want to take misai kucing [Orthosiphon stamineus, a traditional herb] tablet, you can. But before you take it, you have to carry out a fasting blood sugar test first, and then it is okay to take the tablet for one week. After one week, you should do another blood sugar test to see if there is any difference before and after taking misai kucing. Then only you can claim that it is effective’. I told him that. We can’t just say ‘My body feels better after taking misai kucing.’” (Healthcare provider = HCP, Male, Private Primary Care Clinic)*

Overall, experimentation was a trial-and-error concept until arriving at a desired outcome or personal goal. Patients continue to evaluate the treatment outcomes and might be dissatisfied when their expected health outcomes or personal goal were not achieved, resulting in continued experimentation. Trial and error could involve testing different treatment modalities aside from the routine medication or treatment prescribed by a doctor. The process of undertaking experimentation will be further discussed in Section 4.7. Four essential components made experimentation possible and will further explored in the next sections.

#### **4.4 Triggers for experimentation**

Triggers are perceptions by patients that involve a feeling of something needing to be done to achieve their expectations in the context of their disease. Therefore, unmet expectations could trigger a series of attempts with different types of treatment modalities. Triggers generate experimentation, even if the experimentation is limited to dietary changes, which represent a form of self-care management. Once an expectation is met, the triggers keep the patient on the same treatment-seeking strategy.

Several types of triggers were observed among participants. These included the desire to: 1) resolve signs and symptoms, 2) avoid the complications or deterioration of the illness, and 3) re-adjust a new balance between their desired quality of life and disease control. The following sections will further explore various types of triggers, with supporting data from participants.

#### **4.4.1 Resolving sign and symptoms**

Patients with T2DM could experience intermittent symptoms, which could be due to disease progression, uncontrolled dietary intake, and unhealthy lifestyles. When symptoms such as tiredness, frequent urination, and thirst occurred and became unpleasant, they became signals for patients to alleviate them. The cycle might continue once a patient experiences additional signs or recurrent symptoms.

The following excerpts illustrate how traditional and complementary medicine became an immediate remedy whenever one particular patient encountered a problem with blood sugar levels or diabetes symptoms:

*“When my body feels a bit uncomfortable [sign of blood sugar increase] then I ask for some [traditional remedies] from my friends who are also diabetic patients.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

#### **4.4.2 Avoiding complication & deterioration of illness**

Diabetes complications could affect the daily life of patients, especially involving physical or social functions and the ability to function at work. The feeling of fear or the thought of complications could lead patients to seek other forms of diabetes treatment perceived to be more effective. Thus, the desire to be free from complications, or to avoid deterioration of illness, represents the trigger point for patients to proceed with

trial-and-error through various types of treatment, which may sometimes go against the medical advice they had been receiving from their doctor.

The following is another quote from an asymptomatic patient attempting to avoid complications and preventing the illness from deteriorating. Her fear and worries led her to search for information on complementary treatments, which made her feel better after trying the complementary once.

*“That’s why I am worried, as the progression of diabetes differs every day. Our glucose level will shoot up if we accidentally take something sweet. So I asked around. I heard Dr.X is good in making our blood circulation [detoxification] better. His medicine costs RM150. After that, I felt more energetic!” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

#### **4.4.3 Readjusting to a new balance between desired quality of life & disease control**

Another factor encouraging patients to experiment with multiple treatment modalities was the desire to obtain a better quality of life. Patients wanted to feel better, or at least enhance their quality of life through their chosen treatment. One of the participants has tried a form of complementary treatment, he will be very satisfied with its outcome as it will enable him to enhance his daily quality of life:

*“Sorry to share this, it’s very private. [It is about] active sexual life. The worst case scenario diabetes is that you just feel tired, but then I think it helps to take vitamin E. Vitamin E has the same effect as Viagra, for your information, because vitamin E, from what I read, and from what I experience, improves the blood flow because the blood flow is okay, then I think everything is okay.”(Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

Essentially, patients' expectations of having an improved quality of life, avoiding illness deterioration and the presence of symptoms were the triggers for them to begin experimenting. The outer circle of the diagram from the theoretical model (see Figure 4.1) outlines the dynamic process in which the trigger is not static, but rather iterative.

#### **4.5 Searching for information & knowledge**

In experimentation, patients needed to prepare for tests and the “trial-and-error” process of different treatment modalities, which required evaluating their best possible options. Actively seeking information from various sources and exploring new treatment options were part of their experimental journey. This process included searching, obtaining, evaluating, and using information to make decisions on the type of treatment they prefer. As previously noted, the experiments were experiential; each of these experiments and processes involved searching for sources of information, interacting with the healthcare system, and being influenced by social networks such as family members, friends, peers, and healthcare providers.

The following participant excerpt explains the process she undertook to search for information on the internet, and exploring and evaluating the information prior to trying a treatment:

*“We searched for information from the Internet. My husband was reading all these [information]. Before he tried, we read about it. Yes, we did a survey. First, we tried. It worked. Then I made more [home remedy]...” (Geeta, 52 year-old, diagnosed with T2DM 2.5 years ago)*

Another example outlines how a patient and family member searched for better treatment for diabetes upon being diagnosed:

*“...for me it is something unpleasant [being diagnosed with T2DM], it’s like a disaster [when first hearing about the diagnosis]. I kept asking others who had experience with diabetes. At the beginning, I was scared. Everything was unexpected. She then tried to seek traditional treatment. Indeed we were trying to seek traditional medicine all over the place.” (Patient’s husband, 60 year-old)*

As shown in the theoretical model (Figure 4.1), upon diagnosis, patients searched for information from various sources and obtained knowledge related to treatment characteristics to help them make decisions on treatment management. The following subsections discuss sources of information, the influence of social networks, and the types of information sought by patients (treatment characteristics) as part of the experimentation process.

#### **4.5.1 Sources of information & knowledge on treatment characteristics<sup>3</sup>**

The main source of information for patients was the people around them – their social networks – that included their significant others, family members, friends, peers, healthcare providers, and other sources (e.g. mass media). Some patients took passive roles as part of expressing their sick roles, and depended on input from their family members, friends, peers, healthcare providers, and mass media for information. Some were more resourceful in sourcing information than others.

***Family members.*** Partners, spouses or significant others, parents, children, siblings, or even more distant relatives actively provided information related to diabetes treatment. The patient’s decision-making process depended on instructions and

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<sup>3</sup> Part of this has been published in Lee Lan Low, Seng Fah Tong, Wah Yun Low (2016) Social influences of help-seeking behaviour among patients with type 2 diabetes mellitus in Malaysia. *Asia Pacific Journal of Public Health*, Vol. 28(1S) 17S–25S (DOI:10.1177/1010539515596807)

information provided by family members. The following male patient admitted that his wife sought information related to his diabetes, and that she had planned for his treatment management:

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

Healthcare providers were also aware of their patients’ treatment-seeking behaviour and the influence of family members, particularly parental advice, on traditional treatment. One healthcare provider shared his view on parental influence on trying a traditional herb:

*“They [parents] will pass it down to the new generation. That’s why the new generation, at least some, still believes in this traditional medicine [herbs], even though they are university graduates or educated – some of them even hold a master’s degree – but when the parent says, ‘oh, you must use this, these are natural plants, herbs, all these things’. The influence of, what they call, parents, is very strong.” (HCP, male, private primary care clinic)*

**Friends and peers.** Besides significant others and family members, friends and peers also played an important role in providing information. Since some peers had gone through the same experiences and had experimented with different types of treatments, the patients frequently sought advice from them. Patients also spoke of 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.” (Fatima, 55 year-old, diagnosed with T2DM 3 years ago)*

*“They [friends] say the kidneys will be affected first, because they are the filtering organs, once in a while you must take something to cleanse your kidneys. They say many types of (traditional) remedies can cleanse your kidneys. So we just take them.” (Geeta, 52 year-old, diagnosed with T2DM 2.5 years ago)*

Apart from providing information on treatments for diabetes, which included alternative treatments, friends and peers also helped in taking patients to consult traditional and complementary medicine practitioners.

*“My friend recommended a shaman to me and asked me to try. He took me to see the shaman.” (Ali, 52 year-old, diagnosed with T2DM 21 years ago)*

The following excerpt was shared by a HCP who knew that her patients were getting advice from peers on the treatment choices.

*“They see others doing okay [trying alternative treatment]. A 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)*

**Healthcare providers.** The healthcare providers, as part of the health system that includes primary care physicians, nurses, and others, were also important sources of information. They played an important role in the management of diabetes; hence, their influence was inevitable. Patients often filtered the health information received from different sources, including those from the healthcare providers and the treatment(s)

they perceived as being the best. The excerpts below highlight the amount of faith one patient and his family member had in the advice provided by a doctor:

*“My wife told me ‘you should not try other treatments or try to seek care from other places 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’.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

Healthcare providers’ advice was significant when patients had to decide between oral medication and insulin therapy for diabetes management, particularly when the information received from family members or friends was varied or contradictory, or they doubted the information received. In the following case, the professional advice of healthcare providers was sought. Hence, the role of healthcare providers was critical to ensuring that patients obtained the correct information and adhered to their treatment regimes:

*“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 - I should choose for insulin treatment.” (Selvi, 52 year-old, diagnosed with T2DM 3 years ago)*

One patient suggested that healthcare providers should emphasise the importance of diabetes prevention among the family members of patients with T2DM. He believed diabetes is hereditary, and thus diabetes education programmes and preventative care should be put in place for family members that may have inherited the illness:

*“I think those family members, for example whose parents who have diabetes, the hospitals should give sessions [diabetes health education] to the children. They need to start teaching the children [knowledge on diabetes and how to prevent diabetes].”(Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

**Books and electronic materials.** Patients mentioned gaining knowledge and information related to diabetes care from books, pamphlets, and electronic materials – including sources from the internet and social media. The source of some media involved recommendations from others or casual surfing on various websites:

*“The nurse gave me a book... said to me, ‘this one is good for you to read.’” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

The increasing availability of health information on the internet, and the ease of sharing information in social media, has made these 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 on the internet. The American Association of Diabetic, you know, they have a good website.” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

However, the healthcare providers were worried that patients might receive unreliable information lacking any verification. Therefore, one healthcare provider voiced his concerns and encouraged his patients to ensure that the information obtained be discussed with their healthcare providers:

*“Normally I will tell my patients: ‘you can surf internet for information, but you cannot, on your own, go look for treatment based on what you read. You must discuss with your doctor first. You can have information from elsewhere, but you must discuss it with your doctor [before you try it]’.” (HCP, male, private primary care clinic)*

#### **4.5.2 The strength of influence and impact of information sources**

The information received could support patients’ decision-making process in choosing the treatment type. Therefore, a significant influence on the decision-making process among patients with T2DM was observed. Although patients received advice and recommendations from various sources, the strength of the influence on patients’ decisions and choices of treatment depended on their relationship with the person from whom they received the advice or information. Additionally, the impact of these influences also depended on the level of trust, support, and ease they received information from social networks. Patients were more open to suggestions and accepted advice from those they felt comfortable with.

***The strength of a relationship.*** A relationship is a state of being related to on or two groups of people. However, the strength of relationships can vary. Patients tended to accept information provided by those who were close to them. Thus, the closer or stronger the relationship, the greater the impact and influence on patients’ decision-making in treatment options. Aside from spouses, the bond developed with other family members such as sons, daughters, or siblings could have the same effect. Such advice from this category of people could motivate patients to remain positive if they possess a strong bond with each other. Patients were also more inclined to accept recommendations and suggestions to seek better treatment from the advice given.

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

Similarly, the provider-patient relationship could have a huge impact on a patient’s choice of treatment and adherence to treatment regimes. Strong communication between healthcare provider and patient was essential, and usually resulted in developing a better relationship. Consequently, the patient would feel satisfied with the service and treatment received. The following excerpt illustrates how one participant was unsatisfied with the services received from a public primary care clinic, resulting in her seeking medical attention from a private clinic:

*“I told them [public healthcare providers], but it seems that what I had said had fallen on deaf ears. That’s the reason why, sometimes I would rather go to the private.” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

Patients want to be in control of their health. This is the reason why they expect to be informed or updated on their illness, in relation to their overall health status, by their healthcare providers. Patients satisfaction with communication during consultation or healthcare services is paramount in patients selecting and maintaining treatment modalities. This will prevent them from consulting multiple clinics or doctors. When patients do not have a positive relationship with their healthcare providers, they are more likely to switch treatment facilities or attempt another type of treatment. Therefore, the dynamic interplay between patients’ unmet needs and doctor-patient relationships is evident from the preceding patient excerpt.

**Level of Trust.** The level of trust between patients and their social networks was identified as a factor that influenced patients in accepting provided suggestions and advice. Trust in human relationships provides a sense of confidence that could drive patients to believe and accept advice and suggestions provided by trusted individuals (Thiede, 2005). This is especially true if recommendations come from peers that have experienced a similar situation:

*“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.” (Fatima, 55 year-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 peer recommendations. The level of trust could undermine the cost of treatment. This is illustrated in the following scenario, which was observed by one of the healthcare providers:

*“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] it cannot be cured. Having to pay one Ringgit Malaysia is a problem, but you can see the amount of supplements they are taking, it is not cheap.” (HCP, female, public primary care clinic)*

Faith and trust in a relationship, especially between a healthcare provider and patient, were very important to producing a strong influence. Another participant expressed her satisfaction with treatment received from her doctor, as she trusted the treatment given to her: *“I’m satisfied with what she [advice and treatment given]. I trust my doctor.” (Geeta, 52 year-old, diagnosed with T2DM 2.5 years ago)*

Conversely, if a person had no confidence in the health information or service provided by healthcare providers, they would not accept the advice given. For example, one of the patients shared his experience in receiving an incorrect prescription from a clinic. After that incident, he no longer trusted the doctor and would always have his wife double check the medications:

*“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.” (Raja, 52 year-old, diagnosed with T2DM 21 years ago)*

**Perception of being cared for.** Patients with T2DM often experience a high level of emotional distress resulting from fluctuating blood sugar levels (Kadirvelu et al., 2012). Thus, receiving support from a caring person would produce a positive feeling, which would lead to a sense of security and further motivate patients to readily accept advice on treatment options. Strong support produces emotional encouragement to the extent that patients would rely on what family members decide for them. One family member described how strong mutual support developed between spouses, which 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 her... don’t stop taking the clinic medicine. I want her to have the best.” (Patient’s husband, 53 year-old)*

Patients were exposed to various types of diabetes management, either directly or indirectly. With strong influence and support from social networks, this would

eventually encourage them to conduct a trial-and-error process involving different types of diabetes management methods. Given the influence that peers tended to have on the participants' perceptions overall, the information obtained from peers usually shaped the participants' decisions on preferred treatment.

The subsequent sections will further discuss which information on treatment characteristics patients considered prior to deciding to experiment with a given treatment.

#### **4.5.3 Type of information required: treatment characteristics**

Patients would look for certain information regarding treatments to help them choose. Pertinent information includes treatment efficacy, side effects, the simplicity of the treatment regimes, and the accessibility of the treatment. The following section discusses each of these characteristics.

##### **4.5.3.1 Treatment efficacy**

Treatment efficacy pertains to treatment performance, which could produce a positive outcome such as the illness condition improving after treatment (Polonsky & Skinner, 2010). When patients seek treatment, they may need to consider the efficacy of the treatment and its effectiveness. The most important aim of choosing a treatment strategy is to achieve a desired goal. The goal can involve reducing blood sugar level, or simply alleviating diabetic symptoms in order to restore quality of life. Therefore, when a variety of treatments are presented to patients, regardless of whether they are modern, traditional, or home remedies, patients would not refrain from attempting them assuming they could locate information supporting the effectiveness of those treatments in achieving their goal. The information need not be rationale from a medical science perspective. It was noted that information was considered if the source of information



was considered trustworthy by the patient. A friend represents a typical example in demonstrating this phenomenon, because friendships are established on trust:

*Sometimes I heard my friends saying they had the herb which could control [blood sugar level]. A Chinese herb, then I tried. I did try. So I am taking it, now...I can sleep very well.” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

When patients tried various types of treatment modalities, they hoped for positive outcomes that could ultimately fulfil their goal. The information on efficacy could also be the result of their own experimentation:

*“Sure, the effect [of traditional herbs] is there. The effect is that the symptoms of diabetes will decrease. Like if I drink at night, I had tried, you know. There was that one time I had to see the doctor the following day, so I drank it the night before; when checked by the doctor, my diabetes had gone down. My urination became less frequent, unlike before every hour I had to urinate. I took this and it stopped.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

#### **4.5.3.2 Side effect of treatment**

Side effects refer to the negative outcome of a medication or treatment with regard to patients' expected outcomes. Patients' treatment choices also depended on the side effects of treatment. Ideally, patients would prefer a treatment free of side effects. However, they were aware that side effects were sometimes unavoidable. Therefore, patients would want to know if the side effects of treatments sought are potentially dangerous. The perceptions of dangers were subjective and patient-based. For example, one participant opted for alternative treatment upon hearing from others about the

harmful and long-term negative effects of the chemicals, used in modern medicine on the kidneys:

*“People say if we take that medicine our kidneys will be affected. They affect our kidneys. I already have the perception, from taking the medicine from the clinic, that chemicals have their effect. So, with these traditional medicines, they help to reduce the amount of pills [diabetes medication], which usually can cause kidney stones.” (Hassan, 58 year-old, diagnosed with T2DM 7 years ago)*

This anxiety was reiterated by another participant. Patients tended to choose alternative treatments with the hope of reducing the effects of chemical products while continuing to consume diabetes medicine simultaneously. This was substantiated by the following patient feedback:

*“I’m going for all these things [alternative medicine] rather than getting more from modern medicine to overcome the problem that was created by the first batch of modern medicine. In the long run, I think, there’s some truth in it. To me, because I experienced it, there’s some truth in it.” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

While modern medicine appears to be perceived as containing many side effects or negative effects, it is evident that participants using traditional and complementary medicine have the perception that it carries no negative effects compared to modern medicine:

*“Chinese traditional herbs won’t affect our body...they [friends/peers] said the [modern] medicine can affect the body; our body becomes very weak.” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

Diabetes treatment can also involve other aspects. For example, in deciding between oral medication and insulin therapy, patients' preferences were determined by the treatment and its side effects. To this point, the following was shared by one participant:

*“There were people who said insulin is dangerous, troublesome. ‘Better take tablet’, they said.” (Selvi, 52 year-old, diagnosed with T2DM 3 years ago)*

Based on the information gathered from patients, it appears that patients with T2DM also feared or carried the perceived pain of insulin injections. Consequently, this provided patients with a negative perception towards insulin intake. Evidence for this notion is shown in the following excerpt:

*“I don't want an injection, it is painful. I am scared whenever I see other people getting injections.” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

However, the same opinion was dismissed by another participant that had been living with diabetes for over 10 years, and took regular insulin injections. She claimed that insulin was less harmful than oral medication. Therefore, it is evident that patient perceptions can vary:

*“If we get an injection, our kidney function will be preserved. But if we take oral medicine, our kidney function will be affected.” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

The side effects of modern medicine were also cited, particularly their perceptions on how these chemicals would harm their kidneys, and concern existed regarding the side effects of traditional medicine:

*“No [never tried traditional treatment], I am scared indeed. I am scared of taking traditional medicine. I am already taking modern medicine; if added with traditional medicine, it might contradict. What happens if I got side effects from taking it together with modern medicine?” (Selvi, 52 year-old, diagnosed with T2DM 3 years ago)*

Essentially, it can be said that patients’ perceptions and experiences differed in nature. This cannot be disputed, since patients came from different backgrounds and cultures. What one may consider as having minimal side effects, another may disagree with because the perceptions they carry are different. This perception of side effects is based on individuals’ unique experiences and the significance of the information they received.

It appears that another patient, who had been on diabetes medication for over 18 years and never tried traditional and complementary medicine, was not convinced of the safety of traditional and complementary treatment. She was reluctant to try traditional medicine due to concerns about its negative effects; in fact, she was satisfied with modern medicine:

*“There are many traditional medicines from India [for diabetes], but I have never tried. I do not want the troubles of trying this and that. Taking this medication [from clinic] is enough for me.” (Devi, 50 year-old, diagnosed with T2DM 18 years ago)*

#### **4.5.3.3 Simplicity of treatment regimes**

The simplicity of treatment regimes refers to the preparation of certain traditional herbs or natural remedies that is considered simple, or could be easily prepared and consumed by patients. Simplicity regimes also encompass modern medicine; for

example, taking oral medication simply involves consuming pills. Traditional medicines can also vary, and can be as simple as chewing and swallowing the leaves of medicinal plants, or may involve complex processes involving traditional herbs. This was illustrated by a participant who demonstrated the easy preparation of traditional herbs for use:

*“The traditional herb is easily prepared. You drink it like you normally drink water. For 2 days you drink it and [frequent urination] will stop”. (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

In today’s fast-paced lifestyle, people want something simple that does not upset or interfere with their daily routines. However, not all traditional medicines can be easily prepared, and certain traditional herbs are said to be troublesome in their preparation. Due to this, patients also expressed their preference for ready-made traditional herbs, which are sold in the market and are convenient and accessible for patients to buy and consume directly without the hassle of preparation. One patient provided her input by mentioning the following:

*“I am not a hardworking person [the preparation process], I just buy those ready-made.” (Fatima, 55 year-old, diagnosed with T2DM 3 years ago)*

With modern medicine, the complexity of the treatment regime seems to carry certain procedures which some participants complained about; for example, the strict timing of medications and the hassles of insulin injections. Often, patients that needed to take their medicine frequently (e.g. three or four times a day) would also miss their dosage:

*“Most of the time when I go for lunch I forget to take the medicine...” (Chong, 58 year-old, diagnosed with T2DM 10 years ago)*

Consequently, patients found that the administration of medication is not as simple as commonly perceived, and some complex procedures can only be understood by those who are experiencing it. Nevertheless, one person’s perception of convenience might not be the same for another. Therefore, the degree of adjustment for patients had to be based on the individual interpretation of convenience, which naturally varied among individuals. Ultimately, when a choice exists for patients in selecting the mode of medication, they will choose what appears to be the most simple and convenient for themselves, accompanied by the ease of preparation or administration of the treatment modality.

#### **4.5.3.4 Accessibility**

Accessibility refers to the affordability and availability of a diabetes treatment for patients, and how it can be accessed within a given local healthcare system. This accessibility is also applied to seeking traditional and complementary medicine or home remedies. Both affordability and accessibility are relative terms, and represent a balance between the cost and ease of access to treatment and patients’ abilities – different patients have different abilities. More financially secure patients could afford expensive treatments, and could reach out to more difficult-to-access treatments. Hence, patients would want information on the cost and ease of access to a treatment in order to assess their ability to select it.

##### **(a) Cost of treatment (affordability)**

Information related to the cost of treatment was paramount to patients in seeking diabetic treatment. This was especially true for patients suffering from chronic

illnesses such as diabetes, which requires long-term treatment that incurs high costs. Cost can also be affected by the possibility of escalating medical expenses. In that regard, patients were more inclined towards cheaper treatment modalities that would serve their treatment goals:

*“I’ve got one man I met at the hospital, he said ‘if you want to cure [your diabetes], you go buy Indian herbs, only about one Ringgit Malaysia.’ Normally, it sells at Indian grocery shops. It can be obtained easily and it is also cheap. The total cost is low. It’s sold in the convenience shops.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

The Malaysian healthcare system is a dual-sector system consisting of government-subsidised public health clinics and private paid services both among general practitioners and private hospitals, as described in Chapter 1. In Malaysia, patients can choose to go to any place they want for treatment, which, as previously mentioned, depends very much on their affordability. For patients who cannot afford high expenses, public healthcare facilities would be their option, and occasionally, patients would switch from private facilities to public clinics to continue their treatment. This implies that such a patient’s decision is also based on affordability. For example, this choice was accounted for by patients who switched to public facilities when they were unable to continue with treatment in private clinics due to the higher cost:

*“For the few months I cannot afford [the private]. So I turn over to here [public primary care].” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

*“We were... from that day when my mom was diagnosed we started to support her, we asked her to take medication. We support her to going to the clinic, wait to finish it completely. We register her in the government clinic because the medications out there [private] are very expensive.” (Patient’s daughter, 31 year-old)*

Although affordability was closely related to cost, and information on cost was important, this was ultimately dependent on the financial abilities of the patients. Patients would continue with the more expensive option if they could afford it:

*“About RM90 [treatment cost], it is ok, not a burden...” (Fatima, 55 year-old, diagnosed with T2DM 3 years ago)*

Patients with T2DM not only sought treatment, but they were also be obliged to practise self-care and their diet intake and in today’s world. It appears that certain foods that have been perceived as good for diabetics can be quite expensive. For instance, the type of rice that is considered suitable for diabetics can cost much more than ordinary rice.

*“Expensive, expensive, for five kilograms of Basmati rice [type of rice with has lowest glycaemic index] it costs me about RM34.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

Affordability or the ability to pay treatment fee be it modern or traditional medicine and certain forms of self-care, was important to certain participants. Thus, affordability was one of the determining factors in choosing the type of treatment modalities, and information regarding treatment cost was important.



(b) *Availability*

Availability refers to the type of treatments, services, and resources available when needed; the availability of treatments, especially when warranted, is essential. This is relevant to healthcare providers or facilities and specialist services, or traditional remedies. Participants spoke about how they and their family members searched for information regarding the availability of treatment, regardless of it being modern medicine or traditional and complementary medicine.

*“Sometimes, I take a drink made from ‘kratum’ [Mitragyna speciosa] leaves...whenever there are available and I ask from those people who also take this drink.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

With regard to availability, it appears that patients were influenced into trying a product, depending on the availability of the product - whether it is complementary medicine or natural remedies:

*“Here I got the direct-selling, [I] just order and the product will send to my house.” (Fatima, 55 year-old, diagnosed with T2DM 3 years ago)*

Apart from traditional and complementary medicine, modern medicine also provides diabetes care in the public and private healthcare system. However, the availability of certain services or treatment choices made by patients is dependent on other factors. For instance, patients may be restricted in their choices of getting specialist services offered by public primary care due to only one family physician being present in each public primary care clinic. Thus, it appears that patients were unable to seek specialist treatment during their visits to those clinics, as substantiated by a statement from one patient:

*“Here doctors are limited every time I come [public primary care clinic]. [I have] never been seen by a specialist... normal doctor only.” (Selvi, 52 year-old, diagnosed with T2DM 3 years ago)*

(c) **Physical access**

Physical accessibility refers to the context where an individual gains entry into the healthcare system and receives care or services offered by the system. This notion is related to the ease patients have in accessing diabetic care under the Malaysian healthcare system. The notion of physical accessibility includes physical access to the types of treatment provided, the flexibility of clinic hours, the level of waiting time, and the location of health clinics, all of which are also relevant to traditional and complementary treatment.

In addition, it appears that physical access represents another determining factor affecting patients' choice of diabetic treatment. For instance, a particular treatment may be available, but if difficulty exists in physically accessing that particular treatment, it may hinder a patient from obtaining the treatment. This is exemplified by the journey a patient took in seeking the treatment offered by a public primary care clinic. In some cases, the journey to seek treatment may be easy, and treatment fees may be nominal. However, if the level of waiting time is long and the opening hours of the clinics are inconvenient to patients, they may even forego the treatment. This situation can be seen through one participant's excerpt when he recalled how he had searched for and decided to seek treatment at a clinic that provides easy access, and was conveniently located near his home:

*“I have to look for a clinic that is nearer, not many people, so it is easier, right? Yes, it is near my house, more convenient.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

Another hindrance in seeking treatment may be the travelling process, since travelling from one place to another to seek healthcare could be tiring – especially if the journey is long and difficult. Nonetheless, peer social support could assist the person involved to overcome the difficulty of travel. One healthcare provider shared how her patients managed to seek the treatment offered by primary care through the support of sharing transportation:

*“Sometime patients follow their friends to the clinic. They come together, three or four patients. Maybe one of them who is slightly healthy can drive the car, and then the rest will follow him. They are all staying nearby.” (HCP-paramedic group)*

In addition, a clinic’s opening hours may represent another factor affecting patients’ decisions in seeking diabetic treatment. A clinic’s opening hours are not within the control of patients, but for those travelling from a long distance to seek treatment, the lack of flexibility in opening hours of public clinics can actually inconvenience patients. In contrast, participants who sought diabetic treatment in private primary care have discussed the advantages of the longer operating hours of some clinics, which provided flexibility in access to care as well as convenience. For example, a clinic could be open after regular work hours or during weekends. The input provided by one patient highlighted this situation:

*“Yeah, my panel clinic is open until 9 o’clock at night, so I can go after work. Very convenient. I think it only takes 3 minutes if I drive there. The other thing*

*is the clinic has two free parking spaces for the patients.” (Chong, 58 year-old, diagnosed with T2DM 10 years ago)*

It appears that the Malaysian healthcare system offers the ability to choose either public or private healthcare. Some patients who have the privilege of accessing private healthcare facilities for instance, are employees subsumed under the coverage of employee benefits. These patients would continue to seek treatment at their company-appointed panel clinics due to the flexibility mentioned, which is supported by the following patient excerpt:

*“We have a panel, a company panel. So it is better going for a [frequent] check up. The company pays of course. We are covered by a company panel, very convenient for me, right? Yes, very convenient in terms of time and payment.” (Geeta, 52 year-old, diagnosed with T2DM 2.5 years ago)*

From the interviews conducted with participants, it appears that ease of access to a treatment was an element affecting their decision to opt for certain treatment modalities. The ease of access factor encompassed the patients' easy access to medication. For example, traditional herbs which can be easily accessed through convenience stores or direct sellers or can be delivered as medical orders directly to a patient's home address. This not only saves time and effort, but is also extremely convenient.

Further detail regarding how patients evaluate the result or outcome of their experimentation, which is a part of the experimentation process, will be explained in the following section.

## **4.6 Evaluating the results of the experimentation**

The results of experimentation are an element of the experimentation process. Experimentation produces outcomes that may or may not fulfil patients' expectations. Their expectations are typically related to achieving a better quality of life. When the first cycle of trial-and-error experimentation fails to achieve the desired outcome, the cycle then repeats with another type of treatment:

*“We keep changing [different treatments] and trying [alternative treatments]. We want to see if the sugar level [glycaemic control] will come down. Thank God [positive result].” (Fatima, 55 year-old, diagnosed with T2DM 3 years ago)*

The subsequent sections further explore the outcomes of experimentation, as experienced by patients, and their perceived quality of life.

### **4.6.1 Outcomes and expectations (personal goal) of experimentation**

As explained above that some patients performed their own experiments with regard to treatments. In terms of the results of their experimentation, it appears that responses range from positive to negative outcomes. In this regard, negative outcomes resulted in unmet expectations. Positive outcomes, as perceived by patients, were those that were able to alleviate the symptoms of the illness and restore a higher quality of life – thereby achieving their desired goal. The negative outcomes, as claimed by the participants, were those that failed to achieve the desired goals, or that treatments result in any improvements for the patients. In such cases, patients continued to suffer from the disease, or did not achieve their desired goals. Such negative results appeared to trigger patients into persevering with other treatment modalities until they were able to achieve their desired goals.

The most important factor for patients in seeking treatment modalities was the benefit they could gain from the treatment. Such benefits, if they occur, were able to restore their quality of life. Despite the fact that participants were aware that diabetes is an incurable illness, they maintained hope for the illness being manageable and without future complications or deteriorations. This notion is evidenced by the following patient's acknowledgement: *"...wanting to totally be free from diabetes is difficult. Indeed you cannot, you can't say you're 100% cured."* (Ali, 52 year-old, diagnosed with T2DM 4 years ago)

Feeling overwhelmed by their illness and quality of life affected, them to seek other forms of diabetes treatment – whether through trial-and-error or with intentions – all in the hope of finding alternatives for reducing their symptoms. The ability to self-adjust the effects of the symptoms of the illness by attempting other forms of treatment was shared by all participants in this study. Among them, one participant said:

*"Besides controlling my diet intake, I also tried taking a traditional plant, people called it 'pasak bumi' [Eurycoma longifolia], almost regular [taking it] or whenever my body felt weak [symptom of diabetes]. I have tried and yes very effective."* (Hassan, 58 year-old, diagnosed with T2DM 7 years ago)

#### **4.6.2 Patient quality of life<sup>4</sup>**

The following subsections explore the type of quality of life as perceived and shared by patients. It appears that patients' quality of life is an important component which

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<sup>4</sup> Part of this has been published in Lee Lan Low, Seng Fah Tong, Wah Yun Low (2014) Mixed feelings about the diagnosis of type 2 diabetes mellitus: A consequence of adjusting to health related quality of life. Coll. Antropol. 38 1: 11–20

impacts on patients' expectations. If patients' quality of life is affected, then unmet expectation would trigger another episode of experimentation with different treatments.

#### **4.6.2.1 Achieving good physical functioning**

Physical function is the most important domain for a person's quality of life and this applies to those with chronic illnesses. In such circumstances, having the ability to function in daily life without experiencing any physical shortcomings is the wish of any patient. However, for patients with T2DM, fatigue is a common phenomenon they share. For some, fatigue could be due to the effects of treatment, but for others, as claimed by one of the participants of this study, fatigue possibly developed due to strict dieting that had resulted in energy depletion. Because of this, patients sometimes attempted to skip medication or non-compliance of diabetes management. This was supported by a participant who shared her experience in adjusting to the quality of life, but did not necessarily strictly adhere to advice regarding food intake:

*"... getting very tired. Tiredness is the main thing. They [the healthcare providers] will tell you many types of fruit you cannot eat, this fruit, that fruit. But, I am still taking fruit." She further explained that the feeling of tiredness was due to "the body...is not taking enough of normal food." (Geeta, 52 year-old, diagnosed with T2DM 2.5 years ago)*

T2DM is a chronic illness that carries many symptoms and complications. The symptoms may vary from a mere feeling of thirst or the need to urinate frequently to more serious symptoms including fatigue and blurring of vision. These symptoms invariably affect a patient's quality of life, and the person may frequently feel worried:

*"I am not sturdy when I walk; I will sway, not stable. But it is not giddiness. I can't even walk properly. I don't know, but diabetes is like that; our body will not*

*be normal when walking. At noon, the face will be very pale; I am worried that something can happen, like falling down in the middle of the road, because I go to work on a motorcycle.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

Patients with T2DM not only experienced various symptoms but also needed to perform physically demanding tasks in their daily lifestyles such as driving or travelling. These tasks imposed by their lifestyles can also affect them, since the physical limitations imposed by their illness can develop important and devastating emotional consequences:

*“Whenever I am driving back, before I reach my office, I could experience hypo. I must eat along the way. I must buy one soft drink, to make sure that I reach here [office] safely.” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

Some patients, for instance, experienced the side effects of insulin injection such that their daily physical activity and work was hampered. To overcome this, patients resorted to self-adjusting in order to enable them to carry on with their normal life. Although the patient above had experienced the side effects of insulin injection, she managed to overcome it through her own efforts. She did not feel frustrated, but had instead accepted that insulin injection will always be part of her diabetes management.

*“If I have insulin in the morning, I can’t work because I will feel very tired; my body will be very weak. I don’t know why. I have the injection at night. After the injection, I sat down, or just lay down and go to sleep. I felt nothing. In the morning, I was not okay. I felt weak and my body felt weak and sleepy.” (Selvi, 52 year-old, diagnosed with T2DM 3 years ago)*



#### 4.6.2.2 Social functioning

As a multi-ethnic country, Malaysia celebrates different festivals according to the various ethnicities that comprise the nation. During such festivals, a variety of food is served. In addition, Malaysians also like to socialise; hence, it can be said that socialising and eating out are common activities for Malaysians, whether with friends or family members.

*“Sometimes during festive seasons, I am a bit less cautious about dieting.”*

*(Chong, 58 year-old, diagnosed with T2DM 10 years ago)*

However, there will also be patients who may be slightly more careful with their food intake, as is evidenced by one such participant that mentioning: *“Even though there are always some functions here and there, whenever we go to functions, we also have to be careful with the food intake.”* (Geeta, 52 year-old, diagnosed with T2DM 2.5 years ago). It is apparent that this patient was satisfied with the daily management of her illness. She was not only able to contain her illness; she adjusted well in her social activities. This implies social functioning in that a person wishes to take on a task willingly (and happily) without any feeling of obligation. An example be going to a social function and, being able to enjoy oneself as long as a person is able to manage their diabetes and emotions.

Although physical functioning may have a huge impact on patients' daily lives, it is important that patients learn how to deal with their emotions and their need to attend social functions. Participants voiced their frustrations with diabetes management, which often involves altering dietary intake and tends to occur irrespective of how vigilant a patient may be with dietary or blood sugar monitoring. In this respect, it would seem

that adherence to a healthy diet (self-care) can be a challenge, as patients must exercise an increased level of discipline:

*“Normally, after dinner, I will go for my religious class which usually ends around 10 or 11pm, when they start serving food. That’s the problem. If the food is served in front of you, I pick it up, then I know, tomorrow it’s [blood sugar level] going to be up. I expected that. That’s my problem, I am not disciplined enough.” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

#### **4.6.2.3 Work function**

The findings of this study also indicated that diabetes serve as a barrier for patient’s self-management, and also affects a patients’ work functions and working environment. In this study, participants related their concerns when diabetic symptoms affected their work:

*“If the air conditioning is cold, not even for 5 or 10 minutes, I will have the urge to pass urine. I leave the counter [dealing in customer service] too long... that’s my dilemma.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago).*

In patients with T2DM, their job function or working environment can also affect their medication compliance. The following participant related how she was unable to strictly follow her prescribed medication because her work environment was not conducive for doing so:

*“I will [did not take medication for days], sometimes I also forget. For example, in the morning we had to take food, then I take the medicine. I have to keep some there [workplace], because when the counter is open we also have to follow their*

*rules... very rushed during that time. So I forget the time to take medication. This can happen.” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

#### **4.6.2.4 Social obligations**

In this study, it was found that social obligations (e.g. in a family or society) emerged as one of the domains of quality of life for patients with T2DM. The social obligation as what the participants spoke was the need to fulfil their expectations or emotional needs of their loved ones. It is reflected as a notion of responsibility such as being in a role of responsibility or taking on the task by obligation. They discussed their moral obligations as well as how they simultaneously managed their treatment regime, symptoms, and blood sugar level:

*“I can feel the effect of taking the medicine. After taking the medicine, I cannot achieve an erection. I apologise for saying it. I try to avoid disappointing my wife. Sorry. The medicine, to me, and I am sure, makes my ... [penis] weak. So, when I stopped taking this medicine, then I felt there was much improvement. I have the sexual urge, but physically, I can't [get an erection].” (Hassan, 58 year-old, diagnosed with T2DM 7 years ago)*

*“For example, yesterday I went to eat chicken rice. My son offered me a glass of carbonated drink and asked me to finish it. I was reluctant. Then I looked at the drink and said to myself if I took it my sugar level would surely go up. Nevertheless, I ended taking the whole glass of the drink! My sugar level was more than 11 this morning!” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

The above excerpt suggests that the patient's adjustment to and coping mechanisms for diabetes management required some level of discipline. However, with social

obligations, this became a challenge to many patients with T2DM. Their inability to fulfil the need of the love one or the people around them entailed negative feelings towards diabetes. This implies that seeking alternative medicine to overcome the symptoms of the illness in order for them to fulfil social obligation represents an option for experimentation.

#### **4.6.2.5 Dietary freedom**

As mentioned earlier, eating is a part of the Malaysian lifestyle, as it is involved in many festivals celebrated in the nation. Nonetheless, feeling restricted in one's choice of preferred foods on an everyday basis is something that patients with T2DM encounter. This can indirectly affect their quality of life, which would eventually lead to a greater psychological impact. Several participants lamented about the loss of what they considered to be a normal life, one that they had enjoyed prior to being diagnosed with T2DM. Interestingly, one participant used a metaphor to describe the feelings before and after diagnosis:

*“I used to eat some moon cakes [sweet Chinese cake] before, but now I have reduced the amount. So now, we know our quota for all these is up already [limitation] for ice cream and soft drinks” (Chong, 58 year-old, diagnosed with T2DM 10 years ago)*

This patient also added: *“Yeah, very important discipline, I try to refrain from it. If you want to have a long life, you must try to stop this thing [favourite food], because this thing ‘quota’ for you; it’s already up (to it).”*

Patients with T2DM wanted to have the freedom to eat whatever they like. For example, this participant, even though she knew the consequences of non-compliance in following a strict diet for her diabetes, she was unable to comply. Many times, she just

did not care. She claimed that her body felt very weak if she did not get to eat her favourite food whenever she felt like eating it. The reason given by her was: *“I cannot control eating the food I like; I just need to taste it”* (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago). On the other hand, she was also worried about her uncontrolled blood sugar level, which required changing the treatment regime from oral medication to insulin injection. She shared: *“[my doctor] was scolding me; my reading so high and suggested for injection [insulin]. I said I don’t want an injection.”* From this excerpt, it was obvious that the same patient was experiencing ambiguity in terms of the adjustments she made in fulfilling her quality of life and diabetes management. She had wished for the freedom of eating any food she liked, and yet she was bound by the common restrictions of food intake prescribed by her healthcare practitioner.

Another participant also spoke about his experiences with regard to controlling his dietary intake:

*“I do not know. I really don’t know. Because you’re so confident that you know how to manage, you kind of take the risk; once in a while I take a risk. Once in a while I go and take durian [tropical fruit]. You know, things like that. Although, I [know] should not be eating durian [fruit which contains a high amount of sugar].”* (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)

Whether it is obvious or not, it cannot be denied that patients suffering from diabetes are like normal people who have cravings and just want to feel the freedom of eating the food they like – just as a healthy person would want. This desire can ultimately prompt them to seek alternative treatments with the hope of finding ways of controlling blood sugar level.

#### 4.6.2.6 Conforming to management and treatment standards

Besides all of the aforementioned challenges which patients with T2DM experienced, the ability to conform to treatment standards represents an additional challenge affecting patients' treatment management. Patients' ability to follow treatment regimes, and their ability to adjust to minimal interference in daily treatment was one of their main aspirations. Many patients experienced an uphill struggle in finding ways to conform to the illness management and treatment standards prescribed by their healthcare providers. In this study, participants confessed that finding the strength to conform to diabetes management was always a dilemma for them. Such worries, if not handled correctly, can affect patients' quality of life. Based on the interviews conducted, it became obvious that such concerns did not strictly relate to the condition of their diabetes, but also their dilemma in conforming to treatment requirements.

Taking medication is part of a patient's daily ritual. Therefore, when a patient misses a dose, they will naturally become frustrated. One of the participants shared how he had struggled with taking the required dosage, especially in times when he was required to take it three times a day:

*"I think taking medicine also involves discipline. Sometimes, I missed taking medicine, and always forget to take it after lunch, because most of time, I go for lunch and forget about the medicine. I always go out for lunch; I don't come back [to the office,] and I kept the medicine in the office here." (Chong, 58 year-old, diagnosed with T2DM 10 years ago)*

In order to suit a patient's daily lifestyle, the patient's doctor made some medications adjustments by changing the frequency and dosage from three times to twice a day.

This issue of non-compliance also worried some patients, for they were aware that their own doctors would reprimand them for non-compliance:

*“My blood sugar was high because I didn’t take medication...my medication finished, because I had missed the appointment, but I didn’t tell the doctor. I was scared that the doctor might scold me.” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

Despite these challenges, it was also noted that some patients were disciplined enough to comply strictly with the treatment standards and doctor’s advice:

*“I am scared of getting kidney failure. My glucose level is high, so I had to take injection and followed the doctor’s advice.” Even when going abroad for a holiday, the same patient did not have any problems managing her medication. “I bring it along with me. 24 hours. Even during my vacation, I will bring my diabetic pen and the medicine along with me in my luggage bag.” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

Living with T2DM is like travelling on a long journey, for it not only involves accepting the illness as part of your entire life, but also involves knowing how to manage diabetes: adjusting to the illness’ ups and downs, taking precautionary steps, and planning for treatment procedures.

In essence, the symptoms and complications of T2DM are widespread, for both of these factors can affect patients’ daily activities. If not managed correctly, it can affect their ability to perform their daily responsibilities. The ability to have a good quality of life without setbacks in their diabetes control would serve as their main aim and

expectation. Thus, it serves as the main trigger for patients to seek and try various types of treatments, some of which may go against medical advice they receive.

The following section explores the decision-making process regarding treatment types and how patients conduct their experimentation process.

#### **4.7 Undertaking the experiment (deciding on the type of treatment)**

The process of experimentation required weighing the benefits of treatment against the potential for achieving the desired quality of life, before deciding on the types of treatment modalities (see Figure 4.1). Any decision made was constantly reconsidered. It was not a linear process, because overall, both the desired goal and perceived benefit of treatment were constantly changing, and a new balance was constantly re-established. For instance, the process involved considering multiple components situated within a constantly changing healthcare system, illness condition, social network, perceived characteristics of treatment, and patient expectations. The decision-making process involved trade-offs between the ideal and the practical, in which patients attempted to maintain a balance based on their goals and their abilities. In this study, patients with T2DM were exposed to various types of diabetes management - through either direct or indirect influence from the people surrounding them.

One participant claimed that through this process, he was able to achieve some form of “success” from his own experimentations. The experimentation had provided him with a feeling of satisfaction, as he was able to achieve some results – in this case, an improved sex life:

*If I take diabetic medicine, I cannot achieve an erection. Actually, I did some experiments, to be truthful. Not the scientific method, but experimenting based on my knowledge... if I monitor my diet intake, then my blood sugar level reduces... I*



*think I have success. Yes I have success [with the self-experimentation].”*  
(Hassan, 58 year-old, diagnosed with T2DM 7 years ago)

Subsequent sections in this paper discuss the decision-making process made by patients attempting to determine their choices of diabetic treatment by balancing each treatment characteristic in order to achieve their personal goals. These treatment characteristics included: (1) treatment efficacy and affordability, (2) treatment efficacy and the side effects, (3) treatment efficacy and the simplicity of treatment, (4) treatment affordability and physical accessibility, and (5) treatment availability and affordability.

#### **4.7.1 Balancing treatment efficacy and affordability to achieve personal goals**

When searching for the best option of treatment, a patient usually has hopes and aims for accomplishing successful treatment, aimed at curing the illness or eliminating the symptoms. In this regard, treatment efficacy can refer to a patient's priorities in deciding on certain treatments. However, issues of affordability might prevent patients from opting for certain treatments. Thus, disappointment would be experienced when patients discover that they are unable to try certain treatment modalities due to financial constraints, particularly when they had perceived such a treatment to be more effective than others.

Money is always involved in seeking treatment, and it cannot be denied that patients seeking private primary care would experience high or exorbitant costs, especially for those without health insurance coverage. Those without insurance would have no option but to select treatments that have a lower cost, or choosing an alternative treatment. Alternatively, such patients may choose other types of treatments, for example traditional medicines. However, contradictory to popular assumption, traditional medicine can be very costly and a financial burden to some patients. This is especially

true when the cost of such a treatment is compared to the nominal fee of one Malaysian Ringgit per consultation, which a patient has to pay when seeking diabetic treatment in public primary care facilities. Moreover, a few over-the-counter traditional products can also be quite expensive, and the impact is felt when such traditional treatments are not covered by health insurance in Malaysia.

In this study, reasons for trying traditional and complementary medicine varied. These reasons depended on patients' priorities and the ability to balance the effectiveness of such treatments with their affordability. Patients who could not afford these treatments on a long-term basis changed their options and reverted to taking other types of traditional medications or herbs that are less costly. One of the participants, for example, claimed that the traditional herbal tea that she was taking provided positive effects for her diabetic symptoms. But due to the high cost incurred, which became a financial burden to her, she had to forego that treatment and selected alternative herbs instead:

*“It helps me to sleep. I always go to urinate [before taking traditional herbs], but now I can control the urination problem at night. However, those [traditional herbs] are expensive [for long-term consumption]. I took a few bottles then I stopped, it was expensive...So I now I turn over [to drink] the normal Chinese tea.” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

Despite the factors patients seem to share, it seems that patient's individual priorities varied from one to another. It appeared that patients would weigh the benefits of their treatment by looking at their health and finances. There were participants who considered health as important, so they would continue with an ideal treatment as long

as they could afford to. This is supported by one participant concerned with regaining her health and leading a better life:

*“Health is important. Not money.” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

Another participant shared the same opinion. He considered health to be important, and as long as he could afford to spend the money for additional complementary medicine, he would continue to do so:

*“Traditional medicine is expensive, you know. People are selling at RM1,000, RM800 or RM1,500. The money is not an issue. The money will come, no problem, right? But I think health is more important.” (Jamal, 53 year-old, diagnosed with T2DM 13 years ago)*

One participant had T2DM for over 22 years, and experimented with several treatment modalities – including spiritual treatment. During the interview, he explained his search for a treatment he hoped could effectively cure this illness. His search for treatment had even incurred the higher costs of spiritual treatment. Nonetheless, he expressed his disappointment with the type of traditional treatments he had sought in the past, as they had not brought about any positive outcomes for him – even though he had spent a large sum of money:

*“The shaman gave me a drink made from eel...its blood was mixed with milk, and the shaman cast some spell. He said that with 100% certainty that my kidneys would be cured, but until now they are still not cured. Yes, seeking faith healer... payment RM500 per treatment. All have to pay.” (Raja, 55 year-old, diagnosed with T2DM 21 years ago)*

From these excerpts, it is evident that patients' desires to try a new treatment modalities was based on several courses of evaluation which aimed to determine if the new treatment was effective in the management of T2DM. It appears that a trade-off exists between treatment efficacy and affordability.

#### **4.7.2 Balancing treatment efficacy and side effect to achieve personal goals**

The side effects of treatments is another concerning factor for patients seeking treatment modalities. Firstly, patients would evaluate the treatment efficacy and its side effects. If patients perceive treatments to have side effects, or if patients experience negative effects from certain treatments which they have taken before, they may opt for a treatment modality that has less side effects. This may occur even though the treatment they select has been found to have positive outcomes. The following is an example of one such worry, which led a patient to reduce the intake frequency for a type of medicine plant, although he claimed it could produce positive outcomes:

*“My friends drink this kratum leaf [Mitragyna speciosa (Purintrapiban et al., 2008)] every day, but I am scared. I only take it when my body does not feel good [sign of blood sugar increase], then I will ask for some from my friends. This [kratum leaf] is good, effective, and can reduce your blood sugar level, but I am scared of other side effects [if taking it too often].” (Ali, 52 year-old, diagnosed with T2DM 4 years ago)*

#### **4.7.3 Balancing treatment efficacy and simplicity to achieve personal goals**

The management of diabetes has become a part of patients' life routines. However, certain treatment regimes may require stricter procedures that can also make life more troublesome for patients. The management of diabetes includes the administering of insulin, which needs to be done constantly. However, it is an effective treatment – a

sentiment noted by the following participant: *“Insulin is ok, good.”* (Selvi, 52 year-old, diagnosed with T2DM 3 years ago). However, due to its requirement to be kept in cold storage, either in a refrigerator or a cooler bag, administering insulin can also become bothersome. The same patient would opt for oral medication whenever she had to be away for training in the course of her work. *“If I go travelling anywhere, I can’t take insulin along. If I go for courses, I don’t bring it because there is no fridge at the venue. So, I am forced to take oral medication.”*

#### **4.7.4 Balancing physical access and affordability to achieve personal goals**

Balancing a treatment’s physical accessibility with its affordability also represented a trade-off process for patients. It appears that when participants seek modern treatment from primary care (either private or public) the treatment is straightforward. When faced with the choice of traditional and complementary, however, the practice may vary greatly, since the cost of such treatments could range from free (home remedies or herbal plants) to incurring a nominal fee to buy certain traditional herbs, or to the high costs associated with expensive commercial products that have to be acquired from markets or shops. Upon examination of the healthcare delivery system available in Malaysia, it is evident that the system allows patients to choose their preferred health facilities or providers. Due to this freedom, switching from one facility to another is a common scenario, just as experimenting with one treatment modality or another is evident in this study. However, despite the flexibility of physical access to treatment modalities, the issue of barriers or impediments for those who cannot afford expensive treatment fees remains a factor in patients’ decision-making processes.

There appears to be many mixed reactions regarding how patients select a particular treatment modality. Some patients experienced barriers related to physical access, while others had problems related to affordability. Both issues remain important factors in

patients' decision-making processes. This outcome is supported by the following excerpt, provided by a participant that sought specialist treatment from private facilities, but found it too costly:

*“My younger sister went there [private specialist facilities] for treatment, so I followed her. I thought I would try, hoping it could cure my diabetes. But the medical fee was so expensive. I could not afford it.” (Yi Moi, 61 year-old, diagnosed with T2DM 10 years ago)*

Although most patients sought healthcare treatment in public healthcare facilities, some patients preferred seeking care from private primary caregivers – often because of the shorter waiting time for consultation. In this regard, the waiting time for a patient to see a doctor or consultant could be one of the predictors for accessibility to treatment choice. In reality, it cannot be denied that patients may have easy access to public health facilities involving a very nominal sum of money. However, a prolonged waiting time can become an issue affecting patients' outlooks and emotions, thereby motivating them to seek alternative treatment facilities. This was supported by a statement from a family member of a patient, who explained how uncomfortable his wife was with the long waiting time at a public health clinic:

*“Public facilities are indeed cheaper. It only costs one Ringgit Malaysia [RM1] but we have to wait for almost half a day. We are not rich, but she [my wife] cannot stand for half a day. We have little money; we paid about RM40 [at a private primary care facility]. It was very fast [waiting time to see the doctor]” (Patient's husband, 60 year-old)*

#### **4.7.5 Balancing availability and affordability to achieve personal goals**

Patients' decisions on types of treatment also appear to be dependent on the

availability of health services within a system, aside from their affordability. In comparison to public healthcare facilities, private primary care has the ability to accommodate a choice of provider. For example, patients could choose a doctor who can speak the same language, particularly in multi-ethnic society of Malaysia. Thus, the doctors seeing such patients can speak the same language, which gives patients more confidence in expressing their problem. In contrast, such a privilege may not always be accessible or available, particularly if patients are speaking a minority language. Despite the privilege, not all patients can afford the costs imposed by private primary care, which can be extremely high, and effectively deter patients from seeking treatment at such facilities:

*“Going to the private clinic is easier, faster, and communication is quite clear [able to speak with healthcare provider in the same language/dialect]. But if you go to a government clinic, too many patients, they [doctors] do not explain details. But at private [clinic] we have to pay the fee.” (Su Lin, 55 year-old, diagnosed with T2DM 8 years ago)*

In essence, this study showed the decision-making processes experienced by patients in seeking their chosen type of treatment modalities, and from the excerpts provided, it appears that decision-making factors differ among patients. While balancing cost, patients’ perceptions of efficacy, side effects, simplicity of treatment regimes, and accessibility led them to choose a particular treatment modality; therefore, expectations and goals were the deciding factors.

#### **4.8 Summary**

To summarise, the entire concept of experimentation is exciting and creative. Each experience or expectation, such as avoiding complications, resolving symptoms, and

maintaining quality of life are all part of a patient's personal goal. Therefore, the outcome, expectation changes, or the perception thereof could trigger another cycle of experimentation. This type of experimentation is an on-going process, which continues until one achieves a positive or satisfactory outcome; however, the next cycle would begin if the expectation is unmet. Patients will continue attempting different treatments, even to the extent of what some would call "shopping for a doctor or a healer". Patients' perceptions and expectations are important factors when dealing with the self-management of chronic illnesses.

The decision-making process among patients requires them to maintain a balance between the efficacy, side effects, simplicity, accessibility, and affordability of treatment regimes. Nevertheless, unmet needs still exist when patients must forgo their desired choice of treatment modality or treatment facilities due to financial constraints. The nature of deciding on the type of treatment modalities was dependant on which criteria was important, based on each patients' perception and capability. It was also noted that patients selecting treatment strategy indicated that a "best fit" did not exist in a single treatment modality for all patients, or even for an individual, and that the action of trying and testing new treatment modalities was an on-going and iterative process aimed at achieving a better quality of life.



## CHAPTER 5: DISCUSSION

### 5.1 Introduction

This chapter discusses the key findings and the substantive theory that emerged from the application of the grounded theory in this study. This study aims to explore what determines patient treatment-seeking strategy and the process of selecting a treatment type for type 2 diabetes mellitus (T2DM) in the Malaysian healthcare system. Two questions address the aim of this study: (1) what are the underpinning determinants that affect patients' treatment strategy? and (2) How do these determinants interact and influence each other in selecting treatment options in the current Malaysian primary healthcare system?

This chapter begins with the key findings of this study (section 5.2), followed by a discussion of the key findings in the context of existing literature (section 5.3). Then, the strengths and limitations of the study are discussed (section 5.4). Finally, a summary of the chapters is presented (section 5.5). The overall conclusion of the thesis, including recommendation for future studies and implications for the future direction this research is discussed in Chapter 6.

### 5.2 Key findings

This study adopted a grounded theory methodology, and managed to explore the pattern of patient behaviour and the process that patients undertook in deciding on their treatment strategy (see Figure 4.1). The key to explaining the treatment-seeking behaviour of patients with T2DM was the concept of “experimentation to achieve their desired goal”.

Experimentation to achieve their desired goal represented the core category and required triggers and information seeking as the precedent. The information related to

treatment characteristics was sought from entrusted family members and friends of patients, as well as from healthcare providers and mass media. Information related to diabetes treatment enabled patients to decide which treatment strategy could help them in achieving their personal goals. The entire process can be described as dynamic and iterative, since patients interact with the healthcare system. The decision-making process in choosing the types of treatment among patients with T2DM was complex, as it also involves a trial-and-error approach. The patients' experimentation was challenging, as it involved evaluating and weighing treatment choices. Moreover, patients' decision-making strategy were dependent on a number of factors, including treatment efficacy, the side effects of the treatment, the simplicity of the treatment regimes, and their accessibility to different types of treatment – be it modern, traditional, or self-care. The anchor of this experimentation process among patients was the need to fulfil their own expected outcome. Once an outcome did not meet their goal (a negative outcome), the cycle of experimentation continued with another treatment strategy, and retained negative outcomes as a trigger. Negative outcomes could also result from shifting goals, such as when the outcome no longer meets the new goal.

### **5.3 Discussion of key findings and comparison with existing knowledge**

This section discusses the principal findings derived from empirical data. The discussions are organised based on the emerging theoretical model, which encompasses the underpinning determinants affecting patients' decision-making when selecting the best treatment choices, and the process by which patients manoeuvre through the current Malaysian healthcare system in their treatment strategy.

#### **5.3.1 Discussion of the theoretical model with references to existing theories**

Although the grounded theory approach does not encourage a researcher to engage with extant theories at the beginning of a study, so as to avoid any form of influences

exerted by existing concepts (Dunne, 2011), it was found that aligning grounded theory with theoretical concepts is crucial for the overall research process. Thus, engaging with existing theoretical concepts in the current study allowed the researcher to draw on conclusions and use empirical data to demonstrate how their findings fill knowledge gaps, and subsequently contribute to the existing body of knowledge.

The substantive theoretical model as shown in Figure 4.1 illustrates that the treatment strategy is not static, but that it involves an on-going and multifaceted process that varies with each patients' experience. The determinant factors for this model illustrated are more diverse than earlier models such as the Health Belief Model, Health care utilization model, and Kroeger's Model (Hausmann-Muela et al., 2003; Kroeger, 1983; Mackian, Bedri, & Lovel, 2004). These models tend to describe health-seeking or help-seeking behaviours, and access to healthcare as a linear process that is moving in one direction. Nonetheless, the current study supports the argument raised by Mackian (2003), which suggests that earlier models do not comprise a flexibility that facilitates an understanding of how people make decisions, and the actions they take in the help-seeking process. While exploring the treatment strategy and the behaviour among patients with T2DM, the current study noted an element of uniqueness that existed in patients: each episode or experience of symptoms and complications was unique to the individual patient. An important concept to note from the current study was the emergence of "experimentation" existing among patients interacting with the current healthcare system in the process of seeking diabetes treatment, and deciding treatment options should be adopted.

Although the health belief model notes that people balance their actions against the cost of treatments and their efficacy (Rosenstock et al., 1988), it was also noted that the efficacy of treatment has always been perceived as the overriding factor in treatment

choice (Broadbent, Donkin, & Stroh, 2011; Polonsky, 2000). A similar behaviour was also found in the current study. However, the current study also observed additional characteristics that may affect patients' decisions as well as their choice of treatment. The concept of trade-offs with patients' own priorities could fulfil their expectations and desired goals. Furthermore, the health belief model does not emphasise or consider patients' personal goals, which a critical component evident in theoretical model presented in this study.

Similarly, the healthcare access model provided by Penchansky and Thomas (Penchansky & Thomas, 1981) had shown that patients' access to healthcare is based on availability, accessibility, accommodation, affordability, and acceptability, and that these domains are all part of the barriers or facilitators of treatment. However, it was noted that availability of excellent treatment options may not guarantee patients' physical accessibility, as affordability can be a factor preventing patients from receiving their desired treatment. Patients in the current study were able to prioritise or consider their choices of treatment modalities based on their life goals and desired outcomes. For some, the high cost of treatment did not deter them from access when it was perceived to fulfil their personal goals. Thus, healthcare providers may need to be aware that this behaviour and patient decisions regarding treatment type are based on their own prioritisation process.

The substantive theoretical model obtained from the current study also demonstrated the process of patients' treatment strategy, which involved the "triggers". Moreover, seeking information was added as a preceding factor that helped support patients' decision-making processes. Triggers emerge when expectations are not met – where there is a gap between a patient's goal and their current health status. This model helps to explain that actions are implemented following a careful evaluation of the

information obtained from various sources, including information accessed from a patient's social network; such information must be matched with the patient's perception and experience. It was noted that resolving signs and symptoms, avoiding complications or deterioration of illness, readjusting to new balance of desired quality of life and disease control, and fulfilling unmet expectations encompassed the "triggers" patients experienced before executing experimentation in treatment modalities (Shaw, 2001; Shaw, Brittain, Tansey, & Williams, 2008). A similar behaviour was discovered among urinary incontinence and breast cancer patients (Unger-Saldana & Infante-Castañeda, 2011).

### **5.3.2 The core category 'experimentation' and concept of trial and error**

This study identified "experimentation" as the core category having an explanatory grip on the treatment strategy of patients with T2DM whilst they interact with the healthcare system in Malaysia. Academically speaking, the term "experimentation" contains many descriptive definitions. First, the *Oxford Dictionary* defines "experimentation" as "something to do with tests, the action or process of trying out new ideas or methods to see if something works". The search for positive outcomes is guided by an action of trial-and-error. In expanding on this definition, the concept of trial and error was defined as "the process of experimenting with various methods of doing something until one finds the most successful" (<http://www.oxforddictionaries.com>, retrieved 1/3/2015). In other words, trial and error means attempting something one time after another; trial and error is a form of rejecting those factors that are perceived to be ineffective or have negative outcomes. If trial and error comes under experimentation, then the concept of experimentation can be considered to be experiential, wherein those trying attempting trial and error are actively looking for different treatments that work while omitting those which do not.

Experimentation also concerns patients' decision-making strategy, which are tied to their experiences with the illness they are suffering from in addition to the knowledge they might have acquired from entrusted, reliable, and comfortable sources.

The experimentation process is viewed as one that reflects the experiential learning element, where learning is accomplished through the action of testing one new treatment with a strategy; this phenomenon is reflective of the concept of adult learning. Experiential learning, as highlighted in Kolb's Theory of adult learning (Kolb, 1984) suggests that it is the process where knowledge is created through experience transformation. Therefore, it involves a cognitive process whereby a person involved is constantly adapting and engaging with their surroundings (Kolb & Kolb, 2005). In this context, learning is acquired through testing something and trying it out, which is followed by an evaluation of the outcome of that process.

Similarly, learning also occurs when the person involved learns to choose and weigh their own perception of the best treatment in the hope that said method would produce positive results that simultaneously address the issue being experienced. Although adult learning theory is commonly applied in educational research, it appears that there is an increasing interest in health behaviour studies being adapted into other areas of study, such as in the area of chronic illnesses and coping processes (Behrens, Irnich, Licht, & Schmitt, 2013), information-seeking behaviours (O'Grady, Witteman, & Wathen, 2008) and medication intake behaviours (Bajcar, 2003). It cannot be denied that the concept of adult learning is problem-based. As a problem solving process, it reflects how an illness like diabetes can impact on the quality of life of patients, and that certain triggers can influence patients to try new treatment modalities. A study by Cooper and colleagues (Cooper, Booth, & Gill, 2003) determined that the experiential learning process was favoured by patients who felt that learning is a continuous process that involves

interacting with the individual's social-environment. Such was the case in this study, where these patients constantly had to survive their ordeal.

A similar study conducted by Dima and colleagues (Dima et al., 2013) explored primary care patients with chronic lower back pain. They also discovered that patients' treatment-seeking strategies were related to the concept of trial and error, with findings indicating that diverse treatment was based on four key dimensions: credibility of treatment and practitioner, effectiveness of treatment, concerns with costs, and safety of treatment. The study also found that patients bear characteristics demonstrating a hope for acquiring effective treatment. The trial and error procedure practised by patients with chronic illness is a part of their treatment-seeking and coping strategies in the management of illness. This finding is also consistent with patient self-management (Kralik, Koch, Price, & Howard, 2004) and medication intake (Gallacher, May, Montori, & Mair, 2011; Price, Taylor, Dal Grande, & Kralik, 2014; Sav et al., 2013), which aims at achieving a higher quality of life. In this regard, the practice of the trial and error process reflects the possibility of patients being active agents that are adjusting to and coping with their illness treatment. Both these elements are a part of their strategy in managing the illness. However, Price's study (Price et al., 2014), indicated that those who were actively practising a trial and error method were likely to practice non-adherence to their medication intake. The cause might be attributed to the possibility of patients skipping the medication whilst trying out other treatment modalities such as traditional and complement medicine.

Although the social determinant factors have a huge impact on patients' health outcomes (Braveman & Gottlieb, 2014; Hill, Nielsen, & Fox, 2013), the current study demonstrated that factors such as age, sex, ethnicity, and even location did not influence treatment strategy among patients with T2DM. Similarly, while patients had varying

socio-demographic backgrounds, their approaches toward deciding type of treatment were similar to the concept of experimentation. The study also indicated that patients, regardless of multi-ethnicity, sought traditional or spiritual treatments that were not from their particular ethnicity. A patients' focus regarding treatment strategy is to fulfil their personal goals and restore their quality of life.

### **5.3.3 Triggering the experiment**

Triggers generate experimentation, which is why it is important to understand what triggers patients to engage in the trial and error process as a strategy for treatment seeking and eventually, as a catalyst in deciding on the type of treatment to be adopted. Although the healthcare providers are aware that patients with diabetes experiencing symptoms can be triggered to seek treatment (Punamaki & Kokko, 1995; Usher-Smith, Thompson, & Walter, 2013), healthcare providers may not understand why patients continually seek better treatment options when they do not experience any symptoms. Many studies (Nguma, 2010; Scott, Grunfeld, Auyeung, & McGurk, 2009 ) have only explored the initial triggers leading patients to seek treatment, but less attention has been placed on addressing the triggers that set patients off in seeking experimentation with different treatments.

As noted previously, triggers are perceptions that patients hold about something that needs to be done to achieve their expectation of the illness from which they are suffering. Apart from experiencing signs and symptoms of the illness, which is quite common even with other chronic illness (Usher-Smith et al., 2013; Welch, Taubenberger, & Tennstedt, 2011), triggers can occur for many reasons, and can drive patients to conducting trial and error with other treatment modalities. In line with the concept of the health belief model, patients that understand the susceptibility or severity of an illness are more likely to seek care, particularly when they perceive the



deterioration of an illness such as diabetes (Ayele, Tesfa, Abebe, Tilahun, & Girma, 2012; DiMatteo, Haskard, & Williams, 2007). Thus, in chronic illness management such as slow progress diabetes or in asymptomatic conditions, patients are frequently concerned about their condition, which is unavoidable. From this perspective, it can be said that patients' perceptions and beliefs regarding their illness can play an important role in how they adhere to treatment (Becker & Janz, 1985; Sharifirad, Entezari, Kamran, & Azadbakht, 2009). This belief behaviour of patients might also lead to attempting alternative and complementary treatments, often accompanied by the hope of preventing further complications. A study conducted in Taiwan (Chang, Wallis, & Tiralongo, 2011) also indicated that patients with T2DM sought complementary and alternative treatments for improving other health-related conditions. In this study, patients were actively seeking treatment from multiple providers simultaneously, or were frequently seeking what they perceived to be the best treatment. This occurrence indicates that patients' help-seeking patterns are not static.

Similarly, another related issue that can propel patients to experimentation is their desire to readjust to a new balance between their desired quality of life and disease control. This can drive patients to actively conduct trial and error experimentation of other treatments while they are on prescribed medication. This highlights the patients' personal goals, and quality of life is an important component of illness management. Reducing unmet expectations can enhance the patients' satisfaction level and eventually lead to improved health outcomes (Lateef, 2011). The perception of patients may outweigh their non-adherence to treatment management, which can subsequently trigger the need for them to try alternative treatments. Patients' perceived treatment needs might sometimes differ from their provider's (Zola, 1973). This concern was highlighted by Atwine and colleagues (Atwine et al., 2015) suggesting that a mix of

different treatments and inconsistent treatment patterns entail a risk for inappropriate control of diabetes. This concern requires urgent attention from various stakeholders.

#### **5.3.4 Information seeking for treatment characteristic**

Information is a pre-requisite for experimentation. Although information-seeking may be perceived as a complex and multifaceted process (O'Grady et al., 2008) for patients living with T2DM, actively seeking information from various sources, exploring new treatment options, and evaluating the best possible options are all part of the experimentation journey. Information related to treatment is an integral part of illness management, particularly for chronic illnesses such as diabetes.

Exploring patient information-seeking interest regarding health has been investigated by many researchers from various disciplines (Anker, Reinhart, & Feeley, 2011; Wang, Wang, Lam, Viswanath, & Chan, 2013). Many studies examining similar topics have been conducted, but many of these were focused on the illness itself (Kalantzi, Kostagiolas, Kechagias, Niakas, & Makrilakis, 2015; Lubi, Vihalemm, Krikmann, Paju, & Taba, 2013). Other studies tended to focus on information related to patient self-care (Longo et al., 2010), although some may specifically explore how patients sourced information regarding illness treatment, and where such information came from, especially now that information can be easily sourced from the internet or other electronic sources (Hamine, Gerth-Guyette, Faulx, Green, & Ginsburg, 2015; Higgins, Sixsmith, Barry, & Domegan, 2011; Shaw & Johnson, 2011). To some extent, the current study also found how patients with T2DM sourced information.

It was noted that the information patients received came from those close to them, such as family members, friends, or someone with similar ailments, and that this kind of information was likely to affect the way patients addressed their illness (Chew, Khoo, &

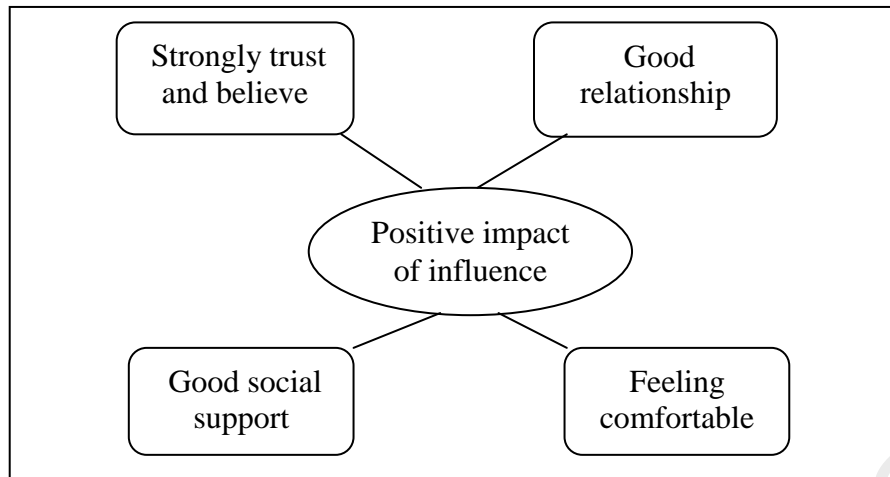
Chia, 2011; van Dam et al., 2005). The same information can also enable patients with T2DM to determine their choice of treatment modalities. Besides this kind of information, it appears that social networks comprising family members, friends, peers, and healthcare providers can also be considered as part of the social influence affecting patients' decision-making strategy. This is because the information they acquire may come from the internet or other forms of social media which patients have social interactions with people around them (Langford, Bowsher, Maloney, & Lillis, 1997). The increasing popularity of online networks and platforms for searching and sharing health and treatment related information has led to its widespread use among patients. Moreover, the information acquired may circulate through social media very quickly, and if this information is inaccurate, the consequences could be serious. It is hereby emphasised that such information patients acquire from other non-professional or even unreliable sources could hurt patients long-term, as they may lack credibility, evidence, or be inaccurate, which may eventually lead to poor decision-making among patients.

From this description, it is evident that such information raises new challenges for the medical field, though many studies have highlighted the benefit of social media for health education. It is imperative that patients with T2DM be made aware that information searches need to be made only through reputed sites and validated by their healthcare providers (Masic, Sivic, Toromanovic, Borojevic, & Pandza, 2012). There are other negative effects of information gained through social media (Antheunis, Tates, & Nieboer, 2013), and it is therefore necessary to maximise the positive impact of information shared via social media. A regular update of relevant information from the official or professional body's website is also essential (Ventola, 2014).

Many studies have examined the effects of family, friends, and peers on effective diabetes management, including self-care (Gallant, 2003; Kadirvelu et al., 2012),

physical activity (Komar-Samardzija, Braun, Keithley, & Quinn, 2012), adherence to medical regimes (Miller & DiMatteo, 2013 ; Sankar, Lipska, Mini, Sarma, & Thankappan, 2015) and glycaemic control (Adibah, Idris, & Osman Ali, 1998; Mayberry & Osborn, 2012; Stopford, Winkley, & Ismail, 2013), though the effects varied. Support from healthcare providers was also cited as a source of information affecting diabetes management (Gensichen et al., 2009). These findings are consistent with the findings of previous studies, which state that social support and relationships could benefit the health of patients with chronic illnesses such as diabetes (Gunn, Seers, Posner, & Coates, 2012) albeit to a different degree. For instance, the influence of family members (Pollard, Zachary, Wingert, Booker, & Surkan, 2014), friends and peers (Vaccaro, Exebio, Zarini, & Huffman, 2014), the healthcare providers (Gensichen et al., 2009), the internet and social media (Labate, 2013) have been shown to significantly impact patients' treatment-seeking strategy.

However, not all information and recommendations provided by patients' social networks can influence their choices. As previously noted, the impact of influence from social networks is varied. As shown in Figure 5.1, the findings of this study depended on the relationship between patients and the people who provided information or suggestions for treatment options, the degree of trust they have in the information received from the healthcare system, the relationship with their social network, the social support they receive, the perception patients have regarding how they were cared for, and the degree of comfort they feel with the person providing advice, including healthcare providers. All of these factors could produce a positive influence on patients' decision-making processes, and ultimately, could induce a positive impact on patients' treatment-seeking strategy.



**Figure 5.1: Factors associated with impact of influence by social networks**

It was previously mentioned that a patient’s level of trust is of great importance. The term trust is sometimes used interchangeably with words such as “believe in”, and trust could generate confidence or faith among patients. Studies examining the concept of provider-patient trust and a patient’s adherence to treatment management are extensive, and often linked to treatment compliance (Martin, Williams, Haskard, & DiMatteo, 2005; Müller, Zill, Dirmaier, Härter, & Scholl, 2014), improving treatment outcomes, and investigating the effect of good provider-patient communication (Kaplan, Greenfield, & Ware, 1989; Rolfe, Cash-Gibson, Car, Sheikh, & McKinstry, 2014). Having trust and confidence regarding the source of information gathered are additional factors that could impact on patient’s treatment-seeking strategy. Thus, in the current study, it was also found that patients claimed to feel confident with the suggestions provided by those who have had the same experience in dealing with diabetes – as well as from professionals and reliable websites. Previous studies indicated that trust and distrust in physicians had an impact on care-seeking and non-adherence behaviours among patients (Keating, Gandhi, Orav, Bates, & Ayanian, 2004; Peek et al., 2013).

Aside from the trust patients place in provider-patient communication, it was noted that patients could be easily convinced by information that they had gathered from

people with whom they share a good relationship, as well as those with whom they felt comfortable. The findings of the current study affirm the observations highlighted in past studies (Low et al., 2011; Tjia, Givens, Karlawish, Okoli-Umeweni, & Barg, 2008). In this regard, it cannot be dismissed that good provider-patient relationships in diabetes care are of importance and should be further emphasised.

Many studies have also examined the impact of peer support groups on treatment outcomes (Chan et al., 2009; Chan et al., 2014; Sachmechi et al., 2013; Smith et al., 2011), but findings from the current study indicated that although the influence of peers and friends are common, only people with whom patients are strongly attached to or have good relationships with could affect a patient's diabetic management. The impact of influence such people have on patients varied depending on the level of trust. This too, it appears, may have implications for formal peer support group programmes, which has been highlighted in a previous study (Dale, Williams, & Bowyer, 2012). Thus, a formal peer support group programme might not be beneficial unless some positive group dynamics are developed. When designing any programme based on peer support group, it is encouraged to take the degree of trust and rapport into consideration. A well-designed evaluation may also be necessary if the policy option is to develop an intervention programme for diabetes.

### **5.3.5 Evaluating the experimentation (patient expected outcomes)**

A patient's expected outcome or desired goal can involve a perceived quality of life and conforming to management and treatment standards, as highlighted in previous chapters. Quality of life ranges from physical and social functioning to work function, social obligation, and dietary freedom. While many studies indicate that knowledge and awareness are good indicators for the success of a patient's self-care and good management of T2DM, this study indicates that even though diabetic patients knew and

understood the dire consequences of eating unhealthy foods or non-compliance with medication schedules and doctor's advice, their desire to maintain a good quality of life over-rode good diabetes management if there were competing demands of a job or social obligations. This was also found in other studies (Vanstone et al., 2013). Furthermore, diabetes affects a person's physical functioning has been well documented and recognised in many studies (Barendse, Singh, Frier, & Speight, 2012; de Grauw et al., 1999). This study confirmed that physical and social functions, including work function, affected quality of life - especially for those on insulin injection (Debono & Cachia, 2007; Funnell, 2008). The study also revealed that the aim of patients who skipped medication or tried out traditional medicines was to fulfil their social obligations. The sense of responsibility or the reluctance to reject the needs of others, might complicate diabetes management or self-care because of the feelings of obligation.

As previously mentioned, patients with T2DM have the tendency to experiment with different treatment modalities with the aim of finding an appropriate remedy that suits their needs. Thus, the emphasis should shift from solely clinical outcomes to a strategy that also includes patients' perceived outcomes. This is because the outcome would reflect a patient's quality of life and the psychological impact the medication has on their daily lives (Rubin & Peyrot, 2001). Moreover, achieving a desired quality of life, while reducing diabetes symptoms and preventing complications, is part of the triggers that drive patients towards experimentation. Treatment outcomes are often associated with a person's feelings - whether positive, negative, or mixed. Ideally, healthcare providers are responsible for helping patients to achieve this balance, but the reality remains that providers and patients might have different perspectives towards treatment

outcomes. For instance, providers' views of treatment improvement may be based on clinical outcomes, whereas patients focus on their quality of life outcome.

The findings of the current study appear to be similar to a study by Morton and colleagues, who focused on patients with chronic kidney disease (Morton, Tong, Howard, Snelling, & Webster, 2010). Their study revealed that patients were more concerned about their quality of life, and their preference in treatment choice was based on the need to minimise any disruption to their daily activities in addition to upholding their responsibilities while maintaining personal interests. Failure to achieve an optimal balance of their quality of life on a daily basis often results in poor diabetes control. Hence, an understanding of patients' perceived needs, which can serve as a trigger of their treatment strategy, could ultimately overcome the unmet needs and result in increased treatment satisfaction. Consequently, this could offer a solution to developing improved diabetic control.

The effectiveness of diabetes care is multidimensional, involving multi-specialty healthcare teams and a self-care approach (Bowen & Rothman, 2010; Raaijmakers et al., 2013; Worswick et al., 2013). If teamwork is being completed successfully, effective diabetes care can greatly impact a patient's quality of life, though good diabetes care requires a change in lifestyle and the need to pay compliance to treatment plans - both of which often represent major challenges for patients. Patients often strive to both improve their quality of life and reduce diabetes-related complications (Debono & Cachia, 2007) though this is not an easy task. Therefore, when patients make the effort and strive to balance their daily lives, it is a reflection of their treatment-seeking behaviour and approach to treatment strategy.



### 5.3.6 Undertaking the experiments

The current study suggests that patients' treatment strategy involved a decision-making process that is iterative. Upon reflecting on the term "strategy", it is noted that the Merriam Webster dictionary (<http://www.merriam-webster.com/dictionary/strategy>, retrieved 1/3/2015) defines it as "carefully planning or a plan of action designed to achieve a particular goal over a period of time". Thus, as stated in the context of this study, treatment-seeking strategy would involve patients deciding on the best treatment options based on their own experiences, as well as based on the knowledge or information they had acquired from entrusted people in their lives.

In attempting to decide on which treatment is right for them, it appears that patients' decisions could be shaped by various factors. For example, predisposing, enabling, and need factors have been suggested in Andersen's model of healthcare utilisation (Anderson et al., 1995). Another model, Kroeger's determinant model (Kroeger, 1983), suggests that a patient's choice of treatment may be affected by three factors: characteristics of patients/households, the illness itself, and the healthcare services provided. In the current study, it was found that patients' decisions on the type of treatment to take were varied, and could be based on the expectations and perception of the patients themselves, who were constantly attempting to maintain a balance between the treatment efficacy, side effects, simplicity of treatment regimes, and the accessibility to various types of treatment. Patients were found to be actively weighing between each treatment based on their characteristics with the concepts of trade-offs with their ultimate aim of fulfilling their desired goals.

Treatment goals are common for all patients, as they aim to produce positive outcomes for those involved, such as restoring a better quality of life, preventing the illness from deteriorating, and reducing diabetes symptoms. Many factors including

cost, side effects, availability, and efficacy of treatments have been reported to influence patient decisions regarding treatment type (Purnell, Joy, Little, Bridges, & Maruthur, 2014; Weller et al., 1997). However, how the impact of each on decision is made is not often studied. Cost could be an issue to one patient, but not another because the notion of “costly” is relative. Likewise, the notion of accessibility and the level of tolerance to side effects also varies between patients. The fundamental concern is actually whether these factors represent trade-offs for achieving patients’ desired goals.

Shillington and colleagues (Shillington, Col, Bailey, & Jewell, 2015) investigated the components of assistance in serving patient needs by focusing on the potential benefits and side effects of medication options. They covered the domains of treatment efficacy, side effects of medication, convenience of preparing medication, administration of medication, and cost of treatment. Their findings, which were similar to the current study, indicating that patients’ decisions on the type of treatments they desired were based on the treatment characteristics as previously mentioned, but the process of decision-making was more complex, and involved a trade-off between each treatment characteristic.

An illness with a chronic condition requires long-term of monitoring. The longer the period, the more patients will be encouraged to resort to alternative treatments or attempt different therapies, which can lead to a higher probability of patients trying traditional and complementary medicine (Dey, Attele, & Yuan, 2002 ; Kroeger, 1983). In the current study, it was determined that in the choice of seeking treatments, patients with T2DM sought traditional and complementary medicine alongside modern medicine as a treatment option. Although the reasons for taking the treatment offered by traditional and complementary medicine may vary, this practice seems to be quite common in diabetes treatment, which has been explored in previous studies (Bodeker &

Kronenberg, 2002; Pandey, Tripathi, Pandey, Srivatava, & Goswami, 2011). Some studies had in fact discovered that patients with T2DM had opted for traditional treatment due to the barriers they faced in accessing modern treatment. Nevertheless, seeking alternative or traditional treatments may also be due to reasons such as cheaper costs, convenience of administration, and the influence asserted by family members and friends (Rutebemberwa et al., 2013).

Although many studies have determined that the higher treatment costs of modern medicine might be influencing patients' decisions toward choosing traditional medicine, this should imply that people with lower incomes might be using traditional medicine more than a higher income group. However, some studies have found that traditional medicine was also frequently used by patients with higher income and education (Thorsen & Pouliot, 2015). A similar scenario was found in current study. This shows that patients' choice of treatment may vary based on their patients' desired goals.

A previous study conducted in Malaysia to investigate patients' preferred system of medicine for diabetes mellitus had found that the choice can be affected by the influence of family members and peers (Ching et al., 2013). It was also noted that some of the patients considered traditional and complementary treatment to be more effective than modern medication. The present study, which examines how patients with T2DM made choices regarding their system of medicine, found that this decision was based on their own priorities, and was balanced with the elements of treatment efficacy, side effects of medication, treatment simplicity, and accessibility to a treatment. Patients might encounter financial barriers as a hindrance to accessibility to modern medicine, as observed among some of the study participants. Nevertheless, those who benefited from company-appointed panel clinics may not consider the accessibility of private primary

care as a problem. Variation exists in this factor, as evidenced in cost being a factor in deciding type of treatment, yet may not be for another person.

#### **5.4 Strength and limitations**

This section discusses the strengths and limitation of the current study.

##### **5.4.1 Strength of the study**

Adopting a grounded theory approach allows the data collection and the analysis procedure to be carried out concurrently due to the need to make constant comparisons, a process that permits the generation of a core category, and eventually, the formation of a theory itself. The process of using grounded theory is an iterative one; it utilises the practice of using theoretical samplings until theoretical saturation, so that no new properties and dimensions are related to the identified concepts.

As stated in the self-reflection in Section 3.6, being a medical anthropologist with years of experience in studying human behaviour was an advantage for the researcher in conducting the current study. A good rapport was first established between myself (the researcher) and the participants to encourage participants to express their real experiences and perceptions with regard to the illness management and treatment-seeking processes. Through social interactions throughout the fieldwork, the participants felt comfortable, allowing them share their real experiences. These shed light on treatment behaviour, which might not have been otherwise revealed to their healthcare providers during consultation. Furthermore, being a Malaysian exploring the perception and experience of patients within a local setting is another added advantage that aids in a better understanding the local culture much when compared to researchers unfamiliar with the local environment and culture.

This good rapport also facilitated the capturing of participants' misconceptions regarding the management of T2DM, their unmet needs, and the underlying causes of their health-seeking behaviour. Using the grounded theory approach, this study was able to provide a built-in mandate which strives towards verification of data while applying several strategies during the selection of participants. The study also included the triangulation of data collection (using different methods and sources including patients, family members, and healthcare providers) and the analysis process wherein member checking was completed, as discussed in Chapter 3, to ensure the rigour and trustworthiness of the data.

#### **5.4.2 Limitations**

The results of the current study should be interpreted within the context of relevant limitations. This study focussed on a primary healthcare setting, which only covered primary care clinics at public and private clinics. The patients from hospital or tertiary care treatment were excluded in this study. However, primary care clinics were the “gatekeepers” of the healthcare system and had a higher percentage of patients with T2DM seeking care.

Another limitation for this study is related to data collection, where the researcher served as the primary data interviewer. Although there are criticisms debating the relevance of the researcher as a research tool, it is also emphasised that this role may be viewed as an advantage in terms of consistency in exploring information, and the ability to explore information gaps from each participant. Additionally, it was imperative to develop a good rapport with participants to ensure the trustworthiness of data. Therefore, the participation of the researcher became a necessity.

Although three different languages (Chinese-Mandarin, Malay, and English) were used during the interviews, efforts were made to ensure that the translation and interpretation of the contents from such interviews were accurate, with clear meanings from participants during the process. This gap was narrowed by the fact that the researcher is fluent in all three languages used, and is familiar with the context of the study. This helped to ensure that the meanings of those interviews remained unchanged, aside from exploring the different cultural background of the participants who were of three main ethnic groups.

As is the case with qualitative research, the emphasis of this study is on an in-depth exploration of experiences and perceptions. Thus, in using the grounded theory approach, the findings may not represent average patient with T2DM experiences, though the substantive theory developed would allow for generalization of the concepts. This theory provides explanatory power that details treatment strategy and decision-making processes among patients with T2DM in a primary care setting. The theory demonstrates the treatment-seeking behavioural patterns and highlights the relevance of the experimentation process as the concept explaining treatment strategy choice.

## **5.5 Summary**

The current exploratory study presents an evidence-based theoretical model of treatment strategy among patients with T2DM, and the findings help to shed light on different people experiencing a variety of treatment strategies. It appears that all patients have a strategy in experimenting with their decision-making process on the type of treatment they want. The study also highlights the crucial role that family members, friends, peers, and healthcare providers play in a patient's life by providing reliable information and appropriate advice related to diabetes treatment, as their source of information may influence a patient's choice of treatment. This model underlines the importance of providing diabetes patients with a safe environment to experiment with

different treatments within the current healthcare system. Therefore, it is not practical to prevent patients from trying different treatments because the trial and error process is part of their treatment-seeking strategy. Denying patient access to the trial and error process may produce negative consequences including patients experiencing unmet needs, since patients may turn to alternative treatment modalities or switch to another provider. All these terms are commonly known as “healer shopping”, which has been noted in other studies (de-Graft Aikins, 2005; Shiva, 2011). Patients should be encouraged to share their treatment strategy with their healthcare providers. At the same time, the healthcare providers should encourage patients to verify any new information received from sources other than the medical experts. This could avoid certain risks and eventually to prevent any risky behaviour with regard to diabetes management.

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## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATION**

### **6.1 Introduction**

The previous chapters provided insights into the process of developing the substantive theoretical model. This process outlined the justification for conducting this study. Chapter 1 elaborated the details of the research objectives and research questions. Chapter 2 discussed the background information and the provided a literature review. This was followed by Chapter 3, which discussed the justification of the research method, how data were captured, and the manner of analysis. In Chapter 4, a substantive theory explaining the process of patients selecting treatment strategy was presented. The core of the process was experimenting treatment to achieve the desired goal. Chapter 5 provided a discussion of the substantive theoretical model that explained patients' with T2DM treatment strategy, including their decision-making process for adopting various types of treatment in a primary care setting. In this chapter, the overall conclusion of the thesis draws on the important aspects of the findings, and study implications are presented. Recommendations for future studies are subsequently highlighted in the final section of this chapter.

### **6.2 Value of grounded theory approach**

The constructivist grounded theory approach was used to facilitate the development of a substantive theoretical model. Symbolic interactionism was adopted as an overarching theoretical concept in the analysis of the process used by patients with T2DM in selecting and deciding on the best treatment care for themselves in a primary care setting. The substantive theoretical model that was developed as a result of this thesis indicated that help-seeking behaviour, particularly regarding the treatment strategy process, is complex and associated with diverse determinants rather than a one-off decision.



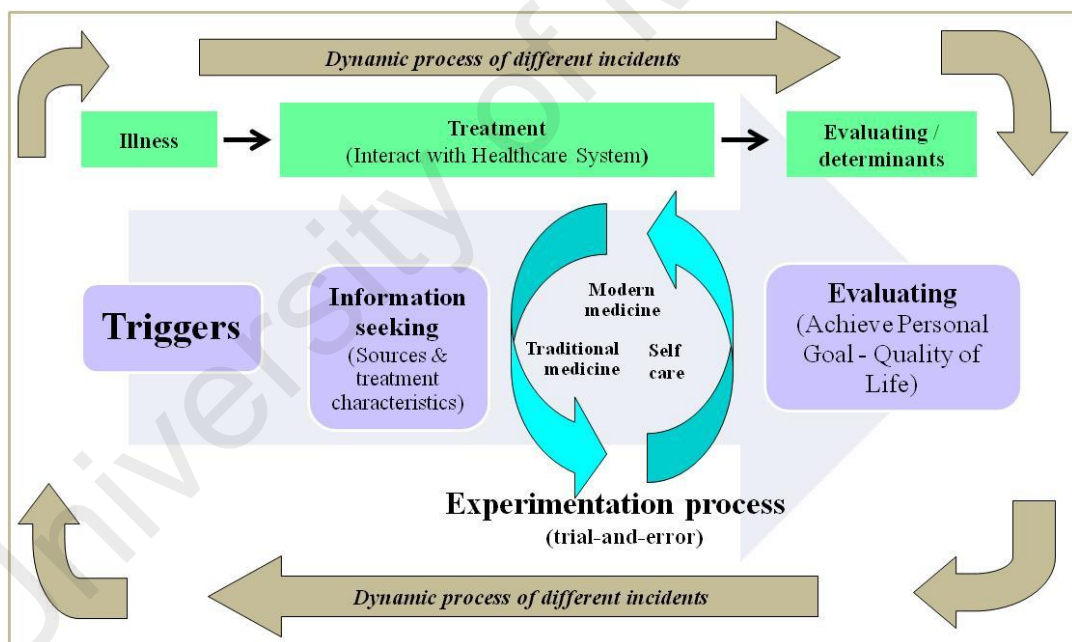
The experience of undertaking the constructivist grounded theory, combined with my medical anthropology background in studying human behaviour, had provided an advantage in facilitating the smoothness of this fieldwork and the exploration of patients' treatment strategy. The anthropological approach, which examines the diverse aspects of human social life, enabled the exploration of the complexity of illness experiences and patients' interactions with current healthcare systems situated within their local cultural context. This approach also provided a structure that enabled the application of an in-depth understanding of patients' decision-making processes, which were the actual platform that enabled the data to be collected. The entire process had enabled deep immersion into the large and rich set of interview data, which, upon analysis, allowed for the construction of categories. The friendly interview approach used during data collection enabled the development of a good rapport with patients, while simultaneously creating a level of trust with the research participants. As patients with T2DM, the participants shared their experiences and thoughts willingly throughout the interviews and FGDs.

The substantive theoretical model that emerged from the empirical data collected helped to explain the treatment strategy process of patients with T2DM in selecting their treatment options. This study is unique because the theory explaining the overall patterns of treatment-seeking behaviours among patients with T2DM was grounded in the data, and provided insight into how patients manoeuvre themselves through the current healthcare system in Malaysia, particularly in a primary care setting.

This study also highlights the emergence of various complementary and traditional treatments options that patients with T2DM currently have access to. Overall, this thesis helps to illuminate the treatment-seeking behaviour of patients with T2DM and the process behind their decision-making within the current healthcare system. The

findings, specifically the substantive theoretical model, provide insight into how patients with T2DM chose different types of treatment, both of which reflected the concept of experimentation. Moreover, this thesis highlights the importance of patients' goals as triggers for experimentation. The substantive model also outlines a process indicating how patients made the effort to search for treatment information, and how they evaluated the information received. The entire process represents a dynamic and iterative process rather than a linear process.

Figure 6.1 provides a simplified theoretical model that highlights the key components of the model and the process of how patients select treatment strategy to meet their goals.



**Figure 6.1: Simplified model for treatment strategy adopted by patients with Type 2 diabetes mellitus in a primary care setting**

### **6.3 Study implication and recommendation**

This section highlights the implications of the study based on the findings and discussions provided in previous chapters, followed by recommendations for medical practice and policy change. Five components of the issues are discussed.

#### **6.3.1 Understanding experimentation as a process that patients utilise to decide suitable treatment strategy**

The aim of this study was to develop a substantive theoretical model that may be helpful to medical practitioners, by providing them with an understanding on how patients decide on their treatment strategy. The study findings indicated that experimentation was the underpinning concept patients used to decide on best options, based on their own priorities. The results explain typical behaviours of patients with T2DM in selecting treatment strategy within the local primary care setting, and how patients interact with the current healthcare system when seeking treatment.

With the understanding of experimentation as the core in patients' treatment-seeking behaviours, treatment strategy must be planned accordingly. As previously discussed, the experimentation process is similar to the concept of adult learning, it reflects a problem-based approach that requires learners to experience an on-going treatment process. Therefore, advising patients to avoid alternative treatments, or preventing them from being involved in trial and error experimentation, is unlikely to be accepted by patients. Modern contemporary treatment is just one of the options patients consider. Patients search for treatments that meet their goals and needs. The patients may not want to disclose the actual treatment they adopted. A focus could be placed on empowering patients in undertaking experimentation. A potential solution involves encouraging shared decision making, which involves exploring patients' treatment

strategy and helping them in identifying their goals while monitoring treatment outcomes.

Based on the findings of this study, it is also suggested that policy makers responsible for diabetes programmes in the Ministry of Health may develop a programme that emphasises a good strategy for assisting patients experimenting with diabetes treatment. For example, providing a safe environment for promoting could encourage patients to measure their treatment goals or targets to achieve in a more objective manner. This can be accomplished by showing them the need to monitor their blood sugar level before and after trying other alternative treatments. Other tangible outcomes exist that may encourage patients to be increasingly aware, such as dietary intake and monitoring of the signs and symptoms of their illness. This suggestion serves as part of the process of empowering patients to have more responsibility in their treatment management.

### **6.3.2 Understanding the triggers for experimentation**

The experimentation process usually begins when there is a trigger, when patients feel the need to try new treatments, or when there is a desire to do something to fulfil their personal goals. Therefore, exploring patients' goals is important. A shared goal can be established to promote mutual agreement on treatment strategy. Furthermore, creating a good rapport among providers and patients could be another suggestion. Thus, exploring the mechanisms for building the good rapport or doctor-patient relationships should be considered as an urgent need. It is hoped that reducing the unmet needs could help address the issue of non-compliance and seeking multiple treatments or "healer shopping". Possibly, identifying patient goals, and hence their triggers, could be an important step for programme improvement.

### **6.3.3 Information – seeking process**

The findings acquired from this study demonstrated that patients with T2DM were actively seeking and evaluating information regarding treatment. This process is part of their experimentation process. Their sources of information regarding diabetes treatment also appeared to be varied: from social networks such as family members, friends, peers, and healthcare providers to other aspects being gained from social media. Thus, the empowerment of patients is suggested by helping to critically evaluate information received from all sources in order to consider reasonable treatment strategy.

Family members also played an important role in patients' treatment strategy, as they serve as the patients' support and confidantes in providing recommendations on treatment, which has an implication for treatment management. In this regard, healthcare systems should recognise the importance of diabetes programmes with good collaborations between patients and their family members. This strategy could provide sufficient and appropriate information to enable patients and their family members to become wiser decision-makers capable of evaluating the best diabetes treatment during the experimentation process.

Not all advice received from healthcare providers will receive compliance from patients, as healthcare provider influence can vary, and the decision may depend on the level of trust and relationship between patients and their healthcare providers. This reiterates the importance of building trust in the doctor-patient relationship. Good interpersonal skills are most likely needed to gain patients trust and faith.

The findings also indicated that social media could influence patients' decisions regarding treatment. The increasing popularity of online networks as platforms for searching for and sharing health and treatment-related information, and its widespread

use among patients, could pose either a benefit or risk to patients, especially with information from unreliable websites. Thus, it may be necessary for professional bodies and health departments to develop their own websites to ensure that the platform created can serve the needs of the patients where possible.

#### **6.3.4 Patient's expected outcomes (quality of life)**

Patients' perceived quality of life is an important outcome in today's healthcare systems. Objective and subjective outcomes are equally important in assessing the impact of treatment, particularly for chronic illnesses such as T2DM, which require lifelong treatment. This finding indicated the quality of life of patients to be subjective and personalised in nature, which acted as a trigger for experimenting with treatment. This complexity was translated into patients' treatment-seeking behaviours, such as trying different treatment including traditional herbs or changing their dietary intake. Therefore, to understand a patient's quality of life, the patient's feelings should also be considered apart from the physician's perceptions on the clinical outcome. The ultimate goal of diabetes care is to enhance the quality of life of patients and improve their feelings.

#### **6.3.5 Undertaking the experiment**

As the findings of this study indicated, the decision-making strategy of patients with T2DM indicated that there are other underlying fundamental issues. The results suggested that a complex interplay of determinants exists which reflects the patients' choice of treatment. Additionally, the balancing process involved in the trade-off between each treatment characteristic, such as treatment efficacy, side effects, simplicity of treatment regimes, and accessibility enable patients to achieve their personal goals. Thus, any form of decision-making aids or interventions designed for educational programmes among patients with T2DM should consider the concept of

trade-offs as an approach to patients' decision-making process. Otherwise, patients could be evaluating these issues based on their own unique priorities and personal goals for each treatment option selected.

Similarly, in terms of modern medicine and accessibility, financial barriers created a discrepancy among the study participants' choice of treatment. The Malaysian healthcare system, especially with regard to private sectors requiring the highest cost treatment fees, could represent a barrier to care. However, this may not be the main barrier, as patients have the option to access diabetes care from public primary care facilities. Only those who benefited from company-appointed panel clinics may not consider the accessibility of private primary care to be a problem. Thus, some form of healthcare reform might be an option to overcome financial barriers and reduce the inequality of access based on patients' choice.

#### **6.4 Future directions for research**

The development of a substantive theoretical model complemented the understanding of patterns exhibited by patients with T2DM in deciding on the type of treatment to be adopted. It also contributed to the existing knowledge regarding help-seeking behaviours. In addition, the concept of experimentation, which was generated from grounded theory, can be used to sensitise the analysis in studies of different diseases or illness, particularly non-communicable diseases in the Malaysian healthcare system.

The concept of experimentation highlighted the importance of patients' personal goals and self-satisfaction regarding their quality of life. This concept is useful for healthcare providers while managing patients with diabetes. Healthcare providers should place a greater emphasis on patient goals in treatment strategy, and work in a patient-centred care approach in clinical practice. Further studies are suggested to

explore the mechanisms that facilitate healthcare providers in exploring these goals during doctor-patient encounters. In addition, the patients reported outcome study related to diabetes management at the primary care setting may be useful for conceptualising experimentation as a patient's treatment strategy.

Furthermore, the findings of this study should inform the choice and design of interventions, such as the intervention on peer impact and significant of influence from social network on patients' decision-making process. Thus, designing any intervention based on peer support group should encourage taking the degree of trust and rapport into consideration. Further intervention study that collaborative of patient's goal-setting which was informed by the substantive theoretical model in this study may be more likely to improve patients' treatment outcome.

## **6.5 Conclusions**

This exploratory study presented a substantive theoretical model of treatment strategy to explain how patients with T2DM interacted with the current healthcare system in selecting treatment for their illness. Evidently, patients tend to experiment with different diabetes treatment options in order to achieve *their* goals, against which the outcomes of experimentation were compared. The substantive theory presented in this study provides some explanation of complex process of patients' treatment strategy and the underpinning determinants that affect their decision in selecting the best available treatment. The potential implications for practices and research studies highlighted by this study may provide a guide for further action in diabetes management, as well as health programmes for healthcare providers, policy makers, and patients with diabetes. Consequently, a responsive healthcare system is warranted to support patients' experimentation processes while providing a safe environment for their experimentation within the current Malaysian healthcare system.



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## LIST OF PUBLICATIONS AND PRESENTATIONS

### List of publications:

1. Lee Lan Low, Seng Fah Tong, Wah Yun Low (2014) Mixed Feelings about the Diagnosis of Type 2 Diabetes Mellitus: A Consequence of Adjusting To Health Related Quality Of Life. Coll. Antropol. 38 1: 11–20
2. Lee Lan Low, Seng Fah Tong, Wah Yun Low (2016) Social Influences of help-seeking behaviour among patients with Type 2 Diabetes Mellitus in Malaysia. Asia Pacific Journal of Public Health, Vol. 28(IS) 17S-25S
3. Lee Lan Low, Seng Fah Tong, Wah Yun Low (2016) Process of selection of treatment strategies among patients with Type 2 Diabetes Mellitus in Malaysia: A grounded theory approach. PLOS ONE, January 2016 (DOI: 10.1371/journal.pone.0147127 )

### List of presentation (International):

1. Low LL, Tong SF, Low WY. *Mixed reaction towards the diagnosis of Type 2 Diabetes Mellitus: A consequence of adjusting to Quality of life.* Presented at 34<sup>th</sup> Anthropology and Health Conference, Dubrovnik, CROATIA, 11 September 2013 (Oral presentation)
2. Low LL, Tong SF, Low WY. *Health Seeking Behaviour among Patients with T2DM in Primary Care Setting: A Grounded Theory Approach.* Poster presented at The 45th APACPH (Asia Pacific Academic Consortium for Public Health) Conference, Wuhan, P. R. CHINA, 25<sup>th</sup> to 27<sup>th</sup> October 2013 (Poster presentation)
3. Low LL, Tong SF, Low WY. *Help-Seeking Behavior among Patients with Type 2 Diabetes Mellitus in Primary Care Setting.* Video Conference Presentation at

National Institute of Health, USA video conference and virtual presentation, 10<sup>th</sup> March 2015 (Oral presentation)

4. Low LL, Tong SF, Low WY. *Health Seeking Behaviour among Patients with T2DM in Primary Care Setting*. Poster presented at Regional Forum and Conference “From Evidence to effective implementation: improving the prevention and control of diabetes and other NCDs”, Sri Lanka, 28<sup>th</sup> to 30<sup>th</sup> May 2015. (Poster presentation)
5. Low LL, Tong SF, Low WY. *Unmet Expectations prompt people with Type 2 Diabetes Mellitus to attempt different treatment modalities*, IDF World Diabetes Congress 2015, at Vancouver, Canada, 30<sup>th</sup> November to 4<sup>th</sup> December 2015 (Poster presentation)

**List of presentation (Local):**

1. Low LL, Tong SF, Low WY. *Factors Influencing Health Seeking Behavior among Patients with Type 2 Diabetes Mellitus in Primary Care Setting. Example of Social Influence*. Presented at National Public Health Conference 2013, Concorde Hotel, Shah Alam, Selangor, MALAYSIA. 12 November 2013 (Oral presentation)
2. Low LL, Tong SF, Low WY. *Help-Seeking Behavior among Patients with Type 2 Diabetes Mellitus in Primary Care Setting: Theoretical Model*. Presented to Steno Diabetes Education Group, at Public Health Institute, Kuala Lumpur, Malaysia, 29<sup>th</sup> June 2015 (Oral presentation)

**List of presentation to stakeholder (Oral presentation)**

1. Low LL, Tong SF, Low WY. *Help-Seeking Behavior among Patients with Type 2 Diabetes Mellitus in Primary Care Setting*. Presented at District Health Office, Sabak Bernam, 28<sup>th</sup> April 2014 (Oral presentation)

2. Low LL, Tong SF, Low WY. *Help-seeking behaviour among patients with Type 2 Diabetes Mellitus: A grounded theory approach*. Presented to Society of Shared Decision Making (Malaysia), University Malaya, Kuala Lumpur, Malaysia, 4<sup>th</sup> April 2015
3. Low LL, Tong SF, Low WY. *Help-seeking behaviour among patients with Type 2 Diabetes Mellitus: A theoretical Model*. Presented at Mini CME, NCD Division, Ministry of Health Malaysia, Putrajaya, 8<sup>th</sup> April 2015

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