

**PATIENTS' LIVED-EXPERIENCE OF USING
INSULIN TREATMENT FOR TYPE 2 DIABETES
MELLITUS MANAGEMENT**

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Abstract

The prevalence of Type 2 diabetes mellitus (T2DM) has increased dramatically over the past 10 years in Malaysia due to the modernisation of the country. The most recent national health survey revealed that more than 15.2% of Malaysian adults are suffering from the diseases.

Insulin treatment has been demonstrated to play a clinically significant role to improve glycaemic control among selected Type 2 diabetes mellitus (T2DM) patients. However, studies from several local hospitals showed that more than half of T2DM patients are reluctant to initiate insulin treatment. There is an increasing trend for the Malaysian healthcare sector to invest in understanding patients' health experiences. This qualitative study focused on T2DM patients' insights about their lived-experience of using insulin treatment as part of their diabetes management. This study aimed to understand the facilitators, which encourage patients to accept insulin treatment and also the psychological, social and behavioural barriers to effective diabetes management.

Drawing on interview data with 37 participants, the three main barriers to initiate insulin treatment were worries about inability to handle using insulin, a sense of personal failure and negative perceptions of injections due to past experiences. The facilitators that encourage patients to accept insulin treatment were prior exposure to insulin injections, better side effect profile and wanting a better quality of life. However, there were many obstacles faced by T2DM

patients when coping with insulin treatment such as the restriction of lifestyle and concerns about social acceptance.

In general, knowledge of T2DM and insulin treatment are still lacking among the Malaysians interviewed in this study. There are still many distorted beliefs and misconceptions about insulin among T2DM patients. At the same time, patients' concerns and beliefs regarding insulin use are greatly influenced by their experience and support from others. Many participants felt embarrassed and self-conscious when self-injecting insulin in public places. They felt that the Malaysian public often associate the use of injections to drug abuse. Social stigma is one key point, which leads to poor adherence to insulin treatment. Thus it is crucial to increase public awareness about insulin treatment in order to help these patients to be more comfortable about injecting, and also to encourage other people to be more open minded towards insulin treatment. Apart from raising public awareness, there is a need to empower T2DM patients with adequate knowledge through early, simplified, tailored education focusing on the disease nature and the role of insulin. Making them more aware of their health condition and the uses of modern insulin devices at an early stage will better prepare them mentally for insulin therapy.

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Awards

Awarded best Research Showcase oral presentation at University of Nottingham Malaysia campus 2013: Injecting Insulin? How tough can it be?

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List of Terms and Abbreviations

CRC	Clinical Research Centre
DRC	Diabetes Resource Centre
GT	Grounded Theory
MGT	Modified Grounded Theory
IDF	International Diabetes Federation
IHBB	Institute for Health Behavioural Research
IPA	Interpretative Phenomenological Approach
MOH	Ministry of Health
MREC	Medical Research and Ethics Committee
NHMS	National Health Morbidity Survey
NIH	National Institute of Health
NMRR	National Medical Research Registry
OAM	Oral Anti-diabetic Medication
OSOP	One Sheet Of Paper
UK	United Kingdom
PDM	Diabetes Malaysia (Persatuan Diabetes Malaysia)
PH	Studied public hospital
PIR	Psychological insulin resistance
T2DM	Type 2 Diabetes Mellitus
TA	Thematic Analysis

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CHAPTER 1

INTRODUCTION

1.1 Background

Diabetes mellitus is an ancient disease yet remains today a worldwide threat with an alarming rise of prevalence and is creating a massive health burden. The term diabetes mellitus describes a chronic, persistent hyperglycaemia disorder, accompanied by other metabolic abnormalities. WHO classified Diabetes Mellitus according to their aetiologies namely Type 1, Type 2, gestational diabetes and other specific types (Alberti & Zimmet 1998). Type 2 diabetes mellitus (T2DM) includes the common major form of diabetes and it is characterised by dysfunction action of insulin at peripheral tissue, or impaired insulin secretion from pancreatic beta cell or both. There is also an unusual increase of hepatic glucose output and abnormal metabolism of carbohydrate, fat and protein, thus leading to a marked raised level of blood glucose (Ministry of Health Malaysia 2009; Alberti & Zimmet 1998; International Diabetes Federation 2013). T2DM is traditionally found in the older population, but recently it has been increasingly seen in younger adults and even children.

T2DM is a chronic and progressive disease, there is no known cure for the disease but medication is used to maintain a near normal blood glucose level. T2DM is a progressive disease, which characterised by worsening glycaemia.

At diagnosis, most patients were found to have only approximately 50% of normal pancreatic beta cell function. It is estimated that the diagnosed patient's pancreatic beta cell function will further decline at a rate of approximately 5% per year (Turner & Holman 1995).

Uncontrolled T2DM can lead to long-term permanent damage, dysfunction and failure of various organs. Macrovascular and microvascular complications are the major consequences of poor glycaemic control, which contribute to a significant rate of mortality and morbidity. Micro-vascular complications refers to damages on smaller blood vessel causing nephropathy, neuropathy and retinopathy which lead to the need of dialysis, amputation and loss of vision; on the other hand, macro-vascular complications increase risk of cardiovascular and cerebro-vascular events causing damages to other peripheral vascular systems. As a result of these complications, T2DM poses an enormous health and economic burden from repetitive hospitalisation, pharmaceutical costs and loss of productivity due to various disabilities. Furthermore, it causes a substantial impact to the patients' longevity and quality of life and indirectly affects their family members.

1.2 Literature Review

1.2.1 Epidemiology of Type 2 Diabetes in Malaysia

In a recent International Diabetes Federation (IDF) report, it was estimated that the current population of diabetes is already at the bar of 382 million and this number will continue to increase to 592 million by 2035. The report highlighted that 80% of the diabetes population lives in low and middle income countries such as Malaysia (International Diabetes Federation 2013).

The prevalence of Type 2 diabetes mellitus (T2DM) in Malaysia has increased dramatically over the past 10 years due to the modernisation of the country. The 2006 National Health Morbidity Survey (NHMS III) reported as many as 1 in 7 Malaysian adults over age of 30 years are suffering from diabetes. Despite the less stringent criteria for diagnosing diabetes in 2006 NHMS III survey compared to 1996 NHMS II survey, the prevalence of diabetic patients ≥ 30 year old had increased from 8.3% in the 1996 survey to 11.6% in 2006 (Letchuman et al. 2010; Zaini 2000).

The most recent National Health Morbidity Survey (NHMS 2011) reported the prevalence of diabetic patients has increased to 15.2% (Kaur et al. 2011). Among the diabetes population in Malaysia, the Indians had the highest prevalence at 24.9%, this was followed by the Malays at 16.9% and lastly, the Chinese diabetes population was sitting at 13.8% (refer Figure 1).

The figures shown that the in the space of 5 years, the prevalence of diabetes in Malaysia has increased by 31.0%, from 11.6% in 2006 to 15.2% in 2011 (refer Figure 2). NHMS 2011 concluded that this dramatic increase was due the result of the increased proportion of "undiagnosed diabetes". This current figure placed Malaysia in sixth place in the world for the highest prevalence of T2DM in the age group 20-79 years (International Diabetes Fedaration 2013). Judging from the trend, the prevalence of diabetes in Malaysia will also exceed the projected prevalence by International Diabetes Federation for all regions in the world for year 2025 (Wild et al. 2004).

Figure 1 Percentage of diabetes patients among main ethnic groups.

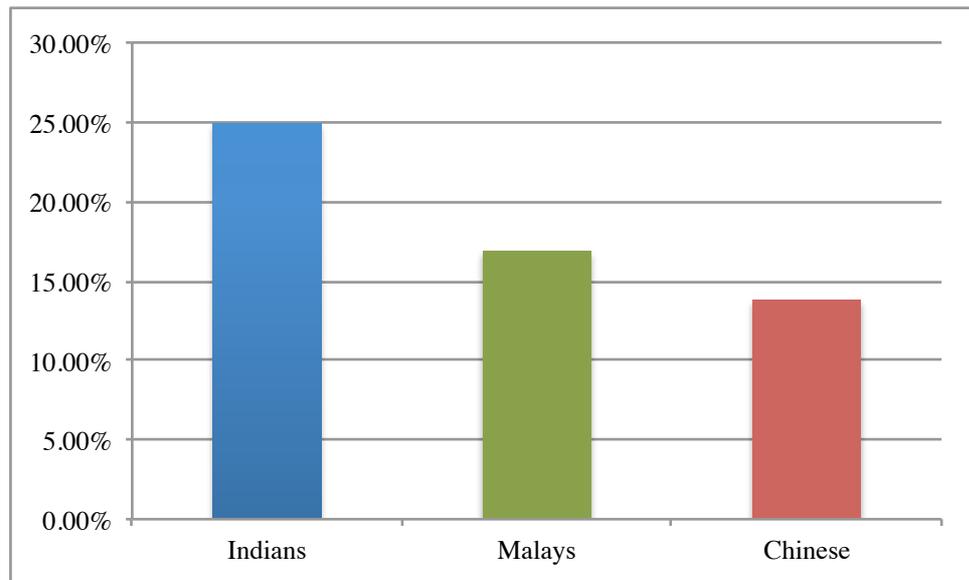
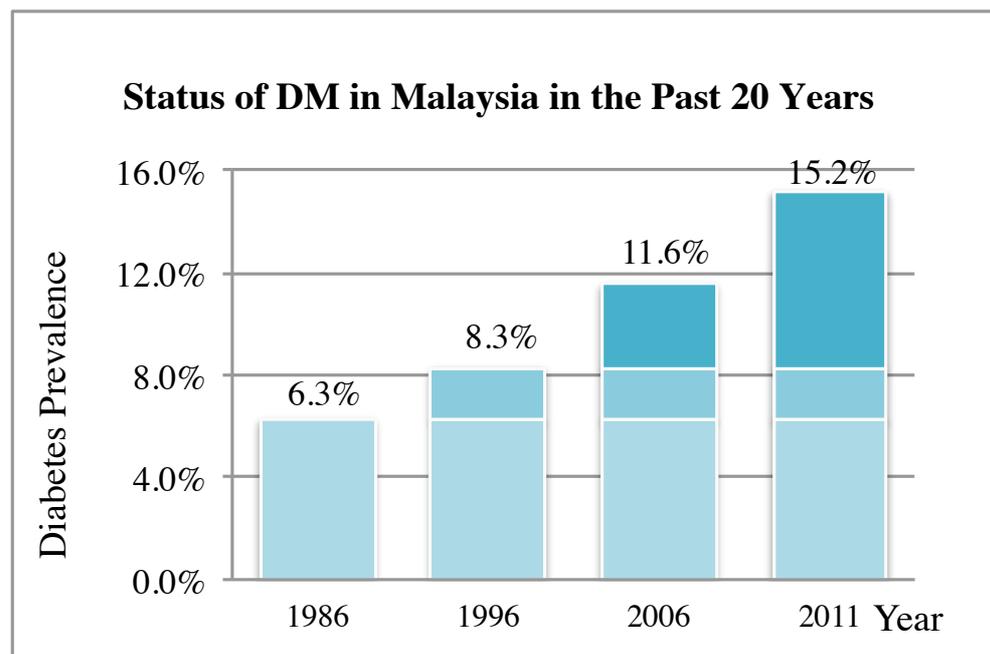


Figure 2 Status of Diabetes Mellitus in Malaysia in the past 20 years



1.2.2 Economic Burden

The dramatic rising prevalence of T2DM has mainly occurred in developing countries where there has been rapid urbanisation causing major lifestyle changes. In Malaysia a developing country, modernisation has rapidly transformed the country and also modified the lifestyle of the population. Furthermore, the Malaysian diet is high in carbohydrates and fat, but lacking in vegetable and fruits intake; synergising that with the urbanising lifestyle, lack of physical activity; the rise of diabetes prevalence is indeed very alarming (Kaur et al. 2011). This growing population of diabetes patients has not only put an enormous economic burden on individuals, but also the country's health system and economy. In 2010, International Diabetes Federation (IDF) estimated that US Dollar (USD) 376 billion was spent on treating and preventing diabetes, which translated to 11.6% of the total healthcare expenditure worldwide (Whiting et al. 2011). Three years later, IDF (2013) reported this figure has increased to USD 548 billion.

Poor glycaemic control leads to long term complication and contribute to a significant rate of mortality and morbidity. The NHMS III survey revealed that as high as 4.3% of diabetic patients had have lower limb amputations, 3.4% suffered strokes and 1.6% were on dialysis or had kidney transplants due to micro-vascular complications (Letchuman et al. 2010). These complications resulted in repetitive hospitalisation, pharmaceutical cost and loss of productivity and causing an immensely burden to Malaysia.

Therefore, good glycaemic control is very critical to prevent the development of diabetic complications. Due to the progressive nature of diabetes, most T2DM patients eventually will require exogenous insulin to control their blood glucose levels. Most patients with T2DM only retain 50% of pancreatic beta cell function at diagnosis, and the function of these cells is declining at 5% each year. By the 6th year of treatment with oral hypoglycaemic medication, over 50% of the patients will eventually require insulin intervention to maintain a healthy blood glucose level (Turner & Holman 1995).

1.2.3 Development of Insulin Products

Since the discovery of insulin by Frederick Banting and his student Charles Best back in 1921, insulin has been widely used for treatment of diabetes. Oral hypoglycaemic agents were later introduced in the 1950s, transforming the treatment of diabetes mellitus (Watkins et al. 2003). The initial production of insulin contained significant amount of impurities but manufacturing technique was rapidly improved to allow the manufacturing of higher quality insulin formulation (Hirsch 2005). By early 1980s, a new technology, recombinant human insulin technology, was developed to replace bovine and porcine sources in the manufacturing process. This technology improves the side effect profiles of insulin particularly insulin allergy and immune-mediated lipotrophy.

The first long-acting preparation, protamine zinc insulin, was developed in the 1930'. The development of this long-acting insulin preparation reduced the frequency of injection required in a day. In 2001, insulin glargine, the first of the long-acting insulin analogues, was introduced which is widely used today as basal insulin injection (Hirsch 2005). This is followed by the development of insulin detemir, another long-acting analogue that only required to be injected once daily offering additional benefits of lifestyle flexibility and improved glycaemic control.

1.2.4 Improvement of Insulin Delivery Devices

Over the years, there have been many significant developments to improve the efficacy and safety profiles of insulin; the mechanical devices used to deliver insulin have also been improved. Insulin product was originally available in glass vials and to be administered with glass syringe and large, long needles. The glass syringes and the needles were reusable and had to be sterilised by boiling, furthermore the reusable needles needed to be sharpened with a pumice stone (Bohannon 1999). Insulin syringes still to play an important role in diabetic care today, they are now available as a single-use, disposable plastic syringe and used with much shorter and finer attachable needles.

After years of using glass vial together with syringes and needles, drug companies that manufacture insulin product have developed a more ‘personal’ version of the mechanical devices to encourage of self-administering of insulin at home (Griffin & Hieronymus 2002; Selam & Charles 1990; Bohannon 1999). The developments of insulin pen devices make the process of injecting insulin much more pleasant compared to the traditional insulin syringes and needles. These injecting devices consist of a reusable injecting device and a replaceable insulin vial that comes in 3mL cartilage. This device is to be used with a new and improved needle, a single-used, disposable needle. These disposable needles are much finer and smaller in size compared to the traditional insulin needles and therefore causing less pain and more acceptable to patients.

The latest development is the new fully disposable modern insulin pen devices. The principle of the devices is similar to its predecessor, instead of having to change the cartridge; these new disposable pen devices have the cartridge 'built-in'. This development has further increased flexibility and acceptability by patients (Griffin & Hieronymus 2002; Bohannon 1999). Other insulin delivery systems such as insulin pumps and jet injectors are available overseas but not popular in Malaysia (Griffin & Hieronymus 2002).

Since the first introduction of insulin in 1921 by Frederick Banting and his student Charles Best, insulin has been administered as an injection and this delivery method had no major breakthrough until 2006, when Pfizer drug company launched the first ever inhaled insulin, Exubera® (US Food and Drug Administration 2006). However, it was not well received by the public and any health authorities. Therefore Pfizer, the manufacturer has ceased its production in 2008, only 2 years after it first launched. The National Institute for Health and Clinical Excellence (NICE) concluded that using this new treatment option is not more clinically and cost effective than the current available injectable insulin and has since withdrawn the product from British National Formulary (National Institute for Health and Clinical Excellence 2006).

Over the years, many researchers have spent an immense effort in the development of an alternate delivery method for insulin such as transdermal and oral-buccal route, unfortunately face with many challenges (Carino & Mathiowitz 1999; National Institute for Health and Clinical Excellence 2009). Thus, until today injectable insulin treatment remains the only effective

delivery method to control and maintain healthy blood glucose level for many diabetic patients.

1.2.5 Treatment Aim

The aim of diabetes management has remained the same throughout the century: to maintain a satisfactory glycaemic control and subsequently reducing both micro-vascular and macro-vascular complications. The short term goal is to achieve appropriate glycaemic control to avoid any hyper or hypoglycaemia, the long term aim is to reduce the concurrent risk factors such as cardiovascular risks, identification of complications and management of any existing complications (Ministry of Health Malaysia 2009).

Diabetes management involves lifestyle adjustment, medication and in the more recent years, focus has been shifted to incorporate patient education and to encourage self-care. Malaysian healthcare has been advancing in diabetes treatment. Diabetic medications are widely available in Malaysia, from the traditional oral hypoglycaemic agents such as biguanides and insulin secretagogues, to the newer generation of insulin sensitizers and dipeptidyl peptidase-4 inhibitors (Ministry of Health Malaysia 2009). Injectable medication also evolved from the well-established different classes of insulin to the later class of glucagon-like-peptide such as liraglutide and exenatide.

The Ministry of Health, Malaysia has been making the public aware that the epidemic of T2DM has been rising dramatically and affecting the nation. The ministry constantly updates treatment guidelines to provide healthcare providers the best available evidence on the current concepts in management of T2DM. The two recent publications, Management of Type 2 Diabetes Mellitus and Practical Guide to Insulin Therapy in Type 2 Diabetes Mellitus, solely

focus on T2DM management with an extensive updates on the treatment guidelines (Ministry of Health Malaysia 2009; Ministry of Health Malaysia 2010). Because beta-cell failure is progressive in T2DM, most patients can be expected to require insulin therapy to maintain glycaemic control. As a result, increased emphasis has been placed on the earlier use of insulin therapy in patients with Type 2 diabetes. NHMS 2011 estimated 79.9% of the known diabetic patients were on oral anti-diabetic (OAM) drugs and 19.3% were on insulin treatment.

Among these diabetic patients, majority (80.6%) sought treatment from MOH facilities. NHMS 2011 estimated that 56% sought treatment at MOH health clinics, followed by 24.6% at MOH hospitals. The rest of diabetic patients referred to private clinics (15.0%) and private hospitals (2.5%). Around 1.6% of diabetic patients self-medicated by purchasing medications directly from retail pharmacies and 0.2% opted for traditional and complementary medicine (Kaur et al. 2011).

1.3 Research Interest

Due to the progressive nature of Type 2 diabetes mellitus (T2DM), insulin therapy can significantly reduce morbidity and mortality if introduced to suitable patients at an early stage, or aggressively enough to achieve their glycaemic control. However only 7.2% of diabetes patients are on or are willing to use insulin treatment. Furthermore, many T2DM patients who could potentially benefit from insulin therapy do not receive the treatment or do not have treatment initiated in a timely manner (Ministry of Health Malaysia 2009; Ministry of Health Malaysia 2010). The Malaysian Ministry of Health has issued a guideline to advice T2DM patients to maintain HbA1c of less than 6.5%. However, due to multiple factors and barriers, only 22.5% of the patients are able to achieve this target (Abdul Rahman 2012). This phenomenon is partly attributed to the patients' reluctance to initiate insulin therapy. This reluctance arises from many factors such as patients' cultural health beliefs, knowledge of diabetes disease, perception of insulin therapy and other social and economic barriers. The reluctance towards initiating insulin treatment might also reflect that there is unsatisfactory quality of care and poor relationship between patients and their healthcare providers, which may result in poor adherence.

Medicines adherence or compliance is a major health issue in chronic diseases such as diabetes. Non-adherence significantly impact on our healthcare system. Like many other countries, Malaysia's healthcare policies are largely driven by cost containment strategies. With the exponentially increasing healthcare cost, health policy makers are focusing on reducing wastage and inappropriate

expenditure (Pollock 2005). The large number of diabetes patients failing to take medication as prescribed deems to be both inexplicable and intolerable. Poor adherence not only leads to a tremendous wastage of expensive resources but also heavy burden on the country health system as a result of diabetes complications. In 1997, The Royal Pharmaceutical Society of Great Britain developed a concept of concordance from concern about patient non-compliance. The aim was to refocus from a preoccupation with non-compliance as a technical issue to an increase in understanding of patient's experience of illness as well as the values and aspirations underpinning his or her preferences for treatment.

Much quantitative research conducted in the pharmacy field focuses on improving adherence of insulin treatment among T2DM patients (Lindenmeyer et al. 2006; Drab 2009; Krass et al. 2007; Nur Azmiah et al. 2011). While quantitative research reveals theories on why it is important to initiate insulin to control HbA1c, and how crucial is the input from pharmacists to achieve better compliance; qualitative research is needed to explore and capture the complexity of patients' perspectives on their diabetes. A detailed qualitative study will lead to an in-depth understanding of patients' lived experiences of diabetes and their social-psychological aspects which underpinning their preferences for insulin treatment.

In recent years, more emphasis has been put on the social-psychological aspects of patients with T2DM. There are numerous studies overseas using both quantitative and qualitative methodologies, conducted by different

disciplines focusing on patients' perspectives on insulin therapy. However, little is known about Malaysian patients' lived-experience with insulin treatment.

The qualitative research approach has gained the popularity in Malaysia due to its strengths. There are a few qualitative studies conducted in Malaysia looking at the barriers and factors influencing insulin acceptance among T2DM patients (Hassali et al. 2013; Lee et al. 2012; Abu Hassan et al. 2013; Ng et al. 2013). Lee et al. (2012) and Ng et al. (2013) used the strength of qualitative study to explore healthcare providers' perceived barriers to insulin initiation. Their findings are important, as they have identified substantial barriers to optimising insulin treatment. On the other hand, Hassali et al. (2013) and Abu Hassan et al. (2013) conducted qualitative studies on the patients' perspective of insulin treatment; both published their studies recently. Abu Hassan et al. (2013) focused on finding the initial reasons for accepting insulin treatment and their barriers of using insulin. Whereby Hassali et al (2013) employed a phenomenological approach to explore barriers to initiation of insulin and to evaluate the impact of a short educational intervention regarding patients' resistance to using insulin injections. Both studies which were conducted while I was undertaking my research yielded positive results, which corresponded to some of my findings, and they are used in the discussion in my study.

An important quantitative study was published in 2011, looking at the psychological insulin resistance (PIR) among T2DM patients in two public hospitals (Nur Azmiah et al. 2011). Nur Azmiah and her colleagues used a

self-administered questionnaire for a cross-sectional study to determine the magnitude of insulin refusal or PIR. The questionnaire utilised a five-point Likert scale on eighteen attitudinal items, measuring the perception of fifteen negative attitudes and three positive attitudes about insulin treatment. These attitudinal items were adapted from three different studies conducted in United State of America and Germany. Nur Azmiah's research highlighted that T2DM patients in Malaysia do develop similar misconceptions regarding insulin treatment. These misconceptions were pre-determined by questionnaire, which mainly based on studies done in western countries. Therefore, they might not be able to reflect Malaysian T2DM patients' perspective. However, some of these misconceptions were similar to the findings of this study.

Malaysia being a multi-ethnic country populated by Malay, Chinese, Indian and other indigenous ethnicities; the socio-cultural dimension underlying a Malaysian patient's health values, beliefs and behaviours is very unique when compared with other countries particularly the west. For example, some Malaysians believe that long-term medication will 'weaken' the body systems and once started, it has to be taken for life; and diabetes is represented by 'sweet urine' and is not associated with high blood glucose (Ariff & Beng 2006). Scottish research on the lay perceptions of T2DM in Scotland however, yielded a different perception of the disease. For example, Scottish patients have a notion that hospital referral signified worsening of their T2DM; they interpret non-referral to hospital as meaning that their T2DM is 'mild' and cannot be serious (Lawton et al. 2005). However, the vast majority of Malaysian patients will go to hospital to receive their regular and follow up

appointments due to the different structure of healthcare system. As reported in NHMS 2011, 24.6% of diabetes patients sought treatment at MOH hospitals 2.5% at private hospitals. For The notion of hospital referral is different from countries-to-countries and culture-to-culture. Therefore, understanding the underlying socio-cultural dimension of Malaysian diabetes patients is crucial towards a successful outcome of a clinical encounter.

As a result, I have decided to utilise the strength of qualitative research methodology to enable a detailed exploration of the lived-experience of Type 2 diabetes patients who are using insulin treatment for their glycaemic control in Malaysia. Qualitative methodology using an interpretative phenomenological approach is employed to develop theory to explain these phenomena. The methodology and methods are discussed in CHAPTER 2. The findings of this study are discussed in chapters 3 to 7, following patients' lived-experience of being diagnosed with T2DM (see CHAPTER 3), followed by their initial reactions to insulin treatment (see CHAPTER 4: facilitators, CHAPTER 5: barriers). In CHAPTER 6, I discuss patients' coping strategies and lifestyle adaptation. In CHAPTER 7, I focus on the social factors that influence patients' experiences of using insulin injection to manage their diabetes.

CHAPTER 2

METHODOLOGY AND METHODS

2.1 Introduction

In this chapter the methodology and methods used in this study are discussed. This begins in section 2.2 with the rationale of choosing qualitative methodology instead of quantitative methodology for this study. This is followed by a discussion on qualitative methodology and the use of the interpretative phenomenological approach. This leads to a discussion on the modified grounded theory principles as tool to analyse the qualitative data in this study. This is followed by a discussion on the use of semi-structured interview as the qualitative interview research method.

In section 2.4 the methods used in this study are discussed in detail, starting with a discussion of the aims of the study. This is followed by a discussion of the research questions. This leads to discussions about the study site, the process of gaining research and ethical approval, field activities, patient recruitment, data collection, data analysis and confidentiality.

Section 2.3 focuses on the concerns regarding quality in qualitative research and this is followed by a discussion on reflexivity.

2.2 Part One: Methodology

2.2.1 Choosing the Research Methodology and Rationale

Healthcare is a knowledge-based system (Ziebland et al. 2013), research into health and medicines seeks to improve health, health outcomes and improve health services (Bowling 2002). Quantitative biomedical research has a long tradition to demonstrate the knowledge in the healthcare system. Quantitative methodologies are used to gather and demonstrate scientific knowledge, epidemiological knowledge, and clinical knowledge on diseases and treatment interventions. But research in healthcare has often overlooked knowledge about how people experience health, illness, treatment and delivery of healthcare (Ziebland et al. 2013).

Quantitative research often employs experimental designs such as randomised controlled trials usually to test hypotheses. Quantitative orientated research using randomised controlled trials is only able to assess whether complex interventions have the desired outcomes; however it cannot provide an explanation for either the outcomes nor can it include evidence on how people experience the intervention or how it fits with their lifestyle or matches with their preferred choices or expectations. (Pope & Mays 1995; Britten 2010; Bowling 2002; Noyes 2010). Randomised controlled trials are able to demonstrate result with statistical analysis but do not provide any answer about how people experience the complexity of health issue (Jones 2003). As a result, a randomised controlled trial has a limited role when trying to explain a social phenomenon such as why patients do not adhere to their medication.

This is especially important when a piece of research is trying to draw the attention of policy makers and commissioners of health services, who are looking for other types of evidence such as patients' views and context in order to make decisions to improve health services and health outcomes (Noyes 2010).

Similarly, a quantitative questionnaire or a cross-sectional survey can generate numerical data, which can be analysed statistically and used to demonstrate what the majority's view on a health subject or compare results from a sample population (Ziebland et al. 2013). However it does not give the insight of peoples' experience, which is more meaningful (Brikci & Green 2007). Questionnaire questions are usually 'closed' and offer only a specific set of pre-coded response options (Ziebland et al. 2013), therefore they do not offer any room for answers that fall between the grey areas, for example answers such as 'it depends' or 'maybe'. It often based upon pre-coded or pre-determined assumptions built into the researchers' question (Jones 2003).

Furthermore, Malaysian patients' experience has seldom been investigated in the past, so using a questionnaire for this would not be a good idea as there is no firm foundation to build upon and too much would be based on the researcher's assumptions. Pre-determined assumptions therefore would be based on questionnaires that were conducted in other countries with different cultures; as a result they might not be able to explain the complexity of health issues faced by Malaysian patients.

Due to the advancement in medical treatment, increased specialisation and exposure of the public to modern technology, patient expectations of treatment and health outcomes are rising. As a result, healthcare professionals are working in an increasingly complex arena (Pope & Mays 1995). This rising complexity and expectation from patients has generated a gap in healthcare provision, in which traditional quantitative research such as randomised controlled trials are inadequate and difficult to apply in the current clinical practice. This gap is related to the knowledge of how people experience health, illness, treatment and the delivery of care (Ziebland et al. 2013).

In order to cater for the rising complexity of patients' experiences with different health issues, a different approach in conducting research is required to gain deeper understanding of these phenomena (Pope & Mays 1995). There is a paradigm shift in research approach, we are exploring improving patients' health outcomes; we are interested to know more about how patients feel about a particular subject. Research into the complexity of patient health experiences requires researchers to explore and reveal what is going on and not just attempt to measure how often an issue or event occurs (Black 1994). In short, researchers are more concerned with answering the "what" question, not the "how often" question (Table 1).

Not everything that can be counted counts, and not everything that counts can be counted
(Albert Einstein)

Qualitative methodology does not simplify the views of the subject in order to measure and count the occurrences of an issue or events (Table 1), however it takes on a more holistic perspective which preserves the complexities of human behaviour (Black 1994). It places emphasises on the meanings, experiences, and views of people and it is particularly suited for understanding subjects such as why do patients worry about using insulin treatment and how do patients adapt to insulin treatment in their everyday lives (Pope & Mays 1995). It helps us to understand the nature, strengths, and interactions of variables. This approach is particularly useful in complex situations such as patients' health behaviours or where the relevant variables associated with an outcome are not apparent (Black 1994). As a result qualitative research is notably a more useful tool for policy makers and healthcare professionals because it allows a clear understanding of descriptive information and the context in which policies are implemented (Murphy et al. 1998).

Table 1 The overstated dichotomy between quantitative and qualitative social science (Pope & Mays 1995)

Quantitative	Qualitative
Testing hypothesis/theories	Generating hypothesis/theories
Demonstrate	Exploratory
Experiment, survey	Interview, observation
Numbers (How many Xs)	Words (What is X)
Statistical sampling	Theoretical sampling
Reliability: Representative, generalizability	Validity: Rich, detailed, trustworthiness

2.2.2 The Qualitative Methods

I have established in section 2.2.1 that qualitative research takes a holistic perspective, which preserves the complexities of human behaviour, and places emphasis on the meanings, experiences, and views of people. Research question on ‘what?’ is best answered with qualitative research, ‘what?’ research question do not require a hypothesis (Pope & Mays 1995) but generate hypotheses or themes; this is discussed in the previous section. By asking the ‘what?’ question, we are able to seek the deeper truth through exploring knowledge in a natural setting, and it also attempts to understand the participants and what it means to them to live with a particular condition or in a particular situation (Murphy et al. 1998; Greenhalgh & Taylor 1997). Therefore it is an appropriate tool to facilitate an understanding of the complexity of a phenomenon and offer possibilities of interventions to policy makers and healthcare professionals (Biggerstaff & Thompson 2008). In this study, I am interested to find out ‘what’ is the experience of using insulin treatment by T2DM patients, an area that has not previously been researched in Malaysia. In addition, I want to explore patients’ perspectives and their experiences of insulin treatment; therefore qualitative methodology and methods were selected to design this health experience research.

To design this study, different research strategies within the qualitative methodology were examined and carefully considered. The choice of research strategy is influenced by factors such as the researcher’s preference of certain ontological and epistemological assumptions; his or her perceived link

between preferred research methods and research strategies; and also pragmatic factors such as time and funding (Blaikie 2010).

Ontology is the starting point of all research, it is about what we may know; epistemology is one of the core branches of philosophy and is about how we come to know what we know (Grix 2002). For this study with the research question focusing on the lived-experience of using insulin treatment to control T2DM, an interpretivism epistemology was considered as the most appropriate approach. Qualitative researchers situating on interpretivism epistemology put emphasis and value on the human, interpretative aspects of knowing about the social world and the significance of the researcher's own interpretations and understanding of the phenomenon being studied (Ritchie & Lewis 2003). I have landed myself with interpretivism epistemological assumption when designing this study. It is the most appropriate epistemological way to explore the lived-experience of T2DM patients in order to link their experience with the social, cultural and health aspects of their lives, and to understand the meanings and interpretations that the patients have and consider these in the network of their own statement and beliefs.

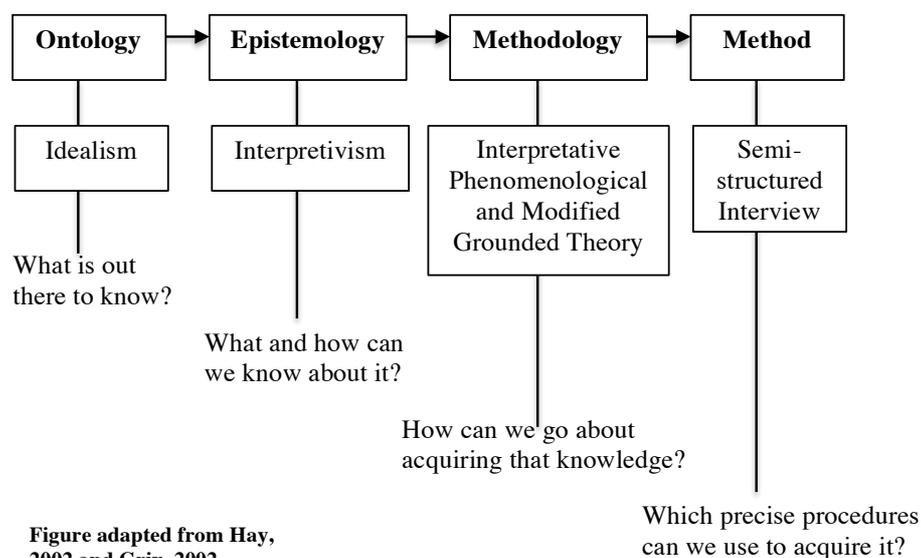
Interpretivism epistemology adheres more closely to an idealism ontology standpoint; this standpoint assumes that reality is only knowable through the human mind and socially constructed meanings. Therefore we have no way of understanding the reality other than through the lens of our own beliefs and understanding (Ritchie & Lewis 2003).

2.2.3 Interpretative Phenomenological Analysis

Social research using qualitative methodology has been conducted against a background of some traditions of theoretical and methodological ideas (Blaikie 2010). Blaikie refers these traditions as research paradigms, other qualitative researchers might refer them as ‘approaches’, which I adopted in this chapter (Bryman 2006). Qualitative research has developed and evolved over the course of the twenty first century and a number of different schools of thought have emerged (Ritchie & Lewis 2003; Blaikie 2010).

There are several research approaches within qualitative research and they differ radically in their assumptions and implications (Maxwell 2008; Blaikie 2010). It is important to shape the conceptual framework for qualitative research; therefore it is crucial to choose the best-fit approach to match one’s assumptions and methodological preferences. Blaikie stated that it is possible to choose a research approach, however Maxwell argued that selection of the research approach is not a matter of free choice (Blaikie 2010; Maxwell 2008). As I have mentioned in section 2.2.2 that I have selected idealism as my ontological position and selected interpretivism epistemology, I have already made assumptions about the reality and how I understand the world, and my assumptions and knowledge of my research topic. As a result of my pre-conceived assumptions, they have guided me to adapt the principle of interpretative phenomenological analysis approach (IPA) and modified grounded theory (MGT) to design this study. The principle of grounded theory is discussed in section 2.2.4.

Figure 3 The interrelationship between the building blocks of research



Interpretative Phenomenological Analysis (IPA) is a newly developed qualitative research approach. IPA was introduced in 1996 in a seminal paper by a psychologist, Jonathan Smith (Smith 1996). Since then, it has spread from the psychology field and gained recognition from other research disciplines particularly in applied areas such as clinical, health and counselling psychology.

Interpretative phenomenological analysis (IPA) is concerned with trying to understand peoples' lived-experience and how people make sense of their experiences. Therefore it is particularly suited in this study concerned with patients' experiences of using insulin treatment and how it holds for them. IPA is theoretically underpinned by the tradition of phenomenology and interpretation. This approach is phenomenological because it is used to explore an individual's personal perception or account of an event or state (Smith & Osborn 2008). Thus, one important theoretical touchstone for IPA is

phenomenology, which originated with Husserl's attempts to construct a philosophical science of consciousness with hermeneutics and with symbolic-interactionism. It attempts to explore personal experience through an interpretative process (Biggerstaff & Thompson 2008).

IPA also considers that one cannot get close to the participant's personal world directly or completely. This hermeneutics interpretative process must also depend on the researcher's own conceptions which are required to understand the participant's world through another level of interpretative activity. Therefore the second important theoretical current for IPA is that it is a two-stage interpretation process, or a double hermeneutic (Smith & Osborn 2008).

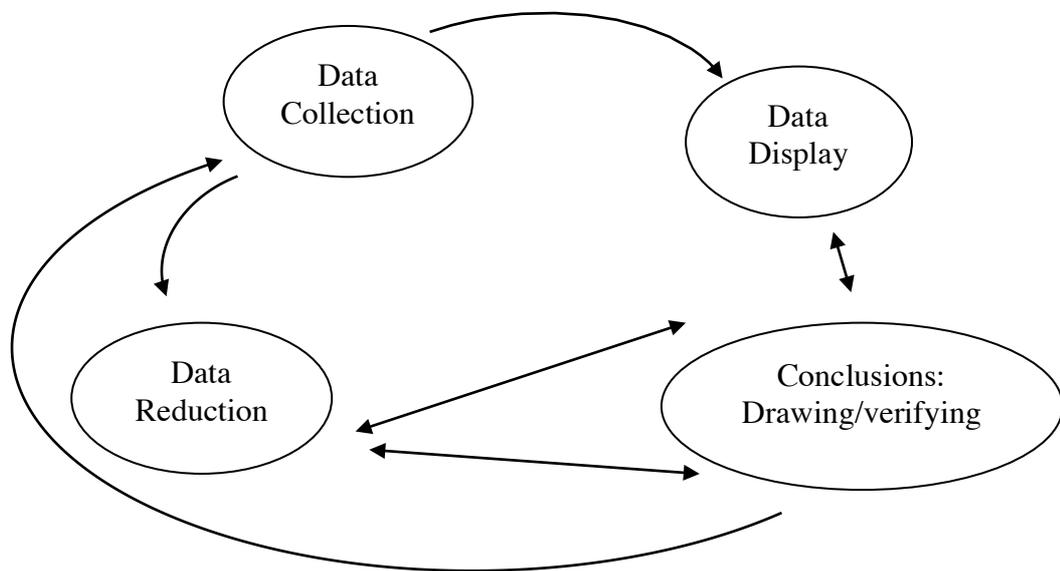
The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world.

IPA is a suitable approach in the research as the T2DM patients are trying to understand how they perceive insulin therapy and find out how the introduction of insulin therapy is affecting their personal and social world. Using semi-structured interview, the participants were asked to tell their story through their own interpretation of the experience; I would listen to their story and try to interpret what they said and how they interpreted their experience.

The aim of any qualitative research is to explore, flexibly and in detail, an area of concern. With an IPA approach, qualitative researchers are allowed to have

their own conceptions when conducting interviews to explore a phenomenon or an area of concern, but researchers should not make any attempt to test a predetermined hypothesis. (Smith & Osborn 2008). Therefore, the principles of grounded theory approach were employed in designing this research in particular the iterative process of collecting and analysing data (refer Figure 4).

Figure 4 Process of data in qualitative research.



2.2.4 Modified Grounded Theory and Thematic Analysis

2.2.4.1 Grounded Theory

Grounded theory (GT) was originally developed by Barney Glaser and Anselm Strauss in 1967 and it is one of the major philosophical approaches widely used in qualitative research. The approach of GT has evolved and diversified over the years and both Glaser and Strauss have also shifted their perspective (Charmaz 2008; Heath & Cowley 2004). In general, GT offers a systematic methodology to obtain data and emphasises the development of theory from data in the process of conducting research (Boeije 2009; Glaser & Strauss 2009). Glaser and Strauss stressed that the data is the centre stage in reaching a theoretical description of a phenomenon and explaining people's actions. GT emphasises developing theory through an iterative process of collecting and analysing data which is different from other branches of qualitative research approaches (Boeije 2009; Glaser & Strauss 2009; Murphy et al. 1998).

In the initial part of grounded theory research, researchers are required to go through a series of cycles in which they move back and forth among the data collection and the analysis, hence the iterative process (Smith & Osborn 2008). The data are analysed with a technique called 'coding', in which relevant parts of the data, for example a section from an interview transcripts, are highlighted and labelled. Coding process in GT is a very detailed approach as data is said to be at the center of the stage during GT research. During the coding process, researchers have to go through the interview transcripts, line by line to highlight and label the relevant parts. This initial coding process is referred as

'open coding'; researchers have to pay attention to every sentence to avoid missing out any important information.

This initial part is explorative, but as the research progresses and starts to generate more data, the researcher will focus on verifying results or theories found earlier on in the initial research process (Boeije 2009). The researchers have to compare data to data, codes with codes throughout the whole research project. This process is referred as constant comparison, in which each item is checked, compared and verified with the rest of the data (Pope et al. 2000). This process of constant movement between theory and data is an important feature of GT proposed by Glaser and Strauss (Murphy et al. 1998). Constant comparison of theory generation and refinement process is sought to expand, confirm or deepen the newly found theory.

The analysing process gradually advances from simply coding the data, to conceptual categories, and then to develop theory to explain the studied phenomenon (Boeije 2009). The later process of conceptualised categories and developing new theory is important in influencing the recruitment of further participants; it is another important feature of GT. This recruitment or sampling technique is referred as theoretical sampling. This principle of sampling technique is adopted in this study and is discussed in section 2.2.5.

Researchers using grounded theory approach only develop theoretical categories during the analytic process; they do not know in advance what they will be sampling. Thus theoretical sampling is a unique feature of GT and it is

different from other selective sampling which most qualitative researchers employ as they set criteria for their research problem (Murphy et al. 1998). In comparison, interpretative phenomenological analysis (IPA), which is associated with phenomenological approach, uses another technique, purposive sampling. IPA researchers usually select a defined group of homogenous sample be relevant to the research question (Chapman & Smith 2002). IPA researchers usually focus on small sample sizes ranging from six to ten participants, IPA focuses on gathering the detail of the perceptions and understandings of a particular phenomenon. Therefore a pure IPA uses case-by-case analysis of individual transcripts and it takes a long time to complete an IPA study (Smith & Osborn 2008).

2.2.4.2 Modified Grounded Theory

Since its original development back in the 1960's, grounded theory (GT) has been modified by different qualitative researchers during the years (Murphy et al. 1998; Charmaz 2008). Charmaz describes GT as an analytic method of producing qualitative research, it is a set of methods that are systematic, but there are flexible guidelines for collecting and analysing qualitative data to construct theories which are 'grounded' in the data (Charmaz 2008; Guest et al. 1971).

The original 'pure grounded theory' suggests that researcher should only look at the data from an absolute neutral point of view without any preconception. However, it is impossible in real practise for any researcher to conduct research without any prior knowledge. Even before data collection, a researcher will have ideas about what to be found in the data, drawn from his or her own experience, discipline, reading or awareness of theory (Ziebland & McPherson 2006; Charmaz 2008). Charmaz has recognised that researchers' pre-existing knowledge can affect a pure grounded theory analysis process; in her study she modified the 'pure' grounded theory approach, and allow more flexibility in generating theories from analysing her data (Charmaz 2008). Charmaz modified the 'pure grounded theory' approach to suit her constructivist grounded theory and it is suggested to other researchers that they can also use the principle of GT and modified it when they are coding qualitative data. In real practice, most researchers have adapted the modified grounded theory approach. Since most researchers have preconception or theories in mind when they look at their data, by modifying ground theory,

they can combine their pre-defined categories and new founded ones which emerge out of the data (Charmaz 2008; Braun & Clarke 2006).

In this qualitative study, I have modified the pure approach to grounded theory and used some of the principle features of grounded theory. Particularly in the process of theory generation, theoretical sampling, and constant comparative method of data analysis. Thematic analysis is used during write up where the results section contains emergent themes with a separate discussion linking the analysis to literature review (Smith & Osborn 2008).

2.2.4.3 Thematic Analysis

Thematic analysis (TA) evolved from grounded theory but it has been poorly branded. TA is similar to interpretative phenomenology analysis and grounded theory (GT), they all seek patterns in the data however TA is not theoretically bounded and therefore has more flexibility compared to the 'pure' grounded theory approach (Braun & Clarke 2006). It is more accessible to researchers who have less experience or a limited time frame to conduct their studies, especially when working with large data sets, as pure GT can be very time consuming.

Researchers using the thematic analysis approach need not subscribe to the implicit theoretical commitments of 'pure' grounded theory which they will have to produce a fully worked-up grounded-theory analysis (Guest et al. 1971; Braun & Clarke 2006). Through its theoretical freedom, TA provides a more accessible and flexible research tool that provide a rich and detailed, yet complex, account of data. It is well suitable for large data sets with variation samples and relatively large studied population, which can be more than 40 or more interviews. The other advantage of using thematic analysis is that it is not wedded to any pre-existing theoretical framework, and therefore it can be used within different theoretical frameworks (Braun & Clarke 2006).

Ziebland and McPherson suggested that thematic analysis works well in studies with a relatively narrow research question and potentially dominated by anticipated themes. TA focuses more on interpreting anticipated and emergent themes in interview data. Although there are anticipated themes, it is vital to

explore all the relevant data thoroughly and ensure that the explanation is robust (Ziebland & McPherson 2006). The aim of this study is relative focus and narrow: to find out the barriers and facilitators to either hinder T2DM patients or encourage them to use insulin and adhere to the treatment. I was aiming to be more explorative in studying this phenomenon and therefore bracketing technique is used. While conducting the interviews and reading the interview transcripts, I have made several attempts to suspend pre-existing knowledge and judgments. Bracketing involves suspension of critical judgment and a temporary refusal of critical engagement, which would bring in the researcher's own assumptions and experience. It is a self-reflective process whereby the researchers acknowledge but set aside their priori knowledge and assumptions to allow the analytic goal of attending to the participants' accounts with an open mind (Biggerstaff & Thompson 2008; Starks & Trinidad 2007). I tried to hide behind my pharmacist role and using a different lens when interviewing the participants. During interviews, I had to temporarily suspended my pharmacist knowledge and identified myself as a PhD student. This helped me to position myself as researcher and built a better rapport with the participants.

In this study, the initial part of the data collection employed interpretative phenomenological analysis approach and the principle of grounded theory; later data analysis leaned towards thematic analysis which sit within the modified GT and IPA frameworks. Similar to grounded theory, thematic analysis is used in identifying, analysing and reporting patterns or themes within data (Braun & Clarke 2006). TA looks across all the data to identify and

describe both implicit and explicit ideas within the data referred to as a 'theme'. A common theme summarises all the views that are identified within the data (Brikci & Green 2007; Guest 2006). It captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set. Themes sometimes come from the researcher's prior knowledge or understanding of the phenomenon being studied, it is referred as priori approach or Strauss calls it 'Data in the head' (Ryan & Bernard 2003; Charmaz 2008). Priori themes are discussed in section 2.2.4.1, these 'data in the head' arise from the background of the phenomenon being studied; from prior study of the phenomenon found in literature reviews; from local, common-sense constructs; or from researchers' awareness of the theory, or sometimes it can simply be part of the researcher's personal experiences (Ryan & Bernard 2003; Ziebland & McPherson 2006). As data collection progresses it is useful to record the ideas or 'data in the head', as it could possibly be some initial analytic interests or thoughts which can develop into themes later (Braun & Clarke 2006; Ziebland & McPherson 2006).

It is important to point out that the stages of data collection and data analysis are closely related and they are not independent processes. Data collection and analysis do not occur in a linear sequence, they are cyclic in nature and the analysis process is part of an iterative process (Miles & Huberman 1984). But for the purpose of this report, the steps involved in this study are discussed in sequence and the collected qualitative data is presented as interview

transcripts. The steps involved in data collection and data analyses are discussed in detail in section 2.4.8 and section 2.4.9 respectively.

In these recent sections, I have described my ontological, epistemological and methodological positions that underpinning this research. In the following section, I will discuss the utilisation of these approaches in conducting the qualitative interviews.

2.2.4.4 Qualitative Interviews

The methods used in qualitative research depend partly on a researcher's own epistemological and ontological positions (Ritchie & Lewis 2003; Carter & Little 2007). Ontology influences a researcher's epistemological position, which in turn influences the methodology adopted and the way data are collected. The main methods used in ethnographic studies involving naturally occurring data are observation, documentary analysis, conversation; the main types of generated data in qualitative research such as phenomenological studies are interviews and focus group discussion (Ritchie & Lewis 2003). In other words, an interview is used to find out from the interviewee things that we cannot directly observe.

As my epistemological stance for this study is interpretivism epistemology, using interviews to collect data deems to be appropriate in learning about patients' lived-experience of using insulin treatment as part of their diabetes management. Focus group discussions were considered for this study, they are useful for studies focusing on attitudes or for difficult and technical issues which involvement of many participants will facilitate the understanding of the research topic (Ritchie & Lewis 2003). However, as this study focuses on patients' own lived-experience of using insulin treatment, one to one interviews were deemed to be more suitable, given the consideration of patient's privacy. Furthermore, this study is bounded by the ethics committee approval from Ministry of Health Malaysia and must be carried out within the hospital compound (see section 2.4.3); it was impractical to set up focus group

meetings in the hospital compound due to space constraints and also difficulties in arranging group meetings with selected participants.

Apart from focus group discussions, there are three main types of interviews: structured, semi-structured, and in depth (Britten 1995). Structured interviews involve the administering of structured questionnaires, which are often used in quantitative research. In depth interviews allow in depth understanding of the personal context within which the research topic is located, and provide a detailed investigation of each person's personal perspective (Ritchie & Lewis 2003). Semi-structured interviews use open ended questions that define the area to be explored initially, and then may diverge in order to pursue an idea in more detail (Britten 1995). After serious consideration of the practicality and cultural sensitivity, I decided to use semi-structured interview for data collection.

Semi-structured interviews are more appropriate to illuminate this research topic as it offers patients the opportunity to express their own definitions of their experiences, it allows them to tell their story like it is and interpret what they feel personally. At the same time, the interviewer may diverge in order to pursue an idea in more detail (Britten 1995). Therefore semi-structured interview offers more dynamic and more flexibility compared to a structured questionnaire. In real practice, any interview may diverge from what was originally planned; therefore semi-structured interviews provide the interviewer with the assistance of an interview topic guide to steer the topic back to the area of interest. The interview is therefore 'semi-structured' with a

guide but not restricted to it. It is vital to decide the right questions to ask during interviews and participants being interviewed might not share the same perspective on the world as researcher, therefore a list of pre-defined questions would be helpful in this instance (Brikci & Green 2007). An interview topic guide is a set of key issues, themes, possible probes or pre-defined key questions to cover during an interview, it is designed to encourage the interviewee to talk about specific issues or when the interviewee is stuck at a particular question or when topic has been diverge considerably from what was originally envisaged.

There are different models of semi-structured interviewing, and definition of 'semi-structured' interviews may be termed differently by different researchers (Ritchie & Lewis 2003). A semi-structured interview might be described as unstructured or in-depth or even open-ended survey interviews. In this IPA study which focuses on patients' lived-experience of using insulin treatment, semi-structured interview allowed me to steer the conversation from one topic to another, creating transitions with a semi-structured questions to ask. The flow of the interview followed the sequence of when the patients diagnosed with T2DM, followed by their experience of using oral medication to control their T2DM, and then went into how they were being prescribed insulin followed by their experience of using insulin treatment. As each interview is different from another, sometimes I altered the sequence of questions or the way in which they are phrased; sometimes there were fixed structure with some probing.

2.2.5 Purposive Sampling and Theoretical Saturation

Sampling strategies are determined by the purpose of the research project, probability sampling is often used in quantitative research for statistical purpose and to sought statistical representativeness but it is not suitable in qualitative research (Ritchie & Lewis 2003; Britten 1995). Quantitative research uses probability sampling to choose participants from a population randomly to represent in the sample in their true proportions. On the other hand, qualitative research uses non-probability samples to select participants. Participants are deliberately selected to reflect particular features of the sampled population. It is not intended to be statistically representative but participants are selected according to pre-determined criteria for the purpose of the research objective hence purposive sampling (Ritchie & Lewis 2003).

Participants are chosen with two 'purposes' in mind: firstly they are likely to generate useful data for the research topic and secondly to ensure that this sample is credible. The second purpose is to ensure that some diversity is included especially in this study of Malaysian T2DM patients. Malaysia is a multicultural country and the prevalence of T2DM is higher in the minority ethnic group (Kaur et al. 2011). According to the National Health and Morbidity Survey 2011 (NHMS 2011), the minority ethnic group, Indian, had the highest prevalence at 24.9%, followed by the Malays at 16.9% and lastly, the Chinese at 13.8%. Therefore the participants in this study were selected not only for the relevance to the research topic, but also to cover the main ethnicity groups for maximum variation, which are likely to have an impact on participants' view of the research topic.

Sampling for participants was inductive and continued until theoretical saturation, which follows the principle of grounded theory (see 2.2.4.1). With this sampling technique, the researcher would not be able to estimate upfront the number of participants required for the study. It often poses as an obstacle for the qualitative researcher when compiling a research proposal or applying for ethics committee approval (Guest 2006). Guest has summarised guidelines for determining the sample size in qualitative research (refer Table 2).

Table 2 Summary of estimated sample size for qualitative study approaches

Study Approaches	Estimated Sample Size
Ethnographic studies	30-60 (Bernard) >15 (Bertaux) 30-50 (Morse)
Phenomenological studies	>6 (Morse) 5-25 (Creswell)
Grounded theory	30-50 (Morse) 20-30 (Creswell)

Theoretical sampling is a particular kind of purposive sampling and is associated with grounded theory as mentioned earlier (Ritchie & Lewis 2003). Theoretical sampling guides the researcher to recruit participants that aim toward the development of the emerging theory which is grounded in the data (Glaser & Strauss 2009; Murphy et al. 1998). The sampling process is iterative: the researcher starts with the initial data collection, analyses the data for emerging theories, and then uses the emerging theories to focus on

subsequent data collection until 'data saturation' or when there is no more new theory emerging, thus referred as theoretical saturation.

This study used Interpretative Phenomenological Analysis and modified grounded theory approach; the sampling technique was purposive and the stopping point for recruitment was until theoretical saturation.

2.3 Quality in Qualitative Research

The strength of the quantitative research lies in its reliability or repeatability; on the other hand, the strength of qualitative research lies in validity: closeness to the truth (Greenhalgh & Taylor 1997). It is impossible to judge the quality of a qualitative research using the traditional framework such as that of quantitative research. However it is still vital to review the validity and quality of qualitative research by specific criteria that are appropriate to it.

There are no mechanical or “easy” solutions to exclude the likelihood of errors in qualitative research but there are several ways of improving validity and ensuring rigour in quantitative research (Mays & Pope 2000).

2.3.1 Validity, Reliability and Generalisability

Thematic analysis is the most commonly used method of analysis in qualitative research (Guest et al. 1971). Guest states that a thematic analysis is most useful in capturing the complexities of meaning within a textual data set. Reliability is greater with thematic analysis compared with other word-based analyses such as content analysis because more interpretation goes into defining the codes as well as applying the codes to chunks of text.

This issue is even more pronounced when working in teams. In this study, all the transcripts were shared with supervisors and emerging themes were discussed regularly during data collection and data analysis. Data analysis is a part of an iterative process, this involved reading and re-reading for any possible missing data and identify emerging themes in the constant search for understanding and the meaning of the data. Collected data was repeatedly read and discussed to ensure that detailed, high quality codes and subsequent themes were identified. The principle of constant comparison also being employed throughout the analysis process to improve the validity of the study.

During the data analysis process, especially when searching for themes from the initial coding process, any presentation of cases that are inconsistent with the emerging analysis were discussed with supervisors. Mays and Pope suggested to search for, and discuss any ‘deviant case’ for improving the quality of explanations in qualitative research (Mays & Pope 2000). Such “deviant case analysis” helps refine the analysis until it can explain all or the vast majority of the cases under scrutiny. This study used theoretical sampling

technique which also facilitated the search for negative cases. Theoretical sampling encourages researchers to establish the limits of their findings through systematic search for disconfirming cases (Murphy et al. 1998).

The findings from qualitative research are not meant to be generalisable or transferable; generalisations of the rationalistic variety are not possible because phenomena are intimately tied to the times and contexts in which they are found (Murphy et al. 1998). 'Generalisability' in qualitative research uses the theory developed within one particular study and extends it to provide explanatory theory for the experiences of another individuals who are in comparable situations. Participants in this study were purposively chosen based on their intended ability to generate relevant data for the research topic; this is to ensure at the data generated is credible. Furthermore, a purposive sampling technique was employed to include the main ethnicity groups for maximum variation, this is to ensure that the findings were sufficiently detailed to be relevant for the healthcare providers or policy makers. According to Mays and Pope, another important dimension of relevance is the extent to which findings can be generalised beyond the setting in which they were generated (Mays & Pope 2000).

2.3.2 Reflexivity

Reflexivity means sensitivity to the ways in which the researcher and the research process have shaped the collected data, taking account of the researcher's own personal experiences, theoretical biases, recognising the role of values and a priori assumptions in shaping any research account (Murphy et al. 1998; Mays & Pope 2000)

The bracketing technique was employed during data analysis. As I had been working as a clinical pharmacist in a public hospital overseas and locally in Malaysia, the perception I have towards diabetic patients overseas and in Malaysia might interfere with the research process. Other factors that might interfere with the research process including interpretation of findings were acknowledged and I remain aware of it and do constantly reflect upon (see section 8.2 Reflexivity: Practical Application in the Study).

2.4 Part Two: Methods

2.4.1 Study Objectives

This is an exploratory study; the aim is to explore the lived-experience of Malaysian patients with Type 2 diabetes mellitus who are using insulin as part of their glycaemic control. The objectives are to explore how these participants experienced using insulin, in order to understand what are the barriers perceived by a lay person regarding insulin treatment, at the same time to learn from these participants what facilitate or motivate the adherence to treatment.

Specifically this involved:

- Obtaining approval at the study site to conduct the study (section 2.4.3).
- Obtaining National Research Ethics Committee approval to conduct the study (section 2.4.4).
- Screening patients list for suitable participants (section 2.4.5 and 2.4.6).
- Obtaining formal written consent from all participants in the study (section 2.4.6 and 2.4.7).
- Conducting initial semi-structured qualitative interviews (section 2.4.8).
- Refining interview technique.
- Analysing data along with interviewing patient (section 2.4.9).
- Continuing to recruit and interview patients until theoretical saturation had been reached.

A qualitative study is not a linear process; it is iterative and constantly reflects onto the research question. Therefore the analytical process was started whilst the interviewing was being carried on. This allowed constant comparison and reflecting on the interview questions, the participants' experiences and the technique.

2.4.2 Research Questions

The main objective of this study was to explore the patients' lived-experience of using insulin to manage T2DM. The research questions linked between the interpretive paradigm and the phenomenological approach for data collection.

The following research questions, using 'what' and 'how' were employed during the semi-structured interview to obtain rich details of peoples' lived-experience. They reflect on the aim of this qualitative study more appropriately and shaped the direction of the research methodology as discussed in section 2.2.1:

- *What is your experience of using insulin to control diabetes?*
- *What influences these experiences?*
- *How do your perspectives of insulin treatment change overtime?*

The First Research Question

What is the experience of using insulin to control diabetes?

The main research question was to develop an understanding of how patients experience diabetes disease and the initiation of insulin. A phenomenological approach was used to discover and understand the lived experience.

Guiding Questions

- How did you find out about having diabetes?
- How was insulin introduced?
- How do you find using insulin injections?

The Second Research Question

What influences these experiences?

The second research question focused on the influences of people around the patients. These people could be any healthcare professionals, their family members, colleagues, or friends from their social circle. This was set to explore how social issues and culture influences the experiences of being diabetic and using insulin as part of the treatment.

Guiding Questions

- How did you react when insulin was mentioned as part of your treatment plan?
- How did you inform your family and friends about insulin therapy?

The Third Research Question

How do patients' perspectives of insulin treatment change overtime?

The third research question aimed to explore how patients' attitudes toward insulin treatment changed with their experience. This study is an exploratory study to find out the contributing factors which change patients' behaviour towards insulin and to develop new theory on the topic.

Guiding Questions

- How have you adapted to insulin treatment?
- What has changed in your life since insulin was introduced?

These are the guiding question which underpin the study aim of this research, the interview topic guide which was used in the semi-structured interview are summarised in appendix 3. The process of semi-structured is discussed in section 2.4.8.

2.4.3 Study Site and Local Research Approval

A public hospital (PH) was selected as the research study site. PH is located at the government administrative town of Malaysia peninsular, around 35km from Kuala Lumpur city centre with easy access by public transport via train or buses. This hospital is a 341 bedded hospital providing both primary and secondary level care and specialised in endocrinology, rheumatology and general medicine. The National Health and Morbidity Survey 2011 stated that 24.6% of known diabetics patients sought treatment from public hospital such as PH. Most patients can get free treatment including doctor consultations and medication. Malaysians who are over 60 years old, under schooling or working at any government department are entitled to free treatment at PH. For others patients they have to pay a very minimal fee of around RM1 for each registration and also RM1 for each prescription.

This hospital's administration and data storage system is run on an electronic system called Total Hospital Information System; this has added advantage to the patient recruitment process. The process was much easier and faster with this electronic system as it provided faster access to patients' medical profiles, which facilitate the recruitment of T2DM patients who have been prescribed any insulin product (see section 2.4.5 and 2.4.6).

PH has been classified by the Ministry of Health, Malaysia (MOHM) as a model hospital in the country. The other reasons to select PH as my study site was because it has a well-established Diabetes Resource Centre (DRC), which

caters for a large number of diabetes patients and also recently set up a Clinical Research Centre (CRC) in 2010 one of the first in Malaysia.

The Diabetes Resource Centre (DRC) was set up in September 2002 in line with MOHM initiatives to strengthen diabetes education and services. DRC provides counselling and support to diabetes patients especially those initiated on insulin treatment. Recruitment of patients participating in this study was conducted at DRC using their Total Hospital Information System; field activities at DRC are discussed in section 2.4.5. Clinical Research Centre (CRC) was established in 2010 and it was chosen as a Centre of Excellence. It aims to facilitate MOHM to achieve the goal set by the National Key Economic Area, which encourages industry-sponsored research. The other function of CRC is to facilitate and monitor research done in PH, either conducted by staff in PH, other health services or students from other institutions. An application to conduct this study at PH was submitted to CRC to gain local approval in early August 2011. The head of endocrinology, Dr Zanariah Hussien who also agreed to be the field supervisor and the hospital director, Dr Nora'I Binti Mohomad Said, approved this initial application; permission to conduct this proposed study at PH was granted at the end of August 2011. Second stage of the approval was subsequently sought from MOHM, which will be discussed in the next section.

2.4.4 Research and Ethics Committee approval

All research conducted at MOHM facilities in Malaysia must be registered with National Medical Research Registry (NMRR). It is a web-based service to support the implementation of the National Institute of Health (NIH) guideline on the conduct of research (<https://www.nmrr.gov.my>). NMRR streamlines all research application and submit relevant documents to respective authorities such as the Medical Research and Ethics Committee (MREC).

Application for this study was lodged at the end of August 2011 after gaining local approval from PH. The application was submitted with the study proposal which included a Patient Information Sheet, consent form, the interview guide and other relevant supporting documentation. The Patient Information Sheet and consent form were printed in both Bahasa Malaysia (the national language of Malaysia) and English language and are included in appendix one and two. The interview topic guide used is included in appendix three.

The application was first reviewed by the Institute for Health Behavioural Research (IHBR) under NIH, which acts as the gate keeper. The application was then reviewed by MREC and subsequently approved by NMRR on 23th December 2011. The approval letter was received in early January 2012 which was in time to start patient recruitment in February as planned (appendix four).

2.4.5 Study Process and Field Activities

Initial observations were conducted to familiarise myself with the outpatient diabetes clinic setting within PH. These included outpatient diabetes clinic working environment, events and people, work patterns, patients' appointment system, consultations, referral process, and all activities relating to operation of diabetes clinic.

At PH, different specialists run their outpatients clinic on a particular day of the week. Diabetes clinic is scheduled to run every Thursday within the endocrine clinic. Endocrinologists or medical doctors review T2DM patients at the endocrine outpatient clinic together with other Type 1 diabetes patients, and patients with hyper- or hypothyroidism, Cushing syndrome or any other endocrinology related diseases.

Patients with T2DM are given an appointment slot on this day for their regular check-up, medical review and refill of medication. T2DM patients are normally given a four monthly outpatient follow-up appointment. Patients with uncontrolled T2DM are given more frequent follow-up and might be referred to the Diabetes Resource Centre (DRC). The appointment list for Thursday diabetes clinic is usually managed by a staff nurse and usually finalised one week before the diabetes clinic day. T2DM patients who are referred to DRC will have a separate appointment list which is kept by the diabetes nurse in DRC.

Patients with an appointment on the day will register at the front hospital counter and then leave their appointment books for re-registering at the endocrine clinic counter. The staff nurses will then call up the patients for measurement of weight, blood pressure and waist circumference. Subsequently patients wait at the waiting area for a medical consultation. The waiting period can be up to a few hours and it gave me the opportunity to approach the pre-selected T2DM patients for interview (see section 2.4.5). After the medical consultation, patients may be referred to diabetes pharmacists or diabetes nurses for extra counselling. Otherwise patients may collect their medication from the outpatient pharmacy and leave the hospital.

Endocrinologists and the medical team usually start seeing patients from 8AM until 1 or 2PM. On average around 200 endocrine outpatients are seen in a day. Recruitment for this study involved filtering these patients and targeting T2DM patients who were currently using insulin treatment, the details of the recruitment is discussed in the next section below.

2.4.6 Recruitment of Participants

Purposive sampling technique (as described in section 2.2.5) was employed to select T2DM patients who were using any insulin treatment. Patients were selected with the purpose that they are likely to generate useful data for answering the research question.

Inclusion criteria for this study were:

- Malaysian male and female patients with Type 2 diabetes who are using insulin treatment to control T2DM,
- Aged over 18 years,
- Patients who initiated insulin treatment at diabetes clinic or other health facilities as a result of consultation between prescribers and patients,
- Patients with no known serious medical conditions, which may affect their experience of insulin initiation.

Patients with serious medical conditions such as having an emergency cardiac bypass surgery followed by the initiation of insulin treatment were excluded from this study. The reason being that the traumatic event from the immediate medical condition may greatly influence their experience of insulin initiation.

Exclusion criteria were:

- Patients who had gestation diabetes and had used insulin,
- Patients with mental health issues,
- Patients who started insulin treatment as an emergency procedure,
- Patients who have been residing overseas for a long period of time.

Patients were excluded based on the above criteria because they were often not given an option for their initiation of insulin treatment. Patients who have been residing overseas for a long period of time or their insulin treatment was initiated by overseas doctors were excluded. This group of patients may encounter different experiences from Malaysian patients because of the differences approach in healthcare systems and expectations.

Patients' medical information is stored electronically and accessible by using a computing system called Total Hospital Information System. I was assisted by the diabetes nurses at DRC to access patients' medical information. Based on the diabetes clinic appointment list which I usually obtained early in the week, I was able to screen through the appointment list and identify T2DM patients who were coming for the Thursday endocrine clinic. T2DM patients who were on insulin treatment were then identified and pre-selected for participating in the semi-structured interview.

2.4.7 Confidentiality

All participated patients were informed about the confidentiality arrangements. All field notes, transcriptions and recorded audiotapes were secured in a lockable cabinet at the researcher's office and will be stored thereafter for six years. All attempts were made to protect the identity of patients by the usage of pseudonyms, and places or persons mentioned in the interviews. This applied to all the interview transcripts, and any articles related to the interviewee. All the information which might lead to the linkage to the interviewee were disguised. However, some of these linkages remain such as their ethnicity as I felt that it is an important piece of information which could give the context more meaning and also enrich the data.

The location and name of the participating hospital (PH) is made anonymous, however this information is available to the MOHM and it might be used for auditing and reporting purpose. All participated patients were made aware that their interview transcripts would be used for publication and education purposes.

2.4.8 Qualitative Data Collection: Semi-structured Interviews

Semi-structured interviews were conducted for data collection. The participants in this study were mainly T2DM patients recruited from the diabetic clinic on a Thursday. A small proportion of participants were patients recruited from the DRC appointment list. As mentioned in section 2.4.6, pre-selected T2DM patients were approached after they left their appointment card to be re-registered at the endocrine clinic counter (see section 2.4.5). During the initial observations, I had noticed that all hospital personnel wore uniforms, including pharmacists and doctors who are required to wear a clinical lab coat. It might not be appropriate for the interviewer to wear uniform lab coat as this might mislead the participants into thinking that the interviews were a proper clinical consultation. As a result the interviews might not be as relaxing and the explorative nature be inhibited. In the first few interviews, I introduced myself as a pharmacist to the participating patients; I had noticed it was harder to build a good rapport with the patients and I was asked clinical questions by interviewee. I did not want the participants perceiving my role as such, as this could lead to interviewee giving responses he or she thinks a health professional wants (Britten 1995).

After fine-tuning my interview skills, I introduced myself as a PhD student from The University of Nottingham and explained briefly about the purpose of my research at PH. The patient information sheet was given to the patients to read. For those patients who agreed to take part in the interview, I then explained further about the study aims and at that point a consent form was given to them. I then explained to them about the confidentiality arrangements

and informed them that the interview would be audio-recorded. A signature on each of the consent forms was obtained from patients who agreed to participate. A copy of the consent form and patient information sheet was given to participating patients.

Before I started recording the interview, I would ease the interviewee into the interview by reassuring them that the interview questions were designed to explore their lived-experience, therefore there were no right and wrong answers. And also letting them know they could stop the audio-recording at any time if they felt uncomfortable. I had taken into account that it might take the interviewee some time to speak comfortably and freely in front of the audio-recorder; I often started with an open-ended question or simple question. As suggested by Britten, I minimised note taking activities during interviewing and retained more eye contact with interviewees which encourage them to talk more openly and comfortably (Britten 1995). After each interview, I would write down some field note to highlight the interesting points regarding the interview. The field notes were useful as a reminder regarding each of interviews conducted and were used to generate the topic guide and also were used to support data analysis (refer to section 2.4.9.2).

When I approached the participants, I used the English language to introduce myself. If the participants responded in Bahasa Malaysia, then I would start to converse in Bahasa Malaysia. I would use languages which the participants were comfortable converse in to build a good rapport. This was done before I actual carried out the interviews and I would spend around ten minutes to

introduce myself, my research project and explained to them how they could help. Majority of the interviews were conducted in English with a mixture of Bahasa Malaysia. Some Chinese participants were using terms or phrases in Cantonese and Mandarin during the interviews. Similarly, a few Indian participants used some Tamil terminologies during the interviews, which they had to translate into English. I have reflected on these language and cultural issues in section 8.2; it would be beneficial to conduct separate studies focusing on each ethnic groups in Malaysia and their perception of using insulin treatment.

2.4.8.1 Transcribing and Translating of Interview Data

Majority of the interviews were conducted in English language with Malaysian accents and slang. When transcribing these interviews, I had made some adjustments to the sentence structure and translations. For interviews conducted in English language with minor translations, the translated terminologies were transcribed into English with parentheses. For example:

ZA: I would think insulin when teruk (terrible), I mean [when] the diabetes is very, very bad then [only] you should take insulin.

“Teruk” in Bahasa Malaysia means bad, or terrible; the translated meaning was put in parenthesis. Malaysian English has a unique local style, often the past tense was replaced with the use of ‘already’ which signified that an action has been taken or done; or very often relative pronouns are skipped in a sentence. Square brackets were used in these situations to give a better meaning of the transcription.

Six interviews were conducted in Bahasa Malaysia and these interview transcriptions were translated into the English language. The initial translated transcription would have the English version next to the sentence for cross checking (see example below). The English version was then imported into Nvivo® software for analysis process.

AM: Tak teruk la dan dia kasi makan pills sahaja. (Not in critical stage, he just gave me the pills)

2.4.8.2 Interview Topic Guide

Although the interview was semi-structured with guiding questions (see appendix three), the interview itself was conducted in a conversation like manner to encourage patients to open up and express more freely about their lived experience and also to build rapport. The interview topic guide for this study was developed to provide a direction to explore patients' lived-experiences of using insulin treatment as part of their diabetes management. The topics guide was a set of key issues, themes and possible probes; it contained questions in which I was interested and intended to cover during the interview. The topics of interest were formulated as: experience of being diagnosed with diabetes; experience of using insulin treatment; influences of these experiences; perspective of insulin treatment overtime. The initial questions covered in the topic guide were developed based on my own experience with diabetes patients. They were questions I was interested to learn from T2DM patients, especially about how they experienced their diagnosis, their story of being introduced to insulin treatment and how they managed insulin injections. When developing these questions, I had kept in mind of my original research questions which are:

- *What is your experience of using insulin to control diabetes?*
- *What influences these experiences?*
- *How do your perspectives of insulin treatment change overtime?*

Often questions were asked in a different way from the interview topic guide, sometime questions were asked but were not specifically in the interview topic guide. This was to encourage patients to talk about their experiences and express their perspectives in their own words. Questions were asked at points that flowed from what patients said, generally to clarify or explore the responses given, rather than sticking rigidly to the order in the guide. Guiding questions were useful when patients got side-tracked and ramble or became repetitive. As Ritchie and Lewis warned:

Every interview situation is unique, and every interview a step into unknown territory. What is important is to be alert to changes in the dynamic of the interview and in the participant's demeanour, to ponder what might be bringing about this change, and to shape the response accordingly (Ritchie & Lewis 2003).

2.4.8.3 Interview Venue

Semi-structured interviews generally last for a considerable amount of time compared to structured questionnaires (Smith & Osborn 2008). Sometimes the interview can become intense and involved, therefore choosing the venue for the interview must take into account of such situations.

This study was approved by the PH and bounded by the term set by the Ethics Committee of the Ministry of Health Malaysia, that is all interviews must be carried out within the hospital compound. After the initial observations at the studied site, I identified a few potential areas for conducting interviews. These included the waiting area at diabetes clinic and the diabetes resource centre (DRC), which had sofas and counselling desks. The waiting area at the diabetes clinic has a corner with chairs but it can be noisy and sometimes during the peak hours other patients might occupy the seats nearby. It might hinder patients' freedom of speech when their privacy is compromised. However the area was an open-planned floor, the interviews itself would not feel like a consultation and patients could relax and feel more at ease and comfortable during the interview. In contrast, the diabetic resource centre was just around the corner from the waiting area, had a coffee table and sofas; it looked comfortable. However the diabetic educator and nurses were often in the room. Occasionally I used the desk for interviewing patients, which felt like a counselling session.

The participants for this study were approached at the diabetes clinic waiting area, after I introduced myself and explaining the purpose of this study, they

were requested to be interviewed either at the corner of the waiting area or to go to the diabetic resource centre.

2.4.9 Qualitative Data Analysis

This study used semi-structured interviews to collect data from patients with T2DM. Interviews were recorded and transcribed verbatim. Transcripts from interviews are the raw data which are descriptive record of the research, but they cannot provide explanations without analysing the data (Pope et al. 2000). The researcher has to make sense of the data by closely examining and interpreting them. The process for data analysis used thematic analysis approach. The following table (see Table 3) summarises the steps involved in thematic analysis which I adapted for the data analysis in this study (Ziebland & McPherson 2006; Burnard et al. 2008; Brikci & Green 2007; Braun & Clarke 2006)

The steps involved for data analysis are described in stages (refer Table 3). However, in practice they are not independent processes but cyclic in nature. It is important to execute the principle of constant comparison in this study. Therefore, both data collection and analysis processes were cyclic in nature, iterative process and not a linear process (Miles & Huberman 1984). The data analysis is discussed as a linear step for the purpose of this report.

Table 3 Steps of thematic analysis

Phase	Description of the process
Familiarising with collected data	Transcribing data, reading and re-reading the data, immersing oneself in the data, start thinking of the themes.
Generating initial codes (open codes)	Noting down ideas (codes) to summarise what is being said in each of the transcripts.
Searching for themes	Collecting together all of the initial codes from all of the interviews and collates codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes (Constant comparison)	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic 'map' of the analysis.
Defining and naming themes	On going analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

2.4.9.1 Computer Software for Data Analysis

During data analysis process, coding technique was used. Coding can be done manually which involve the use of coloured pens or highlighters, scissors and glue to literally cut and paste sections of text onto cards or piece of poster that could later be examined together in a bigger picture (Ziebland & McPherson 2006). In this study, both manual cut and paste as well as a computer-assisted qualitative data analysis (CAQDA) software Nvivo® software were used.

Nvivo® software is a sophisticated software tool to store and manage the data, however it does not provide analysing function. It facilitates accurate and transparent data analysis process whilst also providing a quick and simple way of counting who said what and when (Welsh 2002). It can display and assist in categorising themes and making links between sections of the data for easy retrieval later. Thus software package such as Nvivo® software enables the researcher to look across all the data easily and effectively to label codes and identify themes. Especially during the thematic analysis process, the transcript is read and re-read several times and sections of the text are highlighted under different headings, which might be merged or subdivided or changed through the analysis process.

2.4.9.2 Familiarisation with Data

The first step of analysing using thematic analysis is to get familiar with the collected data and start thinking about the data collected (Braun & Clarke 2006; Ziebland & McPherson 2006). After transcribing the interview data, I checked through the transcripts together with the audio files. At this stage, the field notes were used to further conceptualise the conversation. It is crucial to get familiar and immerse oneself into all aspects of the collected data so that the researcher can get familiar with the depth and breadth of the content. The process of familiarisation with the data is to build a strong foundation of structure for data analysis later (Ritchie & Lewis 2003). If this foundation is weak or incomplete, it could jeopardise the integrity of the research.

The method to get familiar and immerse oneself into the collected data involved 'repeated reading' of the data and searching for meanings and patterns. Due to the intense repeated reading process, qualitative research tends to use smaller samples compared to quantitative research as it can potentially generate huge amount of data (Braun & Clarke 2006). After reading the transcripts a few times, I made a preliminary observation of my data and started to develop a few general ideas which were noted down to be used in the following analysis process: coding. It is an important step to get familiarised with the first few transcripts first to generate an overall feel of the data.

2.4.9.3 Initial Coding

Before any theme is identified, a coding technique is used to mark and identify themes and subsequently applied or linked to the collected interview data, as a way of organising data into manageable units and as summary markers for later analysis (Guest et al. 1971). After re-reading a transcript a few times, I noted down short phrases (initial codes) that sum up what was being said in that transcript. The aim of initial coding is to offer a summary statement or word for each element that is discussed in the transcript (Burnard et al. 2008). They refer to the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon (Braun & Clarke 2006).

After re-reading the first few transcripts and reviewing the range and depth of the data, I generated a list of initial codes to categorise or index the data. Some researchers note down such concepts as they emerge during reading or listening to a piece of paper (Ziebland & McPherson 2006; Ritchie & Lewis 2003). I used similar method but creating nodes (codes) in Nvivo® software during the reading or listening of the transcripts. Table 4 is an example of the initial coding framework used in the data generated from one of the interview:

Table 4 An example of an initial coding framework

Interview transcript	Initial coding framework
BK: At where I stay, the clinic there provides health-checking service like for diabetes; I regular go there for checking. During one time, the doctor said my blood sugar is high, but it is ok.	Diagnosis

I created several codes to organising the data into meaningful groups such as diagnosis, symptoms, diabetes complication, initial oral treatment, healthcare services and other descriptions of the transcripts data. These are referred as initial coding or open coding which describes the raw data and provides a summary statement for each element that is discussed in the transcripts but they are not the units of analysis or the themes yet (Braun & Clarke 2006; Burnard et al. 2008). Themes are often broader and are only developed in the following steps (see next section 2.4.9.4) where the interpretative analysis of the data occurred, and in relation to which theories about the phenomenon being examined are made (Braun & Clarke 2006).

2.4.9.4 Searching for Themes

Next step in data analysing started after all the raw data were initially coded and collated. I have now created a long list of the different nodes or codes that were identified across all the transcripts. This is followed by the next step, that is to sort the different nodes into potential themes, and collating all the relevant coded data extracts within the identified themes (Braun & Clarke 2006). Essentially, it is a process to re-focus the created codes at the broader level and consider how different codes may combine to form an overarching theme.

Some researchers use tables, or mind-maps, or write a name for each code with a brief description to create a thematic map to search for the overarching theme (Braun & Clarke 2006). I adapted the 'one sheet of paper' (OSOP) method as described by Ziebland and McPherson to search for potential themes. Nvivo® software allows exporting the list of initial codes together with the coded section of the transcripts. Using the printout, I switched to manual method: cut and paste on a sheet of paper. OSOP involves reading through each section of data in turn and noting on a single sheet of paper all the different issues raised by the coded extracts (Ziebland & McPherson 2006). From 'one sheet of paper' (OSOP) it was easy to observe that some potential themes were not really themes as there were not enough data from transcripts to support them.

Using the OSOP method, I have developed a set of overarching themes, and then I created them as new nodes in Nvivo® software to categorise the initial codes. Example of the categories are shown below:

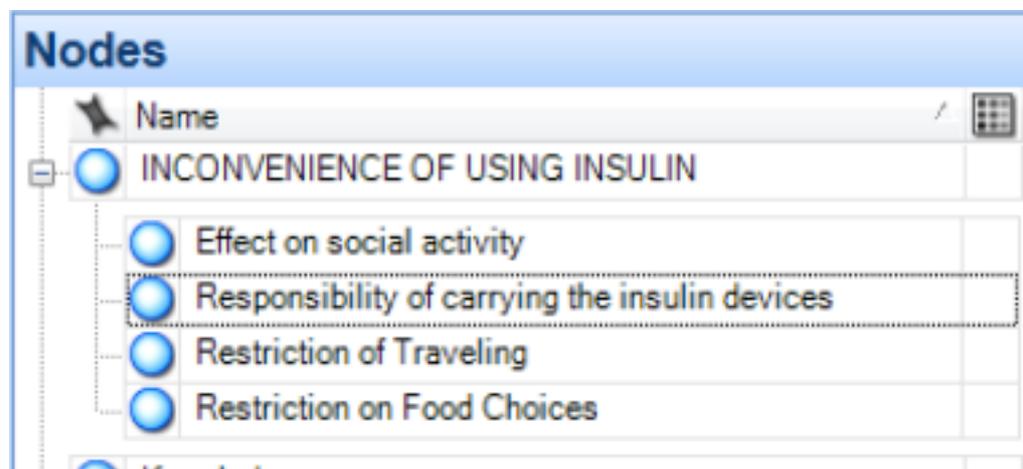
- Positive effect of insulin
- Side effect of insulin
- Peer influence on diet
- Availability of healthy food
- Restriction on travelling
- Effect on social activities
- Restriction on food choices

2.4.9.5 Reviewing Themes

After I started to develop a set of overarching themes, at this point it is important to review and refine these themes. During this step, I also merged two apparently separate themes to form one overall theme and some themes were split into separate themes. Data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes (Braun & Clarke 2006). There were constant reflections throughout this process as well as discussion with supervisors to enrich the analysis. Discussing the findings with colleagues from another disciplinary background can provide new insights and interpretations (Ziebland & McPherson 2006). During this analysis process, themes were reported and discussions with the endocrinologist at the data collection site.

These potential themes were then created in Nvivo® software and linked to all previously created nodes (codes). A screenshot of an overarching theme created for this study is displayed as follow:

Figure 5 Screenshot of Nvivo® software showing a theme and the nodes associated to it.



Nvivo® software not only stores qualitative data for easy referencing but also efficient in retrieving the transcripts data. The newly created themes linked across the transcripts and encoded the part of the transcripts that converse to that particular theme. It is an essential function in Nvivo® software, which facilitated constant comparison between themes and also between transcripts. The next step was to define and name the themes and this process was easily managed in Nvivo® software.

2.4.9.6 Defining and Naming Themes

At this step, researcher is required to define and further refine the themes and analyse the data within them (Braun & Clarke 2006). The identified themes should capture the 'essence' of what each theme is about, it needs to fit overall 'story'. I have identified the overarching themes and linked them to the individual 'stories' told by the participants. In Nvivo® software, I can easily retrieve the identified themes and the individual stories that linked to that particular theme. Then I refined and renamed these themes to create a stronger connection to the stories being told and capture the essence from the stories.

During the process of refining and renaming of themes, reviewing literature was again being carried out. Ziebland and McPherson suggested going back to the literature as the most common method to seek depth in qualitative data analysis (Ziebland & McPherson 2006). Apart from the constant reflection, this analysis process is also enriched by going back to the literature to explore how other theoretical literature fitted and how it could further support the analysis.

2.4.9.7 Producing the Report

Quantitative studies are often designed to answer one or more main research questions; in contrast qualitative interview studies explore the experiences and meanings (Ziebland & McPherson 2006). The resulting data are rich and have the potential for many different analyses. It is necessary to identify the story that can be told with the qualitative data to produce new and useful theories.

It is important that the analysis, and the resulting report, provides a concise, coherent, logical, non-repetitive and interesting account of the story the data describe (Braun & Clarke 2006). During the study, findings were constantly discussed with supervisors. Interesting and potentially useful theories were presented and discussed in this report.

The findings are presented in the order of patients' lived-experience of using insulin treatment to manage their T2DM. This report begins with exploring participants' reactions to T2DM diagnosis, and then followed by their reactions to initiation of insulin treatment, and lastly looking at how the participants coping insulin injection in their day-to-day life.

2.5 Chapter Summary

In CHAPTER 2, a detailed description of the methodology and methods used in this study has been discussed. The following chapters will present the findings of this study. Demographic information of the interviewees is presented in appendix 5.

CHAPTER 3

REACTION TO DIAGNOSIS

3.1 Introduction

This aim of this chapter is to discuss the analysis of the data from the interviews that concerns these thirty-seven patients' perspectives on reaction to the diagnosis and initiation of insulin treatment. Key points are summarised in the final section of the chapter.

3.2 Information-Knowledge of Diabetes

At the beginning of the interview, patients were asked about their experience during diagnosis with T2DM and how much they knew about the diseases. And how they perceive T2DM. From the discussion with the patients during interview about their knowledge prior to diagnosis, most patients had little knowledge of diabetes diseases. The average patients were diagnosed with T2DM 13.5 years ago; they had been given limited information about their condition. Internet and computers were not readily available as SA explained below. Patients obtained their limited knowledge of T2DM mainly from friends or family such as KK explained how the ‘old people’ referred diabetes as a disease with sugar in the urine.

SA: So at that time, when the doctor told me I got diabetes, I did a lot of research: what is diabetes? You don't know what is Diabetes at that age, a disease called diabetes. And those days, you don't have Internet you can look up thing quite easily.

CH: Very little at that time. At that time very [little knowledge]... I know that it is the diabetes, but I am not really sure what is the actual diabetes, the disease and all these... It is something like you don't know more... how to say it... we don't understand actually how is this diabetes ... and how it affects our future and all these.

KK: Just that, sugar in the urine, that was what the old people used to say. I don't have a very clear idea of it.

Patients such as SA explained that when he was diagnosed with T2DM, he had no knowledge of the diabetes. With no Internet at the time, he went the extra mile to read up about information of diabetes.

Most patients had limited knowledge of T2DM when they were diagnosed, especially in the 90's when prevalence of T2DM started to increase at an alarming rate. In 1986, the prevalence of T2DM In Malaysia was reported at 6.3%; ten years later this figure had increased by one third to 8.3% (Letchuman et al. 2010). This dramatic rise spurred the initiation of numerous national healthy lifestyle campaigns by the Ministry of Health Malaysia. As a result, the ministry has set up a national committee to improve the screening and management of diabetes in primary and secondary care clinics. Non-government organisation Malaysian Endocrine and Metabolic Society (MEMS), National Diabetes Institute (NADI) were also set up and focusing on screening, counselling and educate public, and also running exhibitions targeting to raise awareness of T2DM. With this greater attention paid to diabetes education, it has created more awareness of T2DM and better accessibility to diabetes screening and detection. However, a number of participants in this study concerned that these diabetes campaigns were only seen in urban areas and sometimes confined to health facilities only.

LM: I would say that the younger generation should be aware of and take care... But people should be aware and help them what I

would say. More awareness... more talk, to the rural area, not to town area... To the uneducated.

LT: All because of lack of awareness... The only awareness is only [seen] in hospitals. So it is not out there. Is not out there, it is not. Heart attack is out there, cancer is out there... But you can put your advertisement on midnight... but this is an awareness needed. ... Because this is not a problem in hospital. You can promote in hundred of hospitals, but you will get the same thing.

Overall, the level of awareness and knowledge of T2DM among Malaysians remains low and there is a greater need to improve the design of T2DM educational campaign as supported by the findings of other recent studies (Yun et al. 2007; Al-Qazaz et al. 2011; Tan 2004; Rampal et al. 2010; Ali 2009). As the participants suggested, these diabetes campaigns should be spread to a wider community especially in rural areas and also promoted in the media to a wider audience. The focus should be targeted at younger Malaysians in raising the awareness of healthy lifestyle and diabetes preventative measure.

Rampal and et al reported that less than 4 out of 10 diabetics are aware of their problem and seek treatment (Rampal et al. 2010). Yun et al revealed up to 85% of diabetes patients have good to very good degree of knowledge of the diseases; whereas only 55.8% of the healthy population has the same degree of knowledge (Yun et al. 2007). It highlighted that in general, the Malaysian public does not have the adequate knowledge of diabetes and its preventative measures such as healthy lifestyle. Because of the unhealthy lifestyle which

has led to an increase in obesity rates, Malaysians are at greater risk of developing T2DM (Pank 2012). Awareness and education about healthy lifestyle among the Malaysians, particularly the younger population who are at risk, needs urgent attention.

Yun's suggestion to design two separate education programs: a prevention program which targeted healthy individuals at risk, and diabetic's program for secondary and tertiary prevention for patients with diabetes (Yun et al. 2007). It is important to design a separate educational campaign from those focusing on diabetes patients. This would aim at improving the health literacy of the general public; in particular knowledge and awareness on healthy lifestyle, which includes information about risk factors of diabetes, diet, exercise, and screening. This can be promoted at many levels, including schools, work places, and community events across the country. Printed materials such as posters were criticised by participants in this study, as they "do not speak to people" and therefore do not have much impact and get the message across especially to those with a lower education level. Campaign activities should be interactive and involve the target audience. In addition, education campaigns need to be well structured to address the population who live in the rural and remotes of Malaysia. It should be tailored to meet the culture needs and lifestyle, and delivered through series of talks or screening activities at community halls, clinics and religious venues.

3.3 Health Screening and Diagnosis

Participants in this study appeared to have an adequate knowledge and awareness of diabetes symptoms. Some of the participants took immediate action to seek medical attention when they experienced the signs and symptoms. The other participants were diagnosed during diabetes screening services either provided by the public hospital or privately. As reported by many participants, the availability of diabetes screening at various healthcare facilities provided an approachable channel for self-diagnoses.

AM: There was this... blood screening here, at the diabetes center. They offer people to check their blood. After checking, he said my blood sugar level reached 13 and then he asked me to come back here for two to three times more to follow-up.

ZZ: I did a test, a random test in a [private hospital], they had this diabetes week. It's just a campaign. I realised that my sugar was very high.

BK: At where I stay, the clinic there provides health-checking service like for diabetes; I regular go there for checking. During one time, the doctor said my sugar is raised, but it was ok. So after a long while, there isn't any symptom. But in 2004, my sugar level is over the borderline.

With the greater awareness and easy accessibility to public health services, many participants attended their medical check up at a public health clinic or hospital, and therefore were diagnosed with T2DM in the public system. Participants such as MY attended a public health clinic for a body check-up and was diagnosed with T2DM and high blood pressure; MJ on the other hand was diagnosed with hypertension and attended the regular follow up at which he subsequently discovered that he is also diabetic.

*MY: Went for check-up. Clinic at a [government health clinic] ...
Just went [for check-up] since our age 50 over... time for check-up.
So we check-up, we found out I am diabetes then high blood
pressure, all these things.*

*MJ: During the blood test. I was having the hypertension at first...
For every four months, I got to take the blood test. From the blood
test, they discovered that my blood sugar is high.*

Apart from the diabetes screening service provided by the public health system, some privately owned companies also provide annual health check-ups and have been shown to encourage employees to discuss their health issues with the healthcare provider. Two of the participants were diagnosed with T2DM through their companies' routine body check up.

SR: When I was working there, they will have a periodic check... So that makes me to go to see the doctor to get consultation.

SA: That time I was with a company called [private company]. A company doctor, a panel doctor said that I have diabetes. But we didn't believe it, so he said come back in two or three days, and then [confirmed] it is diabetes.

In general participants were satisfied with the healthcare service and the support that they received from either a private hospital or the public health system. However, none of the participants mentioned the health screening and diagnostic services provided by the pharmacy sector. This could be due to the lack of recognition of the role of pharmacists by the Malaysian public; and also the lack of confidence, time and funding for the pharmacists to run such activities as reported in a number of studies (Hassali et al. 2009; Eades et al. 2011; Sarriff et al. 2010).

An exploratory study to ascertain the public's awareness of Malaysian community pharmacy and pharmacists was conducted in 1997, it was reported that Malaysian public has a very low knowledge of the community pharmacists and their role (Hashim et al. 2001). Hashim et al reported that less than 12% of respondents will choose to go to community pharmacy for screening purposes and less than 50% will ask community pharmacists for advice on medication. This could be due to the lack of recognition of the pharmacist role and lack of confidence in community pharmacists. It was reported in Malaysia that the

community pharmacists showed a lower perception of the importance of and competence for the current pharmacy practice activities including public health promotion compared to the pharmacists in the hospital setting (Sarriff et al. 2010). There are also insufficient supporting materials and training for community pharmacists for providing health promotion activities. In addition, there is no standard guidelines for offering health education and insufficient management support which has hindered community pharmacists from involving themselves in health promotion activities (Hassali et al. 2009).

Community pharmacists are keen to expand their role as public healthcare provider and become involved in health promotion activities. Sarriff et al also concluded that the majority of general medical practitioners in Malaysia are in favour of community pharmacists' involvement in providing public health activities (Sarriff et al. 2012). With increasing attention in the mass media on the issue of dispensing separation and the role of the community pharmacists, the public's perception towards the pharmacists has since improved.

3.4 Reaction to Diagnosis and Link to Family History

At the beginning of the interview, patients were asked what was their reaction when doctors diagnosed them with T2DM. Patients with close family members who were also diagnosed with T2DM did not have such a big reaction to the news as compared to the others. As indicated by Al-Qazaz's study on perception of diabetes among T2DM patients in Malaysia, genetic factors or family history were perceived as the main cause of T2DM by the participants (Al-Qazaz et al. 2011). This group of patients expected to have T2DM at some point of their life, therefore their reactions to the diagnosis were somewhat expected. In fact, family history is one of the prompts to encourage participants to seek medical attention when they experienced the signs and symptoms of diabetes.

YP also expected to have T2DM because of his family history; therefore he did not react emotionally to the news:

YP: Because it's genetic... No reaction because I expected it. Because we know that it is genetic, it is Type 2 thing and it will come. The chance of getting it is about 90%. It is nothing to be a shocked.

YP represents an example of preparedness for diagnosis connected to an absence of negative emotion. However, he was not alone in this respect. Participants HT and AZ also have similar expression:

HT: My reaction was.... was normal because my family is diabetic, [and] my mother, [and] my mother's father.

AZ: I didn't, I didn't think of anything because my dad was diabetes.

ZZ was diagnosed during a random blood glucose test at a diabetes campaign. He was surprised to find out that he has T2DM but was not unexpected because his father is diabetic.

ZZ: Of course I was surprised also but it wasn't really unexpected. I think the family there was a history. My father he is a diabetic patient and also that I know I was a little bit of overweight. I presumed that it contributes a lot to it.

LV is 35 year old Indian lady with a strong family history of T2DM, both LV's parents and one of her aunty are diabetic. When she was diagnosed with T2DM at the age of 33, she reacted differently:

INTERVIEWER: So, when they tell you that you have diabetes, what was your reaction?

LV: I said, "ha? Ai-yah!" you know... Yeah, genetic.

LR had a very strong diabetes background, she explained that she is a ‘carrier’ for the gene and therefore during the interview, she had no strong reaction towards the diagnosis process:

LR: I didn't take any junk food or soft drinks or whatever and I don't have that kind of habit of drinking soft drinks. But I think my father, my mother, my grandmother, both side my grandparents; have a very strong gene for diabetic, I am the eldest of the family and I was the carrier...

In both LV and LR’s response to the diagnosis, there was no strong emotional reaction to the bad news. However, there was an attendant sense that they felt ‘unfairness’. LV said she felt “unlucky” and she expressed it in a local slang “Ai-yah”, it is a common expression in response to unlucky event. LR emphasised in the interview that she was trying to stay healthy by refraining from junk food and bad eating habits, but in the end she was still diagnosed with T2DM. She felt that being the ‘eldest of the family’ would have to carry the ‘gene’. It is common in South Asian culture that eldest female sibling carries extra responsibility (Waxler-Morrison et al. 1990).

In contrast, patients without a family history of diabetes received the news differently and mostly reacted in shock and were unable to accept the news. For example, ET did not know much about diabetes and with no family history; when he was diagnosed with T2DM, he was very upset and worried because he thought that T2DM is a serious disease. LT got a shock when receiving the news, and he was worried how to cope with living with diabetes.

ET: Upset and very worry. I lost a little bit of weight too.

LT: Got a shock, I mean nobody will want it, that is the only thing.

Then [I started] thinking of how to go on with my life.

From the interview, it is found that participants who have family member living with T2DM reacted less emotionally when diagnosed with T2DM. Peel et al described this as ‘suspected diabetes’ route to diagnosis, this sense of preparedness was evident in the emotional reactions described experiencing when their diagnosis was given (Peel et al. 2004). With prior awareness of T2DM, these participants group emphasised that they had not experienced ‘shock’ when diagnosed. In contrast, participants without any prior awareness of T2DM was emotionally affected by the receipt of bad news as they often expressed in ‘shock’ and upset by the news.

Prior awareness of T2DM and family history has an impact on patients’ emotional reactions at the time of their diagnosis. This finding coincides with Peel et al finding as the commonly cited ‘shock’ reaction to diagnosis does not feature prominently in T2DM.

3.5 Chapter Summary

The average period patients were diagnosed with T2DM is 13.6 years; information technology was not as advance and accessible as today. Patients were less aware of T2DM and its complications except those who have had family members who also diagnosed with T2DM. Patients with family history have neutral reaction when diagnosed with T2DM, they were 'expecting' it at some point of their life and were not surprised.

However, the other group of patients without a family history were shocked and mostly sad when diagnosed with the disease. Some participants felt that it was 'unfair' and that they were unlucky to 'get' diabetes. When they learned more about T2DM being a chronic illness and with no cure, they felt worried and 'hopeless'. They understand that they won't be able to cure the disease and for life will have to live with diabetes. Delivering the 'bad' news to patients is challenging and needed to be handled with patience and care, patients' emotional reactions to the news can be complex and diverse. At the same time, health care providers need to provide sufficient information at the point of diagnosis. Therefore, simple but detailed and specific information forms an important part of initial counselling for patients newly diagnosed with T2DM.

CHAPTER 4

FACILITATORS TO INSULIN INITIATION

4.1 Introduction

During the interview, one of the objectives was to explore patients' reactions toward initiation of insulin treatment. Patients were asked to describe their reactions and thoughts when their doctors suggested adding an insulin injection to their diabetes treatments. In the following sections, I will be discussing the facilitators toward initiating insulin treatment, which were expressed by participants in the interview. The barriers toward insulin treatment will be discussed in the next chapter (see CHAPTER 5).

During the interviews, participants were asked about their reaction about initiation of insulin treatment, one prominent theme is the association with prior experience or prior exposure to insulin injection and the acceptability of insulin treatment. This phenomenon of preparedness is also seen during diagnosis, when participants who have family history of T2DM often have less emotional reaction to the news.

The second facilitator discussed in this chapter is the patients' health beliefs especially about the mechanism of action and side effect profiles of both oral anti-diabetic medication (OAM) and insulin. The third facilitator that encourages participants to take up insulin treatment is to have T2DM under

control. The motivators that prompt the participants to control their blood glucose level are to prevent diabetes complications and thinking about the future with a better quality of life.

4.2 Prior Exposure to Insulin Injection

Similar to the reactions reported by participants who have family history of T2DM, participants who have close family members using insulin injection have more awareness of insulin; they did not have such a large reaction towards the suggestion of using insulin. In fact it was more acceptable for them to make the transition from oral therapy to insulin treatment when suggested by their healthcare providers. AZ, HH and SL reported that because of their prior exposure to insulin injection, they felt it's just a 'normal' treatment that is no different from taking tablet and they were not feeling 'strange' about insulin.

*AZ: I said insulin was ok because my dad is diabetic. I was injecting him while he was sick. So, is like a **normal** thing for me... I don't have any fear [towards injecting insulin].*

*HH: I think I am the same. Before I started using insulin, I saw my parent using insulin; so when it is my turn, I don't feel any big reaction. Because I was prescribed the same thing. Same as what my parent used to use, so I **don't feel strange** to insulin.*

SL: Yup, my mother. My mother got diabetes. We used to [inject insulin] for her...I got the experience, so I not scared...So, I know how to use...I am ok because I know what is insulin, how to put in insulin because my mother is on insulin.

One participant, YP, requested to be on insulin treatment because a few of his close family members are on insulin treatment. As a result, he could see the positive effects of insulin treatment and that it facilitates improved glycaemic control:

YP: No fear, no fear, because I requested for it. Because I mean, you see I come from a family of diabetics, from both side of them, father side and mother side. So, we have a lot of experience with those older than us. It is nothing for me to be shocked about or even insulin, I was the one who actually requested for it.

Participants who have had prior exposure to insulin treatment were very positive towards adding insulin to their T2DM management. Participants usually encountered insulin treatment because of close family members with T2DM who were using insulin. As a result these participants had a better awareness of the positive effect of insulin treatment and also the side effects involved. Because they have been exposed to insulin devices, they are more familiar with the modern insulin pen devices and also the techniques required. This prior experience of insulin treatment has eased them into taking up insulin treatment as compared to those who have less awareness of the insulin devices. In a recently study conducted in Malaysia, participants agreed to initiation of insulin through learning about benefits of insulin from other people's experience. They affirmed that their acceptance became stronger as they personally experienced the benefits of insulin in terms of improved general health, well-being (Abu Hassan et al. 2013). These findings were supported by overseas research conducted by Hunt (Hunt et al. 1997). They showed that

previous personal experience, observations and interactions with others influence people's attitudes towards insulin, they concluded that T2DM patients are involved in an active process of assessing the expected benefits and costs of using insulin based on what they have seen and felt, as well as what they have heard from friends, family, and health professional.

Prior exposure to insulin injection is a facilitator in my study to encourage insulin initiation, participants who had the opportunity to observe others using insulin appeared to manage T2DM accepting insulin with ease and this experience also helps them to alleviate their negative concerns and misconceptions about insulin injections. Support from relatives and friends who used insulin also promoted their insulin acceptance. PG's willingness to initiate insulin treatment was a result of support from patients who used insulin:

PG: I wanted to go on insulin. I heard from other people that insulin would be a good solution for my problem and it actually turn out quite well. After trying it for the first three, four months I found [that] it's very good, the insulin is very good. Overall sugar comes down very fast.

In addition, many participants also expressed their willingness to promote insulin treatment to others T2DM patients who are not able to control their blood sugar level. Four participants from the interviews were willing to use their own experience of using insulin treatment to encourage other T2DM to

use insulin for a better glycaemic control. BK and YF explained the positive effect of insulin treatment and used their own personal experience to promote and support their friends and family into accepting insulin treatment:

BK: The advantage of using insulin, they [can] see it from me. This is something obvious, so all my sisters now are on insulin injection.

YF: I am insulin user so you can take my advice. If I am not using insulin but I am telling you the good thing about insulin, then you can the doubt about my story.

Experiential learning through observing T2DM patients coping well with insulin treatment and having positive effect of insulin can help other diabetes patients to alleviate their negative attitudes and misconceptions about insulin. Apart from the support and counselling by the healthcare providers, support from relatives and friends who use insulin also plays an important role in promoting insulin acceptance among T2DM patients.

4.3 Side Effect Profile

In the interviews, many participants talked about the side effects of ‘western’ medicines. In general Malaysian patients have the notion that ‘Western’ medicines can harm the body because they are synthetic and made from chemical substances (Jose et al. 2011; Babar et al. 2012). In this study, one of the facilitators for insulin acceptance is that many participants worried about the side effect of oral anti-diabetic medication (OAM). They think that oral tablets would cause undesired effect to the body organs if they take them for a long period of time. Especially medication for chronic illnesses that patients have to take on a long-term basis, they are said to ‘weaken’ the body system (Ariff & Beng 2006):

SR: [Oral] medication I came to know that there are a lot of side effects. So, I think insulin is much better compared to [oral]... So when I came in to see the doctor, they [also advised me that] the medication doesn't help for long term, it got side effects and all that. When I heard that, I decided to take up insulin.

YF: Yes, I have asked around. I have considered that taking all the medication is not good for my body so I had been thinking of using injection.

This negative perception of ‘western’ medicine was also reported by diabetes patients in a study conducted in Taiwan (Lai et al. 2005) as well as in western

countries. A meta-ethnographic study among English speaking countries highlighted that non-adherence to medication could be due to negative concerns of the potential harm from taking medicines on a long-term basis (Pound et al. 2005). This notion that western medication for chronic diseases would cause organ damage is universal rather than culturally specific. In my interviews, participants showed worries taking oral tablets because they believed that oral medication could cause undesired effects to body organs such as liver, kidney and pancreas:

*ET: Insulin is better. Actually with tablets I don't think it is good. It will **affect our liver, affect our body organs...** With modern medicine nowadays, it will affect your body parts; I know that most of the medicine will.*

*LV: Because tablet I heard it will it **can spoil your pancreas**, I heard but not sure if it is true [or not].*

*WM: if I were taking the medicine... the pills, I was more worried then! So much of this pills then the cholesterol pill and then they wanted to put me on high blood pressure pill, but I told them I didn't want to add that one on. Because I saw all these things that will **damage my kidney**, I was more worried about the pills.*

With the notion that oral medication could ‘deposit’ in the body organs causing unwanted side effect, most of patients find that insulin is more straightforward and therefore it is more acceptable to initiate insulin treatment. Participants not only worried that oral medication could ‘deposit’ in the body and cause organs failure, they also fed up with taking too many oral medications throughout the day:

HH: I think if insulin is prescribed earlier to me, then I would end up with less medication to take. If I have started insulin first then I don't have to take so many medication

BK: Insulin is better compared to tablet, do you know why? Because with insulin, I only have to inject it in the morning, and then once at nighttime. But with pills, I have [taken] the diabetes pills a few times a day and I already on so many other pills for my heart and others problems. I counted I need like 10 medication! Sometimes I am felt very angry because I have so many tablets to take.

LT: You see, everyday I have to take 17 tablets! I need to count this number... morning one session, afternoon one session then night one session. So nevertheless it is crazy, because I also have hypertension. So everything all add up about 17 to 20 tablets per day. My box is almost full, cannot fit anymore already. I was thinking that I might as well go for insulin.

NA: I feel it is better to use insulin than tablet. I was taking too many types of tablets. I have tablets for cholesterol and high blood pressure. So, I am taking many tablets... Maybe the tablets ... have effect on stomach, uncomfortable.

T2DM often presented in patients with multiple health conditions such as hypertension and dyslipidaemia. Hypertension is a common comorbidity of diabetes and the prevalence of hypertension is reported near 80% among diabetes patients in Malaysia (Ministry of Health Malaysia 2009; Blonde 2005). Because the notion that oral medication will go through the body systems therefore causing harm to the organs, taking multiple medications will furthermore multiply their fears of taking medication. As a result, many participants in this study preferred to use injection as they think that injection 'goes directly' into their body system. Participants believed that insulin is injected directly into the blood stream and exerts its effect by lowering the blood sugar. Therefore insulin injection would not 'go through' or 'deposit' in other body organs, as a result it is perceived to have has fewer side effects compared to oral medication and it could 'preserve' kidneys and other vital organs.

*MM: Because for long run of taking tablet, got side effects. But with this insulin, it goes direct... For long run, [oral tablet can cause] side effect. Because this insulin, **it goes direct**, so it doesn't [go around your body organ].*

*RK: Because the tablet doesn't work. So they want to use the insulin to fast into the blood stream and control [diabetes]. Tablets, I think will take certain hours to go inside the blood stream, **insulin goes straight into your blood**. Once insulin goes in, I can feel the effect. ... It is better than tablet. Because **insulin goes direct**, and we can feel the effect.*

YP also explained in the interview that oral medication would go through kidneys and would subsequently be excreted through urine, therefore he believed that the drugs would 'deposit' in the kidneys, which could lead to kidney failure. Whereas insulin is injected directly into the blood stream and directly lower blood sugar level, therefore it would not harm the kidney. This notion may also be accentuated by the metaphor of the kidney in Chinese culture (Lai et al. 2007). The kidney is seen as a vital organ containing the inherited 'vital essence' and sperm. Medication, which goes through kidney, is therefore causing loss of vital essence, and leads to a shortened lifespan.

YP: Plus also too much drugs goes through the kidneys and all that. Maybe it is a concluded fact or not I don't know but to me anything that goes through the kidney gets deposited there, is not as good as something that goes right through to the bloodstream. So in a way I think why not, I was prepared and asking the doctor to give insulin to me... If it works and it doesn't go through the kidney, it just goes directly into the bloodstream and does its works there, that's all that matters to me.

Healthcare providers have a great influence on patients understanding of how insulin works. Using simplified explanation of how insulin is delivered into the body, healthcare providers can alleviate many of the participants' concerns about insulin. In addition, good healthcare provider-patient relationships will contribute to achieving long term treatment targets for both the patient and healthcare provider (Abu Hassan et al. 2013). As non-adherent patients frequently felt their healthcare provider had not adequately explained the risks and benefits of insulin. Good interactions and interpersonal relationships between patients and their healthcare providers had been found to be the main promoters for insulin initiation (Abu Hassan et al. 2013; Hunt et al. 1997; Nair et al. 2007). The importance of good doctor-patient communication is underscored by the association between insulin initiation and health literacy (Karter et al. 2010).

The initial patient education program should be simplified and tailored to the individual patient. As reported by many participants a simplified explanation of how insulin works promotes the acceptance of insulin treatment. The guidelines for insulin initiation should be simplified and delivered together with tailored, individualised counselling. Studies show that initiating insulin may be successful when appropriate glycaemic targets are chosen and a systematic titration of insulin dosage is agreed on by both the healthcare provider and patient (Meece 2006). There should not be a mandate to aggressively titrate insulin therapy as this might create a barrier with the patients. As reported by MZ in the interview that she felt that the pharmacist-

lead diabetic counselling program at the public hospital was too strict with her glycaemic target which put her off:

MZ: They (pharmacists) really control stringently! Sometimes it put me off. They are even worst than the doctor, when come to think of it. Even my doctor, my specialists don't do in that manner.

LR, LV and LT had sought opinion from healthcare provider on insulin treatment, the information on insulin were explained in a simple term, which tailored to their understanding. After they learned that exogenous insulin is replacing the 'lost' endogenous insulin, which their body could no longer produce; their negative concerns on insulin dismissed:

LR: And I asked the doctor, when I go visit my normal GP in my housing area, I asked her what happens if we take insulin. She said, "Very good, it goes directly into the bloodstream and control your blood sugar"!

LV: And then the doctor explained to me about the insulin. She said, "It's not bad, it's like replacing your insulin in your body, because your body not producing enough insulin." So I said ok.

LT: So I went to consult my panel clinic and asked "how about insulin? Is it a very bad thing or what?" He said "Don't think

about that, insulin is just a step ahead. If you are taking dosage tablets, is a one step behind” ... He said, “When you taking insulin, which is lost in your body, so you [are replacing] back directly, so it’s one step ahead”.

As reported by these participants, their explanations about how insulin works are comparatively simple and easy to comprehend; the explanation given is neither pharmacologically accurate nor scientific but it has been tailored to the understanding of the general public and is therefore more acceptable.

It is highlighted by many studies that good interactions and interpersonal relationships between patients and their healthcare providers are vital for building trust and effective communication, which will promote better health outcome by increase medication adherence and better disease control (Abu Hassan et al. 2013; Hunt et al. 1997; Nair et al. 2007; Karter et al. 2010; Adolfsson et al. 2008). Apart from building a good interaction and interpersonal relationship with patients, health professionals must also take into account the cultural influences in medicine. Peyrot (2012) suggested that country differences reflect the interplay of cultural beliefs, healthcare provider training and health system characteristics. Ethnic and cultural considerations should be highlighted and to be integrated into the health delivery system in Malaysia to further improve care and health outcomes (Ariff & Beng 2006).

4.4 Quality of Life: Thinking of Future

Another prominent facilitator that encourages participants to accept insulin treatment is to achieve optimal control of T2DM. The motivators behind this facilitator are to prevent diabetes complications and thinking about the future and well-being. Many participants mentioned in the interviews that they agreed to initiate insulin because they want to live a healthier, longer life:

CH: Because you know about in the future you will get something probably affect other organs and all these... Whatever [complication] in the future, anything that will be affected.

LM: Get a better health. Like your eyes, kidney, and all that. Depending on [insulin], if you want a good health... I have to live for the rest of the life well.

LV: If I take insulin now, and then I will be ok in the future. I am talking about like 10 years... You need to see for the future... We have to look for the future, diabetics and this and that.

There is a strong association between well being and diabetes complications. Diabetes complications are one of the predictors for T2DM patients to seek insulin treatment, as they want a better quality of life. A few participants in the interview understand that insulin treatment is effective to improve glycaemic control and to diminish future diabetes complications and therefore agreed to

initiate insulin treatment. They were not scared about insulin injections; in fact, they were more scared to suffer from diabetes complication and symptoms:

AZ: And then I started feeling numbness on my feet. That is the reason why I said ok, why not take insulin... Because I could not feel my feet, I was numb... the medication, because I need this.

NR: To prevent more complication... I was very worry that sooner or later my kidney will die off. So I have to accept the treatment.

MY: I am worry only about kidney. I am not worry about the insulin. Doctor said your kidney a little bit affected.

However, some patients who accepted insulin treatment to prevent diabetes complications had a negative attitude as they often felt that they had no choice but to use insulin. This negative attitude is also reflected by other participants who had close relatives suffered T2DM complication, which resulted unpleasant experiences:

YLC: Maybe my brother case, because his legs are all blacken, he had trimmed off one of his toe. The doctor did say that he wanted to trim [the leg]. ... That maybe triggers me, before that also trigger me that I feel like I do not want to suffer like him...

LR: Because I have a family member, my uncle recently passed away. His eye was completely blind, kidney damaged, heart was swollen, he can't walk and he was bedridden.

These participants understand that diabetes complications could affect their quality of life and therefore they had to accept insulin treatment in turn for better glycaemic control. As mentioned by Peyrot (2005) in a multinational study, as patients' diabetes controls worsen, they may become more receptive to a treatment strategy they have previously avoided. In this instance, participants became more receptive to insulin treatment that they would have previously avoided. At least six patients expressed that they had no choice but to start on insulin treatment:

CH: We have no choice you have consider that, we get the sickness already then we have to [take] medication... We have to put [insulin], no choice, we have no choice.... Because when the time tablet cannot control, you have to go to insulin... Of course we don't like to put a needle. But the thing is I want it to be better, I have no choice.

HT: Because, because I got no choice already. Because I have come to a stage that the tablet doesn't work, is either you have to use it by all mean because the tablet had been changing from dosage, had been changing from brand, still no...no effectiveness.

If I got the choice, but I got no choice, is either you like it or you don't like it, you have to use [insulin].

ZT: What can I do? I have no choice; since the tablet is not effective the only way is to use insulin. What else can I do? If the tablet can't control our blood sugar well, and [if] I don't want to use insulin, I will die faster!

The participants explained that if they had a choice they would not use insulin. They felt that they had no other alternatives and were forced into accepting insulin treatment. Lai et al. (2007) reported in their qualitative research that many patients wrongly assumed that the T2DM progressed in a step-by-step, uni-dimensional manner. Therefore, insulin to many patients would mean the last resort when other agents failed to control their T2DM. Similarly in this study, the participants knew that insulin would be their last resort when tablets failed to control their blood glucose level. As mentioned by ZT, “*if I don't want to use insulin, I will die faster!*” This shows again the importance of good healthcare provider-patient communication. When discussing the initiation of insulin treatment, it is essential to ask patients about their thoughts or feelings about insulin. Many studies have reported that starting insulin treatment is often perceived as a personal failure; patients often felt a strong sense of failure when it was suggested for them to go on insulin treatment (Polonsky et al. 2005; Brod et al. 2009; Korytkowski 2002; Neumiller et al. 2009; Morris et al. 2005). It is essential to understand patients' thoughts or

feelings about insulin to ensure that counselling about insulin is supportive, tailored for each individual patient, and effective (Funnell 2007).

One of the powerful motivators to prompt participants into accepting insulin treatment is their bonding with their family and their wanting a better quality of life for the future. LR said that her reason to accept insulin treatment was due to the fact that she wanted to start building a family. She was certain that insulin treatment would improve her glycaemic control thus providing her a better quality of life:

LR: Then they asked then “why do you want to go for insulin?” I said because I wanted to get pregnant, I want to have a good lifestyle...

Some older participants accepted insulin treatment because they want to improve their physical well-being. They were not only wanting a better quality of life but also not to burden their family members. As described by the participants below, they have a strong connection with their family members and that is their motivators to stay healthy. They mentioned about ‘great grandchildren’, ‘longer life’, ‘until end of the day’ which suggested that they are thinking about their future with their families in long run.

S: And I got great grandchildren. I feel that I should take care of myself.

*YLC: I should follow this way, I should monitor. At least I have a...
longer life... something that you can take care of your own self.*

*LR: I definitely don't want to be like this. I don't want to torture
anybody else; I want to be on my own self until the end of the day.*

4.5 Chapter Summary

Healthcare providers affirmed that an early intervention of insulin treatment could prevent or delay complications for most patients, however some still are reluctant to prescribe insulin because of worries about the risks of hypoglycaemia and weight gain (Hayes et al. 2008). In addition, delays in initiating insulin for T2DM might be due to uncertainty for healthcare providers about how best to make the transition from oral therapy to insulin treatment (Meece 2006). Therefore, by exploring patients' experiences of using insulin they could review their concerns and beliefs about diabetes and insulin. The findings, especially the facilitators could be beneficial to assist healthcare providers in the diabetes field in delivering patient-centered care. As reported by the participants in this study and also in Abu Hassan and colleagues' study, one of the facilitators for T2DM patients to accept insulin treatment is their concern about complications of poorly controlled diabetes and the side effects of other treatment regimes (Abu Hassan et al. 2013). These findings could be used in educating T2DM patients and raising their awareness of disease prevention, and also best used as a facilitator to initiate insulin treatment for those insulin-naïve patients.

In some instances, T2DM patients think that diabetes in a uni-dimensional manner; they considered the disease as progressing uni-dimensionally and that the perceived severity could be measured on a uni-dimensional scale. Therefore this poses as an obstacle when discussing initiation of insulin

treatment to T2DM patients. As reported by many studies, many T2DM patients think that insulin is for severe diabetes or used as a last resort and even worse is thinking that the need for insulin reflects a personal failure (Polonsky et al. 2005; Neumiller et al. 2009; Abu Hassan et al. 2013; Brod et al. 2009). As a result, initiating insulin would signify that they do not have any other option but to accept insulin treatment. This negative perception obviously will cause resistance to insulin treatment and often will have a negative impact on a patients' emotional well-being. Meece (2006) suggested that healthcare providers need to reveal this particular reason for insulin resistance by having appropriate conversations with the patients. Healthcare providers need to be aware of culturally sensitive issues and to be aware of the patient's perspective, and use every opportunity for education and clarification. In addition to early education on T2DM, which should be tailored and individualised; continuous educations as well as practical and emotional support from others are valuable for insulin acceptance (Abu Hassan et al. 2013).

For some patients, their first exposure to insulin was via a relative who used insulin as part of their T2DM management. It is shown in this study that this might be a positive facilitator for insulin acceptance. Experiential learning through observing their relative coping well with insulin treatment can help the patients to alleviate their negative attitudes and misconceptions about insulin. Practical as well as emotional support is not only confined to healthcare providers, support from relatives and friends who used insulin also play a crucial role in promoting insulin acceptance among T2DM patients.

CHAPTER 5

BARRIERS TO INSULIN INJECTION

5.1 Introduction

During the interviews, one of the objectives was to explore patients' reactions toward initiation of insulin treatment. Semi-structured interview questions were used to explore patients' perspectives of insulin treatment. In the following sections, I will be discussing the negative perspectives of insulin treatment, which acted as a barrier and resulted in low acceptance of and non-adherence to insulin treatment.

Reluctance to accept insulin treatment in T2DM patients has been examined in several studies, the term psychological insulin resistant (PIR) is used to define this psychological opposition towards insulin injection (Brod et al. 2009; Polonsky et al. 2005; Korytkowski 2002; Peyrot et al. 2005; Snoek 2001). Many participants reported that their negative perspectives of insulin treatment are due to their lack of knowledge of modern insulin pen devices and also miss-information on the availability of modern insulin pen devices and injection process involved.

In the following sections, I will be discussing the influences of Malaysian society on the use of insulin injection, and how the participants anticipate it. This is followed by the discussion about how lack of awareness and knowledge

of modern insulin pen devices resulted in needle phobia, and how past experiences with injections influence people's knowledge of insulin injection, and the fears faced by participants when handling insulin injections.

5.2 Personal Failure

In this study, thirteen participants had commented that their first impression of insulin injections was that injections are meant for severe, uncontrolled disease. In addition, many T2DM patients have the notion that T2DM progressed in a step-by-step, uni-dimensional manner as mentioned in section 4.4. When discussed switching from oral anti-diabetic medication to insulin injection, patients often felt reluctance because of the use of an injection. Patients felt that tablets are generally used for “non-acute conditions” while injections are reserved for “serious conditions” (Brod et al. 2009; Polonsky et al. 2005; Korytkowski 2002; Peyrot et al. 2005; Snoek 2001). As a result, many T2DM patients think that initiating insulin treatment signified that they have failed to control their health and have reached a critical state and this created a strong sense of personal failure (Polonsky et al. 2005; Brod et al. 2009; Korytkowski 2002; Neumiller et al. 2009; Morris et al. 2005).

In the interview with participant ZA, her impression of insulin injections was that insulin is indicated for severe cases. She used the word ‘teruk’ in local language to emphasise that insulin is indicated for those T2DM patients in a severe, terrible state of uncontrolled diabetes.

ZA: I would think insulin when teruk (terrible), I mean [when] the diabetes is very, very bad then [only] you should take insulin.

Many participants think that T2DM progressed in a uni-dimensional manner; therefore they think that insulin injections are only used in the last resort. In the interview with CH, he mentioned that to use insulin injections signified the 'final stage' of diabetes; 'normal' people or patients with well-controlled T2DM will not require insulin injections:

CH: I know that patient [who] is serious, and then only you need to use insulin. Normal people they don't need insulin... That is the final stage already; you have no other way, to do anything already.

CH expressed that he has failed to control his diabetes and he has no other option but to use insulin injections. He illustrated that initiating insulin treatment was like a personal failure. It is a common finding which is also reported by other studies that patients often perceive insulin to be the last option of treatment, or a form of punishment, or a failure of their own doing (Polonsky et al. 2005; Brod et al. 2009; Korytkowski 2002; Neumiller et al. 2009; Morris et al. 2005). Personal failure is one negative perception often reported by studies as a common barrier to initiating insulin treatment. Nur Azmiah et al. (2011) reported that the most frequently expressed negative attitudes by Malaysian T2DM patients were personal failure (59.2%). In my study, participants expressed that this negative perception is often inflicted by the society:

*LR: I have knowledge that **people** will say when you take insulin, that means your blood sugar is not under control... Because **people** keep on saying [that] insulin is for people who have no control.*

*LT: Older generation, **they** think insulin is [a] very dangerous thing! For them, it [means that] you are in critical stage already.*

*SA: Insulin... **they** think it is very serious.*

Lee et al. (2012) documented that negative influences from family members has resulted in a barrier toward insulin initiation faced by Malaysian healthcare providers. Some participants in my study also reported that the comments from their friends and family have contributed to their negative perception of insulin treatment, which has magnified the negative attitudes and feelings of personal failure:

SL: Yeah, some friends they know [that I am on insulin], but they [are] scared. They said: “Why, your diabetes very high?” “Why, your kidney got problem?”

SR: Usual reaction for those who are not diabetic, they said “so serious your diabetic!”

Healthcare providers in Malaysia expressed that negative influences towards initiating insulin treatment and poor support from family members especially from their spouses have created a barrier for healthcare providers to suggest

insulin treatment to patients (Lee et al. 2012). One participant ZZ, who thought that insulin injection is for emergency use, his wife was 'not very happy' when she learned that he needed insulin treatment. Her gestures implied that ZZ has failed to control his health and her lack of support has created the sense of guilt and personal failure for him, which resulted his reluctance to accept insulin treatment:

ZZ: I thought it was very weird, [I thought insulin is] for very severe case that you have to go emergency. I didn't know that even for normal [patient] you can also use [insulin]... My wife was not very happy. She thought that I was not... it shows that you are not controlling to diabetes.

Lack of knowledge and education about insulin injections have resulted in misconceptions about insulin treatment among Malaysian patients and the general public. The misconceptions about insulin injections in that they are reserved for severe cases or for emergency treatment has been reported by studies conducted in Malaysia and also overseas (Peyrot et al. 2005; Nur Azmiah et al. 2011; Abu Hassan et al. 2013; Hassali et al. 2013). These misconceptions are reflected in poor knowledge regarding diabetes and insulin in the general public in Malaysia, which not only resulted psychological insulin resistant in T2DM patients but also the negative attitude from the general public. The negative attitude and lack of support from family members and friends might contribute to the reluctance of initiation insulin treatment because of the stronger sense of personal failure. Therefore, healthcare providers must be equipped with effective counselling skills and prepared to

provide adequate information to ensure the delivery of diabetic education is effective, yet simplified and individualised to the patients' needs. Early education at the point of diagnosis regarding the progressive nature of diabetes and function of insulin could mentally prepare T2DM patients and alleviate their misconceptions.

Raising public awareness of T2DM and the role of insulin is vital to allay the negative attitude towards insulin treatment. Support from family members, relatives and friends plays an important role in encouraging insulin acceptance among T2DM patients. Lack of public awareness of insulin injection also resulted social stigma, which will be discussed in CHAPTER 7.

5.3 Past Experiences with Injection

During the interviews, some participants reported that they have little knowledge about insulin devices especially the participants who did not have prior exposure to insulin injection. When insulin treatment was suggested, these participants would associate insulin injection with the needles and syringes used in media such as movies, or associated them with their bad experience in the past, such as from venepuncture or vaccinations (Tan et al. 2011; Korytkowski 2002). Malaysian children are scheduled for immunisation at the age of 6 and later again at age of 15 (Ministry of Health Malaysia 2014). As a result, some participants expressed the fear of injection and their first impression of insulin injection would be ‘painful’, required long needles and might leave a scar:

ZZ: I think the most common misconception about people taking insulin is that of course it involves the injection part.

LT: The main thing is people scared of needle, the feeling. When you are in standard 6 you will have a jab, BCG (vaccination). That bloody needle is damn painful. That is the main thing that makes people scared. They said “jab? oh shit long needle!”

The wrong perception of long, big needles involved with insulin injection has generated a high prevalence of needle phobia for many T2DM patients. Many patients with diabetes are initially apprehensive regarding self-injecting, about

one per cent of patients suffer from a phobia for injecting and about 5 per cent of patients experience emotional distress and feelings of disgust related to the self-injecting of insulin (Snoek 2001). Tan et al (2011) suggested that the needle phobia might be due to anxiety and not actual needle phobia. Healthcare providers should dissociate the bad experiences of previous injection encounters in order to address this psychological barrier. In addition, the route of administering of insulin should be discussed, patients should be informed the different between venepuncture and intra-muscular injection which often experience during immunisation, with that of subcutaneous insulin injection. The development of modern insulin pen devices also provides diabetes patients with an easy-to-use, convenient, and accurate method of insulin delivery (Griffin & Hieronymus 2002; Spollett 2008; Bohannon 1999). It provides less traumatic methods of insulin delivery, which reduce the complexity of insulin dosing and minimising pain associated during injection. The availability of finer, shorter needles could alleviate the pain of injections (Korytkowski 2002).

The association of insulin injections to past experiences with injections has contributed to the psychological insulin resistance. It also highlighted that most patients have a poor knowledge and awareness of modern insulin pen devices, thus some participants worried that they were not able to handle injecting insulin. This psychological barrier toward insulin injection is discussed in the next section.

5.4 Worry that They Cannot Handle Using Insulin Injection

During the interviews, some participants reported that they have little knowledge about insulin devices especially the participants who did not have prior exposure to insulin injection. When insulin treatment was suggested, these participants would associate insulin injection with needles and syringes used in media such as movies. In movies, injection usually used in emergency or critical scenarios and often portrayed with big syringes and long needles. As a result, some participants associated insulin injection with critical stage of the diseases. ZZ explained in the interview that he learned about insulin injection from movies, and it was used in movies to treat patients at critical stage:

ZZ: I get that information of course from movies and every time you see people who are really serious [with] diabetes issues that they use insulin. That is I think just based on what was in the media.

Lack of knowledge and awareness of modern insulin pen devices has contributed towards the barriers to initiate insulin treatment. Many participants in this study reported that before they started insulin treatment, they had little knowledge of what the insulin injection looks like or of the techniques used to administer insulin. SA used the metaphor of ‘going into a dark room’ to reflect his experiences of first starting to use insulin injection:

SA: And when you have not use insulin before, it was... you don't know you are going into a dark room. You don't know what is going to happen.

The influences of the media also resulted in some participants thinking that injections required comprehensive training and that they were only able to be administered by healthcare providers because of what they have seen in the media: injections often given by doctor or highly trained healthcare providers. Patients with T2DM often considered initiating insulin treatment as a complex and complicated task and this caused the reluctance and delay in insulin treatment (Lee et al. 2012). Patients were also concerned that insulin treatment might add to the burden and stress that they already experience from managing diabetes on a daily basis, and therefore they do not feel confident that they can handle the day-to-day demands of insulin injections (Brod et al. 2009; Polonsky et al. 2005). Participants from the interviews reported that they were very concerned initially because they had no knowledge of insulin injections and they thought that injections required highly skilled techniques and it is a complicated task. Therefore they were worried that they would not be confident in handling this complex task of injecting:

LV: I scared you know. I don't know how to [handle it]...

S: Initially I [was] worried on how to handle the injection but then slowly you become more of an expert.

Many participants reported that their initial thoughts about insulin injections were associated with long needles, vials and syringes. Furthermore they thought that it is a complex and invasive task requiring training on withdrawing insulin from vials or bottle and skilful injecting technique. PG expressed his initial hesitation with insulin injection because he had not been shown the modern insulin pen devices. He visualised insulin injecting uses big needles and therefore worried how he could handle injecting himself:

PG: Before I started insulin, I can't even imagine what the needle look like. There is no education to show that actually it is just a very small needle only, not a very big needle. You know, people [might] think "Wah the bloody big needle, don't know how to jab". Initially I think [like that too]... People don't know what they are getting into.

SA: I was quite hesitant. Because, because the needle is too long and have to withdraw insulin from the ... Vial and all those things.

A few participants explained that their impression of insulin injections were associated with the older, traditional insulin injections that involved needles, glass vials and plastic syringes. This can be attributed to the fact that there is a lack of educational campaigns or channels for promoting the modern insulin pen devices. A few participants reported that the traditional insulin injections

had a negative role which discouraging T2DM patients in accepting insulin treatment because of its complicated procedure and invasive:

MM: But with these new devices, only recent year I know about it. Before was, the bottle, the syringe, withdraw from the bottle, my god! [That was] 10 years ago!

TC: No, but maybe the earlier form of insulin injection probably gave people a wrong idea. Those days we had this syringe and vials and all that.

Diabetes patients have a high prevalence of psychological insulin resistance (PIR); patients often worry about technical concerns, fear that injections will be painful, fear of inflicting self-harm, fear of self-injecting or dislike of daily injections (Mollema et al. 2001; Zambanini et al. 1999; Brod et al. 2009)(Hassali et al. 2013). During the interviews, participants were asked about their first reaction to insulin treatment, a few participants expressed their initial fear was due to having to self-inject insulin. This could also attribute to the lack of knowledge of modern insulin pen devices and the ease of using the pen devices.

MZ: People are scared. I was scared initially also [because] I have to jab myself.

LV: They explained but you know it is the first time we have to use it ourselves.

Psychological insulin resistance such as fear of self-injecting should be addressed and discussed when initiating patients on insulin. Breaking the barriers and understanding the needs and concerns of individual patients could facilitate healthcare providers to assist patients to overcome psychological barriers to insulin treatment. Early education focusing on diabetes disease and its progressive nature would have mentally prepared T2DM patients into accepting insulin treatment later in the disease course. T2DM patients should be made aware the availability of modern insulin pen devices and the function of insulin, which would allay the image of long needles associated with insulin injection. Many participants praised the new design of modern insulin pen devices; it not only alleviated the needle phobia but also make the injecting process simple:

SA: No phobia, I think long before gone. The needle it is so fine, so thin, that's convenient. I think people are ok. Formal needle used to be that long, that they need the vial, and then depends on the angle, you could draw more, draw less. How you [handle it]...

E: Not so hard. Easier now with the new pen, the new pen is simple. Simple, after you use and then you throw away.

S: But once you started on the pen, the pen make it easier for you. Because once it has been used, you don't have to refrigerate it... Now this is, this is very easy, you set the dial, you cannot go wrong, unless you don't know how to read one two three four. Just set the dial...

There is an increase in the range of modern insulin delivery systems, which have revolutionised insulin self-care. New modern insulin pen devices provide diabetes patient with an easy-to-use, convenient, and accurate method of insulin delivery (Griffin & Hieronymus 2002; Spollett 2008; Bohannon 1999). There are two types of insulin pens available in Malaysia: prefilled and reusable. Prefilled insulin pens are prescribed and dispensed to the patients from the majority of Malaysian public hospitals. The availability of the modern insulin pen devices should ease the patients' concerns about handling insulin injection. It should be made aware during the early diabetes education together with knowledge on the progressive nature of T2DM. Education and hands-on practise with a placebo should alleviate their fear and anxiety (Griffin & Hieronymus 2002; Spollett 2008; Bohannon 1999). However, the information should be simplified and individualised. Patients might be overwhelmed by the instructions and were not confident to handle injections.

5.5 Chapter Summary

One of the aims of this study is to explore patients' perspectives of insulin treatment. In this chapter, I have highlighted the negative perspectives of insulin treatment faced by the participants. These negative perspectives such as sense of personal failure, fear of self-injection, influence from past bad experience with injection, have resulted in psychological insulin resistance (PIR) and act as barriers toward insulin treatment (see Figure 6 Barriers to initiate insulin treatment). The lack of knowledge and awareness of modern insulin pen devices has further hindered the acceptance of insulin treatment among T2DM patients; this is further discussed in section 8.1 Practice Implications. Patients would associate the needles used in insulin injections with the long needles portrayed in movies or from their past experiences, thus some patients had initial doubts and worries that they were not capable of handling insulin injecting without medical assistance. They perceived that injecting insulin was a complicated procedure, which required intensive technical training and precision.

Figure 6 Barriers to initiate insulin treatment

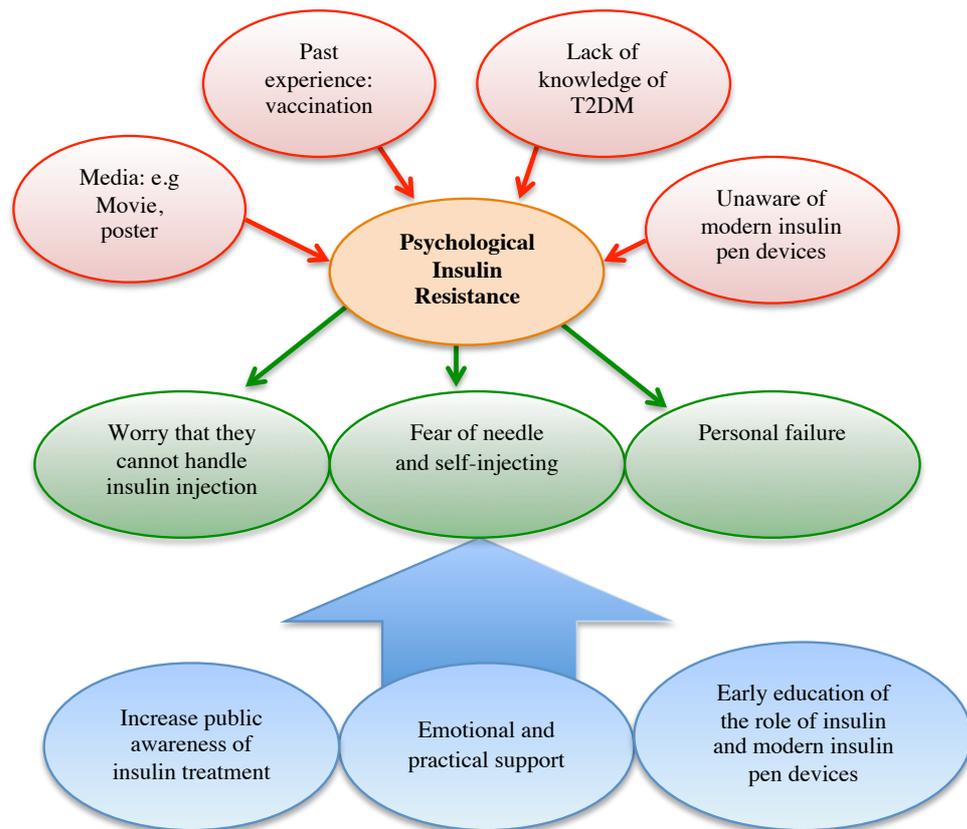


Figure 6 above summarised the factors lead to PIR among T2DM patients, and the suggestions that could potentially alleviate these barriers.

PIR should be addressed at the early stage of T2DM by trained healthcare providers through education focusing on the nature of T2DM and also the role of insulin. Early, simplified and tailored diabetes education should make T2DM patients more aware of their health condition and the function of insulin and better prepare them mentally for insulin treatment. Emphasis should be placed on practical and emotional support in order to help patients to accept insulin and become more self-efficient to use insulin injection. On the other hand, educational campaigns to raise the public awareness of T2DM and promote the availability of modern insulin pen devices could alleviate the

negative perception of insulin treatment; subsequently ease the patients to be more acceptable about injecting, and also encourage the society to be more open minded towards insulin treatment.

Patients' perception of insulin treatment might change over the time, their reluctance to accept insulin treatment is also dynamic, therefore they might be more willing to accept insulin treatment (Tan et al. 2011). Healthcare providers should follow up with patients who were once reluctant to initiate insulin treatment. As patients' perceptions of insulin treatment might change, in the next chapter I will be discussing how patients cope with the introduction of insulin injection into their T2DM management.

CHAPTER 6

COPING WITH INSULIN TREATMENT

6.1 Introduction

This qualitative study aimed to examine the insight of Type 2 diabetes patients, and explored their lived-experience of using insulin treatment as part of their diabetes management. One of the aims is to explore how patients' attitudes toward insulin treatment changed with their experience. In this chapter, I will be discussing how the participants coped with the introduction of insulin injection into their diabetes management.

From the data analysis, a few prominent themes have emerged which either encourage participants to adhere to their insulin treatment or posed as an obstacle for insulin compliance. One prominent theme suggested participants often make lifestyle adjustment to adapt insulin injection into their existing diabetes management routine, despite a few participants feeling that they have been forced into accepting insulin treatment. Many participants expressed the restrictions and inconveniences to their daily life as a result of the initiation of insulin treatment.

6.2 Restriction of Lifestyle

One of the strong themes from the interviews is that insulin injections restricted their lifestyle. Many participants complained that insulin treatment causes many inconveniences to their day-to-day activities, and also restricted them from travelling. Lifestyle restrictions have been reported in many studies as a barrier to initiate insulin treatment and has a negative impact on their social life (Abu Hassan et al. 2013; Karter et al. 2010; Brod et al. 2009; Morris et al. 2005). Patients perceived that insulin injections would ‘take over’ and ‘control their lives’ (Morris et al. 2005; Polonsky & Jackson 2004). In my study, AM affirmed that insulin treatment had a great impact on his life and he feels as if the insulin injection is taking control of his life. He expressed that he is deliberately not bringing his insulin injection with him when going out of his home however he was very concerned about the effect of food on his blood sugar levels. To avoid the dilemma, he had to give up his social life and was staying at home more often and he expressed that he felt like it was a big commitment to manage T2DM:

AM: Until now [if] I want to go somewhere, I don't bring it. But we will be concern of what not to eat. But our body, blood sugar is high, we cannot control. That is why, I am doing less now, I go out less, just stay at home... Less travelling, less. Before I can go, travel anywhere. Now all has reduced. Now just stay at home alone. Nothing much happening, our activity also reduced, I don't go socialising too... We have to commit... to the disease.

One of the common inconveniences faced by participants while using insulin treatment is to carry and taking care of insulin injections while travelling. As expressed by AM that he had to give up his social life and commit to the diseases, many participants reported that they travel less because of using insulin injections. They felt that to carry insulin injections while travelling is an extra responsibility:

LM: I am finding it difficult, because I travel a bit of here and there... Sometime I forget to pack my injection, especially for the lunchtime dose.

S: I was not very keen. Because insulin you got to carry your insulin here and there.

AM: I feel like the injection had restricted my activities, meaning that I cannot go anywhere freely, like holidays or outstation or even to Haji. Felt like we cannot do that anymore. If taking pills is much easier, before we take lunch or dinner, we just take the pills.

MJ: A bit uncomfortable with it because you want to travel. For example [if] you want to go on holiday, you got to carry the pen along and put it in a briefcase and carry that. If you forgot, you cannot use the insulin. But for tablet it's easy.

Travelling is one vital factors affecting non-adherence to insulin treatment as reported by Peyrot et al (2012). 43.6% of physicians and 16.2% of participants

agreed that travelling is the second most common reasons for insulin omission. One of the reasons why they felt that insulin injections restricted their travelling was because they had to pack all the necessary medical equipment such as extra needles, alcohol wipes, glucometers and others accessories. As commented by AM and MJ, they were comparing insulin injection with taking oral tablets. They were concerned that there are too many accessories that they had to remember to pack with their insulin injection despite the use of modern insulin pen devices. They expressed that they had to remember to pack ‘this and that’ and bring along ‘all these’ with their insulin injection when they were planning to travel:

CH: Sometime [when] you [are] travelling, you [have to] bring along your jab, your insulin and this and that; got a lot of problems. You take tablet, [it is] easier to carry, convenient.

HT: Because I thought is very inconvenient, you have to inject and you have to bring your pen along all these, carry all these.

AZ: Basically, because I have been travelling a lot for work. But it is ok. Because they know, I will show them the syringe and they said that is ok. But you can't carry too many needles. Can't carry too many, maybe can carry like two. Because I think, [it is] for security reason.

The other factors that restricted participants' travelling plans were the changing of their dietary patterns especially when they traveled to a foreign country. As explained by LT, besides having to bring the accessories with insulin injection, he was concerned with the food and insulin dosage:

LT: So beside that, insulin is kind of a trouble if you travel... because you go to different places, you eat different things.

As a result of these restrictions, some participants felt that their lives have been 'controlled' by insulin injection, they felt that they are 'dependent' on insulin, giving the sense of insulin treatment taking over their life. T2DM patients who are on insulin treatment are often concerned about the inconveniences and complexities associated with insulin treatment especially those using short-acting human regular insulin (Meece 2006). Patients have to know exactly what they will be eating and the timing of their meals as well. Similar to LT's experiences of travelling to foreign countries and eating different foods, MZ explained how her insulin injections affected her life especially when she needs to dine out or when having to attend social functions:

MZ: Insulin we have to take it before food. If you go out for dinner and lunch, that makes it inconvenience, you have to jab before you eat... Because you have to jab before you eat. Sometimes, you jab at home; you think that you are on time for your food [when you go] outside. [But] only when you go out, you have all this function [and] it is difficult.

As illustrated in MZ's case, insulin injections have caused an unnecessary restriction on her social lifestyle. And this restriction of her social lifestyle leads to non-adherence of insulin treatment. Funnell (2007) reported that other lifestyle concerns are related to timing, difficulty in travelling, and loss of spontaneity and flexibility. As reported by YF in the interview, he felt that the inconvenience cause by insulin treatment was not related to having to bring the insulin pen devices, but the loss of spontaneity and flexibility:

YF: No, it is not because it is inconvenient to bring the insulin. It is because when I want to eat, I will eat. But you need to inject half an hour before you eat, I can't do that when I am with my clients. It is impossible to inject in front of your clients.

Use of modern insulin pen devices has addresses many of the barriers to insulin treatment and offers substantial improvements in convenience, freedom, and flexibility; therefore improves patients' satisfaction and adherence for all insulin-using diabetes patients (Spollett 2008; Bohannon 1999; Meece 2008). Although many participants were concerned about the restriction of their lifestyle with the introduction of insulin injection, a few participants were delighted with the new modern design of the insulin pen devices. Participants acclaimed that the modern insulin pen devices provided by the hospital PH is discreet and easy to carry around, the insulin injection in pen design could easily fit in pockets and handbags:

SR: But then carrying a pen is not an issue; it is in a pen form. You know the pen they are providing here, normally you can just put it in pocket, for the ladies just put it in their handbags.

KK: Travelling wise, no problem. Because it is all in a pen form, in a pen form it is easy to carry around.

MM: If I go travelling or what, no problem, I just bring one pen only.

The availability of modern insulin pen devices has greatly improved the convenience, freedom, and flexibility as compared to the traditional insulin in vials. Quantitative research involved 1156 participants had reported that switching from administration of insulin therapy by vial/syringe to a prefilled insulin analogue pen device was associated with improved medication adherence, fewer claims for hypoglycaemic events, reduced emergency department and physician visits, and also lower annual treatment costs (Lee et al. 2006). T2DM patients should be made aware of modern insulin pen devices preferably at the initial counselling stage of T2DM to better prepared them mentally and also offering them an additional treatment option. During discussion on insulin treatment, it is important to consider that the addition of insulin injection might lead to lifestyle changes for some patients. The objective is to minimise a dramatic lifestyle change among T2DM patients, poor patients' satisfaction with their treatment often lead to poor adherence, and therefore sub-optimal diabetes control.

6.3 Timing of Injection

For T2DM patients who are naïve to insulin treatment, introduction of a basal insulin analogue is an excellent strategy when compared to complex regimens requiring multiple injections (Neumiller et al. 2009). Basal insulin analogue is a long acting, once- daily insulin injection that provides even more freedom and convenience and often favoured by patients. In my study, participants felt ‘blessed’ when initiated with basal insulin injection, and most of them expressed that it was easy to manage and did not cause any inconvenience to their daily lifestyle:

AH: My insulin, used to be three times a day. So now it has changed to once a day at nighttime, easier to manage.

CH: So blessed that I only use it initial at nighttime, so I don’t feel so much [of a] problem.

NA: I don’t feel inconvenient because I only jab at night only. I don’t have the experience of jabbing in the daytime. I don’t know how insulin in the day will affect me; maybe there will some restriction to the activities. Maybe have to stop some activities because of using insulin. Because I only take it at night, so no problem.

For participants who required multiple injections in a day, they reported that insulin treatment resulted in many disruptions to their daily routines. As a

consequence, participants frequently skip or manipulate the timing of their injection especially the afternoon dosage as it tend to interfere most with their daily activities:

SL: Sometime I [will] miss... sometimes [when] I go outside, If I go out, I [will] miss the afternoon one.

LM: Sometime I forget to pack my injection, especially for the lunchtime dose.

KK: But then insulin I only take it in the morning and evening... Afternoon dosage I seldom take.

YF: I inject every morning and night, and one in the afternoon...then the afternoon is with the timing of the meal too, something when I want to start eating but I have no time to inject. So I usually just inject once and I tend to skip my afternoon dose.

In my study, many participants admitted that they had intentionally skipped their lunchtime insulin injection because of the timing of the injection. It is one of the biggest factors for non-adherence to insulin treatment. T2DM often requires significant lifestyle changes and multiple medications to manage blood glucose level and prevent complications. Adherence to prescribed therapies is a critical factor in the management of T2DM. Taking insulin injection at the prescribed time and frequency are identified as most common

difficulties by both patients and physicians (Peyrot et al. 2012). A review paper reported that a significant proportion of T2DM patients exhibit poor adherence that will contribute to less than optimal glycaemic control (Bailey & Kodack 2011). Timing of medication is an important factor for poor adherence to the management of T2DM. The timing of the dose appears to be highly manipulated by participants, and most of them indicated that they took their medications daily but not at the exact recommended time (Al-Qazaz et al. 2011).

Awareness of insulin analogues with improved pharmacokinetic profiles is useful in clinical practice especially for T2DM patients who are naïve and reluctant to insulin treatment because of the potential disturbance on their daily activities. Suggesting a basal insulin analogue initially for T2DM management is an excellent strategy to overcome the fear of ‘insulin injection taking over their life’. Basal insulin analogue such as insulin glargine is a long acting, once- daily insulin injection which patient usually injects during nighttime at home, it provides freedom and convenience and causing minimum disruption to patient’s daily activity.

Healthcare providers in the diabetes field have a key role in promoting patient adherence with insulin treatment. T2DM patients often need more than emotional support but also practical information to increase their confidence in self-managing their T2DM (Stotland 2006). Healthcare providers should take initiative to ask about concerns relating to insulin dosing and take into account of individual patients’ needs and tailored the insulin treatment to fit into

patients' lifestyle. Good communication between healthcare provider and patients to develop trust could overcome many barriers the T2DM patients might have relating to insulin therapy.

6.4 Getting Into a Routine

During the interviews, participants were asked to express their fears or concerns about initiation of insulin treatment, at the same time they were asked about their solutions to overcome these fears and barriers. The literature revealed that resistance to initiate insulin or comply with insulin treatment over time may be affected by patients' fear of restrictions required by insulin use and hence lifestyle adaptations (Brod et al. 2009). From the data analysis, participants had tried adjusting their lifestyle and adapted into using insulin injection. Although instructions and counselling were provided, some participants were still faced with a great challenge when they first tried to self-inject insulin. However, with more time and increased experience, they were able to master the techniques and adapt into a routine of injecting insulin:

MM: Before that, doctor asked [me] to use, I just followed the instruction. Only later I got to know more on how to control [diet and] how to adjust [dosage]. Because I am using it for many years, I know the dose well. After you eat, you know the [insulin] dose.

YLC: They did teach me how, but during the first few times I really do not know how... Then later on, you realise which part of your body you should inject. Those part which the fats in it, those part without the fat will feel pain.

T2DM is a complex, progressive disease that can impact substantially on patients' lifestyle and patients often require multiple medications to lower blood glucose, reduce cardiovascular risk and address comorbidities (Bailey & Kodack 2011). Together with other healthcare providers, pharmacists play a crucial role in helping T2DM patients ease into using insulin treatment (Drab 2009). Pharmacists often have access to counsel T2DM patients on the timing of their medication. Participants in my study had mentioned that they could get into insulin routine fairly quickly if they knew how to arrange their timetable. Pharmacists could use this opportunity to work with these patients to organise the timing of their insulin injection in relation to other concurrent medication, and fit with their timing of meals and daily activities. As explained by MY, he had great difficulty when he first started using insulin injections in particular the timing of his insulin injections. However, he was able to get into routine after two weeks time. Another participant ZZ also reported the similar experience, which he was able to get used to the whole injection process in a few days.

MY: At first you find it very difficult, because you [have to] know your timing you need to go for insulin. So after these two weeks, you know already, before lunch you have to take insulin, dinner you have to take insulin... Routine already. Before I felt very difficult, I had to see the timetable. Now automatically you know already.

ZZ: I mean just [take] a few days you have to get used to the whole process. But now I can do it in less than 1 minute. So it is not really an issue... It is faster and it is easier and it is just a matter of getting used to and really not an issue.

S: Once you get used to it, it became part of a puzzle of your life already. So, it's nothing because you know how to plan such as how long you are going away, how much insulin you got to bring.

Both practical and emotional support from healthcare providers is crucial to ensure patients are able to adapt into using insulin injection quickly. Practical skills and techniques of injecting insulin should be carefully demonstrated to T2DM patients who are willing to initiate insulin treatment to minimise the initial frustration. Without the advice on practicality, patients might find it difficult initially in coping with insulin treatment. MR complained that he was forced to change his daily routine because of the introduction of insulin treatment:

MR: I can imagine a problem. Because during work and before sleeping I have to use insulin. So I was forced to arrange my timetable.

MR expressed that he could predict the problem of the timing of insulin injection when he was prescribed insulin treatment. Healthcare providers should help T2DM patients to identify potential conflict and working with

patients to discuss the barriers of using insulin injection, and allow them to integrate insulin treatment into their daily life with minimal disruption.

During the interviews, participants were asked about their fear of needles and self-injecting. I was interested to learn how they overcome the fear of needle or fear of self-injecting; participants reported the fear would slowly diminished after trying out the injection. They explained that the fear of needles was a 'temporary psychological' factor, after injecting a few times, they would be more comfortable with injecting and subsequently just getting used to insulin injection:

ZM: Yes, I was scared. The needle! I have to inject myself with the needle right? Needle must bring pain! It looked painful, but after a while I get used to it.

INTERVIEWER: You don't have fear of needle?

MM: No, I get used to it. I am used to it. Yes at that time, at that time the needle is this long. Now even better, you are used to it, that's all.

YHK: Time, after sometime you will get used to it. Initially I was so scared to do the injection myself; instead my wife helped me to inject the insulin. She used to inject them on my limbs which I can't turn my head and not seeing it. But then after I get used it and I

can inject it myself. After you get used to it, I just inject the insulin when it is time!

INTERVIEWER: Fear about injection, do you have that fear now?

MJ: No, I am used to it, two years already. The needle [fear] is temporary that is psychological, temporary psychological fear... After I used to that and then I am ok.

PG: Just take the first step and try, after you try a few times, you find its ok.

From the interviews, participants expressed that they just ‘get used to it’. For T2DM patients who are willing to initiate insulin treatment, Funnell (2007) suggested they could start off by dry injection; patients might want to try poking themselves with an insulin needle subcutaneously without actually injecting insulin. Healthcare providers could give a demonstration of dry injection to themselves in front of the patient or ask patients to give a dry injection to themselves at the time of the initial education. Modern insulin pen devices are a great tool, which can allay the fear for patients who are concerned about the pain of injections. As agreed by MM, he was scared of the ‘long needle’ in the old days but was much happier with the modern insulin pen device. Funnell (2007) explained that some T2DM patients are often described as “needle phobic,” but only a few patients actually have true needle phobias.

Although needle phobia is often presumed to be the single largest contributor to psychological insulin resistance, it might be overstated as true injection phobia is rare (Polonsky & Jackson 2004). This is consistent with the findings in this study as the participants explained in the interviews that the fear of needles was a ‘temporary psychological’ factor, which could be easily overcome by practising and perfecting the insulin injecting techniques. Polonsky and Jackson (2004) explained that this ‘temporary fear’ often represents a broader reluctance to consider insulin therapy, reflecting their many negative beliefs about insulin or lack of knowledge about its use. This suggested the importance of good trust and respectful relationships between healthcare providers and patients. Therefore patient-centred education should help to alleviate this fear and help T2DM patients to ease into accepting insulin treatment to optimise their T2DM management.

6.5 Chapter Summary

This qualitative study aimed to examine the insight of Type 2 diabetes patients, and explored their lived-experience of using insulin treatment as part of their diabetes management. It is important to understand how patients' attitudes toward insulin treatment changed with their experience. The themes emerged from my data analysis indicated that T2DM patients are often faced with lifestyle restrictions while on insulin treatment. These restrictions had impacted on their social activities and also prohibited them from travelling. The factors causing these restrictions were often due to the timing of injection, and the inconvenience of bringing all the accessories with insulin injection.

Starting T2DM patients on simple insulin regime is a great strategy to overcome the fear that insulin treatment is restrictive. Long acting, once-daily insulin such as insulin glargine provides freedom and convenience, therefore causing minimal disruption to patient's daily activity. Furthermore, T2DM should be made aware the modern design of insulin delivery devices, which is discreet and flexible compared to the traditional insulin in vials.

Healthcare providers in the diabetes field have a key role in promoting patient adherence with insulin treatment. T2DM patients often need both emotional support and practical information to increase their confidence in self-managing their T2DM especially when starting on insulin injections. Healthcare providers need to identify the potential conflicts which patients might have with insulin treatment and address them at the early stage of the insulin

treatment. Practical and emotional support are both critical to ease patients getting into a routine faster and at the same time minimising the disruption to their existing lifestyle.

CHAPTER 7

SOCIAL ACCEPTANCE

7.1 Introduction

In chapter 7, I have highlighted the negative perspectives of insulin treatment faced by the participants, which have resulted in psychological insulin resistance (PIR) and act as barriers toward accepting insulin treatment. In CHAPTER 6, I have discussed how the participants coped with the introduction of insulin injection into their diabetes management. In this chapter, I will be discussing the social factors, which influences patients' acceptance of insulin treatment.

7.2 Embarrassment and Social Stigma

The most frequently reported negative attitudes by Malaysian T2DM patients were personal failure (59.2%) and embarrassment of using injection (55.9%) (Nur Azmiah et al. 2011). From the data analysis, one prominent barrier of coping with insulin treatment is the embarrassment factor. Participants affirmed that it was embarrassing to inject in public due to their psychological factors. As a result, often patients would intentionally skip their insulin injection. Public embarrassment has been identified as a key factor in insulin non-adherence behavior; T2DM patients often believe that they have to hide their injections to avoid disturbing other people (Brod et al. 2009; Peyrot et al. 2012; Korytkowski 2002; Abu Hassan et al. 2013). Many participants reported that injecting insulin in public were inconvenient because the curiosity of others, therefore they preferred to have more privacy and would try to find a room with privacy to inject insulin:

PG: Sometimes if you are in a crowded place it's very hard to jab.

People will come and look at you, what is that you are doing...

WM: I don't feel comfortable with that... I just do it in morning before I go out of the house. Personally I find it very inconvenient to go to a public toilet or a coffee shop toilet to do the injection...

Why do you have to do it in front of public? So I didn't see the need to do it in front of the public... So anyway, I do it in the morning and nighttime I do it.

AM: But with injection you need to have to find a place, to inject. Normally take some times; we need to find a private place. We also don't want to let others people see right? Not comfortable, uncomfortable... How can [I] take injection anytime, anywhere? No privacy. When there are a lot of people, very difficult. Like where I work, one room sometime can have up to 8 people. Very difficult. When you are there, always scared. Because insulin has a set time to inject, very scared that not to get to inject... But embarrass.

Participants' perception of social stigma resulted them to hide when injecting insulin. However they often faced with difficulties to find an appropriate environment to inject insulin in Malaysia. For example, AM complained that there were too many people in the room where he worked, therefore he did not feel comfortable to inject insulin there and it was very inconvenient for him having to look for a place with privacy to inject insulin. As a result, many participants would selecting suboptimal locations to inject themselves while away from home, such as in public toilets, and might also cause some patients to skip or delay injections and avoid social activities. Thus, patients who have such psychological barrier usually would feel that their lifestyle being restricted (see section 6.2). In the interview with MZ, she voiced that insulin treatment had restriction of her social life. She would have to inject her insulin dose before she attends any function, because she did not want to inject it in public. Therefore she could not time her insulin injection nor the dose because

she would not know what time you would get to eat and what sort of foods were served.

MZ: I bring, but then you want [me] to jab in public? It is not convenient that you have to expose yourself to jab... That's why sometimes I don't jab... it's just that you need some privacy. Or you can go to the restroom but sometimes the restroom is so far away. So inconvenient. So just done with it, let go with it.

From the interviews, participants often complained that it was inconvenient to use insulin injection. The convenience was not due to the injection itself, but because the participants were embarrassed to expose injecting insulin in the public: “*It is not convenient that you have to expose yourself to jab*”. One of the participants, MM, explained his reason for the embarrassment. He would hide in the toilet to inject insulin when he was younger because he felt the sense of embarrassment:

MM: Long time ago when I use insulin, I normally go to toilet. But now [I inject] directly.

INTERVIEWER: Why do you go toilet?

MM: Embarrass. But now old already, so it is OK.

I explored further the reason why MM felt that it was embarrassing for him to inject insulin in public when he was younger, but he did not have any problem to inject insulin now. His explanation:

MM: Embarrass, so young and have to use this, now I am sixty plus so doesn't matter... I didn't want to tell anyone. I don't want them to know that I was still young and have this case.

MM explained that the public often think that insulin is indicated for older people therefore he felt embarrass and he did not want to inform others that he required insulin injection. Patients often have the misconception that insulin is a medication for old people (Lee et al. 2012). This misconception has contributed to the barriers for Malaysian healthcare providers to initiate insulin treatment for T2DM patients. Funnell (2001) reported some patients have justifiable concerns about the loss of their jobs if they need to initiate insulin treatment. LT, a 36 year old male participant explained that he was concerned that diabetes would interfere with his work. On top of that, his parents asked him not to tell anyone as well. He expressed that it would be an embarrassment to expose your bad health:

LT: Because of work, then you cannot like telling customers like I am taking vegetarian, I am diabetic all these things. My parents asked me not to tell. For first year I didn't tell anyone that I am diabetic. Parent asked me not to expose your bad health.

Abu Hassan et al. (2013) reported in a recent study that social and cultural factors such as social stigma and embarrassment have contributed to insulin non-adherence, resulting in omission or skipping of insulin injection among Malaysian patients who are on insulin treatment. Patients' perceptions of social

stigma for the self- injection of insulin in public can have a restrictive effect on disease-management efforts. Brod et al. (2009) reported that due to patients' previous negative experiences, or fear of negative experience, have contributed inconvenience and embarrassment related to injections. Therefore leading to a lack of motivation among these T2DM patients. One of the negative perceptions of self-injecting of insulin in public is the association with recreational drug use which I will be discussing in the next section.

7.3 Association with Recreational Drugs Abuse

During the interviews, one prominent barrier for injecting insulin in public places is due to the concern that if they inject in public places they would be perceived as injecting illegal substances or recreational drugs abuse. Participants felt that the Malaysian public is educated about recreational drugs abuse. Ultimately when the general public see someone self-injecting, they would associate it with recreational drugs abuse.

HT: Another, people thinking maybe you are a... maybe they don't know you are the diabetic depend on injection, so they thought you maybe [a] drug addict trying to inject...

YF: Of course it is not good, they will look at you and think why are you inject something when you eat? Like you are fixing your addiction to recreational drug by injecting it.

NR: So I stop using it if too many people around. I don't know, later people will say, "What are you doing?" "What are you injecting?" ... Still have friends [asking] if I am taking recreation drug!

Because of patients' previous negative experiences, or fear of negative experience, they would omit or delay their insulin injection. As commented by NR, a 30 year old male patient, he would not inject insulin when there were people around him because he was concerned that the public would perceive

him injecting a recreational drug. He was even questioned by his friends about taking recreational drug. NR attributed the public's negative perception to the educational material about illegal substances abuse:

NR: People will think "what are you jabbing", right? What's this?

People are educated about recreational drug, stay away!

Education and awareness of recreational drugs has increased the knowledge of public about this issue, but at the same time it has created negative experience for those T2DM patients who required insulin injection such as participants NR. Malaysians are aware that some recreational drugs are injected intravenously, but most of Malaysians do not know that insulin injections are administered subcutaneously. Participants from this study also illustrated the perception that recreational drug abusers would inject via vein and tend to have needle holes:

YF: It shouldn't be, it is a different kind of injection: one is injected into tummy and the other is injected into the vein. Those people are uneducated on this subject. It is different sort of injection; see it doesn't leave any needle hole on my skin.

YHK: Just like a drug addict who needs his fix when the time arrives. But they inject into vein, I inject into my skin only and the needle is very fine.

YF had pointed out that although the public members have the awareness of recreational drugs abuse, they were not fully informed and therefore would associate any self-injection with illegal drugs abuse. Malaysia declared drug abuse as a threat to the security of the country on February 19, 1983 (Scorzelli 1988). As a result of this declaration, Malaysia initiated a massive effort in law enforcement, preventive education and rehabilitation. A government initiative, “Anti-Dadah” task force was set up to combat the growth of recreational drugs abuse. (Dadah means dangerous drug in Bahasa Malaysia). Anti-Dadah task force focuses on preventative education and campaigns. The images used in the campaigns often involved portrays syringes and needles and sometimes with the image of the self-injecting action (refer to Figure 7 and Figure 8)

Self-injection, needles and syringes attributed a strong negative connotation associate with recreational drugs abuse. Given that injection is the only common route of administration for insulin treatment, it is not surprising that social stigma plays a key role in psychological insulin resistance. Reluctance to self-inject in public places are associated with the fear of being stigmatised, being looked upon by others an ‘addict’ (Snoek 2001; Brod et al. 2009; Morris et al. 2005).

Some T2DM patients have the perception that to inject insulin made them feel like a drug addict and losing ‘normality’, people with diabetes want to live as ‘normal’ a life as possible in a social context (Morris et al. 2005). LM felt that the Malaysian public had strong stigma associated with T2DM and insulin injection. She commented that people and even her friends made remark about her T2DM and the need of using insulin injection, which she was very concern about and she wanted to be ‘normal’ and not ‘odd’:

LM: I [told] my friends I am an insulin dependent , but everybody look at me [weird]... Social stigma. They think you are very odd. Even my old people call me “ The sweet person coming” . We have a phobia, people think you are an insulin dependent, they think, something you are out...I mean the [Malaysians]... “Oh she is an insulin dependent”. They give that kind of remarks you know? Especially those who are not aware of this.

LM's comment suggested that there is a need of raising public awareness of T2DM and insulin treatment to alleviate the social stigma. One prominent theme from participants' interviews is the need to raising public awareness of T2DM and insulin injection, which is discussed in the next section.

7.4 Raising Public Awareness

Lack of awareness and education about insulin injections have resulted in misconceptions about insulin treatment among Malaysian patients with diabetes and the general public. These misconceptions have not only resulted in psychological insulin resistance among T2DM patients but also the negative attitude from the general public. Misconceptions such as insulin treatment are indicated for severe cases and signified personal failure; insulin injections are only for old people have illustrated a significant lack of knowledge of diabetes and role of insulin among T2DM patients. Other social stigma such as the association of insulin injection with recreational drugs abuse and the embarrassment to self-inject insulin in public highlighted the need to raise public awareness of insulin injection. Many participants in this study suggested there should be more awareness of insulin treatment for the public and de-stigmatise the public misconception about injection. LM was being called names by her relatives and she felt being discriminated because of her T2DM and that she had to use insulin injection. Another 58 year old participant, BK sounded frustrated because how the public perceived her as sick person and she would like to be treated as 'normal'. They explicitly stated that there should be more awareness about T2DM and insulin treatment to the public:

LM: But everybody look at me [weird]... Social stigma. They think you are very odd... they should have awareness for the people.

BK: It's true that we have diabetes but the public shouldn't perceived us as sick people, we are not physically sick everyday and you can't tell who has diabetes and who need insulin. Insulin works well for me and I do not think that I am sick just because I inject insulin.

Due to the lack of knowledge and awareness of insulin injection in the general public, and the influence of media about recreational drug abuse, people are curious about the injection and the resultant the unwanted social stigma. PG felt that Malaysian society is not very educated on the subject of insulin and that people would comment about their injection and think that they were taking a recreational drug:

PG: Most people just don't know what you are doing, just too much on TV you know. People taking drugs and all this, people actually think you are jabbing yourself with don't know what. Once they know it is insulin, they couldn't be bothered... Need to be more open, people also need to think more openly.

PG suggested that there should be more awareness of insulin injection so that people are educated about it and they could be more supportive toward T2DM patients using insulin in public places. Increased public awareness might ease T2DM patients to be more comfortable about self-injecting, and also encourage other people to be more open minded towards insulin treatment (Chai et al. 2013b). Public education also needs to be focused on knowledge of

T2DM, not only the preventative measures but also the role of insulin treatment and in particular dealing with hypoglycaemic events. SR voiced the opinion that there should be an information card such as medical bracelets to be carried by T2DM patients who use insulin injection.

SR: They should know what medication or what are the things that you have, so that they are more aware. So if I am having hypo and any of my friend is nearby or there then they know what to do... If they have [something] that they can carry around saying that you are a diabetic patient that really helps. It is a kind of signal or a piece of info saying that you are a diabetic patient, if you have anything just to let the public that you are a diabetic patient. Only for fast action that's really helpful.

Medical-identification products are available via Diabetes Malaysia (PDM) but it was not greatly promoted and Malaysian public and even patients are not aware of the products (Diabetes Malaysia 2007). Medical-identification products can save time in an emergency event. They contain important medical information that is crucial for diagnostic purposes such as during a hypoglycaemic event. SR's statement also suggested that the awareness of hypoglycaemic event among the general public is very low. In fact, another participant, LT, also voiced the opinion that diabetes awareness is not 'out there'. Agreed by LT that information on T2DM and insulin treatment were not greatly promoted unlike cancer and cardiovascular diseases:

LT: All because of lack of awareness... The only awareness is only [seen] in hospitals. So it is not out there. Is not out there, it is not. Heart attack is out there, cancer is out there... But you can put your advertisement on midnight... but this is an awareness needed.

From the interview with LT, his comments suggested that there were much publicity on medication, healthy lifestyle, cancer and cardiovascular diseases, but not much information on T2DM and how to cope living with T2DM. LT mentioned, “*People who really want to spend money on medication but don’t want to spend money on awareness*”, he was referring to Malaysians in general who needed to be more educated on healthy lifestyle to prevent T2DM. Because the lack of awareness, they would suffer more when diagnosed with T2DM (hit the jackpot):

*LT: People who really want to spend money on medication but don’t want to spend money on awareness... All because of lack of awareness, when they needed it, when they **hit the jackpot** that time only they suffer... Actually they do, Malaysian government they only tell you [about] healthy lifestyle.*

LT used the analogy of ‘hitting the jackpot’ to describe the reaction of T2DM patients when they were diagnosed; he felt that it was like winning a lottery, an unexpected but unfortunate event due to the lack of awareness. He suggested that the public should spend more effort to prevent T2DM rather than spending money on treatment (quick fix). This comment highlighted that in general, the

Malaysian public does not have the adequate knowledge about diabetes and insulin treatment.

It is important to incorporate insulin treatment in educational campaign to create an awareness of the importance of insulin injection for T2DM patients. This would aim at improving the health literacy of the general public, in particular to de-mystify and de-stigmatise self-injecting of insulin in public. Raising public awareness of T2DM and the role of insulin is vital to allay the negative attitude towards insulin treatment. Awareness can be promoted via local television or social media, such as having a character in a drama or video clip playing T2DM patient who required insulin injection. It would help the audience understand the difference between recreational drugs and insulin injection, and also the importance of insulin treatment to some T2DM patients. Ultimately, patients' understanding of and adherence to appropriate diabetes self-management practices would only able to be translated into practice if the perception of social stigma is alleviated (Brod et al. 2009).

7.5 Chapter Summary

Social stigma and embarrassment are the key factors related to psychological insulin resistance. The association of insulin injection and recreational drug abuse has resulted in fear to use insulin injection in public, thus causing poor adherence. The availability of modern insulin pen devices has enabled patients to inject more discretely. Understand patients' lifestyle and needs, and starting patients with basal insulin or longer acting insulin analogues regimens can also eliminate this barrier for some patients.

Raising public awareness via television and social media should help to demystify and de-stigmatise self-injecting of insulin in public. Alleviation of social stigma should facilitate T2DM patients to adhere to insulin treatment and improve self-management. At the same time, public education campaigns should include information on hypoglycaemic events, which might experience by T2DM patients on insulin treatment. There is a need to promote medical-identification products to T2DM and the general public, such identification can save time in an emergency as medical identifications provide emergency personnel with important information that allows them to act quickly.

CHAPTER 8

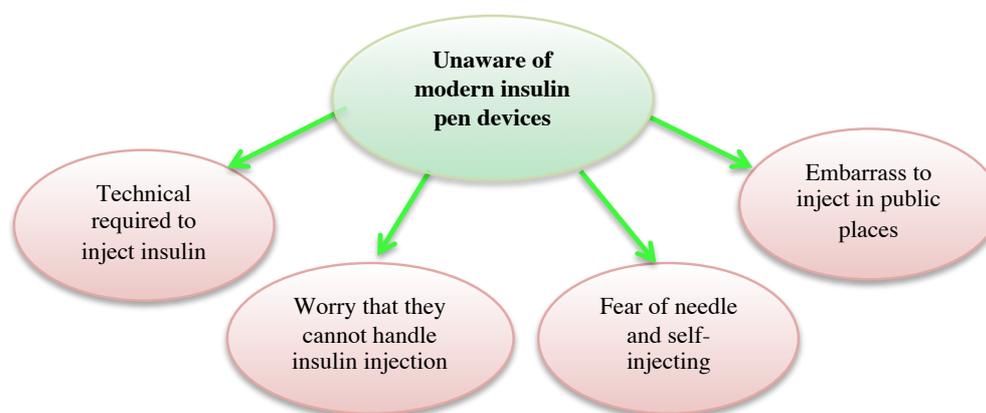
CONCLUSION

8.1 Practice Implications

The findings of this study have provided valuable insights that further our understanding of the complexities of initiating insulin treatment among T2DM patients in Malaysia and how they perceive insulin treatment. This section draws on the findings of this study and presents the implications for healthcare providers working in the field.

This study raises several issues that are of importance to T2DM patients in Malaysia. The findings of this study suggest that there is a lack of awareness of modern insulin pen devices. Many patients associate insulin injections with past experiences with injections such as vaccinations, which is a complicated procedure and involves drawing medicine from glass vials via needles and administered either via intramuscular or intravascular (Tan et al. 2011; Korytkowski 2002). As a result, patients perceive that injecting insulin is a complicated procedure, which required intensive technical training and precision. Additionally, patients would relate injection to syringe and needles and fear of needles and perception of pain (see Figure 9 Consequences of lack of awareness of modern insulin pen devices).

Figure 9 Consequences of lack of awareness of modern insulin pen devices



The development of insulin pen devices has greatly reduced these negative perceptions. Ease of learning how to use a modern insulin pen is a crucial factor for encouraging early acceptance of insulin treatment (Spollett 2008). The availability of modern insulin pen devices is particularly useful for insulin-naive patients, elderly patients, and those patients with visual or manual dexterity disabilities. Modern insulin pen devices are not only easy to handle, easy to use, but also can improve dosing accuracy compared with conventional needles and syringes (Meece 2008). The pen-shaped design of insulin injection also provides more flexibility and convenience to patients; their compact size allows ease to carry around and discreet insulin administration.

Thus, many barriers of using insulin injections could be addressed at the early stage of T2DM by making patients aware the availability of modern insulin

pen devices. It would be particularly beneficial for those patients who have not seen insulin pen devices before; healthcare providers could demonstrate the injecting procedure and let the patients experience handling the pen devices. During counselling, emphasis should be placed on both practical and emotional support in order to help patients to accept insulin treatment and become more self-efficient to use insulin injection.

To alleviate the negative perceptions of insulin injection by Malaysian society, educational campaigns directed to the public are needed to raise awareness of diabetes and the important role of insulin treatment; subsequently to ease the patients with Type 1 and Type 2 diabetes mellitus to be more acceptable about self-injecting in public. These campaigns should encourage society to be more open minded towards insulin treatment and address the current social stigma toward self-injecting insulin in public.

Awareness of T2DM and role of insulin injections should be promoted to a wider community not limited to only healthcare facilities. The Malaysian Health Promotion Board, MySihat (Sihat means Health in Bahasa Malaysia), was established in 2006 to support non-profitable organisation and community empowerment (Kaur et al. 2011). MOHM and MySihat could evolve to take on a bigger role in enhancing diabetes awareness in Malaysia. This could be promoted at many levels, including schools, work places, and community events across the country. It should also be promoted in the media to a wider range of audience via local television or social media, such as having an acting character in a drama or video clip portraying T2DM patient who is using

insulin injections. It would help the audience understand the difference between recreational drugs and insulin injection, and also the importance of insulin treatment to some T2DM patients. The perception of social stigma need to be addressed so patients' understanding of and adherence to insulin treatment only able to be translated into practice.

Early diabetes education should make T2DM patients more aware of the progressive nature of T2DM and the function of insulin, this would better prepare them mentally for insulin treatment in the future especially to allay the negative perception of personal failure. This suggestion to have early discussion about insulin treatment corresponded to the suggestion by Hassali et al. (2013).

Healthcare providers across different disciplines such as doctors, pharmacists, and diabetes nurses should have a systematic program in place for early diabetes education to enhance the patient's knowledge and awareness. Healthcare providers should provide adequate but simplified practical support together with emotional support when suggesting insulin treatment. Patients' concerns relating to insulin dosing need to be addressed early on and healthcare providers also need to take into account of individual patients' needs and tailor the insulin treatment to fit into patients' lifestyles.

Starting T2DM patients on a simple insulin regime such as once-daily injection with insulin glargine is a good strategy to overcome the fear and worry that insulin treatment is restrictive and complicated to handle. Simpler insulin

regimes provide more freedom and convenience, therefore causing minimal disruption to a patient's daily activity and therefore would ease the transition from oral anti-diabetic medication to insulin treatment. Practical and emotional support are both important to help patients getting into routine and minimising the disruption to their lifestyle.

8.2 Reflexivity: Practical Application in the Study

Reflexivity means sensitivity to the ways in which the researcher and the research process have shaped the collected data, taking account of the researcher's own personal experiences, theoretical biases, recognising the role of values and a priori assumptions in shaping any research account (Murphy et al. 1998; Mays & Pope 2000)

Theoretical considerations about reflexivity for qualitative research have been discussed in section 2.3. In this study, I have employed an interpretative phenomenological analysis (IPA) approach, in which I had to try to understand patients' lived-experience and how they made sense of their experiences. I tried to explore personal experience through an interpretative process. (Biggerstaff & Thompson 2008). IPA also considers that one cannot get close to the participant's personal world directly or completely, it is a two-stage interpretation process, hence a double hermeneutic (Smith & Osborn 2008). This hermeneutics interpretative process must also depend on the researcher's own conceptions, which are required to understand the participant's world through another level of interpretative activity.

I have attempted to present the participants' perspectives as truthfully and honestly as I can in this thesis. I recognise that this thesis is the product of the interaction between the participants and myself and is socially contingent. The data were constructed and interpreted by the patients and interpreted by myself

and are affected by a variety of factors such as age, sex, social class, and professional status (Mays & Pope 2000).

During the first few interviews with participants, I introduced myself as a pharmacist and subsequently I had noticed that my role hindered me from building a good rapport with the participants (see section 2.4.8). There were a few occasions in the interviews where participants asked me health-related questions. Participants were asking my opinion on insulin injection, which I did not want the participants perceiving my role as a pharmacist. This could lead to interviewee giving response he or she thinks a health professional wants and therefore data collected would not be as truthful as it should be (Britten 1995). Questions asked by MZ and YLC below were targeted to a healthcare professional, which I did not feel comfortable giving my opinion:

MZ: I think I want to stop [using insulin]. Can you be off insulin?

YLC: Different companies? Or different stage of patients using different needle? The needle and the insulin itself? Because the insulin I use is different and my brother used different.

In the subsequent interviews which I had finely-tuned my interview skills; I introduced myself as a PhD research student instead of mentioning my pharmacist role. However my pharmacist background has given me an advantage especially in terminology and clinical knowledge. There were

numerous occasions in the interviews where participants referred to a medical procedure such as angioplasty, or a name of a medicine. This might have been a problem if the interviewer did not have a clinical or hospital background; it might be an obstacle of the flow of conversation because patients expected the interviewer to resonate with the contents of their conversations.

However, my pharmacist background also posed a limitation in this study. As much as I tried to suspend my clinical knowledge, there was occasion when I finished participants' sentences especially when they were referring to a medical terminology and they had difficulty with the terminologies. These interruptions might divert the participants from explaining more in-depth about a particular situation and how they dealt with it.

Besides my pharmacist background, being Malaysian and understand the local slang give me an advantage as well during interviews. The majority of the interviews were conducted in English, but there were many occasions when the participants would use local slang and mixed languages which is the feature of how Malaysians talk. A few occasion the participants used Tamil language in the interviews but I was no able relate to. The majority of participants would use a few Bahasa Malaysia terms or expressions in the interviews such as "teruk", "aiyah". Overall it did not hinder the flow of conversation because the participants expected me to know what they meant. I was not very fluent with Bahasa Malaysia during some of the interviews, which the participants were not able to understand English. I found that I could not build a good rapport as well as those interviews conversed in English language. There was more

degree of interpretation necessary in order to justifiably articulate the participants' perspective. My understanding of the content was an interpretation of my understanding at the time rather than necessarily what they actually meant. Having that in mind, future research will be required to explore patients' perspectives of insulin in different cultural groups by interviewers who can speak the same language to obtain rich data and also avoid the context 'lost in translation'.

8.3 Limitations

All research studies have limitations and these should be taken into account when interpreting the findings. This study was designed to be undertaken in one public hospital in the government administrative town in Malaysia. Therefore the transferability of the findings to other settings will be challenging. Murphy et al. (1998) stated that generalisations of the rationalistic variety are not possible because phenomena are intimately tied to the times and contexts in which they are found. The theories developed from this study at PH might not be able to be applied to patients who sought treatment from a rural hospital; the findings might, however provide explanatory theory for the experiences of other patients who are in comparable situations from similar background.

Recognition needs to be given to the differences in experiences, which can be attributed to cultural background. Whilst some experiences were common across these participants there were certainly experiences that were unique to participants from different ethnic groups. This limitation of the current study has opened up a potential area that could be addressed by future research (see section 8.4 Future Research).

8.4 Future Research

This study has highlighted future research that could help to further detail patients' perceptions of insulin treatment in different cultural groups and in rural areas as well, where patients' beliefs about insulin use may be different. Prevalence of T2DM are seen among Malay, Chinese and Indian, the three major ethnic groups in Malaysia (refer Figure 1), therefore future research is required to better understand and observe the differences in perceptions between ethnicity groups. This would help to determine which approaches and strategies would facilitate insulin acceptance and help improve the psychological care of diabetes patients within particular ethnicity groups.

Patients' perceived barriers to initiate insulin treatment and their perceptions have attracted many researchers in Malaysia (Abu Hassan et al. 2013; Lee et al. 2012; Lee et al. 2013; Nur Azmiah et al. 2011). There are many findings reported from patients' perspectives and also from healthcare providers (Abu Hassan et al. 2013; Chai et al. 2013a; Lee et al. 2012), these findings could be used to design quantitative research to further enhance and established the phenomenon of psychological insulin resistance.

8.5 Concluding Remarks

To study the phenomenon of diseases without books is to sail an uncharted sea, while to study books without patients is not to go to sea at all
(William Osler)

There is an increasing global trend for countries to invest in understanding patients' health experiences (Ziebland et al. 2013). This study aim has generated Malaysian T2DM patients' accounts of their experiences with insulin treatment as part of their glycaemic control. In this thesis, I have presented an insight of T2DM patients and their experiences of managing their glycaemic control with insulin treatment in the 'real world'. It allows us to understand what was important to a lay person as a diabetic patient in Malaysia, in particular the barriers perceived by a lay person regarding insulin treatment, and also the facilitators or motivators to adherence to the treatment.

This study used qualitative methods in order to provide an explorative investigation of the lived-experiences of the participants. I have employed qualitative methods in order to preserve the complexities of human behaviour, this research method enabled me to focus on the meanings, experiences, and views of people, such as why do patients worry about using insulin treatment and how do patients adapt to insulin treatment in their daily activities. This approach is particularly useful in unveiling patients' lived-experiences because the relevant variables associated with an outcome are not apparent. I have

employed face-to-face, semi-structured interviews with participants to obtain answers to the aims and objectives of this study. Face-to-face interviews provided a rich description of how 'real' T2DM patients experienced their diabetes in everyday life and how they contextualised their experiences.

One of the findings about patients' reactions to initiation of insulin is that their response is greatly influenced by their prior exposure and encounters with insulin injections. Patients with prior knowledge of insulin injections, such as close friends and relatives who are on insulin, react more calmly to the suggestion of insulin treatment. This could be due to the fact that the majority of Malaysians often live in a close-knit society, with patients' experiential learning and observing of others managing T2DM with insulin injection, this group of patients are therefore more aware of the efficacy of insulin treatment. They also exhibit motivation to achieve a better control of T2DM and to prevent its complications. Another facilitator to initiate insulin treatment is believing that insulin is effective to warrant a better quality of life. 'Thinking of the future' encourages patients to accept insulin treatment because they want a better quality of life and not to depend or burden their family members.

On the other hand, patients with poor knowledge or no prior exposure to insulin injection are often reluctant to accept insulin treatment. This could also be attributed to the lack of awareness of the modern insulin pen devices and the influences of past experience with injection. The portrayals of syringes and needles in media and the government initiatives against recreational drug abuse also play an important role at influencing T2DM patients' perceptions of

insulin and contributed to the well-documented psychological insulin resistance (PIR). They often perceived that injecting insulin was a complicated procedure involving needles, syringes and vials, and required intensive technical training and precision. As a result, some T2DM patients have a great difficulty to accept insulin treatment because they often worry that they are not capable of handling insulin injecting without medical assistance.

Psychological insulin resistance such as personal failure and embarrassment are reported by many other studies, which ultimately contributed to the initial fear of accepting insulin treatment, and also affecting the adherence of insulin injection (Polonsky et al. 2005; Nur Azmiah et al. 2011; Brod et al. 2009; Abu Hassan et al. 2013). The misconceptions that T2DM progressed unidimensionally and about the need to initiate insulin indicating a personal failure have shown the lack of knowledge of T2DM and the role of insulin treatment. A sense of personal failure and embarrassment regarding injecting insulin in public also resulted in poor adherence to insulin treatment. Typically, T2DM patients with such psychological insulin resistance could rather skip or delay their insulin injection during the daytime or when they are out and about. They preferred to inject insulin away from public and often hide in a toilet or in their car while injecting. Or they would inject the dose at home before going out or skip the dose entirely. Because of the sense of embarrassment and the lack of social acceptance of self-injecting insulin in public, patients often feel that their insulin injection has restricted their freedom, and taking control of their life. These factors have resulted in poor

acceptance of insulin injection and resulted in many T2DM patients not achieved good glycaemic control even though they are on insulin treatment.

The extent of psychological insulin resistance is magnified if the patients need to inject insulin more than once daily, especially if they required an afternoon dose of insulin. Patients were often reluctant to self-inject insulin in public because the fear of social stigma. In general, the Malaysian public is not well educated on the subject of insulin treatment. Often people would associate any self-injection to recreational drug abuse. As a result, many participants felt uncomfortable to self-inject insulin in the public places. On top of the social phobia, patients often find it hard to cope with a midday injection because the uncertainty of what food to eat and the timing of injection. Some patients might feel that they are being force into changing their lifestyle because of insulin injection, thus the perception of lifestyle restriction. Some patients adapted into the routine quicker than others, often because they were started on basal insulin and with adequate trainings on the injecting technique and counselling.

Effective counselling and early education facilitate the acceptance of insulin treatment, especially the metaphors used to describe the mode of action of insulin. Many Malaysians believe that western medicine could potentially be 'deposited' in the body after consumption, and therefore would cause undesired side effects such as organ damage. In comparison, insulin injections would be injected directly into the bloodstream to exert its effect. Patients

believed that insulin injection would just replace their own dysfunction insulin and it should be more 'natural' compared to oral anti-diabetic medication.

Therefore, it is crucial for healthcare providers in Malaysia to be aware of the health literacy and cultural considerations among the patients. It is hoped that these would be integrated into the health delivery system in Malaysia to empower patients, improve patients' self-efficacy and thus improve care and health outcomes.

The experiences of T2DM patients using insulin treatment have provided novel insights into patients' perception of diabetes management. The findings from this research offer the potential for healthcare providers and other organisation working in the diabetes field to improve patient care and adherence to diabetes medication, therefore prevent diabetes complication and subsequently reduce cost as a result from the better health outcomes.

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Appendix 1: Patient Information Sheet

	PATIENT INFORMATION SHEET	 The University of Nottingham <small>UNITED KINGDOM · CHINA · MALAYSIA</small>
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Patients' Experience of Insulin Therapy for Type 2 Diabetes Management *Pengalaman Pesakit dalam Terapi Insulin untuk Pengurusan Diabetes Jenis 2*

About the Study: You are invited to take part in a study which is exploring your experience of using insulin therapy.

Perihal Kajian: Anda dijemput untuk menyertai dalam satu kajian yang berkaitan dengan pengalaman anda dalam penggunaan terapi insulin.

Purpose of the Study: Currently, very little research has explored this issue in Malaysia. We would like to better understand some of the barriers and potential solutions so that we are able to improve any future service development in this area.

Tujuan Kajian: Pada masa kini, penyelidikan di Malaysia yang berkaitan isu ini amat terhad. Kami ingin mendalami dan memahami segala rintangan serta merumuskan suatu penyelesaian yang berpotensi supaya kita dapat menimbang balik tentang kemajuan dalam perkhidmatan berkaitan bidang ini pada masa hadapan.

Participation: Participating in this study is voluntary and will involve being interviewed by a researcher, which will take around 1 hour. The interview will be tape recorded and later transcribed and you may be quoted anonymously (no name mentioned) in publications, e.g. reports and published papers. Even if you agree to being taped, you may choose to have the recorder turned off at any time and withdraw from the interview without any negative outcome or prejudice.

Penyertaan: Penyertaan dalam kajian ini adalah secara sukarela dan peserta akan ditemuramah oleh seorang penyelidik, yang akan mengambil masa kira-kira 1 jam. Temuramah ini akan dirakamkan dan kemudian disalin dan anda mungkin dipetik tanpa nama (nama tidak disebut) di dalam penerbitan, contohnya laporan dan kertas yang diterbitkan. Malah jika anda bersetuju untuk dirakam, anda berhak untuk meminta perakam itu dimatikan pada bila-bila masa dan menarik diri daripada temuramah itu tanpa apa-apa hasil yang negatif serta prejudis.

Confidentiality: If you choose to participate in this study, the research processes will provide confidentiality for you. If the information you provided is reported or published this will be done anonymously. All attempts will be made to protect the identity of interviewees, and places or persons mentioned in the interviews, although for some individuals who are representing professional or other organisations, it might be possible for someone who knows them to identify them as a source. Transcriptions will be kept for six years for future reference for the purposes of publication of reports or peer reviewed publications and will be stored in a locked filing cabinet separate from consent forms. After this time period it will be professionally destroyed.

Kerahsiaan: Jika anda memilih untuk menyertai dalam kajian ini, proses penyelidikan akan menyimpan segala maklumat secara rahsia. Jika maklumat yang anda berikan dilaporkan atau diterbitkan, ia akan dilakukan tanpa nama. Segala usaha akan dibuat untuk melindungi identiti bagi orang yang ditemubual dan tempat atau seseorang yang disebut dalam temu bual itu, walaupun bagi sesetengah individu yang mewakili profesional atau organisasi yang lain-lain, ia mungkin mustahil bagi seseorang yang mengetahui mereka untuk mengenal pasti mereka sebagai sumber. Transkripsi akan disimpan selama enam tahun untuk rujukan masa depan bagi tujuan penyiaran laporan atau penerbitan kaji-semula dan akan disimpan di dalam almari berlaci yang dikunci berasingan daripada borang keizinan. Selepas tempoh masa ini, ia akan dimusnahkan secara profesional.

Results: The information that you provide will be used to help us plan future research and service provision in this area. You will also be able to request a summary of the research.

Keputusan: Maklumat yang anda berikan akan digunakan untuk membantu kami merancang penyelidikan masa depan dan peruntukan perkhidmatan dalam bidang ini. Anda juga boleh memohon untuk mendapatkan rumusan penyelidikan.

Further information: If any further information is required by the participant, he/she is free to contact the researcher, Jim Chai, via email: khyx1jch@nottingham.edu.my or local supervisor, Mr. KT Wong via email: Kok-Thong.Wong@nottingham.edu.my.

Maklumat Lanjut: Jika ada apa-apa maklumat lanjut yang diperlukan oleh para peserta, sila hubungi penyelidik, Jim Chai, melalui e-mel: khyx1jch@nottingham.edu.my atau penyelia tempatan, Encik KT Wong, e-mel: Kok-Thong.Wong@nottingham.edu.my.

Appendix 2: Research Consent Form

<i>Patient's Copy</i>	PATIENT CONSENT SHEET	 UNITED KINGDOM · CHINA · MALAYSIA
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Patients' Experience of Insulin Therapy for Type 2 Diabetes Management Pengalaman Pesakit Insulin Terapi untuk Diabetes Pengurusan

1. I confirm that I have read and understand the information sheet dated 5/8/2011 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
Saya mengesahkan bahawa saya telah membaca dan memahami lembaran maklumat yang bertarikh 5/8/2011 untuk kajian di atas. Saya akan berpeluang untuk mempertimbangkan maklumat, bertanya soalan dan mendapatkan jawapan yang memuaskan.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
Saya faham bahawa penyertaan saya adalah secara sukarela dan saya bebas untuk menarik diri pada bila-bila masa, tanpa memberi apa-apa sebab, tanpa menjejaskan hak undang-undang saya.
3. I understand that relevant data collected during the study, may be looked at by responsible individuals from The University of Nottingham. I give permission for these individuals to have access to this data.
Saya faham bahawa data yang berkaitan adalah dikumpulkan semasa kajian, boleh dilihat oleh individu yang bertanggungjawab dari University of Nottingham. Saya memberikan kebenaran untuk individu-individu ini mendapatkan maklumat daripada data ini.
4. I give my consent for the audio-taping of interview as described in the information sheet.
Saya memberi persetujuan saya bahawa temuramah boleh dirakamkan seperti yang diterangkan di dalam lembaran maklumat.
5. I give my consent for anonymised direct quotes to be used in reports and publications.
Saya memberikan persetujuan saya bagi pemetikan langsung tanpa nama yang akan digunakan dalam laporan dan penerbitan.
6. I agree to take part in the above study.
Saya bersetuju untuk menyertai dalam kajian di atas.

Name of Participant

Date

Signature

Researcher

Date

Signature

Appendix 3: Interview Topic Guide

What is the experience of being diagnosed with diabetes?

- When did you find out having diabetes?
- How that happened?
- Anyone in our family with diabetes?
- Do you remember what medications were prescribed?
- Anything thing in your daily changes after you found out about diabetes?

What is the experience of using insulin to control diabetes?

- When was insulin introduced?
- Why did the doctor start you on insulin?
- How did you react when insulin was mentioned as part of your treatment plan?
- How much do you know about insulin back then?
- How did you find it using insulin injection initially?

What influences these experiences?

- When the doctor started you on insulin, was your family around?
- How did you tell them about the news?
- What was their reaction?
- How about people you work with, do they know?
- How about your friends, what do they think about insulin?

How do patients' perspectives of insulin treatment change overtime?

- How do you adapted to insulin treatment?
- What changes do you have to make after using insulin injection?
- If someone who has reluctant to use insulin, how would you advise them?

Appendix 4: NMRR Approval Letter



PEJABAT TIMBALAN KETUA PENGARAH KESIHATAN
OFFICE OF THE DEPUTY DIRECTOR-GENERAL OF HEALTH
(PENYELIDIKAN & SOKONGAN TEKNIKAL)
(RESEARCH & TECHNICAL SUPPORT)
KEMENTERIAN KESIHATAN MALAYSIA
MINISTRY OF HEALTH MALAYSIA
Aras 12, Blok E7, Parsel E, Presint 1
Level 12, Block E7, Parcel E, Precinct 1
Pusat Pentadbiran Kerajaan Persekutuan
Federal Government Administrative Centre
62590 PUTRAJAYA

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Faks : 03-88895184

JAWATANKUASA ETIKA & PENYELIDIKAN
PERUBATAN
KEMENTERIAN KESIHATAN MALAYSIA
d/a Institut Pengurusan Kesihatan
Jalan Rumah Sakit, Bangsar
59000 Kuala Lumpur

Ruj. Kami : (2) dlm.KKM/NIHSEC/08/0804/P11-544
Tarikh : 23 Disember 2011

Encik Jim Chai
Fakulti Sains
Universiti of Nottingham
Kampus Malaysia

Tuan,

NMRR-11-488-9663

Patients' Experience of Insulin Therapy for Type 2 Diabetes Management

Lokasi Projek : Hospital Putrajaya

Dengan hormatnya perkara di atas adalah dirujuk.

2. Jawatankuasa Etika & Penyelidikan Perubatan (JEPP), Kementerian Kesihatan Malaysia (KKM) mengambil maklum bahawa projek tersebut adalah untuk memenuhi keperluan akademik Program Doktor Falsafah Farmasi, Universiti of Nottingham Kampus Malaysia.

3. Sehubungan dengan ini, dimaklumkan bahawa pihak JEPP KKM tiada halangan, dari segi etika, ke atas pelaksanaan projek tersebut. JEPP mengambil maklum bahawa kajian ini tidak melibatkan sebarang intervensi dan hanya temuramah pesakit untuk mengumpul data kajian. Segala rekod dan data pegawai adalah SULIT dan hanya digunakan untuk tujuan kajian dan semua isu serta prosedur mengenai *data confidentiality* mesti dipatuhi. Kebenaran daripada Pengarah Hospital di mana kajian akan dijalankan mesti diperolehi terlebih dahulu sebelum kajian dijalankan. Puan perlu akur dan mematuhi keputusan tersebut.

4. Laporan tamat kajian dan sebarang penerbitan dari kajian ini hendaklah dikemukakan kepada Jawatankuasa Etika & Penyelidikan Perubatan selepas tamatnya projek ini.

Sekian terima kasih.

BERKHIDMAT UNTUK NEGARA

Saya yang menurut perintah,

(DATO' DR CHANG KIAN MENG)
Pengerusi
Jawatankuasa Etika & Penyelidikan Perubatan
Kementerian Kesihatan Malaysia

Appendix 5: Demographic Data

The aim of the study was to conduct semi-structured qualitative interviews with a sample of T2DM patients who are using insulin treatment as part of their diabetes control to explore their experience of using insulin treatment. More than 100 patients were approached but only forty-two patients agreed to be interviewed. Patients with Type 1 Diabetes Mellitus or gestational diabetes were excluded from the study. Patients who had emergency insulin treatment were also excluded. In total thirty-seven T2DM patients who were currently using insulin treatment were interviewed.

Demographic data of the participated patients are summarised in Table 6. More than Thirty-seven T2DM patients were interviewed; all of the patients were Malaysian. The average years of diagnosing with T2DM is 13.6 years and the average HbA1c is 8.88%. The mean HbA1c reported by the Malaysia Diabetes Clinical Audit (2011) was 8.2% (Abdul Rahman 2012)

There were 24 male and 13 female patients who participated in the study. 17 patients were Malay, nine patients were Chinese, eight patients were Indian; followed by two mixed races patients and one patient was from Iban (indigenous tribe from Sarawak state of East Malaysia) background (refer to Table 5 and Figure 10).

The National Health and Morbidity Survey 2011 reported the Indians had the highest prevalence of T2DM at 24.9%, followed by the Malays at 16.9% and Chinese at 13.8% (Kaur et al. 2011). There were more Malay patients recruited

than Indians despite the prevalence of diabetes is highest among Indians, this is because the Malays was the predominant ethnic group in Peninsular Malaysia which constituted 63.1% (Department of Statistics Malaysia 2011).

Table 5 Summary of patients' particulars

Total Participants	37
Race	
Iban	1
Chinese	9
Malay	17
Indian	8
Mixed	2
Average years of T2DM	13.57
Average HbA1c	8.88%
Average number of Insulin	1.4
Average number of OAM	4.1

Figure 10 Ethnicity of participated patients

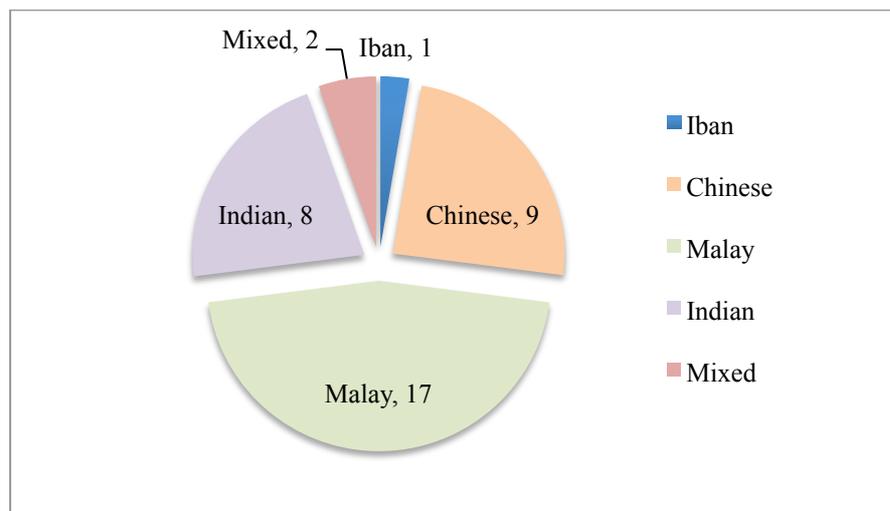


Table 6 Demographic data of participated patients

Patient	Age	Gender	Race	Language Used in Interview	No. of Co morbidity	Length of T2DM (Year)	HbA1c (%)	No. of Insulin	No. of OAM
AH	53	Male	Malay	Malay	2	6	14.6	1	3
AM	68	Male	Malay	Malay	2	11	6.7	1	5
AZ	50	Female	Malay	English	3	10	8.2	2	5
BK	58	Female	Indian	Malay	2	21	13.9	1	5
CH	50	Male	Chinese	English	2	17	7.2	1	6
E	59	Female	Malay	English	2	8	7.6	1	3
ET	55	Male	Iban	English	2	27	9.1	1	3
HH	51	Male	Malay	Malay	2	8	8.9	1	6
HT	59	Male	Chinese	English	3	26	8.1	1	5
KK	58	Male	Chinese	English	2	10	6.5	1	5
LM	61	Female	Indian	English	1	15	8.4	2	1
LR	50	Female	Indian	English	1	20	8.6	2	2
LT	36	Male	Chinese	English	1	25	7.7	1	3
LV	35	Female	Indian	English	3	2	12.7	1	4
MJ	60	Male	Malay	English	3	7	7.7	1	6
MM	52	Male	Malay	English	2	19	8	1	4
MR	38	Male	Malay	English	4	6	8	2	4
MY	51	Male	Malay	English	2	2	6.30	2	2

Patient	Age	Gender	Race	Language Used in Interview	No. of Co morbidity	Length of T2DM (Year)	HbA1c (%)	No. of Insulin	No. of OAM
MZ	60	Female	Malay	English	2	22	9.3	2	4
NA	44	Female	Malay	English	1	3	9.3	1	2
NR	30	Male	Malay	Malay	3	3	8.4	1	4
PG	52	Male	Mixed	English	1	11	9	1	3
RK	61	Male	Indian	English	6	4	8.7	2	5
S	65	Female	Malay	English	4	17	7.6	1	6
SA	60	Male	Indian	English	2	32	7.9	2	5
SL	50	Female	Indian	English	1	5	10.6	2	5
SR	46	Male	Indian	English	2	16	7.6	2	6
TC	69	Male	Mixed	English	3	13	6.9	1	5
WM	50	Female	Chinese	English	2	25	7.7	2	3
YF	52	Male	Chinese	English	2	12	11.4	2	3
YHK	52	Male	Chinese	English	3	21	13.3	2	7
YLC	56	Female	Chinese	English	5	15	6.7	1	4
YP	66	Male	Chinese	English	2	18	7.3	1	5
ZA	46	Female	Malay	English	1	13	9.1	1	3
ZM	56	Male	Malay	Malay	1	10	11.1	2	6
ZT	42	Male	Malay	Malay	1	17	7.5	2	2
ZZ	40	Male	Malay	English	3	5	11.1	1	3