

**PATIENTS' UNDERSTANDING OF DIABETES SELF-  
MANAGEMENT EDUCATION AND SUPPORT IN A PRIVATE  
PRIMARY CARE CLINIC IN KUALA LUMPUR:  
A QUALITATIVE STUDY**

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KUALA LUMPUR**

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**ABSTRACT**

Patients with diabetes mellitus should be actively self-managing their disease, since this can aid in producing better glycaemic control. Thus healthcare professionals managing diabetes patients, irrespective of whether they are in the public or private setting, need to focus on educating patients in order to empower them to carry out self-management practices. Little evidence is available to determine whether patients, especially those managed in private primary care clinics, are able to understand the education provided to them on diabetes self-management. This study aimed to explore patients' comprehension of content and perception regarding delivery and quality of diabetes self-management education at a private primary care clinic in Kuala Lumpur, Malaysia. Qualitative in-depth interviews were carried out via Zoom with 21 diabetes mellitus patients being followed-up for at least 6 months at the chosen private primary clinic. Most respondents felt overwhelmed with the information given during the DSME, were mostly satisfied with quality of the delivery of DSME but not so with the deliverer of the DSME, and majority of the respondents felt that the instructional delivery of DSME did not influence either their self-efficacious behaviour nor their health literacy. Patients being followed-up in a private primary care clinic seem to have shortcomings in comprehending DSME, with further research and interventions necessary to improve patient outcomes in the Malaysian setting.

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**ABSTRAK**

Pesakit yang menghadapi diabetes mellitus sepatutnya lebih aktif mempraktikkan pengurusan sendiri supaya membantu mereka memastikan penyakit mereka dalam kadar terkawal. Para professional kesihatan, tidak kira samada di sektor kerajaan atau swasta, sepatutnya memberi tumpuan untuk mendidik pesakit supaya mereka diperkasakan untuk melakukan pengurusan sendiri diabetes bagi diri mereka. Bukti kajian sebelum ini tidak begitu kukuh dalam menentukan samada pesakit dapat memahami pendidikan yang diberikan kepada mereka dalam mengajar mereka tentang pengurusan sendiri. Kajian ini bertujuan meneroka pemahaman pesakit mengenai kandungan dan persepsi mereka tentang teknik serta kualiti pengajaran mengenai pengurusan sendiri diabetes di sebuah klinik primer swasta di Kuala Lumpur Malaysia. Temuduga mendalam kualitatif dijalankan melalui Zoom bersama 21 pesakit diabetes yang menerima rawatan susulan sekurang-kurangnya 6 bulan di klinik primer swasta tersebut. Kebanyakan pesakit berasa diberikan terlalu banyak maklumat mengenai pengurusan sendiri; berasa puas hati dengan kualiti penyampaian tetapi tidak begitu puas hati dengan penyampai maklumat tersebut. Kebanyakan pesakit merasakan pengajaran tentang pengurusan sendiri ini tidak mempengaruhi sikap seharian mereka atau kadar literasi kesihatan. Pesakit yang menerima rawatan susulan di klinik primer swasta mungkin mempunyai kekurangan dalam memahami pengajaran yang diberikan mengenai pengurusan sendiri diabetes. Lebih banyak kajian dan intervensi perlu

djalankan untuk memperbaiki situasi ini supaya dapat meningkatkan kadar pesakit diabetes yang mempunyai kadar penyakit yang terkawal dikawal di Malaysia.

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## CHAPTER 1: INTRODUCTION

### 1.1 Study Background

The entire world is now concerned with the transmissible or communicable disease called the 2019 novel coronavirus (SARS-nCOV-2) which started from a district called Wuhan in China (Lipsitch et. Al., 2020). As of latest situation reports dated 1/4/2020 from situation reports no. 72, WHO, 2020, there are 1,279,722 confirmed coronavirus cases and 77,634 coronavirus deaths cases worldwide. However, the noncommunicable disease such as diabetes mellitus, hypertension, cardiovascular diseases, cancer, and many more are causing a much higher number of mortalities among us. It has caused a whopping 36 million (63%) out of 57 million deaths worldwide in 2008. Diabetes mellitus alone caused 1.3 million deaths (Alwan et. al., 2010).

On the home front, the National Health and Morbidity Survey 2019 (NHMS) reported that one in every five adults over the age of 18 years old have diabetes. This is equivalent to 3.9 million of the adult population living with diabetes. The prevalence of adults who did not know that they have diabetes had rocketed to 8.9% in 2019 compared to 4.0% in 2011. Whereas adults have been diagnosed with diabetes have shown steady increase from 7.2% in 2011 to 9.4% in 2019. If we were to see the prevalence of diabetes according to age groups; the age group from 18-29 years had the lowest prevalence (0.6%) of diabetes being diagnosed compared to age group 60 years and above who had the highest prevalence of diabetes (30.4%) being diagnosed. The highest prevalence (12.4%) of adults who did not know that they had diabetes was from age group 40-49 years of age. The states of Negeri Sembilan, Perlis and Pahang had a prevalence of 33.2%, 32.6% and 25.7% respectively. These three states had among

highest number of diabetic patients in Malaysia. In Kuala Lumpur, the prevalence of diabetes is between 16.22% to 18.12%.

*“Those labouring with this Disease, piss a great deal more than they drink. Authors who affirm the drink to be little or nothing changed are very far from the truth, because the urine very much differed both from the drink taken in and also in being wonderfully sweet as if it were imbued with honey or sugar”.*

*THOMAS WILLIS (1621–75), THE PISSING EVIL*

Araetus of Cappodocia (81-138 AD) had used the term diabetes which is of Greek origin; meaning ‘to pass or flow through’ (i.e. excessive urination) and it was Thomas Willis in 1675 who added the word mellitus meaning ‘honey sweet’ to the above Greek word (Ahmed,2002) . This gave rise to the terminology of Diabetes Mellitus that we use today. It is a disease caused by a relative or absolute deficiency of insulin. If, 30 years ago diabetes mellitus was known to be disease of the old age; currently it knows no boundaries of age gender, race, and religion. Our fast-paced world with our sedentary lifestyle secondary and automation of every aspect of lives has given rise to several bad lifestyle modifications in our lives.

NHMS, (2019) reported that Malaysians have among the highest intake of sugary drinks in Southeast Asia. About 53.2% of Malaysians take self-prepared drinks with 3 teaspoons of sugar in each cup of drink. Another 4.2% take carbonated and noncarbonated drinks with 6 teaspoons of sugar in each serving. Lastly, about 6.7% of Malaysians take premixed drinks which contains 3 teaspoons of sugar in each serving. NHMS, (2019) also reported that 95% of Malaysians do not eat the recommended daily amount of vegetables and fruits and the states that have this highest prevalence are

Selangor, Kuala Lumpur, Pahang, and Sarawak, among others. Automation of most tasks have reduced our involvement with physical activity. The NHMS, 2019 reported that about 28% female, 59% of the elderly above the age 75 and above, 39% of students and 27% of urban dwellers were inactive.

Treatment with insulin started with the discovery of insulin by Banting et al. in 1921. The first diabetic patient to treat his diabetes with insulin was a 14 year old male patient in 1922. The batch of insulin made by Banting caused an abscess and was not responsive. The 2<sup>nd</sup> batch of insulin made by Collip worked relatively well for the patient (Banting F. et. al., 1922). Over the years with the advent of modern technology in medicine, we have managed to treat and manage diabetes mellitus with variety of medication ranging from oral antihyperglycemic agent to insulin. These different classes of medicine help to control diabetes mellitus via multiple pathophysiological pathways with different peak concentration levels in the blood which can be tailored to suit individual needs. In this current age an individual rarely has diabetes alone, they will usually have multiple comorbid, for example hypertension, chronic respiratory illnesses, and cardiovascular events. Which all needs multiple medication to control and manage their diseases.

Physicians have hypothesized that diabetic patients who can self-manage their diabetes, might produce better glycaemic control. This was evidenced from the studies done by Ji *et al*, (2014) and Yu et al, (2013). Both studies investigated whether self-management and self-efficacy behaviours impacted participants' HbA1c results and glycaemic control. However, both studies had found negative correlation between diabetic patients' self-efficacy and self-management behaviour and their glycaemic control. This was because both the studies had varying levels of self-efficacious



behaviour and different levels self-management behaviour. This in turn was caused by improper diabetes self-management education of the patients, which had resulted in varying levels of understanding of the disease itself, its treatment modalities, the appropriate lifestyle modification that is needed, self-blood glucose monitoring and the necessary remedial actions that would be taken in case of emergency such as hypoglycaemia and hyperglycaemia.

Both studies had only analysed the results from the healthcare workers perspective. Both studies were quantitative in nature, rather than qualitative. Ockleford *et al*, (2008) had conducted an interventional qualitative study to gain diabetic patients' perspective on DESMOND based structured diabetes education versus the usual general practise education given at their respective practise. Interestingly, this study found that not one educational approach was applicable to everybody diagnosed with diabetes. The patients were also found to have varying opinions both type of educational approach. In conclusion Ockleford *et al*, (2008) had found most patients had preferred group education rather than individual counselling. They also recommended to have educational tools to be tailored to individual needs of the patient.

Hence the latest edition of the National Standards of Diabetes Self-Management Education and Support (2014) have outlined 12 key standards that any diabetes self-management education should ideally adhere to. This was to ensure that the quality and content of the diabetes self-management education programme is standardized, and patients can be assured that they have access to evidence-based information for shared decision making with their physician. While there was abundant literature on self-efficacy and the benefits of diabetes self-management education for glucose control; there are not many qualitative studies which explores patient understanding of the

diabetes self-management education given by the healthcare professionals in a private primary care clinic in the Malaysian context.

## **1.2 Theorised Education Problems**

As nonmedical background patients might have some medical knowledge about their disease, its pathophysiology, treatment, and complication; however, it is important to firstly educate patients correctly about these matters. Once the patient has the correct basic schemata built, patients can then further build upon their basic knowledge via peer support or healthcare worker support. Herein lies the second education problem; building an effective standard operating procedure of peer or medical worker support groups for patients to access.

The next educational problem that this study foresees is whether the existing educational programmes can be personalised to individual's educational and socioeconomic status. There will be no benefit if good medical educational programmes cannot be translated to local settings, to suit the local population. This is because the educational scaffolds needed to ensure understandability among patients needs to be in a language and presentation that patient can relate to and understand. Following this, the next educational problem that physicians encounter is how patients process the information received from the healthcare workers. It is important for physician to know how patients process information, as this will help physicians to develop an educational programme that is best suited for their diabetic patient population. Once this problem is addressed, the educational programme can be further enhanced by understanding what methods are suitable for patients to have meaningful learning rather than rote learning. Rote learning would not enable the diabetic patient to apply the knowledge learnt in a meaningful way. It would not enable patient to dose adjust their insulin by themselves

based on their glucometer reading. The final educational problem that will surface is the diabetic patient's motivation to learn the new information or knowledge. Motivation plays an important role in education; the same applies to diabetic patients as intrinsic motivation will ensure learning for better self-management of their glucose control. The next section will explore the learning concepts and its application, to address the above educational problems encountered when educating diabetic patients with regards to their disease management.

### **1.3 Problem Statement**

Diabetes is a complex chronic disease. This is because, diabetes causes a whole range of complications and end organ damages. Hence treatment with medication alone will not suffice. For best results, diabetes should have multiprong management which includes self-management education, dietary counselling by the dietician, and assessments by various medical specialists. Practising a multidisciplinary approach will ensure, the diabetic patient to achieve good glycaemic control. As stated above diabetes self-management education plays a key role in shaping patients' lifestyle changes with diabetes. Even though healthcare workers around the world can refer to the committee of The National Standards of Diabetes Self-Management Education and Support for diabetes self-management educational programme content, whether patients themselves actually comprehend the given content and are able to apply the learnt knowledge to their daily life is an issue that warrants an investigation. This is because application of learnt knowledge and practices will translate into clinical results which is good glycaemic control.

## **1.4 Research Gap**

One of the important aspects of management of diabetes is patients' self-management of the disease. Patients need to understand how to self-manage their own disease and the components that make up this aspect of care. NHMS, 2019 reported that 1 in every 3 adults have low health literacy. This finding is bound to have effect on how patients understand the diabetes self-management education given to them. Only by understanding the education given, can patients be able to manage their disease well and have stable levels of control over the long-term. Education of patients on how to self-manage varies widely between private and public settings. One of the important gaps is that little evidence is available on whether patients can understand the self-management education provided to them. This may have a direct impact on their disease management and subsequently their disease control. Analysing whether patients can understand what they are being taught about self-management will help healthcare professionals build and deliver better educational strategies. This problem, which although looks very superficial; may well be one of the driving factors behind the poor individual and even national control issues of diabetes.

## **1.5 Study Aim**

This study aimed to explore patient's comprehension of content and patient perception regarding instructional delivery and quality of diabetes self-management education provided in a private primary care clinic.

## **1.6 Research Objectives**

### General objectives

The objective of this study was to explore patients' comprehension of content of diabetes self-management education, perceptions regarding instructional delivery and quality of DSME provided in a private primary care clinic.

### Specific objectives

The specific objectives of this study were:

- i) To explore patient's comprehension of the content of diabetes self-management education provided in a private primary care clinic.
- ii) To explore patient's perception of the quality of diabetes self-management education provided in a private primary care clinic.
- iii) To explore patient's perception on the effectiveness of the instructional delivery of diabetes self-management education provided in a private primary care clinic.

### **1.7 Research Questions**

The research questions for this study were:

- i) How good is patient knowledge about diabetes as a disease and content of diabetes self-management education provided in a private primary clinic.
- ii) What is patients' opinion about the quality of diabetes self-management education provided in a private primary clinic. How helpful was it towards their diabetes self-management?

iii) What are the patients' opinion about the quality of mode of diabetes self-management education provided in a private primary clinic. How helpful it was for creating appropriate awareness of diabetes self-management?

## **1.8 Significance of the study**

Data produced from this study can be used by healthcare workers dealing with educating diabetic patients on diabetes self-management in the local context. As discussed in the problem statement section, by understanding what the diabetic patient grasp from the diabetic self-management education, the researchers can design and include features into the diabetes self-management education programme that are more relevant to the Malaysian population in terms of culture, ethnicity and socioeconomic factors in attempt to make it more effective.

## **1.9 Operational definitions**

The operational definitions for some of the more commonly used terms within this study are as defined below.

### **1.7.1 Diabetes self-management education**

Diabetes self-management education (DSME) in this study refers to the ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care.

### **1.7.2 Diabetes Mellitus**

Diabetes mellitus in this study refers to a chronic disease associated with abnormally high levels of glucose in the bloodstream

### **1.7.3 Patient**

Patient in this study refers to a person receiving or registered to receive medical treatment or education.

#### **1.7.4 Ethnic**

Ethnic in this study refers to a population subgroup (within a larger or dominant national or cultural group) with a common national or cultural tradition.

#### **1.7.5 Race**

Race in this study refers to a population within a species that is distinct in some way, especially a subspecies.

#### **1.7.6 Private Clinic**

Private clinic in this study refers to a clinic owned and operated by an organisation other than the state (which may include for-profit and non-profit companies) and/or which provides care funded other than by the state, for example funded by patients themselves ("self-pay"), by insurers, or by foreign embassies.

#### **1.7.7 Primary Care**

Primary care in this study refers to healthcare provided in the community for people making an initial approach to a medical practitioner or clinic for advice, education or treatment.

#### **1.7.8 Comprehension**

Comprehension in this study refers to the ability to understand something.

### **1.7.9 Perception**

Perception in this study refers to the way in which something is regarded, understood, or interpreted.

### **1.7.10 Quality**

Quality in this study refers to the standard of something as measured against other things of a similar kind; the degree of excellence of something.

### **1.7.11 Instructional Delivery**

Instructional Delivery in this study refers to the interaction among the patient, the healthcare worker, the content, and the knowledge/skills/dispositions patients will need for learning and collaborating with others in a diverse society and rapidly changing world.

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## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter will elaborate in detail the background information related to the areas of interest in this proposal. This chapter will summarise the information related to the landscape around the area in which this study is based. Discussed within this section will be the concepts underpinning this educational area, the related challenges and what are the gaps within the research area that needs to be addressed which then make up the foundation stones for this research and why it is being carried out.

### **2.2 A Historical Perspective of Diabetes and Insulin**

Unlike popular beliefs, diabetes mellitus has existed since through the antiquities. Ahmed, (2002) found that diabetes was first mentioned in the Egyptian manuscripts nearly 3,500 years ago. Egyptians had assumed a collection of symptoms that includes polyuria, sweet urine is most probably diabetes. They also had prescribed various treatments to these collections of symptoms (Ahmed,2002). Whereas further to the east, the Indians in their ayurvedic medicine had clearly defined and described what diabetes as a condition is like, and further classified them into 2 types, which was congenital and late onset (Ahmed, 2002). Sushranta, a famous Indian physician from the 5<sup>th</sup>-6<sup>th</sup> century AD and Aretus of Cappodocia from 81-138 AD had been the first to associate the symptoms of polyuria with a sweet tasting substance (Ahmed, 2002). It was Areatus of Cappodocia who 1<sup>st</sup> introduced the term Diabetes which is of Greek origin meaning siphon (Araetus C., 1856). Another notable Arabian physician by the name of Avicenna (960-1037) then proceeded to clearly describe the clinical symptoms and some know complications of diabetes such as erectile dysfunction, gangrene, and peripheral neuropathy (Ahmed, 2002).

In the modern times, it was Banting and Best (1922) who first isolated insulin from the pancreatic extract. However, Banting's formula of insulin for therapy did not result in success (Banting F. et. al., 1922). It was James Collip who developed a successful formula of insulin which managed to treat the first patient, a 14-year-old boy to receive insulin as a treatment for his diabetes mellitus (Banting F. et. al., 1922). Oral hypoglycaemic agents were also developed around the same era. Precisely, it was in 1930 that the hypoglycaemic properties of sulphonamides were detected (Ruiz et. al.,1930). This discovery led to development of tolbutamide and chlorpromide in the following ten years. Further research and development had led to the development of Metfermin and pferformin in the 1950s, from the active ingredient of an herb called *Galega officinalis*.

Apart from the oral hypoglycaemic agents, physicians in ancient times had also prescribed various dietary recommendations to their diabetic patients. Among these ancient physicians were the Egyptians and Indians. They recommended fresh cereals, bones, wheat, and other substances to treat diabetes. In 1797, it was John Rollo who first described the possible influence of dietary regime on diabetes. He suggested a diet consisting of high content of meat and low content of carbohydrate (Ahmed, 2002). In modern times, Lyon, 1924, established dietetic department catering for medical and surgical patients (Lyon DM., 1924). His work also became the foundation for dietary management of diabetes. The content of carbohydrates and fat have varied over time. The British diabetic association had recommended the use of complex carbohydrates rather than simple sugars to improve glycaemic control in 1982.

As for the first mentions of diabetes complications, it was Professor Julius Dreschfeld who described the various types of diabetic comas, in 1886 (Dreschfeld J., 1886). Today these diabetic comas are better classified as diabetic ketoacidosis and

hyperosmolar nonketotic coma, respectively. Rollo, 1797, also discovered the relationship of diabetes and the development of peripheral neuropathy (Rollo J. 1797). Before the advent of insulin, hardly any female diabetic patients became pregnant. If they did become pregnant, maternal, and perinatal mortality was high, with rates of about 40% of cases. Reece, 1995, had found, with proper diabetic control, both maternal and perinatal mortality can be reduced (Reece EA., 1995).

### **2.3 Diabetic Self-Management Education and Support (DSME) & (DSMS)**

The management of diabetes mellitus has evolved tremendously over the years. Technological advances have made the delivery of insulin almost painless secondary to the development of inhalable insulin. The health literacy rates among patients also shown vast improvement. Increasingly in the early 21<sup>st</sup> century, health care personnel were starting to notice diabetes self-management education is an important aspect of diabetes management Norris et. al. (2002). Taskforce was formed to standardize the quality of diabetes self-management education and support, and to aid health care personnel who were providing the diabetes self-management education. Norris et. al. (2002)'s meta-analysis has shown that diabetic self-management education given to patients by their physicians or other healthcare personnel has shown improvement in their glycaemic control.

What is diabetic self-management education? The National Standards of Diabetes Self-Management Education and Support (2014) defines Diabetes Self-Management Education (DSME) as an “ongoing process of facilitating the knowledge, skill, and ability necessary for prediabetes and diabetes self-care. This process incorporates the needs, goals, and life experiences of the person with diabetes or

prediabetes and is guided by evidence-based standards. The overall objectives of DSME were to support informed decision making, self-care behaviours, problem solving, and active collaboration with the health care team and to improve clinical outcomes, health status, and quality of life.”. Whereas, Diabetes Self-Management Support (DSMS) is defined as “activities that assist the person with prediabetes or diabetes in implementing and sustaining the behaviours needed to manage his or her condition on an ongoing basis beyond or outside of formal self-management training. The type of support provided can be behavioural, educational, psychosocial, or clinical” (Haas, L. et. al., 2014).

Factors that can possibly influence the efficacy of a diabetes self-management educational programme are patients’ health literacy and numeracy, patients’ motivations to learn the new material, patients’ socioeconomic background, patients’ cultural and religious beliefs, the quality of DSME and DSMS, and the mode of delivery of DSME and DSMS (Haas, L. et. al., 2014). These standards can be applied to an organization or individual practitioners. An individual private primary care practitioner might find these aspects of DSME daunting if proper support and material were not readily available to them. Our Ministry of Health Malaysia on the other hand, has adopted a comprehensive diabetes self-management educational programme for its nursing diabetic educators (Ahmad, B. et. al., 2014) (Ahmad, B. et. al., 2017). The public hospital and primary care clinics have adequate access to these trained diabetic educators, who follow a comprehensive curriculum that is equivalent to the National Standards of Diabetes Self-Management Education and Support’s standard (Ahmad, B. et. al, 2014) (Ahmad, B. et. al., 2017). The private hospital in Malaysia also provide easy access to a diabetic educator for their patients. But the same cannot be hold true for private primary care physicians. As most of these practices ae owned by solo practitioners, diabetic self-

management education would be mostly provided by the residing physician themselves. As such it would be difficult to assess whether the 12 standards set by The National Standards of Diabetes Self-Management Education and Support taskforce were fulfilled and secondly, it was also never been assessed in the local setting, whether patients in private primary care clinic understood the diabetes self-management education provided to them.

Nagelkerk, et. al. (2006) had analysed potential perceived barriers of diabetes self-management education encountered by diabetic patients in a remote primary care setting. Among the factors found were the lack of knowledge in dietary and glycaemic control, and disease progression despite perceived adherence to self-management programme. In a private primary care clinic, the physician in charge, assumes different roles while providing care for a patient, unlike a public primary care facility, where the roles of physicians, nurse, paramedics, pharmacist are clearly defined; here in the private primary care, the physician assumes all these roles in view of logistics restraints. Mafauzy, (2005), found that only 20% of patients from private primary care clinic participating his study had their HbA1c less than 7%. About 6.9 % only, self-monitored their glucose at an average of 11 times per month at home. Diabetic complications such as neuropathy (30.1%, stroke (2.5%) and myocardial infarction (2.1%) were prevalent in these patients secondary to poor glycaemic control. In conclusion, Mafauzy, (2005) revealed that patient receiving diabetic management at a private primary care clinic throughout Malaysia, had poor control of their diabetes. He highlighted the need for education of both physicians and patients on diabetic management and on achievement of these clinical targets.

Culture of an individual also plays a huge role in influencing how a person learns. Greenhalgh et. al. (1998) study of Muslim Bangladeshi patients with Diabetes, revealed the patients' cultural health beliefs influenced the acceptance of the diabetes diagnosis, the acceptance to change their diet, exercise, and ability to self-manage their diabetes post self-management education given by health personnel. Similarly, Dao et. al. (2019) had found patients from Pacific Islanders and Lebanese culture in Australia have difficulty in adapting to the dietary requirement even though diabetes self-management education has been given. It considered rude to decline food when it is offered. These studies clearly showed that patients were unable to clearly understand how to adapt the information from the diabetes self-management education received by the health care personnel, to sync with their cultural beliefs about health and diabetes.

As we can see above, majority of these studies available private primary care management diabetes were of quantitative in nature, and very few studies have explored the perceived barriers to diabetes self-management education in a private primary care setting. It would be hypocritical to assume that all patients all over the world to have the identical views, opinions, and belief systems. Patients are bound to have differences in opinions and views based on their own cultural background and socio-economic status. This statement was proven true by Ockleford *et al*, (2008). In his study that was published in SAGE journal of chronic illness, he and his team had explored newly diagnosed diabetes mellitus patient's perspective on his intervention arm educational approach which used the DESMOND education (group education) and another set of patients were randomised to get the usual care from the local general practise. The study identified four main orientations which are 'resisters', 'accepter', 'consequence resisters and accepters', and 'identity resisters and accepters. Patients were found to have different levels of personal responsibility that must be undertaken upon the diagnosis of

diabetes mellitus. They could not identify obvious variations of themes between the two arms. This study found that patients were generally more receptive to group education as opposed to the usual general practise care. Finally, the author concluded the different orientations identified in the study could be used when planning educational strategies for self-management.

Murphy et al, (2015) had done almost similar study in South Africa, where he and his team had explored the motivation among diabetic patients for self-management. The study had involved 22 patients from public healthcare clinic and participated in the study interviews. The authors had used self-determination theory as their theoretical framework to explore patients' motivation for self-management of diabetes and lifestyle modification. Murphy et al, (2015) found that most patients had not received useful amount of information from their healthcare providers. Patients also did not receive adequate counselling or autonomy support from their healthcare providers. The patients were left with anxious and frustrated feelings about their healthcare. In conclusion, the author found most patients were poorly equipped to self-manage or to have empowered role in their self-care. This provided a foundation for more patient centred educational strategies, so diabetic patients could be empowered to take charge of their control.

Morrow et al, (2008) had explored the factors that influences older adults' diabetes self-management. Interestingly, the study found that denial and retirement of adult were the motivating factors for diabetes self-management. The older adults needed to feel useful, and it became one of the motivating factors to self-manage their illnesses. Whereas, Mathew et al, (2012) had studied differences of experiences between the genders in self-management of diabetes. This study involved 35 patients that were recruited from diabetes education centre in Toronto, Canada. The methods used were

focus groups discussion and individual interviews. The literature identified five main themes. The five themes are disclosure and identity as a person living with diabetes; self-monitoring of blood glucose (SMBG); diet struggles across varying contexts; utilization of diabetes resources; and social support. The fairer sex was found to be more ready to share their diagnosis with close family members and friend whereas men were not so. Men tended to focus on the more practical aspects of self-blood glucose monitoring rather than women. Men also tend to not self-control of their diet and habit when in a social situation. In this aspect women were found to be better self-discipline to restrict food that is sweet and unhealthy. Women had tendency to be more receptive to socially interactive resources rather than men. Here men were more interested in self-directed learning. However, both genders had expressed their need of wanting more help and assistance from their respective physicians. In conclusion, this study had brought to attention the differences in need and barriers of diabetes self-management among both genders. This can used as foundation to build a more gender sensitive diabetes care, counselling, and support.

Provider patient interaction and provider consulting style play an important role in determining the success of diabetic education by increasing the self-efficacy behaviour of diabetic patients. van Dam, H. A. et. al., (2003), in their systematic review, concluded that it was more efficacious to provide patient-centred education models for patient behavioural change rather than focusing on provider behavioural change to a more patient centred consulting. This systematic review found that a single provider implementing a diabetic educational programme brought minimal in patient self-efficacious behaviour. it was also most labour and cost intensive to focus on provider behavioural change rather than patient centred approach.



In summary, since the discovery of diabetes as a disease, there has been many advances in medicine to treat it. As reviewed above a multitude of factors influence patients' ability to learn new information and implement them for a better self-management of diabetes. Among them are types of educational programmes, provider consulting style, gender of patient, patients' motivation to learn and educational level of patients. There is limited literature to be found on patients' understanding of diabetic self-management education in a local setting. This study aims to explore patient's comprehension of content and patient perception regarding instructional delivery and quality of diabetes self-management education provided in a private primary care clinic in a local setting.

University of Malaya

## **CHAPTER 3: THEORETICAL AND CONCEPTUAL FRAMEWORKS**

In this chapter, the theoretical framework and conceptual framework will be presented.

### **3.1 Theoretical Framework**

In management of any disease, a working partnership between the treating physician and patient is particularly important. For this partnership to succeed, the physician must be able to communicate information clearly to the patient with regards to his disease pathophysiology, its treatment, its medicine related problems, disease complications and goals self-management of the disease. The process above is clearly medical education between the physician and the patient. For the process to effectively come to fruition several learning concepts can be used to build an effective education program and apply it for these diabetic patients. The first step is to identify the education problems that exist among diabetic patients.

### **3.2 Theoretical Concepts and Application in Theorized Education Problem**

#### **3.2.1 Jean Piaget's Cognitive theory**

The first learning concept which could be relevant in this context is Jean Piaget's Cognitive Theory. Even though Jean Piaget's cognitive theory are mostly for children, however in this study the first 2 stages of the cognitive theory is an important basis for the development of subsequent learning concepts that will be described later. This theory can be said is the foundation for learning as Diabetes can affect children and adults alike. Cognitive theory has 3 stages:

- a) Schemas (building blocks of knowledge)

- b) Adaptation process (equilibrium, assimilation, and accommodation)
- c) Stages of cognitive development:
  - i) Sensorimotor
  - ii) Preoperational
  - iii) Concrete operational
  - iv) Formal operational

Piaget (1952) has described that schemas are units of information, whereas Wadsworth (2004) as described it as schemata; in this study the schema or schemata is the disease diabetes mellitus as patient from nonmedical background will find medical information as new information. To form this new schemata, information provided to patients has to be precise, clear and easy to understand language (preferably in their mother tongue) Once the schemata has been formed, the patients then can assimilate, accommodate, and reach equilibrium of diabetes mellitus knowledge as evidenced in this figure below. It is not guaranteed that all adults will be able to reach the formal operational stage of cognitive development (Dasen, 1994) as such, educational methods developed and employed, must be tailored to individual's educational background. Information can be presented to them in visual, printed and audio format. The physician can introduce the disease information via a short verbal explanation using simple non jargon language and anatomical models and printed information for revision later.

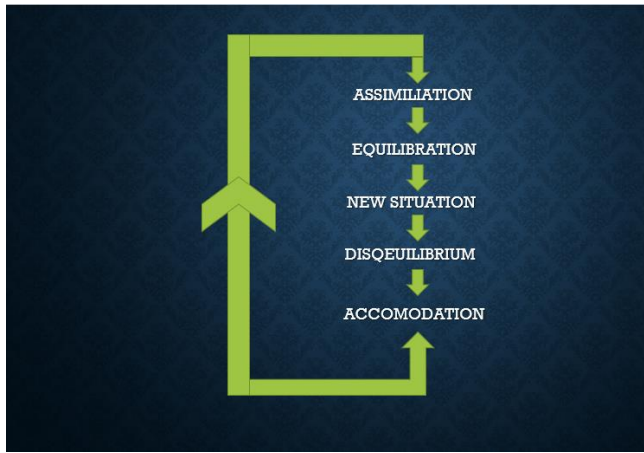


Figure 1: Assimilation pathway, adapted from Wadsworth (2004)

### 3.2.2 Vygotsky's Social Constructivist theory

The second concept that this study will explore is Vygotsky's cognitive theory. Vygotsky (1962) had stated that language plays a key role in any educational programme. Language is the main means of communication between peers, in this instance between patient and their peer support group as well as with their physicians. Language also is a powerful tool of intellectual adaption. Vygotsky (1987) also had classified language into three types. First is the social speech; speech that is used in daily communication.

The second and third type are more for children development, as such it would not be discussed in detail in this study. It is important for physicians or other healthcare workers to educate diabetic patients using everyday simple language that patients use in their social speech. Apart from language, Vygotsky also proposed that an individual could learn better with a more knowledgeable other (MKO). This MKO would be patients' peers in a peer support group for diabetes. Peers who are veterans in the self-management of diabetes and have good control would be more likely persons that new

diabetes can relate to and exchange views and information in learning about diabetes mellitus and its management.

Vygotsky (1978) introduced the zone of proximal development (ZPD). He proposed that this when MKO helped or guided a learner who is in ZPD, the learner's learning curve is much more rapid compared to the learner learning alone via discovery learning alone. Shaffer (1996) and Freund (1990) proved this concept via their experiments, where with the presence of MKO the children in the experiment had exponential learning and problem solving skills compared to if the child was left to learn alone via discovery learning. This same concept is being applied when healthcare system or patient group form peer support groups for their diseases. In these support groups, the peer (MKO) would act as a guide in helping patient to master the art of self-management of diabetes.

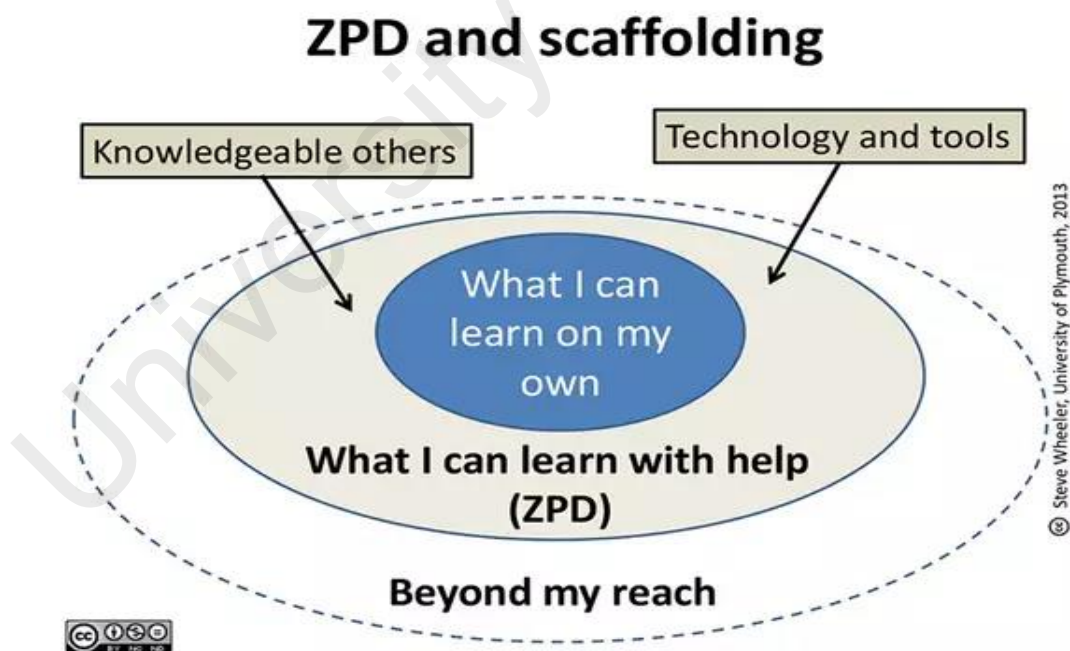


Figure 2: Vygotsky cognitive theory with ZPD and MKO adapted from Freund (1990).

### 3.2.3 Pintrich's Metacognition Theory

The next concept that will be the basis of this study is Pintrich's metacognition in lay man's term '*Thinking About Thinking*'. This theory explains how patients learn to learn. It explains self-regulated learning. Self-regulated learning is mainly about patients' ability to think metacognitively, motivationally and behaviourally, (Zimmerman,1990). This study proposed this theory, as it helps learners to explore and understand what they do not know. Learners can only learn if they first know what their learning gaps is, their shortcomings in the process of learning, and how to address those issues. Learners will be able to learn and apply a new material if they were able to increase their awareness about the topic learning. Palinscar *et al*, (1984), states that gaining higher level of awareness is possible because the learner can think about tasks and contexts of various leaning situations as well as thinking about themselves as learners in those various situations. Pintrich, (2002) had stressed that " Students who know about the different kinds of strategies for learning, thinking and problem solving will be more likely to use them" (p.222), he had further observed that in order for learners to do so they must first 'know about' or comprehend the various ways one could solve a problem and not just using them.

This theory is applicable in this study, could be foreseen that most diabetic patients might not be able to self-manage their diabetes secondary to the fact that they are not aware what they do not know. If patients can think about their thinking process then they might be able to extrapolate possible complications, knowledge gaps and solutions that they need to address those issues. For example, diabetic patient must first know the principles behind possible strategies to manage a hypoglycaemic episode and not just practise them blindly. Pintrich's metacognition theory will most probably help

them to identify their problem area in learning the new medical information in order for them to successfully self-manage their diabetes. As Zohar and David (2009) stated, a “*conscious meta-strategic level of H[igher] O[rder] T[hinking]*” (p. 179) is a must. Conscious metacognitive strategies can assist patients to identify their weak areas in learning the new material, support groups and other resources that are available to them. One of the important aspects of this theory is the ability to identify one’s own limit of a knowledge and then able to find solutions to expand their knowledge or their ability. For example, patients must be able to identify their knowledge gaps and actively seek to find methods to fill the gaps of knowledge if they want to successfully self-manage.

### **3.2.4 Self Determination Theory**

This theory is a wide template for the study of human motivation and personality. It is a theory explains that a person’s motivation and focus for an activity is governed by that person’s experience of autonomy, competence, and relatedness. Ryan & Deci (2000) extrapolated that people needed to feel the above three feelings, in order to attain psychological growth. They defined:

- a) Competency as the ability to master various skills. If people are able to master a skill or many, then they are more likely to definitive actions that will help attain their aims.
- b) Connection /relatedness as the ability to have a sense of belonging and attachment to other people around them.
- c) Autonomy as the ability to be to control their life goals. This ability will help people to self-determined.

Apart from this, self-determination theory has two main assumptions, which are:





Figure 3: Self-Determination Theory and the Facilitation of Intrinsic Motivation, Social Development, and Well-Being adapted from Ryan & Deci (2000)

### 3.2.5 Information Processing Theory

One of the main contributors of this theory are Atkinson & Shiffrin (1968). It came about in the 1960s with the advent of computers. Cognitive psychologist then had found a perfect analogy to study the internal process of learning. The birth of cognitive psychology is often said to originate from George Miller's (1956) "*The Magical Number 7 Plus or Minus 2*". Atkinson & Shiffrin (1968) had built upon initial theory and had introduced the relevant terminology for the above information processing theory. This theory proposes that *homo sapiens*'s is akin to the computer's motherboard. It equates the process of a computer processing information via its process of receiving information, processing it and delivering it for use. Similarly, the human mind receives input via its five senses, it is then stored and processed in the brain, and finally the output of the said information is the behavioural response from a person. The above theory of input-processing-output was formulated by Atkinson & Shiffrin's (1968) stage theory. Craik & Lockhart (1972) further elaborated this theory by introducing the terminology of 'level of processing'. They explained that the degree of information will affect how well the information is learned.

To go further, Morris *et al* (1977) elaborated that information learnt will be easily remembered if it is retrieved the same way it has been stored. Rumelhart & McClelland (1988) formulated that a single information can be processed at different areas of our brain, hence, the more connection a single information has in our brain, the more easily it can be brought forth for application. This is known as their connectionist

model. The information processing theory has 3 main parts, which are the sensory memory, working memory or better short-term memory and long-term memory.

This study proposes diabetic patients are bound to experience some knowledge decay during the initial process of receiving new information. The information processing theory can help the healthcare personnel understand how new information is processed. As we know, the education of a patient on self-management of diabetes will have an initial information overload. It is then, not surprising to find most diabetes patients forgetting the new information given to them. Another common scenario that is frequently faced by patients is misunderstanding of the information given to them. If healthcare personnel can understand the patient's perspective on what can help them remember the information given, this will help healthcare workers formulate what kind of reminders needed to be in place to facilitate the above.

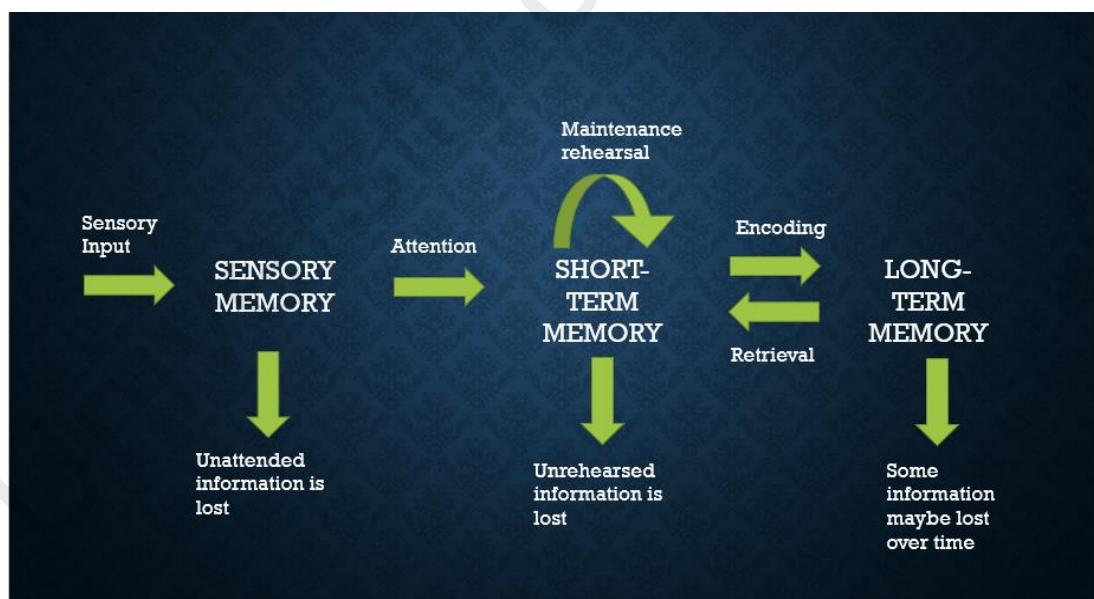


Figure 4: The Information Processing Theory Model, adapted from Atkinson & Shiffrin's (1968).

Below is the summary of the theoretical framework in the form of a figure.

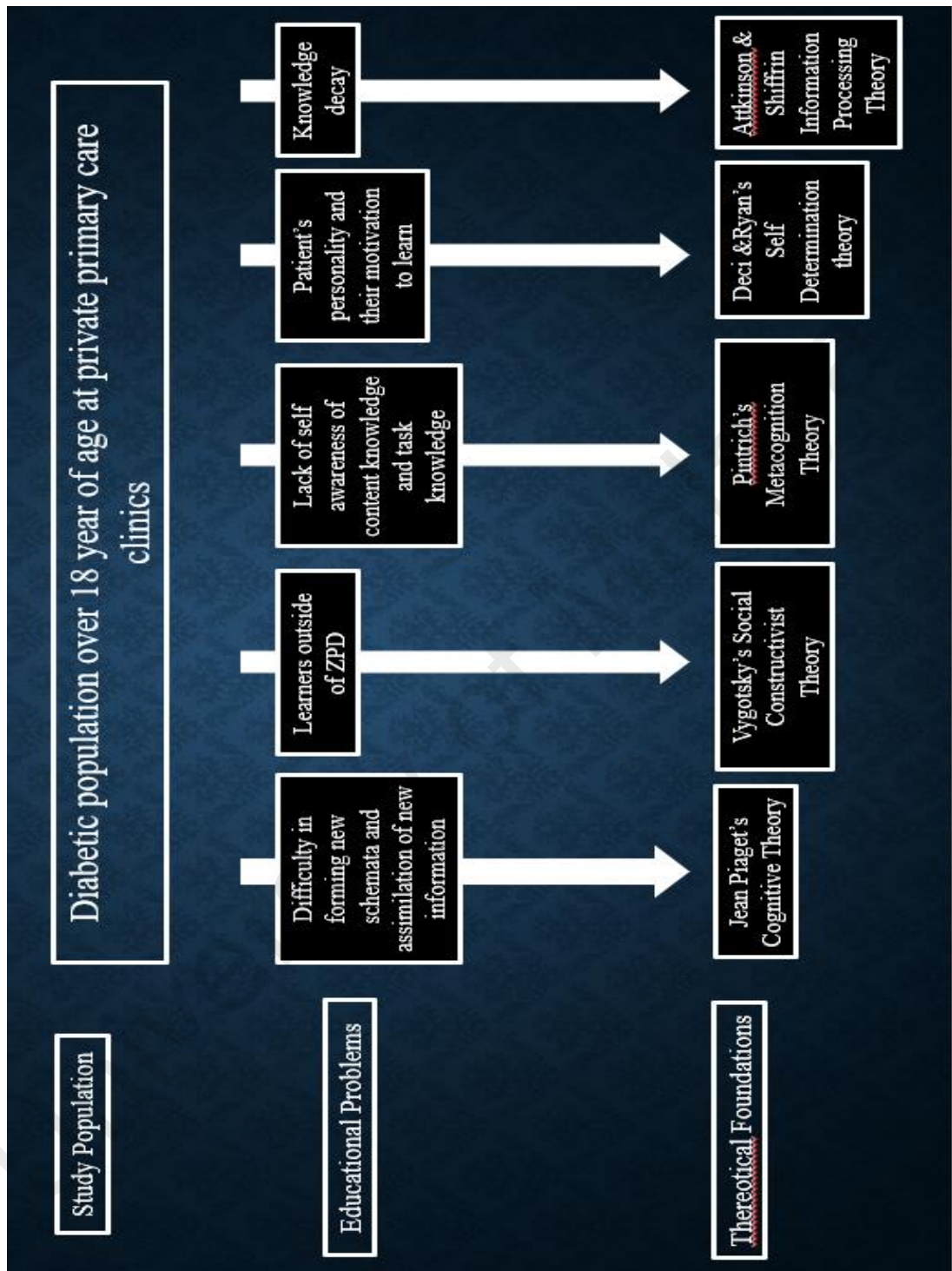


Figure 5: Theoretical framework of the study

### 3.3 Conceptual Framework

According to literature, there are many factors that influence an adult learning capability. Brady, (1984) also reported that these factors play a huge part in an adult's possible educational problems.

Generally, among the common factors that can influence a person learning are their sociodemographic factors such as age, educational status, ethnicity, and gender (Darkenwald et. al. 1988). Darkenwald, (1988) had found higher level of education to be greater predictor for capacity of learning in adult. The same beholds for higher income household, where the findings were statistically significant for more positive outlook for learning in an adult. However, it is does not hold true for race and ethnicity. This study does show statistically significant result for the above two factors influencing an adults learning capacity or capability. Generally, the female gender showed greater propensity for learning compared to the male gender. The above findings are important as physicians will able to cater to the above factors into consideration when giving a patient diabetes self-management education.

From the behavioural characteristics point of view, motivation of a patient plays an important role in determining patients' ability to learn. Inherently, this determinant will be able to overshadow the sociodemographic factors of a patient. An individual's capacity for learning can be greatly influenced by his intrinsic or extrinsic motivation. As we all know in learning, intrinsic motivation plays a much greater role in helping an individual maintaining a sustained attitude towards learning and applying the elements that have been learnt. Intrinsic motivation also determines an individual's approach and capacity to learn. A person who is not motivated, will not be able to learn at all. An individual who is extrinsically motivated might only attempt learning for short term

gain or goal. This type of learning is detrimental for diabetes self-management as diabetes is a chronic disease that needs sustainable lifestyle modification for good outcomes (Courtney, 2018).

Another important determinant is illness-related factors. Patients' ability to learn is also greatly affected by their number of medications, comorbidities, illness duration, and disease complications. These factors will affect patients' interest to learn, ability to implement the learned information or behaviour, the ability to sustain the learnt behaviour for good outcome (Lane & Evans, 1979).

The final determinant that influences an individual's learning ability is the educational strategies themselves. Factors such as, content of curriculum used, quality of the delivery and deliverer and types of instructional delivery used affects a patient learning behaviour. Lane & Evans (1979) revealed that the higher the number of classes had an effect their disease outcome. Similarly, quality of the educators and number of the educators used is also likely to influence the patients' disease outcomes. Lastly, the multi-method approach is more likely to give a favourable outcome to the education given a patient. The multi-method approach has a greater chance to change and sustain the altered behaviour for diabetes management.

The figure below is a diagrammatical representation of the above conceptual framework.

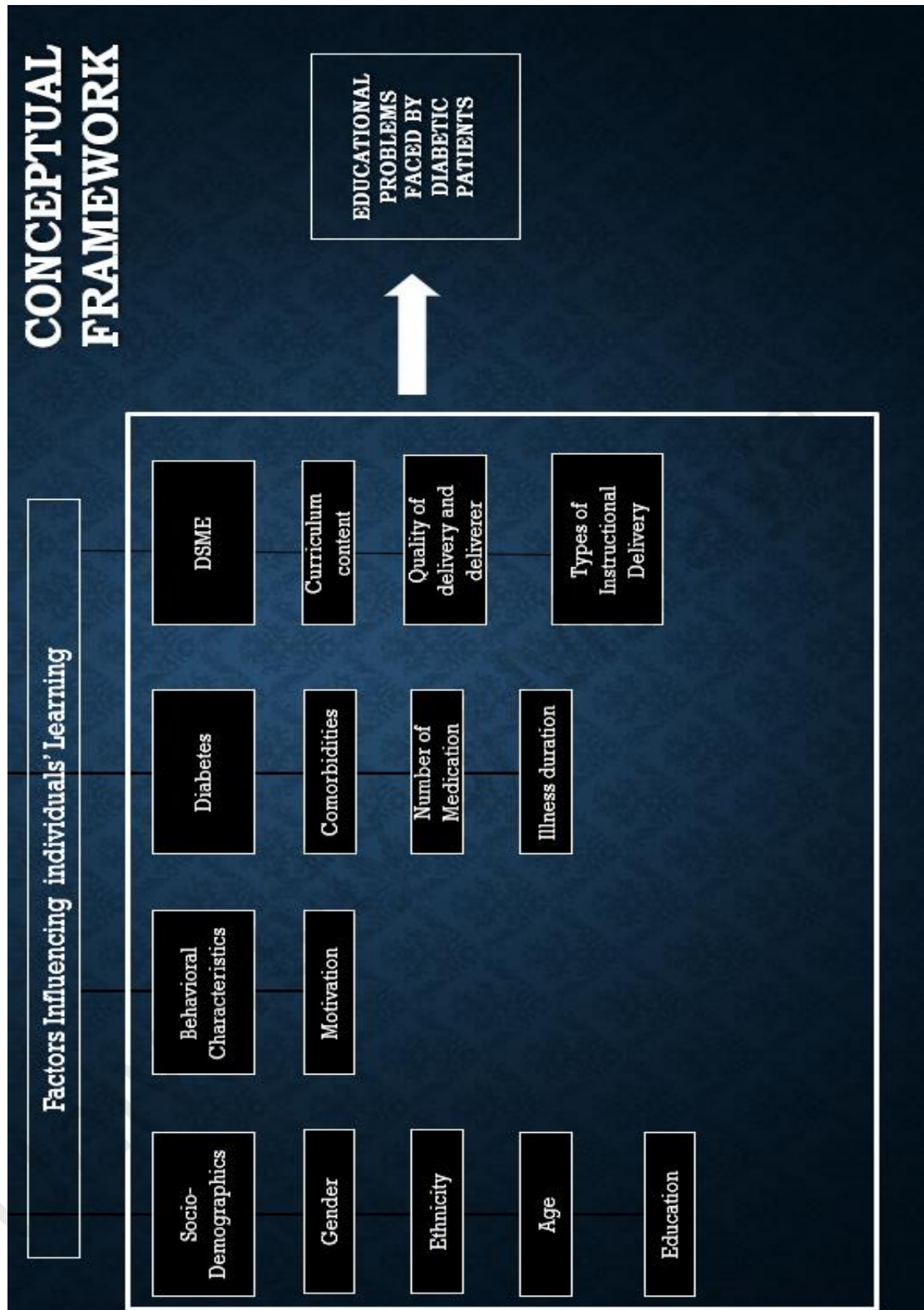


Figure 6: Conceptual Framework

## **CHAPTER 4: METHODOLOGY**

In this chapter, the methodology of this study will be discussed in detail.

### **4.1 Study Design**

This study utilised qualitative study design with a narrative approach. The research questions for this study were intended to explore the depth of participants' understanding of the subject and subsequently, map out the ideas and input from the participants before summarising them in thematic categories; and representing them numerically as appropriate (Harper, D., 2011). This required the approach to be able to cater for both thematic analysis and content analysis (Harper, D., 2011). As such semi-structured in-depth interviews were chosen as the method of choice for the study as the input provided from them would enable these analyses to be carried out and answer the research question.

In view of the current pandemic, these interviews were carried out via Zoom (a web-based video conferencing application) as well as in clinic interviews complying with the standard operating procedures during a pandemic.

### **4.2 Study Area**

The study area for this study was conducted at a private primary care clinic in Kuala Lumpur.

### **4.3 Study Duration**

The duration of the study was for 12 weeks, starting from May to August 2020. Data collection was carried out between 17<sup>th</sup> June to 17<sup>th</sup> August 2020.

#### **4.4 Study Population**

The study population involved adults diagnosed with diabetes mellitus and have been following up at the study clinic for at least the past 6 months.

#### **4.5 Inclusion and Exclusion Criteria**

##### **Inclusion criteria**

- i) Participants have been diagnosed with Diabetes Mellitus.
- ii) Participants must be above 18 years of age
- iii) Participants must be able to speak and read in English.

##### **Exclusion criteria**

- i) Participants that have been diagnosed with psychiatric illness..
- ii) Participants who have mental disability or vascular dementia.
- iii) Participants who have refused to participate in the study.
- iv) Participants who were not adults older than 18 years of age.

#### **4.6 Sample and Sample Size**

The sample was taken from the participating private primary care clinic in the study. Adult patients who have been diagnosed with diabetes mellitus and have been seeing the resident clinic doctor for at least the past 6 months was part of the sample. Patients who have consented, were recruited and in-depth interviews were carried out till saturation of information was achieved. 27 respondents consented to participate in this study. These 27 respondents fit the inclusion criteria of this study. Out of these 27 respondents were unable to continue with the study as they had moved state for a job



offer. Another 3 respondents were dropped from the study due to language barrier. These respondents were found not to be able to fully understand or converse fluently either in English completely during initial part of the interview. Another respondent had to withdraw from the study secondary to hospitalization for a complication of diabetes. A total of 21 respondents managed to successfully participate in the in-depth interviews.

#### **4.7 Sampling Technique**

The sampling technique for this study was purposive sampling. As all the patients have diabetes, patients were sampled according to four main racial groups. Within each racial group (Malay, Chinese, Indian, Others) it was ensured that different subsets representing patients' socioeconomic status, age, gender, and comorbidities will be instituted. This is so that maximum variation sampling can be ensured. This also to ensure a wide heterogeneity as well. Participants for each subset was recruited until data saturation was obtained. The data collection for this study was deemed completed when data saturation for each subset was obtained.

#### **4.8 Recruitment and Data Collection Procedure**

Patients was recruited from the study's private primary care clinic and have been regularly following up with the residing clinic doctor for their diabetes for at least the past six months. These patients were given the Patient Information Sheet on this study, as the study information dissemination process. Patients who agreed to participate were assessed by the researcher to review if they fit the inclusion and exclusion criteria and were given online or hardcopy consent forms to be signed. Patients who are not able to participate, were excluded. Patients was either called via ZOOM or scheduled for a in clinic interview lasting about 60 minutes each. Patients who were having difficulty in downloading the ZOOM application were called one week prior to the actual interview

for aiding them with the application. The semi-structured interview was carried out in English by an empathetic interviewer who is trained to do motivational interview and is able to counsel coping skills to patients. The interview was conducted based on the interview guide provided to them (Refer to Appendix 1). The interview guide also covered the methodology of conducting an in-depth interview. The participating patients was given a small stipend at the end of the in-depth interview for their time.

#### **4.9 Research Instrument**

The person conducting the interview used a formulated interview protocol. In order to make sure the questions asked are in line with topic of the study, it was pilot tested on four different patients from the respective racial backgrounds. This interview protocol is built upon the standards of content that should be given to patients at four various point of their diabetes journey (Figure 2: DSME and DSMS at four critical times, Powers et. al., 2017). These four critical points will represent the four arcs of this interview guide. At the start of the in-depth interview, the interviewer asked questions covering demographics of the patients and overview of diabetes with patients explaining when and how they were diagnosed, where are they treatment wise and do they have any diabetes related complications.

a) At Diagnosis:

At the first arc, the interviewer explored patients' understanding of:

Patients' cultural influences, health beliefs, current knowledge of diabetes, physical limitations, family support, financial status, medical history, literacy, numeracy with regards to medication, self-monitoring blood glucose, physical activity, preventing, detecting and treating acute complications, nutrition, risk reduction, developing

strategies to resolve psychosocial issues and developing strategies to promote health and behavioural change.

b) At annual assessment of education, nutrition, and emotional needs:

At the second arc, the interviewer explored patients' understanding of reinforcement of treatment and self-management goals, education on preventing complications and promoting quality of life, education on adapting diabetes with current life demands and finally on the support by health care personnel for sustainment of behavioural changes and coping strategies of diabetes and its complication.

c) When new complicating factors influence self-management:

At the third arc, the interviewer explored patients' understanding of the support by health care personnel on self-care skills, provision or referral for emotional support by the health care personnel, development and support by health care personal on behavioural and coping strategies of patients to the diabetes complications.

d) When transition in care occurs:

At the fourth and final arc, the interviewer explored patients understanding of the identification of needed adaptation to self-management by the health care personnel, provision of support self-efficacy and self-management skills, assistance from the health care personnel in facing challenges of any kind, on provision of emotional support for patient and patient's family, provision of diabetes education to other new members who are involved in the care of the patient, and finally on the communication and follow-ups between the health care personnel and the patients, their family members and others.

All questions were open ended in nature and the interviewer strived to obtain a complete opinion at each arc, prompting the patient if necessary. The complete interview guide is attached in the appendix.

Diabetes Self-management Education and Support Algorithm: Action Steps			
Four critical times to assess, provide, and adjust diabetes self-management education and support			
At diagnosis	Annual assessment of education, nutrition, and emotional needs	When new <i>complicating factors</i> influence self-management	When <i>transitions</i> in care occur
<b>Primary care provider/endocrinologist/clinical care team: areas of focus and action steps</b>			
<ul style="list-style-type: none"> <li><input type="checkbox"/> Answer questions and provide emotional support regarding diagnosis</li> <li><input type="checkbox"/> Provide overview of treatment and treatment goals</li> <li><input type="checkbox"/> Teach survival skills to address immediate requirements (safe use of medication, hypoglycemia treatment if needed, introduction of eating guidelines)</li> <li><input type="checkbox"/> Identify and discuss resources for education and ongoing support</li> <li><input type="checkbox"/> Make referral for DSME/S and MNT</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Assess all areas of self-management</li> <li><input type="checkbox"/> Review problem-solving skills</li> <li><input type="checkbox"/> Identify strengths and challenges of living with diabetes</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Identify presence of factors that affect diabetes self-management and attain treatment and behavioral goals</li> <li><input type="checkbox"/> Discuss effect of complications and successes with treatment and self-management</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Develop diabetes transition plan</li> <li><input type="checkbox"/> Communicate transition plan to new health care team members</li> <li><input type="checkbox"/> Establish DSME/S regular follow-up care</li> </ul>
<b>Diabetes education: areas of focus and action steps</b>			
<ul style="list-style-type: none"> <li>Assess cultural influences, health beliefs, current knowledge, physical limitations, family support, financial status, medical history, literacy, numeracy to determine content to provide and how: <ul style="list-style-type: none"> <li><input type="checkbox"/> Medications—choices, action, titration, side effects</li> </ul> </li> <li><input type="checkbox"/> Monitoring blood glucose—when to test, interpreting and using glucose pattern management for feedback</li> <li><input type="checkbox"/> Physical activity—safety, short-term vs. long-term goals/recommendations</li> <li><input type="checkbox"/> Preventing, detecting, and treating acute and chronic complications</li> <li><input type="checkbox"/> Nutrition—food plan, planning meals, purchasing food, preparing meals, portioning food</li> <li><input type="checkbox"/> Risk reduction—smoking cessation, foot care</li> <li><input type="checkbox"/> Developing personal strategies to address psychosocial issues and concerns</li> <li><input type="checkbox"/> Developing personal strategies to promote health and behavior change</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Review and reinforce treatment goals and self-management needs</li> <li><input type="checkbox"/> Emphasize preventing complications and promoting quality of life</li> <li><input type="checkbox"/> Discuss how to adapt diabetes treatment and self-management to new life situations and competing demands</li> <li><input type="checkbox"/> Support efforts to sustain initial behavior changes and cope with the ongoing burden of diabetes</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Provide support for the provision of self-care skills in an effort to delay progression of the disease and prevent new complications</li> <li><input type="checkbox"/> Provide/refer for emotional support for diabetes-related distress and depression</li> <li><input type="checkbox"/> Develop and support personal strategies for behavior change and healthy coping</li> <li><input type="checkbox"/> Develop personal strategies to accommodate sensory or physical limitation(s), adapting to new self-management demands, and promote health and behavior change</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Identify needed adaptations in diabetes self-management</li> <li><input type="checkbox"/> Provide support for independent self-management skills and self-efficacy</li> <li><input type="checkbox"/> Identify level of significant other involvement and facilitate education and support</li> <li><input type="checkbox"/> Assist with facing challenges affecting usual level of activity, ability to function, health beliefs, and feelings of well-being</li> <li><input type="checkbox"/> Maximize quality of life and emotional support for the patient (and family members)</li> <li><input type="checkbox"/> Provide education for others now involved in care</li> <li><input type="checkbox"/> Establish communication and follow-up plans with the provider, family, and others</li> </ul>

Figure 7: DSME and DSMS at four critical times, Powers et. al., 2017

#### 4.10 Reliability and Validity

Reliability in a qualitative study was determined in terms of consistency of the research instrument. This was established via the interviews that was conducted in each theme completely before proceeding onwards to the next theme. This way the previous interview data acted as verifying data for newer data sets from the newer interviews. Whereas, validity in a qualitative study was determined in terms of trustworthiness of the responses of the participants associated with answering the study's research question. Data analysis for each subgroup was carried out immediately once the collection for a subset was completed. This collated data was available for the

researchers to compare against, at the start on the next subgroup.

#### **4.11 Data Analysis**

The in-depth interview sessions was conducted in English. Interviews was recorded electronically and transcribed verbatim into English as required. An inductive approach was used to thematically analyse transcripts. The researcher read and re-read the transcripts independently to be familiarized with the data and developed a framework for coding the interview data. The transcripts was then analysed by the researcher to find significant ideas and opinions using systematic and comprehensive coding. The coded data was summarized to determine code frequencies and then grouped by similarity into themes and sub-themes. Comparisons between the participant's answers was then carried out with patterns and associations found and explanations for the findings generated before final categorization and conceptualization completed.

#### **4.12 Ethical Considerations**

Ethical approval was sought and obtained from the University Malaysia Research Ethic Committee (attached in the Appendix). However, due to the concern about the use of a patient population for the study, UMREC informed the author that it would not be able to process such an application for ethical approval.

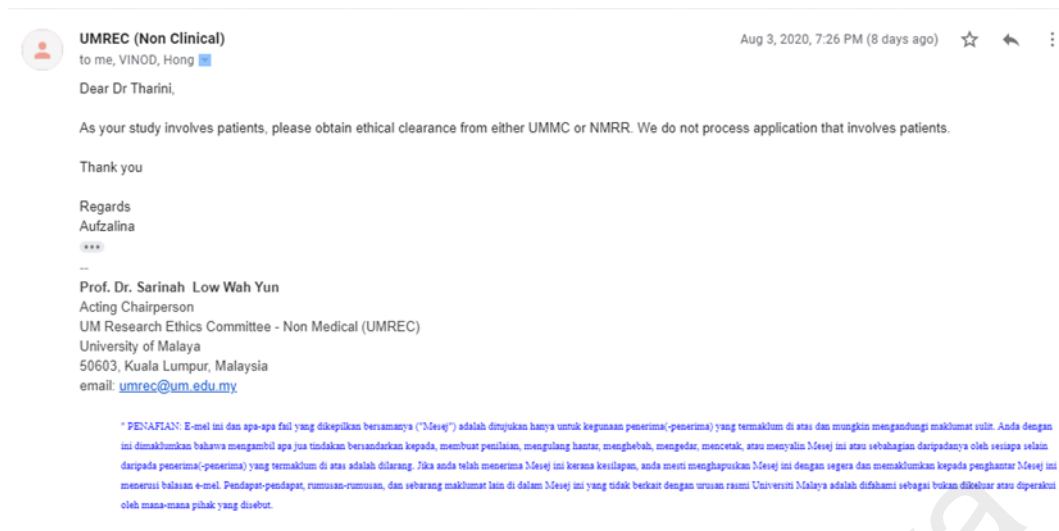


Figure 8: Response from UMREC

Despite this being a ‘patient’ population i.e. consisting of those who have been diagnosed with diabetes, as mentioned earlier this was a qualitative non-interventional study focusing on their educational needs and is thus not treatment based.

From another angle, consent was also obtained from the private primary care clinic for the conduct of this study at their premise (appendix 6).

Remaining consistent with international research and ethics procedures, the Informed Consent of each participant was obtained along with confidentiality and privacy measures to ensure that their data is safeguarded and not utilized for any purpose outside the purpose of this study.

#### 4.13 Data Storage

Recordings of interviews, which is in digital format was stored in a secure password-protected hard drive maintained only for this purpose and destroyed upon completion of the thesis/related publications in the time frame legally allotted for this purpose, after seven years. Data sheets and other hardcopy material pertaining to the study was stored securely within a locked cabinet in researchers’ home cabinet and

stored for the legal duration required. Personal data will remain disaggregated from interview data on hardcopy or electronic files to ensure security. All hardcopy information and data analyzed on a computer, would be destroyed after the storage duration, unless required.

#### **4.14 Data Access**

All medical and research records for this survey would be maintained appropriately in compliance with the principles of good clinical practice, regulatory and institutional requirements for the protection of confidentiality of participants. The study team members and the relevant bodies will have access to the records when requested. Participants or their legally acceptable representatives would not be given direct access to the personal information and study data as to protect confidentiality and privacy of other participants. They would be informed of the final survey findings and / or any publication via email.

## CHAPTER 5: RESULTS AND DISCUSSION

This section will explain the results of the study in tables and excerpts from respondents.

### 5.1 Sample Characteristics

The characteristics of the sample were divided into two different categories: i) respondents' demographic and the clinical characteristics. Each different category is described in detail below.

#### **Respondents' Demographic**

In this study, 27 respondents consented to participate. These 27 respondents fit the inclusion criteria which are respondents must be adults above 18 years old, must be able to speak and read in English and must be diagnosed with diabetes. Of these 2 respondents were unable to continue with the study as they had moved state for a job offer. Another 3 respondents were dropped from the study due to their language barrier. These respondents were found not to be able to fully understand or converse fluently either in English completely during initial part of the interview. Another respondent had to withdraw from the study secondary to hospitalization for a complication of diabetes. A total of 21 respondents managed to successfully participate in the in-depth interviews.



**Table 5.1 Sample sociodemographic characteristics**

Sociodemographic variables (N=23)	n (%)
<b>Gender</b>	
Male	9(42.9)
Female	12(57.1)
<b>Age</b>	
20-29	1(4.8)
30-49	3(14.3)
50-69	15(71.4)
70 and above	2(9.5)
<b>Education</b>	
Primary education	3(14.3)
Secondary education (Completed Form 5)	15(71.4)
Diploma/Degree	2(9.5)
Postgraduate	1(4.8)
<b>Ethnicity</b>	
Malay	4(19.0)
Chinese	3(14.3)
Indian	13(61.9)
Others	1(4.8)

Based on table 1, more than half the respondents were female (57.1%) and about 42.9% were male. 71.4% of the respondents were from the age group of 50 – 69, whereas about 4.8% from 20 – 29, 14.3% from 30 – 49 and 9.5% from 70 and above age category, respectively. 71.4% of respondents had completed their secondary school education, whereas about 9.5% earned their diploma or degrees. Another 3 respondents had only completed their primary school education and 1 respondent had postgraduate degree. When the respondents were represented through the ethnicity category, there were about 4 respondents who were Malay, another 3 were of Chinese ethnicity, 13 of them were Indians and one participant belonged other ethnicities.

**Table 5.2 Sample clinical characteristics**

Clinical characteristics (N=23)	n (%)
<b>Duration of living with diabetes</b>	
< 1 year	1(4.8)
1 – 5 years	3(14.3)
6 - 10 years	6(28.6)
>10 years	11(52.3)
<b>No. comorbidities present</b>	
None	1(4.8)
1 – 2 comorbidities	6(28.6)
3 - 4 comorbidities	12(57.1)
≥ 5 comorbidities	2(9.5)
<b>No. of medications taken</b>	
1 – 2 medications	4(19.0)
3 – 4 medications	13(61.9)

5 – 6 medications	3(14.3)
> 6 medications	1(4.8)
<b>No. of end organs damage</b>	
Present	17(81.0)
Absent	4(19.0)

On the clinical front, the majority (52.3%) of the respondents have been living with diabetes for more than 10 years. Among the rest of the participants, 4.8% had been living with diabetes less than a year, 14.3% had been living with diabetes between 1 year to 5 years and 28.6% had been living with diabetes between 6 to 10 years. 4.8% of the respondents have no known comorbidities. Most of them (57.1%) had between 3 to 4 known comorbidities. Another 6 respondents had 1 to 2 comorbidities and another 2 respondents had 5 or more comorbidities. In terms of number of medications taken by the respondents, the majority (61.9%) of them have been taking three to four medications for their diabetes and their comorbidities. Only one respondent was taking more than six medications for his diabetes and comorbidities. The rest of the respondents (19.0%) (14.3%) are taking one to two medication and five to six medication respectively for diseases. Lastly, 81.0% of the respondents have some form of end organ damage and the remaining 19.0% does not have end organ damage from diabetes.

## **5.2 Themes and sub-themes**

The emerging themes found while conducting this study can be coded into 3 mains themes. The first theme that emerged during the interview was comprehension of DSME content, the second theme that emerged was perception of the quality of the DSME and finally the third theme that emerged was perception on the effectiveness of

the instructional delivery of the DSME. The table below shows the subthemes for each that have been found while conducting the 21 in-depth interviews.

**Table 5.3 Themes and sub-themes of the findings**

Themes	Subthemes	
Comprehension of diabetes self-management education content	i)	Diabetes as a disease
	ii)	Medication and its management
	iii)	Nonpharmacological interventions
Perception of the quality of diabetes self-management education	i)	Quality of the delivery of DSME
	ii)	Quality of the deliverer of DSME
Perception on the effectiveness of the instructional delivery of diabetes self-management education	i)	Self-efficacy
	ii)	Health literacy

### **5.3 Comprehension of diabetes self-management education content**

The first theme that has been identified in the in-depth interview is the comprehension of the respondents to the content of DSME given by the GP. The content of the DSME can be further divided into 3 subthemes. The first subtheme is diabetes as a disease. In this subtheme, the topics covered in the DSME were diabetes signs and symptoms, its pathophysiology, and its complications. In the second subtheme of medication and its management, the topics covered are the types of medications used

to treat diabetes, its side effects, compliance, its storage and disposal especially in case of insulin, and coping strategies in the event of hypoglycaemia and hyperglycaemia. The last subtheme of this theme is nonpharmacological interventions, the topics that this subthemes cover were dietary control, physical activities, behavioural changes, risk mitigation strategies, coping strategies and peer or family support mechanisms. Below were the excerpts that represents each subtheme.

### 5.3.1 Diabetes as a disease

Most respondents (17/21) in this study found the content of DSME on the topic of diabetes itself overwhelming as it was presented in a detailed format. This was because these 17 of these respondents were from the age group 50 years old and above. These respondents from this age category felt that the general practitioner (GP) should summarize the content and only inform them about bare basics of diabetes as a disease. This consensus was held true as all the respondents from this age category as they had completed only secondary school education. The remainder 4 respondents found the content of the DSME on this topic satisfying their learning needs. Generally, across the respondents, they were able to understand that diabetes can be hereditary (Respondent 1 said, “ *I know how I get diabetes, my family got history of diabetes.....i know if you don't take care of your health and you are fat you can get diabetes.....when you get old, your organs also old.....they don't work properly. So you can get diabetes.*”).

That it can be caused by pancreatic insufficiency (Respondent 10 said, “*Thank god Dr X is my family doctor, he explained everything clearly and properly, I know that diabetes is caused because your pancreas is not working properly.....so your sugar in blood increases.*”)

That it could be diagnosed by the presence of high glucose in your blood stream and that it was not curable (Respondent 9 said, *“Aiyo, the doctor was explaining in detail to me, but I cannot understand everything...but I know that it cannot be cured but can be controlled. That gives me hope.”*)

But respondents believe that

diabetes can be controlled (Respondent 15 said, *“The doctor did explain to me what is diabetes is about, but I cannot tell you what causes diabetes.....all I understand about diabetes is that.....diabetes cause increase of sugar in your blood.”*).

### **5.3.2 Medication and its management**

All the respondents had generally understood the basic mechanism of antidiabetic medication and its management. Respondent 12 said, *“I’m on insulin Dr, I understand how insulin works and how to take care of it, but it is very difficult to go about daily life with insulin. For example, I must remember to inject the insulin if I am going out for dinner. Sometimes the dinner comes late, sometimes I eat too much.....this causes the sugar to be high and low.”*

The respondents understood the importance of the antidiabetic medications as well as medications for their respective comorbidities. About 10 respondents felt overwhelmed by the sheer amount of information with regards to insulin and its management. Respondent 13 said, *“Aiya, you have diabetes..... very difficult one.....got a lot of medicine. I take insulin, very difficult to remember all the rules!”*

They also felt insulin was troublesome, painful and hindrance to their daily life.

Respondent 21 said, *“You knowlah Dr, I am a lorry driver, Dr told me my diabetes not*

*controlled, so he started me on insulin. Even though I have to inject only 2 times a day, I feel its troublesome to do so. I'm scared I will hypo....very to difficult to work if hypo."*

Fifteen of the respondents admitted to not being compliant to their medications.

Respondent 3 said, *"Dr X got explain to me about my medications, I understand the basics. I know it is important to take them correctly but sometimes I do forget to take them."*

### **5.3.3 Non-pharmacological interventions**

All respondents had a broad understanding on what is being meant by nonpharmacological interventions from the DSME given to them by the GP in charge. Most respondents had a general idea on what resources and support mechanism were available to them in order to apply these nonpharmacological interventions for their diabetic control. Respondent 5 said, *"Last time when I stress, I always eat a lot. Now when I stress, I pray or meditate. Dr X help me.....because of this my sugar better. I also got reduce my smoking and drinking alcohol."*

*"Before diabetes, I always go out with my friends and have a drink or two, now I only go out 2 weeks once. What to do? I have to change, if not my sugar very high!"*

*Respondent 16*

Some respondents genuinely understood the importance of nonpharmacological interventions role in managing their diabetes. Respondent 11 said, *"From what I understand, carbohydrates and fats are also sugar when they enter your body. That is why I have reduced my rice intake. I also try to squeeze in 30 minute walk 3 times per week. I hope this can help me control my sugar."*

The respondents also understood that they could rely on their family member for support in managing their diabetes. Respondent 4 said, *“After I was diagnosed with diabetes, my wife now does not use sugar when cooking, she does not use coconut milk, salt also she use less nowadays because of me. Thanks to her, my sugar not high anymore.”*

#### **5.4 Perception of the quality of diabetes self-management education**

The second theme explored the respondents’ perception towards the quality of the DSME in terms of quality of the delivery and deliverer of the DSME, which became the subthemes of this second theme. Since the study was carried in a single private primary care clinic, the perception of the respondents was only of the GP of the study clinic. The topics explored in delivery of DSME subtheme are, types materials and technology used in delivery, were the resources user friendly, and was the delivery easily comprehensible. In the second subtheme, the topics explored are, the approachability of the deliverer, the language and body language used, and was the deliverer knowledgeable in all aspects of DSME.

##### **5.4.1 Quality of the delivery of DSME**

Here in this subtheme, almost half of the respondents expressed that they were satisfied with the delivery of the DSME. *“I like to follow up here for my diabetes because Dr X always do yearly check-up and always remind me and explain to me what to do for my diabetes. He always making sure that I follow the diet.....ermmm... exercise and so on. He even show me how to do the exercises.”* Respondent 17



The other half were not satisfied with only verbal delivery of DSME. *“I feel very boring listening to someone talk only, for me its better if can watch video or cartoon, so I’m not so happy with how Dr X explain to me about diabetes.”* Respondent 4

They would be happier if the GP had used electronic or hard copy materials such as flipcharts or brochures. *“When I was first diagnosed with diabetes, Dr X explained everything to me. I could understand everything that was said but couldn’t remember it all as he only told me verbally. I only had one brochure on signs and symptoms of hypoglycaemia.”* Respondent 2

The GP had mostly given the DSME verbally and illustrated the salient points on paper when needed. *“2 years back I transferred to KL because I got job transfer. I started to follow up here. I feel Dr X can explained better about diabetes. He makes it interesting to listen and easy to understand, better than my old place. He teaches me how to remember to take my medicine, how to store them and so on.”* Respondent 14

*“10 years after I was diagnosed with diabetes, I cannot see. When I check up my doctor said that my eye got diabetic retinopathy. He explained to me why I got it and how not to make it worse.”* Respondent 6

#### **5.4.2 Personal effectiveness of GP in delivering DSME**

During the interviews, there was consensus that Dr X was well liked and loved by all his patients. They all expressed that he was approachable and was able to relate to them on a personal level. *“I was very unhappy when I was diagnosed with diabetes because I thought young people cannot get diabetes, but Dr X help me with my depression. I feel Dr X understand my feelings and hopes. He helped me change my eating habits, help me loose weight. He is great!”* Respondent 15

The respondents expressed that Dr X was able to put DSME into their cultural context.

*“I am Muslim, Dr X also takes the time to explain the changes I have to make to my diet and medication regime during Ramadan. Other places I go they don’t do that.”*

Respondent 18

He was also deemed to be very patient with all the respondent’s queries and doubts.

*“I’m always scared to see doctor. But I’m not when I’m seeing Dr X. Even though my sugar high, he does not scold. He always patient and explain to me.”* Respondent 20

*“Any problem I have, anything I do not understand, I see Dr X. I talk to him, he will tell good things, I feel happier and more confident to solve my problems with diabetes. He also helps me come up with ways to solve any problem, so I do not get stressed.”*

Respondent 8

### **5.5 Perception on the effectiveness of the instructional delivery of diabetes self-management education.**

The last theme explores the respondent’s perception on the effectiveness of instructional delivery of DSME. Here, open ended questions were asked to subjectively assess whether the DSME given had an impact on their self-efficacy and self-management of diabetes and improvement in their own health literacy, numeracy, risk mitigation behaviour and health promoting behaviour. In the event of a good instructional delivery method of any education, the learner is bound to understand the content of the programme and will be able to apply the learnt content to their daily living activities. The results can be seen in improvement of respondents glycaemic control, healthier dietary intake, formation of healthier habits such as exercise, healthy coping strategies, and risk mitigation behaviours.

### 5.5.1 Self-efficacy

About a quarter of the respondents felt the instructional delivery of DSME played a role in improving their self-efficacy in managing their diabetes and comorbidities.

*“After meeting Dr X, I realised that I have to take active part in treating my diabetes. I cannot just take medication only. I change how I eat based on Dr X recommendation. My Hba1c has shown improvement!”* Respondent 17

Others felt the instructional deliver was not effective in influencing them to change their current behaviour or self-management of diabetes. *“When I met Dr X, I was 98kg, 2 years later I’m 99kg, Dr X got tell me to loose weight, exercise, control my sugar.....I understand what he is saying....but difficult for me to changelah!”* Respondent 14

*“Dr X always scold me! He say I never control my diet. But I actually do! Last time I used to drink coca cola, ribena and so on. Now I only take coffee or teh tarik. Human cannot survive without sugarlah. Can die one you know!”* Respondent 10

Most felt, more could be done to effect change in their behaviour.

*“I use insulin for my diabetes, but it is very mafan (troublesome) one you know! I understand only a bit. My daughter always poke for me. I can do but I scared. Dr X got teach but I always forget.”* Respondent 4

### 5.5.2 Health literacy, and respondent concerns and expectations.

In this final subtheme, most respondent felt that it was Dr X duty to provide them with necessary information for their management of diabetes. *“Everything I want to know, I come to clinic and ask doctor. Easy mah like this! No need go everywhere look for information. Only diabetes what..... take medicine sure ok one!”* Respondent 11

Only a handful of the respondents took an active role in searching for information from other resources than their GP. *“I always go on the internet and read about diabetes and what can eat and what cannot eat. Dr X also intro me a health app. This app help me very much one. I learn some many new info.i know it is my responsibility to take care of my health.”* Respondent 3

*“Dr X told me diabetes is just like asthma, I just have to understand how it works then I can manage it. So I started learning about diabetes and how I can manage it myself from other sources as well. I now know the difference between low and high glycaemic index food, what exercise to do, if I have problem....who to see and how to solve.”*

Respondent 15

Since health literacy was moderate to begin with respondents, most felt that the GP could provide them with more free and easy resources to help them understand about their diabetes, its management, and their concerns.

*“Everybody say smoking bad for you, Dr X also say same thing. But then if I stop suddenly sure heart attack one!.....I don't know lah.....Dr X always ask me to stop. Difficult to stop lah...”* Respondent 16

From the results above, more than half the respondents were female, majority of the respondents were only educated till secondary school level, were predominantly of Indian ethnicity, aged above 50 years old, had been living with diabetes more than 10 years, had 3 to 4 medication on board, had 3 to 4 comorbidities and majority of them had some form of end organ damage. From thematic results, we can summarize that most respondents felt overwhelmed with the information given during the DSME, were mostly satisfied with quality of the delivery of DSME but not so with the deliverer of

the DSME, and majority of the respondents felt that the instructional delivery of DSME did not influence either their self-efficacious behaviour nor their health literacy. It was clearly established the meaning and relationships of the contextualisation of the emerged theme within existing theories and framework will be analysed in the following discussion section of the study.

## **5.6 Discussion**

This study explored patient's comprehension of content and patient perception regarding quality of diabetes self-management and instructional delivery and education provided in a private primary care clinic. These were the three themes of the study. The study then coded the above 3 themes into several subthemes each. In the first theme patient's comprehension of the content of diabetes self-management education was further divided into three subthemes, which are diabetes as a disease, medications and its' management and nonpharmacological interventions. Next under the patient's perception of the quality of diabetes self-management education theme, the study explored the quality in terms of the delivery and deliverer of the DSME. Finally, under the patient's perception on the effectiveness of the instructional delivery of diabetes self-management education, the study explored the self-efficacy and health literacy of diabetic patients. The following section will offer analysis and interpretation for the above themes and subthemes for restructuring DSME and policy making decisions.

## **5.7 Analysis of the Results**

The first theme is comprehension of the content of DSME. Here the theme was further divided into three subthemes which were diabetes as a disease, medication and its' management and nonpharmacological interventions. From the results, it was noted

that 17 out of 21 respondents found the content of DSME overwhelming, hence they only managed to grasp the extremely basic of information in all 3 subthemes. Adjei Boakye., (2018) reported that sociodemographic factors such as lower education level and older age were among the key factors that influence the patient comprehension of DSME. The same was held true in this study, whereby majority of the respondents were above 50 years old and have completed secondary school only. The theoretical framework that could explain this phenomenon is Vygotsky's theory of zone of proximal development. In this theory, the more knowledgeable other plays an important role in helping the learner learn new information faster as the learner can relate to the more knowledgeable other as his or her peer (Chaiklin, S., 2003).

Another reason the respondents only had extremely basic comprehension of all the 3 subthemes could be because of knowledge decay secondary to poor reciprocal teaching (Palinscar, A. S., 1984). Atkinson & Shiffrin, (1968) information processing theory states that for information from the short-term memory to be encoded into long term memory for usage later, the learner should have repeated maintenance rehearsal of the information. For example, for diabetic patients to remember the sequence of injecting insulin, they have to practise repeatedly. Respondents should have information presented to them in clear, simple, precise manner for easy assimilation of the information. Pintrich, P. R., (2002) metacognition theory can be used to explain the premise where an adult learner first needs to realise their lack of self-awareness of diabetic content and task knowledge. This leads to poor comprehension of medication management and practising correct nonpharmacological interventions.

In the second theme, the results revealed that the respondents were satisfied with the quality of the delivery of DSME, but they were not satisfied with the personal

effectiveness of the GP. As in Dao, J., et. al., (2019) patient provider (GP) relationship plays a crucial role in patient satisfaction of DSME. In an Australian study set in low socioeconomic area of Sydney, provider who managed to engage in a patient centred and personal approach, garnered more satisfaction from patients. Here the delivery of DSME used multiple method such as animated videos, brochures and task orientated workshops (Dao, J., et. al., 2019). Hence patients were satisfied with the delivery of the DSME but was not satisfied with personal effectiveness of the GP in this study. Similarly, in this study, the respondents were satisfied with the quality of the delivery of DSME because the GP not only verbal delivered the DSME in simple language but also drew and doodled whenever patient had any questions or uncertainty. Piaget (1952) stated that to form new units of information, information should be delivered in a language that is native to the respondent, is in simple, precise, and clear. The GP applied this theory when he drew and doodle to reinforce comprehension of the respondents. Dasen, P., (1994) also corroborated the above method by encouraging the physician to use non jargon language and physical anatomical models for education.

Mathew, R., et. al. (2012) found that female patients preferred a more interactive classes with their peers, whereas men were keener on learning by themselves. Because of majority of female respondents in this study, they were not satisfied with the overall perceived effectiveness of the GP. They were not satisfied because the GP did not allow their peers or family member to join the session. Mathew, R., et. al. (2012) also reported that both the genders need physician support and time when it comes to practical parts of diabetic self-management such medication management, blood sugar monitoring and management of hypoglycaemic and hyperglycaemic situations. In this study as the GP was a lone practitioner, allotted time for each patient was limited. This contributed to the overall dissatisfaction with perceived effectiveness of the GP.

Finally, the results of the third theme revealed that respondents' perception on the effectiveness of the instructional delivery used by the GP, was not effective in influencing the self-efficacious behaviours and health literacy of the respondent. Bandura, A. (1977) hypothesized that 4 main sources of knowledge forms self-efficacious behaviour. The 4 sources of knowledge are from the accomplishments of tasks, through experience, via verbal persuasion and last through various physiological states. Since the instructional delivery of DSME in the study primary care setting only utilised the verbal persuasion format, it was not sufficient to influence all the respondents adequately for successful self-efficacy. From the perspective of a learning theory, a patients' motivation and personality plays a pivotal role in determining their successful self-efficacious behaviour (Ryan & Deci, 2000). From the study, most respondents were extrinsically motivated, hence a single method of instructional delivery was not sufficient to sustain a long and successful self-efficacious behaviour.

Ahmad, B., et. al. (2017) revealed that diabetic education that has been contextualised to local setting can significantly improve patients' glycaemic control. This can only be achieved if the health literacy of the respondents has improved significantly via the application MY DEMO diabetic education programme. This module was developed adapting it to the national language and by considering the local cultural preferences (Ahmad, B. et. al, 2014). Lantzy, T. (2016) proved that whether it was a virtual delivery or face to face delivery of a health education, it did improve the health literacy of the study participants. However, in this study a single method instructional delivery did not improve the health literacy of the study respondents. This was probably because of the secondary school education status of the respondents (Lane, D. S., & Evans, D., 1979).



In summary, most respondents felt overwhelmed by the sheer load of information in the first theme of comprehension of diabetes self-management education content. In the second theme of respondent perception of the quality of delivery of DSM and personal effectiveness of the GP; the respondents were generally satisfied with the method of delivery; however, they were not satisfied with GP's effectiveness. Finally, in the third thematic analysis, respondents felt that the instructional delivery of the DSME did not influence them enough for improvement of self-efficacious behaviour, health literacy nor their concerns adequately. It can be said that diabetic self-management education is of utmost importance in managing a diabetic patient. As such, more local studies can be done to gauge patient perception of existing DSME, as this would reveal the need for improvisation and contextualization to the local context.

## CHAPTER 6 RECOMMENDATIONS AND CONCLUSION

### 6.1 Study Recommendations

From this study, one large recommendation that arises is the need for more research into developing structured, guided patient education modules of diabetic self-management such as the MY DEMO which was done in the Malay language, in Chinese and Indian context as well.

Development of such patient education needs to rely on the still highly relevant principle of adult education as first postulated by Knowles (Knowles, 1980). First, adult learners must always be appraised of the need for them to learn, and this was never more relevant in a disease management context.

Second, health educators should always follow the rules of teaching. They should always progress from simple to complex knowledge when educating a patient about their disease. Health educators should always assess the patients' existing knowledge and health literacy capabilities before embarking on an educational programme.

Third, adults learn better through experiential learning. As such it would be important for a patient education programme to be two ways rather than one way. Programmes should include patient participation as it would be an enriching experience for the patients.

Fourth, adults need opportunities in which to practice their newly learnt skills. Patients need to be provided opportunities in which they can do so. For example, asthma patients were required to demonstrate the usage of their metered dose inhaler at each physician visit.

Fifth, adults need behavioural reinforcement. Short term follow-up sessions should be scheduled for reinforcement of skills and knowledge taught in previous

sessions. In view of recent pandemic, the usage of telemedicine would have been a better method to modulate this.

Sixth, feedback plays an important role in adult learning. When feedback was given immediately learners can correct their misconceptions, confusions, fake news, and pseudoscience in an appropriate manner. In the primary care setting, physicians often ask their patients to restate the salient points of the newly learnt skills or knowledge.

Sadly, although the above recommendations can easily be visualised in patient education context, it may not be so simple in actual life. These recommendations need huge resources in terms of money, personnel, and energy to develop and deliver a beneficial patient education programmes.

## **6.2 Strengths of the Study**

This study is among the first in gauging patients' comprehension of the DSME content, perception towards the quality of the DSME and patients' perception of the effectiveness of the instructional delivery of the DSME at a local private primary care clinic setting. Most studies done were quantitative in nature and there is a lack of literature in the local context that explored patients' perspectives on the above-mentioned topics.

## **6.3 Limitations of the Study**

Among the glaring limitations of this study was that it was carried out in a single private primary care clinic in an urban setting. The study design was of purposive sampling. These may have resulted in an under-representation of the population. As a result, the findings of this study cannot be generalised to the general population in Malaysia. This also led to poor representation of all ethnic/races in the study especially

the Orang Asli and the ethnic groups from East Malaysia. Since the study was based on perceived effectiveness, the opinion may vary and are subjective. It may not be the actual effectiveness of the method or the provider. As such, while this study and its findings act as a barometer to sound out the depth of the field, further better designed perhaps even quantitative studies are required in order to further validate the results obtained here.

#### **6.4 Conclusion**

In conclusion, patient understanding of the diabetic self-management education was shown to be one of the important aspects of managing diabetes, it remains to be poorly understood among the local patients. This in turn gives rise to poor achievement of target glycaemic control which leads to increased morbidity and mortality. The development of DSME in the local context would be important more so than never. Further comprehensive research is needed to gauge patient perception and needs for the development of DSME that is better suited for population in the local context.

## REFERENCES

Adjei Boakye, E., Varble, A., Rojek, R., Peavler, O., Trainer, A. K., Osazuwa-Peters, N., & Hinyard, L. (2018). Sociodemographic factors associated with engagement in diabetes self-management education among people with diabetes in the United States. *Public Health Reports, 133*(6), 685-691.

Alwan, A., MacLean, D. R., Riley, L. M., d'Espaignet, E. T., Mathers, C. D., Stevens, G. A., & Bettcher, D. (2010). Monitoring and surveillance of chronic non-communicable diseases: progress and capacity in high-burden countries. *The Lancet, 376*(9755), 1861-1868.

Ahmad, B., Ramadas, A., Fatt, Q. K., & Zain, A. Z. M. (2014). A pilot study: the development of a culturally tailored Malaysian Diabetes Education Module (MY-DEMO) based on the Health Belief Model. *BMC endocrine disorders, 14*(1), 31.

Ahmad, B., Zain, A. Z. M., & Fatt, Q. K. (2017). Type 2 diabetes patients are more amenable to change following a contextualised diabetes education programme in Malaysia. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews, 11*, S901-S906.

Ahmed, A. M. (2002). History of diabetes mellitus. *Saudi medical journal, 23*(4), 373-378.

Araetus C. On causes and symptoms of chronic diseases. Translated by Adam CF. London, (UK): London Sydenham Society; 1856. p. 138.

Atkinson, R. C., & Shiffrin, R. M. (1968). Human memory: A proposed system and its control processes (Vol. 2). *The Psychology of Learning and Motivation: Advances in Research and Theory*, 89-195.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological review*, 84(2), 191.

Banting F, Best C, Collip JB, Campbell WR, Fletcher AA. Pancreatic extracts in the treatment of diabetes mellitus: a preliminary report. *Canadian Medical Association Journal* 1922; 12: 141-146.

Brady, E. M. (1984). Demographic and Educational Correlates of Self-Reported Learning among Older Students. *Educational Gerontology*, 10, 25-38.

Chaiklin, S. (2003). The zone of proximal development in Vygotsky's analysis of learning and instruction. *Vygotsky's educational theory in cultural context*, 1(2), 39-64.

Courtney, S. (2018). *Why adults learn: Towards a theory of participation in adult education*. Routledge.

Craik, F. I., & Lockhart, R. S. (1972). Levels of processing: A framework for memory research. *Journal of verbal learning and verbal behavior*, 11(6), 671-684. Levels of processing: A framework for memory research. *Journal of verbal learning and verbal behavior*, 11(6), 671-684.

Dao, J., Spooner, C., Lo, W., & Harris, M. F. (2019). Factors influencing self-management in patients with type 2 diabetes in general practice: a qualitative study. *Australian journal of primary health*, 25(2), 176-184.

Darkenwald, G. G., & Hayes, E. R. (1988). Assessment of adult attitudes towards continuing education. *International journal of lifelong education*, 7(3), 197-204.

Dasen, P. (1994). Culture and cognitive development from a Piagetian perspective. In W.J. Lonner & R.S. Malpass (Eds.), *Psychology and culture* (pp. 145–149). Boston, MA: Allyn and Bacon.

Dreschfeld J. The Bradshawe Lecture on diabetic coma. *Br Med J* 1886; 2: 358-363.

Freund, L. S. (1990). Maternal regulation of children's problem-solving behavior and its impact on children's performance. *Child Development*, 61, 113-126.

Greenhalgh, T., Helman, C., & Chowdhury, A. M. M. (1998). Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *Bmj*, 316(7136), 978-983.

Haas, L., Maryniuk, M., Beck, J., Cox, C. E., Duker, P., Edwards, L., ... & McLaughlin, S. (2014). National Standards for Diabetes Self-Management Education and Support. *Diabetes Care*, 37(Supplement 1), S144-S153.

Harper, D., & Thompson, A. R. (Eds.). (2011). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. John Wiley & Sons.

Ji, J. J., Liu, L., Lou, Q. Q., Yuan, X. D., Yao, P., & Zhang, D. Y. (2014). Self-management behaviors and glycemic control in patients with type 2 diabetes mellitus. *Chinese Journal of Nursing*, 49(5), 617-620.

Knowles, M. S. (1980). *The modern practice of adult education*.

Lane, D. S., & Evans, D. (1979). Measures and methods in evaluating patient education programs for chronic illness. *Medical Care*, 17(1), 30-42.

Lantzy, T. (2016). Health literacy education: the impact of synchronous instruction. *Reference Services Review*.

Lipsitch, M., Swerdlow, D. L., & Finelli, L. (2020). Defining the epidemiology of Covid-19—studies needed. *New England Journal of Medicine*.

Lyon DM. Standard diets for use in diabetes. *BMJ* 1924; ii: 326-329.

Mafauzy, M. (2005). Diabetes control and complications in private primary healthcare in Malaysia. *Medical Journal of Malaysia*, 60(2), 212.

Mathew, R., Gucciardi, E., De Melo, M., & Barata, P. (2012). Self-management experiences among men and women with type 2 diabetes mellitus: a qualitative analysis. *BMC family practice*, 13(1), 122.

Miller, G. A. (1956). The magical number seven, plus or minus two: some limits on our capacity for processing information. *Psychological Review*, 63 (2): 81–97.

Morris, C. D., Bransford, J. D., & Franks, J. J. (1977). Levels of processing versus transfer appropriate processing. *Journal of verbal learning and verbal behavior*, 16(5), 519-533.

Morrow, A. S., Haidet, P., Skinner, J., & Naik, A. D. (2008). Integrating diabetes self-management with the health goals of older adults: a qualitative exploration. *Patient education and counseling*, 72(3), 418-423.



Murphy, K., Chuma, T., Mathews, C., Steyn, K., & Levitt, N. (2015). A qualitative study of the experiences of care and motivation for effective self-management among diabetic and hypertensive patients attending public sector primary health care services in South Africa. *BMC health services research*, 15(1), 303.

Nagelkerk, J., Reick, K., & Meengs, L. (2006). Perceived barriers and effective strategies to diabetes self-management. *Journal of advanced nursing*, 54(2), 151-158.

Norris, S. L., Lau, J., Smith, S. J., Schmid, C. H., & Engelgau, M. M. (2002). Self-management education for adults with type 2 diabetes: a meta-analysis of the effect on glycemic control. *Diabetes care*, 25(7), 1159-1171.

Ockleford, E., Shaw, R. L., Willars, J., & Dixon-Woods, M. (2008). Education and self-management for people newly diagnosed with type 2 diabetes: a qualitative study of patients' views. *Chronic Illness*, 4(1), 28-37.

Palinscar, A. S., & Brown, A. L. (1984). Reciprocal teaching of comprehension-fostering and comprehension-monitoring activities. *Cognition and instruction*, 1(2), 117-175.

Piaget, J., & Cook, M. T. (1952). *The origins of intelligence in children*. New York, NY: International University Press.

Pintrich, P. R. (2002). The role of metacognitive knowledge in learning, teaching, and assessing. *Theory into practice*, 41(4), 219-225.

Powers, M. A., Bardsley, J., Cypress, M., Duker, P., Funnell, M. M., Fischl, A. H., ... & Vivian, E. (2017). Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American

Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. *The Diabetes Educator*, 43(1), 40-53.

Reece EA. The history of diabetes mellitus. In: Reece EA, Coustan DR editors. *Diabetes Mellitus in Pregnancy*. New York, (USA): Churchill Livingstone, 1995, p. 1-10.

Ruiz CL, Silva LL, Libenson L. Contribucion al estudio sobre la compisicion quimica de la insulina: estidio de alganos cuerpos sinteticos sulfurados con accion hipoglucemiante. *Reviea Societa du Argentina Biologica* 1930; 6: 134-141.

Rollo J. Account of two case of the diabetes mellitus: London, (United Kingdom): Dilly; 1797. p. 260

Rumelhart, D. E., McClelland, J. L., & PDP Research Group. (1988). Parallel distributed processing (Vol. 1, pp. 354-362). IEEE.

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American psychologist*, 55(1), 68.

Schaffer, R. (1996). *Social development*. Oxford: Blackwell.

van Dam, H. A., Van der Horst, F., Van den Borne, B., Ryckman, R., & Crebolder, H. (2003). Provider–patient interaction in diabetes care: effects on patient self-care and outcomes: a systematic review. *Patient education and counseling*, 51(1), 17-28.

Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Vygotsky, L. S. (1987). Thinking and speech. In R.W. Rieber & A.S. Carton (Eds.), The collected works of L.S. Vygotsky, Volume 1: Problems of general psychology (pp. 39–285). New York: Plenum Press. (Original work published 1934.)

Vygotsky, L. S. (1962). Thought and language. Cambridge MA: MIT Press.

Wadsworth, B. J. (2004). Piaget's theory of cognitive and affective development: Foundations of constructivism. New York: Longman.

World Health Organization. (1/4/2020). Coronavirus disease 2019 (COVID-19): situation report, 72.q1

Yu, P., Xiao, X., Wang, L., & Wang, L. (2013). *Zhong nan da xue xue bao. Yi xue ban= Journal of Central South University. Medical sciences*, 38(4), 425–431.

Zimmerman, B.J. (1990). Self-Regulated Learning and Academic Achievement – An Overview. *Educational Psychologist*, 25(1), 317. doi:10.1207/s15326985ep2501\_2

Zohar, A., & David, A. B. (2009). Paving a clear path in a thick forest: A conceptual analysis of a metacognitive component. *Metacognition and Learning*, 4(3), 177-195.