

An Exploration of Self-Care Practice and Self-Care Support of Patients with Type 2 Diabetes in Malaysia

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TABLE OF CONTENTS

TABLE OF CONTENTS.....	2
List of Tables	8
List of Figures.....	9
List of Appendices	10
Abstract.....	11
Declaration.....	12
Copyright statement.....	12
Acknowledgement	13
Background to the author.....	14
Organisation of the thesis.....	15
Chapter 1	16
Study Background.....	16
1.1 Introduction.....	16
1.2 Background to the research problem	16
1.3 Self-care in type 2 diabetes	18
1.4 Overview of study context.....	20
1.4.1 Overview of Malaysian healthcare system	22
1.5 Summary	23
Chapter 2	24
Literature Review.....	24
2.1 Introduction.....	24
2.2 Literature search strategies.....	24
2.2.1 Research objectives for literature review	24
2.2.2 Research questions for literature review	25
2.2.3 Search strategies.....	25
2.3 Findings of the search	27
2.3.1 Assessment of the reviewed studies	28
2.3.1.1 Overall weight of evidence	30
2.4 Synthesis of study findings	32
2.4.1 Level of adherence to self-care of patients with type 2 diabetes	33

2.4.2 Experience of patients with type 2 diabetes and factors influencing engagement with self-care.....	36
2.4.2.1 Invisible disease and lack of acceptance.....	36
2.4.2.2 Challenges of integrating self-care in to daily life.....	39
2.4.2.3 Facilitators to self-care.....	41
2.4.3 Provision of self-care support.....	44
2.4.3.1 Importance of support from HCPs.....	44
2.4.3.2 Effectiveness of self-care support provision.....	48
2.5 Theoretical underpinned the self-care support interventions.....	52
2.6 Summary of literature review and justification of current study.....	54
Chapter 3.....	56
The Research Paradigm and Methodology.....	56
3.1 Introduction.....	56
3.2 Research aims and objectives.....	56
3.2.1 Research aims.....	57
3.2.2 Research questions.....	57
3.2.3 Research objectives.....	57
3.3 Principles underpinning the study methodology.....	58
3.3.1 Qualitative methodology.....	61
3.4 Underpinning philosophy: Pragmatism.....	62
3.5 Summary.....	63
Chapter 4.....	64
Case Study Design.....	64
4.1 Introduction.....	64
4.2. Case study research.....	64
4.2.1 Definition a case study.....	65
4.2.2 Propositions in a case study.....	68
4.3 Type of case study design.....	69
4.5 Defining the ‘case’.....	72
4.6 Description of case study settings.....	74
4.6.1 Case study site one.....	76
4.6.2 Case study site two.....	78
4.6.3 Case study site three.....	79
4.7 Summary.....	82

Chapter 5	83
Research Methods.....	83
5.1 Introduction.....	83
5.2 Identifying the data source.....	83
5.3 Process of gaining access.....	84
5.4 Sampling and recruitment of participants	86
5.4.1 Sampling and recruitment of HCPs	87
5.4.2 Sampling and recruitment of patients with type 2 diabetes	89
5.4.3 Recruitment for interviews.....	92
5.4.3.1 Recruitment of HCPs for the interviews	92
5.4.3.2 Recruitment of patients with type 2 diabetes for interviews.....	92
5.4.4 Recruitment for observations	93
5.4.4.1 Recruitment of HCPs to the observations	93
5.4.4.2 Recruitment of patients with type 2 diabetes to observations.....	94
5.5 Data collection process	97
5.5.1 Interviews.....	97
5.5.1.1 Consideration of interview method.....	97
5.5.1.2 The interview topic guide	99
5.5.1.3 Conduct of interviews	100
5.5.1.4 Transcribing interview data	102
5.5.2 Observations	103
5.5.2.1 Consideration of observation method	103
5.5.2.2 Conduct of observations.....	105
5.5.3 Analysis of documents.....	108
5.6 Data analysis	110
5.6.1 Consideration of data analysis method	110
5.6.2 Framework technique in analysing interview and observational data	112
5.6.2.1 Data management.....	113
5.6.2.2 Descriptive accounts	115
5.6.2.3 Explanatory accounts	116
5.6.3 Analysis of participants' interview data: application of framework.....	116
5.6.3.1 Developing the thematic framework.....	116
5.6.3.2 Process of indexing.....	118
5.6.3.3 Thematic charts.....	119

5.6.3.4 Summary of data	120
5.6.3.5 Developing descriptive accounts	122
5.6.4 Analysis of observation and documentary data: application of framework.....	126
5.7 Methodological rigour	131
5.7.1 Credibility	131
5.7.2 Dependability	132
5.7.3 Transferability.....	132
5.8 Ethical considerations	133
5.8.1 Informed consent and voluntary participation	133
5.8.2 Anonymity and confidentiality	134
5.8.3 The dual role	134
5.8.4 Empathy and research-mindedness	135
5.8.5 Research governance and ethical approval	136
5.9 Reflexivity.....	136
5.9.1 Reflexivity account: The role of the researcher.....	138
5.10 Summary	140
Chapter 6	141
Describing Self-Care of Type 2 Diabetes in Malaysia.....	141
6.1 Introduction.....	141
6.2 Part 1: Description of the participants.....	141
6.2.1 Characteristics of patient participants	142
6.2.2 Characteristics of HCP participants	143
6.3 Part 2: Self-care of type 2 diabetes in Malaysia.....	145
6.3.1 Practice of self-care.....	146
6.3.1.1 Diet control	146
6.3.1.2 Compliance with medication	153
6.3.1.3 Use of alternative medicine.....	160
6.3.2 Factors influencing self-care.....	162
6.3.2.2 Barriers to self-care.....	177
6.4 Summary	186
Chapter 7	188
Management of Type 2 Diabetes within the Malaysian Healthcare System.....	188
7.1 Introduction.....	188
7.2 Management of type 2 diabetes within the Malaysian healthcare system	189

7.2.1 Service provision within primary-care settings.....	193
7.2.1.1 Community-based approach	193
7.2.1.2 Group education programme	196
7.2.1.3 Collaborative practice	198
7.2.2 Service provision within secondary-care settings	207
7.2.2.1 Individual consultations	208
7.2.2.2 Importance of SMBG.....	211
7.2.3 Concept of self-care within the support documents	215
7.3 Summary	220
Chapter 8	222
Perspectives of Diabetes Educators on Their Role in Supporting Self-Care	222
8.1 Introduction.....	222
8.2 Diabetes educators’ perspectives on their role in self-care support provision.....	223
8.2.1 Importance of knowledge.....	224
8.2.2 Individualised support.....	227
8.3 Factors that influenced self-care support provision	233
8.3.1 Patient factors.....	233
8.3.1.1 Patients’ acceptance of diagnosis.....	233
8.3.1.2 Patients’ interest in self-care	235
8.3.2 Environmental factors	237
8.3.2.1 Space	237
8.3.2.2 Crowded clinics	238
8.3.3 Diabetes educators’ internal factors	240
8.3.3.1 Lack of opportunity to practice	240
8.3.3.2 Poor job satisfaction.....	243
8.3.4 Systemic factors (fragmented medical system).....	245
8.4 Summary	247
Chapter 9	248
Discussion and Conclusion.....	248
9.1 Introduction.....	248
9.2 Overview of the study	248
9.3 Study propositions	250
9.4 Originality and contributions of the research.....	250
9.5 Review of the methods.....	251

9.6 Discussion of the findings.....	253
9.6.1 Discrepancy between the self-care needs of patients and the support provided	253
9.6.2 Traditional medical model vs patient-centred care	260
9.6.3 Role and autonomy of diabetes educators.....	265
9.7 Implication for policy, practice and education.....	267
9.8 Implication for future research.....	268
9.9 Limitations	270
9.10 Conclusion	272
References.....	274

List of Tables

Table 2.1 List of studies included in the review	29
Table 4.1 Yin’s categories of case study (Yin, 2009).....	69
Table 4.2 Variant of case study design (Yin, 2009)	70
Table 5.1 Proposed data collection methods.....	84
Table 5.2 Criteria for assessing quality of documentary evidence (Scott, 1990)	109
Table 5.3 The thematic framework for patients’ interviews.....	117
Table 5.4 The thematic framework for the HCP interviews	118
Table 5.5 Thematic chart for analysis of patients’ interview data	119
Table 5.6 Thematic chart for analysis of HCPs’ interview data	120
Table 5.7 Thematic framework to analyse field notes and documents.....	126
Table 5.8 Framework chart for analysis of observational data.....	129
Table 6.1 Number of participants recruited	141
Table 6.2 Characteristics of patient participants.....	143
Table 6.3 Characteristics of HCP participants.....	144
Table 6.4 Themes and categories describing self-care of type 2 diabetes in Malaysia ..	145
Table 7.1 Themes and categories describing self-care support provision	189
Table 8.1 Themes and categories describing perspective of diabetes educators on their role in self-care support provision	223

List of Figures

Figure 1.1 Map of Malaysia.....	20
Figure 4.1 Structure of the case	73
Figure 4.2 Flow chart depicting the management of patients with diabetes in case study site 1	77
Figure 4.3 Flow chart depicting the management of patients with diabetes in case study site 2	79
Figure 4.4 Flow chart depicting the management of patients with diabetes in case study site three	81
Figure 5.1 Flow chart of recruitment of HCPs	95
Figure 5.2 Flow chart outlining the recruitment of patients	96
Figure 5.3 Layout of one of the observed consultation rooms	107
Figure 5.4 Transition of data from summary (thematic chart) to categorisation (patient data).....	124
Figure 5.5 Transition of data from summary (thematic chart) to categorisation (HCP data)	125
Figure 5.6 Process of classification and cateorisation of observational data.....	130
Figure 7.1 Levels of diabetes prevention and control within the Malaysian healthcare setting.....	192
Figure 7.2 Level of diabetes prevention and control within the Malaysian healthcare Setting	192

List of Appendices

Appendix 1 – List of keywords used in literature search and detail of search strategy	303
Appendix 2 - Flow diagram of retrieval studies for review	304
Appendix 3 – Hawker’s assessment tool	305
Appendix 4 – Quality assessment of the included studies	308
Appendix 5 – Invitation letter for case study sites (Gaining access)	328
Appendix 6 – Ethical approval from the University of Manchester	335
Appendix 7 – Approval to conduct research in Malaysia	337
Appendix 8 – Ethical approval from Medical Research Ethic Committee Malaysia (MREC)	339
Appendix 9 – Letter of invitation for HCPs.....	340
Appendix 10 – Participant information sheet for HCPs.....	341
Appendix 11 – Consent form for HCPs	347
Appendix 12 - Poster advertising the study	348
Appendix 13 – Invitation letter to patients.....	349
Appendix 14 – Participant information sheet to patients	351
Appendix 15 – Reply slip to patients	366
Appendix 16 – Consent form for patients	368
Appendix 17 – Topic guide for interview with HCPs.....	370
Appendix 18 – Topic guide for interview with patients	372
Appendix 19 – Observation schedule	374
Appendix 20 – Example of patient’s interview transcript and reflexivity account.....	376
Appendix 21 – Example of observation field notes	383
Appendix 22 – Thematic chart (developed in Nvivo 9).....	388
Appendix 23 – Process of classification and categorisation	393

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ABSTRACT OF THESIS submitted by Sanisah Saidi for the degree of Doctor of Philosophy and entitled:

An Exploration of Self-Care Practice and Self-Care Support of Patients with Type 2 Diabetes in Malaysia

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Abstract

Background: A marked increase of type 2 diabetes and associated morbidity and mortality rate over the last 10 years has been recorded in Malaysia. Ineffective diabetes management and a lack of self-care practice among type 2 diabetic patients have been identified as the major reasons for this problem. Research in other countries has highlighted a range of factors influencing effective self-care of type 2 diabetes including patients' perspectives of diabetes, sociocultural issues, religious beliefs and support from healthcare. Nevertheless, there is paucity of research conducted in Malaysia. Therefore, the exploration of self-care practice and self-care support provision in patients with type 2 diabetes in Malaysia is needed to understand the problem.

Aims: To understand the self-care practice of patients with type 2 diabetes in Malaysia and the factors that influence the patients' self-care practice. To understand the type 2 diabetes' self-care support provision in Malaysia from the perspective of patients, healthcare professionals, and healthcare system.

Methods: A qualitative, single embedded case study design was utilised. Eighteen patients with type 2 diabetes and 19 healthcare professionals (physicians, diabetes educators, nurse, pharmacist and dietician), involved in self-care support provision primary- and secondary-care settings in Kuala Lumpur and Putrajaya, Malaysia, participated in in-depth semi-structured interviews between November 2012 and June 2013. In addition, data were collected through participant-observation of clinic consultations, and analysis of relevant documents used in the provision of diabetes management in the respective clinics. The framework technique supported analysis of data. Data were stored and managed using Nvivo 9 software.

Findings: The findings indicate that patients with type 2 diabetes had a good understanding of diabetes and self-care, but a lack of self-care support meant that effective self-care was difficult to sustain. Healthcare professionals' (HCPs') provision of self-care support was restricted due to several factors, including lack of opportunity to provide self-care support, unsuitable clinic environment and a fragmented management within primary and secondary care. Additionally, barriers in patient-HCP communication, a combination of the personal, interpersonal and inter-professional HCP factors, and a traditional medical model adopted by Malaysian healthcare system, seem to have influenced the practice and quality of the service delivered.

Conclusion: It is clear that the increased incidence of uncontrolled type 2 diabetes is not merely due to poor self-care practice by patients, but also due to constraints in service delivery and underdevelopment of self-care support provision. The evidence generated can assist in the development of strategies to improve the quality of care and facilitate changes in the self-care support provision in Malaysia.

Declaration

No portion of the work referred in this thesis has been submitted in support of an application for another degree or qualification of this or any other institute of learning.

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Dedication

I dedicated this work to my parents for providing me love more than I deserved and for their continuous support and encouragement throughout this journey.

Background to the author

I am currently a Lecturer in Adult's Nursing at the Faculty of Nursing, International Islamic University Malaysia. I obtained my Diploma in Nursing in 1999 and Bachelor Degree in Nursing in 2006 from the School of Nursing, Faculty of Medicine, National University of Malaysia. I obtained my Msc in Advanced Nursing in 2008 from the University of Nottingham, United Kingdom. My background is in adult nursing where I worked in an Intensive Care Unit for five years before subsequently taking up an academic position.

My research experience was started with a small survey at Undergraduate level looking at the recollections of experience of post-mechanically ventilated patients in Intensive Care Unit in Hospital University Kebangsaan Malaysia (HUKM). During my Msc study, I conducted a systematic review looking at the effectiveness of computer assisted modalities in skill acquisition of pre-registered nurses. Research experience that I gained from both of the studies developed my knowledge and confidence in conducting this study.

Organisation of the thesis

The thesis is divided into nine chapters. First chapter address the background of the problem from the global and Malaysian context which become the impetus of this study. In addition, explanation of the term 'self-care' that is relevant to the type 2 diabetes was also provided. Chapter two provides the process and findings of the literature review that illuminated the gap in knowledge and practice that justified the relevant of this study. The third and fourth chapters describe the research paradigm, methodological underpinning and the research design of this study. Chapter five details the working methods and data analysis process. The next three chapters present the findings of the study. The final chapter presents a discussion of the findings, with particular reference to the body of literature and policy context relevant to the self-care of type 2 diabetes.

CHAPTER 1

Study Background

1.1 Introduction

This chapter sets out the background of the problem related to long-term conditions and type 2 diabetes globally and the current situation in Malaysia. The description of the concept of self-care within the context of long-term conditions and type 2 diabetes is provided. In addition, this chapter provides overview of the study context. The background to the problem presented in this chapter directed the development of questions that guided the literature review and initiation of this study.

1.2 Background to the research problem

There is evidence that suggests that long-term health conditions continue to impact on the lives of people around the world. In 2005, the World Health Organisation (World Health Organization, 2005) reported that 47% of the global burden of disease and 60% of deaths worldwide have been caused by long-term conditions, including cardiovascular disease, chronic respiratory disease, cancers, mental disorders, and diabetes. Diabetes mellitus has become the greatest concern as its prevalence is rapidly escalating worldwide, especially in developing and newly industrialised countries (Rugayah, 2007). Although the European region currently has the highest number of sufferers of diabetes with 48 million people, it is forecast that the epidemic will increase greatly in Asian regions in less than 25 years (International Diabetes Federation, 2009). By 2025 it is estimated that the total number of diabetes sufferers in the Southeast Asia region will reach its peak of more than 170 million (Wild et al., 2004). This situation is due to the economic development and urbanisation of the countries in this region (International Diabetes Federation, 2009). As

an impact, health care costs are expected to rise in the respective countries due to the increase in health service utilisation and medical care supplies (Juliana et al., 2009).

Malaysia, a developing country which is located in Southeast Asia, has not been spared from the diabetes epidemic. The incidence of diabetes in Malaysia has increased rapidly over the past 20 years. In 1986, the prevalence of diabetes in those aged ≥ 30 years was 6.3%, and this kept climbing to 14.9% in 2006, of whom approximately 92.8% had type 2 diabetes (National Health Morbidity Survey 1 (NHMS 1) 1986-1987, 1990; Letchuman et al., 2010). The prevalence of type 2 diabetes is expected to rise in the future with increased risk factors, which include urbanisation, obesity, and a sedentary lifestyle (Rugayah, 2007). High morbidity rates have also been observed due to diabetic complications, with 4.3% of diabetic patients having lower limb amputation, 3.4% having strokes, and 1.6% relying on dialysis (Letchuman et al., 2010).

These phenomena are of even more concern because since 2006 Malaysia has been ranked first in diabetic kidney failure in the world (Williams, 2010). A large proportion of the healthcare budget was allocated by the government in preventing and controlling the diabetes and several steps have been carried out at strategic and operational levels to reduce the prevalence of diabetes and to prevent its complications (Ismail, 2008). Nevertheless, the outcome has been extremely unsatisfactory, with approximately 93% of patients still having uncontrolled diabetes (Rampal et al., 2010; Mafauzy et al., 2011). These phenomena are thought to be associated with ineffective disease management and poor self-care practice (Chan, 2005; Ramli & Taher, 2008; Rampal et al., 2008; Mafauzy et al., 2011). The situation in Malaysia is parallel to that in other countries, where several studies had shown that poor self-care practices and a lack of concordance of the patients have become the major reasons for the poor control of type 2 diabetes globally (Ruggiero et al., 1997; Whittemore et al., 2005).

1.3 Self-care in type 2 diabetes

Self-care has been defined as ‘the ability of individuals, families and communities to promote health, prevent disease and maintain health and cope with illness and disability with or without the support of healthcare professionals’ (World Health Organization, 2009). In essence, self-care can be understood as a part of day-to-day living, whether a person is healthy or ill. It ranges from simple actions to promote health, including daily hygienic activities and avoiding hazards in the environment, to more complex actions to restore health, such as, understanding symptoms and taking appropriate action, selecting appropriate treatment, taking medicine, monitoring treatment, and rehabilitation activities (Rijken et al., 2008; Newman et al., 2009).

In the case of long-term conditions, the concept of self-care always refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial impacts, and lifestyle changes inherent with the illness (Barlow et al., 2002). Patients with long term conditions like diabetes are expected to be responsible for self-managing their disease and coping with the consequences of the illness, which has a huge impact on their lives.

Type 2 diabetes is a lifelong illness that requires prolonged treatment and lifestyle adjustments. Treatment of diabetes is mainly aimed at achieving good metabolic control, minimising complications, and maintaining a good quality of life (Krans, Porta, & Keen, 1992). The success of diabetes management largely depends on the ability and willingness of the patients to carry out complex and multifaceted self-care activities (Evangelista & Shinnick, 2008). Therefore, patients living with diabetes are expected to actively manage their diabetes and cope with the demands of the disease and its complications (Funnell & Anderson, 2008).

In achieving better health outcomes, patients with type 2 diabetes are required to follow their meal plan daily, to lose weight if they are overweight or obese, to engage in appropriate physical activities, and to monitor their blood glucose level regularly. In addition, patients also need to make decisions about their diet adjustment, physical activity level, or the dosage of medication to avoid episodes of hypoglycaemia or hyperglycaemia (Ruggiero et al., 1997; Lerman, 2005). As such, four components of self-care in type 2 diabetes: diet modification, physical exercise, adherence to medication, and self-monitoring blood glucose (SMBG) have been identified as the cornerstones in diabetes management (Whittemore & Roy, 2002).

Researchers have argued that, in addition to the rigorous medical treatment needed to control blood sugar levels, concordance with a self-care regimen will help in reducing the possibility of complications and improve patients' quality of life. Results from a large, randomised, controlled trial study conducted in the United Kingdom involving 4,075 participants suggested that patients who adhere to the self-care recommendations usually achieved better short- and long-term health outcomes (United Kingdom Prospective Diabetes Study Group, UKPDS, 1998). Furthermore, this study also showed that adherence to self-care had minimised the occurrence of complications associated with diabetes (UKPDS, 1998).

In each aspect of self-care activities, a recent review, which covered four systematic review papers, three meta-analyses, 18 randomised, controlled trials, and 16 experimental studies, suggested that exercise had a positive effect on glycaemic control and reduced cardiovascular risks in type 2 diabetes in the short term (Kavookjian et al., 2007). Nevertheless, due to the lack of studies, the full effect of exercise on type 2 diabetes in the long-term could not be confirmed. On the other hand, a retrospective study which was conducted by reviewing 69 medical records of type 2 diabetes patients revealed that patients' control of diabetes was significantly associated with their understanding of

diabetes, adherence to meal plans, and performing self-glucose monitoring regularly (Hartz et al., 2006). Therefore, it could be expected that patients' adherence to the suggested self-care component would be able to provide positive outcomes on the control of their type 2 diabetes.

1.4 Overview of study context

Malaysia is situated in the Southeast Asia region and benefits from a tropical and equatorial climate. The total land area of Malaysia is 330,803 square kilometres with a peninsular part bordered by Thailand to the north and Singapore to the south. East Malaysia is bordered by Kalimantan, Indonesia and the Sultanate of Brunei (Figure 1.1). Malaysia is a federation of states and a parliamentary democracy with the prime minister as a head, and the constitutional monarchy elected by sultans. The federation of Malaysia comprises 13 states, with the Federal Territory of Kuala Lumpur identified as the capital city. Malaysia has been classified by the World Bank as an upper middle-income country and its society and economy were transformed by rapid economic growth in the latter half of the 20th century.

Figure 1.1 Map of Malaysia



Malaysia is populated by over 28.5 million people with multiple races, ethnicity, culture and religious beliefs. While Malaysia is a secular state, Islam is the official religion and there are sizeable populations of Buddhist, Hindus, Christians and Taoists. Malay and English are the main languages used. The culture of Malaysia is varied with influence from other Southeast Asian cultures (Malaysian Department of Statistics, 2011). The Malay, Chinese and Indian comprise the ethnic makeup and diverse cultures of these three main races form a part of the culture of Malaysia. The unity and diversity of the culture could be observed from the celebration of festivals by all races. Furthermore, family values have a strong foothold in the culture of Malaysia. In terms of food, rice and noodles are the staple of food of Malaysian and are consumed by people in the country regardless of their races and ethnic group.

In 1950's to 1960's, 73% population of Malaysia resided in rural areas and they commonly engaged in agriculture activities (Abdullah, Abdul Aziz & Mohammad, 1987). However, the situation changed where the percentage of people residing in urban areas gradually increased. Statistics have showed that, in the year 2000, two-thirds of the Malaysian population resided in urban areas. This increase was influenced by internal and external migration to urban centres due to the opportunity of employment in multiple sectors including civil services, industry and private business companies (Yaakob, Masrom & Masami, 2011). This urbanisation had an impact on the health status of the population demonstrated by increasing number of people with obesity, a higher risk of type 2 diabetes and other non-communicable diseases. This was thought to be due to the sedentary lifestyle, commonly adopted by the urban population and dietary change to a more westernised diet with an increased intake of fast food and high calorie diet (Ministry of Health Malaysia, 2008).

1.4.1 Overview of Malaysian healthcare system

The Malaysian healthcare system consists of government-run healthcare organisations (public healthcare sector) and a private healthcare sector. Public sector healthcare services are organised under a civil service structure and centrally administered by Ministry of Health. The public healthcare sector provides about 82% of inpatient care and 35% ambulatory care. Whereas, another 18% of inpatient care and 62% of ambulatory care is provided by private healthcare sector. The Ministry of Health (public healthcare sector) offers a comprehensive range of services including health promotion, disease prevention, curative and rehabilitative care delivered through primary, secondary care and tertiary care clinics and hospitals.

With regards to the prevention, control and management of type 2 diabetes, it is collaboratively managed at all levels of healthcare service delivery including primary, secondary and tertiary care. The management of diabetes is uniform throughout the country as stipulated by the national health policy and clinical practice guidelines. Management of diabetes involves multi-disciplinary healthcare professionals including family medicine specialists, endocrinologists, physicians, diabetes educators, general nurses, dietician, pharmacists and nutritionists. Diabetes educators, who undergo six months diabetes post-basic training, have been identified within the policy and clinical practice guidelines as being responsible for the provision of health education, counselling and teaching clinical skills to patients with type 2 diabetes and facilitate their engagement with self-care and self-management (Clinical Practice Guideline, 2009). Therefore, the importance of diabetes educator role is increasingly recognised. The number of diabetes educators within the Malaysian healthcare system is gradually increased parallel with demand due to increasing numbers of patients with diabetes. Management of type 2 diabetes within Malaysian healthcare system is one of the aspects explored in this study. Therefore, further elaboration and discussion of this aspect is presented in chapter seven and eight.

1.5 Summary

Several studies conducted in Malaysia reported that self-care of the patients with type 2 diabetes in Malaysia were poor, and the researchers have argued that, it is the main reason for the high prevalence of uncontrolled diabetes and the high incidence of diabetes complications. Furthermore, ineffective disease management has also been identified as a reason that has led to the unsatisfactory situation regarding type 2 diabetes in Malaysia. However, the nature of self-care practice of the patients with type 2 diabetes, and the reason for the high incidence of diabetes complication in the Malaysian context was not clearly understood.

Current evidence indicates that self-care is an essential component in diabetes management and can lead to improved health outcomes. However, the skills required for effective self-care are complex. Substantial changes in behaviour and lifestyle are required which need to be constantly adapted and integrated into a patients' complicated life situation (Lippa & Klein, 2008). These changes make the process much more difficult and challenging (Whittemore, Chase, Mandle, & Roy, 2002). Therefore, a comprehensive literature review was performed in order to understand the experiences, difficulties, and factors that influence self-care practices of patients with type 2 diabetes. In addition, this review also explored the perspectives of patients with type 2 diabetes and the perspectives of healthcare professionals (HCPs) on self-care support provision.

CHAPTER 2

Literature Review

2.1 Introduction

This chapter introduces the literature relevant to this area of research. The studies related to the patients' level of adherence with self-care, experiences with self-care, factors influencing self-care, and perspectives of patients and healthcare professionals on self-care support provisions are discussed. This review identifies the need for further research in relation to self-care practices and the provision of self-care support in Malaysia.

2.2 Literature search strategies

The aim of the literature review was to identify the primary studies that provided evidence related to the adherence, experience, and factors that influenced the engagement of patients with type 2 diabetes with self-care. In addition, this literature review also aimed to identify the effectiveness of self-care support for type 2 diabetes, and perspectives of the patients and healthcare professionals (HCPs) on self-care support provisions. The included studies were systematically reviewed and critically analysed to illuminate the knowledge gap and justify the relevance of the current study.

2.2.1 Research objectives for literature review

- To identify level of adherence of patients with type 2 diabetes towards self-care.
- To identify the experience of patients living with type 2 diabetes and adapting to self-care.

- To identify the factors that influenced the self-care practices of patients with type 2 diabetes.
- To identify the effectiveness of self-care support provision and its influence on patients' engagement with self-care.
- To identify the experience with self-care support provision from the perspective of patients with type 2 diabetes and HCPs.

2.2.2 Research questions for literature review

- What is the level of adherence and the factors that influenced patients' adherence to self-care?
- What are the experiences of patients living with diabetes and adapting to self-care?
- What is the level of effectiveness of self-care support provision?
- What are the perspectives of patients and HCPs on self-care support provision?

2.2.3 Search strategies

This is not a formal systematic review, however, a systematic approach to reviewing the literature was undertaken based on the guidelines from the Centre of Review and Dissemination (2009). Electronic databases that are relevant to the area of self-care in long-term conditions were searched: Medline, CINAHL, PsychINFO, ASSIA, EMBASE, British Nursing Index (BNI), ISI Web of Knowledge, and Social Science Citation Index. The search strategy used the terms 'self-care', 'self-management', 'self-efficacy' linked to 'type 2 diabetes', 'non-insulin dependent diabetes', 'diabetes control', 'health behaviour', 'adherence' and 'concordance' in order to identify the relevant articles on the experience and factors that influence self-care practices of patients with type 2 diabetes in terms of glucose control and behaviour change. Subsequently, the search was expanded by linking the initial keywords with other keywords including 'self-care support', 'allied

health personnel', 'primary care', and 'service delivery'. This was to capture the perspective of self-care support provisions for type 2 diabetes patients in relation to service delivery. The results of each category were combined using Boolean terms 'AND' and 'OR' to narrow down the search findings. The process of the literature search strategy and the key terms used has been detailed in Appendix 1.

The literature search was limited to a timeframe of 1990–2015. Through the process of scoping, it has been identified that the studies related to self-care in diabetes were mostly conducted post-1990. Furthermore, the importance of understanding the psychological and psychosocial aspect of the patients, particularly in improving their self-care, has been increasingly recognised during this period of time. Thus, it was expected that by limiting the literature search to this timeframe would reveal the papers most closely related to the review questions.

In maintaining the focus of the review, several inclusion and exclusion criteria regarding the inclusion of studies in the review had to be applied. As this study focused on adult populations, only studies that reported self-care of type 2 diabetes in adults whose ages were ≥ 18 years were included. In addition, this study was carried out in patients with type 2 diabetes thus, the studies that reported the management of other type of diabetes were excluded as they might have different purposes. Furthermore, studies regarding type 2 diabetes and other co-morbidities have different experience and needs. Due to the cost and time limitations for translation, this review only included studies written in English or Malay. The inclusion and exclusion criteria used to limit the search are listed below:

Inclusion criteria

- The report was written in English or Malay.
- The report carried data about adults aged ≥ 18 years old.

Exclusion criteria

- Studies carried out that investigated the self-care of diabetes patients aged <18 year old.
- Studies that reported on self-care in other types of diabetes such as type 1 diabetes and gestational diabetes.
- Studies conducted with adult patients who have type 2 diabetes and co-morbidities.

2.3 Findings of the search

The databases search yielded 6,726 articles relevant to the research. After the removal of duplications and screening of irrelevant articles, 495 abstracts were retrieved. Through assessment of the abstracts, 452 articles were excluded because they did not meet the inclusion criteria. The full text of 43 articles was retrieved along with four additional articles identified from the reference lists of the relevant articles. The findings of the literature search have been detailed in Appendix 2. Of the 47 articles assessed, 12 studies have been excluded as they were not empirical or review papers. Finally, 35 studies, consisting of 11 quantitative studies, 16 qualitative studies, one mixed-method study, and seven review papers were included in this review.

The studies included in the review were methodologically varied; thus, a universal appraisal tool developed by Hawker et al. (2002) was used to assess the quality of the papers in general. The appraisal tool provided guidelines to review the studies systematically within various research paradigms. Furthermore, this appraisal tool enabled the researcher to rate the quality of the studies, including the clarity of the information provided in each sections of the studies using a four point scoring scale – 1 (very poor) to 4 (very good). Total score for the quality according to Hawker's appraisal tool is 36 (full score of 4 in nine sections including: abstract and title, introduction and

aims, method and data, sampling, data analysis, ethics, findings, transferability, and implication of the study). Therefore, a study was rated as high quality if it achieved a score of 30 or over. Scoring elements of Hawker's tool are detailed in Appendix 3. However, the elements provided in Hawker's appraisal tool seemed to be very general, focusing on the content included in the article, and it was unable to assist the researcher in critically appraising the specific aspects of the studies. Therefore, several additional appraisal tools were used to fit the purpose of different methodologies of the included studies. Additional tools used to critically appraised the studies include two Critical Appraisal Skills Programme (CASP) guidelines for reviewing qualitative studies, meta-analysis, and meta-synthesis papers (Public Health Resource Unit, England 2006), guidelines for reviewing quantitative studies by Coughlan, Cronin, & Ryan, (2007) and guidelines developed by Long (2005) for reviewing mixed-method studies. Details of the quality assessment of the included studies have been presented in Appendix 4.

2.3.1 Assessment of the reviewed studies

From the 35 included studies, 28 of them were empirical studies and seven were review papers. Contextually, the empirical studies were conducted in various countries. Table 2.1 presents the list of included studies and the context and setting of each study. Three studies were conducted in United Kingdom, three studies were conducted in continental European countries including Sweden and Malta, one study presented analysis of findings from seven European countries, one study from Norway, eleven studies were conducted in United States, and two studies in Canada. Out of 35 studies, only six studies were conducted in Asian countries: three studies in Taiwan, two studies in Thailand, and only one study in Malaysia. Overall, it can be said that most of the studies included in this review were conducted in Western population including United States, United Kingdom, and several European countries. Very minimal studies were found in Asia settings. This shows the scarcity of evidence related to self-care in South East Asia settings, including Malaysia.

Table 2.1 List of studies included in the review

Primary studies (n=28)		Review papers (n=7)
Studies	Context of the studies	
Aljaseem et al. (2001)	United States	Cramer et al. (2008)
Bai, Chiou, & Chang (2009)	Taiwan	Deakin et al. (2005)
Bhattacharyya et al. (2011)	Canada	Gomersall, Madill, & Summers (2011)
Chang et al. (2005)	Taiwan	Heinrich, Schaper, & de Vries (2010)
Davies et al. (2008)	United Kingdom	Minet et al. (2010)
Formosa, Mandy, & Lucas (2011)	Malta	Norris et al. (2002)
Hartz et al. (2006)	United States	Vermeire et al. (2005)
Harris (2001)	United States	
Holmstrom & Rosenqvist (2005)	Sweden	
Hornsten, Sandstrom, & Lundman (2004)	Sweden	
Huang et al. (2010)	Taiwan	
Hunt et al. (1998)	United States	
Karter et al. (2000)	United States	
Lai, Chie, & Lew-Ting (2007)	Taiwan	
Lippa & Klein (2008)	Canada	
Meetoo (2004)	United Kingdom	
Naemiratch & Manderson (2006)	Thailand	
Nagelkerk et al. (2006)	United States	
Nelson, Reiber, & Boyko (2002)	United States	
Oftedal, Karlsen, & Bru (2010)	Norway	
Polonsky et al. (2010)	United States	
Rayman & Ellison (2004)	United States	
Samuel-Hodge et al. (2000)	United States	
Siripitayakunkit et al. (2008)	Thailand	
Tan & Magarey (2008)	Malaysia	
Thomas, Alder, & Leese, 2004)	United Kingdom	
Vermeire et al. (2007)	Seven European countries	
Whittemore et al. (2002)	United States	

2.3.1.1 Overall weight of evidence

In general, most of the studies included in the review were of a good methodological quality. Most of the studies scored 30 or higher against Hawker's appraisal tool (Hawker et al., 2002). The abstract of the included studies provided adequate information to the reader as regards to the aim, methods, and findings of each study. However, through detailed assessment of the quality of the studies, several aspects were found to have flaws that might affect the credibility of the evidence provided. Nevertheless, limitations such as the limited length allowed for published studies were recognised.

Several studies provided limited information on the important elements of the study such as recruitment strategies (Aljaseem et al., 2001; Whittemore et al., 2002; Vermeire et al., 2007; Siripitayakunkit et al., 2008). For example, a study by Vermeire et al. (2007) explored patients' health beliefs, patient-HCP communication, and problems in adhering to a treatment regimen for patients with type 2 diabetes in seven European countries. The authors did not provide clear information about how the participants from these seven countries were recruited for the study. Furthermore, the lack of discussion regarding contextual differences between the countries and the influence this may have had on the interpretation of study findings might have affected the credibility of the study. More detailed information on how the influence of settings, culture, and context of different countries on study findings might have been valuable in helping the reader to understand this aspect.

Topics with the least description included papers were the elements of reflexivity (in qualitative studies) and ethical considerations (in quantitative studies). For example, a study by Rayman and Ellison (2004) used an interpretive descriptive approach in exploring day-to-day experiences of patients in managing type 2 diabetes in the United States. It was clearly stated in the paper that Rayman and Ellison (2004) had utilised

individual face-to-face interviews and analysis of participants' records in collecting the data. However, the authors did not discuss reflexivity with regards to how the researchers maintained their roles and eliminated bias that might have been introduced during the interview. Therefore, the credibility of the data interpretation could not be guaranteed. Another example of a study that provided implicit explanation about the reflexivity was a study by Naemiratch and Manderson (2006) conducted in Thailand. This study (Naemiratch & Manderson, 2006) explored individual's understanding of their diabetes, their illness experiences, and management strategies in Thailand. It was noted from the paper that the main researcher was Thai, thus it enabling the researcher to understand the patients' experience in-depth, including patients' life circumstances, and cultural and religious influence on their diabetes management. However, as a Thai, the researcher might have a certain degree of influence on data interpretation. Nevertheless, this aspect was not acknowledged by the authors.

With regards to the quantitative studies, it was noted that several papers omitted an explanation of ethical issues. For example, a study by Polonsky et al. (2010) investigated patients' experiences of being diagnosed with type 2 diabetes and the influences on diabetes self-management in the United States. The authors provided only an implicit explanation of ethical issues and how they gained ethical approval prior to the commencement of the study. However, an explanation of other aspects, such as informed consent and how the rights of the participants were preserved during the research. Were not clearly explained.

In summary, the overall quality of the included studies was good. The study design, methods, and process of data analysis used in most of the studies were appropriate in achieving the aims and objectives of the studies. Several minor weaknesses were identified as discussed above, but these did not distort the quality of the evidence produced. The literature review provided a clear understanding of the complexity of self-

care issues pertaining to type 2 diabetes globally. However, the evidence available from this literature review might not be sufficient to inform change in practice, particularly in Malaysia settings as the number of studies conducted in this particular setting was very limited. Furthermore, most of the studies included in the review were conducted in Western countries, thus the evidence base regarding self-care of type 2 diabetes is mainly derived from the western population. Within the literature, there is robust evidence demonstrating differences in perspectives, culture and contexts between western and eastern countries. Therefore, it could be argued that, although the findings of studies included in this review provided a clear understanding of the concept of self-care globally, a lack of reported research in Malaysia means that this evidence may not be applicable to this country. Several themes were identified whilst synthesising the research papers and these are presented in the next section.

2.4 Synthesis of study findings

The findings of included studies were synthesised in a narrative fashion. Narrative review was utilised because it allowed for a systematic synthesis of both qualitative and quantitative studies and the ability to draw conclusions from the findings of the included studies (Snilstveit, Oliver, & Vojtkova, 2012). During the process of synthesis, the relationships of the findings within the studies were explored and organised, and patterns across the studies were identified. Three main themes related to the adherence of self-care, experience and factors that influenced self-care, and self-care support provision were developed.

The themes include:

- Level of adherence to self-care of patients with type 2 diabetes
- Experience and factors influencing engagement with self-care
 - Invisible disease and lack of acceptance
 - Challenge of integrating self-care in to daily life

- Facilitators and barriers to self-care
- Provision of self-care support
 - Importance of support from HCPs
 - Effectiveness of provision of self-care support

The discussion of the themes and critical analysis of the included studies are presented in the following sections.

2.4.1 Level of adherence to self-care of patients with type 2 diabetes

Despite positive outcomes of self-care activities in diabetes management (as explained in chapter 1), the percentage of patients who adhered to and achieved concordance in self-care was relatively low. Two studies included in the review have pointed out that the level of adherence of type 2 diabetes patients on a self-care regimen was at a minimum level, where adherence to diet needs and exercise were identified as the most difficult elements (Whittemore et al., 2005; Nagelkerk et al., 2006).

Data from the Third National Health and Nutrition Examination Survey (NHANES III) in the United States reported that out of 1,480 participants, 31% had no regular physical activity and 38% have less than the recommended level of physical activity (Nelson et al., 2002). Furthermore, this survey also reported that 36% of participants were overweight and another 46% were obese and had a high consumption of fat in their diets (Nelson et al., 2002). In another study conducted in the same country measuring the physical activity levels of type 2 diabetes patients, a self-reported survey showed that only 34% of 406 participants claimed that they had undertaken physical exercise. However, only 9% of them had exercised sufficiently and achieved clinical benefits (Thomas, Alder, & Leese, 2004).

In the UK, the level of adherence of the patients to a diet regimen seems to be consistent with previous studies by Nelson et al. (2002) and Whittemore et al. (2005). A qualitative study involving 49 participants revealed that only 16 participants claimed that they adopted strict adherence to a diet regimen, whereas the remaining participants were practising moderate to highly flexible levels of adherence to a diet regimen (Meetoo, 2004). However, due to the small number of participants and the nature of qualitative research, these findings could not be generalised for the whole population of diabetes patients in the UK. Congruently, in the Asian region, the level of adherence of type 2 diabetes patients on a self-care regimen showed a similar trend, particularly in the diet and exercise aspects. A National Health Interview Survey conducted in Taiwan showed that only 21.8% of 764 participants adhered to meal plans and only 40% of them performed exercise regularly (Chang et al., 2005).

In other aspects of self-care, such as medication intake and self-blood glucose monitoring, the level of adherence of patients with type 2 diabetes does not seem to be very much different. Chang et al. (2005) suggested that the level of adherence to taking medication was varied and depended on the number of medications and types of treatment used. Their data, which was derived from the National Health Interview Survey in Taiwan (n=764), showed that patients with oral hypoglycaemic agents had better adherence (70.8%) compared to the patients with insulin injections (9%)(Chang et al., 2005). These findings parallel a systematic review measuring the adherence of taking medication for three cardiovascular conditions. Out of 139 studies included in the review, 27% focused on diabetes. This review showed that 58% of diabetes patients achieved an 80% adherence level (Cramer et al.,2008). Nevertheless, this review did not divide findings based on treatment method, thus, a comparison between oral medication and insulin treatment could not be made.

Due to the necessity of blood glucose monitoring in patients on insulin treatment, the level of adherence to SMBG was higher among patients needing insulin. Data from the Third National Health and Nutrition Examination Survey (NHANES III) in United States, which involved 1,480 participants, revealed that 39% of 400 participants taking insulin had monitored their blood glucose at least once per day, compared to patients with an oral hypoglycaemic agent which reached the adherence level to only 5%–6% of 680 participants who monitored their level (Harris, 2001). These findings paralleled a large study involving 44,181 participants, 41,363 of which were type 2 diabetes patients. This study reported that 67% of type 2 diabetes patients were not practicing SMBG as recommended (Karter et al., 2000).

In Malaysia, a similar condition has been observed. A descriptive quantitative study involving 126 participants in Malaysia revealed that 80% of the patients had not followed diet recommendations, 54% were physically inactive and only 4% tested their blood glucose regularly (Tan & Magarey, 2008). In contrast with the previous studies, patients in Malaysia showed better adherence to insulin treatment compared to oral hypoglycaemic agents. However, the adherence level was still at just 46% (Tan & Magarey, 2008). Therefore, this study supports the notion that poor glycaemic control in type 2 diabetes patients in Malaysia is due to poor adherence to self-care activities.

From the evidence presented, the level of adherence of patients with type 2 diabetes towards a self-care regimen was poor globally. Lack of knowledge and poor health literacy among patients has been argued to be the reason for this situation (Tan & Magarey, 2008; Polonsky et al., 2010). Nevertheless, it was understood that, apart from adhering to the self-care regimen, patients with type 2 diabetes need to be able to detect and manage problems, understand the dynamic relationship between their lifestyle and the progression of the disease and handle complex situations that may occur in relation to the illness (Lippa & Klein, 2008). It was noted that the relationship between patients'

self-care practices and clinical outcomes is constantly influenced by many factors, including patients' physical, psychological and socioeconomic status, social environment, relationship with HCPs, and the accessibility and availability of the healthcare system (Daly et al., 2006; Hartz et al., 2006). Therefore, several themes were identified to explain these aspects.

2.4.2 Experience of patients with type 2 diabetes and factors influencing engagement with self-care

Several sub-themes were identified to explain the experiences of the patients when diagnosed with type 2 diabetes and the factors that influenced their engagement with self-care. The sub-themes include: invisible disease and lack of acceptance, challenge of integrating self-care into daily life, and facilitators and barriers to self-care. Each of the sub-themes is discussed further below.

2.4.2.1 Invisible disease and lack of acceptance

Six studies provided evidence on the experiences of patients living with type 2 diabetes (Hornsten et al., 2004; Holmstrom & Rosenqvist, 2005; Naemiratch & Manderson, 2006; Lai et al., 2007; Vermeire et al., 2007). From the synthesis of the evidence, it could be understood that, upon the diagnosis of type 2 diabetes, patients developed several stages of life trajectories that influenced their engagement and adherence with self-care.

A qualitative study using in-depth interviews with type 2 diabetes patients (n=44) in Sweden provided a clear understanding of how patients understand and experience their disease. This study suggested that after being diagnosed, the patients experienced several stages in understanding their illness that include getting the image of the disease, meaning of the diagnosis, integrating the illness, taking responsibility for care, and thinking about their future with the illness. Participants perceived diabetes as serious and

endurable when dealing with cognitive and emotional aspects. Throughout this time, participants expressed their acceptance of the disease and thought of the future prospects of their life as diabetes patients. Living with diabetes was viewed as hard and challenging by most of the participants. Therefore, the authors suggested that it is crucial for the HCPs to understand the burden of the patients in self-managing their illness from the patients' point of view (Hornsten et al., 2004).

In contrast, another qualitative study in Sweden using phenomenological research of 18 participants with type 2 diabetes reported that diabetes was not perceived as a 'real disease' by the majority of the participants (Holmström & Rosenqvist, 2005). This notion emerged due to the invisibility of symptoms and patients feeling healthy. Therefore self-care was perceived as unimportant and unnecessary by the participants in this study. This finding was congruent with a large qualitative study conducted across seven European countries, Belgium, Croatia, Estonia, France, Netherlands, Slovenia, and the United Kingdom (Vermeire et al., 2007). This study was conducted using focus group interviews involving 246 participants with type 2 diabetes across the region. The study reported that changes of lifestyle and behaviour are often not accepted by most of the participants. The authors suggested that the severity of the illness was frequently misinterpreted by participants due to unnoticed symptoms. Furthermore, the effects of current treatments were also not fully understood, and this contributed to non-adherence in the self-care regimen (Vermeire et al., 2007). In this study, the method used was clearly presented and data from different countries were merged using qualitative meta-analysis. However, the guidelines used in conducting the focus group in ensuring the consistency of the data were not explicitly explained. As the focus groups were conducted independently in different countries by different researchers, various factors such as language, environment, and situation may have influenced the perceptions of participants. Therefore, a clear explanation on how these factors were addressed would have improved the credibility of the data produced.

Similar to the previous studies conducted in European countries, patients in Asia have also experienced misconception on the severity of diabetes. A study by Lai, Chie, & Lew-Ting (2007) in Taiwan involving 75 participants (n=22 in-depth interviews; n=53 involved in focus groups) revealed that the severity of illness was perceived based on the amount of medication taken, advancement of treatment, high blood sugar level, and the appearance of complications. In addition, participants in this study expressed lack of confidence in the effectiveness of conventional treatment, and this contributed to the problem in adherence to self-care with the participants in this study. Congruent with the study conducted by Vermeire et al. (2007), the authors of the Taiwan study also suggested the importance of information and a clear explanation of the disease process and the effects of treatment in improving patients' understanding of the disease (Lai et al., 2007). Methodological aspects on the conduct of the study were clearly explained and the theoretical model that informed the development of interview protocols used in this study was clearly justified. However, the authors provided only an implicit explanation of data collection procedures, thus several issues were unable to be understood. For instance, the authors mentioned that individual interviews and focus group were conducted in different timeframes (May–June 2002 for interviews and March–June 2004 for focus groups). However the impact of different time lines of data collection on the data generated was not clearly explained.

In line with previous studies in Europe (Holmström & Rosenqvist, 2005; Vermeire et al., 2007) and Taiwan (Lai et al., 2007), a qualitative study in Thailand involving 34 participants with type 2 diabetes also showed a misperception of the severity of diabetes, which becomes a factor that contributes to poor self-care. In this study, participants revealed that they only seek treatment when they feel the symptoms, and most of the participants discontinued the treatment after the symptoms disappeared (Naemiratch & Manderson, 2006). Similar to the earlier study (Hornsten et al., 2004), this study also explained the trajectory of controlled experiences by the participants towards their illness. However, cultural practices strongly influenced how the participants managed their

disease. As presented in the paper, the hierarchical culture present in Thailand shaped the self-care practices of the participants. Participants explained that they only practised strict adherence to self-care two or three days prior to the follow-up in order to please the healthcare professionals who were perceived as being of high status and should be respected (Naemiratch & Manderson, 2006). It seems that implementation of self-care support in this culture is relatively challenging, as the perceptions and beliefs of the patients deviated from the concept of self-care itself.

2.4.2.2 Challenges of integrating self-care in to daily life

The theme ‘challenges of integrating self-care in to daily life’ represented the experience and difficulties that patients faced in engaging and practising self-care within the context their complex daily life. Seven studies provided relevant evidence related to this aspect (Whittemore et al., 2002; Rayman & Ellison, 2004; Siripitayakunkit et al., 2008; Lin et al., 2008; Bai et al., 2009; Huang et al., 2010; Gomersall et al., 2011). Findings of these studies were synthesised and presented below.

A study by Whittemore et al., (2002) explained that patients have faced many challenges in integrating self-care into their daily life. Similar to the study by Hornsten et al. (2004) in Sweden, participants in this study had also experienced several stages in integrating self-care, including dealing with the emotions in accepting the diagnosis, composing the structure to cope with the illness, dealing with self-conflict, and discovering a balance between the illness and their life situation (Whittemore et al., 2002). The author clearly presented the findings of the study and how the themes were derived. However, this study only included women who attended nurse-coaching intervention to support their self-care. Therefore, the perspectives of male participants in this programme could not be understood. In addition, as the interviews took place at the completion of nurse-coaching intervention, the perception expressed by the participants may be influenced by the programme attended. Limited explanation on how these possibilities were overcome in this study affected the credibility of the data.

Rayman and Ellison (2004) also explored the experience of integrating self-care in daily life in fourteen women who were newly diagnosed with type 2 diabetes. Through individual interviews and document analyses, this study also presented several stages experienced by the participants throughout the process of integration, including the stage of engagement, engaged and struggling, and engaged and adjusting. At the beginning of the diagnosis, participants in this study faced difficulties in engaging with self-care and this situation was contributed to by their perceptions of self, meaning of food, and alteration in relationship with family members and social contexts. Subsequently, participants showed a positive response towards self-care by trying to make life adjustments, following the self-care guidance, and finding a way to adapt the self-care practice in to their life routines. Stages of experience of the participants in this study seemed to be similar to previous studies (Hornsten et al., 2004; Whitemore et al., 2002). Again, this study only included women participants. However, the reason for the selection of participants was not clearly explained in the paper. Therefore, the significance of focusing this study on a particular gender could not be justified. From the findings, the author suggested that the engagement process in self-care practice was strongly influenced by emotional responses, self-blame, and negative characterisation, all of which need to be clearly understood by the HCPs.

Another qualitative study using focus group interviews in Taiwan explored the perspectives of 41 type 2 diabetes participants on the process and strategies of engaging in self-care (Lin et al., 2008). Similar to previous studies by Hornsten et al. (2004), Whitemore et al. (2002), and Rayman and Ellison (2004), this study presented three stages which represented the experiences that patients have in integrating self-care into their daily lives. These included dealing with the impact of the illness, the self-regulation process, and the transformation process. In contrast with other studies in Western countries, participants in this study expressed their concern about the inheritance of the disease. It seems that the participants were not only focused on the effects of the disease

on themselves, but they were also concerned with how diabetes would affect their families. These findings might be influenced by a different interpretation of 'self' in different cultural settings, as reported by Gomersall et al. (2011). According to Gomersall et al. (2011), results of a meta-synthesis of 38 qualitative studies showed that the individualistic perspective of 'self' in Western culture seems to contradict that of Eastern countries. In many Eastern cultures, individual persons are tied up in their social context, thus the interpretation of 'self' is made based on their roles and responsibilities in the family. As such, the support and involvement of family in facilitating self-care has been identified as the most important factor in Eastern culture, and this has also been reported by other studies in Taiwan and Thailand (Bai et al., 2009; Huang et al., 2010; Siripitayakunkit et al., 2008)

2.4.2.3 Facilitators to self-care

This sub-theme describes the facilitators and barriers perceived by the patients as influencing their engagement with self-care. Five studies provided information related to this sub-theme. They were Samuel-Hodge et al. (2000), Aljaseem et al. (2001), Lippa and Klein (2008), Bai et al. (2009), and Gomersall et al. (2011).

A study by Aljaseem et al. (2001) provided further understanding on the factors influencing self-care practice of patients with type 2 diabetes. This study was conducted using a self-reported questionnaire. Three hundred and nine participants reported that self-efficacy, which is defined as the confidence that patients have in managing their illness (Bodenheimer, Lorig, Holman, & Grumbach, 2002), becomes the most influential factor for the patients to perform their self-care regularly. Participants who felt confident about carrying out planned tasks at home and away from home were found to practice better self-care and achieved better control over their illness. Therefore, the authors suggested that self-efficacy needs to become the major goal in self-care support

interventions for type 2 diabetes patients. This finding was congruent with a qualitative study conducted in Canada with 20 participants (Lippa & Klein, 2008). In this study, the author grouped the participants based on their level of glycaemic control. Participants who had good glycaemic control expressed confidence in each element of self-care and were able to make decisions based on experience and body cues (Lippa & Klein, 2008). Similar to the study by Aljaseem et al. (2001), the authors of this study also suggested the importance of achieving self-efficacy in self-care intervention. In addition, they also pointed out the significance of individualised self-care, as the patients presented with different needs and problems.

A study by Samuel-Hodge et al. (2000) included 70 African-American women in focus group interviews who provided different perspectives on the facilitators to self-care. Religious beliefs and faith were identified as the most common coping mechanisms adopted by the participants and provided a positive influence on the self-care of the patients in this study. Participants in this study claimed that, 'reliance on God' had provided them with strength in coping with a complicated life and dealing with diabetes. As such, confidence with the power of God in helping them to find a cure for the disease has been seen as a facilitating factor for the patients to engage with self-care (Samuel-Hodge et al., 2000). In contrast, other studies suggested that religious beliefs sometimes provide a negative effect on self-care. Gomersall et al. (2011) and Bai and Chang (2009) reported that participants who rely solely on God to cure the disease become more passive in self-care.

Participants in Samuel-Hodge et al. (2000) study also acknowledged that social support received from family and relatives had become the most significant factor that helped them to improve their self-care practice. However, participants identified several factors, such as childbearing, the role as the caregiver in the family, and the fear of disease progression, that had induced stress and become barriers in adapting and integrating self-

care. In this study, the selection of participants seems to be appropriate with the purpose of the study as the researchers intended to explore the influence of the social role held by women as wives and mothers in families on their self-care activities. Participants in this study were recruited using convenience sampling through posted flyers (Samuel-Hodge et al., 2000). This approach might be suitable for the target population of this study. Nevertheless, a lack of explanation about the recruitment procedure, such as inclusion and exclusion criteria, resulted in a lack of understanding on how the appropriate participants had been identified and included. It was noted that explanation on inclusion and exclusion criteria of the study participants is important as it would help the reader to articulate whether the participants recruited and the data generated fit the objective and purpose of the study (Velasco, 2010).

In Thailand, a quantitative study involving 490 participants reported that a high percentage of participants (68%) were found to be less likely to engage in lifestyle modification. Parallel to the study by Samuel-Hodge et al. (2000), the findings of this study showed that support from family and friends had a large positive effect on patients' engagement with self-care. In addition, this study reported that financial aspects were becoming the strongest predictor of lifestyle modification (Siripitayakunkit et al., 2008). However, effects of finance on the specific aspects of lifestyle being measured were not clearly understood due to a lack of description of the variables. Furthermore, the findings showed that apart from family support, a quality relationship with HCPs was perceived as providing high positive effects on the success of integrating a modified lifestyle into patients' normal life situations (Siripitayakunkit et al., 2008). This has also been pointed out in many other studies included in this review (Rayman & Ellison, 2004; Hartz et al., 2006; Nagelkerk et al., 2006; Polonsky et al., 2010).

2.4.3 Provision of self-care support

This theme explored the perspectives of patients on the importance of self-care support from HCPs. In addition, this theme also provided evidence on the effectiveness of various self-care support interventions conducted in previous studies. Nine primary studies provided evidence related to the importance of self-care support (Hunt et al., 1998; Aljaseem et al., 2001; Rayman & Ellison, 2004; Nagelkerk et al., 2006; Hartz et al., 2006; Oftedal, Karlsen, & Bru, 2010; Polonsky et al., 2010; Bhattacharyya et al., 2011; Formosa et al., 2011). Five systematic reviews and one randomised control trial (RCT) study provided evidence on the effectiveness of self-care support provision (Norris et al., 2002; Deakin et al., 2005; Vermeire et al., 2005; Davies et al., 2008; Heinrich et al., 2010; Minet et al., 2010).

2.4.3.1 Importance of support from HCPs

Evidence presented in the previous themes showed that patients commonly face difficulties in accepting the diagnosis of type 2 diabetes and engaging in self-care activities. A study by Rayman and Ellison (2004) for instance, provided evidence that, upon the diagnosis, patients struggled in accepting that they were diagnosed with type 2 diabetes. Patients in this study commonly experienced psychological and emotional responses that influenced how they conceptualised diabetes and self-care, which simultaneously influenced their decision to engage in self-care. Therefore, participants in this study expressed the need for continuous support from HCPs in helping them to engage and integrate self-care practices into their daily routine, especially in the early stages of diagnosis (Rayman & Ellison, 2004). This notion has also been supported by another qualitative study involving 24 participants with type 2 diabetes in rural settings in the United States (Nagelkerk et al., 2006). Participants in this study frequently experienced a lack of understanding on the plan of care, a feeling of helplessness and frustration from the lack of glycaemic control, and were overwhelmed by the disease's

progression. The participants had also expressed the need for support and a collaborative relationship with healthcare professionals in self-managing their illness.

Collectively, the importance of support from HCPs in facilitating self-care for patients with type 2 diabetes has also been supported by three quantitative studies (Aljaseem et al., 2001; Hartz et al., 2006; Polonsky et al., 2010). A survey conducted by Polonsky et al., (2010) on 179 participants with type 2 diabetes suggested that participants who received clear information from HCPs expressed high confidence in their self-care practice. Nevertheless, 30% of the participants had reported that the action plan facilitating their self-care was not clearly communicated by HCPs. Another study, which was conducted retrospectively by reviewing the medical records of 69 type 2 diabetes patients also reported that patients who frequently received information and support from HCPs had showed better self-care practices and better glycaemic control (Hartz et al., 2006). Results from this study also showed that clinical parameters, which include glucosylated haemoglobin (HbA1c) and fasting blood sugar, were positively associated with a better understanding of diabetes, adherence to the meal plan, and regular glucose monitoring. However, due to the design of this study, which only involved a document review and analysis, the elements that influenced the improvement of self-care from the perspective of the participants were not included.

A qualitative study conducted by Hunt et al. (1998) explored the perspective of self-care and self-care support of patients with type 2 diabetes and HCPs. Compared to other studies included in the review, this study is quite old. However, it was still included as the evidence provided was highly relevant in understanding the perspectives of self-care support provisions from both patients and HCPs. This study involved 87 participants, consisting of 51 patients and 36 practitioners. Discrepancies of perspective between both parties were observed in this study. Patients' perspectives of self-care lie within their life world experience, whereas HCPs viewed self-care based on a clinical context and

frequently used clinical parameters in evaluating self-care (Hunt et al., 1998). Data of this study were derived from independent interviews with each of the participants and a review of relevant medical records. It provided a clear understanding of the perspectives from both parties; however, their actual interaction and how the perspectives influenced the interaction could not be observed in this study. A review by (Lawn et al., 2009) provided a similar conclusion. In this study it was suggested that HCPs were aware of the importance of the psychosocial aspect of the patients. However, due to concerns with the objective outcomes of self-care, patients' opinions and views pertaining to their experience in managing diabetes were often minimised or ignored (Lawn et al., 2009).

The needs of patients with type 2 diabetes have been identified as knowledge and information about the disease, health literacy, participation in decision making, and skills in performing self-care (Newman et al., 2009). Congruently, a qualitative study conducted by Oftedal et al. (2010) in Norway provided similar findings. This study, which involved 19 participants in focus group interviews, pointed out that, apart from the needs identified by the previous study (Newman et al., 2009), participants in this study greatly emphasised the empathic approach of support through understanding, listening, and positive feedback. These aspects were claimed to be poorly met throughout the course of the illness. These findings seem to be relevant with relation to other studies where the management and support approach used by HCPs appeared to be largely oriented from a medical model which lacks an emphasis on the psychological and psychosocial aspects of the patients' lives (Hunt et al., 1998; Lawn et al., 2009). Therefore, in increasing the motivation of the patients, the author stressed the importance of a psychological approach to self-care support (Oftedal et al., 2010).

A mixed methods study was conducted to understand the barriers faced by HCPs in supporting the self-care of ethnic minority patients in Canada (Bhattacharyya et al., 2011). In-depth interviews (n=22) and surveys (n=244) were conducted with several

stakeholders in the healthcare system including clinic managers, HCPs, and community health representatives. Three key factors influencing the self-care provision, which included patient factors, provider factors, and system factors were identified. Patient factors were perceived to have the largest impact on diabetes care by the HCPs. This finding seems to be in line with other studies in this field as the patients are perceived to be solely responsible for their self-care (Funnell & Anderson, 2008). However, Bhattacharyya et al. (2011) suggested that the findings reflected 'patient blaming' as the data were only derived from HCPs. As the data from the patients were not available in this study, it provided a one-sided perspective that was not able to provide a clear understanding on the issue.

Similar to the study by Bhattacharyya et al. (2011), a qualitative study by Formosa et al., (2011) also explored three factors that included patients, HCPs, and the organisation of diabetes management in Malta. This study adopted a reflexive ethnography and was conducted using in-depth interviews with five participants who represented different key stakeholders in diabetes management. In addition, participant observation was also incorporated in order to understand the nature of interactions at different levels of management. Incongruent with the previous study (Bhattacharyya et al., 2011), the findings of this study showed that the three main factors – patient factors, HCP factors, and organisation factors – had contributed equally to the provision of self-care in type 2 diabetes patients in Malta. In addition, the national culture and local practice of Maltese people seems to have a detrimental influence on glucose control and self-care practices in Malta. The cultural traditions of Maltese people have been characterised by the frequent celebration of 'fiestas', involving a variety of foods high in carbohydrates and sugar. As the 'fiestas' are celebrated 90 times per year, it has been argued to be the factor that most greatly influences poor glucose control among Maltese patients (Formosa et al., 2011). In line with the previous studies by Samuel-Hodge et al. (2000) and Naemiratch & Manderson (2006), this study also showed that the self-care concept is highly cultural and situation specific. Therefore, factors that contribute to self-care practices of type 2

diabetes patients are unlikely to be the same across different countries, which justify the need for understanding this concept in a Malaysia specific context.

2.4.3.2 Effectiveness of self-care support provision

It has been argued that active participation of patients is the key influencing factor in improving concordance of type 2 diabetes patients towards self-care activities (Bodenheimer et al., 2002). In meeting the needs of patients with type 2 diabetes, several self-care support programmes have been developed with the aim to enable patients to manage their illness medically, to cope with the effects of the illness, and manage the emotional impacts which result from the illness (Lorig & Holman, 2003). In addition, self-care support also acts to help the patients carry out their normal roles and activities whilst dealing with the complexity of the illness (Barlow et al., 2002).

Various types of self-care support programmes have been developed, ranging from one-to-one and group support, educational programmes alone, or a combination of psychological and psychosocial elements. Five systematic reviews and one RCT study were identified as measuring the effectiveness of various types of self-care support programmes (Norris et al. 2002; Deakin et al., 2005; Vermeire et al., 2005; Davies et al., 2008; Heinrich et al., 2010; Minet et al., 2010), and these studies showed a variety of results for each type of programme.

The reviews were conducted between 2002 and 2010, and the papers included in the five reviews were dated between 1983 and 2009. The wide ranges of papers spanning more than 20 years demonstrated a clear trend regarding self-care support provided for type 2 diabetes patients. Out of five systematic reviews, four measured the effectiveness of diabetes self-management education in improving glycaemic control and how behaviour

changed (Norris et al., 2002; Deakin et al., 2005; Heinrich et al., 2010; Minet et al., 2010), while one review (Vermeire et al., 2005) focused on the wide range of self-care interventions, including educational programmes, collaborative management, type of follow up, and type and frequency of drug prescribed. Besides the five systematic reviews presented above, an RCT study conducted by Davies et al. (2008) measured effectiveness of diabetes education and self-management for an ongoing and newly diagnosed (DESMOND) programme for patients with type 2 diabetes in United Kingdom, which was also included in this review.

From the five systematic reviews, the earliest review, conducted by Norris et al., (2002), evaluated the efficacy of self-management education on glycosylated haemoglobin (HbA1c). It included 31 papers involving 4,263 participants published between 1983 and 1999. Meta-analysis of this review showed that self-management education decreased HbA1c value by 0.76% at immediate follow up (1-3 months). Nevertheless, the level of effectiveness diminished in the long term, where it was only able to reduce 0.26% of HbA1c values at ≥ 4 months follow-up. In addition, the review also suggested that the level of effectiveness increased with frequent follow-ups and longer contacts times between participants and educators.

A review conducted by Deakin et al. (2005) also measured the effectiveness of self-management education, however this review only focused on group-based training. The outcome measures of this review were on clinical parameters (HbA1c and fasting blood glucose), diabetes knowledge, and psychosocial aspects (quality of life and self-efficacy). Eleven studies (eight RCTs and three controlled clinical trials) were included in this review, involving 1,532 participants. This review also showed positive outcomes of the intervention, where group-based education seemed to be effective in reducing blood sugar levels in four months, 12 months, and two year intervals. In addition, diabetes knowledge also seems to be improved in the 12–14 months interval. Nevertheless, the

effectiveness of intervention on the psychosocial aspects of the participants could not be confirmed due to insufficient studies. These findings have been supported by Heinrich et al. (2010), where their review measuring the effectiveness of group education programmes compared to one-to-one counselling session provided similar results. A review by Heinrich et al. (2010) included 14 RCTs and also suggested that group interventions had a greater potential to improve metabolic control compared to individual counselling. However, the studies included in this review also focused on the effectiveness of intervention in a short period. As a result, the ability of a group education programme improving glycaemic control in the long-term still cannot be justified.

A review by Minet et al., (2010) compared the effectiveness of educational programmes and behavioural intervention in improving glycaemic control. This review included 47 studies consisting of 7,677 participants. Out of the 47 studies included, only 18 measured the effectiveness of behavioural and psychosocial interventions, and these involved 3,346 participants. Meta-analysis results showed a minimum improvement in glycaemic control (0.36%) in participants who received self-care intervention regardless of the type of programme. This review showed the positive effects on smaller studies and shorter intervention duration. Although this review concluded that educational intervention was more effective compared to behavioural and psychosocial intervention, this may be influenced by the sample size, where the educational programme studies used a smaller sample size that provided more positive effects in the analysis. Therefore the effectiveness of the education programme in improving glycaemic control in this review still cannot be clearly confirmed.

A review by Vermeire et al. (2005) measured the effects of various types of intervention in improving the adherence of type 2 diabetes patients towards treatment recommendations. Twenty-two studies have been included in this review, which consists of RCTs (n=14), a crossover study (n=1), a controlled trial (n=1), controlled pre and post

studies (n=4), and an epidemiological study (n=1) involving 4,135 participants. This review showed very small effects of various interventions, including nurse-led programmes, home aides, diabetes education and pharmacy-led interventions on glycaemic control, and other outcomes, such as self-reported adherence and patients' satisfaction. However, the authors concluded that current intervention techniques used for improving the adherence of type 2 diabetes patients towards treatment recommendations did not show any significant effects. Therefore, an intervention method that is more effective than the others still cannot be justified.

Similar to the findings of the five systematic reviews above, an RCT study conducted by Davies et al. (2008), measuring the effectiveness of DESMOND programme in 824 patients with type 2 diabetes, also showed positive effects. The self-care support intervention in this study involved a six hour, structured group education programme delivered by two HCPs. The structured group education programme was developed based on psychological theory and incorporated several components, including empowerment and interactive patient-centred education delivery. The control group received education based on the existing guidelines practiced by the National Health Services (NHS) in the UK, such as treatment algorithms as stated in the clinical guidelines, guidance notes on breaking bad news, and other resources that were commonly available to the patients with type 2 diabetes. Additionally, patients in the control group were provided equal contact time with HCPs as provided to the patients in the intervention group. This study reported that the DESMOND programme showed positive effect on patients' HbA1c level with greater reduction of HbA1c in the intervention group (1.49%) compared to the control group (1.21%). However, the difference was too small (0.28%), thus, it was not statistically significant. Nevertheless the DESMOND programme provided benefit in increasing patients' understanding of diabetes and reduced patients' level of depression. Furthermore, patients in the intervention group showed greater improvement in weight loss and smoking cessation after 12 months of diagnosis.

From the analysis of the studies, it can be observed that self-care intervention that incorporated psychological and behavioural aspects appeared later than the studies that focused on education only. Studies included by Norris et al. (2002) focused their intervention on an education programme, whereas studies included in other reviews which were conducted much later (Deakin et al. 2005; Vermeire et al. 2005; Heinrich et al. 2010; Minet et al., 2010) included behavioural and psychosocial aspects in their intervention, and these also became the outcome measures of these reviews. In addition, the RCT conducted by Davies et al. (2008) also included psychosocial aspect as one of their outcome measures. Therefore, it can be understood that the importance of psychosocial and behavioural aspects of the patients have been included in the self-care support only since the 1990s, and this reflected the holistic practice of diabetes management.

2.5 Theoretical underpinned the self-care support interventions

Results from the systematic reviews and a RCT demonstrated positive effects of self-management education programmes in improving the glycaemic control of type 2 diabetes. However, this impact was minimal and most of the studies reviewed only focused on the effectiveness of the interventions for a short-term period of time. Therefore, the effect of self-management interventions in the longer-term could not be confirmed. Furthermore, most of the reviews used clinical parameters as opposed to psychological aspects and success in behavioural change as the indicator of effectiveness of self-care intervention. Although psychosocial aspects were included as outcome measures in several reviews, the impact of the intervention on this outcome was not clear due to the lack of studies. Furthermore, evidence related to the effectiveness of providing self-care support for type 2 diabetes patients in Malaysia was not found. Most interventions included in the reviews were developed and conducted in Western settings, thus, its transferability to the Asian countries particularly Malaysia is questionable. The literature review conducted here has led to the conclusion that, the self-care of patients with type 2 diabetes is highly influenced by contextual and cultural aspects. Therefore, it

is anticipated that, adapting existing evidence based interventions may not be effective without taking Malaysian specific demographics, population and culture into consideration.

Self-care support intervention programmes identified through in this literature review revolved around diabetes self-management education (DSME) with the aim to empower patients and enhance their confidence in self-management of their diabetes. This implies that, the development of the intervention programmes was derived from the concept and application of an empowerment model. Empowerment has been an emerging concept in the field of diabetes management provision, since the 1990s, following the results of a large-scale Diabetes Control and Complication Trial (DCCT) conducted in the United States (Anderson, 1995). Empowerment has been described as a process that facilitates patients' self-care practices, which require consistency in behaviour change (Funnell et al., 2009). Practically speaking, empowering patients entails giving them freedom and authority to make decisions and choose personally meaningful activities that will have impact on their lifestyle changes, self-satisfaction and control of diabetes (Anderson & Funnell, 2010). Therefore, it could be anticipated that, empowerment is an appropriate theory to apply to interventions aiming to improve patients' engagement with self-care. However, although interventions underpinned by the theory of empowerment have demonstrated a positive impact on patients' ability to self-manage and improve medical outcomes, the debate continues on how ready patients and healthcare professionals are to apply the concept of empowerment into practice.

Most of the studies included in the review did not clearly explain the theoretical underpinnings of the interventions. However, the concept of empowerment could be observed through the aims and objectives of the interventions and the measurement tools used. For example, the diabetes education and self-management for ongoing and newly diagnosed (DESMOND) programme developed in the UK identified the philosophy of

empowerment and ‘informed choice’ as underpinning the intervention (Skinner et al., 2006). Furthermore, the development of DESMOND programme was based on several theoretical concepts including Social Learning Theory and Self-efficacy to ensure the programme developed is in line with the complex needs and situation of patients with type 2 diabetes. As stated in the literature review, DESMOND programme was found to be effective in improving patients’ engagement with self-care, medical outcomes and cost-effectiveness (Davies et al., 2008).

Within the Malaysian healthcare system, adaptation of the empowerment model to facilitate engagement of patients with self-care could be a suitable choice. This is because, the management of type 2 diabetes policy and guideline in Malaysia is underpinned by the American Diabetes Association Guidelines (Tan & Magarey, 2008) where the concept of empowerment emerged and was developed (Funnel et al., 2009). However, in applying the empowerment theory to a Malaysian setting, critical analysis of service delivery and the readiness of the patients and healthcare professionals to be empowered needs to be understood to ensure the intervention conducted would achieve its intended outcome. This aspect is discussed further in chapter nine with reference to the study findings.

2.6 Summary of literature review and justification of current study

From the literature review, it is clear that the adherence of patients with type 2 diabetes towards self-care was poor globally. It was also understood that the patients’ engagement with self-care was largely influenced by many factors that are significantly associated with their life situations. The factors include their experience and perspectives on diabetes, religious beliefs, their social role, cultural practices, financial capability, and their relationship with HCPs. Through in-depth interviews in several studies, patients’ experiences in integrating and adapting self-care in their life situation was frequently expressed as difficult and challenging. These feelings reflected the burden that patients have in living with diabetes. Although the experience and perspective of the patients

greatly influenced their self-care practices, several studies reported that these aspects are frequently ignored by HCPs. This is due to the nature of current diabetes management, which is mainly focused on clinical outcomes and is highly medically oriented. In addition, the different orientation that patients and HCPs have in regards to self-care has restricted the effectiveness of self-care support provided, meaning that patients' self-care needs remained unmet. Therefore, these elements can be argued to be the contributing factors to the low level of effectiveness of self-care support provision and unsatisfactory self-care practice of type 2 diabetes patients globally.

In the review, it can be observed that a large amount of research pertaining to this issue has been carried out in the United States and European countries. However, very little of this research has been conducted in Asia, and only one study pertaining to this issue has been found to have been conducted in Malaysia. Whilst being aware of the current overwhelming incidence of type 2 diabetes in Malaysia, factors that influence poor self-care among type 2 diabetes patients in Malaysia seems to be a crucial factor to explore. In addition, apart from patient factors that are assumed to be the most influential barriers in diabetes management, the practice of HCPs in managing diabetes, and the influence of the healthcare system in diabetes management also seems to be an important factor to understand. By including these three elements of diabetes management in this research, a range of factors that influence self-care in type 2 diabetes patients in Malaysia can be explored.

CHAPTER 3

The Research Paradigm and Methodology

3.1 Introduction

This chapter presents the research aims, objectives, and questions. The appropriate research methodology and its philosophical underpinning are discussed and justified. This is followed by an explanation of the study design in chapter four.

3.2 Research aims and objectives

The literature review in chapter two presented a comprehensive overview of research regarding the experience and factors influencing self-care of patients with type 2 diabetes, as well as issues in self-care support provision, in the global context. Self-care in patients with type 2 diabetes refers to the concordance of patients to the important aspects of diabetes management, such as diet modification, medication adherence, engagement in regular physical exercise, and SMBG, which aims to improve patients' quality of life and minimise the possibility of complications (Ruggiero et al., 1997; Whittmore & Roy, 2002).

Self-care of patients with type 2 diabetes has been found to be poor globally and is strongly influenced by several cultural and location-specific factors. However, the reason for poor self-care practice among patients with type 2 diabetes in Malaysia is not clearly understood due to a lack of research in this area. There is also little understanding of the self-care support provision within the Malaysian healthcare system, which may influence patients' ability to self-manage their diabetes. Statistics in Malaysia had reported that, urban population such as in Kuala Lumpur and Putrajaya, Malaysia had the highest incidence of type 2 diabetes, thus, this study is

focusing on this particular population. Therefore, this research seeks to address these issues by obtaining an understanding of the reasons for poor self-care practice and the factors that influence self-care of patients with type 2 diabetes in urban setting in Malaysia. Additionally, this study explores self-care support provision for patients with type 2 diabetes within the Malaysian healthcare system.

The aims, questions, and objectives of the research are stated below.

3.2.1 Research aims

- To understand the self-care practice and factors influencing engagement in self-care, in patients with type 2 diabetes in an urban setting in Malaysia.
- To understand self-care support provision for patients with type 2 diabetes in an urban setting in Malaysia.

3.2.2 Research questions

The research aims led to the formulation of ‘what’ and ‘how’ research questions to facilitate understanding of self-care issues within the Malaysian context.

The research questions are:

- What are the self-care practices of patients with type 2 diabetes in urban setting in Malaysia, and what are the factors influencing their engagement in self-care?
- How are the self-care practices of patients with type 2 diabetes in an urban setting in Malaysia supported in the primary and secondary healthcare system?

3.2.3 Research objectives

Five research objectives are also included. These objectives were developed to guide the process of data collection, including how and from whom data would be collected.

This ensured that issues related to self-care of patients with type 2 diabetes in Malaysia were comprehensively explored.

The objectives of the study were to explore:

- Self-care practices of patients with type 2 diabetes in an urban setting in Malaysia.
- Factors that influence the self-care practice of patients with type 2 diabetes in an urban setting in Malaysia.
- Self-care support for patients with type 2 diabetes in primary- and secondary-care settings in urban areas in Malaysia.
- Patient–HCP interaction during self-care support provision.
- The extent to which self-care support for patients with type 2 diabetes in Malaysia is emphasised in the Malaysian healthcare system.

3.3 Principles underpinning the study methodology

Subsequent to outlining the research aims, questions, and objectives, the next step is to identify the most appropriate methodology to guide the conduct of the study. The primary principle guiding the study is to maintain congruency between the study purpose, research questions, and research strategy (Marshall & Rossman, 1995).

‘What’ and ‘how’ research questions lie within the qualitative paradigm, which investigates little-understood phenomena, and aims to understand patterns and links between these phenomena (Marshall & Rossman, 1995). These research questions enable exploration of experiences and perceptions of patients with type 2 diabetes, and issues related to self-care (Ruggiero et al., 1997; Green & Thorogood, 2009) in the Malaysian context, which have not been explored previously. As the study is exploratory in nature, a qualitative methodology is most appropriate to meet the study objectives. Utilisation of a qualitative research methodology in this study is coherent with the aims and objectives of the study, as it allows an understanding to be built with respect to the meanings, experiences, and processes of individuals in relation to

the phenomena being studied (Kalof, Dan, & Dietz, 2008). Furthermore, the qualitative research approach permits a rich description of the phenomena, which leads to an in-depth understanding of the issues being studied (Denzin & Lincoln, 2005).

Self-care relates to the behaviour of patients in making decisions and taking action to cope with health problems (Denyes et al., 2001), and is greatly influenced by the patients' real-life environment. Therefore, studies conducted on the concept of self-care demand that the researcher understands and can be immersed in the patients' real context. This is in line with the notion of real-world research set forth by Robson (2002), who suggested that research intended to study the real-world context must adopt a flexible research design, as it is intended to investigate complex, poorly controlled, and 'messy' situations. Therefore, qualitative methodologies that feature a flexible research design (Silverman, 2011) are frequently adopted to study the concept of self-care. This can be observed from the papers included in the literature review in chapter two, since 16 out of the 35 papers included in the review included qualitative studies (Hunt et al., 1998; Samuel-Hodge et al., 2000; Whitemore et al., 2002; Rayman & Ellison, 2004; Hornsten et al., 2004; Holmström & Rosenqvist, 2005; Nagelkerk et al., 2006; Vermeire et al., 2007; Oftedal et al., 2010; Formosa et al., 2011).

The literature review also highlighted research in this area that used a quantitative methodology (Aljaseem et al., 2001; Hartz et al., 2006; Polonsky et al., 2010). These studies provide important evidence related to self-care. Quantitative methodologies are derived from the positivist paradigm, in which the related philosophy is based on logic and measurement, truth and absolute principles (Weaver & Olson, 2006). The development of knowledge according to the positivist view is based on the observation and measurement of objective reality that exists in the world (Cresswell, 2003). In addition, positivists believe that the world is governed by laws or theories that need to be tested, verified, and refined (Guba & Lincoln, 1989). Therefore, according to positivists, social phenomena can be studied with reference to natural

sciences, and can include hypothesis testing, causal explanations, and modelling, since human behaviour is governed by laws and regularities (Ritchie & Lewis, 2009). However, application of the positivist paradigm in understanding real-world phenomena has been criticised, as it is unable to satisfactorily address the nature of facts or the interactive nature of inquiry (Denzin & Lincoln, 2005). Moreover, it can be observed that quantitative research used to study the concept of self-care has frequently been limited to objective findings, and is unable to provide a subjective understanding on the situation as experienced by patients themselves (Fisher et al., 2012; Sharoni & Wu, 2012). As the aim of this study is to understand the experiences of patients with type 2 diabetes with respect to engaging in self-care within the context of their daily lives, these aspects can be understood by obtaining basic perspectives from these patients. In addition, understanding can be obtained through observation of patients' social interactions with HCPs within the natural healthcare environment (Pope & Mays, 1995; Cresswell, 2003). As such, a quantitative methodology clearly does not fit the framework of this study, as it would be unable to provide a clear and holistic understanding of self-care issues in the Malaysian context.

Mixed-methods research is another research approach suggested by Robson (2002) as suited to real-world research because it provides flexibility to the researcher to adopt methods that are relevant to their study questions. Mixed-methods research can be defined as a research methodology that involves a combination of qualitative and quantitative study in several phases of the research process, including data collection and data analysis (Cresswell & Clark, 2011). The mixed-methods approach has potential for this study, as it provides a degree of flexibility to the researcher in understanding self-care issue within the real-life context (Robson, 2002). However, this study is exploratory in nature, and its aim is to intensely explore the problem under investigation without making any inferences from the data, which is frequently done through quantitative data analysis (Cresswell & Clark, 2011). Therefore, the researcher decided that the mixed-method approach was not suitable for this study.

Moreover, this study aims to provide a deeper, more holistic understanding of Malaysian patients' self-care practices and their healthcare provision in order to identify how clinical practices can be improved. As such, it is justified to use a qualitative methodology with a flexible research design that allows several data-collection methods from various data sources to be used in understanding self-care issues in the Malaysian context.

3.3.1 Qualitative methodology

The qualitative methodology is derived from the philosophical perspectives of social constructivism and interpretivism, which assert that reality and meaning are constructed through engagement in and interpretation of the real world by an individual (Crotty, 1998). Interpretivists hold a belief that social reality cannot be separated from the person who observes it (the researcher), and interpretation of the social world shaped by the researcher's personal, historical and cultural beliefs, and experience (Cresswell, 2003; Weber, 2004). It is assumed that individuals (the researcher) construct understanding and develop the subjective meaning of the social world through experience with the particular objects or situation or interaction with people (Weber, 2004). Therefore, the qualitative methodology is concerned with the subjective world, and its aim is to explore people's experiences, beliefs, and behaviours within their cultures and contexts (Morse, 2004). As the meanings of the experience, beliefs, and behaviours of individuals vary, the researcher needs to look for complexity when attempting to understand the situation or phenomena being studied (Denzin & Lincoln, 2005).

The qualitative methodology used in this study generated an understanding of self-care issues through engagement with the context of the study, and interpretation of discussions and interactions with relevant people in the study setting (Green & Thorogood, 2009). Several qualitative approaches were potentially relevant to guide this study. For example, an ethnographic approach could be considered useful in exploring 'cultural' influences on meaning and experiences of patients in dealing with diabetes. Alternatively, a grounded theory approach would facilitate explanation of the phases and stages that patients go through when engaging in self-care. The

phenomenological approach would provide an explanation of the ‘lived experience’ of patients with type 2 diabetes through prolonged engagement with the study participants.

However, the aim of this study is to understand the underlying problems related to poor self-care that lead to uncontrolled type 2 diabetes in Malaysia. In addition, this study looks at the appropriateness of healthcare provision in supporting patients’ self-care practices, and these aspects are directly congruent with clinical practice. The aims and purpose of this study are in line with the framework of health service research: finding an explanation or solution to a clinical problem, and identifying healthcare needs and the appropriateness of healthcare provision (Bowling, 2002). Conducting this research will elucidate issues related to self-care in Malaysia, and enable the development of knowledge that will guide improvement strategies in the healthcare system (Baker, 2011). Therefore, pragmatism was identified as the philosophy underpins this study, and drives its methodology and design, as detailed in the following section.

3.4 Underpinning philosophy: Pragmatism

Pragmatism is a research paradigm associated with action, intervention, and construction of knowledge (Goldkuhl, 2012). Pragmatism has been identified as the philosophy to underpin this study because it is in harmony with applied health service research (Adamson, 2005); that is to create knowledge in the interest of change and improvement (Pope & Mays, 1995; Goldkuhl, 2012).

The pragmatic worldview derived from the work of Pierce (1878), James (1907) Dewey (1931) is more concerned with the application of knowledge, looking at ‘what works’ and the solutions to the problem (Patton, 1990). Baert (2005) also supported pragmatism, agreeing that the design and methods in research always stem from the research questions and aims. Pragmatists support both objective and subjective views

and do not believe that cause-and-effect relationships can always be proven in real-world settings (Tashakkori & Teddlie, 2003; Milnes, 2010). Therefore, the method used depends, at least in part, on what the researcher seeks to achieve (Baert, 2005). Thus, pragmatism permits flexibility for the researcher to select the methods, techniques, and procedures of research that best meet their needs and purpose. Pragmatism commonly refers to the philosophical underpinning of mixed method research (Johnson & Onwuegbuzie, 2004; Adamson, 2005). However, synthesis of both interpretivism and pragmatism research paradigms provide a view that these two paradigms have some common ontological assumptions where construction of the meaning of the social world and meaningful actions are based in evolutionary social interactions (Goldkuhl, 2012). Therefore, conducting qualitative research through the lens of pragmatism is considered appropriate and effective in investigating real-world phenomena (Robson, 2002; Goldkuhl, 2012). Utilisation of pragmatism in this study permits flexibility through the use of various research methods to understand self-care practices and self-care support in the Malaysian setting.

3.5 Summary

In summary, the research aims and objectives of this study are consistent with the framework of health service research. Reflecting the notion of health service research, pragmatism has been identified as the philosophy to underpin this study. The research design that parallels the pragmatic approach utilised in guiding this study will be described in the following chapter.

CHAPTER 4

Case Study Design

4.1 Introduction

Chapter three outlined the congruence between the research questions and the methodology underpinning the study. In parallel with the philosophy of pragmatism and the framework of health service research, a case study research design was chosen to guide the conduct of the study. The concept of case study for this study was based upon the definition and the stance of case study by Yin (2009). This case study was focused on one ‘case’– ‘self-care of type 2 diabetes in Malaysia’; therefore, single embedded case study design was utilised in guiding the development and execution of this study. This chapter presents the definition of case study research and justifies the suitability of the type of case study selected. In addition, the ‘case’ will be further defined and the study context where this study was conducted is explained.

4.2. Case study research

As explained in chapter three, the aims and purpose of this study are in line with the philosophy of pragmatism, which aims to understand and provide an explanation for clinical problems. Thus, it requires exploration and understanding of the problem from several perspectives, with the research questions as the central focus of the study (Cresswell, 2003). Case study research has been described as an empirical approach to answer complex and challenging research questions through multiple sources of evidence (Remenyi, 2012). It is seen as useful to generate an in-depth and multi-faceted understanding of complex issues in their real-life context (Crowe et al., 2011). Yin (2009) identified case study research as the most appropriate research strategy when a ‘how’ or ‘why’ question is being asked, and when the study focuses on contemporary events and the investigator has little or no control over these events.

This reflects the issues in this study; self-care of type 2 diabetes in Malaysia has become a significant concern due to the steep increase of diabetes incidences over time. Therefore, it can be considered a contemporary issue within patients' real-life settings, and in the context of healthcare provision.

Self-care of type 2 diabetes is a complex issue, as it is greatly influenced by the complexity of diabetes itself, the patients' life situation, and the complexity of the healthcare environment (Lipson & Steigger, 1996; Whittemore & Roy, 2002; Godfrey et al., 2011). As such, a flexible research design that allows exploration of this issue from various perspectives is needed in order to obtain a clear understanding of what actually happens in the study setting. Therefore, case study design was selected as the most appropriate approach for the purpose of the study. Its ability to address the research questions will now be explored in more detail.

4.2.1 Definition a case study

The case study approach is rooted in social science, but it has been applied in a wide range of research disciplines, including education (Ellis, 1997), psychology (Willing, 2013), and engineering (Darke et al., 1998; Runeson & Host, 2009). It is also increasingly utilised in the nursing discipline; this has been observed in several studies, such as those by Lyte et al. (2007) and Walshe et al. (2008).

Several definitions of case study are available in the literature (Parse & Smith 1985; Hammersley, 1989; Yin 1993). Most authors agree that the main features of the case study approach include collecting detailed information on a particular subject or unit by utilising multiple data-collection methods, including observations, interviews, and documents (Hammersley 1989; Yin 1993; Stake 1995). Yin (1993, 1994, 2009) and Stake (1995, 2006) are two prominent authors whose approaches are frequently used in the field of case study research. There are considerable similarities and differences

between the interpretation and utilisation of case study by these two authors; these will be evaluated below in order to identify the most suitable approach for this study.

Yin defined case study as;

'...an empirical enquiry that investigates a contemporary phenomenon in-depth within its real-life context when the boundaries between the phenomena are not clearly evident.'

(Yin, 2009, p. 18)

Yin (2009) defined case study as a research strategy that provides an action plan to guide the research from questions to conclusions. Yin (2009) addressed five key features that characterise case study; these are:

- the study is an empirical enquiry
- it investigates contemporary phenomena
- the study is conducted within a real-life context
- the boundaries between the variables being studied are not clearly visible
- multiple sources of evidence are used to facilitate in-depth understanding.

Conversely, Stake (1995, 2006) rejected the notion of the case study as a methodological choice, but described case study as involving a choice of what is to be studied (the 'case'). Therefore, instead of defining case study as a research methodology or research strategy, Stake (1995) focused his definition on defining the case, which he saw as:

'...a specific complex, functioning thing ... with each case being an integrated system with a boundary and working parts.'

(Stake, 1995, p. 2)

Whilst Stake's rationale for choosing the case was similar to those of Yin (that is, one that focuses on a contemporary issue, involves a real-life setting, involves no researcher control and uses multiple source of evidence), he placed less emphasis on

the methods used to study the case. Furthermore, Stake (1995) did not insist on the use of a theoretical proposition or the development of theory. This contrasts with the approach used by Yin (2009) who emphasised the importance of theoretical propositions because they serve as a theoretical orientation or blueprint to guide the objectives and design of case study. In addition, Yin (2009) mentioned the process of theory development as part of the purpose of case study.

The contrasting definitions of case study according to Yin (2009) and Stake (1995) underline a philosophical difference to the approach as a research strategy. Stake (1995) frequently referred to case study as a qualitative methodological approach, and this has been supported by several other authors, as it refers to ‘naturalistic inquiry’ (Bergen & While, 2000; Baxter & Jack, 2008; Remenyi, 2012). Under this perspective, case study is frequently characterised by in-depth investigation into the subject or phenomena being studied, with no absolute boundaries (Hammersley, 1989; Bergen & While, 2000). However, this feature frequently overlaps with other types of qualitative research, such as ethnography and phenomenology (Rowley, 2002). Therefore, it is difficult to distinguish case study research from other types of qualitative research strategies.

However, case study also permits the collection of quantitative data to understand the issue being studied (Yin, 2009). For instance, Yin’s approach to case study leans more towards the positivist paradigm; he believed that phenomena are measurable and based on a ‘logical plan’ that is replicable between cases (Yin, 2009). As case study has more than one definition, it has been variously utilised in different research traditions (Appleton, 2002). For example, Yin (1993, 2009) and Sharp (1998) regarded case study as a research strategy (a plan of action in conducting a research systematically), whereas Stake (1995) referred to it as a method to study the ‘case’. Guba and Lincoln (1989) viewed case study as a technique for reporting qualitative findings, while several authors regarded case study as an evaluation tool (Patton, 1990; Marshall & Rossman, 1995). The differences in utilisation of case study have increased the complexity related to characterising the method. However, in

concordance with the notion of case study suggested by Yin (1993, 1994, 2009) and Stake (1995, 2006), many researchers have agreed that a case study can be conducted as quantitative or qualitative, or a synthesis of both approaches (Yin, 1994, 2009; Stake, 1995; Sandelowski, 2006).

4.2.2 Propositions in a case study

The aim of propositions in a case study is to provide a theoretical blueprint for the study to guide the research design, data collection, and data analysis (Yin 2009). The proposition also enables the establishment of boundaries of the study to determine the feasibility of its completion within a particular amount of time (Baxter & Jack, 2008). Propositions are explained as the expected findings that can be speculated upon by the researcher on the basis of the literature and earlier evidence (Rowley, 2002). Therefore, it has been suggested that a proposition is necessary if the study is positivist-oriented and conducted using a deductive approach (Rowley, 2002; Yin, 2009). This indicates that the establishment of a proposition may not be necessary if the study is exploratory in nature, wherein the study topic is not clearly understood (Rowley, 2002; Baxter & Jack, 2008; Yin, 2009). However, several authors have emphasised that although the study is an entity to be explored, the researcher should have a clear focus that is represented in its questions and purpose (Eisenhardt, 1989; Yin, 2009). This is to ensure the success of the case study in achieving its objectives (Yin, 2009).

As discussed in section 3.2 (chapter three), the aims, research questions, and objectives of the study were determined by the findings of the literature review and problems identified within the study context. Current knowledge and understanding of the factors influencing self-care and the trend of self-care support provision for patients with type 2 diabetes are based on a synthesis of the evidence from the literature review (see chapter two). It became the focus of the study and guided the development of the research questions. The research questions that guided the conduct of this case study are listed below:

- What are the self-care practices of patients with type 2 diabetes in urban setting in Malaysia?
- What are the factors influencing self-care practices of patients with type 2 diabetes in urban setting in Malaysia?
- How are the self-care practices of patients with type 2 diabetes in urban setting in Malaysia being supported in the primary and secondary healthcare system?
- How are the interactions of patients and HCPs while undergoing self-care support provisions?
- To what extent are the self-care support of type 2 diabetes being emphasised in Malaysian healthcare system?

4.3 Type of case study design

Having justified using case study as the research strategy, the next step is to identify the type of case study design that will guide the overall study purpose (Baxter & Jack, 2008). Case study can serve several research purposes, including descriptive or exploratory, prospective or retrospective, and can use an inductive or deductive approach to theory (Yin, 2009; Remenyi, 2012). In order to understand the different case study approaches, a description of case study design according to Yin (2009) and Stake (1995) is presented in the following sections; this is followed by justification of the case study design selected for this study. Table 4.1 shows the categories of case study and the purpose of each category as described by Yin (2009).

Table 4.1 Yin's categories of case study (Yin, 2009)

Case study categories	
Categories	Purpose
Explanatory	Used to seek an answer to questions that aim to explain the presumed causal links in real-life intervention that is too complex for survey or experimental strategies.

Exploratory	Used to explore the situation in which the intervention being evaluated has a single set of outcomes, or to develop pertinent hypotheses for further inquiry when the phenomena under investigation are not clearly understood.
Descriptive	Used to describe an intervention or phenomenon and the real-life context in which it occurs.

Yin (2009) also differentiated between single and multiple case studies. Table 4.2 shows Yin's variants of case study design and its applicability to the case study research strategy.

Table 4.2 Variant of case study design (Yin, 2009)

Description and type of single case study strategy	Description and type of multiple case study strategy
Single case study	Multiple case study
Suitable if the case represents a critical case, such as testing a well-formulated theory or proposition. Also applicable if the case is extreme or unique, representative, or typical, and if the case study is conducted as revelatory (case that was previously inaccessible) or is studied at two or more different points in times (longitudinally).	Suitable when a single case is studied in a wider context involving several cases. Multiple case studies need to be executed through 'replication logic' to ensure each of the cases are studied in a similar manner and similar findings can be predicted.
Single case study – Type 1 Study of a single case or a specific case in a unique environment or extreme situation.	Multiple case study – Type 3 Study of multiple case studies, where each case within the study is studied in a holistic manner.
Single embedded case study – Type 2 Study of a single case with the inclusion of multiple subjects that need to be included in the study (also known as units of analysis).	Multiple embedded case study – Type 4 Study of multiple cases with the inclusion of multiple units of analysis in each case within the study.

On the other hand, Stake (1995) distinguished the case study approach into three categories:

- Intrinsic

To be conducted when the researcher has high interest in the unique situation of the case and intends to get a better understanding of it.

- Instrumental

To be conducted if the research is intended to gain insight or understanding of particular phenomena.

- Collective

To be adopted when more than one case is being examined intrinsically or instrumentally, and when the purpose of the case study is representation or generalisation.

Synthesising the different types of case study design outlined by Yin (2009) and Stake (1995), it is clear that utilisation of each case study depends on what the study wants to achieve. The description given by Yin (2009) provides a detailed understanding of when each case study needs to be utilised, and the practical aspects of applying the case study. It includes the need for a study proposition to guide the study framework, and logical linking of methods of data collection to the proposition (Baxter & Jack, 2008; Yin, 2009). Although Stake (1995) divided the case study approach into three categories (as explained above), his explanation of the conduct of case study seems unclear, particularly regarding its applicability. His description is general and broad, which may leave researchers unclear in terms of which strategy should be selected, and when and how it should be applied.

Yin (2009) provided an explicit explanation of the practical aspects of conducting a case study, including choosing the type of case study, defining and selecting the case, and utilising the study proposition to guide the focus of the study. Therefore, the conduct of this case study was based on the case study approach described by Yin (2009). Based on this, the study falls under the category of an exploratory approach (asking 'what' and 'how' questions when the phenomena under investigation are not

clearly understood). The type of case study design that is applicable for this study is a single embedded case study design as it focused on one case – ‘self-care of patients with type 2 diabetes’– and it will be further explained in section 4.5 (defining the case).

4.5 Defining the ‘case’

Defining the case to be studied is vital, yet it is the most challenging aspect of conducting a case study (Appleton, 2002). Yin (2009) defined the case as a contemporary single unit or phenomena of study examined in context, where the boundaries between phenomena are not clearly evident. According to Yin (2009), the definition of a case or unit of analysis is similar to defining the research questions; that is, the case should be considered simultaneously with the development of the research questions (Baxter & Jack, 2008). Posing questions such as ‘Do I want to analyse the individual, a program, a process or interaction between the subjects?’ can assist in clarifying what the case should be (Baxter & Jack, 2008 p. 546). Clearly articulating ‘what the case is’ will serve to maintain the focus of the study and guide the researcher to sources of relevant data for answering the research question (Yin, 2009).

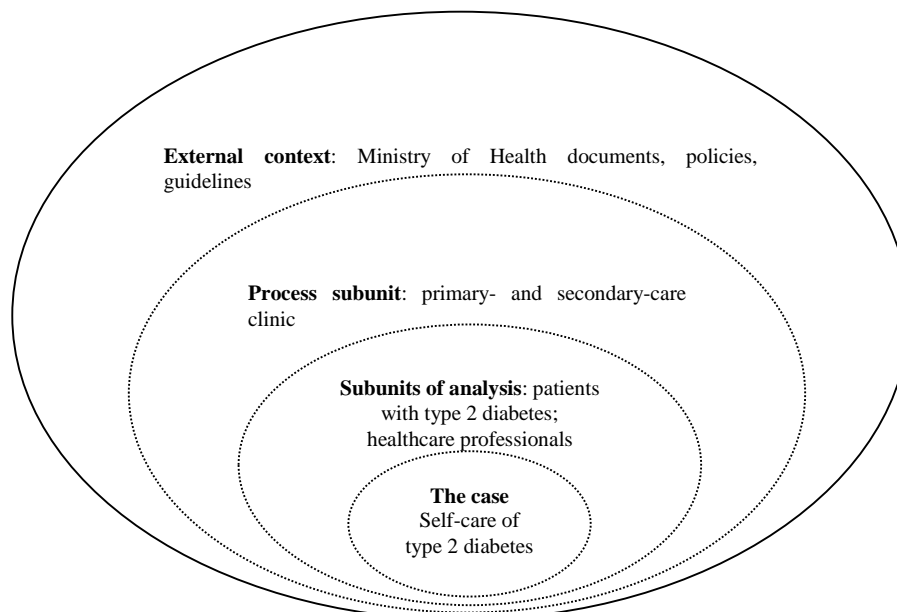
The research questions set out the focus of the study, which is to analyse self-care issues of patients with type 2 diabetes in urban settings in Malaysia. Therefore, the case has also been defined as ‘the self-care of patients with type 2 diabetes in urban settings in Malaysia’.

The study objectives specify the boundaries by stating an interest in looking at self-care practice and self-care support provision within the primary and secondary healthcare system. Therefore, the exploration of self-care practice and support provision is focused on the study setting (primary- and secondary-care outpatient clinics) in relation to the management of type 2 diabetes. The study setting has been

stated as urban setting in Malaysia, the study setting will be defined with reference to the population of patients with type 2 diabetes and the geographical factors of the setting selected. This aspect is further explained in section 4.6.

In designing this study, understanding the self-care of patients with type 2 diabetes involves two subunits of analysis: patients with type 2 diabetes and HCPs involved in self-care support provision. In addition, the practice of self-care support provision in the case study context (primary- and secondary-care outpatient clinics) also needs to be investigated; these have been identified as process subunits. The external context (the Malaysian healthcare system) is assumed to influence the management of type 2 diabetes and self-care support provision, as the healthcare service is based on the operational policies and guidelines stipulated by the Malaysian government (Ministry of Health). Thus, the government would also be included in the investigation. Figure 4.1 shows the structure of the case in this study. The case is placed in the centre as it represents the focus of the study. The dotted line between the unit of analysis and the case represent the unclear boundaries between the case and the context.

Figure 4.1 Structure of the case



As noted in section 4.3, Yin (2009) identified that a case study may involve more than one unit of analysis where attention is given within the case to subunits. He referred to this as an embedded case study design. In the context of this study, the focus is on one case – self-care of patients with type 2 diabetes – and includes two subunits of analysis and a process subunit. Therefore, the most appropriate approach is a single embedded case study design.

The rationale for the utilisation of a single case study design is based on criteria specified by Yin (2009) in section 4.3. As explained in chapter one, self-care has been regarded as common practice of patients with type 2 diabetes. These patients are educated and expected to adhere to and sustain their diabetes self-care regimens. Therefore, self-care cannot be regarded as unique but it can, however, be described as a ‘typical phenomenon’ in the management of type 2 diabetes. Yin (2009) recommended that a single case study design be adopted when a typical phenomenon is being studied. Furthermore, an embedded single case study strategy will enable the analysis of each of the subunits separately (within case analysis), between the different subunits (between case analyses) or across all of the subunits (cross-case analysis) (Yin, 2009).

4.6 Description of case study settings

The case to be explored was the self-care of type 2 diabetes in Malaysia. Malaysia has more than 130 hospitals and 802 primary-care clinics that are managed by the Malaysian Ministry of Health. In order to meet the aims and objectives of this study within the time and resources available, two secondary-care clinics and one primary-care clinic that deliver diabetes management in the Malaysian healthcare system were selected as case study sites.

Prior to selecting the case study sites, consideration must be given to ensure that the sites selected will allow the researcher access to the individuals, organisation, process, or anything else related to the units of analysis for the study (Crowe et al., 2011). Curtis et al. (2000) stated that the selected sites need to be interested in participating in the study, hospitable to the enquiry, and informed enough to answer the research questions. In selecting the case study sites for this study, these considerations were based on trends related to the occurrence of type 2 diabetes in Malaysia, and the provision of diabetes management on offer. Attention was also paid to the demography of the population of patients with type 2 diabetes that the clinics serve, which took into account the culture and context of the individuals, the healthcare team, and the organisation. The criteria considered in choosing the case study sites are detailed in the following sections.

The appropriateness of the case study sites to answer the research questions was decided based on public data available from the Malaysia Health Report (2012) and the Non-Communicable Disease Annual Report (Ministry of Health, 2010). In addition, demographic information about the population was accessed from a national statistics website (Malaysian Department of Statistics, 2011). The reports showed that Kuala Lumpur (the capital city of Malaysia) and Selangor state had the highest population of type 2 diabetes patients, with 38,399 cases in Kuala Lumpur and 128,088 cases in Selangor (Ministry of Health Malaysia, 2012). Furthermore, the National Diabetes Registry (Ministry of Health Malaysia, 2012b) reported that Kuala Lumpur and Putrajaya (federal territory situated in the state of Selangor) had the highest number of uncontrolled diabetes patients, where 24.3% of 28,385 registered patients in Kuala Lumpur and 29.6% of 2,161 patients in Putrajaya scored more than 6.5% in their HbA1c level (Ministry of Health Malaysia, 2012b). Therefore, patients in Kuala Lumpur and Putrajaya are at higher risk of diabetes complications. The high trend of uncontrolled diabetes in Kuala Lumpur and Putrajaya strengthened the line of inquiry on the nature of self-care practices and self-care support provision for patients with type 2 diabetes in the respective areas. Therefore, two secondary-care clinics in Kuala Lumpur Hospital and one primary-care clinic in Putrajaya were selected as the case study sites.

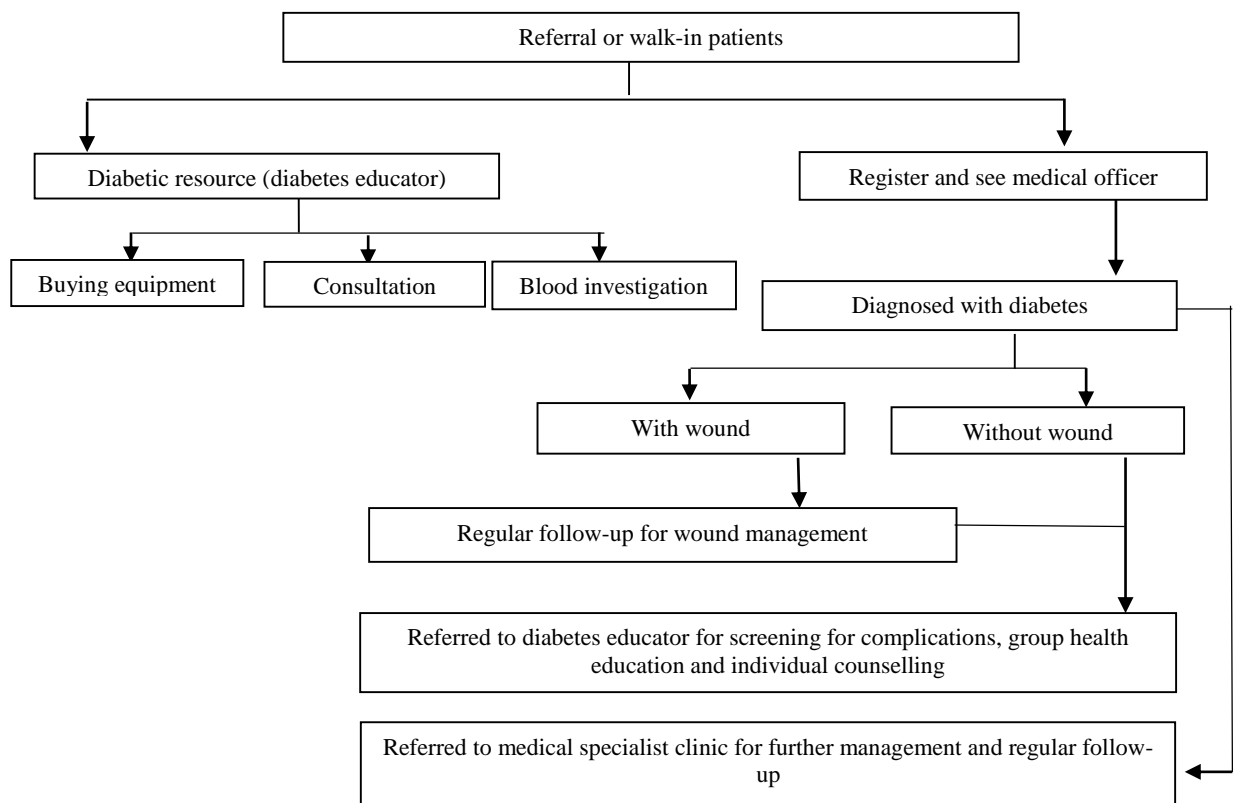
The secondary-care setting in Kuala Lumpur is the largest hospital in the country and the main referral hospital in Malaysia. The primary-care clinic in Putrajaya is situated in a federal territory of Malaysia (federal administrative centre of Malaysia). The management of diabetes in these clinics is performed based on the policy and guidelines stipulated by Malaysia's Ministry of Health and the availability of endocrinologists and family medicine specialists. Therefore, implementation of, or changes to, the policy for diabetes management in Malaysia is commonly implemented in these healthcare organisations before generalising them to the whole country (CPG, Ministry of Health Malaysia, 2009). It was expected that recruiting two secondary-care clinics in Kuala Lumpur and one primary-care clinic in Putrajaya would generate rich information about self-care issues in Malaysia, and allow for analytical generalisation of the findings (Miles & Huberman, 1994). The following section provides a description of each of the chosen case study sites.

4.6.1 Case study site one

Case study site one is a general medical and surgical clinic that provides consultation on various types of illnesses in a secondary-care setting. The services provided include: outpatient care (primary-care services), a family medicine specialist clinic, a clinic and resource centre for asthma and chronic obstructive pulmonary disease, diabetic eye screening, a foot care and diabetes counselling clinic, a medical examination unit, and a laboratory. The outpatient clinic receives a high volume of patients (approximately 500 to 600 patients) with various medical problems every day. The staff at the outpatient clinic include 14 nurses, one of whom is a diabetes educator; seven doctors; one healthcare educator; and five clinic assistants. There is also one pharmacist and one dietician attached to the clinic. Management of diabetes in the clinic includes: consultation with a medical officer, consultation with the diabetes educator, which includes diabetes counselling and buying diabetes-related equipment, blood investigation, screening for complications, and management of diabetic ulcers.

This clinic commonly receives referrals from other primary-care clinics and private practitioners, or walk-in patients. The doctor carries out an investigation to confirm the diagnosis. Once patients are diagnosed with diabetes, they are referred to the diabetes educator for diabetic counselling and screening for diabetes complications. If the patients are confirmed to have diabetes and also require wound management, they are referred to the wound management team for further assessment and treatment. Furthermore, some diabetes patients come to the clinic for consultation on diabetes self-management from the diabetes educator, and to buy diabetes-related equipment available from the diabetic resource centre. Health education seminars on diabetes are also provided to patients who attend the outpatient clinic every Wednesday. These health education seminars are delivered collaboratively by the diabetes educator, health education officer, dietician, and pharmacist. Apart from providing treatment and care to diabetes patients, the clinic also supports patients in getting financial assistance by referring them to the Social Welfare Department, if needed. Type 1 or type 2 diabetics are referred to the specialist medical clinic at the Kuala Lumpur Hospital for further treatment. A flow chart depicting the management of patients with diabetes at case study site one is provided in Figure 4.2.

Figure 4.2 Flow chart depicting the management of patients with diabetes in case study site 1

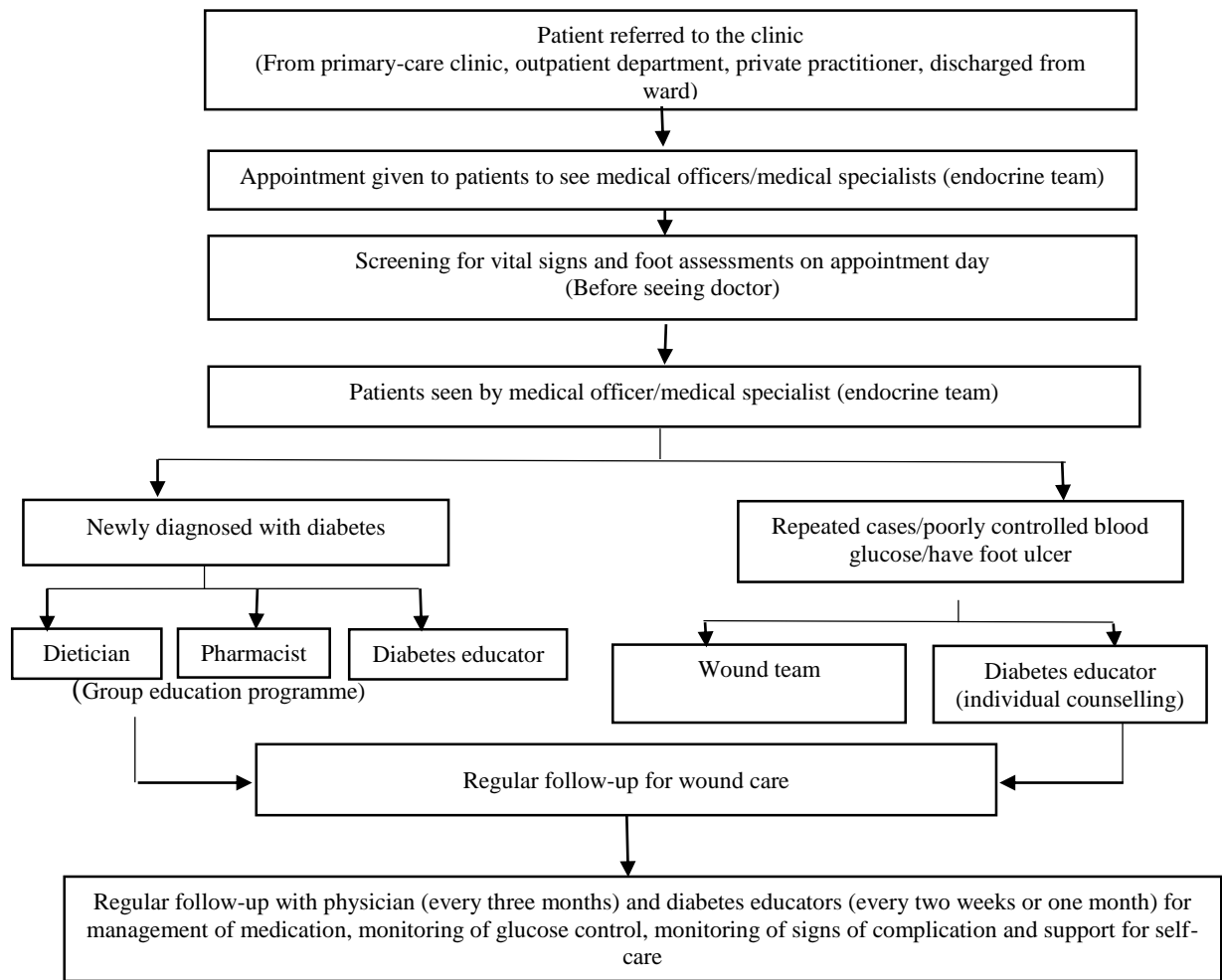


4.6.2 Case study site two

Case study site two is a specialist medical clinic in a secondary-care setting. This clinic provides specialist management and care for patients with several medical conditions, including gastroenterology, respiratory, cardiovascular, endocrine, haematology, and infectious disease issues. In this clinic diabetes is managed by an endocrinologist with help from five medical officers and eight qualified diabetes educators. This clinic receives referral from primary-, secondary- and tertiary-care institutions, including primary-care clinics, outpatient clinics, private practitioners, and patients discharged from wards.

Approximately 4,000 diabetes patients have received treatment from this clinic annually. As the clinic's scope of management is wide, clinic days are divided equally for each discipline, and diabetes clinics are held every Wednesday evening. However, patients are able to see diabetes educators any day from Monday to Thursday, and their visits to the clinic are based on appointments. The sessions with diabetes educators enable patients to discuss their problems and obtain opinions and advice on the management of their diabetes, as they are seen individually. The diabetes educators monitor patients' ability to maintain good glucose control based on self-monitoring their blood glucose records. Patients are given individual insulin dosages, meal plans, exercise plans, and counselling. If patients have any problems that require urgent attention, they are referred straight away to the medical officer. Patients are seen by diabetes educators every two weeks or every month, according to their ability to maintain their glucose control, and are given appointments to see the doctor every three months. Patients with diabetic foot ulcers are referred to the wound management team for wound care. Figure 4.3 depicts the management of patients with diabetes in this clinic.

Figure 4.3 Flow chart depicting the management of patients with diabetes in case study site 2



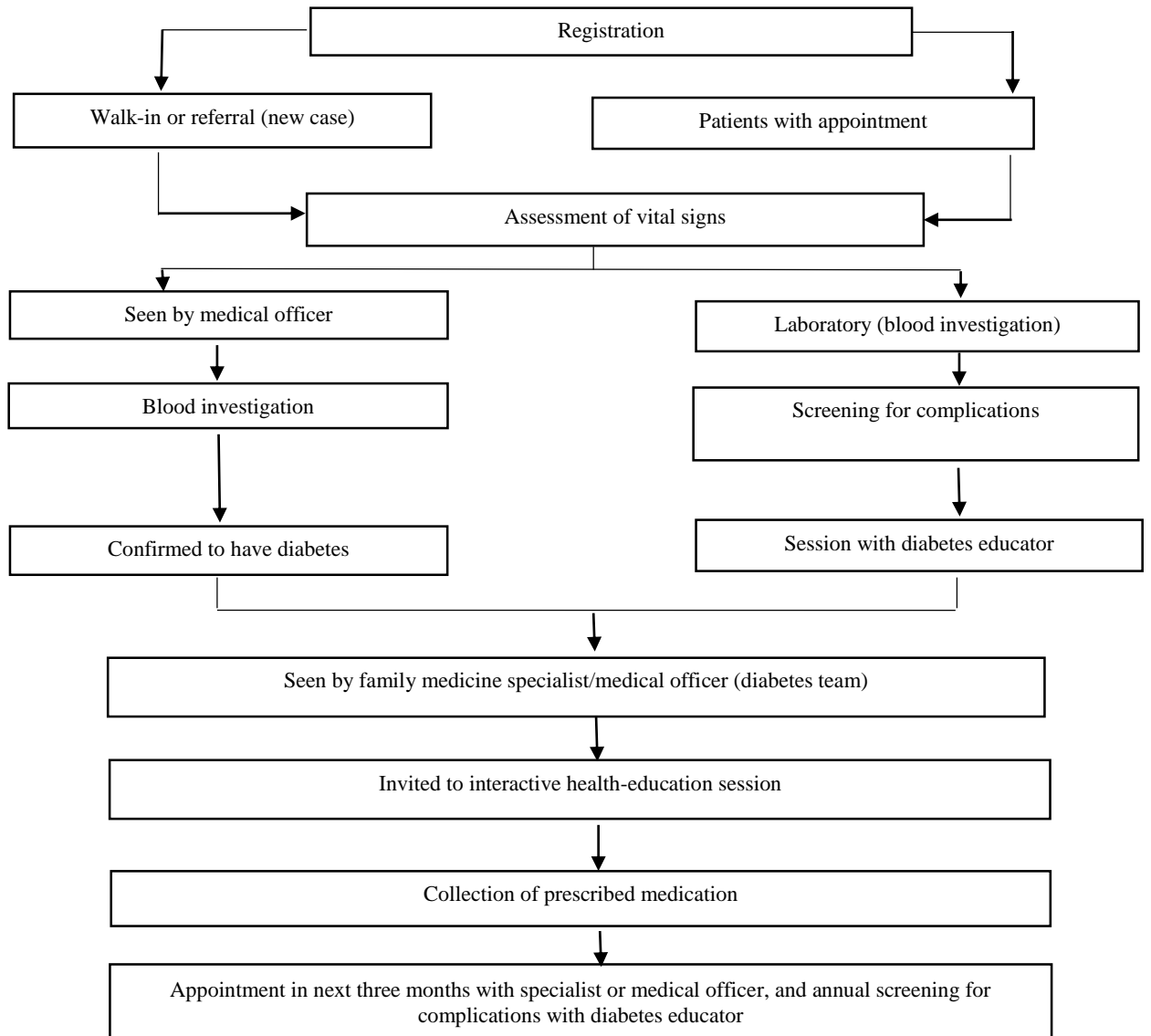
4.6.3 Case study site three

The third clinic that was chosen as a case study site is a primary-care clinic in the federal territory of Putrajaya. This clinic provides primary care and maternity and child health services. The clinic is led by a public health doctor with the assistance of one family medicine specialist, seven medical officers, one nurse manager, 30 nurses, five medical assistants, six pharmacists, two nutritionists, and one occupational therapist. The clinic operates on an integrated basis and is divided into two divisions: the outpatient clinic and the maternity and child health clinic. Although operation of this clinic is divided, both divisions shared the same resources, including space, manpower, and facilities. The outpatient clinic receives approximately 150 patients

every day with various medical problems. A total of 2,194 diabetes patients are registered with the clinic. Management of diabetes in this clinic is led by the family medicine specialist, with support from two medical officers, one diabetes educator, one general nurse, and one medical assistant. This team is also supported by the pharmacist and nutritionist whenever necessary. Management of diabetes in this clinic includes: consultation with a physician, monitoring of blood glucose level, screening for complications, interactive group education sessions, and individual and group counselling with a diabetes educator and nutritionist. This clinic also provides community support, including public exercise sessions, outreach programmes to identify high-risk cases, and health education talks for government organisations and non-government organisations in Putrajaya.

This clinic receives walk-in patients and referrals from private clinics. Patients who come to the clinic are immediately seen by a medical officer to discuss their history and investigate their condition. If the patients are diagnosed with type 1 or type 2 diabetes, they are referred to the diabetic team for further management. They are then seen by the family medicine specialist or a medical officer, and managed accordingly in terms of their medication. The patients are also required to see the diabetes educator for screening of complications, including an eye assessment and a foot assessment, and are given information and advice on the management of diabetes. If necessary, patients are referred to the nutritionist for diet counselling and discussion of meal plans. The patients' glucose control is monitored through blood investigation (HbA1c) every three months, and they are given appointments to see the doctor every three months. Screening for complications is conducted annually or every six months, based on any signs of complication experienced by patients, or at the doctor's request. Thus, patients are only able to see the diabetes educator every six months or once per year. However, patients are invited to participate in a diabetes conversation map tool programme (interactive health-education programme) once a month; this is organised collaboratively by the diabetes educator, nutritionists, and pharmacists. Patients who require secondary care are referred to Putrajaya Hospital for further management. The management of diabetes patients in Putrajaya Health Clinic is depicted in Figure 4.4.

Figure 4.4 Flow chart depicting the management of patients with diabetes in case study site three



4.7 Summary

A qualitative case study with single embedded case study design has been identified as the most appropriate strategy for this study. The single embedded case study design will enable the researcher to explore issues related to self-care of type 2 diabetes in Malaysia from various perspectives, including those of patients, HCPs, and the healthcare system. Themes derived from a comprehensive literature review guided the development of research questions and study framework. The settings where this case study was conducted have been described. In the next chapter, consideration of appropriate methods in executing this study and the working methods of this study, including details of how this study was conducted, will be explained.

CHAPTER 5

Research Methods

5.1 Introduction

Chapter four provided the definition of the ‘case’ and justified the appropriateness of case study research as the study design. In addition, the study settings were also described. This chapter explains the conduct of the study and presents the approach to the type of case study adopted. A consideration of methods related to the research is undertaken. The process of sampling, data collection, and data analysis is explicitly explained. In addition, issues related to data collection and reflexivity on the role of the researcher during the research process is discussed.

As an overview, this study employed a purposive, snowball sampling strategy and adopted three data collection methods: in-depth semi-structured interviews, participant observation, and analysis of relevant documents pertinent to diabetes management in the Malaysian healthcare system. In addition, this study utilised a framework technique for data analysis and followed the framework developed by Guba and Lincoln (1989) in establishing the rigour of the study. The way in which this study was conducted is also explained in detail in this chapter.

5.2 Identifying the data source

In conducting this study, the data sources were identified prior to the field work to ensure that each research question and objective has a direct data source, and that the data gathered are deeply rooted in the research questions (Yin, 2009). Table 5.1 illustrates the structure of the data collection plan for this study.

Table 5.1 Proposed data collection methods

Research objectives	Source of data	Data collection methods
To explore self-care practices of patients with type 2 diabetes in Malaysia	Patients with type 2 diabetes	In-depth semi-structured interviews with patients with type 2 diabetes.
To explore factors that influence the self-care practice of patients with type 2 diabetes in Malaysia	Patients with type 2 diabetes	In-depth semi-structured interviews with patients with type 2 diabetes.
To explore self-care support for patients with type 2 diabetes in primary and secondary care in Malaysia	Patients with type 2 diabetes	In-depth semi-structured interviews with patients with type 2 diabetes.
	HCPs	In-depth semi-structured interviews with HCPs involved in self-care support provision within the case study sites. Analysis of documents related to self-care support provision.
To explore the nature of patient-provider interaction during self-care support provision	Clinical consultation session	Participant observation during clinical consultation sessions between patients and HCPs.
To explore the extent to which self-care support for patients with type 2 diabetes in Malaysia is emphasised in the Malaysian healthcare system	Government policy	Analysis of documents relevant to self-care support provision.
	Clinical practice guidelines	
	Clinics' management documents	

5.3 Process of gaining access

Because this study is qualitative and proposes to investigate the perceptions of patients and the actual practices of HCPs, the process of gaining access to the case sites was one of the researcher's main concerns. It was anticipated that this study may reveal dissatisfaction of the key stakeholders and shortcomings related to practices; this may have generated reluctance to allow the researcher access to patients and staff in the clinics (Laurila, 1997; Okumus, 2007). Furthermore, the researcher would be regarded as an outsider to the study setting because the researcher did not have prior experience working in government healthcare settings (Laurila, 1997). As such, the researcher anticipated difficulties in accessing the case study sites. Therefore, to increase the chances of gaining access to the research participants, the researcher

looked for information related to the management process of the respective clinics, and contacted nurse colleagues who worked in the clinics in order to get a clearer picture of the clinic environments. The process used to gain access to the participants in this study is described below.

The process began by contacting the Ministry of Health, the director of the hospital (for case study site 1 and 2), and the director of public health (for case study site 3), who were identified as the main ‘gatekeepers’. Upon agreement from the directors, an invitation letter (appendix 5) that provided a brief explanation about the study was sent to the heads of departments and the heads of the respective clinics. The respective heads of departments and heads of the clinic were requested to complete a reply form stating their agreement for the study to be conducted in their clinics. In order to increase the chances of being granted access, the researcher met with each respective department head to provide a detailed explanation of the study. In addition, the meetings with the heads of department served to reassure them that the researcher wanted to observe the routine practices in the clinic, without interrupting any activities, and to provide evidence-based suggestions to improve practice. The researcher also offered to provide a final report of the study, in order to provide an added incentive for being granted access to the case study sites (Buchanan et al., 1988; Okumus, 2007). Each of the clinics approached provided their agreement to participate in the study.

The process of recruiting participants commenced upon receipt of approval and agreement from the Government of Malaysia (Appendix 7) Ministry of Health (Appendix 8), the directors of the hospital and of public health, the heads of departments, and the heads of the clinics.

5.4 Sampling and recruitment of participants

As this study employed a single case study design with multiple units of analysis, the sampling procedure in this study focused on the selection of candidates that would represent the unit of analysis under study. As per the qualitative methodology, this study uses non-probability sampling, where individuals are deliberately selected based on their attributes and characteristics to reflect the sample population (Ritchie & Lewis, 2003). Several sampling methods fall under the heading of non-probability sampling and are frequently used in conducting qualitative research. These include criteria based or purposive sampling, theoretical sampling, snowball sampling, and convenience sampling (Marshall, 1996; Higginbottom, 2004). Whilst all four types of sampling method were considered, purposive and snowball sampling were selected as the most suitable recruitment methods in this study.

Purposive sampling entails samples that are assumed to be able to answer the research questions being actively selected based on pre-specified criteria (Marshall, 1996). The sampling plan in purposive sampling is developed practically based on the study objectives, research questions, and study purpose (Curtis et al., 2000). It is decided prior to starting fieldwork. Participants are selected based on particular features or characteristics, such as gender, status or role in an organisation or their experience of the phenomena being studied, which enables detailed exploration and understanding of the phenomena (Ritchie & Spencer, 2002). Purposive sampling is suitable here as it is pragmatically driven based on the study objectives and the research questions (Miles & Huberman, 1994; Curtis et al., 2000).

There is a lack of a clear guidelines on how to conduct purposive sampling, which has led to a certain degree of confusion among qualitative researchers (Coyne, 1997). Patton (1990) described purposive sampling broadly, suggesting that all types of sampling in qualitative research is purposive; this introduced further confusion among qualitative researchers, and led to debates about the difference between purposive and theoretical sampling in qualitative research (Coyne, 1997; Higginbottom, 2004).

Nevertheless, it could be argued that the sampling plan should be clearly based on what the research wants to achieve (whether it aims for theory development or to find solutions for clinical problems). As mentioned in chapter three, the aim for this study is to provide an explanation for a clinical problem and suggest possible solutions based on the available evidence. Therefore, it is clear that purposive sampling is the most suitable method to be employed in this study. Furthermore, Curtis et al. (2000) suggested that sampling in qualitative research shares several common key features: (1) method of sampling is not based on statistical probability, (2) samples are small and intensively studied, which generates large amounts of data, (3) samples are not usually wholly pre-specified, and (4) the sampling plan is conceptually driven either by a theoretical framework or research questions (Curtis et al., 2000). As this study employs purposive sampling, these features have been considered in developing the sampling plan for this study.

Snowball sampling is another sampling method that was employed in recruiting participants in this study. Snowball sampling is described as a sampling technique that utilises the participants as the referral source (Streeton et al., 2004). In conducting snowball sampling, potential participants are recognised through recommendation of participants of others they know who may be eligible (Luborsky & Rubinstein, 1995). Snowball sampling is used frequently in studies that require sampling of hidden or hard to reach populations, as described by Faugier & Sargeant (1997) in studying prostitutes, HIV, and drug misuse. In this study, snowball sampling was utilised to identify the potential HCPs who could not be identified through purposive sampling (Faugier & Sargeant, 1997).

5.4.1 Sampling and recruitment of HCPs

Two groups of HCPs were identified at the case study sites. These were clinic managers or nurse managers, heads of department, or specialists in charge who could provide information about diabetes management provision in the clinic and contextual information about self-care support provision within the Malaysian healthcare system.

Other HCPs were doctors, nurses, dieticians, and pharmacists who were directly or indirectly involved in the management of type 2 diabetes at the case study sites. It was anticipated that these individuals would have knowledge and experience that would inform the research questions, reflect on the situation, provide any interesting incidents or anecdotes and would be willing to participate (Morse, 1994). It was also expected that including HCPs from various professional backgrounds and roles would enhance the richness of the data (Higginbottom, 2004).

Inclusion and exclusion criteria

The inclusion criteria and exclusion criteria of the HCPs recruited were as follows:

Inclusion criteria

- Physicians, Medical Officers, Nurse Managers, Diabetes Educators, Nurses, Medical Assistants, Dieticians, Nutritionists, and Pharmacists involved directly or indirectly in the provision of diabetes management in the case study sites.

Exclusion criteria

- The HCPs who worked in the participating clinics (the case study sites) but were not involved in the provision of diabetes management.

Eligible HCPs were identified through several visits to the clinics, or by reviewing the clinics' organisational charts. Additionally, the HCPs were identified through the snowballing method, whereby the names of eligible HCPs were suggested by other HCPs, particularly those in more senior positions. The introducer helped by introducing the researcher to the respective HCPs and helped the researcher to develop rapport and trust with them, which increased their willingness to participate (Streeton et al., 2004).

The process of HCP recruitment started by conducting informal meetings with them at each of the case study sites. The purpose of the meeting was to introduce the study and explain the process of data collection, and what might be required from them if they were willing to participate in the study. As the HCPs were expected to be involved in individual interviews and participant observations, they were recruited simultaneously to both of these data collection activities. The method of HCP recruitment is detailed in sections 5.4.3.1 and 5.4.4.1. The process of recruitment of HCPs was summarised in Figure 5.1.

5.4.2 Sampling and recruitment of patients with type 2 diabetes

The process used to recruit patients with type 2 diabetes into this study was discussed with the HCPs who had direct contact with them, including nurses, diabetes educators and clinic administrators. The purpose of this discussion was to gain HCPs' cooperation in identifying potential patients who could provide rich information pertinent to the research questions. The aspects discussed included: routine activities of the clinics, number of patients with type 2 diabetes who attended the clinics, inclusion and exclusion criteria of the patients to be recruited, and the best way to approach these patients. During the meeting, the invited HCPs actively engaged in the discussion and showed their interest and readiness to cooperate in recruiting patients to the study. Additionally, with permission from the heads of departments and doctors in charge of the clinics, posters (Appendix 12) advertising the study were placed on the main notice boards in the clinics.

The recruitment of patients with type 2 diabetes to this study began by identifying the number of patients who attend the clinics. With help from the clinics' administrators and diabetes educators, patients' information, including their names, addresses, and diagnoses, was gathered. The patients were selected from the clinics' databases based on the inclusion and exclusion criteria listed below.

Inclusion and exclusion criteria

The inclusion and exclusion criteria of the patients recruited were as follows.

Inclusion criteria

- Diagnosed with type 2 diabetes.
- ≥ 18 years of age.
- Able to understand and communicate in Malay, English, or both.

Exclusion criteria

- Diagnosed with a mental illness or confirmed by a physician to have depression.

Patients were invited to participate in this study if they have been diagnosed with type 2 diabetes, regardless of when they were diagnosed, because self-care is an important aspect of diabetes management at every stage of the condition (Funnell & Anderson, 2008). Furthermore, this study aimed to explore self-care issues in adults with type 2 diabetes; therefore, the patients could only be recruited if they were aged 18 years or older. In addition, as the interviews and observations in this study were conducted by the researcher alone, who is only able to communicate in Malay and English, the patients were only recruited if they are able to understand and communicate in Malay, English, or both.

Patients with type 2 diabetes were excluded from this study if they had been diagnosed with mental illness or confirmed to have depression. This is because the study may have led the patients to self-disclose their life experience in dealing with diabetes. Therefore, patients might reflect on unpleasant feelings or incidents during the interviews, which could worsen any depression or mental illness. However, patients who might have mild to moderate depression but had not been confirmed as such by a physician were included in the study, since mild to moderate depression is common in diabetes patients due to factors including an increase in glucose level, fatigue, and changes in sleeping patterns (Rubin & Peyrot, 2001).

In recruiting patients with type 2 diabetes to this study, two types of recruitment methods were employed. Initially, the clinic administrators and diabetes educators gathered patients' information from the clinics' databases. The administrators posted recruitment packets containing the invitation letter (Appendix 13), participant information sheets (Appendix 14), and reply slip (Appendix 15) to the eligible patients' addresses. Alternatively, the recruitment packets were passed to the nurses and diabetes educators who had contact with patients with type 2 diabetes in the clinics. These nurses and diabetes educators were asked to identify suitable patients based on their features and characteristics, and also the inclusion and exclusion criteria, and to recruit them to the study by distributing recruitment packets to them. As the study used interviews and observations as data collection methods, patients with type 2 diabetes were invited to participate in both data collection procedures. The patients could choose to participate in both the interviews and observations, or either one of the activities.

The purpose of employing two recruitment methods was to increase access to patients with type 2 diabetes in the study setting, as two clinics did not keep patients' addresses in their databases. Furthermore, patients' responses to the postal invitations have been recorded as low in a previous study (Asch, Jedrzejewski, & Christakis, 1997). Therefore, it was anticipated that face-to-face patient recruitment by HCPs whom they know and are used to communicating with would increase the response rate. This recruitment method was successfully used by Kirk, Glendinning, & Callery (2005) in recruiting participants to their grounded theory study. A summary of the recruitment process is presented in Figure 5.2.

5.4.3 Recruitment for interviews

5.4.3.1 Recruitment of HCPs for the interviews

Once the eligible HCPs were identified, a recruitment packet containing an invitation letter (Appendix 9), participants' information sheets and a response slip (Appendix 10) were distributed to the eligible HCPs selected by the nurse managers. The HCPs were provided with the researcher's phone number and advised to contact the researcher if they needed further explanation or clarifications about the study. The HCPs were instructed to return the reply slip or to inform the researcher via phone if they agreed to participate in the study. Invited HCPs who did not respond within 48 hours following distribution of the invitation letter and information sheet were followed up with a further letter of invitation. HCPs who responded positively were contacted as soon as possible to discuss the study further and to arrange a mutually convenient time and venue for the interview.

5.4.3.2 Recruitment of patients with type 2 diabetes for interviews

Recruitment packets were either posted to the patients' addresses or distributed by the HCPs in the clinics. The participant information sheets provided a brief explanation of the study, the process of data collection, how the participant would be affected if they participated in the study, and details on the confidentiality of the data provided (see appendix 14). Patients were provided with the researcher's phone number and e-mail address and instructed to contact the researcher if they required further information about the study. They were asked to return the reply slip or contact the researcher via phone or e-mail if they agreed to participate. Patients were given about 48 hours to decide whether to participate. Invited patients who did not provide any response within 48 hours after distribution of the recruitment packets were followed up with a further letter of invitation. The diabetes educators also followed up the invitations by calling the patients via phone. Patients who responded positively and agreed to participate in the interviews were contacted by the researcher via phone to agree on a date, time, and venue for the interview.

5.4.4 Recruitment for observations

5.4.4.1 Recruitment of HCPs to the observations

Observational activities in this study involved formal observation of clinic consultations and informal observation of the environment within the clinics, such as routine activities and the culture and interaction of people in the clinic, in order to obtain an understanding of the context of the study setting (Yin, 2009). Therefore, agreement from the HCPs had to be obtained before the observation could be carried out. The observation procedure was thoroughly discussed with the heads of departments and heads of the clinics. The purpose of this discussion was to get 'blanket approval' from the HCPs before the observation was carried out. The heads of departments, heads of the clinics, and nurse managers were provided with an explanation on the observation method that would be used, and the role of the researcher as a participant observer in the study settings. In addition, the heads of departments and heads of the clinics were informed about the nature of the data collected during the process of observation, which was limited to the researcher's field notes and did not involve any video or audio recordings. Following this explanation, the heads of departments and heads of the clinics provided their written informed consent, and allowed the observation to be carried out.

HCPs who were involved in consulting patients on the management of type 2 diabetes were eligible to be recruited in the observations. The observation procedure was explained to those HCPs who agreed to participate in the observation; this included the purpose of the observation, when the observation would be carried out, and how the observation would be conducted as detailed in the participant information sheets (Appendix 10). As observations of clinic consultations involved both HCPs and patients, the observations were only carried out upon mutual agreement from both parties.

5.4.4.2 Recruitment of patients with type 2 diabetes to observations

The packets distributed to the patients (as explained in the previous section) contained information that explained the observation procedure to be used in this study. If the patients agreed to participate in the observation, they were asked to provide their nearest follow-up date, and the observations were carried out on that date upon mutual agreement with the HCPs involved in the consultation. Once agreement for the observation had been obtained from the patients, they were contacted and an appointment was made to meet them at the clinics on their follow-up date. During the meeting, the observation procedure was further explained, and informed consent was sought. Patients were given an opportunity to ask questions pertaining to the study prior to the observation to ensure they fully understood what was required of them.

Figure 5.1 Flow chart of recruitment of HCPs

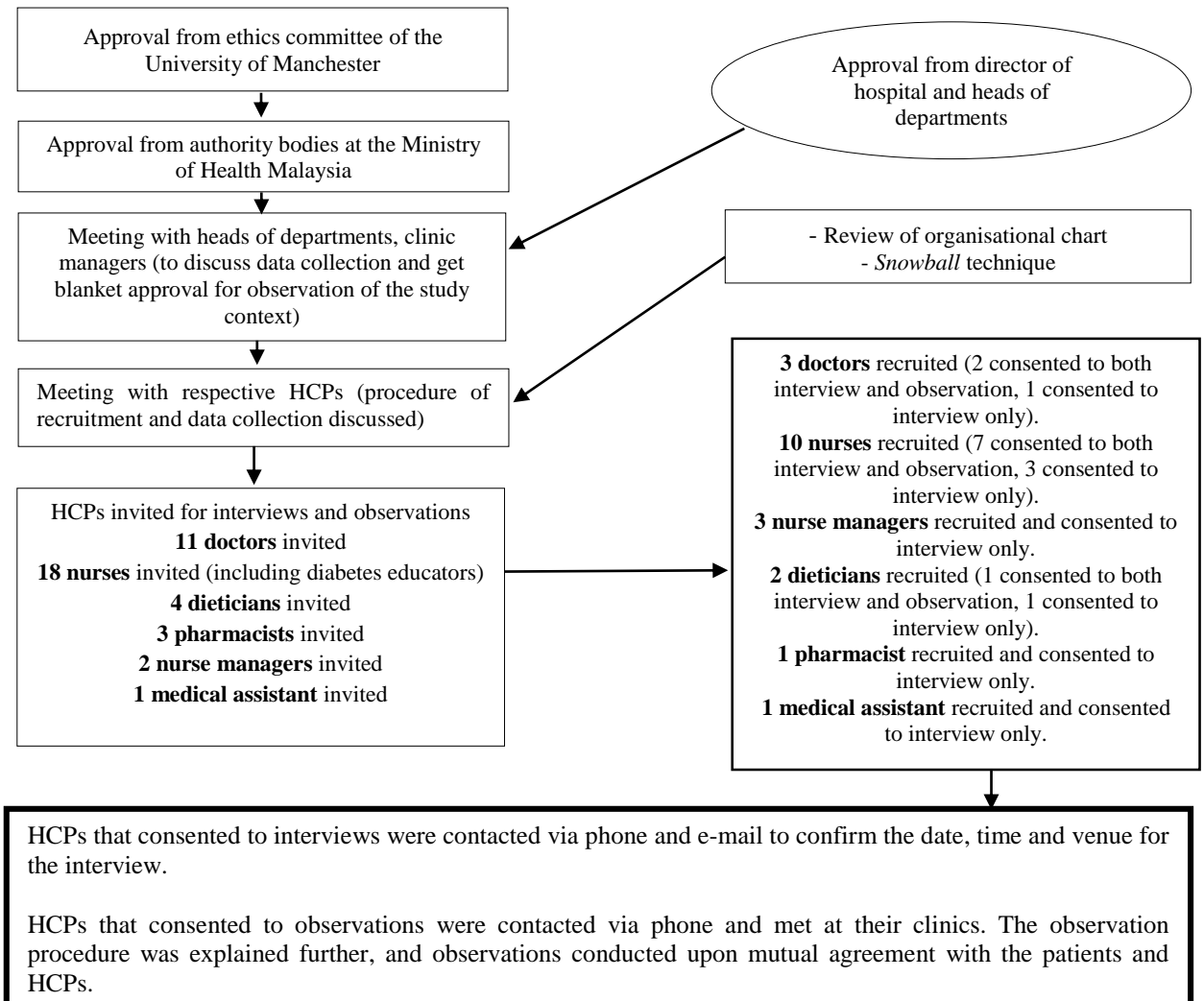
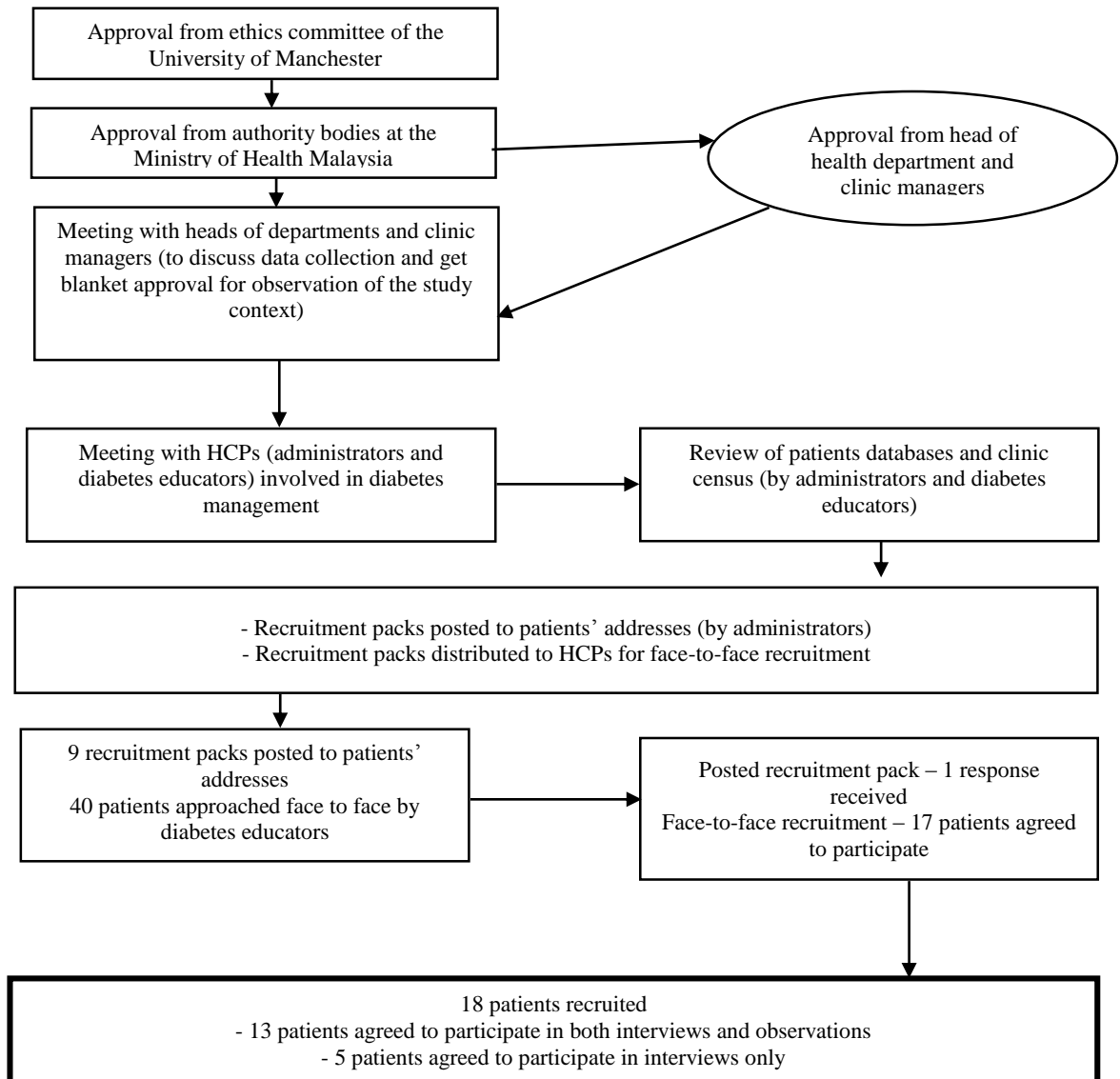


Figure 5.2 Flow chart outlining the recruitment of patients



5.5 Data collection process

The data collection process in this study involved individual, in-depth, semi-structured interviews with HCPs, individual, in-depth, semi-structured interviews with patients with type 2 diabetes, participant observation of the clinic consultations, and analysis of relevant documents pertinent to diabetes management. It was anticipated that collecting data from multiple resources would provide information from several perspectives and enable a holistic understanding of the case being studied (Yin, 2009). Each data collection activity conducted in this study is explained in detail below.

5.5.1 Interviews

5.5.1.1 Consideration of interview method

Interviews are regarded as the most important source of case study information (Yin, 2009). Therefore, in selecting the best interview method for this study, consideration has been given to focus group interviews and individual interviews.

Focus groups are in-depth group interviews involving participants who are purposively selected (Rabiee, 2004). The main feature of focus groups is synergistic interaction between the participants in the group to generate data and insights (Ritchie & Spencer, 2003). Employing the focus group approach for patients with type 2 diabetes in this study, for instance, would generate a range of ideas and feelings that the participants have about managing diabetes, and would illuminate different perspectives on self-care and support that they receive in helping them to manage their condition (Rabiee, 2004). However, focus group discussions were rejected because the aim of the study was to understand individual patients' practices with respect to self-care, and what they perceived as influencing their engagement with self-care. Focus group methods restrict the researcher's ability to understand the in-depth experience, perceptions, or thoughts that each patient has about managing their type 2 diabetes.

Focus groups with HCPs were also considered. However, this method was not deemed suitable either, as the aim of recruiting HCPs was undertaken to understand their practice in supporting the self-care of patients with type 2 diabetes. Placing HCPs together in one group could lead to the focus group discussion being dominated by the HCPs who have higher management roles in the clinic, such as doctors and managers. Other HCPs, such as nurses, may be reluctant to actively participate in the discussion and reluctant to express their feelings about their current practices. Therefore, focus group discussions were not seen as a suitable method for collecting data from HCPs in this study.

Considering the above, it was decided that individual interviews would be the main data collection method in this study. Interviews in qualitative research are often described as a form of conversation that constructs knowledge through normal human interaction (Ritchie & Spencer, 2003). Interviews are defined by their flexibility and open-ended approach, and ability to focus on individual experiences (Berg & Lune, 2011). Interviews provide situations in which the participant's descriptions can be explored, illuminated, and gently probed (Kvale, 1996). They can be either in-depth, unstructured, or semi-structured, and it has been argued that all types should strive to achieve a proper balance between structure and flexibility to meet the research aims (Sorrel & Redmond, 1996). Ritchie & Spencer (2003) suggested that qualitative interviews need to have a certain degree of structure, although they should be participant-directed.

In-depth interviews with a semi-structured approach were selected as the most suitable interview method for this study. In-depth semi-structured interviews allow for flexibility in seeking descriptions (Charmaz, 2006) and an in-depth exploration of the issues while maintaining a specific focus by using an interview topic guide that is developed prior to the interview, and is based on the research questions and study propositions (Sorrel & Redmond, 1996). The interview topic guide used in this study and the conduct of interviews are further explained in the following sections.

5.5.1.2 The interview topic guide

The semi-structured nature of the interviews helped the researcher to create an informal environment, as they were conducted in a conversational manner that creates opportunities for the researcher to develop rapport with the participants (Gaskell, 2000). In order to maintain the focus of the interviews with the patients and HCPs, two sets of interview topic guides were developed (i.e., one for the patient interviews and one for those with the HCPs – see appendix 17 and 18). The interview topic guide is not a list of specific questions, but rather consists of suggested topic areas that need to be explored in relation to the issue being studied (Arthur & Nazroo, 2003). The guide was developed from an extensive review of the literature, the researcher's knowledge and experience of the research field and the study context, and discussions with the researcher's academic supervisors in order to achieve the aims and objectives of the study (Gaskell, 2000). Although the topic guide was structured, the conversational style of the interviews provided flexibility to the researcher to ask follow-up or probing questions based on the participants' responses to the questions constructed from the topic guide (Turner, 2010).

The interviews with patients were mainly based on four topic areas:

- Patients' acceptance of the diagnosis, and experience with diabetes and its treatment.
- The way patients manage their diabetes and how they integrate self-care components into their daily routine.
- The factors that influence their engagement in self-care and the barriers that restrict them from practicing self-care.
- Their experience with support received from the healthcare organisation to help them self-manage their diabetes.

The interviews with the HCPs were also focused on several topic areas, including:

- Their experience managing patients with type 2 diabetes.
- Their current practice or approach with respect to supporting patients with type 2 diabetes.

- Their perception of their role in managing patients with type 2 diabetes and their satisfaction with their role and practice.

The nurse managers were also asked questions related to aspects of management, including:

- Management of the clinics and emphasis on self-care in diabetes management provision.
- Involvement of the Ministry of Health in diabetes management (policies/guidelines available, budget allocation, other resources).

Subtopics and questions were further developed to explore the main topic areas in detail (see appendix 17 and 18). The topic guide was dynamically changed based on the issues raised during the interviews, and the topic guide was modified for subsequent interviews (Gaskell, 2000; Arthur & Nazroo, 2003).

5.5.1.3 Conduct of interviews

The interviews with HCPs and patients were conducted concurrently throughout the data collection period based on the preferences and convenience of the participants.

5.5.1.3.1 Interviews with HCPs

The HCPs interviews aimed to provide understanding of their experience in managing patients with type 2 diabetes, and the support that they provide to this group of patients in helping them to self-manage their diabetes. Upon mutual agreement of the date, time and venue of the interview, the HCPs were met at their chosen location. All interviews with HCPs in this study were conducted in the clinics either during their lunch hour or after their clinic hours. The average duration of the interviews with the HCPs was between one and two hours. With permission from the participants, all of the interviews were audio recorded. Detailed field notes were made immediately after the interviews to capture the environment during the interviews, non-verbal behaviour and the researcher's thoughts during the interviews. This information was used to revise the interview topic guide (section 5.5.1.2) for future interviews with the HCPs.

5.5.1.3.2 Interviews with the patients

The interviews with patients provided understanding of their experiences as type 2 diabetes patients, their self-care practices, and how they integrated self-care in to their daily lives.

Most of the interviews with patients were conducted at the clinics, and two were conducted in the cafeteria, as preferred by the patients. Each interview with patients took roughly a half an hour to one hour. Initially, the interviews with patients were intended to be carried out in their homes, as the situation would be more natural for them. However, all of the patients who participated in the study preferred the interviews to be conducted in the clinic. Strumpf et al. (2001) and Suh, Kagan and Strumpf (2009) encountered a similar situation in conducting interviews with Asian participants. All of these authors have remarked that Asian people prefer to seclude their lives and find it hard to reveal their actual life situation, personal beliefs, and thoughts to strangers. This is one possible explanation that can be applied to this study. Suh et al. (2009) suggested that this situation can be overcome by becoming an insider with the participants; that is, someone who understands their cultural background and life situation. Therefore, although the researcher did not have the opportunity to visit the participants' houses and conduct the interviews in their natural environments, the researcher felt able to understand patients' life situations and feelings, as the researcher comes from the same country and shares a similar cultural background and belief system with the participants. Furthermore, having a mother and sister with type 2 diabetes put the researcher in a similar situation as that experienced by the participants. Therefore, it was expected that the research participants might hold similar views and beliefs to those of the researcher, and this helped in understanding and interpreting the interview data (Suh et al., 2009). However, reflexive accounts of the researcher's thoughts and experience on type 2 diabetes were kept throughout the data collection process to assess their potential impact on data interpretation and analysis. The reflexive account that recorded the researcher's thoughts and insights during the interviews are explained further in section 5.11. With

permission from the participants, all of the interviews were audio recorded, and detailed field notes were made after the interviews.

5.5.1.4 Transcribing interview data

Data transcription is an important stage in qualitative research, particularly when conducted using the interview method. Data transcription is frequently regarded as a technical task that does not involve extensive cognitive functions (Kumar, Little, & Britten, 2003); however, Bailey (2008) argued that the process of transcription requires reduction, interpretation, and representation to ensure the text produced is readable and meaningful. Therefore, it is assumed that data transcription is not an easy task, and requires full attention and concentration to understand the conversation and reflect on the situation and non-verbal responses.

The process of transcribing the interview data was conducted by the researcher herself to ensure that the interviews were accurately interpreted, and that the data transcribed were as intended by the participants. Each of the interviews was transcribed verbatim. The participants' anonymity and confidentiality were maintained at this stage by removing their names and anything that could reveal their identities. All of the transcripts were given unique codes and numbers.

Most of the interviews were conducted in the Malay language. However, for the purpose of discussion with the supervisory team, and to facilitate the analysis process, the interviews were translated into English. The researcher was aware of the biases that can potentially be introduced during the process of translation (Edwards, 1998). Therefore, the researcher considered hiring a translator to ensure that the translation was accurate, and hence increase its validity (Harrington & Turner, 2001). However, Temple and Young (2004) have argued that the language used by the research participants commonly carries expressions of feelings, thoughts, assumptions, and values that may not be able to be captured by someone who has just read the text without being present in the research field. Furthermore, by completing the translation

herself, the researcher became more familiar with the research problem and the situations that arose during the fieldwork, which was very helpful in the process of data analysis and interpretation (Temple & Young, 2004). To ensure that the translation was as accurate as possible, the researcher transcribed the complete interviews in Malay and translated the transcribed text into English. To ensure the translation was as accurate as possible, seven translated transcriptions of early interviews were discussed with the researcher's supervisory team, who are native English speakers. There were several phrases that could not be directly translated into English. For example, the word '*garang*' could be translated as 'fierce'; however, it did not fit the meaning as expressed by the participant. Thus, the context of the word '*garang*', and what was meant by the participants in using it, was explained to the supervisors, who suggested 'intimidating' rather than 'fierce'. During the translation process, the researcher's reflections on the situation and environment during the interview, and the insights that she had were annotated and recorded in the transcripts.

5.5.2 Observations

5.5.2.1 Consideration of observation method

Observation is also considered an important data collection method in a case study. It has been described as a method to understand people's roles, actions, and behaviour, and how these aspects alter in different situations over time (Walshe et al., 2011). In case study research, observation is commonly used to complement other data collection methods, such as interviews and documentary analysis, as it is useful in obtaining additional information about the topic being studied (Yin, 2009). Furthermore, for research conducted in healthcare organisations, Walshe et al. (2011) suggested that observation is a suitable data collection method when the study aim is to understand the structure and processes underpinning healthcare, which is one of the intended aims of this study. Utilising observation methods in this study allowed the researcher to directly perceive HCPs' interactions and reactions when they discussed diabetes management and self-care with patients. In addition, observation helped the researcher to understand the influence of the environment on the participants' body

language, facial expressions, tone of voice, and words used during the consultation; these increased the researcher's understanding of the social interactions between patients and HCPs that might influence self-care practices and self-care support provision within the study context.

Yin (2009) suggested two types of observation to be utilised in case study research: non-participant observation and participant observation. Observational activity is regarded as non-participant observation when the researcher acts solely as an observer who is completely isolated from the social setting and is not involved in any social interaction in the study setting (Gold, 1958; DeWalt & DeWalt, 2011). Alternatively, an observational activity is described as participant observation when the researcher is involved in the activities conducted in the study setting, with the aim of learning explicit and tacit aspects of the participants' routine in the study setting (DeWalt & DeWalt, 2011).

Considering both types of observation and the involvement that the researcher may have while conducting this research, participant observation has been selected as the most suitable method for this study. The aim of observation here is to understand the interaction between patients and HCPs during clinical consultations. Therefore, it was decided that in order to get a clear understanding of the context, environment, and role of each person involved in the situation, including their thoughts, feelings, and actions, the researcher needed to be part of the situation and involved in the activities, in the actual study setting. Furthermore, as the researcher did not have experience working in the study setting, and had never been involved in the management of type 2 diabetes in the case study setting, participant observation would enable the researcher to gain insider perspectives and thus better interpret the situation being observed (Bonner & Tolhurst, 2002). The extent of involvement of the researcher in the clinics' activities, and the way participant observation was conducted in this study, are explained further in the next section.

5.5.2.2 Conduct of observations

Observations were conducted during the clinic consultation session to explore how self-care is communicated.

General observation

The initial stage of observation commenced with general observation of the clinics. The researcher made routine visits to the clinics and familiarised herself with the environments and gathered contextual information. This included aspects of the layout, routine activities and the culture and interaction among HCPs whilst simultaneously conducting descriptive observation (Spradley, 1980). The visits also offered the opportunity to build rapport and long-term relationships with the HCPs and other staff members, so that any intrusion or disturbance that might happen while the observations were underway could be minimised (Holloway & Wheeler, 2010). The observational activities were guided by the observation schedule which developed prior to the fieldwork (see appendix 19). The purpose of this observation schedule is to maintain the focus of the observation and to ensure every element observed is in line with the research aims, objectives and research questions.

At the beginning of the visits, the researcher's role was restricted to that of observer, or what is regarded by DeWalt & DeWalt (2011) as a passive participant, and was not deeply involved in the clinic activities because the researcher did not have experience of working in those clinics. At this stage, the researcher regarded herself as an outsider, with several preconceived ideas about the environment and the situation at the case study sites (as explained in section 5.9 – reflexivity). In the early stages of data collection, most of the HCPs seemed uncomfortable with having the researcher around, as they were not keen to talk to the researcher and seemed reluctant to answer some of her questions. However, after spending a few weeks at the clinics, the researcher's presence at the case study sites was slowly accepted, and her role moved towards that of participant (Walshe et al., 2011), wherein the nurses at the case study sites included the researcher in their team and allowed her to take part in their routine activities. However, participation was limited to calling the patients' names and

sitting down with them in the consultation room, without involving any clinical activities. This was to ensure that participation at the case study sites would not be intrusive or interfere in any clinical activities (Walshe et al., 2011). Observation of the clinic consultations was only conducted once the researcher had been accepted as part of the team.

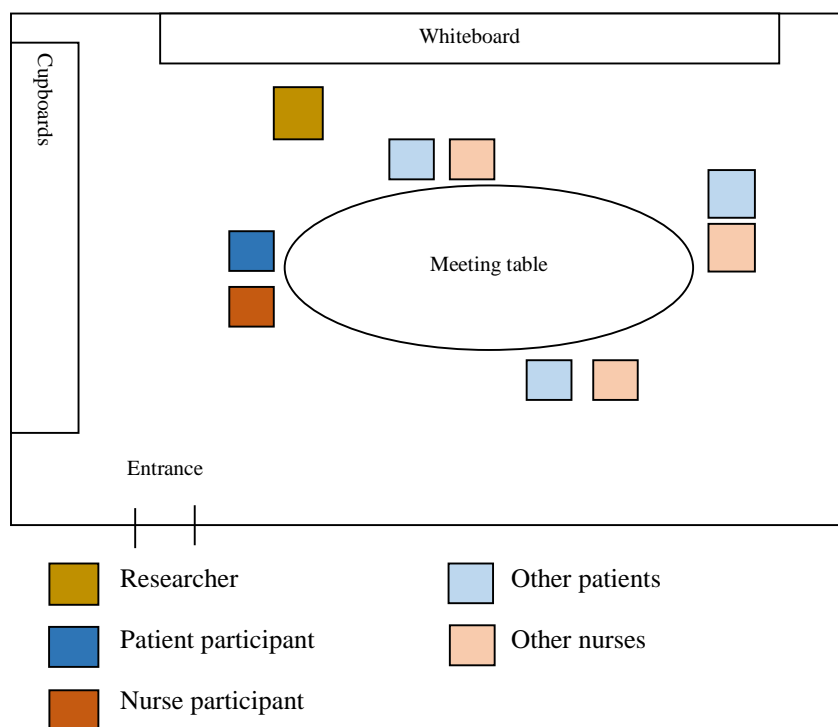
Specific observation of clinical consultation session

Observations of the clinic consultations were conducted upon mutual agreement from the patients and the HCPs involved in the consultations during the period of data collection. Aspects observed during the consultation included: communication between the patients and HCPs regarding how self-care is explained, encouraged, and supported, as well as the patients' reaction to this issue. In addition, the researcher observed the patients' verbal and non-verbal responses, including physical interactions, facial expressions and body language (Appendix 19). By collecting this information, the patients' understanding of self-care practices could be understood. In addition, the way the aspect of self-care was communicated during the diabetic consultation could be explored.

Prior to the start of the observations, consenting HCPs were informed of the patients' participation in the observational activity, and the process of observation was explained to them. The researcher also met the respective patients outside the consultation room to explain the observation procedure and obtain written informed consent. The researcher introduced herself as a researcher to the patient and explained her role as an observer during the consultation session. The patient was called by the researcher to the consultation room and seated in front of the HCP. The researcher sat in the corner of the room, not too near to the research participants, in order to avoid distracting them or interfering in the consultation activity. However, there were some occasions when the researcher needed to sit a bit closer to the participants, as the consultation room was quite small and cramped. It was anticipated that this situation could increase the possibility of intrusion in the observation, where the participants

may have been unable to act naturally with the researcher so close to them (DeWalt & DeWalt, 2011). The researcher tried to minimise this by avoiding direct eye contact with the participants. The researcher also acted as one of the staff in the room by helping the nurse to pass files or equipment. The position of the researcher in conducting observations has been frequently discussed in the literature, and the researcher's influence on the observed environment has also been pointed out (Walshe et al., 2011). However, Walshe et al. (2011) observed that while this situation is unavoidable, it needs to be considered when recording the field notes and in the process of data analysis. Figure 5.3 shows the layout of one of the consultation rooms used in the observation.

Figure 5.3 Layout of one of the observed consultation rooms



Each of the observations took about a half an hour to one hour, depending on the length of the consultation session. With agreement from the participants, the researcher carried out informal interviews or social conversations with them and the HCPs as part of the observations in order to more deeply explore their communication and reactions during the consultations, and these were recorded in the field notes (DeWalt & DeWalt, 2011). In addition, data from the observation, including contextual information, activities during the consultation (the conversation, issues that

rose, interaction, responses, and expressions), and participants' responses after the consultation, along with the researcher's reflexivity account, were recorded in the structured field notes (see appendix 20). At the completion of each observation activities, the field notes were discussed with the participants to clarify the information that been recorded. This discussion had helped in providing further understanding of the situation and the process of data interpretation.

5.5.3 Analysis of documents

Document analysis is another meaningful and appropriate research approach in social research (Mason, 2002), and is utilised in this study. Mason (2002) suggested that analysing information obtained from relevant documents will help the researcher to gain a broader perspective of the issue being studied. She also suggested that this data collection method can be used in conjunction with other methods, such as interviews and observations (Mason, 2002). Additionally, Yin (2009) proposed that documentary analysis can be used in case study research as a method of corroborating and augmenting evidence from other resources. Therefore, employing document analysis in this study enabled the researcher to extend understanding of self-care issues in Malaysia, not only from the perspectives of patients and HCPs, but also those of management within the healthcare system, in which practice commonly takes place. Document analysis in this study involved reviews of documents including health policies, clinical practice guidelines (CPG), clinics' workflow, the country's strategic plan in managing diabetes, and related websites and material used in supporting the self-care of patients with type 2 diabetes. These analyses enabled the researcher to explore evidence that may not have emerged through interviews and observations.

Documents used in supporting patients with type 2 diabetes were gathered from the case study sites, including CPG, standard operating procedures, pamphlets, and samples of patients' glucose record books (blank). Additionally, relevant information from the Ministry of Health website, including policy documents, transcripts of ministers' speeches, annual reports, and information available on the Malaysian

Diabetic Association’s websites were included and analysed. All of these documents were identified as useful in enhancing understanding of self-care issues in Malaysia.

In determining the quality and integrity of the documents included in the analysis, Scott’s (1990) criteria for evaluating the quality of documents were employed. Scott (1990) outlined four criteria for assessing the quality of documents, as summarised in Table 5.2.

Table 5.2 Criteria for assessing quality of documentary evidence (Scott, 1990)

Quality criteria	Questions to ask
Authenticity	Are the documents genuine and of unquestionable origin?
Credibility	Are the documents free from error and distortion?
Representativeness	Are the documents typical of their kind, and, if not, is the extent of their un-typicality known?
Meaning	Are the documents clear and comprehensible?

Most of the documents included in the study were gathered from the case study sites, except for information from the websites. The origin of the documents, such as CPG, standard operating procedures, pamphlets, and patients’ record books, was identified by the nurse managers, who claimed that all documents were developed by the Ministry of Health and are widely used by hospitals and primary-care clinics in Malaysia. In addition, the documents go through yearly reviews by the Ministry of Health, and this ensures that they are up to date. This information confirmed the *authenticity*, *credibility*, and *representativeness* of the documents. As the documents are widely used by HCPs of various professional backgrounds and roles, it could be assumed that they are *comprehensible*. The quality of information gathered from the websites was determined by including only trusted websites from the Malaysian Ministry of Health (www.moh.gov) and Malaysian Diabetic Association (www.diabetes.org.my). Both of these websites are owned by the Malaysian government. Visitors to the websites must register, and the content available is password protected. Both websites are protected with a security system; therefore, the

quality and trustworthiness of the information on them can be assumed to be closely maintained by the government.

In reviewing these documents, content analysis was applied, wherein the contents of the documents were examined to elucidate key patterns, themes, and categories (Marshall & Rossman, 1995; Miller & Alvarado, 2005). The process of content analysis was conducted manually by the researcher. This process began with reading the documents thoroughly and repeatedly, and highlighting words or phrases that represent information related to self-care. Thoughts and impressions that the researcher had at this time were noted alongside the existing data. During this process, the themes that emerged become the initial codes for the data. All of the documents were coded based on these themes, and additional themes that emerged during the coding process were added. Codes were then sorted into categories based on how they could be linked or clustered together (Hsieh & Shannon, 2005). The patterns identified from the group of categories generated in the document analysis were mapped and interpreted simultaneously with themes generated from the interviews and observations using the framework analysis approach; these are explained further in section 5.6.4 (analysis of observation and documentary data)

5.6 Data analysis

5.6.1 Consideration of data analysis method

In qualitative research, data analysis has been described as a process that involves making sense of raw data collected in textual forms, including interview transcripts, field notes, research diaries and memos, by sifting through and interpreting it (Pope et al., 2000). In most types of data analysis within qualitative research, the process is conducted iteratively, which means that data collected at the initial stage is analysed, and insights obtained during that stage inform the subsequent data collection process (Silverman, 2011). Several types of analytical approach can be used to analyse qualitative case study data. These include content analysis (Titscher, 2000), thematic

analysis (Braun & Clarke, 2006), and framework analysis (Ritchie & Lewis, 2003). In addition, qualitative data analysis can be conducted either inductively or deductively (Pope et al., 2000).

The method of qualitative data analysis that was considered most appropriate for analysing data in this study was framework analysis. This analysis method was developed by specialist qualitative researchers at the National Centre for Social Research (NatCen), an independent social research institute in the UK (Ritchie & Spencer, 2002; Furber, 2010). Framework analysis has been widely used as a transparent method to analyse applied social policy research (Ritchie & Spencer, 2002). In addition, it provides a tool by which researchers can demonstrate to the reader the analytical stages that contributed to the final interpretation of the research findings (Furber, 2010). Framework analysis has been argued to be similar to grounded theory analysis (Srivastava & Hopwood, 2009) as it involves iterative process; however, framework analysis starts deductively from the specific research objectives and research questions, pre-identified samples, and *a priori* issues that need to be explored (Ritchie & Lewis, 2003; Srivastava & Hopwood, 2009). Furthermore, framework analysis does not focus on generating theory, but on describing and interpreting the phenomena under investigation in the particular study setting (Ritchie & Spencer, 2002).

Framework analysis has the advantage of allowing structured, rigorous data management and analysis. Furthermore, framework analysis is a well-established method that is pragmatic; thus, it is commonly utilised in applied health research (Ritchie & Lewis, 2003). Framework analysis has also been used successfully by other case study researchers (Walshe, 2006; Woodward, 2006; Lyte et al., 2007). Framework analysis involves a matrix-based method of data display that allows for easy retrieval of data from the original data set and enables collaborative analysis (Ward et al., 2013). Therefore, framework analysis has been selected as the most suitable method for this study. Moreover, the steps of framework analysis, which include data management, and development of the descriptive account and

explanatory account have strong similarities to the process of data management and pattern matching between and within cases as recommended for case study analysis (Yin, 2009). Thus, framework analysis enhances interpretation of the case study because it allows systematic and comprehensive coverage of the data set, as well as flexibility and transparency for others, and simultaneously enhances the rigour of the study (Ritchie & Lewis, 2009).

5.6.2 Framework technique in analysing interview and observational data

The three data collection methods used in this study produced a large amount of data, which consisted of interview transcripts, observation field notes, reflective diaries and documentary data. Therefore, selecting a design that facilitated a systematic and rigorous approach to managing and analysing the data was paramount. Analysing the data using the framework approach would allow a certain degree of transparency so that readers will be able to see how the findings and interpretations were derived and developed from the data (Furber, 2010).

The framework approach involves the systematic process of sifting and sorting raw data based on the framework and key issues identified from the study proposition and topic areas covered during data collection. The analysis process then involved organising the data systematically for abstraction and interpretation. Spencer et al. (2003) clearly illustrated the hierarchy of framework analysis according to three stages of activities:

- Data management
- Descriptive accounts
- Explanatory accounts

These stages were utilised in analysing the interviews and observational data for this study. The framework technique was also used in synthesising the findings from the three sources of data in order to produce explanations of issues across a broader range and convergent lines of inquiry (Yin, 2009). The stages of framework analysis in the

context of this study are described below. Whereas, the application of framework to the data analysis, including the process of development of thematic framework, process of indexing, charting, summarising, and developing descriptive accounts are detailed in the following sections (section 5.6.3 and 5.6.4).

5.6.2.1 Data management

5.6.2.1.1 Data familiarisation and development the thematic framework

Data familiarisation took place by listening to the interview recordings, and reading the transcripts and field notes repeatedly. The interview transcripts and field notes were uploaded to the NVivo 9.0 software to facilitate data management and develop an audit trail for the process of analysis. Different folders were created in NVivo 9.0 to separate the interview data provided by patients and HCPs, as well as and the observational data. The analysis was started by approaching the interview data for the purpose of familiarisation and identification of key patterns. The same treatment was given to each type of data so that the interview transcripts and observation field notes went through the same process of analysis.

Each of the interview data sets (patients and HCPs) was initially analysed separately. The main topic areas covered during the interviews with patients (understanding of self-care, facilitators and barriers to self-care, and experience with self-care support) and HCPs (nature of self-care support, limitations to self-care support, perceptions towards patients), and findings of the literature review (the themes developed in literature review – see chapter 2) were combined, and the framework developed. During the process of familiarisation, common themes were identified and placed according to the framework previously developed. The primary topic areas were regarded as the main themes, and the concepts that emerged from the data were placed according to these main themes and identified as subthemes. Each main theme and subtheme was given an index number for the purpose of data labelling and cross-referencing with the raw data. The framework was continuously refined throughout

the process of data familiarisation and discussion with the academic supervisors until agreement on the framework was achieved.

In analysing the textual data of the observational field notes, a separate framework was developed. The data were coded based on the main aspects of observations, including environment of observed area, words/phrases used to communicate self-care, and verbal and non-verbal interactions. Common occasions or aspects expressed by the researcher in the field notes were identified as subthemes and were placed according to the main themes identified earlier.

5.6.2.1.2 Indexing or labelling data

The process of indexing refers to the application of a thematic framework to the textual data (Ritchie & Spencer, 2003). The process of data indexing was facilitated by the NVivo 9.0 software. Each interview transcript and the observation field notes were reviewed thoroughly, and segments of the text were assigned to the themes and subthemes identified, annotated, and labelled with the relevant index numbers according to the framework.

5.6.2.1.3 Sorting the data (creating a thematic chart)

After the process of indexing, the data were sorted so that data with similar properties were clustered together. This allowed the researcher to focus more on the details and unpack the distinctions that lay within the data (Ritchie & Lewis, 2003). This was done by creating a thematic chart. Details on the participants, such as their location of recruitment, age, and social role were charted in rows. Each row represented each of the participants. The main themes and subthemes were then placed in columns. Each column represented one theme/subtheme. Subsequently, the data were plotted according to the themes/subthemes to which they belonged. The entire process was completed in NVivo 9.0. An actual thematic chart created in NVivo 9.0 is presented in the appendix 22.

5.6.2.1.4 Summarising the data

The final step in data management was to summarise the data. The lines or sections of data in the transcripts and observational field notes that was indexed and annotated earlier were summarised and placed in the thematic chart. During the process of summarising, the data were interpreted; however, this interpretation was minimal. In addition, the words and language used in the summary were kept as close to the original data as possible, in order to maintain the original meaning of the data (Ritchie & Lewis, 2003). After the data had been placed onto the chart, the entire data set could be clearly visualised, which facilitated the process of mapping and interpreting data across the data sets.

5.6.2.2 Descriptive accounts

The next stage in analysing the data using the framework technique was to develop descriptive accounts (Spencer et al., 2003). This stage involved three steps: detection, categorisation, and classification.

5.6.2.2.1 Detection

Detection involved identifying the substantive content and dimensions of the data (Spencer et al., 2003). This was done by reviewing the chart. The summarised data were checked against the original data or within the themes and subthemes to increase familiarity with the data. Common themes across the data were identified and highlighted in a prominent colour to represent different presentations of the phenomena (Spencer et al., 2003). Elements and categories detected in the data were summarised separately to identify similarities and differences in each theme or subtheme.

5.6.2.2.2 Categorisation

Categorisation involved refining the categories and assigning descriptive data to them. The common themes identified earlier were developed into broader categories. At this stage, the data that initially appeared as irrelevant was revisited and checked against the categories developed (Furber, 2010). Separate categories were developed for the data previously identified as irrelevant but that clearly showed links to explaining the

phenomena. The categories developed were placed in an additional column next to the index column. The process of categorisation helped the researcher to make the data more manageable.

5.6.2.2.3 Classification

In this step, the categories were classified and grouped to a higher level of abstraction (Spencer et al., 2003). The process of classification was intended to create a logical structure of descriptive items; thus, the data became meaningful and facilitated description of the nature of the phenomena (Spencer et al., 2003).

5.6.2.3 Explanatory accounts

Explanatory accounts are the final stage of data analysis in the framework approach. The stage has been described as involving the detection of patterns, conduct of associative analysis, and identification of clusters (Spencer et al., 2003). It involves finding links or connections between two or more phenomena. This stage also includes an explanation of the phenomena developed based on the nature of the study, the emergent patterns within the data, and the researcher's own theoretical or epistemological perspectives (Spencer et al., 2003). The explanatory associations between the phenomena were brought together, and are considered in the discussion chapter.

5.6.3 Analysis of participants' interview data: application of framework

5.6.3.1 Developing the thematic framework

Overall, this study consisted of four data sets (data from interviews with patients, interviews with HCPs, observation field notes, and documents). In analysing the interviews with the patients and HCPs, thematic frameworks were developed during the process of data familiarisation. The interview topic guide informed the main themes of the frameworks, and the common themes that emerged from the data built up the subthemes, which were placed under each of the corresponding main themes. Each of the main themes and subthemes were given an index number for the purpose

of data indexing. Table 5.3 illustrates the main themes and subthemes that built the thematic framework of patient data.

Table 5.3 The thematic framework for patients' interviews

Main themes	Subthemes
1. Self-care of patients with type 2 diabetes	1.1 Understanding 1.2 Perceptions 1.3 Practices
2. Facilitators of self-care	
2.1 Internal facilitators	2.1.1 Religious beliefs 2.1.2 Positive acceptance 2.1.3 Fear of complications
2.2 External facilitators	2.2.1 Support from family 2.2.2 Experience of others 2.2.3 Social environment 2.2.4 Role in the family
3. Barriers to self-care	
3.1 Internal barriers	3.1.1 Poor physical condition 3.1.2 Lack of social acceptance 3.1.3 Poor adaptation 3.1.4 Lack of knowledge about illness
3.2 External barriers	3.2.1 Culture and routine 3.2.2 Responsibility towards family 3.2.5 Poor healthcare support

Table 5.4 shows the thematic framework developed to analyse the data from the HCP interviews.

Table 5.4 The thematic framework for the HCP interviews

Main Themes	Subthemes
1. Nature of self-care support	1.1 Physical support 1.2 Psychological support
2. Effectiveness of self-care support	
3. Limitations to supporting patients	3.1 HCP-related factors 3.2 Patient-related factors 3.3 Environmental factors 3.4 Systemic factors
4. Persepctives towards patients	

5.6.3.2 Process of indexing

During the process of data indexing, all of the transcripts were read through in more depth and sections or phrases of the data were coded with the relevant index number to represent the themes and subthemes of the framework (Tables 5.3 and 5.4). The below interview extract with a female patient participant explaining her understanding of self-care exemplifies the process of data indexing.

<p><i>'If I want to achieve good glucose levels I need to control my diet and make sure I do not eat more than I need. We can feel for ourselves what works best for us. We can't depend on other people to decide for us'</i></p>	}	<p>Indexed as 1.1 (Table 5.3)</p>
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(PT 11: female, 50 years, housewife)

This extract was coded with the index number 1.1 on the framework (Table 5.3) to represent the patient's understanding of self-care.

Another example extract from an interview with a health educator, in which she discussed her role in supporting patients with type 2 diabetes, is as follows:

‘My role is to support patients with diabetes and others by giving them knowledge about their care. How they look after themselves at home. For example, in terms of diet and lifestyle, medication, exercise and how they live their lives’

Indexed as
1.2
(Table 5.4)

(HCP 3: female)

This extract was coded with the index number 1.1 on the framework for HCPs (Table 5.4) as the extract provided information about the participants’ practice in supporting patients psychologically (providing knowledge).

There were occasions where phrases did not match any of the subthemes. When this happened, the phrases were coded as ‘others’, and a note was made on the transcript; these phrases were visited at a later stage of the analysis.

5.6.3.3 Thematic charts

After the process of indexing, framework charts were developed. One chart was developed for each main theme. Each column of the chart represented the subthemes and each row represented the participants. An example of a chart developed for the main theme ‘2.1: internal facilitators to self-care’ is illustrated in Table 5.5, and an example thematic chart can be found in the appendix 22.

Table 5.5 Thematic chart for analysis of patients’ interview data

2.1 Internal facilitators to self-care			
Participant ID	2.1.1 Religious beliefs	2.1.2 Positive acceptance	2.1.3 Fear of complications
PT 10 Male, 28 years Civil servant.	<i>Strong religious beliefs helped me to be more calm and patient in order to face the challenge. Diabetes is regarded as a test from God.</i>	<i>I have accepted and am trying to live with diabetes because there are still a lot of things to look forward to.</i>	-Nothing was mentioned-

Table 5.6 presents the thematic chart developed for the main theme ‘3. Limitations to supporting self-care’ from thematic framework for HCPs.

Table 5.6 Thematic chart for analysis of HCPs’ interview data

3. Limitations to supporting self-care				
Participant ID	3.1 HCP factors	3.2 Patient factors	3.3 Environmental factors	3.4 Systemic factors
HCP 8 Female, Nurse manager Case study site 2	<i>Nurses have high workloads and have to multi-task. We do not have time to call patients that default on follow up.</i>	<i>Most patients come to the clinic just to see the doctor and get medication. Not interested in listening to any health education talks.</i>	<i>High numbers of patients visiting the clinic at one time makes the clinic very crowded.</i>	-Nothing was mentioned-

5.6.3.4 Summary of data

Extracts from the interviews which were indexed to fit the framework were summarised and placed on the charts according to their theme and subtheme. One patient extract can be seen below:

‘Now I am still adapting to the situation. I used to be active and ate a lot. Before this, I just ate whatever I wanted without scared of anything. So, for around two weeks, it was a bit hard for me. I look it in positive way that this is a test from God. So I tried to accept it positively.’

} 2.1.1.
(Table 5.3)

(PT 10, male, 28 years).

This extract was summarised as:

Strong religious beliefs helped to be more calm and patient to face the challenge. Diabetes is regarded as a test from God.

The above data summary was placed in the chart for theme ‘2.1 internal facilitators to self-care’ under subtheme of ‘religious beliefs’ in column 2.1.1 against participant ID: PT 10 in row.

Below is an example extract from an interview with a nurse manager:

“We only have five nurses who need to handle everything related to diabetes, including counselling, assisting in clinic management, taking specimens and so on...so the workload

} 3.1
(Table 5.4)

is very high and we don't have enough time to call patients who default on their follow up."
(HCP 8, Female)

This extract was summarised as:

Nurses have high workloads and have to multi-task. Do not have time to call patients that default on follow up.

The summarised data for the nurse manager (example above) was placed in the chart for the theme 'limitations to supporting self-care' under the subtheme 'HCP factors' in column 3.1 against participant ID: HCP 8 in row.

The process of data summary and charting was conducted using NVivo 9. The summarised data placed in the chart was highlighted and matched with the actual extracts from the transcripts. The whole transcript with highlighted extracts appeared in different windows within the program when the summarised data in the chart was clicked. Thus, the researcher could link the summarised data to the actual data and was able to check the accuracy of the summarised data against the original transcripts. This formed part of the audit trail. Any phrases that were identified as not representing any of the subthemes in the framework were placed in an additional column labelled 'notes/comments'. Examples of actual thematic charts for both patients and HCPs developed in NVivo 9 can be found in appendix 22.

5.6.3.5 Developing descriptive accounts

The next step of framework analysis involves identifying common themes to develop categories. Each column of subthemes for each thematic chart was read to identify common themes. This process led to the development of more refined categories. Examples of summaries for the subtheme ‘religious beliefs’ identified from column 2.1.1 of the ‘internal facilitators to self-care’ chart are listed below:

‘I regard diabetes as a test from God. I believe that we live and die at God’s hands but need to try our best to live a better life’.

(PT 10, male, aged 28)

‘I have accepted diabetes positively as it is a test from God to his servant. I am confident that God is the best planner and he causes illness for a reason’.

(PT 16, male, aged 40)

‘I believe that diabetes is the way that God wants me to value my health and life.’

(PT 14, female, aged 56)

“God is the one who gives the illness and will give the relief. But as a human, I need to try my best to manage it.”

(PT 2, male, aged 62).

From the example above, the data charted in column 2.1.1 of ‘internal facilitators to self-care’ generated the refined category of ‘religious beliefs’.

A category entitled ‘poor job satisfaction’ was developed from the summaries of data charted in column 3.1 of ‘HCP factors’ in relation to ‘limitations to supporting self-care’. Examples of summaries of data are listed below:

“I had too much work and a lot of things to handle at the same time. Some important things may have been overlooked.”

(HCP 2, female, diabetes educator)

“The diabetes educators in the clinic have many tasks. We are unable to fully practice as diabetes educators.”

(HCP 5, female, diabetes educator)

“The scope of work is wide. I can’t really concentrate on the role of diabetes educator.”

(HCP 6, female, diabetes educator)

Both of the refined categories (as per the above examples) remained embedded within the conceptual framework under each of its main themes and subthemes. Figures 5.4 and 5.5 illustrate examples of data transition from the summarised form to the stage of categorisation for both data sets.

Figure 5.4 Transition of data from summary (thematic chart) to categorisation (patient data)

Main theme: Factors influencing self-care

Subtheme: Internal facilitators to self-care

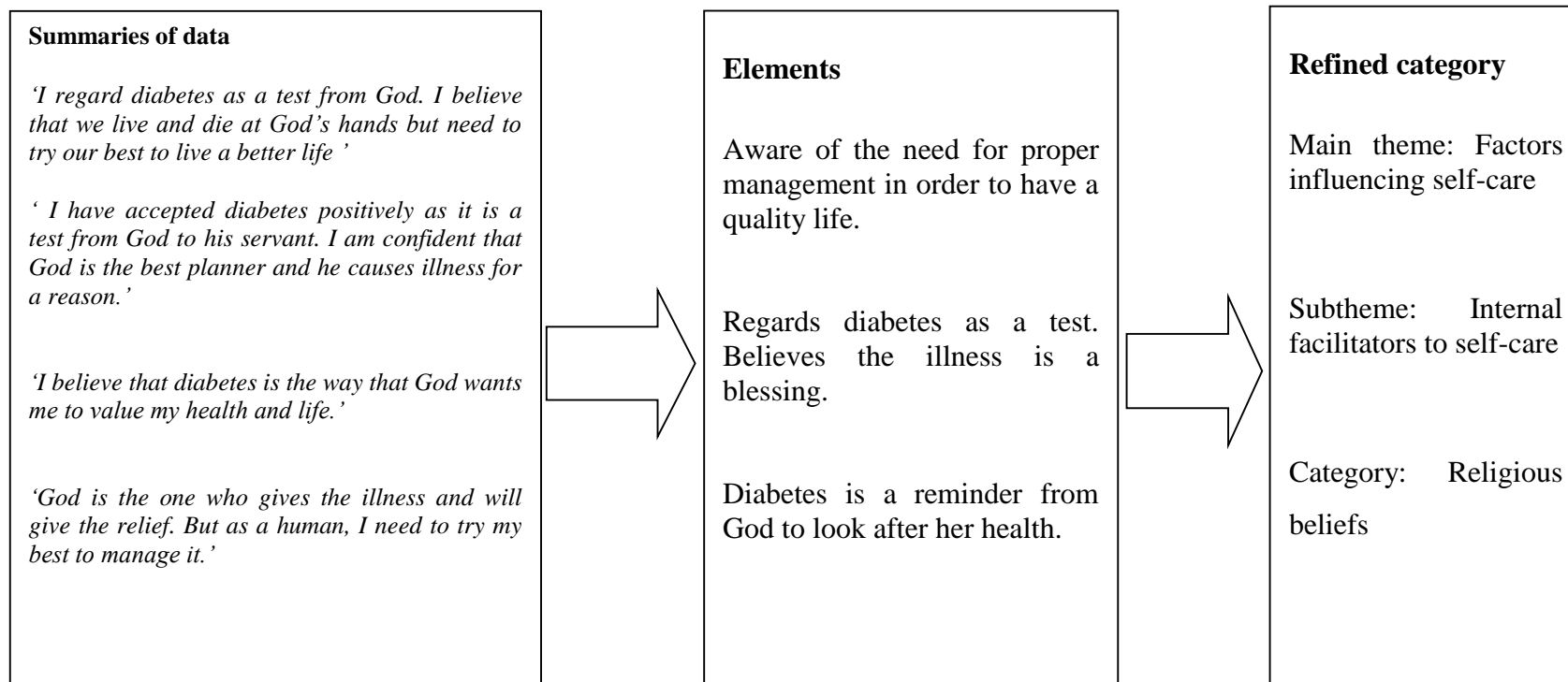
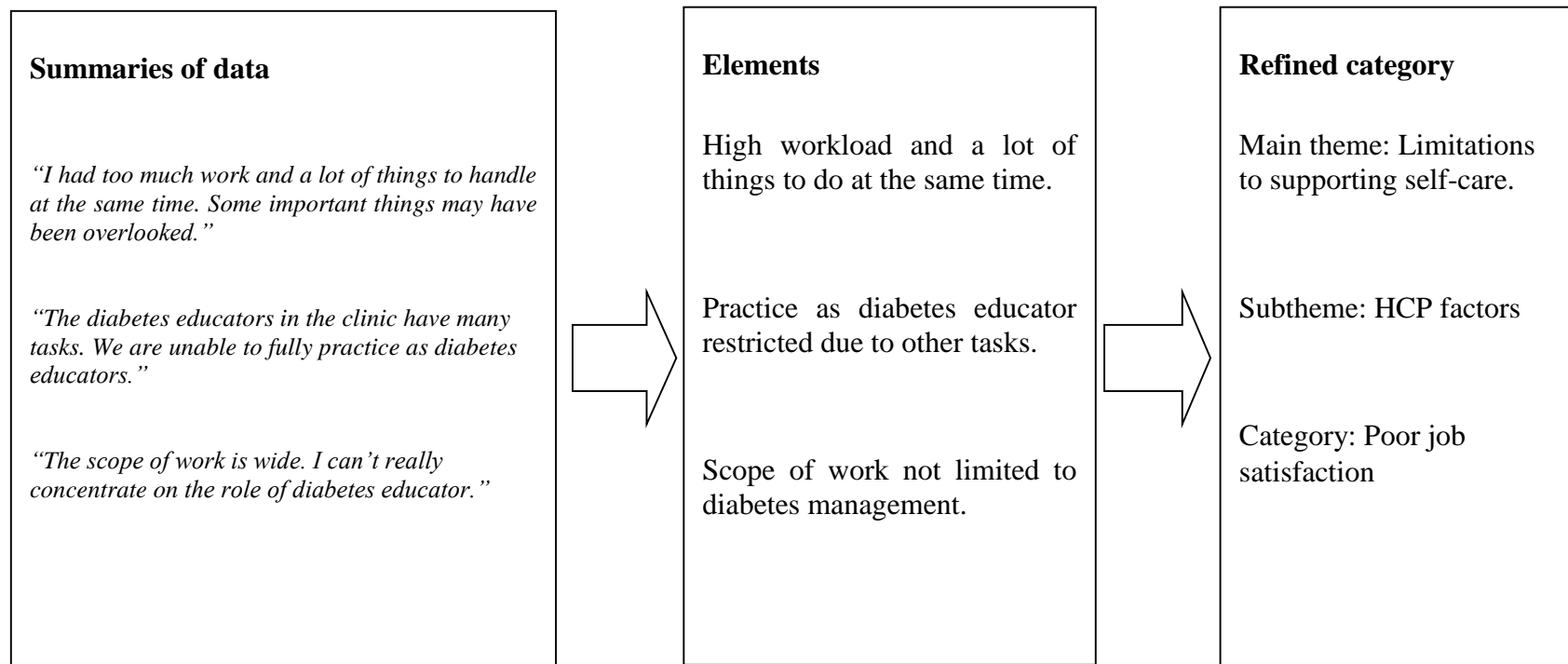


Figure 5.5 Transition of data from summary (thematic chart) to categorisation (HCP data)

Main theme: Limitations to supporting self-care

Subtheme: HCP factors



5.6.4 Analysis of observation and documentary data: application of framework

Framework analysis was also applied to analyse the observation field notes and documents. These were read repeatedly to familiarise the researcher with the data. Each of the observation field notes and documents included in the analysis were given an ID number for the purpose of identification. A thematic framework containing the main themes and subthemes relevant to the data was developed based on the research questions and study propositions. Content analysis was carried for the documentary data to identify common themes (section 5.5.3), which built subthemes relevant to analysing the documents in the framework. Table 5.7 illustrates the thematic framework used to analyse the field notes and documents.

Table 5.7 Thematic framework to analyse field notes and documents

Themes	Subthemes
Observations	
1. Contextual information	1.1 Participants' background 1.3 Venue of observations 1.4 Situation in consultation room
2. Communication of self-care information	2.1 Content of conversation 2.2 Dominance of consultation 2.3 Additional materials used
3. Reactions	3.1 Verbal reactions 3.2 Non-verbal reactions
Documents	
4. Background of documents	4.1 Author/publisher 4.2 Purpose
5. Content of documents	5.1 Focus of document 5.2 Content related to self-care

The same thematic framework was used to analyse both field notes and documents. However, the themes and subthemes were separate as data in the documents did not always fit the framework for the field notes. Each of the themes and subthemes were given an index number for the purposes of data indexing.

The steps of data indexing, charting and summarising, as carried out for the interview data in section 5.6.3, were repeated. The field notes and documents were read line by line and the data indexed to the relevant themes and subthemes. The process of indexing the observational data is visualised in the example below, which was extracted from the observation field notes of a clinical consultation between a type 2 diabetes patient, a diabetes educator and a doctor.

- 1.4 { The door has been left open. The room is quite noisy and seems to be preventing the patients from hearing anything said by the doctor. The patient looks comfortable.
- 2.1 { Mrs S shows her documentation on blood sugar monitoring to the nurse.
Nurse N asks Mrs S about her dietary intake and insulin dosage. Mrs S answers the questions calmly. Because her blood sugar has not been not properly controlled, the nurse asks
Doctor T, who is on standby in the room for his opinion, discusses the patient’s problem regarding her medication intake according to her blood glucose record and insulin dosage. Doctor T asks Mrs S about her dietary intake because Mrs S has poor blood sugar control, despite the high dose of insulin prescribed. According to the discussion, Mrs S seems to have a problem with her dietary management. Mrs S is asked about her food intake during dinner due to high blood sugar levels at night.
- 2.2 { Mrs S is asked many questions at one time.
- 3.2 { Doctor T’s facial expression is straight-faced, and he looks at Mrs S with wide eyes because Mrs S is unable to manage her diet properly.
- 2.2/
3.1 { Doctor T asks the same question several times (‘Did you follow what we told you before?’) in a loud voice, and Mrs S just keeps quiet and looks at the table.

In the example above, each of the phrases has been given an index number based on its relevance to the thematic framework (Table 5.7). For instance, the first and second sentences have been indexed as 1.4, ‘situation in consultation room’, as the data provides contextual information about the environment during the consultation. Any phrases that do not match any of the subthemes in the framework were placed in a theme named ‘other’, and revisited at a future stage of analysis.

Thematic charts were developed for each of the main themes in the framework. Subthemes listed under the main themes were placed in columns, and ID numbers for the field notes or documents were placed in rows. Prior to charting the data, the indexed phrases were interpreted and summarised. This summarised data was then placed in to the chart. The example below illustrates the process of summarising and charting the data from the field notes.

2.1 { Mrs S shows her documentation on blood sugar monitoring to the nurse.
Nurse N asks Mrs S about her dietary intake and insulin dosage. Mrs S answers the questions calmly. Because her blood sugar has not been not properly controlled, the nurse asks
Doctor T, who is on standby in the room for his opinion, discusses the patient’s problem regarding her medication intake according to her blood glucose record and insulin dosage. Doctor T asks Mrs S about her dietary intake because Mrs S has poor blood sugar control, despite the high dose of insulin prescribed. According to the discussion, Mrs S seems to have a problem with her dietary management. Mrs S is asked about her food intake during dinner due to high blood sugar levels at night.

This extract was summarised as:

Patient was asked about her dietary intake and compliance with insulin prescription as she had poor glycaemic control based on her regular self-monitoring of blood glucose. Usual dietary intake and insulin regime were compared to identify the problem.

The extract above was indexed as 2.1, ‘content of communication’, in relation to ‘communication of self-care’. The summarised data was then charted in column 2.1, ‘content of communication’, against field note ID OBS 8 in row in Table 2 ‘communication of self-care’. This process is visualised in Table 5.8.

Table 5.8 Framework chart for analysis of observational data

2. Communication of self-care			
Field notes/document ID	2.1 Content of conversation	2.2 Dominance of consultation	2.3 Additional materials used
OBS 8 Mrs S, Nurse N, DR T Case study site 2	<i>Patient was asked about her dietary intake and compliance with insulin prescription as she had poor glycaemic control based on her regular self-monitoring of blood glucose. Usual dietary intake and insulin regime were compared to identify the problem.</i>	<i>Patient kept quiet and stared at the floor.</i>	-No related data -

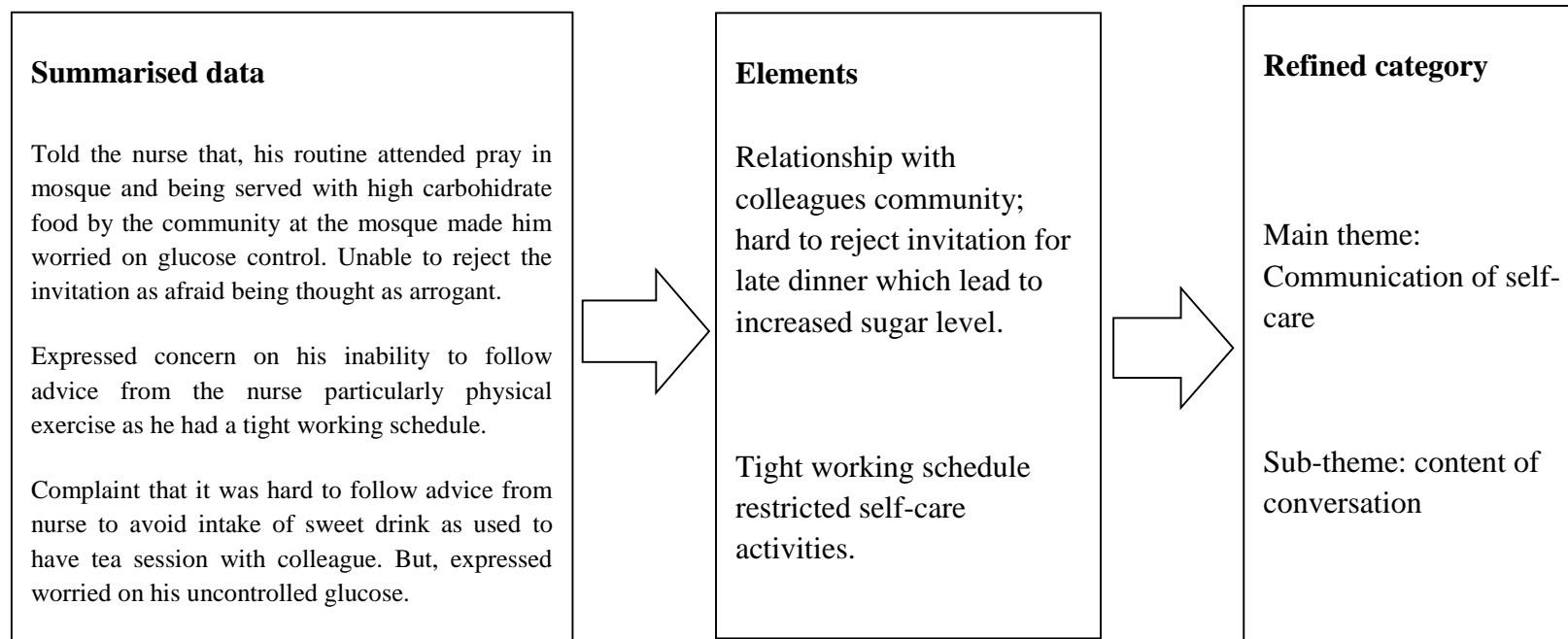
The next stage of analysis of the field notes and documents was that each column in the chart was read to identify common themes within the subthemes of the framework. The common themes were then classified into categories, which remained embedded in the themes and subthemes. Figure 5.6 illustrates the process of classification and categorisation of the summarised data regarding observational field notes.

Finally, cross-case analysis was conducted in which the themes, subthemes and categories that emerged from the interview data, observation field notes and documents was compared and contrasted to identify similarities, differences and patterns within the three sets of data. The findings are reported together, as each of the data sets complemented each other to provide a holistic understanding of self-care issues in type 2 diabetes in urban settings in Malaysia.

Figure 5.6 Process of classification and categorisation of observational data

Main theme: Communication of self-care

Sub-theme: Content of conversation



5.7 Methodological rigour

Maintaining rigour is a crucial part in conducting a research study to ensure the trustworthiness of the research findings (Lewis & Ritchie, 2003). Terms such as validity and reliability are frequently used to determine the quality of case study research (Yin, 2009), but this concept commonly refers to natural science research. Parallel to the epistemological stance of this study, which is underpinned by the qualitative methodology, criteria to determine the quality and trustworthiness of qualitative research include credibility, dependability and transferability, as proposed by Guba and Lincoln (1989). These criteria are now discussed in relation to the methods carried out in this study.

5.7.1 Credibility

The credibility of this study was established through prolonged engagement and relationships that the researcher had with the research participants. During the interviews and observations, the responses from the study participants, especially nurses, were natural, as they regarded the researcher as part of their team. In addition, the researcher maintained a reflexive diary throughout the research process, wherein she reflected on her role as a researcher in the study and identified the possibility of researcher bias arising, as explained in section 5.11 and, appendix 20 and 21.

Interviewing multiple key stakeholders, including patients from different social backgrounds and HCPs in various roles and responsibilities, provided multiple views and perspectives regarding self-care issues in type 2 diabetes in Malaysia. This strengthens the objectivity and trustworthiness of the data (Tashakkori & Teddlie, 2003; Milnes, 2010). Further credibility was assured through the adoption of multiple data collection methods and the utilisation of multiple sources of evidence, so that the limitations of each data collection method could be compensated for, and the trustworthiness of the data produced could be strengthened.

Peer-debriefing was undertaken through regular meetings with the supervisory team during the data collection and analysis process to identify flaws and alternative approaches to refine the research process. The aspects discussed included the accuracy and consistency of the interview transcripts and observation field notes, the process of developing the framework, critical comments on the data interpretation, and presentation of the findings. This process enabled the researcher to explain the analysis process and study findings by presenting example quotations from the participants in the findings section (Guba & Lincoln, 1989).

5.7.2 Dependability

Dependability relates to indications of stability and consistency during the process of inquiry (Riege, 2003), and means that readers can be satisfied that the findings and conclusions of the study were achieved by means of a rigorous research process (Ritchie & Lewis, 2003). The use of clear research questions and study propositions to direct the features and design of the study illustrate consistency of the epistemology of the study and research process. Dependability could also be achieved by providing a description of the process of data analysis and showing the transition from attaining the original data to generating conclusions (Silverman, 2011). Utilisation of framework analysis aided visibility of the analysis process by providing detailed explanations at every stage of analysis, including development of the framework and thematic chart, examples of transition of data from summarised to the process of categorisation. Utilisation of CAQDAS (Computer Assisted Qualitative Data Analysis) facilitated the process of data management and maintained the connection between the summarised data and the original data source, which created an audit trail.

5.7.3 Transferability

Transferability refers to the ability to yield similar findings if the same research process is conducted in a similar context or using similar settings; this is also known

as analytic generalisation (Riege, 2003). Transferability in this study has potentially been achieved through providing a ‘thick’ description of the research process, including the data collection and analysis process and presentation of the findings, using example participant quotations to help readers to assess the potential transferability of this study to their own settings.

5.8 Ethical considerations

In conducting this study, the researcher was aware of her ethical responsibilities as the study involved collecting personal information from a vulnerable group of people – that is, patients receiving treatment from a hospital and clinics (Holloway & Wheeler, 1996). Therefore, several ethical issues related to qualitative research were considered (Holloway & Wheeler, 1996). Most ethical issues in this study relate to consent, anonymity and confidentiality, a dual role, empathy and research-mindedness.

5.8.1 Informed consent and voluntary participation

Informed and voluntary consent has been defined as an explicit agreement given by research participants without any threat or inducement (Holloway & Wheeler, 1996). In providing agreement, participants need to be adequately informed about the research, comprehend the information, and have the power of freedom of choice that enables them to decide whether to participate or decline (Polit & Beck, 2006). To abide by these elements, participant agreement for this study was obtained only after a thorough explanation of the research process and comprehensive information sheets were provided to them for their reference. In addition, potential participants were given time to decide whether to participate (at least 24–48 hours) to allow them to obtain a clear understanding of the research. Their right to discontinue their participating in this study at any time was also clearly explained in order to preserve their right as study participants. Patients’ background information, such as level of education, was identified by the administrators and diabetes educators prior to distribution of the invitation letter and participation information sheets to ensure that

the patients would be able to understand the information provided. In addition, the patients were encouraged to discuss the information and their participation with family members, and to contact the researcher if they had any doubts or queries about the study.

5.8.2 Anonymity and confidentiality

Due to the small number of participants and the requirement for a ‘thick’ description in reporting the qualitative study, the possibility of the participants’ identities being uncovered was considered (Holloway & Wheeler, 1996). Thus, the participants’ anonymity was maintained during data transcription by removing their names and any other aspects related to their identity. As suggested by Holloway and Wheeler (2010), the participants were identified by number. It was ensured that only the researcher was able to match the identity of the participants with the corresponding voice recording; Furthermore, data transcription was done by the researcher only, and was conducted in a private room using headphones to avoid the possibility of the recordings being heard by others. Prior to the study, it was anticipated that there would be a need for peer review of the interview transcriptions by supervisors to confirm the accuracy of data analysis and interpretation. Therefore, the supervisors’ access to the data was explained to the participants, and their consent regarding this matter was sought. The data was stored in an encrypted device and password protected. Hard copies or written versions of the data were kept in a locked cabinet with no access other than by the researcher.

5.8.3 The dual role

Role conflict in qualitative research, particularly in health service research, has been thoroughly debated (Fowler, 1988). Although carrying out the researcher role, nurses were tied up with their professional role and responsibility for the care and welfare of patients (Holloway & Wheeler, 1996). Fowler (1998) suggested that the research process needs to be discontinued if the participants feel threatened by the research or

uncomfortable with the research process. In the context of this study, the role of the researcher has been clearly scrutinized and understood. Prior to the interviews and observations, the researcher introduced herself as a nurse who was conducting research. The participants were also informed that during the interview, the researcher's role only was that of listener, who would not give any opinions or intervene. Having a clear understanding (see section 5.10) allowed the researcher to isolate her professional role.

5.8.4 Empathy and research-mindedness

A research study requires both empathy and distancing (Holloway & Wheeler, 1996). With her dual role as researcher and healthcare provider, the researcher experienced a conflict of feelings between being non-judgemental and experiencing empathy towards the patients (Miller, Hedrick, & Orlofsky, 1991). In dealing with this situation, Miller et al. (1991) suggested 'debriefing' participants and providing emotional support if needed. Throughout the fieldwork, the researcher developed rapport and immersed herself in the participants' environment in the clinics. As this research explored self-care issues, the possibility for the participants – especially patient participants – to reveal their emotional feelings about living with diabetes was expected to be obtained. Therefore, this issue was discussed with the HCPs at the case study sites, and they agreed to help in providing clinical explanations and psychological support to the patients if this problem rose. Throughout the data collection process, several patients began to cry when explaining their experience and the burden of living with diabetes. When this situation arose during the interviews, several methods were employed to deal with the situation. These included waiting for the participants to calm down and feel able to continue, asking the participants if they preferred to stop, and redirecting the interview to a previously discussed issue with less emotional content (deMarrais & Tisdale, 2002). Even participants who became emotional agreed to continue the interviews, except one for whom the interview was terminated early because she needed to go home. The interview ended as requested, and the researcher acknowledged her upset and uneasy feelings. Subsequently, all patients were referred to the diabetes educators in charge for further psychological

support. This support and reassurance was provided by the diabetes educators after the interviews, according to the needs of the participants.

5.8.5 Research governance and ethical approval

Prior to accessing the participants and starting the fieldwork, ethical approval was obtained from the University of Manchester Ethical Committee and the Malaysia Medical Research Ethics Committee (MREC) (Appendix 6, 7 and 8). This process began after the research proposal had been examined and agreed by the supervisory team. No additional ethical issues were raised by the ethics committee, except for the need to obtain agreement from the HCPs with respect to the observation, prior to the recruitment of patients (see section 5.4.1). Accordingly, minor changes were made to the recruitment process. Once approval had been obtained from the University of Manchester Ethical Committee, permission to conduct data collection in Malaysian healthcare organisations was sought from the Malaysia Ministry of Health, Director of Kuala Lumpur Hospital, Director of the Health Department of the Federal Territory of Kuala Lumpur and Putrajaya, and the heads of the departments involved. Ethical approval from the Malaysian Medical Research Ethical Committee was also sought. The data collection activities began only after getting permission from all of the above authority bodies.

5.9 Reflexivity

Reflexivity is an important aspect in maintaining the credibility of research outcomes (Finlay, 2002). The researcher recorded details of her thoughts and perceptions during the interviews and observations, and reflected on how these might influence her interpretation of the data; this was achieved by maintaining a reflexive journal throughout the research process. In addition, the researcher reflected on her previous experience and pre-conceived ideas, as they may also have influenced how she saw and perceived the situation at the case study sites (Rabe, 2003). Therefore, the reflexive journal acted as a record by which to monitor any biases that may have been

introduced by the researcher and that could have a negative influence on the research findings (Roller, 2012). In this study, the researcher was aware of the importance of reflexivity, and that her experience as a nurse in Malaysia may influence understanding of the study context and interpretation of the findings. Therefore, it was important for the researcher to provide explicit explanation on this prior experience in the area of diabetes management, and acknowledge its impact on each element of the research process.

In conducting qualitative research, the researcher is an important tool with respect to the data collection and interpretation of the findings (Williams, 2008). Therefore, the researcher's background and social identity may influence their interpretation of the study context and the data gathered (Morse, 2001). The researcher's perspectives in conducting research are highly influenced by their professional background and whether the researcher is an 'insider' or 'outsider' with respect to the research setting (Morse, 2001). Become an 'insider' may provide benefits to the researcher in terms of becoming familiar with the research setting and getting cooperation during the data collection process as rapport is readily established (Bonner & Tolhurst, 2002). However, as an insider, the researcher may lose intuition and sensitivity as the situation in the research setting is too familiar and routinely observed (Morse, 2001). Being an outsider is frequently referred to in terms of rejection and sceptical perceptions from the research participants (Laurila, 1997). However, become an outsider, it provided an advantage to the researcher in this instance as she became an active observer and did not take for granted the environment and events which may have seemed common in the settings (Bonner & Tolhurst, 2002). Both 'insider' and 'outsider' roles seem to be important in conducting a qualitative study. Thus, it is crucial for the researcher to make self-clarification and maintain reflexivity throughout the research process.

5.9.1 Reflexivity account: The role of the researcher

At the start of this research, I took explicit notes on my personal working experience and my understanding and perception of the management of patients with type 2 diabetes. I also reflected on how I derived the research questions and theoretical propositions based on my experience and understanding of the literature. It should be noted that my understanding of diabetes was very general, as I had not been directly engaged in managing patients with type 2 diabetes during my experience as a nurse. In addition, I did not have experience of working in any government healthcare organisation; thus, I regarded myself as an outsider to the case study settings, and lacking a clear understanding of the management policy and guidelines.

Prior to conducting the study, I had pre-conceptions toward the way patients with type 2 diabetes are supported by government healthcare organisations, as I had observed how my family members with type 2 diabetes had been managed. This aspect somewhat influenced my perceptions on the practice of HCPs, and this impacted my interpretation of the initial interviews and observations. For example, I was aware of the conversation style between the patients and HCPs during the consultation; however, the experience that I have is from different settings and different clinical environments; thus, it can be assumed that the situation was different in the study settings. Furthermore, my perspectives at that time was as a patients' relatives; thus, the way I perceived the service provided seem to be different from the role as a researcher. After becoming immersed in the study setting, conducting informal conversations with HCPs and reviewing relevant documents, I gained an 'insider' understanding of what is actually experienced by the HCPs and what actually happens in the case study settings. This changed my perceptions and uncovered problems that might not have been noted by an outsider. I acknowledged my previous negative perceptions and was aware of the changes in these perceptions throughout the research process.

During interactions with the HCPs, particularly during social conversations and interviews, the issue of power relations was taken into consideration (Nunkoosing, 2005). My position as a nurse who had the opportunity to conduct further study and become a researcher was regarded by other nurses at the case study sites as a higher position. This situation probably made the participants, particularly the junior nurses, feel that I had exercised a certain degree of control in the interviews, so they may have distanced their relationship and limited their role as active data providers in the interviews (Nunkoosing, 2005). In minimising this situation Sorrel and Redmond (1996) suggested that the development of rapport and relationships between the interviewer and interviewee is crucial; thus, the interviews were conducted in relaxed situations. To build rapport with the HCPs in the study, I made regular visits to the clinics and familiarised myself with the environment and people. This method seemed to be effective, as I was increasingly accepted and involved in their social conversations after a few weeks at the clinics. In addition, the HCPs were encouraged to select their own date, time and venue for the interview. This helped to improve rapport.

In relation to power relations Nunkoosing (2005) also became concerned in conducting interviews with patient participants. Naemiratch and Manderson (2006), in their study conducted using Thai participants, claimed that patients tend to have high respect for HCPs as it is embedded in the culture of Asian countries, and this situation was also anticipated in Malaysia. Hence, when I introduced myself as a nurse, the patients might have felt that I exercised control in the interviews as what they experienced in the clinic consultation. To minimise this feeling, I tried to build rapport with the patient participants by calling them via phone upon their agreement to participate in the study. The purpose of the phonecall was to introduce myself to the patients and conduct a social conversation with them, such as asking them how they were. Simultaneously, the patients were encouraged to select their own date, time and venue for the interviews. This ensured that the interviews could be conducted in a natural and comfortable situation, without a sense of power differentials and boundaries between the patients and the researcher (Mack et al., 2005).

5.10 Summary

This chapter provided a detailed explanation of the methods used in this study. It demonstrated how the participants were recruited, and data were collected and analysed. Furthermore, the researcher provided an account of her reflexivity and identified the effects of this on the interpretation and analysis. Additionally, the processes used to maintain the quality and trustworthiness of the study were outlined, and important ethical aspects considered and discussed. The next following chapters present the findings of the study.

CHAPTER 6

Describing Self-Care of Type 2 Diabetes in Malaysia

6.1 Introduction

This chapter consists of two parts. The first part describes the participants' profiles. The second presents the findings on the self-care practices of patients with type 2 diabetes in Malaysia.

6.2 Part 1: Description of the participants

Throughout the data collection period (November 2012 to June 2013), a total of 40 patients with type 2 diabetes and 36 HCPs from three case study sites were approached to participate in the study. Of these, 18 patients and 19 HCPs from an outpatient clinic, a specialist-medical clinic and primary-care clinic in Malaysia participated in this study. A total of 37 individual semi-structured interviews and 13 participant observations were conducted. Table 6.1 summarises the number of patients and HCPs that participated in the study from the three case study sites.

Table 6.1 Number of participants recruited

Settings	Patients with type 2 diabetes		HCPs	
	Approached	Consented	Approached	Consented
Case study site 1	10	4	10	4
Case study site 2	15	5	12	6
Case study site 3	15	9	14	9
Total	40	18	36	19

6.2.1 Characteristics of patient participants

All 18 of the patients participated in the interviews, and 13 of them participated in the observations. The patients had a wide range of ages and came from various social backgrounds. The youngest participant was 28 years old and the eldest was 69 years old, with a mean age of 48. Fifteen of the participants are still in working age group (between 20 to 55 years old) which suggests that the incidence of type 2 diabetes in Malaysia might affect productivity in general. In terms of occupation, eight of the participants were civil servants, eight were housewives, one was a retiree and one worked as a technical consultant in the private sector, but had been suspended from work due to illness (he had undergone toe amputation). The high numbers of civil servants that participated in this study was expected, as the study was conducted at the Federal Administrative Centre of Malaysia which is also a residential area of a large number of civil servants.

The length of time between the participants being diagnosed with type 2 diabetes and the start of this study varied. Five participants had been diagnosed with type 2 diabetes less than one year ago; seven participants had had diabetes for between two and 10 years; and six participants had had type 2 diabetes for more than 10 years. Seven participants in this study were being treated with insulin injections, whereas the remainder were on various types of oral hypoglycaemic agents. Most of the participants, especially male patients were still working, and had a great deal of responsibility in the family and workplace. The female participants were also expected to hold important responsibilities in the family, as most of them were housewives of productive age. These two aspects were expected to influence their experiences and perceptions in dealing with diabetes in challenging situations. The characteristics of the patient participants in this study, including their gender, age, job, time since diagnosis and type of treatment received are summarised in Table 6.2.

Table 6.2 Characteristics of patient participants

Participants' ID	Age (mean: 48)	Gender	Occupation	Duration since diagnosis (mean: 7 years)	Treatment
PT 1	69	Female	Housewife	<10	Insulin injection
PT 2	62	Male	Retiree	<10	Oral hypoglycaemic agents
PT 3	41	Male	On sick leave (private company)	8	Insulin injection
PT 4	46	Female	Housewife	7	Insulin injection
PT 5	53	Male	Civil servant	9	Oral hypoglycaemic agents
PT 6	37	Female	Civil servant	> 1	Oral hypoglycaemic agents
PT 7	59	Female	Housewife	5	Oral hypoglycaemic agents
PT 8	48	Female	Housewife	<20	Insulin injection
PT 9	46	Female	Housewife	5	Oral hypoglycaemic agents
PT 10	28	Male	Civil servant	>1	Oral hypoglycaemic agents
PT 11	50	Female	Housewife	<10	Insulin injection
PT 12	55	Female	Housewife	5	Oral hypoglycaemic agents
PT 13	50	Male	Civil servant	7	Oral hypoglycaemic agents
PT 14	56	Female	Housewife	<10	Oral hypoglycaemic agents
PT 15	54	Male	Civil servant	<10	Oral hypoglycaemic agents
PT 16	43	Male	Teacher	>1	Oral hypoglycaemic agents
PT 17	29	Female	Civil servant	>1	Oral hypoglycaemic agents
PT 18	30	Male	Civil servant	>1	Oral hypoglycaemic agents

6.2.2 Characteristics of HCP participants

Out of the 19 HCPs that participated in this study, nine were nurses, five of whom were qualified diabetes educators, while four were general registered nurses without special training in diabetes management. Three of the participants were doctors, one of whom was a family medicine specialist. Two dieticians, one pharmacist and three nurse managers who held responsibility as clinic managers also participated in the study. One nurse manager also held responsibility as diabetes educator. One HCP responsible for monitoring the progress of patients with type 2 diabetes attending the primary-care clinic (case study site 3) and preparing reports for the National Diabetes Registry also participated in the study. The participants' years of working experience varied between five and 15 years. Two doctors, three nurses and one dietician had worked for more than 20 years.

The distribution of HCPs in this study shows that most were nurses, with the minority made up of other HCPs (this situation is explained in chapter ten (section 10.6)). Therefore, it was anticipated that the understanding of self-care support at the case study sites would mostly be informed by the experience and practice of the nurses. However, the situation did not seem to greatly influence the understanding of self-care support, as the role of educating and supporting patients with type 2 diabetes on self-care was mostly conducted by the diabetes educators and general nurses, as visualised in the clinic's flow charts shown in chapter four (section 4.6) and claimed by the HCPs at the case study sites. The characteristics of the HCPs that participated in the study are summarised in Table 6.3.

Table 6.3 Characteristics of HCP participants

Participants' ID	Role	Years of working
HCP 1	General nurse	8
HCP 2	Diabetes educator	11
HCP 3	Health educator	>20
HCP 4	General nurse	16
HCP 5	Diabetes educator	18
HCP 6	Diabetes educator	11
HCP 7	Diabetes educator/Nurse manager	18
HCP 8	Nurse manager	>20
HCP 9	Diabetes educator	15
HCP 10	General nurse	18
HCP 11	General nurse	6
HCP 12	Nurse manager	>20
HCP 13	Medical officer	4
HCP 14	Family medicine specialist	>20
HCP 15	Public health doctor (physician)	>20
HCP 16	Medical assistant	17
HCP 17	Pharmacist	13
HCP 18	Dietician	15
HCP 19	Nutritionist	10

6.3 Part 2: Self-care of type 2 diabetes in Malaysia

The findings of self-care of type 2 diabetes in Malaysia were derived from in-depth analysis of semi-structured interviews with patient participants, and observation field notes. The data are presented in narrative form, wherein appropriate direct quotations from participants, along with, field notes and reflective diary entries have been included. This is to illustrate the context and process of constructing the themes and categories. Most of the interviews with the patient participants were conducted in the Malay language; the transcripts were therefore translated into English by the researcher, as detailed in chapter five, section 5.5.1.4. Each quotation from the participants in this chapter is presented using the participant's unique code in brackets. Exchanges between the researcher and participants are preceded by letter 'R' for researcher and 'P' for participant.

The process of analysis using the framework led to the development of themes and categories to explain the phenomena being studied. In describing the self-care of patients with type 2 diabetes in Malaysia, two main themes were developed in the framework (Table 5.3 in chapter 5), including the practice of self-care and factors influencing self-care, including the facilitators and barriers. Table 6.4 illustrates the themes and categories that emerged to describe the self-care of patients with type 2 diabetes in Malaysia.

Table 6.4 Themes and categories describing self-care of type 2 diabetes in Malaysia

Themes/subthemes	Categories
Practice of self-care	Diet control Compliance with medication directives Use of alternative medicine
Factors influencing self-care	
- Facilitators to self-care	Fear of complications Awareness to change Relationship with HCPs Religious beliefs Support from others
- Barriers to self-care	Uncertainty and frustration in practice Feeling healthy Malaysian environment and dietary culture Time limitations for physical exercise

Each of the themes and categories is now explained in narrative form.

6.3.1 Practice of self-care

The most important aspect to be explored in understanding the patients' self-care was the nature of their practice. Patients were asked about their routines and the measures that they took to manage the diabetes. Self-care was interpreted by the participants as a way of changing their lifestyle by following the suggestions of HCPs to control their blood sugar level. However, self-care was commonly perceived as difficult by the patients, as they were tied up with their daily routine and the Malaysian dietary culture. Through the analysis process, three main categories emerged (Table 6.4) to explain the practices of self-care of patients with type 2 diabetes in Malaysia. These included: diet control, compliance with medication and use of alternative medicine. Each of the categories is now explained in detail.

6.3.1.1 Diet control

Diet control was consistently described by the participants as: reducing their food intake and avoiding sweet food and drinks in order to maintain good glycaemic control. The interview data indicated that patients had a clear understanding of the types of foods that increase their blood sugar levels, such as: rice and bread, which are high in carbohydrates, sweet cakes and sugary drinks. This understanding was reflected in their practice, where they were concerned about controlling their sugar levels by reducing their intake of rice, sweet foods and sweet drinks. However, the patterns of diet control among the participants in this study varied. From the data, it can be observed that the patients' responses on adherence to diet control varied, and included following a strict diet, a moderately flexible diet, or a very flexible diet (Meetoo, 2004).

6.3.1.1.1 Strict diet

Data from the patient interviews shows that patients who are newly diagnosed with diabetes commonly follow a strict diet. Those patients who followed a strict diet commonly revealed their worries and concern regarding the possibility that blood sugar will increase due to their food intake. For example, PT 10, a male of 28 years old who had been diagnosed with diabetes for less than one month, explained that when he was diagnosed with diabetes he was scared to eat anything, and only ate fruit and drank tap water. He was even scared to look at the food that used to be his favourite, such as rice, curry and sweet drinks, as he believes that those kinds of food would cause his blood sugar to increase. Therefore, he made drastic changes to his dietary pattern by reducing the amount of food compared to previously:

P: 'Right now I am really afraid to eat heavy food like rice or bread since I've been told that this kind of food will cause my blood sugar to rise. When I see food more than usual, I start to feel scared.'

P: 'What makes you have that feeling?'

R: 'I am scared because that kind of food will cause my blood sugar to rise. I like rice very much. Before this, I ate rice three times per day. Since being diagnosed with diabetes, I only eat rice once per day.' (PT 10)

PT 17, a female aged 29, also revealed similar practices pertaining to diet control. PT 17 had been being diagnosed with type 2 diabetes for less than two months. During the interview, she explained that she had adopted a strict diet by reducing her intake of rice and sweet drinks as she was afraid her blood sugar would increase. She also tried to regulate her meal schedule according to the suggestion provided by the HCPs. The reason for her strict diet was that she was shocked and scared when diagnosed with diabetes, and tried her best to cure it, as reflected in her narrative below:

'I was really shocked and it was hard for me to accept that I had diabetes. I took quite some time to accept that I had diabetes. I thought I needed to do something to get rid of it. I reduced my intake of sweet drinks to once per day. Now I have changed my drink to plain coffee. I also reduced my intake of rice and avoid eating rice during breakfast and dinner.' (PT 17)

The examples above reveal the participants' view that diet control is the most important element in reducing blood sugar level. From the interviews, it was apparent that rice was perceived as the main contributor to the diagnosis of diabetes. This is probably because rice is a staple food among the Malaysian community; thus, a high intake of rice has been related to the high incidence of type 2 diabetes, for instance in a recent systematic review where an increased incidence of type 2 diabetes was noted in the Asian population compared to the Western world (Hu *et al.*, 2012). Therefore, it is likely that the patients were advised to reduce their rice intake in order to maintain good glycaemic control, and this reflected in their understanding and practice related to maintaining a strict diet.

Another concern of patients who followed a strict diet was the intake of sweet food. The patients believed that eating sweet cakes, such as *Malay kueh* (which is commonly sweet) and sweet drinks would increase their blood sugar and worsen their diabetes. *Malay kueh* usually has high-calorie ingredients, such as sugar, coconut milk, flour, glutinous rice and oil. It is a popular snack within the Malaysian community and is usually being served during festivals or on special occasions, and is commonly sold at restaurants and food stalls. However, the participants frequently claimed that they did not have a 'sweet tooth'; thus, their desire to eat sweet cakes and *kueh* was not strong. Therefore, they did not find the restriction of sweet food and drink difficult. This is exemplified by an extract from a woman, aged 59, who had been diagnosed with diabetes for more than four years:

'I felt scared, especially with respect to diet. I was afraid to eat sweet drinks or food and I also reduced the amount of food that I ate. I felt worried about eating whatever food. I was afraid that if I ate more that my sugar level would increase. It restricted me because I have been afraid since finding out that I had diabetes. Before this, I really liked sweet things like Malay kueh but now I do not feel interested in eating those sweet foods.' (PT 7)

6.3.1.1.2 Moderate flexible diet

A moderate flexible diet is another dietary pattern practiced by certain patient participants in this study. It was noted that patients who adopted a moderate flexible

diet showed positive acceptance towards diabetes, and an awareness of dietary control in reducing their blood sugar level. However, these patients perceived that they still need to enjoy their life, despite having diabetes. These patients expressed that diet control needs to be achieved according to their knowledge and understanding of diabetes, and based on their self-preferences. For instance, PT 9, a 46-year-old woman, stated that although she had diabetes, it did not restrict her from enjoying the food that she used to eat. She claimed that she still enjoys the same food, yet is able to maintain acceptable glucose levels and have a high quality of life:

'I just accepted it. It does not totally cutting down on everything that I used to eat. I still enjoy eating, although everything has been cut to half the amount. I think it really depends on the individual, what they actually want in their life. If they think that they want to enjoy life then...they have to change. Actually, it is not very difficult to change the lifestyle it is just in you whether you want to do it or not.' (PT 9)

A moderately flexible diet, as adopted by PT 9, seemed to contribute by the patient's acceptance of diabetes. In addition, self-determination to live a better life in spite of the diabetes increased her motivation to adhere to the diet. Furthermore, patients who practised a moderately flexible diet usually spoke about 'allowing for indulgence', wherein they would sometimes permit themselves to eat restricted food to relieve their craving. They believed that adherence to a diet is about having 'self-control' when they allowed themselves to eat certain food. This is illustrated in the narrative of PT 5, a 54-year-old man who had had diabetes for nine years:

'I felt okay about having diabetes but I needed to control it. But sometimes I felt frustrated because a lot of things that I could do before, I can't do now. Food especially... (Laugh). I like some fruits such as banana or mango or durian...but now they [the HCPs] say 'no'. So, there are certain things I have to accept and I have to learn to control. So, all of the frustration...when my wife says "eyy...You can't take a lot of that", I say, "once in a while...It is okay" (Laugh)' (PT 5).

6.3.1.1.3 Very flexible diet

In other cases the diet control practised by the patient participants in this study was very flexible. It was noted that a very flexible diet was usually practiced by patients who had had diabetes for longer. Meeto (2004), in his study of diet patterns of Asian

and Caucasian diabetic patients, explained that the flexible diet pattern in his study was characterised by patients who monitored their blood glucose regularly and adjusted their insulin accordingly, as they believed their practice was not overly risky. Similarly, patients who practiced very flexible diet control in this study were highly aware of their glucose level, as they maintained an SMBG record and adjusted their food intake, medication and insulin dosage according to the glucose reading. This is demonstrated in the extract below:

'I did not change anything. I followed my normal diet and took my medication as instructed by the doctor. When I checked my blood sugar in the morning, the reading would drop to 5 or 6 mmol/L. But I tried to avoid rice during dinner or at night. If I ate rice, it would be in small amounts. I noticed that if I ate much rice, the level increased. That was my experience. If I eat less rice, I replace it with toast or roti canai (paratha).' (PT 2)

It was apparent that this group of patients did not focus only on diet control, but also practiced adjusting their insulin dosage according to their food intake and glucose level to ensure the reading remained within the normal limit. For example, PT 4, a 46-year-old woman who had had diabetes for more than 10 years, experienced a high glucose reading with her current insulin dosage. Therefore, she conducted self-titration of insulin to compensate for her food intake and glucose level. However, she thought of this practice as 'cheating', because it was not prescribed by the HCPs:

'The doctor had prescribed me 20 units of insulin 3 times a day. I found out from the internet that I should take more insulin if I eat more and reduce it if I eat less. But I was never told about that by the doctor and the nurses here. The doctor and nurses here asked me to control, but I don't know what more should I control? Sometimes I did cheat...I increased the dosage of insulin if I needed more food.' (PT 4)

This practice of insulin self-titration has been shown to be effective in helping patients to improve their ability to control their blood glucose (Garber et al., 2006; Meneghini et al., 2007; Khutsoane et al., 2008; Blonde et al., 2009; Ligthelm, 2009). However, from the interviews, it was apparent that self-titration of insulin was not commonly explained to the patients in this study. Hence, the above patient's decision to titrate the insulin dosage based on her glucose reading and food intake was made

based on information she obtained from other sources, such as the internet. Therefore, it can be understood that the patients' approach of very flexible adherence to diet control was not totally dependent on the information and support received from the HCPs. However, it was affected by the self-efficacy of the patients, which appeared to be higher when the patients had a clear understanding and control of their body. This appeared to increase their confidence in making decisions pertaining to their diabetes management. Reflecting on the characteristics of these patients, it was apparent that they all had more than 10 years' experience of living with diabetes. Thus, these patients had gained experience and confidence in diabetes management through trial and error in relation to understanding their body responses towards food intake, physical activities and the medication they took. Furthermore, the SMBG was seen as an essential factor in helping the patients to achieve self-control of their bodies, and make confident decisions.

6.3.1.1.4 Non-adherence to diet control

Despite the three identified patterns of diet control, one group of patients did not practice diet control at all. Their poor adherence to diet control was contributed to by their perception that diabetes was a normal occurrence within their community. In addition, this group of patients commonly did not practice regular SMBG; thus, they were unable to see the immediate effects of diet control to their diabetes. Furthermore, they thought that medication prescribed by the doctor was enough to maintain their glucose control, without the need for diet control. This situation is exemplified in the narrative below:

'At first, when I was told that I have diabetes, of course I felt worried. But after a while, I got used to it and everything went back to normal. It feels like I don't have any illness. Because, I don't see the seriousness of this illness. Even when I saw my friend who had the same problem (diabetes), he looked at it as normal. Nothing has changed in him, even the way he lives his life and types of foods that he chooses is the same as before. So, I think it is normal for me as well. Thus, we just live our lives as normal, and the same as before we had diabetes. I think it is okay...just eat as normal. If we get sick, we have medication.' (PT 13)

It was apparent that awareness of the importance of practicing diet control was developed at the beginning of the diagnosis. However, it was unsustainable as the patients were continuously exposed to the unhealthy lifestyle that had been their practice before the diagnosis. Furthermore, it can be understood that this group of patients was fully aware of the importance of diet control in maintaining their blood glucose level; however, as they did not experience any symptoms and did not see the immediate impact of diet control on their diabetes, they decided to continue with their usual lifestyle. Moreover, these patients frequently expressed stressful feelings about refraining from enjoying their favourite foods. They claimed that high-carbohydrate foods, such as rice, noodles, bread and sweet cakes, were their favourite foods, and were commonly eaten since they are small. Thus, the desire to eat these kinds of food is very high, and it was very hard for them to restrict themselves from eating them. This is demonstrated in the narrative below:

'I think my glucose level is very influenced by the food that I eat. But...Can you imagine, from a child, we have been taught to eat the kind of food that we usually eat; why would we want to change it?' (PT 4)

In addition, several other reasons were suggested to contribute to non-adherence to diet control, including feeling hungry and craving favourite foods, as exemplified below:

'When I reduced the amount of food, I always felt hungry. For example, in the morning I reduced my food intake. Then, within the period to reach the lunch time, I felt that I want to eat other food. But I tried to control this by drinking a lot of water. During lunch, I tried to control the food intake. But it was really hard.' (PT 6)

From the above narratives, it was recognised that patients who did not adhere to diet control actually struggled and tried their best to adhere. However, within their lives, patients frequently experienced difficult situations that affected their motivation and enthusiasm. Furthermore, self-care activities such as diet control were perceived by the patients in this study as their individual responsibility. Thus, the situation frequently made them feel lonely, helpless and frustrated, especially those who did not receive sufficient support from family members, colleagues and HCPs throughout their diabetes management. Hence, they frequently decided to revert to their previous

lifestyle. This resonated with the findings presented by Vijan et al. (2005), who also suggested that effectiveness of diet in improving glucose control among type 2 diabetes seems to be limited and non-sustainable. Several factors were identified as restricting the patients' adherence to diet control, including cost, small portion sizes and hunger when following suggested diet regimes (Vijan et al., 2005). Therefore, it can be understood that besides their awareness of the importance of diet management and the approaches they adopted towards diet control, many of the patients struggled to follow suggested diets, as these frequently contrast with their normal life routine.

From the evidence presented, it is apparent that the patients practiced several methods of adherence to diet control. Their patterns of adherence to diet control were largely influenced by their perceptions of the disease's severity (particularly in newly diagnosed cases), understanding of the causes of increased glucose levels, and self-efficacy in diabetes management. Furthermore, acceptance of diagnosis and understanding of blood glucose regulation with regular SMBG positively contributed to the patients' engagement in diet control, as they were able to make better decisions on the diet patterns that worked best for them. However, this was only achieved by certain patients, particularly those who had longer experience with type 2 diabetes. It was also noted that the individual responsibility for diet control and incompatibilities with their complex life situations and cultural practices made the patients experience feelings of helplessness and frustration, which made them revert to their previous lifestyle and decide not to adhere to the diet. Therefore, all of these aspects can be perceived as reasons for poorly controlled type 2 diabetes in Malaysia.

6.3.1.2 Compliance with medication

From the interviews, it was noted that patients in this study had good compliance with their medication regime. Although many patients stated that they were unable to strictly adhere to suggested diets, most claimed that they strictly complied with their medication and insulin prescription, as they strongly believed that medication prescribed by the doctor would help to reduce their blood sugar level. Most of the

patients believed that their blood sugar level would remain controlled if they took the medication as prescribed, even though they did not adhere to other self-care elements.

6.3.1.2.1 Compliance with insulin injection

In general, patients with insulin injections exhibited better compliance compared to patients with tablet medication. From the patients' characteristics, it can be observed that patients who had been prescribed with insulin injections commonly had longer experience with diabetes (more than five years). Thus, they claimed that taking insulin injections had become part of their lives, and usually felt a lack of something if they did not do it. For instance, PT 8, a 48-year-old woman, stated that insulin injection had become a four-times-a-day ritual that she almost never missed, although she sometimes lacked motivation to manage her condition. This is demonstrated in the extract below:

'Taking insulin injections is part of my daily routine. I need to take it four times a day! Sometimes I do feel stressed and ask myself, how long do I have to live my life like this? Sometimes I do not take the insulin because I am too lazy to inject myself. But when I check my sugar level and it is high, I feel regret and scared. So I have no choice.' (PT 8)

Another patient also provided similar views on compliance with insulin injection. PT 3, who had been diagnosed with type 2 diabetes for more than five years, also agreed that it was very important for him to comply with insulin injection as he needed to strictly maintain his blood sugar level within the normal range. PT 3, who suffered from a foot ulcer due to uncontrolled diabetes, realised his mistake in not complying with the medication and ignoring the importance of modifying his lifestyle:

'It was difficult. I did not keep track of my diabetes and I merely dismissed it. I enjoyed my normal life. That was the reason. Currently I am on a strict diet and I am on insulin. I strictly follow whatever medication they prescribe to me. I am taking two types of insulin four times a day. Ten units of Actrapid three times a day and 14 units of Insulatard during night time. Now, I strictly follow the schedule of insulin injection as suggested by the doctor, no matter how hard it is. Because I believe this is my last chance to avoid anything worse arising [from his health condition].' (PT 3)

PT 3's narrative shows that his awareness on the importance of compliance with medication developed after he experienced a devastating complication that altered his bodily function and life situation. The narratives above demonstrate that the patients had high compliance with insulin injection, which was commonly influenced by their awareness of the effects of uncontrolled diabetes on their body. However, these findings seem to contradict those of other studies. Many studies conducted in this field have reported poor patient compliance with insulin injection (Davies et al., 2013; Peyrot et al., 2005; Peyrot et al., 2012). For instance, a study by Peyrot *et al.* (2012) conducted in Germany reported that 33.2% (n=1530) of patients with insulin claimed not to adhere to their insulin prescriptions, while 72.5% (n=1250) of physicians reported that their patients commonly missed their insulin injection on an average of 4.3 to 5.7 days a month. Furthermore, Davies et al. (2013) reported that most studies included in their review highlighted poor patient adherence to insulin injections. From the review, several factors were found to contribute to poor adherence, including fear of injections, embarrassment of injecting in public, type of delivery device and cost of medication (Davies et al., 2013). Nevertheless, a study by Broadbent et al. (2011) showed similar findings to those obtained in the current study, where patients perceived compliance with medication as more important than other self-care activities, such as diet and exercise. In addition, Broadbent et al. (2011) reported high adherence to medication, including insulin injection, among the patients in their study. Although the current findings deviate from other studies in this area, it is important to stress that this study was conducted qualitatively, and the findings were drawn from in-depth analysis of a small sample. Thus, it may not represent the level of adherence of patients with insulin for the whole country.

6.3.1.2.2 Influence of patient–HCP communication on medication compliance

Patients who took tablet medication generally claimed that they strictly complied with the medication. However, most of them admitted to missing some doses, especially their pre-meal tablet. Reasons given by the patients as contributing to their non-compliance included forgetting to take the medication prior to meals as they were usually in a rush to eat and only remembered the medication after they had finished

their food. Although sometimes they did express feelings of regret on their poor compliance with tablet doses, it did not have a strong influence on their practice. PT 13 is one example of a patient who was unable to comply with the medication, as seen in the extract below:

'I know that the medication will help me to control my sugar level. But usually I tend to forget to take the medication. Although I usually bring the medication to work, after I have my meal I forget to take it. I also have a problem with the tablet that I need to take before meals. Commonly, only halfway through eating do I realise that I have forgotten my medication. Sometimes, when the time for medication is due, I am outside the office doing work. My meal times are not fixed.' (PT 13)

PT 12, who also had difficulties in complying with tablet medication, also expressed a similar experience:

'I admit that sometimes I miss my medication. Especially at night, if I am too tired sometimes I forget to take the medication before bed. But I never missed my morning medication. Sometimes I take medication prior to meals, but I usually forget the medication after meals because I need to take it half an hour after that. It makes me forget.' (PT 12)

It was apparent that difficulties in adapting the dosage time and schedule to their daily routine was a reason for non-compliance. However, several other reasons also contributed to the non-compliance. PT 16, for instance, showed a good understanding of the importance of medication in controlling his blood sugar level. However, this did not influence his compliance. It seems that social factors, such as environment and working schedule, restricted his compliance with the medication regime. However, he claimed that this aspect was not usually discussed during consultations. The patient thought that it was his mistake and he did not want the doctor or nurses to know about it:

'Most of the time I have excess medication. I am supposed to finish the medication before I come to the clinic for follow up, but usually I still have a lot of it. Normally, the doctor asks me about my medication intake. But we also do not have to tell the doctor what our practice actually is. It is not that I am scared of them. Maybe because I take this matter too easy and we think might be, it is not important to tell the doctor about it.' (PT 16)

A similar situation was experienced by PT 8, who mentioned that she rarely discussed problems and difficulties faced in relation to her diabetes management with the HCPs. She also thought that it was not important to discuss this with the HCPs, as she perceived that self-care activities, including medication compliance, are her individual responsibility, although she faced difficulties following the suggestions. This is evidenced in her extract below:

‘Actually, I don’t really discuss with them why my blood sugar remains high, although I followed all their suggestions. I think it is my own problem and I try my best to solve it. As you have seen, they just tell me the things that I should do. So, I just listen to them and try to follow all of their advice.’ (PT 8)

The extracts provide evidence of a communication barrier between the patients and HCPs in this study. It can be understood that the patients frequently experienced one-way communication, wherein the HCPs gave instructions for the patients to follow, regardless of their life situation. The patients also perceived that discussing their problems with the HCPs was not important, and thus chose not to disclose everything. As the patients were reluctant to discuss their situation with the HCPs, it can be assumed that the problems related to non-compliance will remain unresolved and the patients will end up with uncontrolled diabetes, which could lead to devastating complications. Patient–HCP communication has been highlighted in a review conducted by Jin et al. (2008) of the factors affecting patients’ compliance with medication. Jin et al. (2008) reported that communication between patients and HCPs seems to influence patients’ compliance. Patients showed better compliance when the HCPs were psychologically supportive, showed respect and provided continuous reinforcement and reassurance. It was also reported that poor communication between patients and HCPs had a negative impact on patients’ compliance (Jin et al., 2008). Reflecting on the narratives presented above, it can be seen that, besides the patients’ individual perceptions and social factors, poor communication between patients and HCPs also influenced the patients’ ability to comply with medication. However, the influence of poor communication between patients and HCPs on patients’ non-compliance with medication has not been highlighted in previous studies conducted in the Malaysia setting. A study by Abougambou et al. (2010), for instance, which was conducted in a tertiary hospital in Malaysia, reported that 78% out of 1077 patients

with type 2 diabetes suffered from microvascular and microvascular complications. This study pointed out that factors contributing to non-compliance with medication included age, patients' level of education and use of multiple medications (Abougambou et al., 2010). Another qualitative study conducted in a tertiary hospital in Malaysia explored the factors influencing medication compliance among type 2 diabetes patients (Al-Qazaz et al., 2011). This study concluded that poor compliance with medication was influenced by a lack of knowledge held by patients on diabetes and the effects of medication (Al-Qazaz et al., 2011). Although this study highlighted the influence of the patient–HCPs relationship on medication compliance, it did not provide explicit explanations of how the relationship affects patients' ability to comply with medication regimes. Therefore, it is interesting to note that in-depth interviews conducted with patients in this study identified communication barriers as one of the important factors that lead to non-compliance with medication and poor adherence to self-care, as this has not been reported in other studies in the Malaysian context.

6.3.1.2.3 Influence of SMBG on medication compliance

Another aspect that is important here is the practice of SMBG, which seems to have a significant influence on patients' compliance with medication. During the data collection, it was observed that patients with insulin commonly kept a record of their SMBG as they were required to show this to the HCPs during follow up, for revision of insulin dosage. Therefore, during the interviews, it was apparent that patients prescribed with insulin had high confidence in the management of diabetes compared to patients using tablet medication. Furthermore, the intake of medication (insulin) and practice of other self-care activities, such as diet control and physical activities, were often modified based on objective evidence provided by the glucose record. Patients that conducted regular SMBG tended to have proper control of their diabetes, as they usually recognised the effects of their actions on their blood glucose level. This is shown in the narrative below:

'I would try to avoid rice during dinner or night time. From my experience, I am able to control my blood sugar within 5 mmol/L to 6 mmol/L. But of

course, sometimes my blood sugar increases to 7 mmol/L. It actually depends on our diet. At this age [66 years old], I think if I can get the reading less than 10 mmol/L, that is good enough. If it is more than 10, I would be worried. But all this while, it has never gotten that high.’ (PT 2)

However, this situation contrasted to that of patients who were prescribed with oral medication. It was evidenced from the patient interviews and observations that patients with oral medication rarely conducted SMBG, despite being advised to do so by the HCPs. Their reasons for not practicing SMBG including prohibitive cost of machine and strips, and fear of pricking finger:

‘I did not buy the machine for glucose checks...it is expensive! I don’t know what my glucose level is. So, I make the decision to take the medication based on how I feel in my body.’ (PT 6)

‘My daughter bought me the machine with the strips but I did not do it because I was too scared to prick myself. Even my husband and my children are scared to do it for me.’ (PT 14)

Within the self-care continuum, SMBG has been identified as one of the most important elements that should be practiced by the patients in order to maintain good glycaemic control. However, the benefits of SMBG in improving glucose control and the engagement of patients in self-care remain inconclusive (Gulliford & Latinovic, 2004). A randomised control trial conducted in the United Kingdom, for instance, reported that regular and intensive SMBG in patients with non-insulin-treated type 2 diabetes did not provide significant improvements in HbA1c (Farmer et al., 2007). In addition, SMBG has been argued to provide ‘monitoring fatigue’, which has been described as a perceived sense of failure by patients when the results of SMBG remain high (Peel et al., 2007). However, this study seems to provide contrasting results, since the interviews with patients indicated that the practice of SMBG increased their confidence in making decision pertaining to their diabetes management. Conversely, patients who did not practice regular SMBG showed poor compliance with medication, as they were unable to realise the immediate impact of non-compliance on their glucose level. This situation is seen to be in parallel with the

findings of a large scale systematic review conducted in the United Kingdom, which reported that SMBG is beneficial in guiding patients to make decisions that can have a positive effect on behavioural modification, including diet management, engagement in regular physical exercise and medication compliance (Clar et al., 2010). Therefore, it can be suggested that SMBG among the patients in this study provided valuable benefits for their compliance with medication, and increased their confidence and interest in managing their diabetes properly.

6.3.1.3 Use of alternative medicine

Alternative medicine, such as herbs including *ginseng* (a Chinese herb) and *spirulina* (dried cyanobacteria), was commonly used by the patients in this study as one of the methods to control blood sugar level. This practice is becoming common as these kinds of medications are widely sold in Malaysia, and some have been recognised by the Ministry of Health as complimentary medicine (Ministry of Health, 2011). Patients opted to take alternative medicine for various reasons. For instance PT 2, a 62-year-old man, believed that taking conventional medicine for the long term would cause more harm to his body. Thus, he admitted that he had skipped several types of medication prescribed by doctors, as demonstrated in his extract below:

'...there are too many medications. I think that was troublesome. Everything they [HCP] wanted to give. I just concentrated on the diabetes and did not bother much about other things [medication]. Frankly speaking, the more you take medications, the faster other illnesses will come.' (PT 2)

Although he did not clearly mention his practice of taking alternative medicine, he did state that he was not against alternative medicine and had tried several types of medication previously as suggested by relatives, but had stopped as he did not see any difference in his glucose readings. Other patients also confirmed that their decision to take alternative medicine was influenced by suggestions and experiences of other patients and relatives who claimed to have observed the effectiveness of herbs. This situation was frequently seen in patients who were newly diagnosed with diabetes. The interviews indicated that patients were often unable to accept their diabetes at the early stage of diagnosis. Thus, they tended to seek alternative ways to get rid of it. When they were told about the effectiveness of certain herbs, they often tried them

despite the fact that these herbs have not been clinically proven to be effective. This can be seen in the excerpt below:

'In the last few weeks, I tried alternative medicine [herbs] and had stopped my intake of metformin. The herbs have been advised by other patients who were able to control their blood sugar level after consuming them. I also eat bitter gourd every day.' (PT 17)

Another reason that contributed to the use of alternative medicine among the patients was their understanding of, and beliefs about, diabetes. Most of the patients assumed that diabetes is related to 'something sweet' in their body. Therefore, they believed that the sweetness of diabetes could be neutralised by eating something bitter or sour. These beliefs influenced their practice. Some patients consumed lime juice after eating a large amount of rice and sweet drinks, as they believed that the sour taste of lime would counter the sugar content in the rice and drinks. In addition, some patients drank a lot of plain water after eating sweet foods as they believed it would neutralise the sweetness. Furthermore, many of the patients ate foods with a bitter taste, such as bitter gourd and herbs made from plant roots or leaves, as they believed the bitter taste would compensate for the sweetness of the other food and reduce their glucose level. The extract below highlights an example of the use of alternative medicine:

'I have tried some of the tips and traditional remedies that have been advised by relatives, and what I have found from the internet. I have practiced two types of alternative medication. First, I boiled bamboo leaves and drank the water. It was very bitter. Prior to taking the herb, my blood sugar reading was 25 mmol/L. After consuming the herb, my blood sugar reduced to 11 mmol/L the next day and it remained between 11–13 mmol/L. Other than that I also eat caramel [normal sugar boiled until it turns dark brown/black] and the taste is also bitter.' (PT 16)

The narrative above shows that a reduced blood glucose reading, which was thought to be associated with the intake of alternative medicine, increased the patients' confidence in the effectiveness of alternative medicine. Their satisfaction with the perceived effects of alternative medicine frequently reduced the patients' compliance with conventional medicine. From the findings of the interviews, it can be suggested that patients who opted for alternative medicine usually lacked knowledge and found it difficult to accept the diabetes diagnosis. This situation drew them to alternative

medicine, although it was clearly irrelevant (such as eating caramel, which originates from sugar, as practiced by PT 13). However, the doctors that participated in this study claimed that they were unable to change the health beliefs of patients towards diabetes, as these beliefs are rooted from within their culture. Therefore, patients who took alternative medicine were closely monitored on their sugar control, liver function and renal function to ensure their intake of alternative medicine would not cause further harm.

A similar trend regarding the use of alternative medicine was reported in a study by Yoon and Kim, (2013) conducted in Korea. Their findings showed that 89% of 124 patients in their study had used alternative medicine for various reasons, the most common reason being chronic diseases. Similar to the findings of the current study, Yoon & Kim (2013) also reported that factors contributing to the use of alternative medicine in their study included: suggestions by former patients, friends and relatives, and satisfaction with the effects of alternative medicine in relieving the symptoms. In addition, it can be understood that the use of alternative medicine is common in Asian countries such as Korea and Malaysia, and it is influenced by several specific factors, including cultural practices, health beliefs, geographic and regional characteristics and socioeconomic factors (Cheung, Wyman, & Halcon, 2007; Yoon & Kim, 2013). Therefore, it is apparent that the use of alternative medicine in Malaysia is heavily influenced by the culture and health beliefs of Malaysians on complementary therapy and the usefulness of herbs in relieving disease symptoms (Hasan et al., 2011).

6.3.2 Factors influencing self-care

Another aspect explored in this study was the factors influencing patients' engagement in self-care activities including diet control, physical exercise, medication compliance and SMBG. Data from the interviews indicated that factors influencing patients' engagement with self-care consisted of two aspects: facilitators and barriers to self-care. Each of the factors is now explored in detail.

6.3.2.1 Facilitators to self-care

Facilitators to self-care were identified as factors that motivated the patients to manage their diabetes properly, and to adhere to the elements of self-care. Five categories emerged to explain the factors that facilitated the patients to engage in self-care: fear of complications, their awareness to change, religious beliefs, relationship with HCPs and support from others.

6.3.2.1.1 Fear of complications

Patients' feelings on the importance of self-care revolved around their understanding of the dangers related to diabetes. Most of the patients described diabetes as a devastating disease that causes destruction to the body. The possibility of complications was of primary concern for the patients. Moreover, many patients claimed that it is the most common aspect discussed by the HCPs when they were diagnosed with diabetes. This is explained in the extract below:

'I had a discussion with the doctor. He said that this illness is serious. It can cause damage to my kidneys, I will have problems with wound healing, there are people who lose their limbs and if it affects my eyes, I could go blind.' (PT 2)

Another woman expressed similar a understanding of, and feelings about, diabetes:

'When the doctor told me that I have diabetes, I actually didn't know what it was. The nurse told me that diabetes is 'sweet urine'. They (the HCPs) also showed me pictures of people with the leg being cut off because of diabetes. Then I knew diabetes was dangerous. It made me scared.' (PT 12)

Furthermore, content analysis of pamphlets and posters, and observations of consultations, consistently showed that complications from diabetes were most frequently emphasised. It was noted that this was done in order to increase concern, awareness and fear among the patients. The photographs in the pamphlets and posters were usually taken from previous cases that had unpleasant complications from type 2 diabetes. Therefore, it could be interpreted that 'scare tactics' are widely used within the Malaysian healthcare setting, as a method of increasing the motivation and

awareness of patients on the importance of self-care to avoid them ending up with such complications. During one consultation session, for instance, it was observed that reminding patients of diabetes complications appeared to be the main discussion point. This is demonstrated in the researcher's observation field notes below:

Observation of consultation between diabetes educator (DE) and Mrs A.

Observation was conducted between Mrs A and DE in a diabetic consultation room in a primary-care clinic. After completing the eye assessment, Mrs A was asked to sit next to the computer. The image of the eye fundus was shown to Mrs A. The DE explained to Mrs A that her cataract had worsened, with increased white patches in the right eye fundus. Mrs A kept quiet and listened to the DE's explanation. She did not ask any questions. When the DE asked whether she understood what she had been told, she just nodded her head and stared at the floor. Mrs A was then instructed to sit down on a lazy chair and the DE sat down in front of her. Mrs A was asked for her record book. The DE reviewed Mrs A's diabetic record and told her that her HbA1c trend was high. Mrs A's HbA1c result had increased from 12.6 mmol/L to 13.4 mmol/L. When asked whether she knew her glucose level, Mrs A just nodded her head. The DE shook her head and continued to the foot assessment without further questions on Mrs A's concerns regarding her blood glucose level. Mrs A's feet were checked for any signs of ulcer or deformities. The DE asked Mrs A whether she did any exercise at home. Mrs A replied that she did not do formal exercise, but did house chores and sewing most days. Mrs A was told to wear proper shoes and to inspect her feet for any signs of blisters or skin breaks every night before bed. Mrs A just kept quiet and listened to the DE's explanation. In addition, Mrs A was shown a picture of a bad foot ulcer and warned about the possibility of facing the same problem if she did not properly control her sugar level and did not look after her feet. Mrs A looked worried and said 'that is the thing that I worry about the most.' (Observation field notes – April 2013)

It was apparent from the field note that complications were a major concern for the diabetes educator, and the patient was continuously reminded about this throughout

the consultation. Other aspects which were more relevant to the patients' practice of self-care, for example: patients' perceived difficulties that contributed to the inability of her to maintain good glycaemic control was not properly explored by the diabetes educator. Therefore, it could be presumed that Mrs A's problem with diabetes management and the reason for her poor diabetes control may not have been clearly understood by the HCP.

Reminding patients about complications using 'scare tactics' is partially successful in increasing patients' awareness of the need for behaviour change (Witte & Allen, 2000). It seems that the use of scare tactics increased their feelings of fear towards the threats of complication, and this was used by the HCPs in this study to increase the patients' awareness of the importance of controlling their blood glucose. In this study, the impact of this method of increasing understanding and awareness of the patients on the dangers of diabetes could be identified via interviews with several patients. For example, PT 7, a 59-year-old woman, explained her views and beliefs about diabetes and its complications:

'We know that as we have diabetes, we might get a lot of complications. I had also seen a lot of examples from people who had diabetes and needed to have a leg amputated, or have dialysis...So I am scared about ending up the same way. I think I need to control it before it becomes worse.' (PT 7)

The above quotation illustrates PT 7's fear of complications and awareness of the need to control the diabetes to avoid complications. Besides being reminded by the HCPs, self-experience or observing others' complications also increased the patients' consciousness and efforts to control their blood sugar level. This is outlined by PT 15 below:

'I had experienced a wound on my sole and it took a long time to heal. When I had that, then I realised the effect of diabetes on my body and it increased my awareness of the need to control it. But we have choices...In my opinion, once we have diabetes; actually we can control it if we have knowledge about it.' (PT 15)

From the extracts above, it is obvious that a high perception of vulnerability to complications incited fear among the patients, which increased their awareness of the importance of controlling and self-managing their diabetes. From the interview data, it was seen that perceived susceptibility and threats of complication were facilitating factors for the patients in this study to engage in self-care. Furthermore, another aspect that reflected the patients' understanding and awareness of diabetes complications was concern about future burdens and hopes for their future life. As presented in chapter six, the majority of patients in this study were still in the productive age group, and had a responsibility towards family. This group of patients expressed their enthusiasm to manage their diabetes properly as they were looking forward to having a quality life despite living with diabetes. As such, their worries about possible complications increased their engagement in self-care activities, as explained by the patient below:

'Sometimes...It comes to my mind, what will happen in the long term when I am old...If my leg is amputated. I am afraid I will burden my children. That's what usually comes to my mind. Then I will need to spend a lot on the treatment. I don't want to burden my family with my health problem. So that's what makes me feel that I want to try to follow what has been suggested by the doctor and nurses here. I've seen the experience of my sister in law. She had diabetes and it was very bad until the doctor needed to put a wire through her neck...I think it was for haemodialysis. Her blood sugar was very high and uncontrolled. I am afraid I will end up like her.' (PT 6)

Besides getting information from the HCPs and self-experience of diabetes complications, observing others suffering from complications also elevated concerns about the possibility of being a burden in future. Furthermore, the role of the patients as a husband, wife, father or mother also resulted in high motivation to manage their diabetes as they were worried about the future of the family if they were unable to carry out their role. These two aspects were major facilitators for the patients to engage in and adhere to the self-care measures suggested by the HCPs. From the data presented above, it seems that understanding and awareness of complications provided a positive effect on engagement in self-care for certain patients in the study.

However, findings from other studies vary. A study by Mathew et al. (2009), for instance, reported that scare tactics did not provide any significant effect on improving patients' adherence, motivation or interest in diabetes management. In fact, it had negative effects on the patients as they usually felt incompetent and had 'hurt feelings'. Therefore, it is likely that the awareness that the patients gained from a fear of complications would not continue for the long-term. Furthermore, it was noted that a fear of complications sometimes overwhelmed certain patients in the current study, and they interpreted it as 'living in fear'. This condition incited stressful feelings, which made patients feel hopeless, as illustrated in the extract below:

'After I found out that I had diabetes, all of the negative feelings came into my mind. I was scared to eat anything and kept on thinking about my future. How can I get married with this illness and how I will live my life after this...? Another thing is...I am not yet married. So, some people had told me that because I have diabetes, I could get erectile dysfunction (ED). This made me even more scared. The people around us will straight away judge us...When they knew that I have diabetes, they immediately told me that I would have ED. I might not have children. That is really stressful!' (PT 10)

Contrasting views identified pertaining to the patients' perceptions of complications suggested that the use of scare tactics may be effective for certain patients, but might not work for others, especially those who are still at a productive age and looking forward to a quality life. This method of motivation may threaten their motivation to live with diabetes. From the narratives, it is clear that each patient had different understandings and perceptions of diabetes. Furthermore, the patients' perceptions of diabetes and its complications were influenced by many factors, including experience of complications and information received from HCPs, and also reading materials or lay understandings by relatives and friends. Therefore, using scare tactics to motivate patients to engage in self-care, without having concern for the patients' individual psychosocial situation, might provide a different effect on different patients – that is, it could benefit or demotivate them.

6.3.2.1.2 Awareness to change

Most of the patients claimed that diabetes had been caused by their mistakes and previous unsuitable lifestyle. Most patients expressed their regret about not practising a healthy lifestyle prior to contracting the diabetes, although they had been reminded about it. From the interviews, it was understood that most of the patients practised a sedentary lifestyle with a high intake of carbohydrates and sugary foods and drinks prior to contracting diabetes. The patients were also aware that the reason they had been diagnosed with diabetes was related to their ignorance of proper diet management. The patients frequently showed knowledge on the need to follow a healthy lifestyle to avoid getting diabetes. However, several factors were perceived by the patients as challenges to a healthier lifestyle, although it was frequently emphasised through health education talks, advertisements and information in the media:

'We know we cannot eat excessive sugar. But as you know in our routine diet...And the nature of my work means I work outside the office on investigations [PT was a corruption commissioner]. So when we go outside, the tendency to eat is very high, especially if we go out in group after work, we will have tea at a mamak stall and have teh tarik and paratha...That is our normal routine. We also do not think about the consequences of the food that we eat.' (PT 13).

Having tea at a *mamak* stall (stalls/restaurants owned by Indian-Muslims in Malaysia) has become a common lifestyle choice for people in Malaysia, especially in urban areas such as Kuala Lumpur and Putrajaya. Tea with sweet condensed milk and *paratha* is reported to have a high sugar and calorie content, and is thought to be a major contributing factor to the incidence of diabetes in Malaysia and Singapore (Norimah et al., 2008; Odegaard et al., 2008). However, despite their harmful effects, these types of food and drinks were commonly consumed by many participants in this study. Another man also explained his awareness of the inappropriate lifestyle that caused his diabetes:

'Before being diagnosed with diabetes, my lifestyle was not very healthy. I was a heavy smoker. I think, in terms of physical activities I don't have much of a problem. But the most important thing that contributed to my problem was, I was not really looking after my diet.' (PT 10)

Feelings of regret and disappointment about previous lifestyle practices were repeatedly expressed by the participants in this study. Unsuitable diet control was identified as the main reason for them losing control of their diabetes, as stated by the patient below:

'Our company's clients always entertained us with food. They always brought us to good restaurants, morning or evening, because they wanted to keep doing business with us. Because of this, I had a lack of control over my diabetes. You know, sometimes I needed to entertain my bosses. If they called me for lunch or dinner, I had to go. If I did not go, it would not be nice, would it? So, I couldn't control my diet.' (PT 3)

The narratives illustrate the difficulties that the patients had in practising a healthy lifestyle, although they knew it was important for them in order to avoid any chronic diseases, including diabetes. From the narratives it can be seen that the social factors, including environment, nature of work and lifestyle routine, were perceived by the patients as factors that were strongly associated with their diagnosis of diabetes. It was obvious that the patients frequently placed high concern on the problem with diet control that resulted in their diabetes. Therefore, most patients tended to blame themselves because they were unaware of the consequences of their actions. However, they rarely mentioned other aspects that also contributed to their diabetes, such as a lack of physical activities and smoking (Tuomilehto et al., 2011). The patients seemed to be aware of the need to change their eating habits, but indicated that they might continue the sedentary lifestyle that would result in ineffective behaviour change in the long term.

In essence, it can be understood that the patients were fully aware of the previous lifestyle factors that contributed to their diabetes. Feelings of regret and disappointment often provided positive effects that contributed to a change in attitude. Upon diagnosis, most of the patients demonstrated an awareness of the need to change their previous lifestyle to ensure that the diabetes would be well controlled. Most of the patients expressed their awareness of the need for engagement in self-care activities, as illustrated by the patient below:

'When I found out that I had diabetes, I started to change my diet routine. The amount of food eaten became smaller compared to before. I usually fast...Not only due to my worship of God, but also as a way of controlling my diabetes. I have made changes in my routine. Even my cooking methods have changed. I reduced my intake of coconut milk and began to eat less fatty food. I asked my wife to cook more soups and steam food. We tried to eat more vegetables. We try our best to follow the suggestions.' (PT 15)

Another study also showed that the patients' awareness of the need for lifestyle modifications seemed to be high at the beginning of the diagnosis (Skinner & Lawrence, 2002). However, Skinner & Lawrence (2002) highlighted that an awareness of the importance of self-care can be difficult to sustain, and most patients tend to revert back to their old lifestyle several months or years after the diagnosis. The same situation can be expected in the current study. Feelings of disappointment and awareness on the need for lifestyle modifications following their diagnosis can be seen as factors that increased the patients' engagement with self-care. However, patients commonly highlighted the difficulties and challenges in self-care that were frequently associated with their social environment and life situation. Therefore, it could be argued that the patients might have experienced difficulties in sustaining their self-care practice, which should be a major concern of diabetes management provision within the healthcare system.

6.3.2.1.3 Relationship with HCPs

Another category which emerged as a factor that facilitated patients' engagement in self-care was their relationship with the HCPs. Most patients perceived that engaging in self-care was meant by following the advice of HCPs. Although the patients commonly perceived that self-management of diabetes is their own individual responsibility, and that they must decide on the best approach according to their life situations. However, they usually acknowledged the advice and support given by the HCPs. This is illustrated in the narrative below:

'I think they (the HCPs) are very helpful. They give us an understanding about our condition and what to do to handle it. In my experience, the doctors here are very good. Even the nurses are very concerned about us. I think it depends

on the patients themselves how they want to look after their health. How they accept their disease.’ (PT 13)

Generally, patients expressed their awareness to change and described the importance of self-care for managing the diabetes. However, most of the patients suggested that in order to achieve good glucose control they needed to follow the suggestions received from the doctor and nurses:

R: ‘So, do you actually understand how to manage the diabetes?’

PT: ‘I think I quite understand what diabetes is and I had some knowledge about it. But when they told me how to look after myself and what I should do, I just followed whatever I was advised to do. I just continued whatever my routine was and followed their advice. I never missed my follow ups with the doctor or nurse.’ (PT 14)

The data presented in this chapter shows that the patients achieved a certain level of understanding and a sense of responsibility for their body. However, the patients frequently perceived that HCPs have a great deal of knowledge and qualifications to talk and give suggestion about the management of diabetes, and that their advice is meaningful. Thus, most of the patients perceived it as important to follow the advice of the HCPs in order to achieve good control of their diabetes. This was expressed by one patient as follows:

‘I think the most useful help that we can get is still to come here, meet the doctor and discuss it with them. When I had a consultation with the doctor, I felt better because they have the right qualifications to talk about the matter.’ (PT 10)

The influence of the HCPs on the self-care practices of the patients could be augmented by a positive relationship, and the sense of respect that the patients have for the HCPs (Fox & Chesla, 2008). However, based on the findings from the interviews and the observations from this study, it can be argued that the patients’ engagement in self-care partly contributed to their concerns about receiving unpleasant feedback from the HCPs if they were unable to achieve the targeted glucose control. The HCPs’ explanations and reminders about self-care were perceived as intimidating, and made the patients feel it was crucial for them to follow the advice to avoid being scolded. One of the patients expressed this as follows:

'The doctor always told me, "You did not look after your diet very well. If you continue like this, you will need to take insulin injections". I also never discuss my problem with the nurses. Because every time I come, they just check my eyes and foot. They just tell me that I need to reduce my rice intake. That's all. I understand, but I can't tell them that I don't have any other things to eat except rice...Yesterday I was scared to eat rice because today I need to do blood tests. I am afraid of my blood sugar becoming high because I eat too much rice. So, I refrained from eating rice and I hope my blood sugar will be not that high today. I am really scared about my health now. I don't know how to tell you.' (PT 12)

Another woman also spoke about a similar experience:

'The doctor just knows how to scold. He kept on asking me why my sugar level was always high. Every time I saw the doctor he ask the same question: "Why is your sugar level high?" When they ask that I am speechless...I don't know what to say. Luckily here we have the educator, who I feel more comfortable with.' (PT 4)

The researcher also witnessed an intimidating approach used by the HCPs in telling the patients about their mistake in diabetes management. This is demonstrated in the field notes below:

Observation of consultation between diabetes educator (DE), Dr T and Mrs S

Mrs S had had diabetes for more than 10 years. She attended regular follow-up sessions with a physician and diabetes educator at the Specialist medical clinic to get treatment and support to manage her diabetes. A consultation with Mrs S in a meeting room at the Specialist medical clinic, which is used as a consultation room, was observed. During the observation, there were four DEs consulting different patients and one doctor sitting at a round table. Mrs S was scheduled to see SN N, DE in charge. She had shown her documentation of blood sugar monitoring to the DE. The DE asked Mrs S about her dietary intake and insulin dosage. Mrs S calmly answered the questions. As Mrs S's blood sugar level was high and not properly controlled, the DE asked Dr T, who was on standby in this room, for his opinion. Dr T discussed Mrs S's problem (with medication compliance) with the DE based on her blood glucose reading and insulin dosage. Dr T asked Mrs S about her dietary intake because Mrs S's blood sugar level was poorly controlled despite the high dose of insulin prescribed. Mrs S was asked many questions at once. Dr T was straight-faced, and he

looked at Mrs S with wide eyes because Mrs S was unable to manage her diet properly. Dr T asked the same question a few times ('Did you follow what we had told you before?') in a loud voice, and Mrs S just kept quiet and looked at the table. (Observation field notes – March 2013)

From interview and field note extracts, it can be understood that the patients were expected to follow the suggestion provided by the HCPs and achieve the intended glucose control, regardless of the difficulties faced by them in living with diabetes. From the extracts it is also apparent that the patients felt they had done their best to follow the advice of the HCPs, as they were afraid of the complications. However, social problems, such as the financial limitations faced by PT 12, made it difficult for the patients to follow the suggestions given. It was also apparent that the communication between the patients and HCPs was very restricted and frequently one way, with the doctors or diabetes educators focused on providing information and suggestions on self-care activities. Furthermore, the scolding and intimidation used by the HCPs, as highlighted by the patients, restricted patients' willingness to discuss the difficulties they experienced in self-managing their diabetes. Therefore, they frequently chose to follow whatever was advised by the HCPs although it was difficult for them. Chances to discuss personal and social problems that contributed to their uncontrolled diabetes were limited, as they were never asked about them. This is also revealed in the extract below:

'During the consultation, the suggestion given was detailed and good, but it was more about prevention. They rarely asked about the problems that we face at home that makes us unable to control out glucose level properly.' (PT 15)

In addition, the patients mentioned that they rarely had chances to talk to the HCPs outside of their appointment session, which made them feel helpless if they faced problems related to following the suggested self-care regimen:

'When I saw the doctor, I only had the chance to see him for about 10 minutes, although I had waited since morning. In fact, we only have a chance to talk to them during the follow up session. When they give us medication they do not explain anything. If they explain it, they usually do not explain it in detail. They doctor only explains when asked. So we have no choice except to follow whatever they tell us.' (PT 11)

From both of the narratives above, it is apparent that issues related to patient–HCP communication seem to be a central point influencing patients’ engagement in self-care. The patients perceived that the HCPs played a major role in facilitating their self-care management. However, poor communication skills, which were often shown by the HCPs, induced feelings of frustration among the patients. Therefore, the patients often suggested that they followed the self-care regimen just for the sake of pleasing the HCPs and to avoid unpleasant feedback. The situation found in this study is very different to that suggested in the literature with respect to motivating patients to engage in self-care. A study by Martin et al. (2005) conducted in United States, for instance, highlighted that the patient–HCP relationship is essential in maximising patients’ adherence with and engagement in diabetes management. Similarly, a systematic review of barriers to diabetes management reported that a positive relationship and good communication between patients and HCPs has been proven to provide better diabetes self-care and positive outcomes in diabetes management. Reflecting on the situation of the patients and HCPs in this study, it can be suggested that the patients had trust and high respect towards the HCPs; however, poor communication between the patients and HCPs, as evidenced by the interview narratives and observation field notes, limited the patients’ opportunities to discuss their psychosocial-related problems. Therefore, patients’ self-care practices were not augmented by mutual trust and collaboration between the patients and HCPs (Martin et al., 2005), though it was influenced by feelings of fear in the patients towards the HCPs. This restricted the HCPs from understanding reasons for the patients’ inability to manage their diabetes effectively.

6.3.2.1.4 Religious beliefs

The category of ‘religious beliefs’ related to the patients’ acceptance of diabetes. Most patients in this study were Muslim, except for two who were Hindu and one who was Buddhist. When asked how they accepted diabetes, most claimed that they had accepted it positively as they regarded diabetes as a test from God. Most of the patients, regardless of their religion, believed and had confidence that God is the creator of human life and gave them the disease, and would thus help them find a cure

for it. Therefore, it was apparent that the patients used their religious beliefs as a coping strategy in facing and accepting the diagnosis of diabetes and enduring life with diabetes. The Muslim participants, for instance, regarded diabetes as a reminder from Allah (name of God in Islam); they believed that Allah is the best planner and were confident that every illness comes along with mercy. Acceptance and confidence in the power of Allah did not reduce their awareness of, and motivation to manage, the diabetes. They even became more motivated as they believed that they needed to try their best to look after their bodies and keep praying for forgiveness and a cure from Allah. They strongly believed that life and death is in God's hands. Thus, as humans who had been given the disease they needed to keep trying to overcome it and leave the rest to Allah. This was stated by one patient as follows:

'I considered this disease as a test from God. To this point I have been healthy, so I believe that God may want to test me by giving me this illness. But the test doesn't mean that we just accept it without doing anything to treat it. As humans, we also need to try to find a way to manage and cure it if possible.' (PT 13)

Another patient also outlined a similar view:

'We have to believe that this is all from Allah. Always believe...Ask for help from Allah, He is the one that gave us this illnesses and will give us relief. Despite our confidence and belief in the power of Allah, this does not mean that we can do anything we like. That is wrong. Allah asked us to make an effort to make ourselves better. I am already 66 years old; my turn will come anytime [to die]...Only Allah knows when. As humans we can't do anything.' (PT 2)

Submission and remembrance of God/Allah provided psychological relief to some patients, who reminded themselves that God had sent the disease for certain reasons, which they believed would benefit them in some way in this world and the hereafter. This finding seems to be in parallel with a previous study conducted. Focus group interviews conducted by Samuel-Hodge et al. (2000) on 70 Southern American women with type 2 diabetes also found that religious beliefs influence patients' self-management of diabetes. Similar to this study, Samuel-Hodge et al. (2000) reported that religious beliefs and confidence in God provide strength for patients to face the challenges associated with diabetes. Their strong religious beliefs become an

emotional support tool that has a positive influence on their health (Samuel-Hodge et al., 2000).

6.3.2.1.5 Support from others

Support received from others, including spouses, parents, family members, relatives and friends was claimed by the patients as another facilitator for them to engage in self-care. As most of the patients that participated in this study were married, their spouses were recognised as the nearest person and the main one to support them in managing their diabetes. From the data, it was found that male patients totally relied on their wives to help them manage their diabetes, especially in preparing proper food and medication and reminding them of the do's and the don'ts in diabetes management. This can be seen from the extract from PT 5 below:

R: 'What are the things that motivated you to change your lifestyle?'

P: 'I think...it's my wife. It was really support from her. She really understands me and always encourages me to do exercise. She will accompany me on morning walks so we can walk together. Another thing is about diet management, I think I need to make some adjustments. I need to talk to my wife because she is the cook.' (PT 5)

The female patients claimed that the decision to manage their diabetes was totally on them, as they were the cooks and carers of the family. However, they still acknowledged the contributions of their husbands in giving advice and reminders to ensure their adherence to the self-care regimen.

'I think because a role of a mother. You know children...They always request to eat this and that and as a mother, I will cook whatever they request. So, when I cook, of course I will eat the same thing, won't I? So that makes it a bit hard for me to control my diet. But I can't blame them because they are children and they don't understand my problem. We usually keep supporting each other and share any information that we have related to diabetes management.' (PT 4)

The contribution of spouses towards helping with the management of diabetes was confirmed by the patients as the main reason for practising self-care. In addition,

contributions of others, including children, relatives and colleagues in terms of giving advice and respecting their diet restrictions were also seen as an important element in supporting self-care. The patients thought that the concerns of other people and their surroundings regarding their need to control their diet would create a conducive environment to increase their adherence. This seems to be in line with the findings of a study conducted by Wen et al. (2004) among 138 Mexican-American participants with type 2 diabetes. The study also reported that patients who had good family support showed greater confidence in self-care and high adherence to diet and exercise. In addition, the study showed that patients who received support from family members and immediate relatives showed higher adherence towards diet control (Wen et al., 2004). This study supported the findings of the current study, wherein support from family and significant others seemed to be one of the important factors facilitating patients' engagement with self-care.

6.3.2.2 Barriers to self-care

Despite the factors that facilitated the patients' self-care, several factors were considered by the patients to restrict them in this regard. These included uncertainty and frustration in practice, feeling healthy, Malaysian environment and dietary culture and time limitation. Each of these factors is revealed in the narratives below.

6.3.2.2.1 Uncertainty and frustration with practice

Although the patients repeatedly revealed their awareness of the importance of practising self-care to control their diabetes, they frequently expressed feelings of uncertainty regarding the management of diabetes, as the information received was often unclear and difficult to adapt to their daily lives. This is evident in the extract from PT 12 below:

'The doctor told me that diabetes would cause many problems with my eyes and my kidneys. They said that if I don't want to end up with dialysis, I need to look after my condition very well. I actually don't know what to do. They just told me that I can't eat much rice as it will cause my blood sugar to rise

because rice contains sugar. But I don't know how much I should eat every time.' (PT 12)

As highlighted in the previous sections, several patients in this study revealed a good understanding of the types of food that causes blood sugar to increase. However, many of the patients claimed that information given by the HCPs was very general and superficial, and do not help them manage their diet as intended. They frequently did not fully understand what they should do to manage their condition. This led to inappropriate practices, which could have worsened their diabetes. PT 16, for instance, who had been diagnosed with diabetes for less than two months, explained his incomplete understanding of the contents of foods he ate, which made his diabetes remain uncontrolled despite his diet management:

'I actually didn't know that the rice itself contains sugar. So I just ate like usual, but I began to drink tea without sugar or just drink milk. But at the same time, I drink a lot of plain water. I try to avoid sweet food, cakes or drinks. For instance, I avoid bread with jam and changed it to sliced wholemeal bread.' (PT 16)

The narratives demonstrate that patients often faced problems in making decisions on suitable food and drinks that would not cause their blood sugar to increase. This situation seemed to be exacerbated by their lack of knowledge and unclear information received from the HCPs. This led to feelings of uncertainty and a lack of confidence in managing their diabetes during their everyday lives:

'I am afraid of whether the drinks or food that I want to eat have too much sugar. Of course we can read from the label the amount of sugar content in drinks. But I am still in doubt as to whether the information is correct and reliable. I don't know what things I can consume. Moreover, I hear a lot of suggestions and advice from other people that I can't eat this and that I need to use sweetener instead of normal sugar. So this makes me confused.' (PT 10)

This shows that the patients' self-care practice was restricted due to a lack of information on the practical aspects of each element of self-care. As repeatedly mentioned in the examples above, the patients seemed to have difficulties in making food selections. Furthermore, feelings of uncertainty and a lack of confidence in

making decisions pertaining to their self-care activities contributed to their feelings of frustration, which made them revert to their normal lifestyle. Therefore, it is expected that without clear explanations, guidance and continuous psychological support, patients tend to feel frustrated and hopeless with respect to managing their diabetes, which results in a lack of motivation to incorporate self-care into their daily lives.

Another element that increased the patients' frustration and restricted their engagement in self-care was a difficulty in adapting self-care elements into their daily routines. The patients frequently expressed that their life schedules were too tight and they were too attached to their everyday routines. Thus, adding some activities and changing the routines that they were already comfortable seemed to be necessary. This was frequently stated by the patients, as revealed in the narrative below:

R: 'What do you do that limits you from practising what has been suggested?'

P: 'What I see here [i.e. in the activity plan created by the dietician], eating five times a day...Actually, I think it is quite hard for me to achieve this. Because when I am at work, I rarely eat lunch as I rarely have the chance to have a break during lunch time. Most of the time I need to work throughout lunch time and I am only able to eat in the evening. Another thing is that when I need to attend courses or workshops away from my office, my meal times are usually not fixed. That is also something that I need to consider.' (PT 16)

Difficulties related to lifestyle modification and adaptation of self-care activities into daily life routines have frequently been reported in the literature. In fact, this has been reported as the most difficult aspect to be implemented (Magkos et al., 2009). A Study by Rahim-Williams (2011), for instance, reported that lifestyle modification in patients with type 2 diabetes can only be achieved when self-care activities are mutually planned based on patients' life circumstances, health beliefs, and availability of support systems and resources. Reflecting on the situation in the current study, it seems that the self-care activities were suggested by the HCPs based on their knowledge and experience of dealing with patients with diabetes. The patients' preferences and personal life situations were rarely considered or discussed by the HCPs. Therefore, it could be argued that suggestions regarding self-care activities

provided by the HCPs in the current study are frequently incompatible with the existing life situations of the patients.

Frustrations regarding practices also frequently referred to perceptions of the ineffectiveness of medication at controlling blood sugar level. For instance, PT 4, who had been diagnosed with diabetes for more than 10 years, was prescribed high doses of insulin and monitored her blood glucose regularly. She expressed feelings of stress and frustration because her blood sugar level remained high despite compliance with the high dosage of insulin and diet control:

'I am always being scolded because my sugar level is always high. Actually, I feel sad...Because I don't know what to do to bring down my sugar level. I really hope there is another medication that can help me to bring down my sugar level. Or is it because of my high dose of insulin that I currently take? Because I read from the internet that there are several types of insulin available. But I am not sure whether the insulin that they give me right now is really suitable for me.' (PT 4)

Furthermore, PT 4 also expressed her frustration at a lack of support from the HCPs between appointments. This made her felt detached from the HCPs; thus, she opted to search for information from the internet and decided to practice whatever she felt right about without being able to discuss it with HCPs. This was revealed during her interview:

'There is no support between appointments. I just do it myself. I just browse the internet and get the information myself. I have never received any calls from the hospital – neither nurses nor doctor. So, it really depends on me as to how I manage it. If I have any problems or doubts during those times, I just browse the internet and get the information. I think that has helped me to understand diabetes better.' (PT 4)

As frequently presented by the narratives in this chapter, the patients were commonly told to manage their diabetes properly and maintain a normal glucose level. However, they frequently expressed that they were not being clearly told how to do this, and the support that they received from the HCPs was suggested to be very limited. Thus, many patients looked for information from the internet and other sources, and used

trial and error to manage their diabetes. As they were not being closely monitored and only had the chance to see the HCPs every three months, they frequently expressed feelings of being overwhelmed with uncertainty and frustration, which made them ignore the need to practise self-care, although they were aware of its importance. This situation was expected to be worsened as the patients' difficulties in adhering to the self-care regime were not commonly discussed with the HCPs, as evidenced by the field notes below:

Field notes of post-observation interview with Mr A

Mr A, aged 49, had been diagnosed with diabetes for three years. Mr A's consultation with the DE was observed. After the consultation, I asked Mr A whether I could speak with him for a while. He agreed and I invited him to sit down on the sofa in the clinic lobby (the lobby was not very busy as it was lunch hour). Mr A revealed that it was his second consultation with the DE. According to Mr A, this was the first time he had been told how to look after his foot and how to manage his diet. I asked him whether he understood what he had been told. He replied that he understood most of the things said by the DE; however, he wondered why the nurse did not ask him what his routine activities were, or how he managed his diet. During this interview, Mr A stated that he visited a mosque regularly for dawn and evening prayer. According to him, food was frequently donated by neighbours after performing the prayer. The food that was usually available included sweet drinks and one or two types of *Malay kueh*. Sometimes they also served heavy food such as biryani rice after the night prayer, depending on the donation. He thought it impolite for him to just go back home without joining the mosque community in eating and drinking. Mr A thought people might think he was rude and did not want to mix with others. So he continued to join them. He asked my opinion regarding this, but I advised him to discuss this situation with the doctors or nurses. In the meantime, I suggested that he reduce his food intake in the evening to avoid his blood sugar rising and becoming difficult to control. (Observation field notes – April 2013)

During the interview, Mr A revealed feelings of dissatisfaction and frustration as the nurse did not consult with him about his routine activities, which he thought might affect his ability to manage the diabetes properly. From the interview, it could be observed that Mr A was worried about his current lifestyle; however, as it was not being explored by the HCPs, Mr A was left with feelings of uncertainty regarding what he could do to adapt the suggestions regarding self-care into his routine. Therefore, Mr A's problem and difficulties in engaging with self-care activities were left unattended, which might have led to a more serious situation related to his diabetes.

6.3.2.2 Feeling healthy

Self-care was not being regarded as important by several patients in this study as they claimed that they were healthy and did not experience any symptoms. They usually compared their health status to that of patients who had other chronic diseases, such as asthma and cancer, and stated that they were healthy and did not have any health problems. Moreover, being diagnosed with diabetes was seen as normal in Malaysia as it is very common. This influenced their perception towards diabetes, wherein diabetes was not usually seen as a dangerous disease that they needed to aware be of. This can be seen from the narrative below:

'People have already accepted it...Especially Malaysians. There are many people in Malaysia with diabetes. It has become sort of normal to have diabetes. Diabetes is not like people having AIDS. But diabetes...People here just said, "Okay...that's fine if you have diabetes". So we just have to control it. That's all. People accept it as a normal condition, as a lot of people in Malaysia have it.' (PT 5)

Despite being warned about the seriousness of diabetes complications, several patients in this study expressed that they did not see diabetes as a serious illness that may cause fatality. Furthermore, many patients did not monitor their diabetes regularly and were not aware of their glucose levels. Thus, they did not see practicing self-care as an important aspect. When compared to the previous themes presented in

this chapter, the patients' views in this theme seem to contrast those mentioned by other patients. Therefore, it is worth mentioning that this belief was held by certain patients who did not clearly understand the disease process and were unable to accept the diagnosis of diabetes as 'serious'. Therefore, it can be understood that the patients in this study had different views and understandings of diabetes, which influenced their willingness to engage in self-care.

However, several recent studies have suggested that patients usually have positive perceptions about the severity and dangerousness of diabetes, and emphasised about their struggle with adapting self-care elements (Carbone et al., 2007; Nam et al., 2011; Stiffler et al., 2014). Patients' positive perceptions and high awareness portrayed in recent studies were seen to have resulted from the large amount of work being done in this area to improve patients' perceptions and increase their ability to self-manage their diabetes (Funnell & Anderson, 2008; Funnell, 2010; Tang, et al., 2010). Although the findings reported in this theme have not been frequently reported in the literature, a study conducted in Thailand did report similar findings (Naemiratch & Manderson, 2007). The similar perceptions between patients in Thailand and Malaysia regarding diabetes can probably be attributed to the high incidence of diabetes in both countries, wherein diabetes is seen as normal and acceptable among the communities (Letchuman, et al., 2010; Aekplakorn et al., 2011).

6.3.2.2.3 Malaysian environment and dietary culture

The Malaysian diet is high in carbohydrates, fat and sugar, and most types of food consumed by Malaysians are not suitable for diabetes patients. For instance, rice and noodles, which are high in carbohydrates, are a staple food in many Asian countries, including Malaysia. Hence, changing rice to other types of food suggested by the HCPs, such as high-fibre bread and oats, was claimed by the patients as the hardest adjustment to make. Many of them claimed that they did not have a problem complying with medication, but giving up rice was a huge challenge, and many of

them were unable to do it. They even thought that the HCPs' suggestion of changing rice to other foods was 'awkward', as stated by the patient below:

'It is the culture. Malay culture. I was raised eating a heavy breakfast, with coconut milk rice, fried rice, or fried noodles. That is the breakfast routine in my family. We never had cornflakes, toast or oats...We got used to that routine. So, when the doctor or nurse asked me to change my breakfast to cornflakes or oats, it becomes very awkward.' (PT 10)

Furthermore, serving rice, noodles and sweet drinks in Malaysian shows the host's respect towards guests. Therefore, it is interesting to note that the culture of respect was identified as another factor that restricted the patients from engaging in self-care. It was noted that serving food to guests and sharing food with others is commonly practiced in Asia, particularly in Malaysia, as it shows respect and is a symbol of cultural conviviality (Philips, 2014). This situation was repeatedly mentioned by the patients in this study. Many patients expressed how difficult it was to decline if they were being served heavy foods and drinks every time they visited their relatives or attended special events, as they were afraid of being labelled rude, since that kind of attitude is not permissible in the community. This was exemplified by PT 17, a 29-year-old woman who worked as a social development officer. Her job involved visiting people's houses daily to identify social needs and problems. She stated that she was usually served sweet cakes, rice and sweet drinks when visiting these houses as a symbol of respect from the house owner. In her experience, it was difficult to turn these offerings down, so she still accepted them despite knowing the food was unsuitable for her, as narrated below:

'I work as a social development officer and I need to visit a lot of people's houses. Usually, they serve me sweet drinks and cakes. Of course it is not nice for me to say no and refuse the things that are being served. So I still need to eat them, although in small amounts. I also take plain water with me so that I can flush my system every time I eat sweet drinks or food. But now, I try to drink more plain water rather than sweet drinks.' (PT 17)

The environment was also seen as a barrier for the patients in adhering to diet control and other self-care elements. Eating outside at stalls and restaurants is part of Malaysian lifestyle, especially in urban areas. The majority of people living in Kuala Lumpur and Putrajaya work fixed hours (8 am to 5 pm); however, due to traffic, most

of them have to leave the house as early as 6 am and only arrive home at 7 pm. Therefore, the time for them to prepare food is very limited, which makes them frequently opt to eat outside. However, the food that is frequently available in restaurants is high in carbohydrates and fat, which is not suitable for diabetics. Therefore, most of the patients claimed that they did not have much choice, and that avoiding those kinds of food was a huge challenge. This situation made them frequently disregard the importance of self-care practices.

6.3.2.2.4 Time limitations for exercise

The last category that emerged to explain the barriers to practising self-care related to time limitations for physical exercise. From the data, it was apparent that the patients were more concerned about diet management, and little was mentioned about other aspects of self-care, such as physical exercise. The reason for this seemed to be time limitations, since all of the participants in the study lived in urban areas, spent most of their time at work, and had tight working schedules. Thus, many claimed that they did not have time to practice a healthy lifestyle or engage in regular physical exercise.

When asked about their participation in physical activities, many of the patients stated that they did not have time to do exercise as their day-to-day routine was too tight, from early dawn until late evening. Many patients said that they were only able to exercise during the weekend, but that it was not a priority, and that they only exercised if they did not have any other things planned during the weekend. Spending time with family and visiting relatives and friends were regarded as more important for the weekend than exercising:

'If you see my routine, I don't have time to do any exercise. The only thing that I can do is get back from work, cook and do some house chores like tidy up my house or do some laundry. So I don't do serious physical exercise...If I feel like I want to do some exercise, on Saturday or Sunday morning, for instance, I will go for a jog or brisk walk at the park nearby once I finish cleaning the house.' (PT 6)

In addition, most of the female patients in this study were married, and several of them were housewives. Therefore, they often regarded doing house chores every day as a sort of physical exercise which could reduce the glucose level; thus, engaging in structured physical activities was seen as unnecessary.

'If I am at home, I usually walk for exercise. I am usually going up and down the stairs. That is the exercise that I do. I do not go jogging or anything else because I am easily tired. I really don't do what has been advised like jogging. But at home, I do my house chores everyday, like sweeping the floor, wiping the fan, laundry, cleaning the bathroom...That's how I exercise' (PT 8).

6.4 Summary

Chapter six presented the participants' profile and findings of the study regarding the patients' self-care practice and factors influencing their engagement with self-care. Self-care of patients with type 2 diabetes in Malaysia can be summarised into three major aspects: the nature of self-care practices, factors that facilitate the patients' engagement with self-care and factors that restrict the patients' ability to practise self-care. The patients were seen to adopt three elements of practice in managing their diabetes: diet control, compliance with medication and use of alternative medicines. Furthermore, several personal factors pertaining to psychological and social aspects, spiritual beliefs, cultural practices, and their relationship with HCPs largely influenced their engagement with self-care, either positively or negatively. From the data, it can be understood that every individual patient in this study had different preferences regarding their self-care, depending on their health beliefs, experience with diabetes and life circumstances. In this chapter, it was also revealed that the patients repeatedly had their own views on the approaches to self-care support suggested by the HCPs, which also influenced their interest in, and motivation to conduct, self-care. In addition, communication barriers between the patients and HCPs emerged as one of the main contributing factors to poor engagement in self-care. It seems that HCPs are regarded as important individuals that are responsible for influencing patients' engagement with self-care. Therefore, it seems crucial to explore how patients with type 2 diabetes are managed and supported within the healthcare system, as this will help to explain the role and practice of HCPs and how these

influence patients' engagement in self-care. This aspect will be explored in the following chapter.

CHAPTER 7

Management of Type 2 Diabetes within the Malaysian Healthcare System

7.1 Introduction

The Ministry of Health Malaysia has reported that 75% of patients with type 2 diabetes in Malaysia seek treatment at healthcare facilities (Ministry of Health Malaysia, 2008). Furthermore, the findings of the previous chapter showed that the patients in this study acknowledged the importance of HCPs in helping them to manage their diabetes. Although they mentioned their dissatisfaction with their communication with the HCPs, the HCPs were still regarded as experts in managing type 2 diabetes. In fact, the patients perceived that complying with the HCPs' suggestions is essential to achieving optimal glucose control. Therefore, management of type 2 diabetes and self-care support provision within the Malaysian healthcare setting are important aspects to explore, as they seem to have a significant impact on patients' engagement in self-care. Hence, this chapter will describe the diabetes management provision and practice of self-care support at the case study sites. In addition, this chapter will provide an understanding of the extent to which the self-care concept is emphasised within the context of the Malaysian healthcare system. The findings of this chapter were derived from in-depth analysis of relevant documents, observation field notes and interviews with the HCPs. The themes and categories used to explain each element in this chapter are summarised in Table 7.1, and the findings are then presented as narratives.

Table 7.1 Themes and categories describing self-care support provision

Themes	Subthemes/categories
Management of type 2 diabetes within the Malaysian healthcare system	
Service provision within primary-care settings	Community-based approach Group education programme Collaborative practice
Service provision within secondary-care settings	Individual counselling Importance of self-monitoring blood glucose
Self-care concepts within the documents	

Each of themes, subthemes and categories are now explained using narratives.

7.2 Management of type 2 diabetes within the Malaysian healthcare system

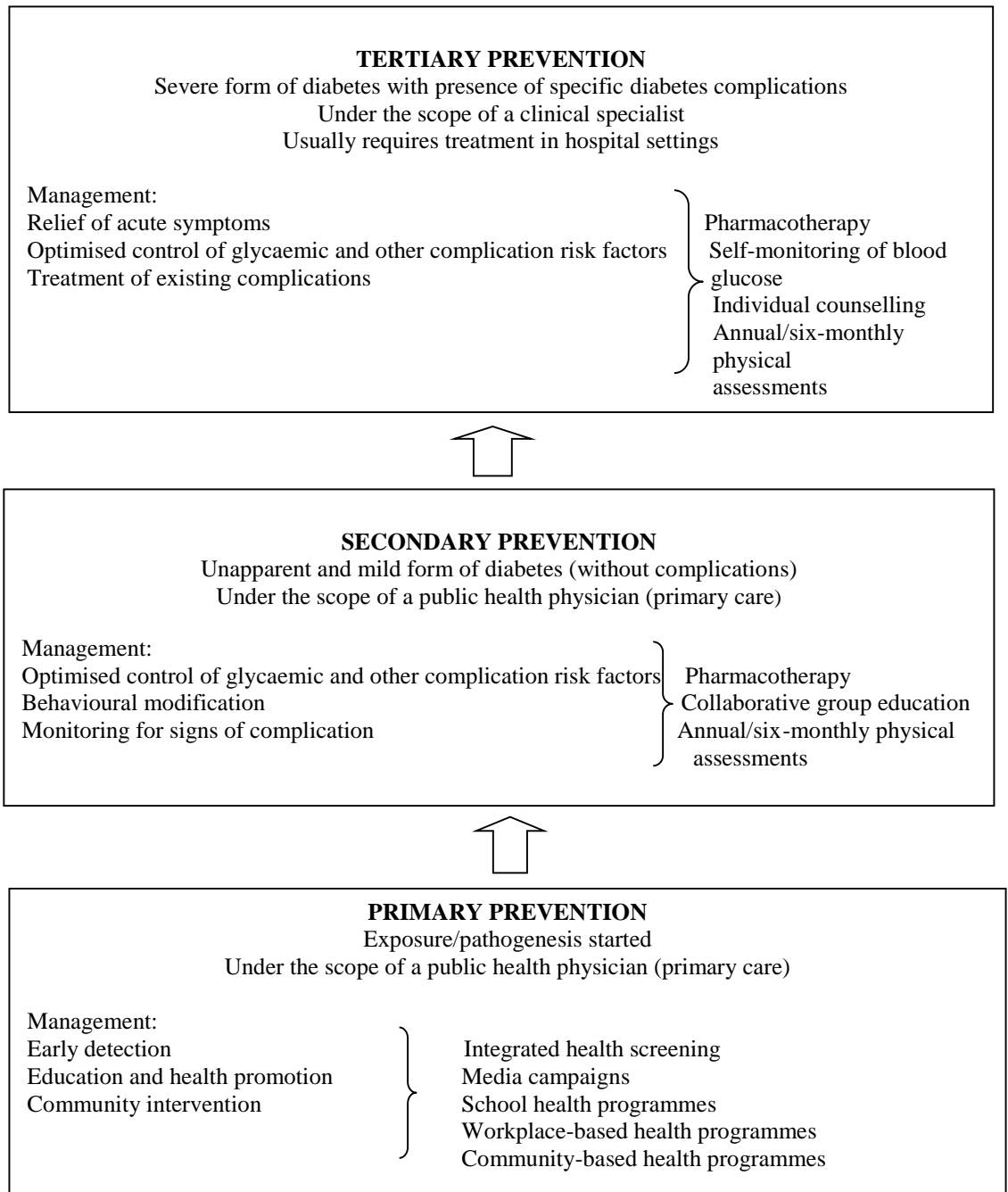
It has been reported that the increasing incidence of type 2 diabetes in Malaysia is due to the increase in prevalence of obesity and physical inactivity resulting from urbanisation (Malaysia Health Report, 2008). These factors have also been identified as causing other non-communicable diseases (NCD) in Malaysia, including heart disease, respiratory failure and cancer (World Health Organisation, 2010). Within the Malaysian healthcare system, prevention and management of diabetes is conducted under the NCD programme, which was implemented in 1991 (Ministry of Health Malaysia, 2010). In line with the policy and guidelines provided by WHO (2005; 2009), the objectives of the NCD prevention and control programme in Malaysia are to reduce morbidity and premature mortality from NCD, and to improve the quality of life of people with NCD (Disease Control Division, Ministry of Health Malaysia). Therefore, management of type 2 diabetes follows stipulated guidelines, which adopt an integrated and holistic approach that also includes the management of hypertension, dyslipidaemia and obesity with the aim of improving quality of life and preventing premature death. To achieve these aims and objectives, diabetes management is directed towards reducing macro- and micro-vascular complications (Ministry of Health Malaysia, 2009).

Content analysis was done on The National Strategic Plan for Non-Communicable Disease (2010); a policy document developed by the Ministry of Health Malaysia to strengthen service provision, particularly in the management of NCD (Ministry of Health Malaysia, 2010). From this document, it can be seen that the prevention and control of diabetes is a main concern in the management of NCD. A special programme for diabetes – the National Diabetes Prevention and Control Programme – was developed in the year 2000. As stated in the above mentioned policy document, the current diabetes prevention and control programme in Malaysia is comprised of three levels: primary prevention, secondary prevention and tertiary prevention (Ministry of Health Malaysia, 2010). The literature shows that these three levels of diabetes prevention and control programmes have also been widely implemented in other countries (Bowman et al., 2003; Murphy et al., 2004). Bowman et al. (2003) described primary prevention as activities that aim to prevent or delay the onset of type 2 diabetes. Secondary prevention has been identified as the measures taken at the early stage of diagnosis that aim to prevent the development of diabetes complications. These activities include: maintaining good glycaemic, blood pressure, and blood lipid control; screening for diabetes complications; and smoking cessation (Bowman et al., 2003). The tertiary prevention stage has been described as activities carried out to ensure early detection and treatment of diabetes complications such as retinopathy, nephropathy and peripheral vascular disease (Bowman et al., 2003). Thus, it seems that each stage of prevention has different aims and involves different activities. However, it has been suggested that a combination of the three prevention strategies is crucial in order to prevent or minimise diabetes-related morbidity and mortality (Bowman et al., 2003; Murphy et al., 2004).

In the Malaysian setting, the three prevention strategies are implemented accordingly within healthcare facilities, including in primary- and secondary-care settings. As described in the Malaysian Health Report and Malaysian National Strategic Plan for NCD (Ministry of Health Malaysia, 2010; Ministry of Health Malaysia, 2008), the management of diabetes between primary- and secondary-care settings differs. Primary prevention involves health promotion programmes that address the main diabetes risk factors, such as unhealthy eating, physical inactivity and obesity. In

addition, primary prevention aims to increase community awareness of cardiovascular risks (Ministry of Health Malaysia, 2010). Meanwhile, secondary prevention of diabetes is implemented through a combination of pharmacotherapy and behavioural modification programmes, and is delivered in both primary- and secondary-care settings. Tertiary prevention is mainly implemented in secondary- and tertiary-care settings as it usually requires specialist and collaborative management. Activities involved in tertiary prevention of diabetes in Malaysia include regular physical assessments and screening for diabetes complications, and treatment of specific diabetes complications (Ministry of Health Malaysia, 2010). Figure 7.1 shows the levels of diabetes prevention and control within the Malaysian Healthcare System, as identified through document analysis, interviews and observations. The focus and approach of type 2 diabetes management in primary- and secondary-care settings are then explained in detail based on the findings derived from interviews with HCPs, observation field notes and documentary analysis.

Figure 7.1 Levels of diabetes prevention and control within the Malaysian healthcare setting



7.2.1 Service provision within primary-care settings

From the analysis of the available evidence derived from the observation field notes, individual interviews with HCPs and analysis of relevant documents, such as the Malaysia Health Report (2008), National Strategic Plan for Non-communicable Disease (2010), and CPG (2009), it was apparent that the management of type 2 diabetes in primary-care settings is focused on primary and part of secondary prevention, with emphasis on education for people who are identified as at risk of developing diabetes, in order to avoid and minimise the incidence of diabetes. Three categories have been identified to explain the service provision pertinent to the patients with type 2 diabetes in primary-care settings: community-based approach, group education programmes and collaborative practice.

7.2.1.1 Community-based approach

Throughout the data collection period, it was observed that several activities related to primary prevention of type 2 diabetes were conducted in the primary-care clinic (the case study site), and most of these were done at community level. They involved screening possible and high-risk cases, delivering diabetes education, early detection of diabetes symptoms and early intervention with respect to diabetes management. This was described by a medical officer in charge of the primary-care clinic:

'...we have good programmes in the clinic, such as approaching them at the community level. Within the communities in this area, we conduct a programme called NCDPIM (Non-Communicable Disease Programme 1 Malaysia). The Ministry of Health allots about a few thousands ringgit per year to allow us to run the programme. Basically, the programme focuses on weekly exercise and aerobics, and talks about healthy foods and quitting smoking. People are also taught to check their blood pressure and body mass index. The programme was launched in 2010. In initiating the programme, we conducted discussions and meetings at community level, and asked for the chairman or the head of the community to become the leader and head of the programme. We wanted them to feel that the programme was initiated by them.' (HCP 14)

The above extract reveals that the community-based approach has been utilised within the primary-care clinic with the aim of increasing the empowerment of patients and

people who are at risk of developing diabetes in the community. As explained by HCP 14, the community-based programme was designed to extensively involve patients and community members at all stages of the programme, from initiation to implementation and evaluation of the programme. A review conducted by Goodman et al. (2006) pointed out the importance of community participation in diabetes prevention. Goodman et al. (2006) suggested that the community-based approach in diabetes prevention is beneficial as it ensures cultural relevance, and facilitates joint decision-making and collaboration between HCPs and the community. However, the review concluded that effectiveness depends on the focus of the programme and participation by community members (Goodman et al., 2006.). Therefore, it can be anticipated that the community-based programme implemented at the case study site will have positive impacts on diabetes prevention and control, although this has not yet been reported. Several elements which seem to be parallel to the suggestions of Goodman *et al.* (2006) are incorporated into the community-based programme, including initiation of the programme by patients and community members, and limitations of HCPs' involvement as facilitators and supervisors. Therefore, it can be expected that the programme will suit the patients' and community members' cultural needs and preferences. In addition, this community-based programme should increase interest and participation of the patients and community members in self-care activities.

Nevertheless, further interviews with other HCPs regarding the implementation of the community-based programme revealed important issues pertaining to the success of the programme. HCP 16, a medical assistant who was directly involved in execution of the programme had pointed out that important aspect that influenced the success of the community-based programme currently being carried out in the clinic was a lack of interest and participation by patients and community members. This is shown in the extract below:

'...usually we did sort of exercise and health talks...We invited those patients who had been diagnosed with type 2 diabetes and people with borderline status [high risk of developing type 2 diabetes]. But the problem was, most of our patients here are difficult to involve. It might be because they are busy with work. We usually called the patients via phone and invited them. On one

*occasion we invited more than 30 patients, but only a few of them turned up'.
(HCP 16)*

Although strategies encouraging patient participation, such as maximum involvement and empowerment of the community were included throughout the programme, active engagement and involvement in the programme by the patients was minimal. The HCPs perceived that the patients' life situations and tight schedules contributed to this problem. Nevertheless, the HCPs did not provide their views on possible solutions to the problem.

In a previous study conducted in rural area of Ethiopia, Argaw et al. (2007) reported that the most important factor that facilitated participation in community-based programmes was active involvement of community leaders in the programme, which influenced the actions of followers. This finding seems to be in line with the approach of the community-based programme in the current study. However, it is worth noting that this approach might be effective in rural areas only, as respect for and the influence of leaders in the community could be higher compared to in an urban setting. A review by Merzel & D'Afflitti (2003) also highlighted the importance of leader involvement in improving community participation; however, most of the studies in their review showed a modest impact of community-based programmes on health outcomes and patients' participation. Several important aspects in enhancing the success of community-based programmes have been suggested, including the integration of social elements into the programme, which emphasise the socio-demographics of the community participants, health characteristics, and perceptions of the influence of the environment on their health situation (Merzel & D'Afflitti, 2003; Reis et al., 2013). However, concern for these aspects in the community-based programme conducted at the case study site was not clearly observed. This may explain the poor participation from patients and people in the community.

7.2.1.2 Group education programme

An analysis of CPG (2009) prepared by the Ministry of Health (a single document that is widely used in guiding the management of type 2 diabetes across the country) showed that diabetes education and self-care are recognised as essential elements of diabetes management. However, the explanation provided in the CPG (2009) regarding the approach to diabetes education and self-care support provision was very limited. For instance, elements of self-care that need to be included in education or counselling sessions were provided as a simple list and bullet points, without detailed explanation or reference to evidence. Furthermore, the involvement of HCPs in self-care support provision seemed to be unstructured and not explicit. In order to provide detailed explanation about the situation, HCP 15, a family medicine specialist in charge of the management of type 2 diabetes in the primary-care clinic, was interviewed further. The specialist highlighted his perceptions of the importance of individual support in helping the patients to self-manage their diabetes. However, he expressed his dissatisfaction with the current service delivered at the clinic. During the interview, it was noted that individual support cannot be provided to patients at the primary-care clinic due to a lack of manpower and a high workload. Therefore, self-care support is delivered through group education programmes and community-based programmes that aim to improve the statistics of uncontrolled diabetes at the clinic. Below are his views regarding the approach to self-care support in the primary-care clinic:

'To a certain extent of course we will do individual counselling, it will be the best. But the workload here is high. So here...basically we have trained a small group of patients about what their status is and what they can do to help themselves. That is another component. Just now I spoke about the community programme and now I am talking about group discussions, whereby my nurse educator will facilitate the programme and look into their status and how to control it. So they provide opinions on their lifestyle and they will map how they control the diabetes and from there, they will discuss how to settle, why the targeted glucose level has not been achieved. It is a group discussion actually.' (HCP 15)

From the extract, it seems that HCP 15 perceived individual counselling as an ideal approach that he intended to have in the clinic. However, due to the limitations pointed out, the specialist seemed to agree that group education is the best approach to

support that can be provided to the patients at this particular time. Therefore, other HCPs involved in the implementation of group education programmes at the clinic were also interviewed. The HCPs consistently stated that the group education programme conducted at the clinic was done in an interactive manner, in order to maximise patient participation. The group education programme conducted at the primary-care clinic is guided by the 'diabetes conversation map tool' (CMT) developed by Eli Lilly Company. A review of Eli Lilly Company's website showed that CMT is a comprehensive guideline for patients and HCPs in discussing issues related to diabetes management, and is widely used in countries including the United Kingdom (LillyPro, 2012). HCPs involved in facilitating this programme at the case study site have undergone special training on the application of CMT to diabetes education programmes. Via an analysis of the content of CMT and observation of the session conducted in the clinic, the programme was seen as facilitating patients' participation and included the patients' individual experience and needs. The programme was conducted in an interactive way and the patients were given the opportunity to directly discuss their problems with the HCPs who facilitated the session. However, data supporting its effectiveness in improving patients' ability to self-manage their diabetes at the case study site is not yet available. In addition, the number of patients invited to the session was very limited due to a lack of space and manpower (around 10 to 15 patients invited every session), which might have limited the opportunity of the patients to attend the programme. Furthermore, as the session was guided by documents, the issues discussed were mainly based on cue cards provided in the toolkit, and did not really originate from the actual experiences of the patients. In fact, some aspects were inapplicable to certain cultural and social situations of the patients, as the document were developed in Western settings. For instance, one part of the programme: 'discussion on the experience with diagnosis' suggested the patients to identify their support network; however, it seems to be irrelevant to the Malaysian setting as the support only available from family members and healthcare system (which some of the patients did not experienced). Furthermore, as highlighted in chapter seven, patients' perceptions and practices of self-care were highly influence by the specific cultural perspectives of the Malaysian community. Therefore, it could be argued that the current group education programme conducted at the case study site may be limited in its applicability to addressing individual

patient needs and problems. In addition, specific cultural practices that seem unaligned with the self-care suggestions might have been overlooked by the HCPs.

In the literature, group education programmes have been reported as effective in delivering diabetes self-management education, as it offers a platform to patients and HCPs to learn together and share experiences, provided that it incorporates the patients' needs, life experience and health goals, and is evidence based (Funnell et al., 2009; Mensing & Norris, 2003). Another randomised controlled trial measuring the effectiveness of a programme for diabetes education and self-management for ongoing and newly diagnosed (DESMOND) in the United Kingdom reported that the programme showed positive improvements in patients' beliefs about diabetes and had a positive impact on patients' ability to lose weight and stop smoking. However, patients in the programme did not show significant improvements in HbA1c within the 12-month period of the trial (Davies et al., 2008). The results of these studies provide evidence of the effectiveness and benefits of group education programmes on patients' biological, psychological and social aspects. Furthermore, it has been suggested that group education sessions should include individual needs assessments to ensure the different needs of patients are catered for, and should be conducted as patient-centred, problem based, culturally relevant, integrative and evidence based (Tang et al., 2006). However, the elements of group education programmes discussed in the literature were not found in the programme conducted in the study setting. Therefore, program's effectiveness and ability to meet the self-care needs of patients is unlikely.

7.2.1.3 Collaborative practice

From the interviews, observations and analyses of relevant documents, it was understood that management of patients with type 2 diabetes in the primary-care clinic was merely focused on providing treatment through pharmacotherapy and health education, with the aim of improving the patients' glycaemic control, and monitoring and screening for diabetes complications (Malaysian Health Report,

2008). HCP 14, a family medicine specialist in the primary-care clinic, shared his approach to managing patients:

'The approach that we use is, we follow the clinical practice guideline (CPG) provided by the Ministry of Health. I am more towards medication, but when it comes to monitoring and a proper holistic approach to making the patients being treated is also by looking at their self-care, self-monitoring is an important component in patient management. Medication is not the only answer for treatment. We need to change behaviour so that the patients will adhere to the treatment and follow our advice later. So, that is the approach here.' (HCP 15)

From the extract, it was apparent that HCP 15's approach to diabetes management was focused more on medical management. However, HCP 15 did emphasise the importance of self-care and self-monitoring in achieving better outcomes. When asked about the practice of diabetes management and self-care support at the clinic, HCP 15 claimed that the practice follows the CPG (2009) and Diabetes Management Action Plan for Primary Care (2012), developed by the Ministry of Health Malaysia and currently in use across the country. Therefore, in understanding the self-care support provision within the primary-care clinic, content analysis was conducted of two important documents that guided the HCPs' practice: CPG (2009) and Diabetes Management Action Plan for Health Clinic (2012). Each of the documents were deductively analysed according to the framework presented in Table 5.4 (in chapter five). The themes developed and used to code the documents included the purpose and focus of the documents, and content relevant to self-care support provision.

The Diabetes Management Action Plan for Health Clinic (2012) was developed by the Department of Health for the Federal Territory of Kuala Lumpur and Putrajaya. The purpose of the document is to act as a guideline and key performance index for HCPs in primary-care clinics, particularly in Kuala Lumpur and Putrajaya, in their practice of diabetes management. This document provides a list of suggested strategies to be conducted in primary-care clinics in order to enhance the prevention and control of diabetes. The percentage of patients with uncontrolled diabetes (HbA1c is higher than 6.5%), and the percentage of patients who have been prescribed insulin is stated as an indicator for HCPs to measure the effectiveness of their activities. The activities

suggested include: group education programmes using CMT, pharmacist-managed Diabetes Medication Therapy Adherence Clinics (DM-TACs), impaired glucose tolerance clinics, gestational diabetes clinics, informing patients about their HbA1c result (by sending short message system (SMS) messages to the patients every three months to tell them about their glucose control), and community-based programmes that incorporate integrated screening, smoking cessation counselling and public exercise programmes. Generally, from the content analysis of this document, it can be understood that diabetes management provision and the programmes conducted at the clinic were merely focused on improving collective glycaemic control parameters of patients in the clinic, with less attention to psychosocial and behavioural aspects. This interpretation was made based on the outcome measure used to identify the level of effectiveness of the activities and programme, which concentrated on biological parameters only. From the document, only two strategies that targeted providing self-care support to patients with type 2 diabetes in the clinic were identified: group education programmes (using CMT) and DM-TAC. However, interviews with the HCPs showed that these two programmes were also parameter-based, and usually focused on patients who had problems with glucose control, wherein improvements were measured based on the patients' ability to meet the targeted glucose control. Consideration of other social aspects, such as the patients' success in modifying certain aspects of their lifestyle or developing self-efficacy, was not demonstrated in the document. Therefore, the functionality and effectiveness of the document in facilitating self-care support provision that meets self-care needs, and enhances the engagement of patients in self-care activities, seems to be questionable.

The CPG (2009) developed by the Ministry of Health Malaysia was also analysed. The CPG (2009) provides detailed explanations of the steps and measures that need to be taken by HCPs in managing patients with type 2 diabetes. The measures suggested by the CPG (2009) include: initial assessment of patients' health status, development of treatment and care plans, targets for glucose control, diabetes education, lifestyle modification, physical activities and protocols for pharmacotherapy. Content analysis showed that the importance of self-care is clearly mentioned in the guidelines.

Furthermore, approaches to self-care support provision, such as diabetes education, individualised support and glucose monitoring, are included as elements of diabetes management. In addition, the roles of each HCP responsible for diabetes management, including the primary care practitioner, diabetes educator, dietician, physician, specialist and ophthalmologist, are briefly explained to guide the HCPs in providing collaborative management to the patients. In light of the role of HCPs in self-care support provision, it is clearly stated in the CPG that the provision of diabetes education and supporting self-care lies with the diabetes educators, and should ideally be carried out collaboratively with other HCPs, including physicians, dieticians, nutritionists and pharmacists. However, when the HCPs in the primary-care clinic (the case study site), including the diabetes educator, nurses, nutritionist and pharmacist, were asked about their role in supporting patients with type 2 diabetes, most consistently mentioned that the management of type 2 diabetes in primary care is the responsibility of medical officers and family medicine specialists. This is demonstrated in the extract below:

'Management of diabetes is headed up by the doctors. We just help in certain areas, such as health education, foot care, diet management and wound management (if they have wound). That's all...What I mean is, it is not that we are not involved but our staff are involved in other areas, so the focus on diabetes patients might be limited. Our diabetes patients will not necessarily go through all the activities every time they come to this clinic, so we can't be involved much in their management.' (HCP 12)

Although it was clearly mentioned in the CPG that providing diabetes education and facilitating behaviour modifications are part of the diabetes educators' role, this was not evident in the interview with HCP 12. From the extract above, it seems that the role of the diabetes educators was limited to technical tasks, including conducting electrocardiograms, foot assessments and eye assessments using a fundus camera. Although elements of diabetes education and advice on self-care were delivered, this was frequently done simultaneously during foot assessments, and seemed to be unstructured, as recorded in the observation field notes below. Therefore, it can be suggested that the diabetes education might not have a significant impact on enhancing the patients' ability to self-manage.

Observation of consultation between Mr A and the DE (primary-care clinic)

A consultation session between Mr A and the DE was conducted at the primary-care clinic. The consultation was conducted in a physical assessment room equipped with a fundus camera for eye assessments and lazy chair for foot assessments. During the consultation, another patient was having a foot assessment with another nurse. Mr A was instructed to undergo his eye assessment while the other patient finished her education session. Mr A sat down in front of the funduscopy machine and his eye was inspected by the diabetes educator using the fundus camera. After the procedure was complete, Mr A's eye condition was explained to him. According to the DE, Mr A's eyes were fine and he was advised to maintain his sugar control to avoid eye complications. After the eye assessment, Mr A was instructed to sit in the lazy chair. The DE sat in front of him. His feet were inspected. The DE told Mr A that there were areas of hardened skin at his ankle and dryness on the skin of his toes and heels. There were also injuries on the big toe of his right foot, where the toenail seemed to be peeling off. Mr A was advised by the DE to cut the toenail to a straight shape. The DE asked Mr A about the injury. Mr A said that the nail began peeled off after something fell on his feet, and he also thought that it had worsened when he played football. The sensations in both feet were checked with a needle, cotton and tuning fork. Mr A was advised about the complications of foot ulcers, and examples of diabetes foot ulcer wounds were shown to Mr A. (Observation field notes – March 2013)

The HCPs also highlighted that they had limited opportunities to see the patients, who were only referred to the diabetes educator every six months or once a year for routine physical screening. This reflected the views outlined earlier of HCP 12, who mentioned that *'the role of nurses in supporting patients with type 2 diabetes is very limited as the nurses only have the chance to see the patients once or twice a year during physical screening'*. Furthermore, instead of discussing diabetes management and self-care activities, patients saw the diabetes educator for different purposes (to carry out physical screening to identify signs of diabetes complications). Therefore, the role of the diabetes educator as a facilitator to support patients' self-care in the

clinic was not clearly observed. Existing evidence has shown that frequent follow-up with nurses or diabetes educators, and close monitoring of patients' progress and self-care practices, increased patients' satisfaction and diabetes outcomes. A study by Mullen and Kelley (2006) that augmented the role of nurse case management with structured twice-weekly follow-up and weekly telephone calls showed significant reductions in HbA1c and total cholesterol levels in patients with type 2 diabetes over a six-month period. Similarly, a study conducted by Whittlemore et al. (2004) showed positive effects of frequent clinic follow-ups and structured phone calls on patients' diet management, engagement in physical exercise and HbA1c levels. The results presented in these previous studies indicate that close monitoring, frequent follow up and better patient access to HCPs is beneficial in improving patients' engagement in self-care and blood glucose parameters. Therefore, it can be suggested that long gaps between patients follow ups, and a lack of opportunity for the patients to discuss their self-care practices with diabetes educators, as mentioned by the HCPs in this study, could be one reason for the high incidence of uncontrolled diabetes at the case study site.

Most of the HCPs at the case study site perceived that family medicine specialists and medical officers are the persons responsible for diabetes management provision in primary-care clinics. In fact, general observation at the clinic showed that patients were mainly managed by medical officers, who were responsible for monitoring the patients' condition (including glucose level and other parameters such as cardiovascular, renal and liver function), providing treatment (pharmacotherapy) and providing education. Therefore, it can be said that collaborative management, as suggested in the CPG (2009), was not being properly implemented within the case study site. However, due to high workload, a medical officer claimed that their management was limited to providing treatment, monitoring clinical parameters, and identifying symptoms and possibilities of complication. This was seen in the narratives of the HCPs, as exemplified by HCP 13, a medical officer involved in the management of type 2 diabetes at the case study site:

'in this clinic, the doctors are only able to see the patients for a few minutes, and I think it is actually not enough for them, especially in terms of education

and to emphasise their treatment, what the benefits and complications are. I think the most important thing is education, in terms of why they need to take their medication and why they have to come for follow up. Why they have to change their lifestyle. So, I think if we can have one counter just to give education on diabetes, emphasise the treatment and talk about the complications, it will be more appropriate. It will make their self-care support become more effective.’ (HCP 13)

From the extract, it can be seen that that medical officers had very limited time with the patients and consultation sessions were short; thus, patient management was focused on medical therapeutic management. The medical officer claimed that there was not ample time to provide diabetes education and self-care support. From the interview, it was apparent that the medical officer perceived the need for assistance in providing diabetes education, which she referred to as ‘a counter for giving education’. However, she did not clearly recognise the role of other HCPs in diabetes management provision. A lack of manpower and unavailability of a dedicated team to manage patients with type 2 diabetes in the clinic was highlighted by a family medicine specialist as a factor contributing to this situation. This is demonstrated in the extract from HCP 14 (family medicine specialist) below:

‘We don’t have a dedicated clinic. That is the problem here that we don’t have dedicated staff only for diabetes. Now, we are integrated, meaning that we share the burden for all the other services. Since that happened, we have been unable to provide the service that we intended. We don’t have a specific clinic for diabetes because our approach is daily concept. This sometimes affects the quality of the service, especially in diabetes care.’ (HCP 14)

The extracts presented above indicate a loophole in the practice of self-care support provision at the case study site. It seems that the self-care of patients with type 2 diabetes at this clinic was not being properly supported. As mentioned earlier in this chapter, group education programmes and community-based programmes have been implemented in this primary-care clinic. However, the effectiveness of these programmes in helping patients to self-manage their diabetes is unclear, and there are a number of limitations to their implementation, as discussed in earlier sections of this chapter (section 7.2.1.1 and 7.2.1.2). In addition, the extracts from the interviews with the medical officer and family medicine specialist demonstrated that these HCPs did not clearly recognise the role and function of other HCPs, particularly the nurses and

diabetes educator, within the continuum of diabetes management. Therefore, the role of diabetes educators, who are supposed to be care coordinators or self-care facilitators (Siminerio et al., 2007), was not being properly implemented; their role was frequently limited to technical and administrative tasks.

Through the CPG (2009) and a diabetes management flow chart in the primary-care clinic (the case study site), the nutritionists and pharmacists were also identified as important people in diabetes management provision. Therefore, these HCPs were interviewed to understand their role and involvement in supporting patients with type 2 diabetes. From the interviews, it was seen that management of type 2 diabetes at the case study site involved multidisciplinary HCPs, and each of their roles and functions are well defined in the CPG (2009). Interviews with the nutritionists, for example, provided information that their involvement in diabetes management was to review patients' individual diet patterns, provide education on healthy diet, and help patients with their diet plans. This aspect can be seen in the extract below:

'Basically, we accept referrals from doctors or the diabetes team (sister). Our main objective in the management of diabetes is to prevent patients from getting diabetes [pre-diabetes cases], and we try to help patients to control their diabetes and avoid complications. Patients are usually seen by a doctor and prescribed with medication, and the doctor refers them to us for advice on dietary intake.' (HCP 18)

The pharmacists, on the other hand, were involved in the management of type 2 diabetes through provision of knowledge and information regarding the pharmacokinetics and side effects of medication, and helping to monitor patients' blood parameters to identify signs of complications or the suitability of the medication prescribed.

'If any patients have already used the medicine for a long time, we will reassess them in relation to their knowledge and understanding of the medication that they take. We usually ask the patients whether they know about the medicine or not. If we notice any problems pertaining to patients' understanding of the medication, we will bring them to the counselling room and provide further consultation.' (HCP 17)

However, as mentioned by the family medicine specialist (HCP 14) earlier, the clinic was managed in an integrated way. Therefore, the resources available, including the HCPs, were shared among the departments in the clinic, including maternal and child health, adolescent health and outpatients. From the clinics' organisation chart, it was noted that only two nutritionists and three pharmacists were available to the clinic. Therefore, besides being involved in the management of diabetes, they were also responsible for the management of other cases, including maternal and child health cases, and were involved in community services. As such, their contact with patients with type 2 diabetes was very limited and mainly based on referrals from physicians. Furthermore, collaborative practice between the physicians and other HCPs was reported as minimal, and evidence was seen of a mismatch between the perceptions of physicians and other HCPs pertaining to collaborative practice (Dey *et al.*, 2011). This situation is anticipated as limiting the contact with other HCPs, including diabetes educators, nurses, nutritionists and pharmacists have with the patients.

Discrepancies between physicians' attitudes towards collaborative management have been widely debated in the literature (Larson, 1999; Thomas *et al.*, 2003; Hansson *et al.*, 2010; Tang *et al.*, 2013). It has been suggested that collaborative practice between physicians and other HCPs is frequently influenced by several factors, including the perceived value of the collaboration, appropriate inter-professional communication, the quality of interaction between HCPs, and understanding of the boundaries of each other's responsibilities and goals (Larson, 1999). However, it has been reported that collaborative practice between physicians and nurses in particular is frequently influenced by power relations, wherein the physician is commonly being perceived as the leader of the healthcare team, and as having a greater role in decision making pertaining to patient management. Nurses, on the other hand, are frequently perceived as 'handmaidens' responsible for carrying out physicians' orders (Thomas *et al.*, 2003; Hansson *et al.*, 2010). Another study conducted to determine the nature of interaction between nurses and physicians in clinical settings reported poor communication and relationships between nurses and physicians, which resulted in poor quality of care delivered (Weinberg *et al.*, 2009). Moreover, a study conducted to analyse the nursing practice environment in Malaysia reported that nurses perceived

their working environment as stressful, while the nurse–physician relationship has been identified as a contributing factor to this stressful situation (Maziah et al., 2011). However, the study was conducted in a different context, as it involved tertiary hospitals. Thus, the hectic clinical environment and the nature of physician–nurse interaction in acute care management may have influenced the responses of the nurses. Nevertheless, the existing evidence, which commonly shows negative perceptions and attitudes of physicians towards their relationship with nurses, could be argued as an explanation for the lack of collaboration between physicians and other HCPs, particularly nurses and diabetes educators, in diabetes management provision in the current study setting (the primary-care clinic).

7.2.2 Service provision within secondary-care settings

Besides the primary-care setting, this study also explored self-care support provision in secondary-care settings. An outpatient clinic and a specialist medical clinic in Kuala Lumpur participated in the study. Similar to the method of data collection used in primary-care clinic, document analysis, observations and interviews with HCPs were conducted to understand the management of type 2 diabetes in these two clinics.

The patients' registration record showed that there were more than 4000 diabetes patients registered at both clinics, 80% of whom had type 2 diabetes. From a general observation of routine clinic activities and HCP practice, it could be understood that the approach to diabetes management in the secondary-care setting differed from that observed in the primary-care one. The clinics were focused on secondary and tertiary prevention, as reflected by the function of the hospitals, which focus more on acute care and curative approaches; thus, their practices were visualised more in terms of treatment and care. Unlike the primary-care clinic, which received walk-in patients, these two clinics commonly received patients from referrals. Patients were commonly referred to the hospital from primary-care clinics, private practitioners or other hospitals. The HCPs involved in the management of type 2 diabetes in these two

clinics comprised of endocrinologists, registrars, medical officers, diabetes educators, nurses, dieticians and pharmacists.

Although the orientation of diabetes management differed, management of type 2 diabetes was implemented according to the CPG (2009), which is universally used in primary- and secondary-care settings. Two categories were identified to explain the management of type 2 diabetes in hospital settings: individual consultation, and the importance of SMBG. Each of these categories will now be explained in detail.

7.2.2.1 Individual consultations

Interviews with the HCPs showed that individual consultations, referred to as 'diabetes counselling' by the HCPs, were consistently mentioned as the main approach used in supporting patients with type 2 diabetes at the case study sites. A combination of individual consultations and group education was observed at the outpatient clinic. However, individual consultations or diabetes counselling were identified as the most common and preferred method used by most of the HCPs in the secondary-care setting. Diabetes counselling in the context of this setting was referred to by the HCPs as individual consultation sessions delivered by diabetes educators to help patients with their diabetes self-care. During diabetes counselling, a range of support was provided, including a review of patterns of glucose control, listening to patients' individual problems pertaining to diabetes self-management and providing information and advice related to diabetes self-management based on patients' problems and needs, in order to help them maintain their glycaemic control.

Individual in-depth interviews with diabetes educators demonstrated that most of the diabetes educators that participated in this study were aware of their role within diabetes management provision in the clinic; that is, to facilitate patients to achieve the targeted HbA1c level. As such, individual diabetes counselling has been perceived as the most effective way to understand the patients' individual problems and support

them in achieving the intended clinical outcomes. This is exemplified in the HCP narrative below:

'we have been given a huge responsibility by the doctor to help to bring down the HbA1C. The doctor's objectives are to minimise the patients' likelihood of complications and to reduce admission to the ward. The doctor wants us diabetes educators to be close to the patients to make them understand their bodies, and hence, avoid complications. So, we think individual counselling is the best way to do this.' (HCP 5)

It is stated in the CPG (2009) that diabetes educators are the primary people responsible for facilitating the patients' knowledge and skills and supporting them to engage in self-care activities. However, the specific guidelines on how patients should be supported, and the approaches to dealing with patients' psychological and social aspects, are not clearly mentioned in the CPG (2009). Therefore, based on experience, the diabetes educators consistently agreed that individual counselling to understand the patients' problems individually and provide support based on the patients' particular needs is the best approach. Furthermore, the diabetes educators said that most of the patients who received treatment in their clinic preferred to have individual consultations, as they felt more comfortable talking about personal circumstances related to their ability to self-manage:

'When the patients come for consultations, they don't immediately tell me about their diabetic problem, but usually start by talking about their personal problems and their family situation. Only then do they talk about their problem with diabetes. Thus, they are not willing to be involved in group counselling. If we consulted with them in groups, the explanations that they received might not be suitable for their personal situation. Thus, most of them do not agree to group counselling.' (HCP 7)

The extract from HCP 7 illustrates the perceptions of HCPs regarding patients' preferences for individual counselling, as the patients might have felt more comfortable talking to the diabetes educators about their problem. Therefore, individual diabetes counselling has been seen as an appropriate approach, as the focus of the management is to help patients maintain a normal glucose level, and simultaneously increase their knowledge and confidence on self-management

techniques. The HCPs consistently perceived this approach as being more proactive compared to group education, which focuses on providing diabetes education through lectures and group discussion. Furthermore, the HCPs at these two clinics consistently agreed that having good rapport and trust with the patients is the most important element in supporting them to self-manage their diabetes. Therefore, the HCPs, particularly the diabetes educators, perceived that individual counselling enhanced their relationships with the patients, and improved patients' trust and confidence in them, which simultaneously increased patients' interest in engaging with self-care. This is demonstrated below:

'When we listen to them, they are more positive towards us. So we can help them in the management of their diabetes. We try to put ourselves in their personal situation and be part of their family, so they can follow our advice and what we ask them to do. They will follow our instruction...to check their glucose level, for instance. I do not frighten them and not to treat them...no. I just want them to know their responsibility towards their own life. That's all. So far, we can. We need to make the patients appreciate their body.' (PT 5)

However, several intervention studies that measured the effectiveness of group vs. individual consultations reported that group education is as effective as individual counselling in helping patients to achieve intended clinical parameters, including HbA1c, blood pressure control and weight reduction (Rickheim et al., 2002; Vadstrup et al., 2010). Furthermore, it has been suggested that group consultation can be more easily conducted compared to individual consultations, and provides a platform for patients to share their experiences of diabetes management, which helps other patients to learn and make adjustments to their lives (Rickheim et al., 2002; Karlsen et al., 2004). However, a more recent study suggested that interventions related to delivering self-care education need to take into consideration the dynamic and evolving condition of the patients' 'real-world' environment and life situation (Funnel et al., 2007). As the concept of patient-centred care and empowerment are key to self-care support provision, individual counselling seems relevant as it was preferred by the patients and support can be individualised based on patients' needs. In line with the perceptions of HCPs in the current study, a qualitative study conducted in the United Kingdom reported that HCPs perceived the following five important aspects as crucial in effective diabetes management provision: sufficient time for consultations, identification of individual patients' progress, opportunities for the patients to ask

questions, patients' feelings of being listened to by HCPs, and recognition of variability of patients' individual experience (Pooley et al., 2001). Therefore, it seems that despite the equal effectiveness of group consultations in improving clinical parameters, individual consultations seem to be preferred as they increase satisfaction of patients and HCPs in service provision. Nevertheless, individual consultations implemented at the case study sites still lacked structure, as they were conducted based on the experience and discretion of the diabetes educators and preferences of patients, without clear, evidence-based guidelines. Furthermore, the effectiveness of this approach to improving the patients' engagement in self-care and facilitating behaviour change is unclear, as it has not been reported anywhere to date.

7.2.2.2 Importance of SMBG

The significance of SMBG from the patients' perspectives in facilitating their engagement in self-care elements including diet control and medication compliance, were presented in chapter six (6.3.1.1 and 6.3.1.2). Findings from the patient interviews showed that SMBG provided valuable benefits to the patients' ability and confidence to make decisions pertaining to their self-care practice. Furthermore, SMBG has been suggested as an important parameter that complements HbA1c, as it is able to distinguish blood glucose readings between fasting blood glucose, and before and after meals. SMBG also helps patients and HCPs to monitor glycaemic deviations and detect any episodes of hypoglycaemia (Dailey, 2007). In addition, a review conducted by Renard (2005) suggested that SMBG can increase patients' confidence in self-management, as it provides immediate feedback about the effects of food intake, physical activities and the effect of medication on glucose level. In the secondary-care setting, the practice of regular SMBG has been introduced as a prerequisite for the patients to have frequent consultations (fortnightly follow ups) with the diabetes educators. Therefore, each patient with type 2 diabetes that attended consultations with the diabetes educators were required to conduct SMBG at home and keep related records. In addition, self-care activities such as diet schedule, frequency of physical exercise and insulin dosage were planned and suggested to the

patients according to their SMBG trends. The enforcement of SMBG in the secondary-care setting is demonstrated in the extract below:

'if the patients need to come for counselling, the doctor asks us to ensure they monitor their blood glucose at home...so we ask them to do it and we support them by lending them a dextrostic machine if they cannot afford to buy it.'
(HCP 17)

The diabetes educator's practice of supporting self-care through monitoring of SMBG was consistently observed during clinic consultations, as presented in the below field notes:

Observation of consultation session between Mrs I and DE

The observation was conducted at a specialist medical clinic between Mrs I and DE. At the beginning of the consultation, the DE greeted the patient and asked about her condition today (the day of the consultation). Mrs I looked happy and energetic and kept smiling. The DE asked about her patterns of glucose levels at home. Mrs I showed her SMBG record to the nurse. The DE told Mrs I that she was satisfied with Mrs I's ability to control her blood glucose level. While reviewing the blood glucose record, the nurse noticed episodes of hypoglycaemia, particularly for morning readings (fasting blood glucose). The DE asked Mrs I how the episodes of hypoglycaemia happened. Mrs I said that during those times she had chosen not to eat anything at night, just to see how her body and her blood glucose would be. According to Mrs I, she took 10 units of actrapid three times a day and 20 units of insulatard at bedtime. Her last meal during the hypoglycaemia episodes was at 6pm and she did not eat anything after that. She took 20 units of insulatard before sleep and when she checked her glucose level in next morning, she was hypoglycaemic. The DE exhibited concern about the effects of hypoglycaemia, and stated 'I don't want this to happen again because it is really dangerous. You could fall into a coma and might die because of this.' Mrs I looked extremely worried and asked 'Really?'; she showed a willingness to learn more about the dangers of hypoglycaemia. (observation field notes – February 2013).

The field notes provided evidence of the value of SMBG in helping the diabetes educator to identify their problems with patterns of glucose control. The problem of hypoglycaemia experienced by Mrs I, for instance, might not have been identified based on HbA1c monitoring only. Therefore, it can be suggested that SMBG not only built patients' confidence in making decisions pertaining to their diabetes management, but also helped the diabetes educator to make proper decisions on management aspects such as modification of diet and physical activity schedule, and titration of insulin dosage. However, as presented in chapter six (section 6.3.1.2.3), the effectiveness of practicing SMBG by patients with type 2 diabetes has been debated. The results of a randomised control trial study and a systematic review (as presented in chapter six) showed unfavourable effects from regular SMBG on patients' clinical parameters, personal perceptions and health beliefs (Farmer et al., 2007; Peel et al., 2007). A more recent systematic review of 12 studies involving 3259 randomised patients also showed consistent findings. The review reported that the effect of regular SMBG on patients' glycaemic control was relatively small within the six-month period of practice, and diminished over a longer period (12 months). Furthermore, a synthesis of qualitative evidence showed that the practice of SMBG does not affect patients' satisfaction with health outcomes and general health-related quality of life (Malanda et al., 2012). Therefore, it has been suggested that the current existing evidence is not sufficient to identify definite benefits of regular SMBG on patients' clinical parameters and psychosocial outcomes. Within the current study, although SMBG was claimed by the patients and HCPs to have a positive influence on the patients' confidence in decision making and facilitate a better quality of self-care support provision, its effectiveness in the current study setting cannot be clearly confirmed as it has not yet been fully examined.

Despite the unfavourable evidence, interviews with the HCPs and observations of clinic consultations indicated that SMBG was commonly practiced by the patients in both clinics. In addition, a lot of support was provided to encourage the patients to practice SMBG in these clinics, such as selling appliances at a cheaper price, lending dextrostic machines to the patients and providing financial assistance to help the patients to buy appliances. The objective of the support provided was to reduce the

barriers that restricted the patients' ability to practice regular SMBG, as demonstrated by the narrative below:

'...why do we sell this equipment? It's because I want them to check their glucose level regularly. When we ask the patients to check their glucose, they need to buy the strips from the pharmacy out there. The expensive price of the strips becomes a reason why they are reluctant to practice SMBG. They also frequently give other reasons, such as that it's hard to find the needle for insulin injections, or that they have no budget to buy the expensive needles; so it becomes a problem. Therefore, we decided to restructure to help our patients. We managed to get lower prices for these appliances compared to other providers. So this helps to relieve their financial burden. I can't ask them to do this and that without supporting them.' (HCP 2)

Patients also provided feedback that the initiatives of the outpatient clinic to develop a diabetes resource centre and sell appliances at a cheaper price helped them a great deal in practicing SMBG. Furthermore, by practicing regular SMBG, the patients seemed to have better access to the HCPs, particularly the diabetes educators, as they were given fortnightly follow-up sessions to review the SMBG and discuss their difficulties in maintaining the intended glucose control. This practice also simultaneously improved the nurse-patient relationships, and patients seemed to have higher satisfaction with the service they received. The intermittent opportunities that the patients had to see the diabetes educators before seeing medical officers or medical specialists were acknowledged and appreciated by most of the patients in the secondary-care setting. Most of them expressed their satisfaction and showed a better understanding of their diabetes and self-care activities compared to patients receiving treatment in the primary-care environment. The researcher expressed her impression of the situation in the field notes below:

Researcher's reflective field notes

During the observation and interview with patients and HCPs in both of the study settings (primary- and secondary-care), I saw a huge difference in the way the patients were approached and managed. In the secondary-care settings, patients were consulted by endocrinologists, physicians and diabetes educators. The one-to-one consultation approach used by the diabetes educators seemed to be more systematic

and the goal of the session seemed to be focused on each patient. Given that the patients in these hospitals had already had diabetes for a long period, they seemed to have a good understanding of their body, the process of diabetes and their medication. When asked about their diabetes, they were able to explain their usual symptoms and the measures they took to manage them. However, most of them stated that they were referred to hospital when they had diabetes for quite some time and experienced symptoms of complications, such as blurry vision. Many patients expressed their frustration at this, and stated that although they were able to manage their diabetes properly, they had to accept that they had developed irreversible complications. Thus, besides being treated for diabetes, they also needed to visit other clinics for treatment of complications, which was described as ‘burdensome’. The patients acknowledged their relationship with the HCPs, especially the diabetes educators who they identified as the most important people to help them in managing their diabetes. The patients in the hospital setting seemed to have higher confidence in managing their diabetes independently, as they had somebody that they could refer to when they had problems (the patients were allowed to contact the diabetes educator at any time).

Therefore, it can be said that despite inconsistencies in findings on the usefulness of regular SMBG in improving patients’ ability to maintain optimal glucose control, the responses and feedback from the patients and HCPs in this study showed that the practice of SMBG at the case study sites seemed to have a positive effect on the patients’ confidence in decision making and engagement in self-care.

7.2.3 Concept of self-care within the support documents

The data presented in the previous section in this chapter was derived from interviews with HCPs and observations of clinical settings. It demonstrated that self-care support in primary- and secondary-care settings was frequently provided based on the experience and discretion of diabetes educator and other HCPs, without the use of clear evidence-based guidelines such as CPG (2009). In view of these findings, further analysis of relevant documents pertaining to diabetes management provision

was conducted to understand the extent of the concept of self-care being emphasised within the Malaysian healthcare system. Documents such as examples of the patients' diabetes record books, posters, booklets and pamphlets used to educate patients about type 2 diabetes, along with relevant websites, were analysed.

From content analysis of the Malaysian Health Report (Ministry of Health Malaysia, 2008) and interviews with the respective medical officer in charge of the primary-care clinic, it was found that the patients' diabetes record book (known as the 'green book') was introduced by the Ministry of Health in the year 2000 to guide HCPs on the aspects to be considered when managing patients with diabetes. HCP 14, an experienced physician involved in diabetes management within the Malaysian healthcare system, provided her views on the green book:

'In the year 2000, I think that was the point where the Ministry and all the clinics were more focused on diabetes management. Before that there was no proper record being given to diabetic patients. We just noted down all our findings and management on the normal yellow card [record used for outpatient cases in medical clinics]. But in the year 2000, the green book was introduced. So, when we saw patients with this book, we knew they were diabetic. The book helps to guide our management of diabetes patients, as it states all the details and outlines what needs to be done routinely and yearly, the blood investigations that need to be carried out, and the physical examinations required, and helped us to record the patients' parameters. I think the green book is a good thing as it provides us with a sort of checklist where we can tick which areas we have covered, which areas we have provided education on, and which areas are still lacking. Although the book is not complete and things still need to be improve, I think as a start it is a very good book.' (HCP 14)

From HCP 14's extract, it can be stated that management of type 2 diabetes has become a concern of the Malaysian Ministry of Health, so that the green book was introduced to guide physicians on clinical management. The green book is used as standard across the country as an identification document for patients with diabetes. It consists of two parts: the first contains information related to patients' parameters, investigations being carried out and clinical consultation summaries, and is kept at the clinic; the second provides a list of investigations and assessments that have been

done and that need to be carried out, and simple instructions on self-care aspects, such as blood glucose parameters and foot care, and is kept by the patients. The patients are required to bring their green book to the clinic every time they attend follow-up sessions. Basically, the green book provides a brief history of patients with diabetes and the underlying risk factors that contributed to the diabetes. In addition, this record book provides a checklist of investigations and screening that need to be done to identify signs of complications. Aspects of diabetes education are also listed, including diet, medication, physical exercise, smoking habits, foot care, hypoglycaemia and SMBG. The HCPs tick the relevant box once health education regarding these aspects has been provided to the patients. Explanations and records for monitoring self-care behaviour are not included in the book. Content analysis of the sample green book showed that its purpose is to remind the HCPs about procedures that need to be carried out to fulfil the requirements of diabetes management as stipulated in the CPG (2009), and is not meant for monitoring of self-care behaviour and progress regarding lifestyle modification by the patients. As this is the only record that is used to keep the patients' information and monitor their management, there seems to be no mechanism currently available to monitor the patients' self-care practice. Therefore, aspects such as patients' goals and treatment preferences, and their plans for behavioural modification to achieve better health outcomes, seem not to be discussed with HCPs as they are not included in the green book.

Pamphlets and booklets were used to deliver information to the patients regarding diabetes, its complications and measures that need to be taken to self-manage it. All of the pamphlets and booklets included in the analysis were prepared by the Ministry of Health Malaysia. The pamphlets included in the study were divided into two categories according to their contents: pamphlets explaining diabetes and pamphlets explaining the food pyramid and diet management in diabetes. In general, these pamphlets seem to place more emphasise on diet, compared to other aspects of self-care.

Content analysis was conducted on three pamphlets that provided information about diabetes. Two of these were written in Malay and one was written in English. The information in the pamphlets mainly focused on general information about diabetes, including pathophysiology, risk factors, symptoms of diabetes, complications of diabetes and measures to control and prevent diabetes. Overall, the pamphlets stressed the dangers of diabetes complications with detailed explanations and vivid images of these complications. Elements of guidance around self-care were included in relation to the control and prevention of diabetes. However, the information provided was very minimal, and was placed on the last page of the pamphlets. The usage of strong verbs such as 'ensure', 'take' and 'keep' provided the impression that patients have to follow the instructions as stated on the pamphlets, rather than the pamphlets giving patients the ability to make informed choices on how they should manage their diabetes. For instance, phrases such as, '*as an individual diagnosed with diabetes, you are at risk to develop various complications*' could make patients feel stressed about their future lives with diabetes. Therefore, it could be interpreted that while the contents of pamphlets may be helpful in facilitating patients' understanding about diabetes, they do not provide helpful guidance for the patients to self-manage their diabetes as the information available is very limited. More relevant content was observed in the pamphlets that provided information related to diet management. These pamphlets informed patients about the food pyramid and diet guidance that is suitable to be applied to their everyday lives. The content of the pamphlets is relevant to the Malaysian culture, as examples of types of food provided are common among the Malaysian community. In addition the images used to show types of food were realistic, and could help the patients to make choices related to their diet management. Nevertheless, these pamphlets were only available from the nutritionists and dieticians, and were only disseminated to the patients during consultations. Therefore, the patients may have had limited access to these pamphlets.

The use of pamphlets as an educational tool has been reported as useful in a review that included 43 studies. It has been suggested that written material such as pamphlets are potentially effective in improving patients' knowledge and facilitating behaviour change in a wide range of health-related issues, including diabetes (Redman & Paul,

1997). However, it has also been argued that the effectiveness of the written material is dependent on the content, language used and design characteristics of the material (Paul, 2003). Reflecting on the content of the pamphlets included in the content analysis of the current study, strong verbs and scare tactics seemed to be used to stress the dangerousness of type 2 diabetes. Furthermore, it is interesting to note that the use of scare tactics was consistently identified within diabetes management provision at the case study sites, as identified in the interviews with patients and with HCPs, and the observations of clinic consultations. Although this seems negative, the usefulness of the approach has been supported by Matthews et al. (2009), who suggested that providing patients with information on the seriousness and consequences of the disease increases their knowledge of risks. It has also been stated that a lack of emphasis on complication by HCPs would lead to patient ignorance, as they often perceive diabetes as simple and not dangerous. However, focusing on this approach alone has been argued to be ineffective in terms of fostering behaviour change, which is the 'gold standard' of diabetes management provision (Delamater, 2006). It has been suggested that scare tactics can result in considerable anxiety on the part of patients, and contribute to building negative perceptions in patients towards HCPs (Kokanovic & Manderson, 2007). Therefore, it can be concluded that while the use of scare tactics provides some benefits to patients as it helps to increase their awareness of the dangerousness of diabetes, it should be applied with caution as it has been proven to stimulate negative effects on patients psychologically, and be detrimental to their relationship with HCPs.

A website for diabetes established by a non-governmental organisation (NGO) with full support from the Ministry of Health was also analysed. The website was chosen as it contains updated information about diabetes that is relevant to the Malaysian setting and is commonly accessed by HCPs and patients, particularly those who live in urban areas. Generally, the website provides a lot of useful information related to diabetes, including statistics on diabetes in Malaysia, and information on pathophysiology, types of diabetes, complications of diabetes and tips and tricks for patients living with diabetes and managing it properly. The website also provides useful information about healthy lifestyle, including announcements of exercise

activities conducted around Kuala Lumpur and Klang Valley, fitness and diet tips and information about nutrition relevant to diabetes patients. In addition, updates on diabetes and treatment that have been published elsewhere, including newspapers and magazines, are uploaded to the website. The downside of the website is that most of the information is written in English, although a few articles are in Malay. This may diminish viewer interest, especially in patients who have difficulties understanding English, to visit the website. In addition, in order to access the content or to interact with the moderator or advisor through the website, HCPs and patients need to be registered with the site, as most of the content is password protected. This might also reduce patients' interest in visiting the website, as it might be difficult to remember the password every time the visitor wants to view the website's content. The website interface, which uses a white background, blue banner and small black font, makes the website unattractive. Despite its limitations, the practicality and usefulness of the website in terms of providing information on diabetes management seems clear. This was also supported through the interviews with patients, who claimed that they preferred to surf the internet to search for information related to diabetes management and find possible solutions whenever they faced difficulties in dealing with the illness. Furthermore, this study was conducted in an urban setting, and the majority of the participants were still in the productive age group; thus, their access to computers and online materials is high. Moreover, high patient participation and effectiveness in facilitating behaviour change has been reported in studies that applied Web-based technology as a platform of information dissemination, and as a medium for interaction among patients and HCPs (Glasgow et al., 2006; Williams, Lynch, & Glasgow, 2007). Therefore, the availability of online material in supporting the patients' self-care within the current study settings seems appropriate, provided it is appropriate and relevant to the Malaysian culture and environment.

7.3 Summary

This chapter outlined the self-care support provision within the Malaysian healthcare system, and the extent to which self-care concepts are emphasised in the practice and documents used to support patients with diabetes. Generally, self-care is considered

an important element in diabetes management, and it was mentioned repeatedly in the policy documents. However, information regarding self-care and guidelines on approaches to support self-care within these documents was found to be very minimal and unclear. In practice, different approaches to diabetes management were observed between primary- and secondary-care settings. However, the effectiveness of each of approach employed in improving patients' engagement in self-care cannot be clearly determined. Furthermore, self-care support within the healthcare system was commonly found to be outcome oriented, where the needs of self-care support were evaluated based on patients' ability to maintain glycaemic control. Therefore, it can be concluded that the concept of self-care has not been adequately emphasised as very limited information about it is available for patients and HCPs.

Through the interviews, observations of clinical consultations and analysis of relevant documents, it was noted that diabetes educators are most responsible for providing diabetes education and facilitating patients' self-care. The diabetes educators' practice seems to be crucial in the implementation of self-care support provision. Therefore, diabetes educators' perspectives on their role in supporting self-care and the limitations they face in providing the intended service is another aspect that should be understood; this is explored in the next chapter.

CHAPTER 8

Perspectives of Diabetes Educators on Their Role in Supporting Self-Care

8.1 Introduction

The findings of chapter eight demonstrated that collaborative practice has been suggested by CPG (2009) as the most important approach to diabetes management provision. Furthermore, it was identified that diabetes educators play a major role in providing diabetes education and supporting patients with respect to self-care. However, from the data presented in the previous chapter, the role of diabetes educators in self-care support provision is not clearly described. Furthermore, the interviews with physicians had showed that the role of diabetes educators as care coordinators and facilitators in supporting patients' self-care has been inadequately recognised, which makes their role limited. Therefore, views and perspectives of diabetes educators on their role within the continuum of self-care support provision are explored further in this chapter. In addition, this chapter identifies the factors that are perceived by the diabetes educators as the limitations or barriers for them to provide the intended care. The findings of this chapter are derived from interviews with diabetes educators at the three case study sites, and observation field notes from the clinic consultations. Themes and categories that emerged from the data analysis are presented in Table 8.1, and the findings are presented using narratives.

Table 8.1 Themes and categories describing perspective of diabetes educators on their role in self-care support provision

Themes	Categories
Perspectives of diabetes educators on their role	Importance of knowledge Individualised support
Limitation in providing support	Patient factors <ul style="list-style-type: none"> - Acceptance of diagnosis - Interest in self-care Environmental factors <ul style="list-style-type: none"> - Space and crowded clinics Diabetes educators' internal factors <ul style="list-style-type: none"> - Lack of opportunities to practice - Job satisfaction Systemic factors <ul style="list-style-type: none"> - Fragmented healthcare system

8.2 Diabetes educators' perspectives on their role in self-care support provision

The data presented in chapter eight demonstrated immense differences in diabetes management provision between primary- and secondary-care settings. For instance, service delivery in primary care was focused on primary prevention and community-based support. In addition, group education was utilised by the HCPs in primary care as a medium through which to deliver diabetes education. In contrast, management of diabetes in secondary care was found to put more concern on a reactive approach in supporting patients with self-care, which is known as 'individual diabetes counselling', and was commonly implemented by the diabetes educators in secondary-care settings. Furthermore, management of diabetes in secondary care placed great emphasis on the practice of SMBG, wherein a number of measures were carried out to support the patients to practice SMBG. Although there were dissimilarities in the approach to service provision, interviews with diabetes educators at the three case study sites showed that they agreed on their perception of their role in supporting patients with type 2 diabetes. Two categories emerged to explain the perspective of diabetes educators on their role in supporting patients' self-care: the importance of knowledge, and individual support (Table 8.1). Each of the categories is now explained in detail.

8.2.1 Importance of knowledge

When asked about their role in supporting patients with type 2 diabetes, most of the diabetes educators perceived that it revolved around providing knowledge and information, which aimed to enhance patients' understanding and enable them to make decisions pertaining to diabetes management. Therefore, from the interviews it was apparent that the role of diabetes educators and the approaches used in diabetes management were mainly targeted to providing diabetes knowledge to the patients, as exemplified by the diabetes educators below:

'My role in supporting patients with diabetes is to give them knowledge about diabetes and what they should do to manage it. How they should look after themselves at home. For example, in terms of diet and lifestyle, medication, exercise and how they live their lives.' (HCP 3)

Throughout the period of study, it was observed that knowledge was provided to the patients every time the diabetes educators met with them, whether formally or informally. For example, it was observed that knowledge was frequently delivered to the patients simultaneously during physical assessments (routine screening for complication) and wound dressing, or formally during group education sessions or individual consultations. Various approaches were adopted by the diabetes educators to ensure the knowledge delivered was beneficial in facilitating the patients' engagement in self-care. For instance, one of the diabetes educators explained that she used the 'information drip-feeding' approach to attract patients' interest in visiting the clinic in order to get more information:

'Usually the first time they come...they have many questions. I won't answer all the questions at one time. I divide the information so they have a reason to come again. If I answered them all at one time, then they might come again and ask the same question. In addition, I think that if I give them a lot of information at one time, they might not be able to accept. I am worried that they will misunderstand, and practice incorrectly at home.' (HCP 2)

The approach to knowledge provision practiced by the diabetes educator above might be beneficial to certain group of patients. However, it could be argued that the practice of 'information drip-feeding' might leave patients with feelings of frustration and uncertainty when practicing, as the information received might have been unclear. Moreover, as presented in chapter six (section 6.3.2.2.1), the patients perceived

unclear information received from diabetes educators as a barrier for them to engage in self-care. In parallel, unclear information provided by the diabetes educators that fail to meet the needs and pique the curiosity of patients has also reported by Lawton et al. (2009) to reduce patients' participation in self-care. Furthermore, the diabetes educators' perception that drip-feeding information will attract patients to revisit the clinic seem to contrast with the findings of Lawton et al. (2009), who reported that unclear information received by patients during consultations reduces their interest in visiting healthcare facilities. Therefore, it can be suggested that although knowledge is perceived as important, the approach to knowledge provision used by the diabetes educators at the case study sites is not always suited to the needs and expectations of the patients.

Diabetes educators in this study frequently perceived that patients lacked knowledge pertinent to diabetes management. In addition, patients were frequently perceived as having an incorrect understanding of diabetes, as they commonly received lay advice from relatives or friends. This aspect strengthened the perceptions of diabetes educators, in terms of the importance of knowledge, especially for patients who were newly diagnosed with diabetes. The diabetes educators recognised that inappropriate information and advice received by patients made them more confused about managing their diabetes, and reduced their concern for, and interest in, self-care, as demonstrated in the extract below:

'Many of these patients frequently receive advice from their relatives and friends. For instance, if somebody tells them not to eat rice...they might think that this is right. Some of the patients think that they can't eat sweet drinks so they just avoid them. But they don't know the rationale behind it because they don't have enough knowledge about it.' (HCP 9)

The interviews with patients presented in chapter seven demonstrated that they gained knowledge about diabetes from several sources, including the media and internet, and friends and relatives. However, the patients acknowledged the information and support received from the diabetes educators and other HCPs, as they were perceived as experts in helping them to manage their diabetes (section 6.3.2.1.3). However, the

patients frequently claimed that they did not have much opportunity to talk to the diabetes educators and other HCPs, and that the support received from them was very limited. Therefore, the information received from the diabetes educators frequently contrasted with the patients' actual life situation, which made the adaptation of self-care difficult.

It has been clearly reported in the literature that providing responses and feedback on patients' attainment of self-care activities is another aspect of support that increases patients' engagement in self-care (Ciechanowski et al., 2001). Ciechanowski et al. (2001), in a study that measured patients' adherence to self-care based on attachment theory, suggested that strong attachment and frequent feedback from diabetes educators had a positive association with patients' adherence to self-care, and better outcomes in diabetes control. Therefore, it can be understood that frequent opportunities to talk with diabetes educators and receive feedback on their achievements related to glucose control enhance patients' motivation to engage with self-care activities. However, data from chapters six and seven highlighted a problem of communication barriers between the patients and HCPs (diabetes educators and other HCPs) in this study. Furthermore, long gaps between appointment (three- to four-month intervals), as outlined in chapter seven (section 7.2.1.3), limited the patients' opportunities to interact and discuss their difficulties with the diabetes educators and other HCPs. Moreover, the diabetes educators in this study frequently pointed out that the 'patient blaming' approach was commonly used by the HCPs when providing feedback on the patients' inability to achieve the desired glycaemic control, as evidenced from the extract below:

'Patients are usually blamed if they do not follow the advice and their sugar is poorly controlled. When they refuse to do certain tests, urine tests for instance, we can expect that they are afraid of being scolded. Of course, the doctors get angry because although the patient claims they have complied with the medication; their sugar level is not being controlled. So surely they have not properly controlled their diet.' (HCP 4)

Based on the available data, it can be suggested that the self-care support being practiced within the case study sites revolved around traditional medical models. The

service delivery appeared to be paternalistic and the ‘patient blaming’ approach, as demonstrated in the extract above, remained embedded in the practice. Although it was mentioned by the diabetes educators that knowledge and education are the cornerstone of facilitating patients’ engagement in self-care, the approach that the diabetes educators and other HCPs used to provide feedback to the patients seemed to be detrimental to the patients’ motivation and enthusiasm to self-manage their diabetes. Furthermore, the traditional medical model, which incorporates patient blaming, has been argued to be unsuitable in supporting patients with chronic condition such as diabetes, as they face complex life situations that are psychologically demanding (Kokanovic & Manderson, 2007). Furthermore, a review by van Dam et al. (2003) reported that a positive patients–providers relationship is essential, and has a strong effect on patients’ motivation in behaviour modification and health outcomes. Therefore, it seems that despite their awareness of the importance of knowledge, the diabetes educators’ approach to providing feedback and support, with its lack of opportunity for patients–providers communication, can be argued to be another reason for the poor engagement of patients in self-care in the current study.

8.2.2 Individualised support

Besides focusing on the information needs of the patients, the diabetes educators also recognised the importance of psychological support in helping the patients to engage in self-care. However, the diabetes educators claimed that this aspect was frequently hard to manage as patients were frequently reluctant to disclose problems they faced at home. Furthermore, the diabetes educators in this study acknowledged that patients usually perceived diabetes educators as outsiders who were only responsible for providing advice, without considering their difficulties in dealing with diabetes. Therefore, the diabetes educators frequently claimed that it was hard for them to really understand the patients’ life situations and problems that contributed to their inability to achieve the targeted glycaemic control. This is demonstrated in the extract below:

'From our record [in the outpatient clinic], 10% of the patients who came with complications are those we have attended to and counselled before. That makes me so frustrated. I think it is really hard to understand the situation that made them unable to follow whatever we suggested. When we give advice, they frequently reply, 'it's easy for you to say it...but I am the one who suffers'. But when we ask about their problems, they are usually reluctant to talk about them.' (HCP 2)

The extract above shows that complications from type 2 diabetes were common at the case study site, although related information was given prior to the patients contracting them. Furthermore, the patients' reluctance to share their problems and difficulties that they experienced pertaining to diabetes self-management made the diabetes educators feel frustrated and uncertain about the best way to support the patients. However, the evidence provided by the diabetes educators seems to contradict the experiences and perceptions of the patients. As presented in chapter six (section 6.3.2.2.1), the patients frequently expressed their frustration with the support provided, as the diabetes educators or other HCPs rarely asked about their routine lifestyle and the issues they faced in managing their diabetes. Thus, it can be interpreted that the diabetes educators were aware of the importance of understanding the patients' individual problems in dealing with diabetes; however, certain aspects limited the diabetes educators and prevented them from exploring the patients' individual situations and providing the self-care support based on the patients' needs and preference.

Individual consultations, or 'diabetes counselling', as described in chapter seven, were identified by the diabetes educators in both primary- and secondary-care settings as the best approach to developing relationships and understanding the patients' problems in-depth. Furthermore, most of the diabetes educators perceived that individual consultation sessions would allow them to spend more time with the patients and enable them to understand the patients' problems that lead to difficulties in maintaining good glycaemic control. One of the diabetes educators explained her experience regarding this aspect as follows:

'Patients are frequently reluctant to share their problems. Like this one patient that I attended...it took months...before he felt comfortable to share his

problems. So, we need time to see them individually. The first time we see them, not many patients want to share their problems...So it is hard for us to identify what actually is the problem that has made them unable to practice self-care.’ (HCP 7)

Although it was identified that patients were frequently reluctant to disclose their personal situations, the diabetes educators perceived that spending more time with them and having repeated consultations with the same diabetes educators would enhance patients’ trust and confidence, which would enable them to share their problems. This approach to support seems to be valuable for patients’ ability to self-manage. This resonates with the findings reported by Beverly et al. (2012) in the United States that patients’ willingness to disclose their problem with self-care were associated with their levels of glycaemic control and depressive symptoms. In parallel, a qualitative study conducted in Canada reported that female participants who more readily disclosed their problems pertaining to diabetes self-management showed better adoption of self-care activities, irrespective of their social context (Mathew et al., 2012). Therefore, it can be suggested that patients’ willingness to disclose their problems and difficulties with self-care impact their coping strategies and ability to adopt self-care activities. However, despite the awareness of diabetes educators of the importance of encouraging patients to communicate their personal situations, implementation of this approach was observed to be restricted, particularly in the primary-care setting. Moreover, only one diabetes educator was available at the primary-care clinic (the case study site); thus, the ability of the diabetes educator to provide individual diabetes counselling to the patients in the clinic was very restricted due to a very high workload. Nevertheless, the diabetes educator in the primary-care setting claimed that she tried her best to provide individual consultations, despite the limitations. This is illustrated in the extract below:

‘If there are patients that need counselling, the doctor will call us and tell us...If I am free at that time, for example, in the evening, I will accept. If not, then I will give another appointment date for the counselling. Actually, the actual role of the diabetes educator is to motivate patients so they can manage their diabetes properly. But since I am alone here, there are a lot of things that I need to cover.’ (HCP 9)

From the narratives above, it can be observed that the diabetes educators were in agreement about the significance of psychological support in addition to providing knowledge and information, which they referred to as ‘motivating the patients’. The provision of individual consultations by the diabetes educators was more often observed in the secondary-care settings. In fact, as presented in chapter seven (section 7.2.2.1), individual consultation is the preferred approach by patients and diabetes educators in the secondary-care settings. However, in the actual situation (as presented in observation field notes in chapters six, seven and eight), it seems that the individual consultation sessions between patients and diabetes educators remained as ‘information-giving’ sessions, and examples of patients being ‘motivated’ were not clearly observed.

Motivating patients through individual consultation and counselling is one of the most important elements in promoting lifestyle changes in type 2 diabetes, as reported in the literature (Johansson et al., 1995; Adolfsson et al., 2008; Wu et al., 2011). Furthermore, several elements were highlighted as crucial for inclusion in the individual diabetes counselling sessions, including: collaborative goal-setting, active problem-solving, patients’ stages of change, barriers to change and decision making related to lifestyle (Kiuru et al., 2004). A study by Poskiparta et al. (2006) conducted in Finland also emphasised the importance of diabetes counselling. However, this study reported that HCPs frequently spend minimal time providing support and counselling on diet and physical activities. In addition, the content of the counselling in relation to these two aspects is commonly superficial (Poskiparta et al., 2006). This seems to be in parallel with the situation in this study. Although individual diabetes counselling was perceived by the diabetes educators as imperative, its implementation was frequently restricted due to the high patient–HCP ratio and limited time that the diabetes educators have with patients. Furthermore, the individual counselling at the case study sites was frequently unstructured, and the elements highlighted in Poskiparta et al.'s (2006) study were not observed during the consultation session in this study, as demonstrated in the field notes below:

Observation field notes – Mrs A & DE (Nurse H)

The observation was conducted at a specialist clinic in the hospital. The consultation session was conducted in a meeting room. During the session there were two other patients and four nurses in the same room having their consultations. Nurse H started her consultation by reviewing Mrs A's history from the case notes and looking at the SMBG record brought by Mrs A. After reading the history, nurse H told Mrs A that she was disappointed as Mrs A's glucose control was still poor. However, she praised Mrs A's good glucose monitoring record. Mrs A explained how she managed her diabetes at home. According to Mrs A, she adhered to the meals suggested, and ate small portions. Mrs A expressed concern about her inability to get good control of her blood glucose. Mrs A told nurse H that she noticed that she had a problem getting normal glucose readings, especially after lunch or dinner. Mrs A's facial expression showed that she was really worried, and she frowned slightly during her explanation. Nurse H explained Mrs A's condition to her, and why her blood sugar increased after lunch or dinner. Nurse H also related Mrs A's problem to the heart disease that she is currently suffering from. She explained that Mrs A's heart disease is a complication of her diabetes. Nurse H also explained about the importance of exercise in reducing blood glucose. The explanation was verbal, without any visual aids. (Observation field notes – March 2013)

In relation to the consultation sessions, or the 'individual diabetes counselling sessions', it was apparent from the field notes that the sessions were limited to providing information and advice regarding the things that patients should or should not do, and remember to apply in their daily lives. From the extract, it can be seen that the patient tried to explain her problems and concerns regarding her inability to maintain glucose control. However, the diabetes educator did not explore the problem further, but provided the patient with general information and suggestions that may not have been relevant to the patient's situation. Throughout the data collection, it was noted that there was a certain mismatch between the perceptions and actual practices of the HCPs pertinent to diabetes management provision. During the interviews, most of the the diabetes educators, expressed the need and importance of understanding

patients' problems and providing support that relates to the patients' individual life situations. However, in practice, this was not clearly observed; the consultation sessions were frequently dominated by the HCPs, while patients were expected to follow whatever was suggested. Therefore, the reasons that restricted the diabetes educators, from providing the intended support need to be further explored.

Another aspect of concern in this study is the resources available to the diabetes educators, to support patients' self-care. During the interviews, the diabetes educators commonly claimed that they frequently gave their personal phone number to patients and encouraged them to communicate any issues or problems that they faced pertaining to self-care practices at a convenience time. The extract below exemplifies this:

'We need to find out why she [a specific patient] has come to be this way. Is it because of her own attitude? Or there are some other things or factors....Maybe she is stressed and fed up with all the things that she needs to do. So she might be giving up. That is why I prefer to give my phone number to the patients. Actually, I don't want to be very strict with them but at the same time I still want to achieve the ideal glucose control. So, I have to do it in a smart way.' (HCP 6)

The above example shows that the diabetes educators in this study were critical and reactive when it came to understanding patients' individual problems pertinent to their inability to self-manage. In other countries, such as the United States, United Kingdom and Japan, for example, telephone follow-ups, automated telephone systems and interactive telephone interventions have been effectively used to enhance patients' adherence to self-care and improve self-efficacy in their diabetes management (Graziano & Gross, 2009; Bird et al., 2010; Nesari et al., 2010). This evidence seems to support the positive impact of the initiatives taken by the diabetes educators in this study. However, the approaches used, such as providing patients with a personal phone number, as in the case of the diabetes educator above, could expose the diabetes educators to threats to their privacy and safety. This situation provided evidence that the resources available to provide effective self-care support to the patients were limited, and the diabetes educators had to use their own initiatives,

although they were aware that this was not permissible. It seems that there were a number of limitations facing the diabetes educators that restricted them in providing self-care support. Therefore, in order to understand these limitations, several categories were identified and are discussed further in the next section.

8.3 Factors that influenced self-care support provision

The data presented in the above section illustrates the difficulties and limitations faced by the diabetes educators, in providing quality self-care support provision. Therefore, the factors that limited the practice of diabetes educators were further identified. These factors were categorised into four aspects: patient factors, HCP factors, environmental factors and systemic factors. Each of these factors is now discussed in detail below.

8.3.1 Patient factors

Two elements of patient factors were frequently perceived by the diabetes educators as restricting the effectiveness of self-care support provision: acceptance of diagnosis and interest in self-care.

8.3.1.1 Patients' acceptance of diagnosis

The diabetes educators frequently expressed that most patients with type 2 diabetes at their clinics found it hard to accept the fact that they had diabetes. This resulted in their poor adherence to diabetes educators' and other HCPs' suggestions about diabetes management. For example, a medical officer mentioned that the management of patients with type 2 diabetes usually depends on their diagnosis acceptance. Furthermore, the diabetes educators frequently conveyed that patients who positively accepted their diagnosis normally had better adherence to the suggestions of self-care compared to patients who were unable to accept it. In their opinion, patients who

accepted the diagnosis were more ready to be involved in self-management, and usually more compliant with the treatment and follow-up schedule. The patients' work and tight schedules were perceived by the diabetes educators as commonly contributing to the patients' noncompliance. The extract below demonstrates the views of one diabetes educator regarding this issue:

'The management depends on their acceptance of the diabetes. If they can accept that they have diabetes, then the management is easier than if they do not accept their diagnosis. And then, in terms of acceptance and sometimes because of their working type. Sometimes their work requires them to travel, for example in the navy or army, or some patients work offshore...so they find it hard to follow our schedule. This is problematic in terms of their medication and treatment. These kinds of patients usually default on treatment, and their glycaemic control is not very good.' (HCP 13)

In the literature, it has been reported that patients' personal factors, including acceptance of their diagnosis, impacts their adherence with treatment and self-care regimens (Oakley et al., 2011; Wattanakul, 2012; Stiffler et al., 2014). In parallel with the findings of the current study, a study conducted in a different clinical setting in Malaysia also reported that patients' acceptance of their diagnosis and lack of knowledge are perceived by the HCPs as a barrier to the initiation of insulin treatment (Lee et al., 2012). Furthermore, a study by de Alba Garcia *et al.* (2007), which compared lifestyle modification and self-management among patients who had good and poor glycaemic control in Mexico, seems to provide a similar view. De Alba Garcia et al. (2007) pointed out that patients who had good glucose control usually have a problem in accepting their initial diagnosis. However, their awareness and understanding of diabetes are frequently gained through extensive reading. This group of patients has also been reported to embrace a healthier lifestyle and be aware of their glucose levels as they have more knowledge about diabetes. On the other hand, patients with poor glucose control usually accepted their diabetes in the first place. However, they commonly face problems in adapting the diabetes into their lives and are more likely to accept lay explanations and tips from others in managing their diabetes (de Alba Garcia et al., 2007). The situation in de Alba Garcia et al.'s (2007) study seems to be in parallel with that of the current study. Although it was perceived by the diabetes educators that patients in this study found it hard to accept their diabetes, this was reported differently in chapter six (section 6.3.2.1.2), wherein

patients were generally shown to accept their diagnosis. However, they frequently expressed difficulties with adaptation of diabetes and self-care, and a lack of support from Diabetes educators, which frequently caused them to accept lay advice. In fact, as also reported in chapter six (section 6.3.1.3), the use of alternative medicine among this group of patients was common, as they were prone to accepting suggestions given by friends and relatives. A comparison between the perceptions of diabetes educators and the experience of the patients pertaining to this issue revealed contradictory views. Therefore, it can be suggested that the diabetes educators and other HCPs involved in diabetes management provision at the case study sites did not clearly understand the experience and life trajectory of their patients. Consequently, the contradictory perceptions that the diabetes educators' and other HCPs' had towards the patients resulted in a mismatch between the self-care support given and the patients' needs. This situation could also be argued as a reason for the ineffective self-care support provision provided at the case study sites.

8.3.1.2 Patients' interest in self-care

The diabetes educators perceived that another reason for the ineffectiveness of the self-care support provision was the patients' lack of interest in self-care. The diabetes educators frequently mentioned that the patients often saw self-care as unimportant, as they usually felt healthy and rarely experienced alarming symptoms. Although the complications of type 2 diabetes were widely emphasised (as presented in chapters six and seven), the diabetes educators perceived that the patients' awareness of the dangerousness of diabetes was still very low. The diabetes educators also explained that the patients would only realise the impact of diabetes once they had experienced complications that affected their physical functions. The views of the diabetes educators in this regard can be seen from the extract below:

'We have many patients with uncontrolled diabetes. In fact, some of them are among the Diabetes educators. When I ask them why they do not manage it properly they usually say that they still young, and they think they might not be affected much. They tell me that they have seen so many patients with diabetes, and claim that they know what to do. But when I ask them further, they actually forget about some of the complications. They forget that even

though they are young, they can still lose their sight, have renal failure, have to do dialysis...’ (HCP 2)

Based on the above extract, it is interesting to note that a lack of awareness and interest in self-care was seen not only in lay patients, but also in patients who had background knowledge about diabetes, such as HCPs. Therefore, it can be suggested that sound knowledge of diabetes does not necessarily result in good self-care practice. A previous review highlighted that the self-management behaviour and perceptions of patients critically depend on the HCPs’ attitude towards diabetes, especially at the time of diagnosis (Nam et al., 2011). Furthermore, the existing evidence shows that there are discrepancies in terms of the knowledge, attitudes and practices of HCPs, which influence the practicalities of self-care support provision (Jacob & Serrano-Gil, 2010). This situation seems to be similar to the current study. Several diabetes educators in this study consistently mentioned that other HCPs often saw diabetes as less dangerous compared to other diseases, and this seemed to develop undesirable behaviour among the patients, as shown in the extract below:

‘They [other HCPs] usually see diabetes as a simple problem and they do not explore it further. This is because they usually hear about other diseases such as cancer which they think is more dangerous...then only they would bother. But diabetes...they usually think that it is a common problem and just an ordinary disease.’ (HCP 1)

Therefore, it can be suggested that the patients’ lack of interest in self-care, as perceived by the diabetes educators, is not only compounded by the patients’ perceptions and attitudes towards the diabetes, but also by the attitudes of the HCPs, who frequently see diabetes as a common disease and not overly dangerous. Apart from the patients’ interest in self-care, this lack of concern by the HCPs with respect to diabetes could also be argued to have an impact on the self-care support provision at the case study sites.

8.3.2 Environmental factors

The clinic environment was another factor that was pointed out by the diabetes educators as a reason for the ineffectiveness of current self-care support provision. Two main aspects were pointed out by the diabetes educators pertaining to the clinic environment: space and crowdedness. Each of these aspects is explained in detail below.

8.3.2.1 Space

Through the analysis of the clinics data, it was noted that the three clinics involved in this study received a high volume of patients. Approximately 2000 to 4000 patients with diabetes were registered at each of the clinics. Furthermore, the three clinics involved in this study operate on an integrated basis, where, besides functioning as diabetes clinics, they were also a general medical clinic, outpatient clinic and maternal and child health clinic (primary care), respectively. Therefore, the resources and space available for the diabetes clinic were very limited and some of the resources needed to be shared with others. The specialist medical clinic, for instance, besides serving patients with diabetes, was a station for other medical illnesses, including those related to respiratory, dermatology, cardiovascular and other endocrine conditions. As such, limited space available in the clinics made them unable to cater to their multidisciplinary functions. Many of the diabetes educators pointed out their dissatisfaction with the space in the clinic, which they claimed as unsuitable for providing individual consultations and counselling to the diabetes patients, as exemplified below:

'I am totally dissatisfied with the current environment in this clinic. There are a lot of distractions and we are also unable to maintain the privacy of the patients. Patients might be reluctant to ask certain questions, especially if it relates to their personal lives...because of the lack of privacy. For instance, the meeting room is currently used as a counselling room; four patients are called at a time and they are seated at one round table with the diabetes educators and other staff. It is really congested and patients can hear each other's conversations. I really don't agree with that.' (HCP 7)

The situation was also observed by the researcher during the data collection period. As presented in chapter five (section 5.5.2), the layout of the meeting room that was usually used as the consultation room for diabetes counselling was seen to be inappropriate for individual consultations. During an observation of one consultation session, for instance, the researcher noticed how uncomfortable the patient felt during the consultation session as her conversation could be heard by other patients and nurses in the room. Furthermore, the high noise level in the room made the patients struggle to focus on what was being said by the diabetes educators. This situation seemed to be detrimental as the patients may have misheard instructions and thus conducted incorrect practices, which could harm them. The example below also demonstrates the dissatisfaction of the diabetes educators with the limited space in the clinics, which restricted them from providing the intended service to the patients:

'We don't have a comfortable place to conduct our activities. For example, one day, the seminar room was being used. All the rooms in this clinic were occupied with other activities. So, we couldn't sit down with the patients to ask about their follow up. How could we carry out the discussion? So, the consultation given was of lower quality. Because there were no suitable spaces for us in the clinic at that particular time.' (HCP 5)

During the interviews with the diabetes educators, it was noted that most of the diabetes educators, regardless of the clinic, mentioned a lack of suitable space as one of the restrictions to providing the patients with a good service. Therefore, it can be suggested that problems with space in the clinic were common at the three case study sites, and was perceived as a factor causing the ineffectiveness of self-care support provision.

8.3.2.2 Crowded clinics

In parallel to the current situation in Malaysia in terms of the rapid increase of incidence of type 2 diabetes, the number of patients who visited the clinics was sharply increasing. Therefore, many diabetes educators in the study pointed out that crowdedness of the clinics was another contributing factor restricting them from

providing good self-care support. In conjunction with the increase in patients, the diabetes educators frequently claimed that they had very limited time with each of the patients, which restricted them from understanding the patients' problems in depth. Therefore, their support was restricted to addressing the glucose level and providing general advice, as they did not have enough time to listen to the patients' problems and plan their care properly based on the patients' needs. Furthermore, the diabetes educators also pointed out that it was hard for them to maintain the quality of services that they provided to the patients as they usually needed to deal with a lot of patients every day. Therefore, the quality of consultations provided may have been low as they were frequently exhausted from their high workload. The extract below exemplifies the diabetes educators' perceptions on this aspect:

'Patients are waiting for us because they come based on appointments. So, like it or not, we need to do counselling continuously. Perhaps our concentration on the earlier patients will be better because we are still fresh, but it might be low, especially when the patients come in the afternoon. In my opinion, it depends on the counsellor herself whether she still has energy to give a thorough explanation to the patients, or just focuses on certain points. That depends on the situation. We may also be less thorough or more complacent because we need to think about other patients who are waiting their turn. In addition, we only have certain sessions for counselling and need to limit the number of patients. It really depends on the environment, space that can be used for counselling and the number of staff that we have on that day.' (HCP 6)

From the interview, it was apparent that most of the diabetes educators perceived the unsuitable clinic environment and high number of patients in the clinics as among the factors restricting them from providing the service they intended to give. Furthermore, during the observation, the current environment of the clinics, which lacked privacy, was identified as inappropriate for patients to share their problems and receive proper self-care support. It can be suggested that this aspect critically influenced the quality of self-care support provision in these clinics.

8.3.3 Diabetes educators' internal factors

Another reason noted by the diabetes educators, as restricting their practice in self-care support provision was internal factors, including lack of opportunity to practice and lack of satisfaction in their work.

8.3.3.1 Lack of opportunity to practice

Most of the diabetes educators claimed that they frequently lack confidence and had a sense of inferiority in terms of carrying out their role, although they had all attended a six-month advanced diploma course. Several diabetes educators, especially those who worked in a secondary setting, mentioned that they actually felt empowered and were given authority by the endocrine specialists to manage the patients, and titrate the insulin dosage based on their judgement of the patients' SMBG trend and self-care practice. However, they lacked confidence to make decisions related to patients' medication dosage, as they did not have qualifications in this regard. The extract below provides an example of this view:

'We have been given the authority to titrate the insulin. But of course we can't change the type of medication that they take. We can adjust their insulin based on SMBG results. But whatever it is, we still need to consult the doctors. We know that we can't prescribe the medication. So, I will let the doctor know about any changes. For our own safety.' (HCP 7)

When asked about their opinion regarding the effectiveness of the advanced diploma course that they attended to prepare them for the role of diabetes educator, several stated that the course merely taught them about diabetes, its medical management and updates related to it. Very minimal input was given regarding the approach to counselling, motivating and dealing with the patients' real-life situations in terms of living with diabetes. In fact, the diabetes educators claimed that those aspects were frequently gained through routine practice in the clinics, and experience of others (senior staff). This is demonstrated in the extract below:

'Personally, as a nurse and diabetes educator for the past three years, after back from post basic, I felt nothing. The nursing authority just leaves us like that and I don't know what my direction is. Just getting post basic for the sake

of to have a post basic. We back and work as a normal nurse in the ward. It seems like diabetes educators do not have any priority in this hospital. I gained a lot of experience and knowledge about diabetes management when working in the field. Compared with what I know now, I think went to post basic is a waste. Whatever we learnt now is way better than what we learnt during the course.’ (HCP 6)

Based on the extract above, it can be interpreted that the role of diabetes educator is not clearly recognised within the healthcare system. It seems that the diabetes educators were not clear on their job description, which is supposed to guide them to carry out their role. Therefore, their role was frequently embedded within routine work as a general nurse, and their skills and knowledge as diabetes educators were not being sufficiently utilised. This was also consistently mentioned by the diabetes educators, as per the example below:

‘What I can say is, diabetes educator in this clinic have not yet been nominated as a unit. We don’t have the space, and we also cannot focus on the diabetes educator role alone. We serve as diabetes educators and endocrine nurses. We complete a lot of tasks, including assisting doctors in procedures, taking specimens and even tracking patients’ files. At the same time, we are involved in diabetes management, such as reviewing SMBG and providing diabetes counselling. So, I would like to stress here that diabetes educators in this clinic are not fully diabetes educators.’ (HCP 5)

It was apparent that the diabetes educators did not have specific job descriptions, and ended up with multifaceted jobs that were largely very technical. Furthermore, the lack of manpower and high workload in the clinics were frequently mentioned by the diabetes educators as limiting their opportunity to focus on the role of diabetes educator and provide proper self-care support to the patients. It seems obvious that the high workload and multifaceted job of the diabetes educators reduced the quality and effectiveness of self-care support provision within the case study sites.

Apart from the lack of confidence and lack of opportunity to practice, the diabetes educators highlighted the lack of opportunity to upgrade their knowledge and continue their study at a higher level. This aspect was perceived as being due to the deficiency of support from higher authorities, which was thought to arise from a lack

of resources and insufficient recognition of the diabetes educator role within the healthcare system. This reduced the motivation and enthusiasm of the diabetes educators to upgrade their knowledge and level of education:

HCP: 'Actually, I also query what is our basis or guidance. As of now we don't have an established one. We also don't have a clear job description as diabetes educators. Currently, our job description is that of staff nurse...So far, our knowledge is based on our experience and we did that ourselves. I have brought this problem to the attention of higher authorities, but there has been no feedback. So I really have no idea about that.'

R: 'In terms of professional development, what is the pathway of a diabetes educator at the moment?'

HCP: 'It is up to us. It might just end like this. If we have the initiative to undertake further study, we might progress to another role, such as what Dr B (head of endocrine unit) suggested: diabetes manager. But at the moment we really don't have that.'

R: 'You just mentioned that Dr B plans to broaden the role of diabetes educator to diabetes manager. Are any steps being taken towards that?'

HCP: 'Even simple things like SOP(Standard Operating Procedure) and guidelines do not exist, so who will do something bigger? The people at the top have a different way of thinking. It is true that Dr B wants to develop the role, but the problem is who is he? He is a doctor and we are nurses. So, if the nursing division does not give any support and agreement then it will not happen. Perhaps there are some people in nursing with greater authority to do that, but there are a lot of obstacles. As for me, I am really interested in improving myself and undertaking further study, but how?' (HCP 6)

From the data presented in this section, it is apparent that the role of diabetes educators in self-care support provision was very limited. In fact, the interview extracts clearly show that the current working situation (with high workloads and multiple tasks) reduced their focus on providing self-care support. Therefore, it can be suggested that patients with type 2 diabetes actually did not receive adequate self-care support from the diabetes educators, and this could be argued as one reason for the high incidence of type 2 diabetes with complications at the case study sites. Furthermore, the diabetes educators in this study frequently expressed their lack of confidence in carrying out their advanced role as diabetes educators. They also argued that the advanced diploma course was insufficient to enable them to carry out the role of diabetes educator as outlined by the American Association of Diabetes Educators

(Davis, 1990), which is currently used as a benchmark in Malaysia. In parallel, Ramli and Taher (2008), who analysed the management of NCD in Malaysia, reported that there is a lack of trained diabetes educators (referring to nurses and other allied health personnel) in supporting the management of NCD, including diabetes. Therefore, it can be asserted that the current training received by diabetes educators, is not sufficient to empower them and prepare them to hold an advanced role in diabetes management provision. In addition, the diabetes educators in this study expressed frustration at the failure of higher authorities to recognise their role. This situation could jeopardise the interest and enthusiasm of the diabetes educators to improve their level of education, which would subsequently reduce the quality of service provided to the patients.

8.3.3.2 Poor job satisfaction

It appeared that the diabetes educators at the case study sites experienced stressful working environments, which contributed to their poor job satisfaction. In general, each of the clinics had a very minimal number of diabetes educators, and the ratios between the patients and health educators were very high (for example: 2194 patients to one diabetes educator in the primary-care clinic). Furthermore, their unclear job description and perceived lack of support from higher authorities, as pointed out earlier, reduced the diabetes educators' focus, which affected the quality of their self-care support provision. During the interviews, the diabetes educators consistently mentioned the multi-tasking that they needed to carry out, which restricted their ability to provide the intended self-care support provision. The extract below is an example of the common views of the diabetes educators regarding this issue:

'I need to do a lot of things. I need to do foot assessments and counselling on foot care, teach the patients about insulin injections, and so on. How I counsel on the types of insulin, for instance, comes from my own initiative, either from discussions with seniors or from our experience. I think we need to improve a lot of things. Every steps from the beginning...' (HCP 2)

Similarly, a nurse manager at one of the clinics mentioned that as the diabetes educators usually had multifaceted jobs, they frequently overlooked patients that

defaulted on treatment and were supposed to be traced. Thus, it was reported that the patients were frequently left unattended until they returned to the clinic with more serious conditions or complications:

'About the follow up...Supposed as routinely told by Dr B, if the patients are unable to come to this clinic, he asked us to give the patient a phone call...Ask how they are doing and why they haven't come to the clinic, and then we are supposed to give new appointments to the patient. However, due to the high number of patients, sometimes we overlook patients' missed appointment....the workload here is very high and we don't have enough time to call patients that default on their follow up.' (HCP 8)

The quality of service provided within the current diabetes management at the case sites seemed to be very poor, and, with very limited manpower, unable to cater to the patients' self-care needs. Furthermore, multi-tasking and heavy workloads due to the high patient–HCP ratios reduced the satisfaction of the diabetes educators regarding the services they delivered to the patients. Many claimed that they had very limited time with the patients and also usually conducted consultation and 'counselling' in a rush. Thus, their ability to explore patients' problems and discuss options for self-management was also very limited. This situation made the self-care support too rigid and focused on improving clinical parameters. Furthermore, the patients remained passive treatment recipients. This limitation of management in the healthcare system has been widely discussed in the literature, and identified as a paternalistic medical approach (Barlow et al., 2002). Most of the diabetes educators were in agreement with the above situation, as exemplified by the extract below:

'Like what you saw here in this clinic, we are too overloaded. We are only able to focus on important things like their medication and their health status at that time. We don't have enough time to ask them clearly what is actually the reason for their failure to manage their diabetes. What is happening at home? We don't have enough time to ask. Patients also sometimes feel uncomfortable telling us because they feel that we are not friendly. We are too rushed.' (HCP 10)

From the data presented in this section, there is evidence of substandard self-care support provision within the case study sites, as the diabetes educators did not have

enough time to practice. In addition, this situation was perceived by the diabetes educators as being due to high workloads and multitasking. It therefore reduced their job satisfaction and subsequently affected the quality of service provided to the patients.

8.3.4 Systemic factors (fragmented medical system)

As pointed out in chapter seven (section 7.2), diabetes management in Malaysia follows the National Diabetes Prevention and Control Programme, which consists of three levels of prevention (primary, secondary and tertiary). In general, patients with pre-diabetes symptoms and early stages of type 2 diabetes are managed at a primary-care level, whereas patients with more serious conditions and diabetes complications are managed in a hospital setting. Based on the interviews with HCPs (as presented in the previous chapter), it was apparent that there were vast differences in the focus and approach of diabetes management between primary- and secondary-care settings. Furthermore, it was noted that the differences in the approach led to a lack of coordination in patients' management between the primary- and secondary-care settings. This situation appeared critical, as it reduced the quality of service delivered. For example, one diabetes educator in a secondary care setting mentioned that physicians in secondary care were not keen on referring the patients to the primary-care clinic. The diabetes educator claimed that they commonly experienced situations where the patients were referred back to hospital with the same or more serious conditions, as they had not been properly managed in the primary-care setting. However, due to several limitations such as a lack of manpower, high number of patients and financial restrictions of patients limiting their hospital visits, the physicians usually have no choice but have to refer the patients to the primary-care clinic:

'If the patients do not want to see us for some reason, such as the distance of their house to hospital or parking problems...they requested to have their consultations at the nearest health clinic, and we allow that. But sometimes the management of diabetes in other health clinics...I don't know. Maybe they don't have much time with patients or they don't have diabetes educators, I am not sure. But we frequently experienced patients coming back to us and complaining that they are always hungry. That is due to the high dosage of

insulin. When we see these patient, we need to re-do everything. We need to re-arrange the insulin dosage, get the patient's history and review their activities at home again. When we review the patients, they actually don't need that much insulin. Actually, we don't want the patients to have consultations at other health clinics, but we still need to refer them because the number of patients here is very high, so we need to ask for help from other health clinics to monitor these patients. We don't have enough manpower and the number of doctors here is also low.' (HCP 7)

This situation was consistently highlighted by other diabetes educators in the hospital. The diabetes educators claimed that there was very minimal interaction between the diabetes educators in the hospital and those in primary care. In fact, the diabetes educators in the secondary-care setting (hospital) mentioned that they never had opportunities to communicate with the diabetes educators in the primary-care clinic. Thus, the diabetes educators in secondary care perceived that the patients in the primary-care clinic were totally managed by the medical officer and family medicine specialist. This situation led to repetitive practice to a certain extent, and some areas were not covered at all. Whereas, in the primary-care setting, there was evidence of a lack of management within the clinic. During the interviews with Diabetes educators in the primary-care clinic, several Diabetes educators claimed that they were aware of the situation, and also agreed that the patients were often overlooked with respect to certain aspects. However, they perceived that this happened due to a lack of manpower and resources:

'The thing is not going parallel. We are increasing numbers of doctors and paramedics, but we still lack devices...We need more BP sets, we need more dextrostics machines, and we need more machines to measure body mass index. The patient flow...For example, at the moment we don't have one stop centre. Patients are scattered. We try our best to provide the services as stipulated in the CPG. But sometimes there are certain things that we are not able to catch up on because the doctors are changing quite rapidly. So maybe they miss diagnoses or miss certain aspects.' (HCP 15)

Furthermore, a survey conducted in Malaysia indicated that a problem of incoordination, particularly in the management of chronic diseases (long-term conditions), within the Malaysian healthcare system (Ramli, 2010). The survey reported that the healthcare system in Malaysia is directed towards the control of

acute outbreaks of infectious diseases and management of acute illnesses. In addition, when compared to the Chronic Care Management model (CCM) by Wagner et al. (2001), which is widely used to improve quality of care and outcomes for patients with chronic conditions, the healthcare system in Malaysia seems to be fragmented, inefficient and poorly coordinated (Ramli, 2010). These problems are consistent with those identified in this study, and could be argued as contributors to ineffective diabetes management which leads to poor self-care support within the Malaysian healthcare system.

8.4 Summary

This chapter presented the findings derived from interviews with the diabetes educators, related to their perceptions of their role and the factors perceived to limit their practice. The diabetes educators pointed out two main aspects within their intended role of supporting the patients: importance of knowledge and individualised support. However, the diabetes educators claimed that their practice was restricted by factors including patients' acceptance of diagnosis, patients' interest in self-care, space and crowdedness of the clinics, lack of opportunity to practice, lack of job satisfaction and fragmented healthcare system. Within this chapter, several key issues were argued to be crucial to be addressed in order to improve service delivery; these are further discussed in the following chapter.

CHAPTER 9

Discussion and Conclusion

9.1 Introduction

The purpose of this discussion chapter is to synthesise the findings from the three units of analysis (patients with type 2 diabetes, HCPs and the healthcare system), and discuss the key issues that have arisen. The chapter will begin with a summary of study findings, and discuss the originality and contribution of the thesis. Subsequently, the overview of the study is provided and the suitability of the case study method for this study will be evaluated by discussing its strengths in achieving the study objectives. The key findings of this study will be further discussed and its wider implications in improving healthcare practice and service delivery evaluated. Finally, overall conclusions will be made and recommendations for further research identified.

9.2 Overview of the study

The initial objectives of this study were to explore the self-care practices of patients with type 2 diabetes and the factors that influenced their engagement in self-care activities. In addition, this study explored the available self-care support provision within the Malaysian healthcare system, and how it influenced the self-care practices of patients. This study was driven by evidence of the rapid increase in type 2 diabetes incidences in Malaysia, which is thought to be due to poor self-care of the patients. The literature review in chapter two highlighted that the patients' engagement in self-care was highly influenced by their individual experience with diabetes and personal life circumstances. However, this aspect was frequently overlooked as support provided usually focused on medical outcomes. Despite the abundance of literature discussing self-care issues in various countries, the phenomena related to self-care of

type 2 diabetes in Malaysia is not clearly understood, as few studies pertaining to this issues have been conducted. Therefore, this study was conducted to understand the experiences of patients with type 2 diabetes in incorporating self-care into their daily activities, and provision of self-care support within the healthcare system.

A qualitative single embedded case study design was chosen in order to gain an holistic understanding of self-care issues in the Malaysian context. A combination of three methods of data collection was used, including semi-structured individual interviews, participant observations and documentary analysis, to understand the views and insights of patients with type 2 diabetes and relevant HCPs, and understand the diabetes management provision in primary- and secondary-care clinics. Detailed data analysis was conducted according to the framework approach, and in order to compare and contrast the findings from the three units of analysis, including perspectives of the patients, practices and perceptions of the HCPs and the existing policy that drives the provision of diabetes management within the healthcare system. The data analysis process contributed to the revision, and further development of the theoretical propositions illuminated gaps in practice pertaining to diabetes management provision in Malaysia.

The findings of this study seem to challenge the existing evidence regarding the factors that contribute to the high incidence of type 2 diabetes in Malaysia. The data in this study clearly suggests that the reasons for the increased incidence of type 2 diabetes and high number of diabetes complications is not merely due to poor self-care practice of patients, but also to the poor quality of service delivery and unstructured self-care support provision. Besides poor patient–HCP communication and therapeutic relationships, a combination of the personal, interpersonal and inter-professional HCP factors and other external factors, including the environment and management of the healthcare system, also have the potential to influence the practice and quality of the service delivered.

9.3 Study propositions

As mentioned in chapter four (section 4.2.2), the research questions, objectives and direction of this study were determined by the findings of the literature review and problems identified in the study context. Throughout the data collection and analysis process, the research questions were revisited. In general, the study findings seem to resonate with the initial understanding of the literature. However, several aspects that seemed to be specific to the Malaysian context expanded the existing ideas. Three propositions relevant to the issues and problems pertaining to self-care of type 2 diabetes in Malaysia were developed, as listed below:

- Patients have good knowledge and awareness about diabetes. Their self-care practice is highly influenced by their life situation, health beliefs, and religious and cultural practices. However, support provided by the HCPs does not meet the needs and expectations of the patients; which influences the engagement of patients with self-care.
- Management of diabetes and the concept of self-care has become of great concern within the healthcare system. However, self-care support provision are limited as service delivery revolves around the traditional medical model with a lack of evidence-based practice.
- HCPs' opportunities to provide high-quality self-care support provision are limited due to several internal and external factors, which had reduced their satisfaction in practice.

These study propositions summarise the core factors that illustrate the situation regarding self-care issues in Malaysia.

9.4 Originality and contributions of the research

The central contribution of this thesis is that it explains the underlying problems in Malaysia that can lead to poor self-care of patients with type 2 diabetes. In addition, this study identifies discrepancies between the self-care needs and expectations of patients and existing self-care support provision. In reporting on the experiences and

perceptions of patients with type 2 diabetes, this study highlighted the overarching problems within clinical practice and health service delivery pertaining to diabetes management.

It was noted from the literature review that prior qualitative and quantitative research has commonly looked at the experience and life trajectory of the patients, and investigated their adherence to self-care regimens. This study contributed a new dimension of understanding by providing evidence on the perceptions and practices of patients, and involvement of HCPs particularly diabetes educators in self-care support provision. This study also provided evidence that, despite poor adherence to self-care, patients have a positive perception of the practice of self-care, though their practice was found to be limited and influenced by psychological and social factors which are beyond their control. Furthermore, this study provided valuable evidence by comparing and contrasting the views of patients, multifaceted HCPs, and the real clinical situation, which illuminated discrepancies between the patients' needs and the support provided. The conclusion of this study is drawn from a multiple and holistic understanding of the situation and issue being studied. Three key issues were identified in this study: discrepancies between the self-care needs of patients and support provided, traditional medical model vs patient-centred care, and role and autonomy of diabetes educators (as presented in section 9.6) offer insight into reasons for patients' lack of engagement with self-care of type 2 diabetes in Malaysia, which have not previously been reported.

9.5 Review of the methods

This is the first time qualitative case study research has been utilised to explore self-care issues in the particular study context. Case study appeared to be the most suitable research approach as it allowed for understanding to be obtained related to self-care from views and perspectives of multiple stakeholders, including healthcare organisations, service providers and service users. It enabled the exploration of self-care issues from multiple dimensions, which provided a holistic understanding of the

issues being studied. The social process within the healthcare system was identified through observations of interactions between the physicians, medical officers, diabetes educators and patients. The actual situation was captured, which enabled the researcher to explore the practice of self-care support provision and its influence on patients' acceptance and decisions to self-manage. The success of this study in achieving its objectives and answering the research questions justifies the appropriateness of utilising a case study strategy to facilitate exploration of self-care issues within the Malaysia setting.

Most of the studies included in the review in chapter two have studied the problems related to self-care experienced by either patients or HCPs only, and the conclusions have been made based on one dimension of understanding. The complexity of the problem that leads to the issue being studied was clearly illuminated. The multiple methods of data collection adopted are also strength of this study, as they revealed interrelationships between the ideas and perspectives of the participants and real-world situation that may not have been possible to visualise from a single data collection method.

Whilst adopting a single case study design, this study was conducted in two different settings (primary- and secondary-care), which provided rich information on self-care related issues across the range of services available to patients. In-depth understanding of the self-care issue was gained from the patients' responses and the views and practices of the HCPs via cross-case analysis of both study contexts. Identification of different approaches in practice and patient responses in both settings revealed underlying problems that affect the service delivery and health outcomes in the different settings.

9.6 Discussion of the findings

The discussion brings together the themes across the three chapters of findings, and discusses and integrates these into existing theory. Through the data analysis and interpretation, three key issues were identified: discrepancies between the self-care needs of the patients and the support provided the professional autonomy and recognition of roles of the diabetes educators, and the need for a paradigm change in healthcare service delivery, particularly in the management of patients with long-term conditions.

9.6.1 Discrepancy between the self-care needs of patients and the support provided

The findings of this study illuminated critical issues on patients' and HCPs' communication and interaction and the quality of self-care support provision, which seems to influence patients' self-care practices. However, before further discussion is conducted on the aspect of service delivery, it is important to discuss the findings related to the patterns of self-care practice of the patients; thus, the situation related to patients' self-care within the Malaysian context could be clearly understood.

It was apparent that the patients' awareness and decisions to engage in self-care activities were contributed to by their recognition of diabetes fatalism. Diabetes fatalism is 'a complex psychological cycle characterised by the perception of despair, hopelessness, and powerlessness' (Walker et al., 2012 p. 2). Within the study, the findings indicated that feelings of fear and concern highly influenced the patients' self-care practices. This finding is consistent with a study by Egede and Bonadonna (2003), which explored the association between self-care management and the concept of fatalism in African-American patients with type 2 diabetes. Diabetes fatalism was conceptualised by the patients in every aspect of the disease, including their understanding and experience of diabetes, and their style of coping. However, it was suggested that diabetes fatalism had a significant negative association with self-

care behaviour, where patients with a fatalistic attitude frequently showed ineffective diabetes self-management behaviour and poor adherence to self-care elements (Egede & Bonadonna, 2003; Walker et al., 2012). A similar situation was clearly observed in the current study. It can be argued that the sense of diabetes fatalism had negatively influenced the patients with respect to practicing self-care. Furthermore, without adequate support from the healthcare system, limited opportunities for the patients to communicate with the HCPs, and a lack of concern from the HCPs for patients' individual psychosocial situations led to a psychological burden on the patients. Patients commonly complained of overwhelming feelings of stress and frustration, which made them tend to disregard the importance of self-care and revert to their normal lifestyle. Therefore, it can be assumed that the style of motivation by introducing a sense of diabetes fatalism (emphasising diabetes complication and life burden) to the patients in this current study would not be able to sustain the patients' engagement in self-care activities in the long term.

Theoretically, perceived health status and self-efficacy have been identified as antecedents of patients' engagement in self-care (Lorig & Holman, 2003; Richard et al., 2011). Therefore, in order to seek further explanations on patients' difficulties in engaging with self-care, the findings of this study were compared and contrasted to the health belief model (HBM) developed by Hochbaum, Kegels and Rosenstock in 1952. HBM is seen as relevant to explain the self-care issue within this study as it can provide predictors for the patients' attitudes and decisions to practice self-care, and simultaneously explain the current situation in the study settings. Utilisation of HBM to explain the patients' health behaviour in diabetes has been seen in several other studies (Cerkoney & Hart, 1980; Bond et al., 1992; Wdowik et al., 2001; Pinto et al., 2006). HBM also has been identified as theoretical underpin the patients' engagement with self-care within the studies included in the literature review (as presented in section 2.5 in chapter 2). Previous studies have reported that emotional responses to the disease, including perceived susceptibility and perceived severity of the disease, which is described as 'perceived threat', have commonly been identified as the strongest predictors for patients to engage in valuable preventive health behaviour (Pinto et al., 2006; Wdowik et al., 2001). This situation seems to be consistent with

the factors that influenced engagement with self-care in this study, wherein patients' understanding and awareness of the possibility of complications and perceived future life burden were the strongest factors that increased their engagement with self-care. However, sustainability of their motivation was seen to diminish as the patients rarely realised the impact and benefits of self-care activities to their health situation. Cues to action have been described as situations or events that trigger health-benefit action (Champion & Skinner, 2008). In this study, knowledge and understanding of diabetes, self-experience with complications or seeing others with complications were seen to become cues to action. However, it is commonly seen did not work for many patients as they frequently expressed 'feeling healthy' and seeing diabetes as an ordinary illness that did not need much concern. In addition, perceived barriers seemed to be restrictions to self-care as patients frequently expressed their difficulties in adapting self-care activities to their established life routine. Furthermore, the attainment of self-efficacy was rarely observed in this study, as the patients strongly relied on instructions from the HCPs, rather than being empowered in decision making. The absence of the important predictors identified in HBM (perceived benefits of self-care, cues to action, and attainment of self-efficacy) can be presumed as the explanation for the lower likelihood of the patients to engage in self-care activities, and failure to sustain enthusiasm and motivation towards self-care. Comparing and contrasting the issue of patients' self-care practices with HBM thus provides a better understanding of the prerequisites that contribute to better self-care practice, and that were not followed by the patients in the current study. However, the analysis of HBM and application of it in the Malaysia setting should not be done at face value. In-depth exploration and analysis on the cultural practice and situation in Malaysia that influenced the health beliefs of the patients need to be critically done to ensure that that it able to clearly represent the actual problem and situation. Although the transferability of this model still not clearly recognised, it can be suggested that further exploration of the elements of HBM, and incorporating it into the current framework of service delivery, particularly in diabetes management, would help to overcome the current situation in Malaysia, and simultaneously enhance the effectiveness of self-care support provision and health promotion activities.

Patient–HCP communication and therapeutic relationships have been clearly highlighted in the literature as imperative, as they have a significant positive impact on patients’ self-efficacy and engagement in self-care practice. However, several recent studies have reported that the quality of patient–HCP communication remains unsatisfactory (Burke et al., 2006; Edwall et al., 2010; Main et al., 2010). The findings of these studies suggest that HCPs often fail to obtain sufficient information and identify the root of the patients’ problems during communications with them. As a consequence, this situation directs consultation sessions towards a medical focus and allows them to be HCP controlled (Burke et al., 2006; Main et al., 2010). These findings seem to resonate with those of the current study. The findings presented in the previous three chapters (six, seven and eight) consistently demonstrated the problems with communication between the HCPs and patients, particularly during the process of consultation. The patients generally expressed their frustration as they did not have the opportunity to communicate personal problems that led to their inability to self-manage. On the other hand, the HCPs commonly claimed that the patients were reluctant to disclose their personal problems, which restricted their ability to understand the patients’ actual life situations. However, observations of the clinic consultations illuminated the actual situation, where issues with patient–HCP communication related not only to the patients’ reluctance to disclose, but also to the style of communication and the HCPs’ power within the consultation session. The present findings also seem to be consistent with a study by Pooley et al. (2001) conducted in the United Kingdom. Through semi-structured interviews with patients and HCPs, Pooley et al. (2001) identified five aspects that are important in effective diabetes management: sufficient time for consultation, being reviewed by the same HCPs, opportunity for the patients to ask questions, patients feel they are being listened to by the HCPs and understanding of the variability of patients’ experience. These five aspects were mentioned by the patients and HCPs in this study; however, they were identified as aspects that were unable to be achieved by the HCPs due to barriers and limitations in the clinical settings. In fact, the aspect of communication is not clearly elaborated within the policy documents and CPG used in the current study settings. This situation can be argued to be due to a lack of awareness of communication issues between the patients and HCPs in this study, as it has not being reported elsewhere before. As such, it has not become a major concern within current

models of health service delivery. Therefore, it seems to be important to highlight that the issue of communication and therapeutic relationships between patients and HCPs need to be given greater concern, particularly in diabetes management provision, as it has a high impact on patients' psychological, social and health outcomes. Communication skills among the HCPs need to be strengthened in order to improve the quality of service provided, particularly when dealing with patients with long-term conditions.

Subsequent to the communication issue, synthesis of the findings illuminated inconsistencies between the perspectives of the HCPs and the experience of the patients, particularly regarding factors that influenced the patients' engagement in self-care. Although understanding patients' individual problems was perceived as important by the HCPs, limitations within their practice restricted their opportunities to explore this facet in depth, which resulted in misinterpretations and misperceptions of patients' actual problems. This situation clearly contributed to the needs and support disparity, where the support given remained general and patients' problems and self-care needs remained unattended. As a result, patients tended to seek alternatives and used trial-and-error approaches in managing their diabetes, without supervision and monitoring by the HCPs. This finding further supports the idea that there are inconsistencies in the way self-care is conceptualised by patients and HCPs, as identified in chapter two. It is also in line with earlier studies, wherein it is clearly understood that patients' behaviour change is the central objective of diabetes management and should become the focus of self-care support interventions. However, several studies have argued that, parallel to the traditional medical model, HCPs' approach to self-care support provision is commonly authoritarian, and the activities conducted during the consultation tend to be 'information and advice giving', and lack opportunities for the patients to participate in communication and decision making (Kokanovic & Manderson, 2007; van Dam et al., 2003a; Zoffmann & Kirkevold, 2012). It has been argued that this style of consultation does not have much impact on behaviour change. Therefore, it can be observed that more recent studies related to diabetes care and the findings of this study support change in diabetes management and self-care support provision from dominated by HCP to

being more patient-centred, through patient empowerment and increased patient participation in care (Funnell & Anderson, 2008; Serrano-Gil & Jacob, 2010; Tang et al., 2010).

The concept of empowerment is frequently related to the implementation of patient-centred care in managing long-term conditions such as diabetes. However, it has been argued that implementation of the concept of empowerment in clinical practice is frequently problematic and difficult to apply in the actual situation (Paterson, 2001; Serrano-Gil & Jacob, 2010; Zoffmann & Kirkevold, 2012). In addition, it has been asserted that a factor that contributes to the difficulties in applying the concept of empowerment in practice relates to the element of empowerment that emphasises patient–HCP interaction and shared decision making. This seems to be incongruent with the training received by the HCPs, which is commonly based on the acute care model, which is focused on a didactic approach to clinical problem solving (Paterson, 2001). Similarly, in the current study, as presented in chapters seven and eight, the practice of HCPs currently remains paternalistic, and based on medically directed outcomes. Therefore, it can be argued that the concept of patient empowerment is not being clearly applied. Furthermore, it was frequently observed that the components of self-care support were given based on the knowledge and expectations of HCPs, without giving the patients opportunities to participate in the process of planning for their own care. The patients were expected to follow whatever was suggested, without their life situation and difficulties that they might encounter in self-managing their diabetes being considered. This approach to management seems similar to the approach used for patients with acute conditions, which is focused on short-term medical outcomes. Therefore, it can be asserted that current approaches to service delivery pertaining to the management of long-term conditions in the study settings are inappropriate; this clearly explains the ineffectiveness of the current service provision, particularly in diabetes management.

Although the application of an empowerment model in the management of long-term conditions was debated in the literature, it is widely used as theoretical underpinning

to intervention programmes related to self-care. However, most of the available evidence related to the application of empowerment model was derived from studies conducted in western countries with very limited evidence available to understand its application in Asian countries. Therefore, it is unclear whether the existing empowerment models or interventions underpinned by an empowerment theory could be transferred to the Asian settings, in particular Malaysia. Reflecting on the study findings, patients with type 2 diabetes in urban settings in Malaysia had good level of knowledge regarding diabetes and high awareness regarding importance of self-care in the ability to control their diabetes. Furthermore, policy and guideline of diabetes management in Malaysia is based on ADA guideline which is informed by the concept of empowerment (as explained in section 2.5 in Chapter two). Therefore, it could be anticipated that, an empowerment model could be adopted and applied in a Malaysian setting. However, the readiness and willingness of patients to be empowered and readiness of healthcare professionals to empower the patients, provided that their clinical environment is highly medical oriented, has not been previously explored. As such, applying an empowerment model to the Malaysian healthcare system needs to be done critically based on patients' preference, the degree of support needed, and readiness of healthcare professionals to change their practice. Patients' readiness to be empowered and to actively engage with self-care should not be evaluated at face value and generalised as it can be influenced by individual patients' circumstances and beliefs. Therefore, the extent of self-care support provided should be based on patients' individual needs and preferences.

It seems clear that the approach to the management of long-term conditions in this study setting contradicts recent evidence provided in the literature. Within the literature, it can be seen that interventions that facilitate patient empowerment have been successfully implemented in several countries, such as the Expert Patient Programme (EPP) in the United Kingdom (Department of Health, 2001), Lifelong Management Intervention in the United States (Tang et al., 2010) and Guided Self-Determination Programme in Norway (Zoffmann & Kirkevold, 2012). EPP, for example, provided a new dimension to the healthcare service by incorporating patients as part of the healthcare workforce and involving them in the provision of

healthcare, through lay-led self-care skills training programmes (Kennedy, Rogers, & Gately, 2005). Implementation of EPP has been criticised as having a modest impact on psychological improvement and reducing the engagement of HCPs in healthcare service delivery (Griffiths, et al., 2007; Kennedy et al., 2007). However, a randomised controlled trial involving 629 participants in the United Kingdom reported that EPP has been proven to be successful in reducing healthcare costs, minimising the utilisation of healthcare facilities and improving patient satisfaction with care (Kennedy, Reeves, et al., 2007). It seems that the benefits from EPP outweigh the drawbacks, and the empowerment and involvement of patients in healthcare that the programme has facilitated is clearly beneficial for both patients and the healthcare system. Therefore, this evidence further supports the findings of this study on the critical need for a change in the model and approach used in diabetes management provision to ensure the service delivered is compatible with the complexity of the patients' life situation, and to meet the expectations of patients.

9.6.2 Traditional medical model vs patient-centred care

In chapters eight and nine, it was highlighted that the patients' ability to self-manage their diabetes was primarily evaluated based on clinical parameters, while diabetes management provision was mainly focused on medical outcomes. Furthermore, feedback from the diabetes educators indicated that the current practices of self-care support provision were physician-directed, and their implementation was based on the HCPs' traditional practice experience, with a lack of evidence-based practice. It appeared that the diabetes management provision in the study settings revolved around the traditional medical paternalistic approach, which puts great concern on patients' medical outcomes and less emphasis on their psychological and social situation. Although the achievement of patients' behaviour change has been stipulated as one of the objectives of diabetes management provision in the CPG (2009), steps taken towards this were not clearly observed. Cross-case analysis of the evidence of self-care support provision between the primary- and secondary-care settings demonstrated that the management of patients between these two settings seemed to be fragmented, and several aspects of patient management seemed to be repetitive.

Moreover, further interviews with the diabetes educators (chapter nine) illuminated incongruities in the management of patients between both settings, which seemed to be detrimental to the patients' progress. In view of this situation, the Chronic Care Model suggests that a lack of coordination in care between primary care and secondary settings is detrimental to the success of chronic disease management and support (Wagner et al., 2001). Furthermore, healthcare system coordination has been identified as a common problem in developing countries due insufficient manpower and resources (Epping-Jordan, 2004). Therefore, the lack of guidelines and a framework to facilitate coordination of diabetes management between primary- and secondary-care settings, alongside critical limitations to clinical practice such as lack of manpower and resources, as highlighted by the HCPs, could be argued to explain the fragmented practice within the healthcare system.

When comparing and contrasting the current study findings with the existing body of literature, vast differences can be noted, particularly in the way in which self-care is conceptualised and the approaches used in self-care support provision. Within the literature, it has been noted that patient-centred care has emerged as an underpinning philosophy for self-care support; it has been argued that patients' 'full engagement' with self-care plans and the execution of self-care activities is an essential part of ensuring the effectiveness of support provision (Kennedy, Rogers, et al., 2007; Pulvirenti, McMillan, & Lawn, 2014). In essence, patient-centred care has been described as an approach that responds to the patients' needs and preferences, wherein patients are given full autonomy to make informed decisions related to their health, and management of their illness (Pelzang, 2010; de Silva, 2014). A large-scale systematic review that included 84 randomised trials and quasi-experimental studies published by The Health Foundation (2011) provided evidence that patient-centred care offers a number of advantages in improving quality in healthcare service delivery. It was reported that patient-centred care is successful in improving patients' self-efficacy, increases patients' satisfaction with healthcare services, improves communication and patient-HCP relationships during the consultation process, and increases HCPs' confidence and job satisfaction. In view of the positive impact of patient-centred care on improving the quality of service delivery and healthcare

outcomes, literature in the United Kingdom, United States and several other countries has demonstrated major changes in the management of patients with long-term conditions, including diabetes, from a medical paternalistic model to a patient-centred approach. Within the literature, it can be observed that management of the healthcare system around the world has been explicitly directed towards emphasising the needs and preferences of individual patients and supporting them in making decisions pertaining to their care (World Health Organisation, 2000; National Health Service, 2005; US Department of Health and Human Services, 2008; Australian Commission on Safety and Quality in Healthcare, 2009).

A review by Kitson et al. (2013) highlighted three core elements of patient-centred care: patient participation and involvement, the patient–HCP relationship and the context of the clinical setting in which the care is delivered. It can be argued that diabetes management provision in the current study seems to be misaligned with the recent evidence pertaining to patient-centred care. Within the current study, there was no evidence to show that patients were actively involved in their management, in which their role remained that of passive treatment recipients. In addition, poor therapeutic patient–HCP relationships clearly demonstrated that the approach to diabetes management within the study settings remained paternalistic, with a focus on medical treatment and clinical outcomes. Furthermore, limitations highlighted within the context of the study settings provided evidence that the current environment is not conducive for patient-centred care; thus, the management remained medically directed. Therefore, it is apparent that the practice of self-care support provision in the current study was clearly not in line with the global standard of management of patients with long-term conditions such as diabetes. Despite the identification of marked changes in the national health landscape due to the tremendous increase in chronic diseases, changes do not seem to have reached the health service delivery, which remains focused on acute-care management. Therefore, it can be suggested that reformation of healthcare management from the traditional paternalistic medical model to a patient-centred care approach should receive close consideration, and become the main agenda of healthcare authorities and government in handling the overarching problems with long-term conditions, particularly diabetes management

provision. This indicates that the gap in practice pertaining to the management of patients with long-term conditions should be discussed in a larger context involving all stakeholders within the healthcare system, rather than focusing on patients' attitudes and the practices of certain HCPs only.

The need for reformation within healthcare organisations pertaining to diabetes management provision has been identified in order to improve the quality of service delivery and health outcomes. However, as highlighted in chapters two and three, dealing with situations such as diabetes is not simple, and requires detailed analysis of the healthcare system including multifaceted views and perspectives. Through the data presented in chapters seven, eight and nine, the issue of poor self-care practices of patients with type 2 diabetes in the current study settings is not rooted in any one reason, but rather entails interrelated problems that involve many aspects of the healthcare system (as highlighted earlier). Therefore, it requires changes at every level of care delivery, which includes policy makers, service providers and service users. Each of these are interlinked thus, by involving all elements, it would maximise the effects of change (Kennedy et al., 2007). Whole-system perspectives embedded within the CCM place the concept of self-care in a wider context, which not only focuses on patients' behaviour change and health outcomes, but also emphasises changes in HCPs' attitudes, improvements in the healthcare system, increased patient involvement in care, and community engagement in self-care support programmes (Kennedy et al., 2007; Protheroe et al., 2008). Studies that have measured the implementation of self-care support intervention based on the whole-system approach have reported that it seems to be effective in facilitating HCPs' training for improving the quality of self-care support provision, increasing patients' participation in care, and improving patients' diabetes outcome and quality of life (Kennedy, Rogers, & Gately, 2005; Kennedy et al., 2010). In addition, a large-scale, multi-site evaluation study conducted in the United Kingdom reported that implementation of the whole-system approach in the management of long-term conditions proved to be cost-effective and reduced utilisation of the healthcare system, particularly among patients with diabetes (Bower et al., 2012).

In the context of the Malaysian Healthcare System, the whole-system perspective seems to be useful as a guideline in tailoring changes to interventions in diabetes management in the current study settings. The whole-system approach, which emphasises engagement of the multifaceted healthcare system to increase the effectiveness of self-care support provision, would facilitate changes at the micro and macro level, as it provides detailed explanations on how it can be adopted in the existing system. At the micro level, adopting the whole-system approach would change the dimensions of self-care support provision from the medical model, which focuses on clinical outcomes, to a psychological and social sciences model, which incorporates the patient-centred approach (Kennedy et al., 2010). It would improve the focus of diabetes management by placing greater concern on patients' individual perspectives and involvement in initiating their behaviour change in a way that is compatible with their needs and preferences. Furthermore, as highlighted in chapter eight, the HCPs, particularly diabetes educators, did not have strategies to support patients' self-care, and their practices were merely based on the discretion of the physicians, with a lack of research evidence. The framework of the whole-system approach details the aspects that need to be strengthened in order to increase the engagement and confidence of HCPs in providing effective self-care support, such as the communication approach, focus of care, and training needed to incorporate evidence into their practice. This would give clear guidelines to HCPs and simultaneously define the role of diabetes educators and other HCPs within the continuum of diabetes management more clearly. At the macro level, the whole-system approach would facilitate service improvement by highlighting the need for change with respect to the service structure that supports self-care, such as by modifying the design of services provided by healthcare organisations (the respective clinics in particular) to be inherent with the philosophy of self-care, redesigning the monitoring and follow-up systems, and reviewing patients' access to healthcare facilities. It is expected that changes to the healthcare system based on the whole-system approach would improve the quality of service delivery and increase satisfaction of both patients and HCPs. Nevertheless, it is anticipated that further

research is required to analyse the existing healthcare system in more detail and identify the possibility of resistance in the implementation of proposed change.

9.6.3 Role and autonomy of diabetes educators

In light of the patient-centred care approach, which emphasises patient empowerment and involvement in care through whole-system perspectives, the role of HCPs as case managers that function as mediators and care facilitators across the healthcare system have been identified as essential (Norris et al., 2002). It has been suggested that case managers, who work closely with patients to facilitate behaviour modification, most strongly contribute to the success of diabetes management provision. However, within the current study, the role of diabetes educators was unclear. It seemed that the diabetes educators in the current study were unclear on their specific role and involvement in diabetes management provision, which made their role very general. Findings from the interviews with diabetes educators, as presented in chapter nine, highlighted the dissatisfaction and frustration of diabetes educators on their practice. The trained diabetes educators in this study were HCPs, including nurses and medical assistants, who had undergone six-month post-basic courses on diabetes management. Although most of them were aware of their role as diabetes educators, they frequently expressed feelings of dissatisfaction as their opportunities to provide the intended service seemed to be restricted.

The majority of diabetes educators that participated in the study expressed a lack of confidence in dealing with the patients and making decisions on diabetes management. Therefore, they frequently relied on the instructions and discretion of physicians in managing patients, although they sometimes knew what they needed to do. This shows that the diabetes educators did not have confidence to carry out their role, although some of them had been given autonomy by the physicians to implement certain aspect of diabetes management. Inadequate knowledge and qualifications can be highlighted as the main reason for this situation. As highlighted earlier, the practice of the diabetes educators was merely directive and based on tradition, with a lack of

evidence-based practice; thus, it can be suggested that the experience gained during the diabetes educator course seemed to be unhelpful in improving their practice. However, as the researcher did not have the opportunity to analyse the content of the diabetes educator course curriculum, the actual situation cannot be clearly confirmed.

Several studies that have measured the effectiveness of case-management intervention led by nurses and diabetes educators have reported a positive effect on patients' clinical and psychological outcomes, improving patients' engagement in self-care and reducing utilisation of the healthcare system in managing long-term conditions, which simultaneously saves on healthcare costs (Loveman, Royle, & Waugh, 2003; Welch et al., 2006; Stuckey et al., 2009). A randomised controlled trial investigating the effect of case managers on reducing the complications of type 2 diabetes in the urban African-American population reported that the availability of a nurse case manager contributed to the improvement of diabetes control (Gary et al., 2003). Therefore, it can be suggested that in order to improve patient outcomes via diabetes management provision, the role of the nurses should go beyond that of diabetes educators, and extended to a more specialist role, such as case manager. However, as observed in this study, current available academic training to prepare diabetes educators does not change the dimension of their practice from generalist to specialist, as it is specifically focused on upgrading medical-related knowledge and is focused on clinical tasks. Therefore, it can be suggested that the current level of knowledge and qualifications of diabetes educators is not sufficient to develop a specialized role for them within diabetes management. As such, a higher qualification, such as a master's or doctorate degree in diabetes management, seems to be crucial for preparing diabetes educators for a more advanced independent role, which would simultaneously increase their confidence and motivation to provide a high-quality service in supporting patients with type 2 diabetes.

9.7 Implication for policy, practice and education

In this research, it was highlighted that there is an overarching problem related to the therapeutic communication and relationship between patients and HCPs. Patients were reluctant to disclose their actual problems, which leads to uncontrolled diabetes. Conversely, the communication approach used by the HCPs was frequently perceived as unpleasant by the patients, and ineffective. It was noted that understanding of the patients' individual problems via a better communication approach, with the use of appropriate words or phrases, may have restricted the HCPs from providing unpleasant feedback. Therefore, it is suggested that the approaches to communication and interaction between HCPs and the patients be revised, especially during consultation sessions as this is the only time when patients have a chance to meet with the HCPs. In addition, it is worth considering reviewing patient access to healthcare to ensure the service delivered is effective in achieving the goal of diabetes management.

This research also highlighted the need for improvements to service delivery. It was evident that the patients' ability to engage in self-care practices was highly influenced by their individual life circumstances. It was also noted that the current service provided, which seems superficial and directed by the medical model, which focuses on clinical outcomes, is not relevant in meeting the needs of the patients. Therefore, it is recommended that the dimension of service delivery pertaining to self-care support provision should move from a medical paternalistic to a more patient-centred approach, as this would improve patients' self-efficacy and empowerment in decision making pertaining to the self-management of diabetes.

Problems pertaining to self-care within the Malaysian healthcare system are very complex, as they are influenced by multiple factors; thus, a multifaceted approach to handling the problem should be considered. It was noted that three aspects, including patients, HCPs (service delivery) and the context of the healthcare system, need to be given equal attention to ensure the changes made are parallel and holistic. Therefore,

it seems to be beneficial to consider a whole-system approach that engages patients, HCPs and service organisations to enable interlinked, multilevel improvement to maximise the positive effect. The whole-system approach was implemented within the National Health Service in the United Kingdom to manage chronic diseases, including diabetes, and had a valuable impact on system re-organisation and cost-effectiveness; this also seems to be relevant to the Malaysian healthcare system.

In bridging the gap regarding fragmented and uncoordinated care, the development of a diabetes case manager role seems to be crucial. The current diabetes educator role is very limited to knowledge provision, and rather generalist. It was noted from previous studies that management of diabetes by specialists shows better health outcomes and higher patient satisfaction. Therefore, it is worth considering the appointment of diabetes educators to a higher clinical role, such as diabetes care manager, which would help in coordinating the care between primary and secondary care. Therefore, in achieving this, upgrading the level of education and qualifications of diabetes educators is an important step to consider.

9.8 Implication for future research

The findings of this study illuminated a gap in the practice of HPCs and the need for change in the approach of service delivery and the healthcare organisation as a whole. However, the implementation of changes that clearly contradict existing practice would be difficult, and strong resistance from HCPs and the healthcare system is anticipated. Therefore, it is important to involve the multifaceted stakeholders as co-researchers at every level of the research process. Conducting action research or participatory research would be useful in the implementation of patient-centred care intervention, as it would empower the stakeholders, facilitate their interest and participation and simultaneously increase their sense of responsibility and ownership of the intervention. This would also reduce the possibility of resistance to implementing changes in the healthcare system.

Whilst the need for the advanced specialist role of diabetes manager has been identified in this study, it is important to understand diabetes educators' perspectives and readiness to carry out an advanced independent role that would require them to upgrade their knowledge and qualifications. By understanding their perspectives on this aspect, it would help higher management authorities to understand the views, perspectives and needs of the diabetes educators. Simultaneously, this will lead to the development of the new role based on the evidence and views of diabetes educators themselves, rather than solely based on the judgement and discretion of policy makers.

Further research is needed to explore the relationship between patients and HCPs, particularly diabetes educators, and the perspectives and expectations of patients regarding diabetes educators. Such research could explore the influence of diabetes educators on patients' self-care practices. It would also provide sound evidence on the suitability and need for higher recognition of the role of diabetes educators as facilitators or case managers, which would help in coordinating the care of the patients.

It is known that, development of qualitative research in Malaysia is still at its infancy and health service research in Malaysia is mainly quantitative. Therefore, it is anticipated that implementing the findings of a qualitative study in Malaysia could be a challenge. For example, as discussed in section 9.6.2, current diabetes management provision in Malaysia has deviated from the concept of a patient-centred care model as most of the evidence related is derived from quantitative research (Kitson et al., 2013). Therefore, an effective mechanism need to be in place to ensure that valuable and rigorously conducted qualitative evidence is accepted and used as evidence in improving clinical situations and service delivery in Malaysia. In disseminating this study's findings and recommendations and to increase interest of people, particularly healthcare professionals, policy makers and Ministry of Health in Malaysia, it is proposed that, this is done in conjunction with addressing the existing problem. Meaning that, the findings of the study could be used as an evidence to analyse the

problem in-depth and as a mechanism to improve service delivery particularly in the provision of diabetes management. Thus, it would help the healthcare professionals to understand the problem clearly within its real life context and the reasons for the existing situation in Malaysia, particularly related to high clinical burden due to uncontrolled diabetes; and subsequently to accept the relevance of proposed change and improvement.

9.9 Limitations

Although the aims and objectives of the study have been achieved, several limitations can be acknowledged.

The first limitation relates to the recruitment of HCPs in this study. The aim in the recruitment of HCPs was to obtain balanced numbers of participants from each professional background and role. This was to ensure that the interpretations made were balanced, without leaning towards one HCP perspective only. However, the researcher faced difficulties in recruiting HCPs in this study, particularly doctors. Although the researcher had background experience as a nurse in Malaysia, it did not help in the process of recruiting doctors, as the researcher did not have previous experience of working in the case clinics. Thus, the researcher was regarded as an outsider in the case study settings. Furthermore, the environment within the clinics was very busy, with high numbers of patients every day, and the HCPs' schedule was very tight; this made them exhausted by the evening. Another aspect that contributed to the difficulty in recruiting doctors was the doctor–nurse hierarchy commonly practiced in healthcare organisations in Malaysia (Brandi, 2000). Healthcare organisations are dominated by doctors, and nurses are considered to be assistants who need to carry out doctors' order (Mccallin, 2001). This situation was apparent when the nurse managers were unable to help in introducing this study to the doctors. This aspect was also mentioned repeatedly by the nurses during the interviews. Therefore, it can be suggested that the doctors may have felt averse to participating in a study conducted by a nurse, as they might have regarded the study as unimportant

(Krogstad et al., 2004). The researcher was also unable to recruit an equal number of dieticians and pharmacists to the study, as there were only two of each involved in the diabetes management at each of the clinics. It is anticipated that the limited numbers of doctors, dieticians and pharmacists recruited to this study may have restricted understanding of the self-care issues in type 2 diabetes in Malaysia from their point of view.

Individual interviews were identified as the most suitable data collection approach to explore the experiences and perspectives of the participants. However, limitations can be identified in the utilisation of individual interviews, as this method of data collection is highly exposed to distortion and bias from participants. It was anticipated that the participants may have provided answers considered 'desirable' by the researcher, due to the short-term relationship and the position of the researcher as an HCP in the study settings. Several efforts were made to minimise this situation, such as wearing ordinary clothes rather than clinical uniform, and allowing ample time to build a relationship before the interviews were conducted. However, this aspect can still be considered a limitation of the study. Nevertheless, the combination of multiple data collection methods from multiple sources, under the supervision of academic supervisors, helped to build an audit trail and enhanced the rigour of the study.

A further limitation of this study is that the findings are limited to the specific geographical and contextual setting. The fieldwork was conducted at a specific time, in particular places, and in a particular environment, which all influenced the data collected. Furthermore, the study was conducted in fulfilment of an academic qualification, so that constraints of time were faced with a single researcher conducting the study. However, the issues that were identified from the study are relevant to the current implementation of policy and guidelines, and should provide valuable recommendations for the improvement of service delivery pertaining to diabetes management within the study setting.

This study is a qualitative case study that focused on an urban population. Therefore, it is anticipated that, the study findings relates primarily to the urban population meaning application to rural population is limited. Nevertheless, as explained in chapter seven, clinical practice guidelines, national policy and documents included in the document analysis is widely used in public healthcare facilities across Malaysia. Therefore, it could be suggested that, if service delivery is guided by these documents across Malaysia then the findings and recommendation of this study might be applicable. However, patients' demographic and characteristics might differ between urban and rural environments and the management of diabetes may also be influenced by differing context and characteristics of the patients. Therefore, transferability of the study findings is limited and further study needs to be conducted to understand the patients experience with diabetes management and service delivery in rural areas.

Potential biases when conducting the observation was anticipated as the sample was very limited. Furthermore, having family members with diabetes provided the researcher with pre-concieved ideas and perspectives on what defined 'good care' regarding diabetes management and this probably had some degree of influence on data analysis and interpretation. However, the potential for bias was reduced as far as possible by maintaining a reflective diary throughout the data collection process. Elements of pre-conceived ideas that might have been introduced in the data collection and analysis was identified and acknowledged.

9.10 Conclusion

The research examined self-care practices and the factors influencing patient engagement in self-care. In addition, this study provided evidence for the existence of self-care support provision and how it influenced the self-care practices of the patients. The evidence was obtained from multiple views and perspectives of patients and HCPs in the context of primary- and secondary-care within the urban setting. This research highlighted the experiences and struggles faced by the patients in dealing with and adapting self-care to their actual situations. It also emphasised the

discrepancies that exist between the self-care needs of patients and the current self-care support provision. It is notable that discrepancies were found to exist between the self-care needs of the patients and the self-care support provided within the healthcare system; this explained the reason for poor self-care of patients with type 2 diabetes in Malaysia. The implications of this research for policy, practice and education have been identified, and recommendations for further research have been made. In particular, this study provided insight into the improvement of service delivery pertaining to self-care support provision in the Malaysian healthcare system.

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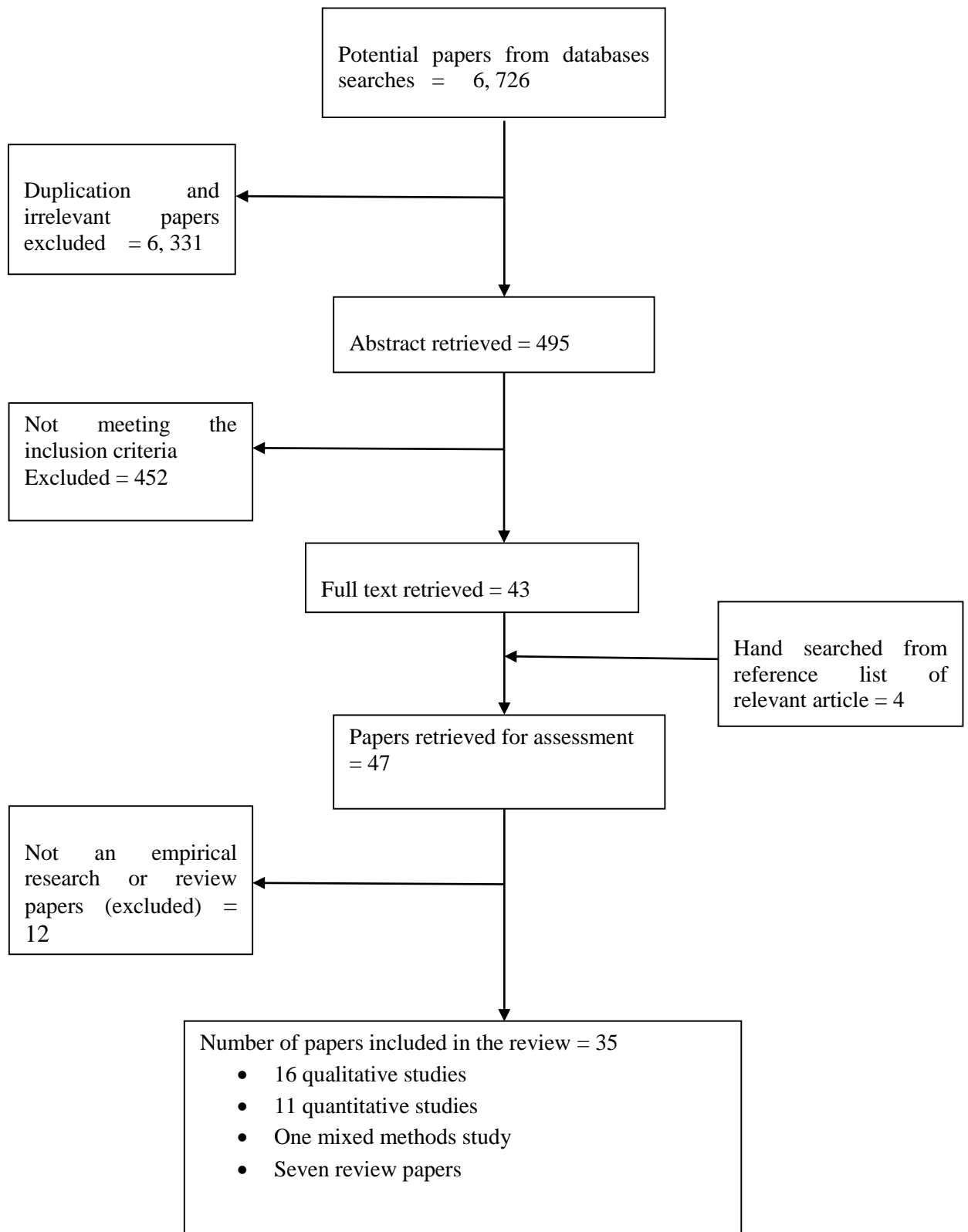
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Appendices

Appendix 1 – List of keywords used in literature search and detail of search strategy

Databases	Keywords used	Number of paper retrieved
CINAHL	*Diabetes type 2, Non-Insulin dependent, Adult, Chronic disease, Long-term condition/illness.	2306
Medline		1174
ASSIA	*Diabetes management, Diabetes education, Self-care, Self-management, Adherence, Compliance, Self-care needs, Adaptation/engagement.	660
British Nursing Index		1468
EMBASE	*Diabetic educator, Health-care system, Primary health care, Empowerment, Decision making, Collaborative care, Self-care support, Patient-centred care, Chronic care model.	283
PsychINFO		153
ISI Web of Knowledge		271
Social Science Citation Index		269
Evidence Based Medicine Reviews		*Keywords in each categories and between categories were combined using Boolean phrases 'OR' and 'AND'
TOTAL		6726

Appendix 2 - Flow diagram of retrieval studies for review



Appendix 3 – Hawker’s assessment tool

Assessment criteria

1. Abstract and title: Did they provide a clear description of the study?

- (1) Good: Structured abstract with full information and clear title
- (2) Fair: Abstract with most of the information
- (3) Poor: Inadequate abstract
- (4) Very poor: No abstract

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

- (1) Good: Full concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge. Clear statement of aims and objectives, including the research questions.
- (2) Fair: Some background and literature review. Research question outlined.
- (3) Poor: Some background but no aim/objectives/questions, OR aims/objectives but inadequate background.
- (4) Very poor: No mention of aims and objectives. No background or literature review

3. Method and data: Is the method appropriate and clearly explained?

- (1) Good: Method is appropriate and described clearly (e.g., questionnaires included). Clear detail on data collection and the recording process.
- (2) Fair: Method appropriate, description could be better. Data described.
- (3) Poor: Questionable whether method is appropriate. Method described adequately. Little description is given on data.
- (4) Very poor: No mention of method, AND/OR method inappropriate, AND/OR no details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?

- (1) Good: Details (age, gender, race, context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates is shown and explained.
- (2) Fair: Sample size justified. Most information given, but some is missing.
- (3) Poor: Sampling mentioned but few descriptive details.
- (4) Very poor: No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?

- (1) Good: Clear description on how analysis was done.
Qualitative studies: Description of how themes derived/respondent validation or triangulation.
Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed.

- (2) Fair:
Qualitative: descriptive discussion of analysis.
Quantitative: The process of data analysis
- (3) Poor: Minimal details about analysis
- (4) Very poor: No discussion of analysis.

6. Ethics and bias: have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

- (1) Good: Ethics – where necessary issues of confidentiality, sensitivity and consent were address.
Bias – Researcher were reflexive and/or aware of own bias.
- (2) Fair: Lip service was paid to above (i.e., these issues were acknowledged).
- (3) Poor: Brief mention of issues.
- (4) Very poor: No mention of issues.

7. Results: Is there a clear statement of the findings?

- (1) Good: Findings explicit, easy to understand, and in logical progression. Tables if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
- (2) Fair: Findings mentioned but more explanation could be given. Data presented relate directly to results.
- (3) Poor: Findings presented haphazardly, not explained, and do not progress logically from results.
- (4) Very poor: Findings not mentioned or do not relate to aims.

8. Transferability or generalisability: Are the findings of this study transferable (generalisability) to a wider population?

- (1) Good: Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
- (2) Fair: Some context and setting described, but more needed to replicate or compare the study with others, plus fair score of higher score in Question 4.
- (3) Poor: Minimal description of context/setting.
- (4) Very poor: No description of context/setting

9. Implication and usefulness: How important are these findings to policy and practice?

- (1) Good: Contribute something new and/or different in terms if understanding/insight or perspectives.

- (2) Fair: Two of the above (state what is missing in comments).
- (3) Poor: Only one of the above.
- (4) Very poor: None of the above.

Appendix 4 – Quality assessment of the included studies

Qualitative studies - Appraised based on CASP for qualitative research (2006)

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Vermeire <i>et al.</i> (2007) EUROPEAN COUNTRIES	<p>Aim: to assess health beliefs, communication with caregivers and problem encountered in adhering to treatment regimen.</p> <p>Methodology: Qualitative meta-ethnography using focus group discussion - conducted in seven European countries.</p>	<p>The recruitment strategy was not clearly mentioned as this study is conducted across European countries. As the study in different countries were conducted independently, the recruitment strategy might be different from one to another. Nevertheless, absence of this information had provide doubt on how the patients were recruited in this study.</p> <p>N=246 participants across seven European countries.</p>	<p>This study had incorporated focus group interviews using Krueger's technique. However, lack of explanation on Krueger's technique and justification in this study had made the understanding on this aspect were unclear.</p> <p>Data were collected independently in each countries by different researcher. However the author did not mentioned on how the consistency of data produced were maintained.</p>	<p>Data were analysed using Meta - ethnography. The author had clearly explained on the data analysis process which enhance understanding of the reader on the study findings.</p>	<p>Ethical consideration were not clearly explained in the article.</p>	<p>As this study involved seven different researchers in seven settings, reflexivity may hard to be illuminate in this article. It provide justification on why reflexivity aspect were not mentioned.</p>	<p>This is a large scale study which conducted in across European region. This study had provide understanding on the barriers that type 2 diabetic patients have in living with diabetes. Nevertheless, lack of explanation on the influence of different context and setting in the interpretation of data had contribute doubt on the credibility of the study.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Hornsten <i>et al.</i> (2004) SWEDEN	<p>Aim of the study was clearly stated - to describe personal understandings of illness among people with type 2 diabetes in Sweden.</p> <p>Design - Qualitative design but not clearly stated on the theoretical framework. N=44.</p> <p>Study was part of on-going prospective educational programme.</p>	<p>Setting - participants were recruited from 15 primary healthcare centres in a healthcare district in northern Sweden. 44 patients from 96 participants in intervention programme were interviewed.</p> <p>- The author did not clearly describe how the 44 participants were selected - no inclusion and exclusion criteria for the qualitative interview stated. Thus not clear on participants were selected from 96 cohort. Maximum variation achieved through different characteristics and treatment used by the participants.</p>	<p>Narrative thematic interview were used - usage of interview guide has been mentioned in the article with broad category of possible themes.</p> <p>Setting where the interview been carried out have been clearly explained by the author thus environmental factor that might influenced the findings could be understood and anticipated.</p> <p>Interview process was clearly explained and the reason in choosing the data collection method was stated.</p>	<p>Data analysis was explicitly explained.</p> <p>Rigour of the findings were enhance through member checks (involving research team).</p> <p>Process on how the themes emerged from the data inductively was explained.</p> <p>Findings was explicitly discussed</p>	<p>Ethical consideration was briefly explained - anonymity, confidentiality, right to withdraw.</p> <p>- did not clearly explained about how inform consent have been sought from the participants - may be due to limited of space.</p>	<p>- Personal understanding or explanatory model of illness have been put aside through inductive coding of meaning units after discussions about the text - had showed a steps taken to avoid self-contamination in data interpretation. However, the explanation was very brief - how the researcher put their role in the study was not clear.</p>	<p>- Method used was appropriate with the aim.</p> <p>- No theoretical framework stated however the author had explicitly described on data collection procedure.</p> <p>- The findings of the research was clearly presented with clear explanation on how themes derived from the data.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Holmstrom & Rosenqvist (2005) SWEDEN	<p>Aim: to describe misunderstandings that Swedish patients with type 2 diabetes have about their illness and treatment.</p> <p>Methodology: Qualitative method using phenomenological approach using interviews and analysis of videotaped materials</p>	<p>Participants were recruited using purposive sampling from GPs or diabetes nurse.</p> <p>Author did not clearly explained on how the participants were identified and approached. As such how the participants were recruited in this study was not very clear.</p> <p>N=18</p>	<p>Two data collection method were incorporated in this study.</p> <p>Patients'-providers' interaction were videotaped. Furthermore, patients were interviewed - to explain the activities that recorded - video-cued narrative reflection.</p> <p>By adopting this type of data collection several ethical issues may arise.</p>	<p>In-depth description of data analysis process were presented.</p> <p>The authors had clearly explained on how the themes and categories were derived from the original data.</p>	<p>The authors had clearly explained on how the ethical approval were sought from the ethical committee.</p> <p>Nevertheless, how the informed consent and confidentiality aspect were handled were not sufficiently explained.</p>	<p>The authors did not clearly explained on the potential bias that might be introduce by the researchers in the study. In addition reflexivity aspect where the way the researcher examined their own role and their influence in data interpretation were not stated.</p>	<p>The study was clearly presented. The findings of the study was sufficiently details where the original quotes from the participants were presented. Nevertheless, lack of explanation in several aspects such as ethical issues and reflexivity had affected the credibility of the study.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Whittemore <i>et al.</i> (2002) UNITED STATES	Objective of research clearly stated - to explore experience of integrating type 2 diabetes treatment recommendation in to an existing lifestyle. N = 9 Adopting interpretive method but the design used was not clear. - as research objective was to explore the patients' experience, interpretive method used seems to be appropriate. Setting of the study was not stated in the article.	- Participants were recruited from the intervention programme that were carried out in other part of study - therefore, sampling procedure used was not clear. - Participant were consists of women with type 2 diabetes but author had emphasized on variation of participants which achieved from socioeconomic status, education, duration of diagnosis, occupation and level of motivation.	Participants' participation in nurse coaching were audiotape (patient-nurse interaction) and contact summary sheet were developed to capture immediate reflection & impression. - Interview were carried after the completion of nurse-coaching intervention - topic guide used and has been clearly stated in the article.	-Data analysis procedure was explicitly explained - how the authors achieved on themes. - Findings was explicitly presented - credibility of data achieved through continuous verification and audit trail. - Findings presented were clearly answered the research question and achieved the objective of study.	Ethical issue was briefly stated include informed consent, consent from gatekeeper, IRB approval and confidentiality.	Author had clearly described on how they put themselves in the research and how role as researcher and clinical expert had influenced in research process and analysis.	- The conduct of the study were clearly presented in the article. -Small numbers of sample had provide doubt on the achievement of data saturation. - Possibility of the course attended by the participants to influence the data were not clearly stated.

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Nagelkerk <i>et al.</i> (2006) UNITED STATES	Aim: To describe perceived barriers to and effective strategies for self-management of adults with type 2 diabetes in a rural setting. Methodology: Qualitative method - an exploratory descriptive design using focus group interviews.	Participants were recruited through purposive sampling from a rural primary care setting. Inclusion and exclusion criteria were clearly explained. These explanations provide clear understanding on how participants were selected from the study population. Sample size: N=24	Data for this study were collected using focus group discussions. 6-12 participants were allocated in to one group. The data collection method seems to be appropriate with the purpose of the study. Observation of non-verbal behaviour during the focus group discussion were also been incorporated in this study.	Content analysis was used to categorized and interpret the data. Authors had mentioned about frequent meeting with the research team members in verifying and clarifying the categories and themes that derived from the data had enhance the credibility of the findings.	Ethical consideration in the conduct of this study was briefly mentioned in the article. Nevertheless, the ethical consideration on preserving participants' rights were not stated.	Reflexivity aspect was not included in the article. Therefore this aspect were not clearly understood in this study context.	The explanation about the conduct of this study in the article was clear. The author had mentioned about the validity and reliability aspects. However applicability of this aspects in data interpretation had provide doubt whether it will affect the data interpretation due to its rigidity as it is more relevant to the quantitative research.

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Rayman & Ellison (2004) UNITED STATES	<p>Aim: to describe the early experience and day-by-day reality of learning to self-manage type 2 diabetes among women who were new to intensive control.</p> <p>Methodology: Qualitative interview and document review.</p>	<p>Recruitment strategy was not clearly explained. However, the author had mentioned the criteria of the participants included in the study. This improved credibility of the study where the participants recruited were appropriate with the data that need to be generated. N= 19</p>	<p>Data were collected using individual interview face to face or through phone. Analysis of participant's clinical record were also incorporated to identify additional relevant data.</p> <p>The author did not clearly discussed on the steps that taken in maintaining the issue that may arise between face to face interview and phone interview. As the context of both type of interview were different thus, it may affect the data generated.</p>	<p>Data analysis process were clearly explained and steps in enhancing rigour during data analysis process was adequately discussed.</p>	<p>The ethical aspect was briefly explained. The author only mentioned about the informed consent that provided by the participants prior to data collection.</p> <p>Nevertheless other ethical aspect such as ethical approval and preserving right of the participants was not mentioned in the article.</p>	<p>Reflexivity aspect was not included in the article. Thus whether bias were introduced or anticipated by the researcher could not be confirmed.</p>	<p>The findings of the study were clearly described.</p> <p>Nevertheless, the author did not include any original quotes from the participants. Thus the authenticity of the data was not clear.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Hunt et al. (1998) UNITED STATES	Aim: To examines how the different contexts and perspectives of patients and practitioners result in distinct approach to type 2 diabetes management. Methodology: Qualitative explanatory descriptive design - open ended interviews.	The inclusion and exclusion criteria in selecting the participants was clearly explained. Nevertheless, the author did not described on how the participants were recruited.	The study had utilised open-ended interview method followed by semi-structure interview with the participants. Analysis of clinical record were also incorporated.	Data analysis was clearly explained which include content analysis and cross-reference. The explicit explanation in this aspect had provide clear understanding on how the author derived with themes in the result section.	Ethical consideration in this study was not stated in the article. Thus, any ethical issues that anticipated by the researcher throughout the study could not be understand.	Reflexivity aspect also not been included in this article. As the author did not clearly reflecting her role and position in this study, the bias that may introduced by the authors throughout the study could not be anticipated.	This study was very valuable as it provided new insight on the understanding of self-care in type 2 diabetes by including both patients and healthcare providers. Nevertheless, lack of explanation on important element included recruitment strategy, ethical issues and reflexivity may affect the credibility of the study.

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Lippa & Klein (2008) CANADA	<p>Aims: to examine how patients with low, moderate and good glycaemic control conceptualize self-care.</p> <p>Methodology: Qualitative semi-structured interview- using naturalistic decision making research framework</p>	<p>Participants were recruited using convenience sampling and snow balling. Study were advertised using flyers in the pharmacy and grocery stores.</p> <p>The recruitment strategy might be appropriate to the target population. Nevertheless, the by using this method of recruitment, the ability of the researcher to identify appropriate participants which rich information is doubt. N=20</p>	<p>This study had incorporated semi-structured interview and self-administered questionnaire. The method chosen were adequately justified and how research objectives were met has been clearly explained.</p>	<p>Data analysis procedure for both qualitative and quantitative data were clearly laid out in the article.</p> <p>Qualitative data was presented clearly by including original quotes from the participants.</p>	<p>The author had mentioned about ethical approval which sought from the university's IRB. However, ethical consideration of participants aspect; how informed consent been sought and whether the confidentiality of the participants were maintained not clearly explained.</p>	<p>Reflexivity aspect was not included in the study. Thus the bias that researcher had introduced during data collection or data interpretation could not be justified.</p>	<p>The finding was clearly presented by providing clear themes and categories. However, this study could be clearer if the aspects of ethical issues and reflexivity were explicitly explained.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Naemiratch & Manderson (2006) THAILAND	<p>Aim: to explore individual's understanding of the disease and to describe their illness experience and disease management strategies.</p> <p>Methodology: qualitative ethnographic method among type 2 diabetes patients at a district in Bangkok.</p>	<p>Participants were identified from hospital and health centres and directly contacted by the researcher.</p> <p>Initially, participants were become the subject of the research where the researcher had spent her days with the participants.</p> <p>Subsequently, another 21 participants were interviewed to extend the data and enhance the credibility and rigour.</p>	<p>In-depth interviews using conversational methods were used in gathering data from the participants.</p> <p>In addition, persistent observation also incorporated as researcher was spending large amount of time with the participants.</p> <p>Several data collection used in this stud had enhanced credibility of data produced and increased trustworthiness of the study.</p>	<p>Data analysis procedure in this study was not clearly stated.</p> <p>Thus, the procedure on how the researcher derived with the themes were not clearly understood.</p>	<p>As this study exploring the in-depth experience of participants with type 2 diabetes, patients were not fall in the vulnerable group.</p> <p>Nevertheless, the possibility of distress situation implied from the interviews could be anticipated. Lack of explanation about this issue in the article had restricted reader's understanding on this issue.</p>	<p>In the article, the authors did not clearly mentioned her role as healthcare providers and at the same time as a researcher.</p> <p>Dual role that researcher has might had influenced the data collection and interpretation of data.</p> <p>Lack of explanation on reflexivity on how the researcher differentiate her role as nurse and researcher in this context had provided doubt on the possibility of bias that may introduced by the researcher.</p>	<p>The study was beautifully conducted.</p> <p>Nevertheless several aspects such as data analysis and lack of explanation on reflexivity had affected the trustworthiness of the findings.</p>

Author and study setting	Research aim and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Lai <i>et al.</i> (2007) TAIWAN	<p>Aim - to identify perception of patients with diabetes - ideas of the illness course, perceived severity and impact on self-care behaviour.</p> <p>Qualitative research using in-depth interview complemented with focus group</p> <p>Focus group (N=53) Interviews (N=22)</p>	<p>Purposive sampling with maximum variation - To achieve perspective of the patients from different background and situation.</p> <p>Setting - rural town in Taiwan.</p>	<p>-Interview (May - October 2002)</p> <p>-Focus group (March to June 2004).</p>	<p>Data analysis was briefly explained and rigour of data achieved through discussion with other researchers in reaching the consensus on emerging themes.</p> <p>Findings had clearly presented with themes and data which contributed to the theme was clearly stated.</p> <p>-the data provided were sufficient to support the findings emerged from the study.</p>	<p>Informed consent taken prior to data collection</p> <p>Oral consent used in illiterate participants - witnessed by other researcher:-may raise ethical issues as the patients are vulnerable group and no family members were involved (witness) in taking consent on illiterate participants.</p>	<p>Role and potential bias might introduced in research design, data collection and data analysis was not discussed in the article.</p>	<p>Method used were appropriate with the aim of the study.</p> <p>Data collection were clearly stated however the purpose of 2 data collection method in different timeline was not clearly justify - possibility of variation in the data which may not able to complement each other - reduce the credibility of data produced.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Lin <i>et al.</i> (2008) TAIWAN	<p>Aim: to understand and document the perspectives of Taiwanese patients with type 2 diabetes regarding the process and strategies used to self-manage their disease.</p> <p>Methodology: Qualitative method using focus group discussion.</p>	<p>Purposive sampling method was used in recruiting the participants. Inclusion and exclusion was adequately detailed. This provide understanding on how the appropriate participants were recruited to generate data relevant to the study.</p>	<p>Data were generated using focus group discussion. Six to ten people were allocated in one group. The number of participants in one group seems to be appropriate as it will be able to generate rich data.</p> <p>Nevertheless the characteristics of the participants in each group were not adequately detailed. This had affected the understanding on the ability of the group to generate data from different background and situation.</p>	<p>Data were analysed base on framework by Colaizzi (1978). The author had clearly described on the steps in data analysis which provide enough understanding on how themes and categories derived from the data.</p>	<p>The ethical issues was implicitly described. The author had described how ethical approval has been sought. However how the right of the participants been preserved were not clearly explained.</p>	<p>Reflexivity aspect were not included in the article. This the influence that the researcher may have in data interpretation were not able to confirmed.</p>	<p>This study had generated knowledge on the perspective to type 2 diabetes patients towards their self-care. Nevertheless this study could be strengthen if aspect of ethical issue and reflexivity were clearly explained.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Oftedal <i>et al.</i> (2010) NORWAY	<p>Aim: To understand how adults with type 2 diabetes perceived different attribute of support provided can influence people's motivation to self-manage their disease.</p> <p>Methodology: Exploratory qualitative design - focus group discussion.</p>	<p>Participants were selected using purposive sampling method - from three sites.</p> <p>Inclusion and exclusion criteria was clearly described in the article.</p> <p>Participants were recruited from various background and conditions - increased richness of the data.</p>	<p>Data were collected using focus group discussion - three focus group discussion were conducted consists of five to seven people in one group.</p> <p>The focus group protocol and topic guide were used - able to maintain the focus of discussion and increase the possibility of meeting the research objectives.</p>	<p>Data were analysed using qualitative content analysis. Steps in data analysis were clearly explained in the article - enhance understanding of the reader on how the author had derived with the findings.</p>	<p>Ethical consideration include the approval from ethical committee and maintaining the confidentiality of the data were clearly explained by the author.</p>	<p>The author had explicitly described on how the rigour of this study has been considered and maintained.</p> <p>Nevertheless, the potential bias that might be introduced by the researcher was not clearly explained.</p>	<p>This study was clearly presented with minimal methodological flaws.</p> <p>The only aspect that not clearly explained in the article was on the reflexivity. Thus the influenced that the researcher has on the interpretation of data could not be confirmed.</p> <p>However the author may had anticipated this aspect by obtaining feedback on the discussion summaries from the participants.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Formosa <i>et al</i> (2011). MALTA	<p>Aim: To explore the effect of culture, religion and government organization on the management of patients with diabetes.</p> <p>Methodology: Reflexive ethnography - Carspecken's five stage method using unstructured in-depth interview and participant observation.</p>	<p>Purposive sampling was used in this study. Five individuals which represented each of key stakeholders in diabetes management were interviewed.</p> <p>Purposive sampling helped the researcher to identify participants with ranged of experience and provide maximum variation in the sample.</p>	<p>Data were collected using in-depth interview and participant observation.</p> <p>Although the author had incorporated two type of data collection method which enhance the credibility of data, lack of explanation on how it conducted particularly the observation had provide doubt on the appropriateness of this method in to this study.</p>	<p>Data analysis procedure was implicitly explained. As the author did not provide the original quotes from the participants in the finding section, the reliability of the interpretation with the original data could not be confirmed.</p>	<p>Approval from ethical committee were obtained prior to the conduct of the study. Consent from the participants were obtained orally.</p> <p>This aspect had provide doubt to the reader on how the consent were communicated and obtained. In addition the measures in preserving the right of participants was not included in the article.</p>	<p>The reflexivity aspect was not included in the article. Thus the authenticity of the data and potential bias that may be introduced by the researcher could not be confirmed.</p>	<p>The conduct of the study was parallel with the current research. Nevertheless, the methodological aspect of this study was implicitly explained in the article. Thus, the trustworthiness of this study were not able to clearly justify.</p>

Quantitative studies - Appraised based on guideline by Coughlan *et al.* (2007).

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Comment
Whittemore <i>et al.</i> (2005) UNITED STATES	<p>Aim: To examine factors associated with metabolic control, self-management (diet and exercise behaviour), and psychosocial adjustment (diabetes-related stress) in women with type 2 diabetes.</p> <p>Methodology: Cross-sectional design using baseline data of women with type 2 diabetes who enrolled in nurse coaching intervention programme.</p>	<p>Convenience sampling has been used in recruiting women with type 2 diabetes from the nurse coaching intervention programme. N=</p>	<p>Data were collected using self-reported instruments asking their demographic data, physiological (BMI & HbA1c), self-management, psychosocial and health functioning variables.</p> <p>The instruments were explained in detail in the article. And the reliability and validity aspect of the instruments were clearly mentioned.</p>	<p>Data analysis conducted using SPSS Ver. 10. The tests include; descriptive analysis, bivariate correlation and regression analysis. The purpose of data analysis tests were clearly justified by matching it with the objectives of the study.</p>	<p>Ethical issues were implicitly explained. Therefore any ethical issues that anticipated by the author throughout this study could not be understood.</p>	<p>This recruitment method seems to be applicable as the study population has been clearly identified. In addition, inclusion and exclusion criteria of sampling were clearly stated thus, the sampling strategy were appropriate.</p> <p>Nevertheless the author did not mentioned about the total population of women who attended the programme. Thus, there is possibility of sampling error and whether the sample size of 53 had represented the whole population could not clearly justified.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Comment
Polonsky <i>et al.</i> (2010) UNITED STATES	<p>Aim: To investigate patients' experiences when diagnosed with type 2 diabetes and diabetes-related distress and self-management years later.</p> <p>Method: Quantitative survey using several sets of questionnaires.</p>	<p>Participants were identified from 3 study sites and invitation letters had send to them explaining about the study. Participants were then been contacted by the researcher to confirm their participation.</p> <p>Sample size: N=179 - the initial numbers of patients been invited were not stated thus the possibility of sampling error is anticipated.</p> <p>The recruitment strategy were appropriate as the researcher had mentioned about the inclusion and exclusion criteria the used to identify the participants.</p>	<p>Data has been collected using self-administered questionnaire detailing the variables that been studied.</p> <p>Mean age of the participants in this study were 56 years old. This method of data collection may be applicable to this population of patients. However, the author did not clearly mentioned about the problem that they anticipated during the data collection process which might affected the responds of the participants of the questionnaires i.e. blurring vision, lack of understanding on the questions asked.</p>	<p>Data were analysed statistically. The test used includes chi square, McNemars test, t test and analysis of variance. In addition multiple regressions also used to explore the relationship between variables.</p>	<p>Ethical issue were implicitly explained. The author only stated about the approval sought from the respective clinics. However, the aspect on how the right of the participants been preserved in this study was not stated.</p>	<p>The conduct of the study was clearly presented in the article.</p> <p>Nevertheless, the author did not clearly mentioned on the aspect of validity and reliability of the study. For instance, the validity and reliability of the instruments used was not clearly mentioned and whether it is reliable to measures the variables in answering the research questions could not be justified.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Comment
<p>Siripitayakunkit <i>et al.</i> (2008)</p> <p>THAILAND</p>	<p>Aim: To examine the causal relationship among personal, psychological and healthcare system factors that contribute to integrating lifestyle in Thai women with type 2 diabetes.</p> <p>Methodology - Descriptive correlational, cross-sectional design.</p>	<p>The recruitment strategy was not clearly mentioned.</p> <p>Sample size – N=490 Thai women with type 2 diabetes.</p>	<p>Data were collected using five established instruments.</p> <p>Pilot testing have been conducted with 30 Thai women had confirmed the reliability and applicability of these instruments in to Thailand context. Each of component of the instruments were clearly described in the article.</p>	<p>The data analysis procedure include univariate and bivariate analysis using SPSS package version 9.</p> <p>However, aspect of data analysis were briefly explained - restricted the understanding of the reader on the study findings.</p>	<p>Ethical issues about the conduct of the study and how the right of the participants were preserved had not been mentioned in the article.</p>	<p>Sample size used in this study quite large thus, it may help in the generalization of the findings.</p> <p>However, as this study is conducted using quantitative cross-sectional method, understanding on psychological aspect seem to be restricted.</p> <p>But as this study is looking at causal relationship between several variables on the ability of participants to integrate self-care in their lifestyle, the method used seems to be appropriate.</p>

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reliability and validity	Comment
Aljaseem <i>et al.</i> (2001). UNITED STATES	<p>Aim: To examine the relationship of diabetes-specific treatment barriers and self-efficacy with self-care behaviour.</p> <p>Methodology: Quantitative correlational cross-sectional study</p>	Recruitment strategy was implicitly explained. It seems that the author had recruited all diabetic patients who enrolled in an education programme.	<p>Data collected using self-administered questionnaire -</p> <p>The variables that being measure in this study include: sociodemographic variable and medical history, health belief measures, self-efficacy measures and diabetes self-care behaviours.</p>	<p>Data were statistically analysed using SPSS III.</p> <p>The tests that carried out include Pearson correlation coefficients and bivariate analysis.</p>	The researcher had stated about the informed consent that sought from the participants prior to the beginning of education programme. This might introduced certain degree of coercion where the participants may felt obliged to participate as they were interested with the programme. Clear explanation on how the participants where approached and explained about the research will provide clear understanding on this matter.	The reliability and validity of the instruments used in the study were considered by the author. Reliability measures of each of the instruments used were clearly stated in the article.	The study had provide evidence on the barriers and self-efficacy which influenced self-care behaviour. The methodological aspect of the study was clearly presented with minimal flaws.

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Comment
Hartz <i>et al.</i> (2006) UNITED STATES	<p>Aim: To assess the reason for improved control for patients with initially poorly controlled diabetes.</p> <p>Methodology: statistical analysis on the status of glucose control and influencing factors that improved the glucose control of the patients.</p>	<p>The study did not involve human participants. However, the data were collected using analysis of the medical record of the patients who diagnosed with type 2 diabetes.</p> <p>The author had clearly explained on the criteria of the participants that their medical record included in the study. As the author did not mention the total population of the patients being studied, the representativeness of 69 medical records included in this study could not be confirmed.</p>	Data were collected by reviewing the medical records of the patients that met the inclusion and exclusion criteria. This method may be appropriate in achieving the objective of the research.	<p>Data were analysed statistically using several tests including analysis of variance and contingency table tests.</p> <p>Results were clearly described in the article and research objectives were met.</p>	As this study did not involve human subjects, ethical aspects may not be relevant to this study. The author had mentioned about the approval that was obtained from the ethical committee. Nevertheless, the author did not clearly explain the confidentiality aspect which seems to be important as this research is dealing with the patients' personal information.	<p>This study was clear and the research objectives were adequately met.</p> <p>Nevertheless, as this study was only focused on the document analysis, a qualitative account on how patients had improved their glucose control from the patients' point of view could not be established.</p>

Mixed method study - appraised based on guideline by Long (2005), University of Sheffield.

Author and study setting	Research aims and methodology	Recruitment strategy	Data collection method	Data analysis and findings	Ethical issues	Reflexivity	Comment
Bhattacharyya <i>et al.</i> (2011) CANADA	<p>Aim: Identifying the quality of care provided by HCP - adhering to the Clinical Practice Guideline by Canadian Diabetes Association 2008.</p> <p>Methodology: Mixed method research involving qualitative interview and quantitative survey.</p>	<p>Participants were recruited using snowball and criterion-based sampling.</p> <p>The author had clearly justified the recruitment strategy. This method seems to be appropriate in recruiting the suitable participants in this study.</p>	<p>1) qualitative Qualitative method were incorporated in the first phase of this study. Semi-structured interview and focus group discussion has been conducted.</p> <p>2) quantitative In phase II of this study, cross sectional chart audit and survey were conducted with three different population: healthcare providers/clinic managers and community healthcare representatives.</p>	<p>Explanation on data analysis were restricted on the quantitative data. This might be because the qualitative phase of this study has been published elsewhere thus, it is not included in this article.</p> <p>Nevertheless, this had restricted reader's understanding on the study.</p> <p>As this study were claimed to be conducted using mixed methods, expectation of the readers to observe the triangulation of data in this study has not been achieved.</p>	<p>The approval from ethical committees were obtained prior to the conduct of this study. As the analysis and finding of this study were focused on quantitative survey, ethical issues which related to the qualitative approach were not included in this article.</p>	<p>Reflexivity aspect also has not been included as the author had focused this article on quantitative phase of the study. Therefore, the possibility of biased introduced by the researcher in qualitative phase could not be included.</p>	<p>This study had provide evidence on the factors that influence diabetes management in Canada. As this article were mainly focused on the quantitative aspect of the study, the qualitative interpretation could not be seen.</p> <p>Therefore appropriateness of survey method which conducted based on qualitative findings could not be clearly justified.</p> <p>In addition, as the patients were not included in this study, the findings of the study seems to be one sided perspective which not able to provide holistic understanding on the issue.</p>

Meta-synthesis article - appraised based on CASP guideline for review paper (2006).

Author	Review aim	Search strategy	Appraisal of the included studies	Method of synthesis	Reflexivity	Comment
Gomersall <i>et al.</i> (2011)	Aim: Integration and critical interrogation of the contemporary qualitative research on patients' perspectives on the self-management of type 2 diabetes.	Author had covered wide range of databases which relevant to the issue being studied. Inclusion and exclusion criteria of the papers included in the review were explicitly described. In addition, time frame used to limit the search were adequately justified.	Assessment on the quality of the papers included were not clearly explained in the article. Nevertheless the author had presented the characteristics of the studies included in the review. In addition specific concept which been analysed in this review were clearly illuminated.	The author had explicitly described the analytical approach used in interpreting the research findings. The author also had clearly explained the theoretical framework used in guiding the synthesis and analysis method in this review.	As this is a review article, aspect of reflexivity may not applicable. Thus it is not been presented in the article.	This meta-synthesis paper had provide analytical understanding on the concept related to self-care in type 2 diabetes. It is very helpful in providing in-depth knowledge on the perspectives of the type 2 diabetes patients towards self-care.

Appendix 5 – Invitation letter for case study sites (Gaining access)



To
Director,

Kuala Lumpur Hospital,
Jalan Pahang, 50586
Kuala Lumpur
MALAYSIA

Principle Supervisor: Dr Jane Griffiths
School of Nursing, Midwifery and Social
Works,
The University of Manchester,
Jean McFarlane Building, Oxford Road,
M13 9PL
UNITED KINGDOM
Phone: +44 (0) 161 306 7681

LETTER OF AGREEMENT

RESEARCH TOPIC: An exploration of self-care practice and self-care support of patients with type 2 diabetes in Malaysia.

15 January, 2012

Dear Dr Zaininah Mohd Zain,

My name is Sanisah Saidi; a lecturer in the Faculty of Nursing, International Islamic University Malaysia, Kuantan, Pahang. Currently I am studying a PhD in Nursing at the University of Manchester, United Kingdom and conducting a research under supervision of Dr Jane Griffiths and Dr Linda Milnes.

My proposed research method is a qualitative case study research. The aim of this study is to explore the nature of self-care practice of patients with type 2 diabetes in Malaysia and to understand the factors that influence the patients' self-care practice. In addition, this study also aim to understand the self-care support provision in Malaysia from patients', healthcare professionals' and healthcare systems' point of view and how it has influenced the self-care practice of the patients. This study is important because Malaysia had experienced steep increase of type 2 diabetes in the last 10 years with high morbidity rate due to its complication. Studies carried out in Malaysia showed that, this condition were due to the ineffective disease management and poor self-care practice of the patients. However, there was limited evidence for us to understand how the patients' practice their self-care and whether the support that currently provided were met their needs in performing self-care. Therefore, by

conducting this research, the actual practice of self-care of patients with type 2 diabetes will be understood and the discrepancies exist between the support provided in the hospital and clinics and the needs of the patients will be able to be illuminated.

This study will involve several data collection activities include semi-structured interview with the type 2 diabetic patients and healthcare professionals (including physician, nurses, dietician and pharmacist), observation of consultation session in the clinic and analysis of relevant documents (treatment notes, policies and guidelines and resources used in supporting self-care of the patients with type 2 diabetes).

I am writing to ask your permission to conduct this study in outpatient department and medical specialist clinic. Potential participants' patients with type 2 diabetes and healthcare professionals who involved in managing the type diabetic patients both clinics. In addition, I also would like to ask your permission to get access in to the relevant documents stated above (patients' case notes, Primary Care policy and guidelines, Clinical Practice Guidelines for diabetes management and resources used in supporting self-care of the patients with type 2 diabetes).

This study has been approved by the ethics committee in the University of Manchester (study reference number: 12238) and Jawatankuasa Etika & Penyelidikan Perubatan, Kementerian Kesihatan Malaysia. The approval letter is as attached. Data collection is planned to be started on January 2013 (upon approval of Head of Department and Director of Hospital). Therefore your agreement is needed in order for me to carry out this study at your place. Herewith also attached the detail proposal of this study.

It will be appreciated if you able to approve this study to enable me to start with the data collection. Your kind consideration and deliberation on this matter is highly appreciated.

With respect I look forward for your reply.

Thank you.

Your Faithfully,

Sanisah Saidi
Researcher,
PhD in Nursing Candidate

Researcher candidate signature

Dr Jane Griffiths
Principle Supervisor


Supervisor's signature

Approval

I give permission to Mrs. Sanisah Saidi a PhD (Nursing) students under the supervision of Dr Jane Griffiths and Dr Linda Milnes from The University of Manchester, United Kingdom to conduct a study that involves patients with type 2 diabetes, healthcare professionals and relevant documents at the outpatient diabetic clinic in the research project: An exploration of self-care practice and self-care support of patients with type 2 diabetes at Kuala Lumpur Hospital, Malaysia.

Name and signature: Dato' Dr Zaininah binti Mohd Zain

Signature:

.....

Print name:.....

.....

Date:.....

To,

Pengarah,
Jabatan Kesihatan Wilayah Persekutuan
Kuala Lumpur dan Putrajaya,
Jalan Cenderasari,
50590, Kuala Lumpur
Malaysia.

Principle Supervisor: Dr Jane Griffiths
School of Nursing Midwifery and Social
Work
The University of Manchester
Jean McFarlane Building
Oxford Road
M13 9PL
UNITED KINGDOM
Phone: +44 (0) 161 306 7681

LETTER OF AGREEMENT

RESEARCH TOPIC: An exploration of self-care practice and self-care support of patients with type 2 diabetes in Malaysia

12th September, 2012

Dear Dr. Balachandran Satiamurti,

My name is Sanisah Saidi, a lecturer in the Faculty of Nursing, International Islamic University Malaysia, Kuantan, Pahang. Currently I am studying a PhD in Nursing at the University of Manchester, United Kingdom, and conducting research under the supervision of Dr Jane Griffiths and Dr Linda Milnes.

My proposed research method is a qualitative case study. The aim of this study is to explore the nature of the self-care practice of patients with type 2 diabetes in Malaysia and to understand the factors that influence the patients' self-care practice. In addition, this study aims to understand the self-care support provision in Malaysia from the points of view of patients, healthcare professionals and healthcare systems and how this provision has influenced the self-care practice of patients. This study is important because Malaysia has experienced a steep increase in instances of type 2 diabetes in the last 10 years with a high morbidity rate due to complications that can arise from it.

Studies carried out in Malaysia showed that, this condition was due to ineffective disease management and the poor self-care practice of the patients. However, there was limited evidence to allow understanding of how patients practice their self-care and whether the support that is currently provided is sufficient to meet their needs in performing self-care. Therefore, by conducting this research, the actual practice of self-care of patients with type 2 diabetes will be understood and the discrepancies that

exist between the supports provided in the hospital and clinics and the needs of the patients will be able to be illuminated.

This study will involve several data collection activities, including semi-structured interviews with type 2 diabetic patients and healthcare professionals (including physicians, nurses, dieticians and pharmacists), observation of consultation sessions in the clinic and analysis of relevant documents (treatment notes, policies and guidelines and resources used in supporting the self-care of patients with type 2 diabetes).

I am writing to ask your permission to involve patients and staffs at Putrajaya Health Clinic (Klinik Kesihatan Putrajaya). Potential participants are patients with type 2 diabetes, physicians, nurses, dieticians and pharmacists involved in managing type 2 diabetic patients. In addition, I also would like to ask your permission to access relevant documents as stated above (patients' case notes, Primary Care policy and guidelines, Clinical Practice Guidelines for diabetes management and resources used in supporting the self-care of patients with type 2 diabetes).

I will be submitting a research proposal for ethics approval to the University of Manchester Ethics Committee in September 2012. Data collection is planned to start in October 2012 (upon approval from the Health Department of Federal Territory of Kuala Lumpur and Putrajaya and the National Medical Research Register). Therefore, your principle agreement is needed in order for me to carry out this study at your clinic. I will provide a detailed proposal of my study once I receive your feedback.

It would be appreciated if you would be able to provide an 'in principle' approval for me to proceed with the next step of this process which is to get ethical approval from the

University of Manchester. Your 'in principle' approval will inform the university about the feasibility of conducting this research. If the 'in principle' approval is granted, kindly sign and stamp the space provided below and return this letter to me using the following address;

Research student: Sanisah Saidi

PhD Candidate

School of Nursing, Midwifery and Social Work

University of Manchester

Jean McFarlane Building

Oxford Road

Manchester M13 9PL

UNITED KINGDOM

E-mail: sanisah.saidi@postgrad.manchester.ac.uk

Thank you very much. Your attention and deliberation on this matter is highly appreciated. With respect I look forward for your reply.

Thank you.

Your Faithfully,

Sanisah Saidi
Researcher,
PhD in Nursing Candidate

Dr Jane Griffiths
Principle Supervisor

.....
Research candidate signature


Supervisor signature

Copy to: Dr. Zainol Ariffin Pawanchee,
Timbalan Pengarah Kesihatan (Kesihatan Awam),
Jabatan Kesihatan Wilayah Persekutuan Kuala Lumpur dan Putrajaya,
Jalan Cenderasari,
50590, Kuala Lumpur
Malaysia.

Approval

I give permission to Mrs. Sanisah Saidi, a PhD (Nursing) student under the supervision of Dr Jane Griffiths and Dr Linda Milnes from The University of Manchester, United Kingdom, to conduct a study that involves patients with type 2 diabetes, healthcare professionals and relevant documents at the community clinic in the research project: 'An exploration of self-care practice and self-care support of patients with type 2 diabetes' at Klinik Kesihatan Putrajaya, Malaysia.

Name and signature: Dr Balachandran Satiamurti

Signature:

.....

Print name:.....

.....

Date:.....

Appendix 6 – Ethical approval from the University of Manchester



Secretary to Research Ethics Committee 5
Faculty Office - Devonshire House

Tel: 0161 275 0288

Email: jared.ruff@manchester.ac.uk

Ms Sanisah Saidi

School of Nursing, Midwifery and Social Work

22nd October 2012

Dear Sanisah

Research Ethics Committee 5 (Flagged Humanities) - Project Ref 12238

An exploration of self-care practice and self-care support of patients with type 2

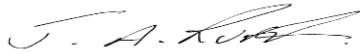
Diabetes in Malaysia (ref 12238)

I am writing to thank you for coming to meet with the University Ethics Committee 5 (flagged Humanities) on 1st October 2012 and for providing the recommended set of amendments requested by the panel.. This letter formally confirms approval for the above project and that no further changes are required to the documentation submitted to the committee.

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee's practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project. I hope the research goes well.

Yours sincerely



Jared Ruff

Senior Research Manager

Faculty of Humanities and Secretary to UREC 5 (Flagged Humanities)

0161 275 0288

Jared.ruff@manchester.ac.uk

UNIVERSITY RESEARCH ETHICS COMMITTEES

Progress or Completion Report Form on an Approved Project

The Committee's procedures require those responsible for projects which have been approved by the Committee to report on any of the following:

- Any incident, accident or untoward event associated with the project (*Please note that if the incident constitutes an accident or dangerous occurrence, the usual Health and Safety reporting mechanism must still be used*)
- Any variation in the methods or procedures in the approved protocol
- A termination or abandonment of the project (with reasons)
- A report **on completion of the project** or a progress report **12 months after approval has been given**.

This form should be completed and returned to research.ethics@manchester.ac.uk

University reference number:

Project title:

Principle investigator:

Date of report:

Progress/completion report (*generally this does not need to be longer than half a page*)

Appendix 7 – Approval to conduct research in Malaysia



UNIT PERANCANG EKONOMI
Economic Planning Unit
JABATAN PERDANA MENTERI
Prime Minister's Department
BLOK B5 & B6
PUSAT PENTADBIRAN KERAJAAN PERSEKUTUAN
62502 PUTRAJAYA
MALAYSIA



Ruj. Tuan:
Your Ref.:

UPE: 40/200/19/2939

Ruj. Kami:
Our Ref.:

Tarikh:
Date:

8 November 2012

SANISAH SAIDI
Apartment 17, Poplar Court,
156 Moss Lane East,
Manchester,
M16 7DH
Email: sanisah.saidi@postgrad.manchester.ac.uk

APPLICATION TO CONDUCT RESEARCH IN MALAYSIA

With reference to your application, I am pleased to inform you that your application to conduct research in Malaysia has been *approved* by the **Research Promotion and Co-Ordination Committee, Economic Planning Unit, Prime Minister's Department**. The details of the approval are as follows:

Researcher's name : **SANISAH SAIDI**
Passport No. / I. C No: **781008-11-5676**
Nationality : **MALAYSIAN**
Title of Research : **"AN EXPLORATION OF SELF-CARE PRACTICE AND SELF-CARE SUPPORT OF PATIENTS WITH TYPE 2 DIABETES IN MALAYSIA.**

Period of Research Approved: **7 MONTHS**

2. Please collect your Research Pass in person from the Economic Planning Unit, Prime Minister's Department, Parcel B, Level 4 Block B5, Federal Government Administrative Centre, 62502 Putrajaya and bring along two (2) passport size photographs. You are also required to comply with the rules and regulations stipulated from time to time by the agencies with which you have dealings in the conduct of your research.

3. I would like to draw your attention to the undertaking signed by you that you will submit without cost to the Economic Planning Unit the following documents:

- a) A brief summary of your research findings on completion of your research and before you leave Malaysia; and
- b) Three (3) copies of your final dissertation/publication.

4. Lastly, please submit a copy of your preliminary and final report directly to the State Government where you carried out your research. Thank you.

Yours sincerely,



(MUNIRAH ABD. MANAN)
For Director General,
Economic Planning Unit.
E-mail: munirah@epu.gov.my
Tel: 88882809
Fax: 88883961

ATTENTION

This letter is only to inform you the status of your application and **cannot be used as a research pass.**

Cc:

Ketua Setiausaha
Kementerian Kesihatan Malaysia
Bahagian Dasar dan Hubungan Antarabangsa
Aras 6, 8 & 11, Blok E7, Kompleks E
Pusat Pentadbiran Kerajaan Persekutuan
62590 Putrajaya
(u.p: Encik Mohd Yasser Bin Mohd Hadzir)

**Appendix 8 – Ethical approval from Medical Research Ethic Committee
Malaysia (MREC)**



PEJABAT TIMBALAN KETUA PENGARAH KESIHATAN
OFFICE OF THE DEPUTY DIRECTOR-GENERAL OF HEALTH
(PENYELIDIKAN & SOKONGAN TEKNIKAL)
(RESEARCH & TECHNICAL SUPPORT)
KEMENTERIAN KESIHATAN MALAYSIA
MINISTRY OF HEALTH MALAYSIA

Aras 12, Blok E7, Parsel E, Presint 1
Level 12, Block E7, Parcel E, Precint 1
Pusat Pentadbiran Kerajaan Persekutuan
Federal Government Administrative Centre
62590 PUTRAJAYA

Tel. : 03-88832543
Faks : 03-88895184

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

Ruj. Kami : (2) dlm.KKM/NIHSEC/08/0804/P12-877
Tarikh : 2 Januari 2013

Sanisah Binti Saidi
School of Nursing, Midwifery and Social Works,
The University of Manchester

Puan,

NMRR-12-972-13253

**AN EXPLORATION OF SELF-CARE PRACTICE AND SELF-CARE SUPPORT OF PATIENTS
WITH TYPE 2 DIABETES IN MALAYSIA**

Lokasi Projek : 1) Klinik Kesihatan Putrajaya 2) Hospital Kuala Lumpur

Dengan hormatnya perkara di atas adalah dirujuk.

2. Jawatankuasa Etika & Penyelidikan Perubatan (JEPP), Kementerian Kesihatan Malaysia (KKM) mengambil maklum bahawa projek tersebut adalah untuk memenuhi keperluan akademik Program Sarjana Kedoktoran Kejururawatan, The University of Manchester.

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

4. Adalah dimaklumkan bahawa kelulusan ini adalah selama setahun dan Puan perlu menghantar 'Continuing Review Form' setiap tahun bagi memperbaharui kelulusan etika. Laporan tamat kajian dan sebarang penerbitan dari kajian ini hendaklah dikemukakan kepada Jawatankuasa Etika & Penyelidikan Perubatan selepas tamatnya kajian ini.

Sekian terima kasih.

BERKHIDMAT UNTUK NEGARA

Saya yang menurut perintah,

(DATO' DR CHANG KIAN MENG)

Pengerusi
Jawatankuasa Etika & Penyelidikan Perubatan
Kementerian Kesihatan Malaysia

Appendix 9 – Letter of invitation for HCPs

Project title: An exploration of self-care practice and self-care support of patients with type 2 diabetes in Malaysia

INVITATION LETTER

Dear Dr./ Sir/Madam,

My name is Sanisah Saidi and I am a research student at the School of Nursing, Midwifery and Social Work, University of Manchester.

I would like to invite you to take part in my research project as stated above. This study is funded by the Ministry of Higher Education Malaysia. The purpose of this research is to understand the self-care practice of patients with type 2 diabetes and how you as a healthcare professional manage the patients and support them in their self-care practice.

Before you decide to take part, you need to understand why this research is being done and what will be involved if you take part in this research project. Please take time to read the information carefully. Talk to others about the study if you wish.

You can contact me using the telephone number or email address on the information sheet enclosed if there is anything that is not clear about the research or if you like more information. Alternatively, if you want to talk to me personally about the study, I will be in the clinic during working hours.

Thank you.

Yours faithfully,

Sanisah Saidi
Research student
School of Nursing, Midwifery and Social Work
University of Manchester
United Kingdom

Appendix 10 – Participant information sheet for HCPs**AN EXPLORATION OF SELF-CARE PRACTICE AND SELF-CARE
SUPPORT OF PATIENTS WITH TYPE 2 DIABETES IN MALAYSIA****PARTICIPANT INFORMATION SHEET (English)****Introduction**

We would like to invite you to take part in our study exploring the way patients with type 2 diabetes manage their illness and how they are being supported by the healthcare professionals at the outpatient diabetic clinic and the community clinic in Malaysia. Before you decide to take part, we would like you to understand why this research is being conducted and what will be involved. I (the researcher) will go through the information sheet with you and will answer any questions you may have. Please discuss this study with your colleagues if you feel useful. I will be at this clinic during the appointment day with the diabetic patients or you can contact me by email or telephone if you would like more information or if you need clarification regarding this study. Please take your time to decide whether you wish to take part in this study.

What is the purpose of the study?

According to statistic in Malaysia, there was a steep increase in the type 2 diabetes incidence in the last 10 years. This phenomenon has been assumed to be related to the ineffectiveness of diabetic management and the lack of abilities amongst the type 2 diabetes patients in self managing their illness. However, patients' experiences in self-managing the type 2 diabetes and the factors which influenced their abilities in managing their diabetes were not clearly understood. In addition, whether the support which was provided by the healthcare professionals met the needs of the patients in self-managing their diabetes was not known. Therefore, the purpose of this study is to explore how patients with type 2 diabetes in Malaysia taking care of themselves and how they are being helped to manage their diabetes by the healthcare professionals including doctors, nurses, dieticians and pharmacists.

Why I have been invited?

You have been invited to take part in this study because you are the healthcare professionals who are involved in the management of type 2 diabetic patients at the Kuala Lumpur Hospital's outpatient diabetic clinic and the Putrajaya's Health Clinic which have agreed to take part in this study. We are expecting to speak to about 15-to 20 healthcare professionals which will include physicians, diabetic educators, nurses, dieticians and pharmacists at these clinics. We would like to understand your experiences of managing type 2 diabetic patients, their routine treatments and the support provided to the patients in managing their own illness. Apart from that, we would like know your opinions regarding current practices in managing the type 2 diabetic patients at these clinics.

Do I have to take part?

No. Your participation in this study is entirely voluntary. If you do not wish to take part, it will not affect you in any way. Also, if you agree to take part, you have the right to withdraw from this study at any time without giving any reason.

What will happen to me if I take part?

If you decided to take part in this study, I will ask you to sign a consent form indicating that you have agreed to be a part of this study. This study will involve two activities which are an interview and an observation of your consultation session with

the patients who have agreed to take part. You may choose to take part in both of the activities or either one of them.

a) Interview

I (the researcher) will conduct an interview with you at this clinic or at another convenient location of your choice. The interview will be audio-recorded and will take between an hour and one-and-a-half hours to complete. You will be asked to describe your experiences of managing patients with type 2 diabetes, the treatments and the support that you have provided to the patients in terms of improving their abilities to manage their own conditions and your opinions regarding current practice. The researcher will have a list of questions to guide you during the interview, but you are free to add any other information which you feel important. You will be interviewed alone. If you feel uncomfortable and need to interrupt or stop the interview, you are able to do so at any time.

b) Observation

The researcher will be doing observation during diabetic type 2 patients' appointments day at the clinic. The purpose of this observation is to observe the interaction and communication during the consultation and teaching sessions between you and the patients. The researcher will only observe the situation and the interaction between you and the patients. She will not interrupt any treatment or activities that are being carried out during the consultation sessions. You may interrupt or stop the observation at any time if you feel uncomfortable,

The duration of this study will take about 7 to 8 months. However, your participation in the study will be once or twice depending on your choice either to participate just in the interview or both the interview and the observation.

What are the possible risk/benefits of taking part?

There will be no direct benefit to you from taking part in this study. However, by taking part in this study, you will provide us with the information on how type 2 diabetes patients are being managed and supported in improving their ability to manage their conditions. By having this information, it will help us to understand the needs of the type 2 diabetes patients and how we can support them in self-managed their conditions. The finding of this study will improve practices and enhance the

quality of care in the management of patients with type 2 diabetes by providing the assistance and support depending on the patients' needs.

There will be no physical risks involve if you participate in this study. However, this research may activate your negative emotions. It is possible that you may have some unpleasant experiences in managing diabetic patients. If you feel uncomfortable with any of the questions being asked during the interview or the observation, you are free not to answer those questions. If you have any concerns regarding the information which has been provided, please feel free to contact the researcher to discuss about it.

Will my part in the study be kept confidential?

Yes, your identity will remain strictly confidential. All information recorded during the interviews and the observations will be handled in the strictest confidence. The consent form and the written information containing your personal details will be stored in a locked cabinet in the researcher's office at the University of Manchester. The laptop and devices used to store the data will be encrypted and password protected. Only the researcher will have accessed to the identifiable information and the entire interview transcripts will be anonymized. No names will appear in any reports that are generated from this study. Results from this study will be in the form of anonymized quotes. Your permission will be asked for the use of these quotes as part of the report of this study. All your personal details will be destroyed once the study is completed or when they are no longer required according to the Manchester University's guidelines. No personal information will be traced back for any reason.

Is this research being conducted as part of an educational project?

Yes. This study is being conducted as part of a PhD programme that is being carried out at the University of Manchester by Sanisah Saidi. The supervisors of this research work are:

Dr.. Jane Griffiths
Senior Lecturer
School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
UK
E-mail: jane.griffiths@manchester.ac.uk

Dr. Linda Milnes
Lecturer
School of Nursing, Midwifery and Social Work

University of Manchester
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
UK
Email: linda.milnes@manchester.ac.uk

What if there is problem?

If you experience any distress or uneasy feelings due to the interview or the observation, you are free to withdraw from the study at any time. If you have any concerns about any aspect of this study, you should speak to me as the primary researcher. I will try my best to provide the information or answer any questions. My contact details are as follow:

Sanisah Saidi
PhD student
School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
UK
E-mail: sanisah.saidi@postgrad.manchester.ac.uk
Tel: 07857528593

Address in Malaysia:
Sanisah Saidi
D-3A-4 Tasek Height Apartment
Jalan Liku 21/146
Bandar Tasek Selatan
57000 Sungai Besi
Kuala Lumpur
Tel: 017 3548353

However, if you still need further explanation or you want to complain, you can contact my supervisors at the address stated above. If you are still not satisfied, you can contact the Head of Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.

Who has reviewed the study?

Prior to this study being conducted, it has been reviewed by the University of Manchester Ethics Committee and Malaysia National Medical Research Register who has given approval for this study to be conducted.

What do I do now?

If you decide to take part in this study, please fill in the reply slip below and return it using the enclosed envelope.

REPLY SLIP	
Name: _____	
I am a (please tick	
<input type="checkbox"/> Doctor	<input type="checkbox"/> Dietician
<input type="checkbox"/> Nurse	<input type="checkbox"/> Pharmacist
I would like to participate in (please tick)	
<input type="checkbox"/> Both interview and observation	

OR you can contact me by phone or at the email address stated above. You can also approach me at the clinic if you would like to discuss the study. Once you have agreed to take part, I will confirm with you the date, the time and the place of the interview.. If you would like to take part in the observation only, I will meet you at the clinic. Prior to the start of the interview or the observation, I will need to ask you to sign the attached consent form.

Appendix 11 – Consent form for HCPs

An exploration of self-care practice and self-care support of patients with type 2 diabetes in Malaysia.

CONSENT FORM

If you are happy to participate in this study, please complete and sign the consent form below.

Box	Please	Initial
1. I confirm that I have read the attached information sheet on the above project		<input type="checkbox"/>
and have had the opportunity to consider the information and ask questions		
and have had these answered satisfactorily.		<input type="checkbox"/>
2. I understand that my participation in the study is voluntary and that		<input type="checkbox"/>
I am free to withdraw at any time without giving any reason and without		
detriment to any treatment/service		<input type="checkbox"/>
3. I understand that the interviews will be audio-recorded.		<input type="checkbox"/>
4. I agree to the use of anonymous quotes.		<input type="checkbox"/>
5. I agree that any data collected will only be viewed by the		<input type="checkbox"/>
researcher and the two supervisors.		<input type="checkbox"/>
6. I agree to take part in the interview and the observational activities.		<input type="checkbox"/>
7. I agree to take part in the interview only.		<input type="checkbox"/>
8. I agree to take part in the observation only.		<input type="checkbox"/>

I agree to take part in the above project.

.....
Name of participant	Signature	Date

.....
Name of person taking consent	Signature	Date

Appendix 12 - Poster advertising the study

UNDERSTANDING HOW PATIENTS WITH TYPE 2 DIABETES TAKE CARE OF THEMSELVES AND HOW THEY BEEN HELPED BY HEALTHCARE PROFESSIONALS IN MANAGING THEIR DIABETES

I AM A RESEARCH STUDENT IN THE UNIVERSITY OF MANCHESTER. I AM CONDUCTING A STUDY EXPLORING HOW DIABETES PATIENTS IN MALAYSIA TAKE CARE OF THEMSELVES AND MANAGE THEIR DIABETES.

IF YOU ARE:

- 18 YEARS AND ABOVE
- DIAGNOSED AS TYPE 2 DIABETES
- ABLE TO COMMUNICATE IN MALAY OR ENGLISH

YOU ARE ELIGIBLE TO PARTICIPATE IN THIS STUDY!



INTERESTED?

KINDLY CONTACT ME: SANISAH SAIDI (THE RESEARCHER)

PHONE NUMBER: 017 3548353

E-MAIL ADDRESS: sanisahsaidi@postgrad.manchester.ac.uk

Appendix 13 – Invitation letter to patients

Project title: An exploration of self-care practice and self-care support of patients with type 2 diabetes in Malaysia

INVITATION LETTER (English)

Dear Dr./ Sir/Madam,

My name is Sanisah Saidi and I am a research student at the School of Nursing, Midwifery and Social Work, University of Manchester.

I would like to invite you to take part in my research project as stated above. This study is funded by the Ministry of Higher Education Malaysia. The purpose of this research is to understand the self-care practice of patients with type 2 diabetes and how you as a healthcare professional manage the patients and support them in their self-care practice.

Before you decide to take part, you need to understand why this research is being done and what will be involved if you take part in this research project. Please take time to read the information carefully. Talk to others about the study if you wish.

You can contact me using the telephone number or email address on the information sheet enclosed if there is anything that is not clear about the research or if you like more information. Alternatively, if you want to talk to me personally about the study, I will be in the clinic during working hours.

Thank you.

Yours faithfully,

Sanisah Saidi
Research student
School of Nursing, Midwifery and Social Work
University of Manchester
United Kingdom

Tajuk kajian: Memahami bagaimana pesakit diabetes (jenis ke-2) menguruskan penyakit mereka dan bagaimana mereka dibantu oleh kakitangan kesihatan dalam pengurusan diabetes.

SURAT JEMPUTAN (Malay)

Tuan/Puan,

Nama saya Sanisah Saidi dan saya adalah, penyelidik daripada School of Nursing, Midwifery and Social Works, University of Manchester.

Tujuan saya menulis surat ini adalah untuk menjemput tuan/puan untuk mengambil bahagian di dalam projek penyelidikan saya seperti tajuk di atas. Tujuan kajian ini dijalankan adalah untuk memahami pengalaman tuan/puan dalam menguruskan diri sendiri sebagai pesakit diabetes.

Walaupun, sebelum tuan/puan melibatkan diri dalam kajian ini, tuan/puan perlu memahami kenapa kajian ini dijalankan dan bagaimana tuan/puan akan terlibat dalam kajian ini sekiranya mengambil bahagian. Sila ambil masa yang secukupnya untuk membaca borang maklumat kajian dengan teliti. Tuan/puan juga digalakkan untuk berbincang tentang penglibatan tuan/puan dalam kajian ini dengan ahli keluarga sekiranya perlu.

Jika terdapat sebarang kemusykilan atau tuan/puan memerlukan lebih maklumat, tuan/puan boleh menghubungi saya melalui nombor telefon atau alamat e-mail yang tertera dalam borang maklumat kajian ini.

Jika tuan/puan bersetuju untuk mengambil bahagian dalam kajian ini, tuan/puan boleh mengisi borang jawapan yang tertera di dalam borang maklumat kajian ini dan mengembalikan kepada saya menggunakan sampul surat yang dikepilkan. Selain itu, tuan/puan boleh juga menghubungi saya menggunakan nombor telefon tertera.

Adalah sangat diharapkan agar tuan/puan dapat mempertimbangkan penyertaan dalam kajian ini agar kualiti penjagaan dan sokongan terhadap pesakit diabetes di negara ini dapat ditingkatkan. Persetujuan tuan/puan untuk menyertai kajian ini saya dahulukan dengan ucapan terima kasih.

Sekian.

Yang Benar,

Sanisah Saidi,
Penyelidik,
School of Nursing, Midwifery and Social Works,
University of Manchester, United Kingdom.

Appendix 14 – Participant information sheet to patients**ENGLISH VERSION****UNDERSTANDING HOW PATIENTS WITH TYPE 2 DIABETES TAKING
CARE OF THEMSELVES AND HOW THEY ARE HELPED
TO MANAGE THEIR DIABETES BY HEALTHCARE
PROFESSIONALS**

Sir/Madam,

As a diabetic patient, you may be expected by your nurses and doctors to take care of yourself at home and maintain your health status. We are interested to understand how you are taking care of yourself and how you are being helped by your doctors and nurses in doing so. Therefore, we would like to invite you to take part in this study.

Before you make the decision to take part, we would like you to understand why this research is being conducted and how you will be involved in this study. This information sheet will explain more about the study. If you like, you could discuss this study with your families and friends

THANK YOU FOR READING THIS INFORMATION

Why are we conducting this study?

According to the statistic in Malaysia, there was a steep increase in the type 2 diabetes incidence in the last 10 years. This phenomenon has been connected to the ineffectiveness of the diabetic management and the lack of abilities amongst the type 2 diabetic patients in self-managing their conditions in Malaysia. However, patients' experiences in self-managing type 2 diabetes and the factors that influenced their ability in managing their diabetes were not clearly understood. In addition, whether the support which was provided by the healthcare professionals had met the needs of the patients in self-managing their diabetes was not known. Therefore, the purpose of this study is to explore how patients with type 2 diabetes in Malaysia are taking care of themselves and how they are being helped to manage their diabetes by the healthcare professionals including doctors, nurses, dieticians and pharmacists.



Why I have been invited?

You have been invited to participate in this study because you are a type 2 diabetic patient receiving treatment at the Kuala Lumpur Hospital's Diabetes Outpatient Clinic and Putrajaya Health Clinic. Both of these clinics have agreed to take part in this study. We are expecting to include between 15 to 20 patients at these clinics to participate in this study. We would like to understand your experience of managing your conditions in your daily life. In addition, we would like to learn more about your opinions in terms of the help and support which have been provided by the healthcare professionals at this clinic in managing your type 2 diabetes.

Do I have to take part?

No. Participation in this study is entirely voluntary. If you do not wish to take part, it will not affect your treatment or care in any way. Also, if you agree to take part, you have the right to withdraw from this study at any time without giving any reason and without detriment to your present or future care.

What will happen to me if I take part?

If you decided to take part, we will ask you to sign a consent form indicating that you agree to be a part of this study. This study will involve two activities which are an interview and an observation of one of your consultation appointments with your healthcare professionals. You may choose to participate in both of the activities or be involved in either one of them.

a) Interview

The researcher will conduct an interview with you in your home or at other location of your choice. The interview will be audio-recorded and will take between one hour and one-and-a-half hours to complete. You will be asked to describe your experience and perceptions of being a type 2 diabetic patient and managing your illness yourself. In addition, the researcher will ask you to describe your perceptions regarding the support you received from the healthcare staff you come in to contact with. The researcher will have a list of questions to guide you during this interview, but you are free to add any other information that you feel is important to you. If you feel uncomfortable and need to interrupt or stop the interview, you are able to do so at any time.



b) Observation

The researcher also will carry out an observation during one of your usual clinic visits. The purpose is to observe the interaction between you and the healthcare professionals during the clinic session. This observation will only be carried out during your usual appointment and it will not interrupt any treatment or care that will be provided to you. You may interrupt or stop the observation at any time if you feel uncomfortable.

The whole study will last about 7 to 8 months in total. However, you will need to meet the researcher only once or twice, which will be during the interview and/or the clinic observation depending on your choice.

Will my part in the study be kept confidential?

Yes, your identity will remain strictly confidential. All information recorded during the interviews and the observations will be handled in the strictest confidence. The consent form and the written information containing your personal details will be stored in a locked cabinet in the researcher's office at the University of Manchester.. The laptop and devices used to store the data will be encrypted and password protected. Only the researcher will have accessed to the identifiable information and the entire interview transcripts will be anonymized. No names will appear in any reports that are generated from this study. Results from this study will be in the form of anonymized quotes. Your permission will be asked for the use of these quotes as part of the report of this study. All your personal details will be destroyed once the study is completed or when they are no longer required according to the Manchester University's guidelines. No personal information will be traced back for any reason.



What are the possible risk/benefits of taking part?

There will be no direct benefit to you from taking part in this study. However, by taking part, you will provide us with the information on the experience of patients with type 2 diabetes in Malaysia managing their illness in their daily life. The information that you provide will help us and the healthcare professionals to understand the difficulties that type 2 diabetic patients may have in looking after their conditions. In addition, your participation will give us the information which enable us to identify ways the healthcare professionals could provide in meeting the needs of the type 2 diabetes patients in helping them to manage their own conditions. Apart from that, we will be informed of the type 2 diabetic patients' opinions regarding whether the support given by the healthcare professionals met the needs of type 2 diabetic patients in managing their conditions...The finding of this study hopefully will improve practices and enhance the quality of care in the management of patients with type 2 diabetes by providing the assistance and support depending on the patients' needs..

There will be no physical risks to you if you participate in this study. However, this research may activate your negative emotions. It is possible that you may have some unpleasant experiences as a diabetic patient. If you feel uncomfortable with any of the questions being asked during the interview or the observation, you are free not to answer those questions. If you do feel upset at any stage, feel free to talk to the researcher or the researcher may get a counselling support for you if appropriate. If you have any question regarding your disease or conditions, the researcher will provide general information. You will be referred to your healthcare professional if necessary.

Is this research being completed as part of an educational project?

Yes, this study is being completed as part of a PhD programme that is being carried out at the University of Manchester by Sanisah Saidi. The supervisors are;

Dr. Jane Griffiths
Senior Lecturer
School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
UK
E-mail: jane.griffiths@manchester.ac.uk
Dr. Linda Milnes
Lecturer
School of Nursing, Midwifery and Social Work

University of Manchester
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
UK
Email: linda.milnes@manchester.ac.uk

What if there is problem?

If you experience any distress or uneasy feelings due to the interview or observation, you are free to withdraw from the study at any time. If you have any concerns regarding any aspect of this study, you should speak to me as the primary researcher. I will try my best to provide the information that you may require or answer any questions. My contact details are as follow:

Sanisah Saidi
PhD student
School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
UK
E-mail: sanisah.saidi@postgrad.manchester.ac.uk
Tel: 07857528593

Address in Malaysia:
Sanisah Saidi
D-3A-4 Tasek Height Apartment
Jalan Liku 21/146
Bandar Tasek Selatan
57000 Sungai Besi
Kuala Lumpur

Tel: 017 3548353

However, if you still need further explanations or you want to complain, you can contact my supervisors at the address stated above. If you are still not satisfied, you can contact the Head of Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.

OR

National Medical Research Malaysia,
(NIH Secretariat, Ministry of Health Malaysia),
c/o Institute for Health Management,
Jalan Rumah Sakit, Bangsar, 50900 Kuala Lumpur.
Phone: 03 - 2287 4032 Fax: 03 - 2287 4030
Email: URL: <http://www.nih.gov.my>

Who has reviewed the study?

Prior to this study being conducted, it has been reviewed by the Committee on The Ethics of Research on Human Beings, University of Manchester Ethics Committee and Malaysia Medical Research Ethics Committee (MREC).

What do I do now?

If you decided to take part in this study, please fill in the reply slip below and send it using the envelope provided.

OR you can contact me (the researcher) by phone or at the email address stated above. I will discuss the date, time and place for the interview with you. If you would like to take part in the observation only, just let me know the date of your appointment and I will meet you at the clinic. Prior to the start of the interview or observation, I will need to ask you to sign the attached informed consent form. Your participation in this study is highly appreciated.

THANK YOU

MALAY VERSION

Tajuk kajian: Memahami bagaimana pesakit diabetes (jenis ke-2) menguruskan penyakit mereka dan bagaimana mereka dibantu oleh kakitangan kesihatan dalam pengurusan diabetes.

Borang maklumat kajian (pesakit)



Tuan/Puan,

Sebagai pesakit diabetes anda tentunya disarankan oleh doktor dan jururawat agar menguruskan dan mengawal penyakit anda di rumah bagi mengekalkan tahap kesihatan anda. Kami berminat untuk memahami bagaimana anda menguruskan penyakit anda dan bagaimana anda dibantu oleh kakitangan kesihatan dalam perkara ini. Oleh itu kami ingin menjemput anda untuk melibatkan diri dalam kajian ini.

Sebelum anda membuat keputusan untuk menyertai kajian ini, kami ingin anda mengetahui tujuan kajian ini dijalankan dan skop penglibatan anda dalam kajian ini. Borang maklumat kajian ini mengandungi penerangan lanjut berkaitan kajian ini. Anda digalakkan untuk membincangkan penglibatan anda dalam kajian ini dengan ahli keluarga atau rakan-rakan sekiranya perlu.

TERIMA KASIH KERANA MEMBACA

BORANG MAKLUMAT INI.

Kenapa kajian ini dijalankan?

Menurut statistik di Malaysia, insiden penyakit diabetes jenis kedua telah meningkat dengan pantas semenjak 10 tahun kebelakangan ini. Keadaan ini telah dikaitkan dengan kurang keberkesanan dalam pengurusan penyakit dan kekurangan keupayaan pesakit untuk menguruskan sendiri penyakit mereka. Walaubagaimanapun, pengalaman pesakit berkenaan dengan pengurusan sendiri diabetes jenis ke-2 dan faktor-faktor yang mempengaruhi keupayaan mereka menguruskan penyakit ini tidak diketahui dengan jelas. Selain itu, sama ada bantuan dan sokongan yang diberikan oleh kakitangan kesihatan menepati kehendak pesakit dalam menguruskan sendiri diabetes jenis ke-2 adalah tidak diketahui. Oleh kerana itu, tujuan kajian ini adalah untuk meneroka bagaimana pesakit diabetes (jenis ke-2) di Malaysia menguruskan sendiri penyakit mereka dan bagaimana mereka dibantu oleh kakitangan kesihatan dalam menguruskan sendiri penyakit diabetes jenis ke - 2.

Kenapa saya dipelawa untuk melibatkan diri?

Anda dipelawa untuk melibatkan diri dalam kajian ini kerana anda adalah pesakit diabetes (jenis ke-2) yang menerima rawatan di klinik pesakit luar diabetes Hospital Kuala Lumpur dan Klinik Kesihatan Putrajaya. Klinik pesakit luar diabetes Hospital Kuala Lumpur dan Klinik Kesihatan Putrajaya telah memberi persetujuan untuk menjalankan kajian ini. Kami menganggarkan untuk melibatkan antara 15 ke 20 orang pesakit di klinik ini. Kami ingin memahami pengalaman anda menguruskan diri sebagai pesakit diabetes di dalam kehidupan harian anda. Selain dari itu, kami juga ingin mengetahui dengan lebih lanjut pendapat anda tentang bantuan dan sokongan yang telah diberikan oleh kakitangan kesihatan di klinik ini dalam membantu anda menguruskan penyakit diabete jenis ke -2.

Apakah pilihan saya? Adakah wajib saya mengambil bahagian?

Jawapannya adalah tidak. Penglibatan anda didalam kajian ini adalah secara sukarela dan adalah diatas kehendak sendiri. Jika anda tidak bersetuju untuk menyertai kajian ini, ianya tidak akan menjejaskan apa sahaja rawatan yang anda terima. Jika anda bersetuju untuk menyertai kajian ini, anda juga boleh menarik diri pada bila-bila masa tanpa memberi sebarang alasan dan anda juga berhak mengambil balik data yang telah diberikan.

Apakah yang akan berlaku sekiranya saya terlibat dalam kajian ini?

Jika anda bersetuju untuk menyertai kajian ini, kami akan meminta anda memberi kebenaran bertulis menandakan persetujuan anda untuk melibatkan diri didalam kajian ini. Kajian ini melibatkan dua aktiviti iaitu temubual individu dan pemerhatian semasa proses temujanji anda dengan doktor, jururawat, pegawai pemakanan atau pegawai farmasi. Anda boleh memilih untuk mengambil bahagian didalam kedua-dua aktiviti ataupun salah satu daripada aktiviti tersebut.

Temubual perseorangan

Saya (penyelidik) akan menemubual anda di rumah anda atau di lokasi lain mengikut pilihan anda. Semasa temubual dijalankan, suara anda akan dirakamkan dan ianya akan mengambil masa sekitar satu jam sehingga satu jam setengah. Anda akan diminta untuk menerangkan dengan mendalam pengalaman anda sebagai pesakit diabetes dan pengalaman anda menguruskan sendiri penyakit anda. Penyelidik juga akan meminta pendapat anda tentang bantuan dan sokongan yang telah diberikan oleh kakitangan kesihatan yang merawat anda dalam membantu anda menguruskan diabetes di rumah. Penyelidik akan menggunakan senarai soalan untuk menemubual anda. Walaubagaimanapun, anda amatlah digalakkan untuk memberi apa-apa sahaja maklumat yang anda rasakan perlu berkaitan kajian ini. Jika anda merasa kurang selesa semasa temubual dijalankan anda boleh meminta agar temubual diberhentikan pada bila-bila masa sahaja



Pemerhatian di klinik

Penyelidik juga akan menjalankan pemerhatian dimasa salah satu hari temujanji anda di klinik. Tujuan pemerhatian ini dijalankan adalah untuk memerhati proses interaksi dan komunikasi di antara anda dengan kakitangan kesihatan semasa temujanji. Pemerhatian ini hanya akan dijalankan semasa temujanji biasa anda di klinik dan ianya tidak akan mengganggu apa-apa rawatan yang akan diberikan kepada anda. Jika anda merasa kurang selesa semasa pemerhatian dijalankan, anda boleh meminta agar pemerhatian dihentikan pada bila-bila masa sahaja.

Keseluruhan kajian ini akan mengambil masa selama lebih kurang 7 hingga-8 bulan. Walaubagaimanapun, anda hanya perlu bertemu penyelidik sekali atau dua kali sahaja iaitu semasa temubual individu ataupun semasa pemerhatian dijalankan di klinik ataupun dimasa kedua-duanya dijalankan mengikut pilihan anda.

Apakah faedah dan risiko jika anda menyertai kajian ini?

Kajian ini berkemungkinan besar tidak akan memberikan faedah secara langsung kepada anda. Walaubagaimanapun, dengan menyertai kajian ini, anda akan dapat membantu kami untuk memahami secara lebih mendalam pengalaman pesakit diabetes jenis ke-2 di Malaysia, dari segi bagaimana mereka menguruskan diri sendiri sebagai pesakit diabetes di dalam kehidupan harian mereka. Selain dari itu, ianya akan dapat memberi maklumat kepada kami untuk mengenalpasti bagaimanakah cara kakitangan kesihatan profesional dapat memenuhi kehendak pesakit diabetes jenis ke-2 dalam membantu mereka menguruskan penyakit mereka. Kami juga akan mengetahui pendapat para pesakit diabetes jenis ke 2 berkenaan dengan khidmat sokongan dan bantuan yang diberikan oleh kakitangan kesihatan professional samaada menepati keperluan mereka dalam menguruskan penyakit mereka. Hasil penemuan kajian ini diharapkan agar dapat membantu memperbaiki kualiti rawatan dan jagarawatan yang diberikan oleh kakitangan kesihatan professional dalam pengurusan penyakit diabetes jenis ke-2.

Kajian ini tidak mendatangkan sebarang risiko fizikal kepada sesiapa yang terlibat. Walaupun begitu, kajian ini boleh menimbulkan perasaan kurang senang didalam diri pesakit yang terlibat. Anda berkemungkinan pernah menghadapi pengalaman pahit sebagai pesakit diabetes. Jika anda merasa kurang selesa dengan soalan yang diajukan oleh penyelidik semasa temubual atau pemerhatian, anda bebas untuk tidak menjawab soalan tersebut. Jika anda mempunyai persoalan tentang penyakit anda, penyelidik akan memberi penerangan secara umum. Jika perlu, anda akan dirujuk kepada kakitangan kesihatan yang merawat anda.

Adakah penglibatan saya dalam kajian ini akan dirahsiakan

Ya, penglibatan dan identiti anda akan dirahsiakan. Semua maklumat yang diperolehi semasa temubual dan pemerhatian adalah sulit dan privasi anda akan dilindungi. Surat kebenaran kajian atau apa-apa sahaja maklumat bertulis yang mengandungi butiran peribadi anda akan disimpan di dalam almari berkunci di pejabat penyelidik di University of Manchester. Komputer dan peralatan yang digunakan untuk menyimpan data secara elektronik akan dilindungi dengan kata laluan. Hanya penyelidik sahaja yang mempunyai akses ke atas maklumat yang diperolehi. Semua transkrip temubual dan catatan akan dikenalpasti menggunakan nombor atau nama samaran. Hasil daripada kajian ini akan dilaporkan dalam bentuk petikan daripada temubual atau pemerhatian tanpa nama. Penyelidik akan memohon persetujuan anda sekiranya pihak penyelidik mahu menggunakan petikan –petikan yang diperolehi semasa temubual sebagai sebahagian daripada laporan hasil kajian. Segala maklumat peribadi anda akan dimusnahkan sekiranya ia tidak diperlukan lagi atau sebaik sahaja kajian ini selesai mengikut garis panduan yang telah ditetapkan oleh University of Manchester, United Kingdom. Maklumat peribadi anda tidak akan dikesan semula walau atas apa sebab sekalipun.



Adakah kajian ini sebahagian daripada projek pembelajaran?

Ya. Kajian ini merupakan salah satu syarat wajib untuk memperolehi kelulusan pengajian Doktor Falsafah dalam bidang kejururawatan di University of Manchester, United Kingdom. Sepanjang kajian ini Puan Sanisah Saidi akan diselia oleh Dr Jane Griffiths, pensyarah kanan dan Dr Linda Milnes, pensyarah dari Jabatan

Kejururawatan University of Manchester. Mereka boleh dihubungi melalui alamat dibawah;

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Bagaimana jika timbul masalah?

Jika anda merasa tidak selesa disebabkan oleh temubual atau pemerhatian yang dijalankan, anda boleh menarik diri daripada kajian ini pada bila-bila masapun. Jika anda ingin berbincang dengan lebih lanjut tentang kajian ini, anda boleh menghubungi saya (penyelidik). Saya akan cuba sedaya upaya untuk memberi penerangan yang jelas dan menjawab apa sahaja persoalan anda berkaitan kajian ini. Anda boleh menghubungi saya melalui maklumat di bawah;

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Walaupun bagaimanapun, jika anda masih memerlukan penerangan lanjut atau anda ingin membuat aduan, anda boleh menghubungi penyelia kajian ini di alamat seperti yang dinyatakan di atas. Selain itu, anda juga boleh menghubungi badan-badan berkenaan menggunakan alamat yang tertera di bawah sekiranya anda masih memerlukan penjelasan tentang kajian ini.

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Siapa yang telah meluluskan kajian ini?

Kajian ini telah diluluskan oleh Committee on The Ethics of Research on Human Beings (Jawatankuasa Etika Penyelidikan Berkaitan Manusia) University of Manchester (No rujukan: 12238) dan Jawatankuasa Etika Penyelidikan Perubatan Malaysia (MREC).

Apa yang perlu dilakukan untuk menyertai kajian ini?

Jika anda berminat untuk menyertai kajian ini, sila isi borang jawapan dan kembalikan kepada penyelidik menggunakan sampul surat yang telah disertakan.

ATAU

anda boleh menghubungi penyelidik melalui telefon/sms atau e-mail melalui nombor dan alamat yang tertera di atas. Anda juga boleh berjumpa terus dengan penyelidik di klinik jika anda memerlukan penerangan yang lebih lanjut berkaitan kajian ini. Penyelidik akan berada di klinik semasa waktu pejabat pada hari temujanji pesakit diabetes di Klinik Pesakit Luar Hospital Kuala Lumpur dan Klinik Kesihatan Putrajaya. Setelah mendapat persetujuan

daripada anda, penyelidik akan menghubungi anda untuk membincangkan tarikh, tempat dan masa untuk temubual. Jika anda ingin mengambil bahagian dalam pemerhatian di klinik, ianya akan dijalankan semasa temujanji anda yang akan datang. Penyelidik akan berjumpa anda di klinik. Sebelum temubual atau pemerhatian dijalankan, anda akan diminta untuk menandatangani borang kebenaran seperti yang dilampirkan.

TERIMA KASIH KERANA BERMINAT DENGAN KAJIAN INI.

Appendix 15 – Reply slip to patients

ENGLISH VERSION

REPLY SLIP

Name: _____

I am a patient at (please tick)

Hospital Kuala Lumpur

Putrajaya Health Clinic

I would like to participate in (please tick)

Both interview and observation

Interview only

Observation only

I don't want to participate

My appointment date: _____

MALAY VERSION**BORANG JAWAPAN**

Nama : _____

Saya adalah pesakit di (sila tandakan x)

Hospital Kuala Lumpur

Klinik Kesihatan Putrajaya

Saya ingin mengambil bahagian dalam (sila tandakan x)

Temubual dan pemerhatian

Temubual sahaja

Pemerhatian sahaja

Saya tidak berminat untuk mengambil bahagian

Tarikh temujanji saya: _____

Appendix 16 – Consent form for patients

ENGLISH VERSION

An exploration of self-care practice and self-care support of patients with type 2 diabetes in Malaysia.

CONSENT FORM

If you are happy to participate in this study, please complete and sign the consent form below.

Please Initial Box

- | | |
|---|--|
| 1. I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily. | |
| 2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving any reason and without detriment to any treatment/service | |
| 3. I understand that the interviews will be audio-recorded. | |
| 4. I agree to the use of anonymous quotes. | |
| 5. I agree that any data collected will only be viewed by the researcher and the two supervisors. | |
| 6. I agree to take part in the interview and the observational activities. | |
| 7. I agree to take part in the interview only. | |
| 8. I agree to take part in the observation only. | |
| I agree to take part in the above project. | |

Name of participant	Signature	Date
Name of person taking consent	Signature	Date

MALAY VERSION

Tajuk kajian: Memahami bagaimana pesakit diabetes (jenis ke-2) menguruskan penyakit mereka dan bagaimana mereka dibantu oleh kakitangan kesihatan dalam pengurusan diabetes.

Borang Persetujuan

Jika anda bersetuju untuk melibatkan diri dengan kajian ini, sila tandakan (x) di dalam kotak yang berkaitan dan tandatangan borang persetujuan ini.

- | | |
|---|--------------------------|
| 1. Saya mengesahkan bahawa saya telah membaca dengan teliti borang kajian dan telah diberi masa yang cukup untuk mempertimbangkan penglibatan saya dalam kajian ini. | <input type="checkbox"/> |
| 2. Saya mengesahkan bahawa penglibatan saya dalam kajian ini adalah secara sukarela dan saya faham bahawa saya bebas untuk menarik diri daripada kajian ini pada bila-bila masa tanpa memberi sebarang alasan dan ianya tidak akan menjejaskan rawatan/perkhidmatan saya. | <input type="checkbox"/> |
| 3. Saya mengesahkan bahawa saya bersetuju untuk memberi kebenaran kepada penyelidik untuk mengakses maklumat perubatan saya. | <input type="checkbox"/> |
| 3. Saya faham bahawa suara saya akan dirakam semasa temubual dijalankan. | <input type="checkbox"/> |
| 4. Saya bersetuju dengan penggunaan petikan tanpa nama yang akan digunakan sebagai hasil penemuan kajian ini. | <input type="checkbox"/> |
| 5. Saya faham bawa maklumat yang saya berikan hanya akan dilihat/dibaca oleh penyelidik dan dua orang penyelia beliau. | <input type="checkbox"/> |
| 6. I bersetuju untuk mengambil bahagian dalam sesi temubual dan pemerhatian di klinik. | <input type="checkbox"/> |
| 7. Saya bersetuju untuk terlibat dalam sesi temubual sahaja. | <input type="checkbox"/> |
| 8. Saya bersetuju untuk mengambil bahagian dalam sesi pemerhatian di klinik sahaja. | <input type="checkbox"/> |

Saya bersetuju untuk mengambil bahagian dalam kajian ini.

..... Nama peserta kajian Tandatangan Tarikh
..... Nama penyelidik Tandatangan Tarikh

Appendix 17 – Topic guide for interview with HCPs

Research questions:

1. What is the self-care practice of patients with type 2 diabetes in Malaysia?
2. What are the factors influenced self-care practice of patients with type 2 diabetes in Malaysia?
3. How is the self-care practice of patients with type 2 diabetes in Malaysia being supported in primary and secondary care?

Interview topic (healthcare professionals)

a) Nurses/diabetic educators/dietician

- Ask the healthcare providers about their experience in managing the patients with type 2 diabetes (duration of working experience, how they involved in managing these patients) i.e. how frequent they see the patients.
- Ask the healthcare providers to explain about the support/facilities provided in the clinic in helping the patients to self-manage their diabetes.
- Ask about the mechanism used in monitoring the health progress of the patients and supporting them in their self-care issues.
- Ask their opinion on the effectiveness of the service provided (particularly in helping the patients to self-manage their diabetes).
- Ask about their perception of their role in supporting the patients in the clinic. Do they satisfy with their current practice.

b) Physician

- Ask the physician on their approach in helping the patients to self-manage their diabetes.
- Ask about their opinion on the self-care practice of the patients in the clinic. What are the barriers/influential factors.

- Ask their opinion of the current practice in the clinic particularly in supporting self-care or the patients - ask their opinion on the effectiveness of the practice, suggestion in improving practice/ obstacles in achieving better quality of care.

c) Head of department/ clinic manager

- Ask the managers on how the clinic being managed (flow of the management process).
- Facilities or service available pertinent to self-care support provision of type diabetes.
- Ask on the involvement of Ministry of Health particularly on self-care support provision of type 2 diabetes (budget allocation, policies/guidelines, and resources).

Appendix 18 – Topic guide for interview with patients

Interview topic (patients)

1. Exploring patients' experience with type 2 diabetes and their understanding on the concept of self-care.
 - Ask the patients about their experience when first diagnosed as type 2 diabetes. How was the experience?
 - The treatment that they received - How they were told about the medication/glucose controlling device/insulin injection device.
 - How the patients live with type 2 diabetes.
 - How they been explained about changing their lifestyle and self-manage their diabetes.
 - How they accepted it and how they change their lifestyle
 - How it affect them (physically and psychologically) .

2. Integrating self-care in to daily routine/activities.
 - Ask the patients about their experience in managing their diabetes while carrying out other daily routine (How they integrate the diabetes management in their daily life routine).
 - Ask the patients to explain the activities that they do in one day (i.e. routine in workplace - how they managed their diet or medication intake).
 - The support that received by the patients at home or working place (do they family or working colleagues understand their condition and supported them in managing their diabetes) and how.
 - Ask about their opinion or perspectives in changing lifestyle and integrating the management of diabetes in their daily routine.

3. Factors influenced self-care.
 - Ask about the motivational factors that help them in managing their diabetes and following the recommendation from healthcare providers.

- Ask about the difficulties/barriers that they experienced in managing diabetes and changing their lifestyle.
- Ask about their cultural or religion practice i.e. in diet, activities, norms etc. What are their opinion about the influence of these factors on their management of diabetes.

4. Support from healthcare providers.

- Ask the patients to explain their routine activities during clinic appointments.
- Ask the patients how long they usually see the doctor during the appointments.
- Ask the patients to explain how the being told about their diabetes and how to manage it - do they attend any educational programme / personal counselling with the healthcare providers.
- Ask about their access to the healthcare system out of appointment date i.e. receive any phone call or home visits from healthcare providers.
- Do they have any experience in needing treatment out of appointment date. How they access the healthcare system.
- How they discussed their difficulties in self-managing the diabetes with healthcare providers.
- Ask the patients to give opinion on what will help them to manage their diabetes successfully (self-care needs)
- Ask their opinion about the effectiveness of the support that they currently received in helping them to manage their diabetes.

Appendix 19 – Observation schedule

OBSERVATION SCHEDULE

Descriptive observation

Descriptive observation will be carried out based on nine dimensions of social situation (Spradley, 1980).

1. Space: the physical places
2. Actor: the people involved
3. Activity: a set of related acts people do
4. Object: the physical things those are present
5. Act: a single action that people do
6. Event: a set of related activities that people carry out
7. Time: the sequencing that takes place over time
8. Goal: the things people are trying to accomplish
9. Feelings: the emotions felt and expressed

Guiding note:

1. Describe in detail about the clinic
 - layout
 - situation
2. Describe how the clinic is organized
 - routine activities of the clinic
 - the flow of activities how the patients being treated in the clinic
 - number of patients being treated in the clinics at one time
 - who are the actors in the clinic and what are their role in the clinics' activities?
3. Describe in detail about any event that happens in the clinic

- what is happening?
- who is involved?
- how does the event occur? Is there any sequencing?
- which actors participate in which events?
- in what ways do events change relationships among actors?

Focused observation

The observation will be focused on the consultation activities between patients and healthcare professionals.

- places of consultation/health education take place
- who is involved in the consultation/health education
- how the consultation/health education is carried out
- how actors react during the consultation/health education
- interaction / communication style during the consultation/health education

Appendix 20 – Example of patient’s interview transcript and reflexivity account

Interview transcript with Mary (pseudonyms), 58 years old. The interview was carried out in diabetes educator room in outpatient clinic (Case study site 1).

Interviewer (R): Researcher

Interviewee (PT): Mrs Mary – PT 1

R: Good Morning Madam...I am Sanisah, a researcher. I would like to discuss with you on how you look after yourself at home. Before I go further, may I ask, how long you have diabetes?

PT: more than twenty years.

R: How old are you when you been diagnosed as diabetes?

PT: I got pregnant when I was 29 years old...I was craved for coca cola. So I took large amount of coca cola and after that I got diabetes.

R: How much coca cola did you took at that time?

PT: almost three big cartoons. I had drank about two bottles every day.

R: Could you tell me your experience when first time being diagnosed as diabetes. How is your feeling at that time?

PT: I am not really understand about diabetes. So when the doctor told me that I have diabetes...I did not felt anything. I have had a high blood sugar during pregnant and I had itchininess all over the body. Doctor had told that it was the symptoms of diabetes. After I delivered the baby, my skin become very dry and diabetes was solved. I had experienced the same thing during my second pregnancy. My glucose level was high again, my baby was big. I had Caesar. After that, I was not really looked after my diet. After five or ten years, I have been confirmed to have diabetes.

R: After that 10 years, how was your understanding about diabetes?

PT: Still not understand. When I came to hospital, the nurse taught me what to eat, things that I should looked after...but...at that time I was still working so I am not really looked after myself well...until I need to use insulin injection.

R: When did you start your insulin injection?

PT: More than 10 years already.

R: You started with tablet medication and then you have to use insulin injection. After you being asked to take insulin injection, how was your feeling?

PT: Because I am not really understand about diabetes, so I did not felt scare at all..I did not felt anything...I just ate like usual, did not looked after my diet at all.

R: At that time, do you know what insulin is?

PT: Insulin? It is a medication....to reduce my diabetes.

R: When you being asked to inject the insulin, did you followed the schedule as instructed by the doctor?

PT: Not really...so, when the doctor asked me to inject, I just inject...That's all. A nurse taught me how to inject the insulin.

R: How you manage it at home? Do you inject yourself or how?

PT: I did it myself...everybody scared to inject me. Even my husband...so I did it myself.

R: How many time did you need to take the insulin every day?

PT: before this, two injection a day. But now, I need to take three times during day time and one at night.

R: Could you share with me your daily routine when you need to take the insulin injection?

PT: Yes...of course my inner feeling felt tortured...every day I need to inject myself...I don't know until when. According to the doctor, it will be the whole life...so I am really felt worried. But when I used to it, I did not think about it anymore...because I was too busy. I need to look after my children, need to work...so I am not able to think about myself.

R: Madam...could you share your experience in 20 years being a diabetic patient. How was your life?

PT: I guess I was unlucky...I have a husband. He loved me but he did not guide me. He did not help me to look after myself. When I got diabetes, he did not help me to manage. Everything was depend on me...so...I need to manage everything myself; children, household, getting money. My life was hard since I was small... so I used to it. I just faced my fate. I have no time to think about myself. I worked, fetching children from kindergarten and school. I started by sending and fetching my own children, and then my friends asked me to carry their children as well. So, I thought it was a good idea to sending and fetching children from school and I can earn some money. When I started carrying children to and from school, the feedback was very good. From an ordinary car, I changed it to bigger van. From there I had earned some, so don't have to ask from my husband. I also can fulfil whatever my children want. After a while the number of children that used my service was increase. So I add another van. When my husband retired, I had three vans. But, because I had diabetes, my body become weak and my sight also become reduce. My leg hurts and now

doctor told that I have problem with my bone. My leg bone were unstable and I can't walk. I stopped working when I was 53 years old. I started working carrying children to and from school since I was 32 years old. Until I was 53 years old, I had three vans. One was drove by my husband, one drove by friend and I had drove one. But when my sight was become poor, and I did not able to find people to drive, I left with one van. My husband continue the work. But when I was 60 years old, my husband had stroke so we can't earn anything. I gave the van to my son and he used it for work.

R: With whom do you stay now?

PT: now I lived with my son...my husband had passed away last two years after had stroke for two years.

R: when you being diagnosed as diabetes, you still working don't you? Could you explain about the changes that you experienced after you have diabetes at that time? How was the effect of diabetes to you?

PT: As I told before, I did not felt sad or anything. Because there were so many thing that I need to manage. During morning and afternoon I was busy sending and fetching children from school. After that, when I am back, I need to manage my household, manage my children. I usually slept quite late at night because I need to plan and prepare for tomorrow. My children needs and the journey that I need to do from house to house to fetch children early in the morning. There were so many things so did not able to think about diabetes. Every day I just I think how to earn more to support my family.

R: so at that time have you think about your illness?

PT: No...Because I did not heard much about diabetes. So I did not felt scared at all. But now, when I was retired, have more time at home then only I thought and realised that this is diabetes. It makes me to have a lot of illnesses, I felt aches all over the body, my muscle felt tense and now my kidney was not function very well. But I don't to think much..I am afraid that if I think too much, I may think that I want to kill myself. Every day at home I am lonely. From morning until night, I am alone at home. I have two sons. One stayed in Sarawak and another one in Kuala Lumpur. But my son not always spend his time with me. Early in the morning he went out for work and only back at night. If he has free time he will go out with his friend. So I always alone at home. Nobody able to listen to my problem, my feeling. But I just stand it. If I think about my condition now, of course I will felt sad. So I don't want to think much. So I just pray to god, watching television. I have interest in Islamic programme. I learnt a lot from there. I don't want to think much.

R: when you realised and understand more about diabetes, have you try to change your lifestyle. Your diet for example...

PT: It is late to change now. Because I have my illnesses now. Now, I just pray to god just take me fast.

R: May I ask, now how did you look after yourself at home. How is your diet, how did you take your medication?

PT: I just follow whatever doctor asked me to do. I took my medication. But on diet...Because I can't cook...So... whatever I have at home I just eat. I just anything I have at home. To have a food is already a blessed...Because I can't prepare the food myself.

R: How is your life routine now?

PT: For the insulin injection, I will follow the schedule asked by the doctor. But...when it comes to food, it is depends on what I have at home. Sometimes I drink milk, eat oatmeal...depends what is available. Sometimes I eat instant noodle. My diet was not proper at all. If on Saturday or weekend, my son is at home, he will buy food for me...so I just eat whatever he bought. I am not really fussy about food. I just eat whatever we have. Of course I want to eat and manage my diet properly. But nobody can help me. I cannot afford to have maid...how can I eat properly? If exercise, I will help to wash and iron my son's cloth.

Before this, I had fall. My leg was operated for five times, so I can't walk properly. My life was really miserable. Before this I had thought to change. But how I want to change because I am alone at home. Everything I need to do myself. If my son is at home I can ask them to help. I felt a little bit release if my younger son who lived in Sarawak come back home. He helps me a lot. He is now brought me to the hospital. If he accompany to hospital, he will the doctor everything. But my eldest son, he did not care much. I did not have daughter. My mother still alive. My relatives all in Indonesia. I am from Indonesia. My relatives asked me to go back to Indonesia. I thought it will be easier if I go back...I will have somebody who can look after me and I have my siblings. But I am thinking of my children. Unless if they are married, then I can let them go. They are not yet married so I think I am still responsible towards them. Now, I just faced whatever happened every day. I don't want to think much because I can't do anything (she started crying)...paused....

R: (I did not ask question and console her until she felt better)

R: May I ask about your visit to the hospital. How long usually you saw the doctor when you came to the hospital?

PT: (still crying)...now the doctor had reduced my insulin to 8 Units. Before this I took 30 Units. If I took 8 Units only, I don't have to eat... (Crying)...how can I eat? Even if I took 30 Units, my sugar level usually high...if took only 8 Units, what can it helps? I think this is not right...but what can I do? Fine...I just follow whatever doctor said. Before this, I don't have any problem if the doctor asked me to take 28 Units or 30 Units insulin. But now...after that much that I had used now the doctor had reduced it and they want to start from the beginning...what should I do now? I think, I just follow it. Just follow whatever they said.

R: Is there any clinic nearby your house.

PT: if there is...what for? I can't walk...I can't go...

R: all this while, is there any nurses or people from hospital come to your house or call you?

PT: Never...nobody cares. Now you want to teach me the better way to eat and to take the medication. Now, I want to ask you...usually I took 30 Units and now 8 Units...what do you think?

R: how frequent is the injection?

PT: three times a day...before this, 30 Units three time a day. Now 8 Units three time a day.

R: did the doctor change your medication? (I asked her son who just arrived from pharmacy collecting her medication).

PT's son: the medication are same...just the dosage has been reduced.

R: how was her glucose level? Did you do self check at home? Just now I did it was 6.6 mmol/L. usually how was it at home?

PT's son: she did it herself.

PT: if I took 30 Units of insulin, 2 hours after meal, sometimes the reading was 13 mmol/L. I had told the doctor just now. Doctor said that is fine. But if I did not get enough insulin, my glucose level will be high, my sight will be darker. Doctor just said never mind...but how if I am blind? That is what I think now. Even I took 30 Units, my sight getting worse every day, what happened if I only took 8 Units? Usually every morning before breakfast I check the glucose about 6 point something...if I take only 8 Units it will not come down even I did not eat anything. What should I do now?

R: I will ask the nurse who in charge in this to speak to you. Maybe she has her opinion about this.

PT: How can I listen to the nurse if the doctor asked me to inject only 8 Units insulin? What the nurse can do? I have to follow whatever doctor said. Doctor has my 3 months glucose reading (HbA1c)...it was high. Before, it was 7.1 and now it is 7.9 mmol/L. That was during I took 30 Units. Now if I only take 8 Units the reading must be higher...so I don't have to eat! I think that's all nurse...I have not much time...my son want to go for work.

R: okay Madam, thank you very much for participating in this study. I will talk to the nurse about this and will ask the nurse to talk to you later. Thank you very much.

PT: okay then...thank you.

-END OF INTERVIEW-

Field notes of interview (Mary)

Mary was recruited by the diabetes educator in outpatient clinic (case study site 1). I met the patient in the diabetes educator room. She actually just finished her consultation with the doctor in medical specialist clinic and came to outpatient department to buy appliance for SMBG and insulin injection. She was on wheel chair and claimed that she was alone as her son went to pharmacy to collect the medication.

At the beginning of the interview she looked happy and answered the questions attentively with extensive explanation when reflecting on her experience at the beginning as diabetes patient. She reflected her life when she was still productive and how she manage the diabetes while she is still working as school van driver. It seem that, she is a tough lady as she mentioned that, she managed to carry out her routine as a wife, mother and van driver while she having diabetes. However, she did told that, she was unable to manage the diabetes properly as she was very busy with the daily routine and did not have time to think about herself. Furthermore with lack of knowledge she had about diabetes and did not understand about body responses or symptoms of diabetes which she might experience at that time, she thought that diabetes was not that serious. It seem that the role as a mother to look after the family and economic burden that need her to get more money to bear the family expenses had made her difficult in managing the diabetes-most of the time ignored that she had diabetes. This is the usual situation happened when a person who had diabetes or other long-term condition and had responsibility that they need to prioritised. Patient usually put the need of managing the disease as less important and frequently being ignored (whether they are aware or not on the consequences of the disease). I realised that, similar situation happened in many of the patients in this study. It seem that, family support play a major role in helping the patient to manage the diabetes. However, it seem that, many of the patient including Mary did not have good family support as their spouse were also busy with the family responsibility (work, raising up children) had made that the patients need to struggle themselves in managing the diabetes and compensating with the responsibility to the family and life situation (economic burden).

In the middle of the interview, Mary looked disturbed when telling her current experience after she experience complication. She claimed that, her health condition was deteriorated after several years of diagnosis and she unable to continue working.

Her life was become worsen when her husband pass away. It seem that, Mary did not have adequate support from family. Furthermore, lack of support that she received from the healthcare professionals had made her felt frustrated and helpless. It seem that, the problem that faced by Mary in managing her diabetes strongly related to the psychological burden that she had due to her physical condition, lack of support from family member and financial limitation. In addition, Mary seem to have the feeling of uncertainty and frustration with the service provided by the healthcare professionals in the clinic – not being properly explained about decision made by the doctor and lack of opportunity to discuss her life situation with the healthcare professionals - *need to explore further in the next interviews*

Appendix 21 – Example of observation field notes

Observation 2 - 4th March 2013

Contextual information.

The Medical Specialist Clinic, HKL today is same like other day, busy as usual. When I arrived at the clinic, 2 diabetes educators and 2 clerks were working at the registration counter and 2 diabetes educators and 1 hospital aid were working at the appointment counter at the back of the clinic. There were about 80 - 100 people in the clinic at that time. The situation was very busy, noisy and quite congested. I had walked and passed the waiting area to the consultation room. All the seats at the waiting area were fully occupied. When I passed the area I could see the patients (or their relatives) waited for their turn to see the doctors. Some of them looked tense, bored and some of them had killed the time by reading newspaper and chatting. The ambience of the clinic was comfortable with the air-conditioner however, the noise level was high from the people, the announcement voice calling the patients' numbers and the diabetes educators calling the patients' name.

Observation

I was arrived in the clinic at 9 AM and straight away went to the meeting room that usually used as consultation room for diabetes patients. However, there was class running by the specialist to the medical students in that room. I had asked the diabetes educator in the clinic and I was told that the consultation for diabetic patients was moved temporarily moved to the other room because the meeting room was occupied. I went to the consultation room which used by the diabetic educators for today. It was a small consultation room which usually used by one doctor to see their patient personally. In that room there were three diabetic educators with three patients. The diabetes educators were consulting one patient each. The room was congested with two tables and one couch. Two diabetes educators had used tables and another one had consulting the patient and using couch as a table. The distance between the patients also very near and this had gave them no privacy to talk about their problem with the diabetes educators. When I entered the room, I was greeted by one of the diabetes educator and she told me that there was one patient that has been recruited waited outside the room. They had told me that they have to change the venue of consultation as the meeting room has been booked by the specialist. According to them, this situation is normal for them as they don't have designated room allocated for them to do the consultation. The diabetes educators had given me the patient's appointment card and I had met the patients prior to her consultation to explain further about the study and observation process. The patient had agreed to participate in both interview and observation and she had signed the consent form. Mrs I has been consulted by Diabetes educator N who also had gave consent for the observation. I helped the diabetes educator to call the patient to the room. During walking to the

room, the patient seems to have little difficulties in her movement (looked like she had pain in the leg while walking)

In the consultation room, I sat down at the corner of the room however, the distance between me; the patient and the diabetes educator were quite close. I tried to sit behind the patient to minimise the distraction of the consultation and to give more privacy to the patient. The diabetes educator had greeted the patient and asked about her condition today. Mrs I looked energetic and smiled to the diabetes educator. The diabetes educator had asked about her glucose level at home. She showed the diabetes educator her self-monitoring blood glucose record to the diabetes educator. Diabetes educator had told her satisfaction of the ability of Mrs I in controlling her blood glucose. During her review of the blood glucose record, the diabetes educator had noticed the episodes of hypoglycaemia during the morning record (fasting blood glucose). Diabetes educator had asked Mrs I how that episodes of hypoglycaemia happened. Mrs I had told that, during that time she chose not to eat anything at night just to see how her body and her blood glucose will be. According to Mrs I, she took 10 units of actrapid three times a day and 20 units of insulatard at the bed time. Her last meal during the hypoglycaemia episode was at 6 pm and she did not take anything after that. She took insulatard 20 units before sleep and when she checked her glucose level in the next morning, she was having hypoglycaemia. The diabetes educator had showed her worried on the effect of hypoglycaemia to the patient by telling that "I don't want this to happen again because it was really dangerous. You may turned to coma and might die because of this'. Mrs I looked so worried and asked "really? Could you tell me how this happened? I thought if I did not take anything at night I will able to reduce my weight and my glucose level will be better". From the conversation, the diabetes educator might notice that the patient had wrong understanding of diabetes and lack of knowledge on the effect of insulin. The diabetes educator had laid down the three type insulin bottle and asked the patient to choose the type of insulin that she used at home. Mrs I had showed the type of insulin and the diabetes educator had asked her about her understanding on the action of the insulin. Mrs I had explained about the action of actrapid however she had told the diabetes educator that she quite unclear about insulatard. The diabetes educator had thoroughly explained about the diabetes and the action of insulin in the body. The diabetes educator also had mentioned the type of food that should be avoid which may cause the glucose to highly increase and difficult to control. The explanation was clear and using lay language such as: very low blood sugar for hypoglycaemia (although patient seem to understand what hypoglycaemia is).

After further discussion, Mrs I had told that she was on T. Metformin daily as well. However, she did not take the Metformin because she afraid of hypoglycaemia as she already took insulin. According to her, during the consultation with the doctor, she know that Metformin is an antidiabetic agent nevertheless, she was not told why she has been prescribed with Metformin and what actually the function of Metformin for her. The diabetes educator had explained about the Metformin and why she has been prescribed with it. Mrs I also has been told when to take the Metformin and the glucose reading that she need to target. The explanation from the Diabetes educator N

was clear however, she did not use any visual aid such as picture or diagram. The patient needs to imagine her body system and how the medications react in her body. Mrs I had told the diabetes educator that she had lack of understanding on her condition. She is actually afraid to eat because she was scared if her glucose level will be high. Mrs I looked not very confident in managing her diabetes at home. However the diabetes educator had told her clearly on the way to manage her condition i.e. when to check her glucose, when to inject her insulin, when to eat, what to eat and the amount to eat. The diabetes educator also had explained clearly the action of insulin and Metformin in her body. After the discussion, Mrs I looked more confident and motivated to manage her diabetes. The next follow up appointment was given at 5 weeks interval to monitor her blood glucose and her self-care performance. From the intonation of the voice and her facial expression when she entered the room, the patient looked comfortable however during the consultation she sometimes had glance at the clock. When the diabetes educator asked whether is she in hurry. She had denied however, she had mentioned that her grand daughter was back from school at that time. Although she had asked her sister to fetch her granddaughter from school, she is worried if her sister had forgotten. After a while, she received a phone call telling her that her granddaughter has been fetched, and then she looked calmer.

After the observation, I had brought Mrs I for lunch and we have further discussion on the situation during the consultation. Mrs I had told that she was satisfied with the consultation given by the diabetes educator. She had compared her consultation session with the diabetes educator and doctor that she had previously. She seems to be happy to see the diabetes educator when she said "the doctors did not have much time to talk to us (patient). They just asked us how we felt now and told us the treatment and medication that we need to take in brief. I even don't know why I need to take those medications until it has been explained by the diabetes educator". She had told that, she don't know where to ask because patient does not have chance to see the doctor out of consultation period and she has to wait her next appointment with the diabetes educator to ask about her enquiry. During the gap of consultation (5 weeks in every consultation interval), she just managed her condition according to her limited understanding and she was so scared because she had warned of the complications by the doctor every time she came for the follow-up. That is why she was scared to eat and had tried and error (as what happened to her during the hypoglycaemic episodes). From the discussion she also had told that she is suffering from rheumatoid arthritis which makes her movement was so limited. Nevertheless, she did not make it as the reason not to manage her diabetic carefully. From the facial expression and body language, Mrs I looked highly motivated in managing her diabetes.

Reflexivity

I had walked to the meeting room which usually used as consultation room however; the room was occupied with the medical students. There was no notice stated anywhere telling if they were moved to anywhere. I had asked the diabetes educator at the registration counter if the consultation room had moved to somewhere else. The diabetes educator had showed me the temporary room which used as diabetic

educator's consultation room that day. The room was situated near to the waiting area. When I entered the room, I was greeted by one of the diabetic educators and they were apologized for the inconvenience that I need to face during this period. The room was small. It was a consultation room which normally used by the doctor to examine and consulting the patient. The room was designated to be used by one doctor and one patient however; three diabetes educators with three patients need to squeeze themselves inside the small room. The distance between each of the patients who were having consultation with different diabetes educators were so near. The environment was looked messy and uncomfortable for the diabetes educators and the patients. The conversation between the patient and the diabetes educator was able to be heard by other diabetes educators and patients in the room. The patients did not have privacy to discuss about their problem. If the diabetes educator had pointed out their mistakes in any aspects of self-care the patients might felt intimidated and low self-esteem as it would be heard by other patients. This would restrict the patients to talk about the problem at home which might be the important component that would help the diabetes educators to understand their patients. Therefore, the counselling and guidance given by the diabetes educators may not able to solve the patient's problem and was not what the patient's need. Because of the feeling of insecurity and shy the patients might reluctant to tell the important things to the diabetes educators and their problem remained unresolved.

During the observation session, I had tried not to sit too close to the patient to avoid distraction and feeling of awkwardness for the patients and diabetes educators. I had sat at the corner of the room however because of the small space that we have in the room, my distance with the patient was quite near. I had sat behind the patient so I will not have eye contact with the patients which I hope will minimise the distraction from me. It seems that the conversation between the patient and the diabetes educator was run smoothly nevertheless, I am not able to clearly observe the facial expression and body language of the patient as I was behind her. However, I am able to see the reaction of the diabetes educator clearly. Patient seems to be quite disrupted during the consultation as she worried of her grandchild at school. It seem that, the role of the patient as a carer who need to look after a child at home might had restricted her ability in managing the diabetes (need to send or fetch the child from school might alter the time for medication and meal). During the consultation, the patient looked motivated and she had asked many questions regarding her management at home. She looked comfortable to talk to the diabetes educator and she had addressed the diabetes educator with her name not a diabetes educator and she had addressed herself as sister (this had showed less barrier between the patient and the diabetes educator - this might be due to the trust built between the patient and the diabetes educator as the patient had seen the same group of diabetes educators for few times - she also had greeted other diabetes educators in the room and asked them whether they had remembered her or not). The patient looked comfortable to talk with the diabetes educator however, because of the presence of other patients in the room she had reduce the tone of her voice. In addition, she looked to felt restricted to talk especially when the diabetes educator asked her about her hypoglycaemic episodes.

After the consultation session I had invited the patient for lunch as I wanted to discuss further about her consultation session and to conduct the interview with her (as agreed by her). She agreed however because of her limited ability to walk, we only can have lunch at the nearest cafe. The cafe was noisy as it was lunch time. We chose to sit at the quieter space at the corner of the cafe. Mrs I had her lunch whereas I had a drink. During that time I had an informal conversation with her asking about her opinion of the consultation session that she had just now. Mrs I looked happy to tell that she was happy and satisfy with the session that she had with the diabetes educator. However, she had mentioned about the congested space that they have which make her a little bit uncomfortable. However, she had expressed her gratitude to the diabetes educator who had talked to her nicely and gave clear explanation on her enquiries. She also satisfied as she had longer time to speak to the diabetes educator so she could understand many things which not being told by the doctors before. She had compared the consultation session that she had between the doctor and the diabetes educator. According to her, if she saw the doctor, she usually not able to ask many questions because the doctor just answer the question in brief as if the patient does not know anything (as mentioned by Mrs I - this showed that the patient felt frustrated with their interaction with the doctors). The time that she had when she saw the doctor also very limited as the doctor had many patient waiting outside thus, they were too rush to see other patient. Mrs I claimed that, she was left with uncertainty after the consultation and just manage her diabetes according to her limited understanding. That is why she had used try and error to see how her body works (i.e. during the hypoglycaemic episodes). Therefore, when she had the consultation session with the diabetes educator, she tried to ask as many question as she can so she able to understand her condition clearer. From the facial expression (smile with confidence) and her intonation of her voice during the conversation, Mrs I looked highly motivated and enthusiastic to manage her condition despite her limited physical movement.

*the patient has been given long interval between follow up session (5 weeks for this patient). During these five weeks, patients was not being followed up on how they were doing at home after the last consultation session (these has been told by the other patients and diabetes educators during previous interview) and they also unable to access the healthcare system if they have doubt or enquiry about their management. These had left patients with uncertainty and frustration which might reduce their motivation to engage in proper self-care practice. The patients were left independent without any guidance from healthcare professionals in managing their medications, diet and other aspects of self-care.

****end of observation****

Appendix 22 – Thematic chart (developed in Nvivo 9)

2.1 Internal facilitator to self-care

PT ID, Age, Gender, Duration of diagnosis, Treatment	A : 2.1.1 Religious beliefs	B : 2.1.2 Positive acceptance	C : 2.1.3 Scared of complications
<p>1 : PT 10</p> <p>Age = 30-39 Duration of diagnosis = Less than one year Gender = Male Treatment = Tablet</p>	<p>Pray and asked help from god - did it most of the time. Accepted it positively. Strong religious beliefs - help him to be more calm and patience to face the challenge which regarded as test from god. Although he believe that live and die is at god's hand but tried his best to live a better life with diabetes - need to move forward.</p>	<p>Accepted diabetes positively - tried to live with diabetes because still have a lot of things to look forward. Be positive - regarded diabetes as a good impulse for him to change to a healthier lifestyle. Believe that everything happened for a reason. Positively think that he able to manage the diabetes well. Although unable to accept it at first but had realised that this is a test from god to him - started to accept it positively. Believe that by facing his fear i.e. needle/medication and involved actively in sports will helped him to manage his diabetes well.</p>	
<p>2 : PT 6</p> <p>Age = 30-39 Duration of diagnosis = Less than one year Gender = Female Treatment = Tablet</p>		<p>Had accepted diabetes positively and realised that she need to have strong discipline to achive good glucose control.</p>	<p>Scared on the possibility of getting complication i.e. leg amputation and afraid it will burden her family physically and financially had influenced her to manage her diabetes properly.</p>

<p>3 : PT 16</p> <p>Age = 40-49 Duration of diagnosis = Less than one year Gender = Male Treatment = Tablet</p>	<p>Took diabetes as a test from god and it had him a lot to accept the diabetes positively. Strong religious beliefs had helped him to be more patience and try to find the solution to the problem. Confident that Allah (god) is the best planner and he give the illness for a reason.</p>	<p>Had accepted diabetes positively and reflected on his practice before. Reflecting and tried to change the things that he not supposed to do before - which lead him to get diabetes. Realised that he need a plan to manage diabetes properly and follow the doctors' suggestion.</p>	<p>Being told about the possibility of complication that he may had - make him to know more and find out what he should do to avoid it (complication). Feels that he need to follow the suggestion given by the HCPs to avoid him to get complication which will burden his family (always pray that he will not burden his family with his disease).</p>
<p>4 : PT 9</p> <p>Age = 40-49 Duration of diagnosis = 1-5 years Gender = Female Treatment = Tablet</p>		<p>Had accepted diabetes positively after being advised by her husband. Motivated to manage diabetes properly as she had a lot of thinks to look forward i.e. children. Belief that everybody in this world will come out with certain type of disease - had motivates him to accept diabetes positively. Belief that he need to change her lifestyle and managed her diabetes properly if she wants to enjoy her life.</p>	
<p>5 : PT 3</p> <p>Age = 40-49 Duration of diagnosis = 6-10 years Gender = Male Treatment = Insulin</p>	<p>Took diabetes as his fate that he needs to face it. Belief that only god can help in whatever situation thus he prayed to god a lot - had gave him strong confidence in life. Just do his pray and take the illness positively. Just keep his fingers crossed all the time.</p>	<p>Accepted diabetes positively. Realised that everything had happened and can't be changes so just take it positively. Had bear in his mind that diabetes is not the end of life as he still has a lot of things to look forward - try to overcome it and live a normal life. Have control on everything. Realised that he need to control and manage diabetes properly as he loves his health and body.</p>	

<p>6 : PT 8</p> <p>Age = 40-49 Duration of diagnosis = 15- 20 years Gender = Female Treatment = Insulin</p>	<p>Belief that diabetes is a test that had determined to her - accepted it positively.</p>	<p>Belief that everyone in the world had problem so she just faced the problem positively - did not think too much about it.Had accepted diabetes positively and feel that diabetes is not a burden - increased her awareness to look after of herself.</p>	<p>Realised that if she did not look after diabetes very well, the sugar level will increase and will cause a lot of complication - had increased her awareness to to comply to the medication and manage the diabetes properly.</p>
<p>7 : PT 7</p> <p>Age = 50-59 Duration of diagnosis = 1-5 years Gender = Female Treatment = Tablet</p>		<p>Had accepted diabetes positively - diabetes had refrained her from taking too sweet or oily food. Always aware that she had diabetes and it had trained her to eat lesser did not felt free to eat anything that she likes.</p>	<p>Seen a lot of example of diabetes complication happened to other people made her scared - had increased her awareness to control the diabetes properly.</p>
<p>8 : PT 13</p> <p>Age = 50-59 Duration of diagnosis = 6-10 years Gender = Male Treatment = Tablet</p>	<p>Accepted diabetes as a test from god. By accepting it, aware that he need to find way to solve the problem and manage it properly.</p>	<p>Tried to accept diabetes positively and do the necessary things to control it - as advice by the HCPs. Accepted the diabetes and find a way to manage it.</p>	
<p>9 : PT 5</p> <p>Age = 50-59 Duration of diagnosis = 6-10 years Gender = Male Treatment = Tablet</p>		<p>Accepted diabetes properly and belief that it is depend on self-preseverence (awareness to control).Belief that he is responsible to manage his diabetes properly. Aware that he needs to control the sugar intake to avoid the blood glucose to raise.</p>	

<p>10 : PT 12</p> <p>Age = 50-59 Duration of diagnosis = 6-10 years Gender = Female Treatment = Tablet</p>			<p>Knowledge of complication i.e. leg amputation had increased her awareness to become extra careful for getting injury. Experiencing complication had made her scared and do anything to reduce the sugar level i.e. skipping breakfast.</p>
<p>11 : PT 15</p> <p>Age = 50-59 Duration of diagnosis = 11-15 years Gender = Male Treatment = Insulin</p>	<p>Accepted diabetes as a test from god - need to accept it positively and try to manage it.</p>	<p>After being explained about insulin had realised that diabetes can be managed and control - increase his motivation to get treatment rather than just ignoring it.</p>	<p>After experienced signs of complication had make him scared and realised on the danger of diabetes to his body - it had increased his awareness to control it.</p>
<p>12 : PT 11</p> <p>Age = 50-59 Duration of diagnosis = 11-15 years Gender = Female Treatment = Insulin</p>	<p>Belief that diabetes as a test from god thus she has to accept it with pure heart. It had motivates her to change and cope with diabetes. Belief that god is a best planner and as a human we just need to accept our fate.</p>	<p>Realised that she is responsible for her body thus she need to change and look after it very well.Aware that she need to be independent and manage the diabetes properly in order to have a good quality of life.</p>	

<p>14 : PT 14</p> <p>Age = 50-59 Duration of diagnosis = 11-15 years Gender = Female Treatment = Insulin</p>	<p>Accepted diabetes as a test from god. Always remember that whatever problem happened is a gift from god and belief that it is the way that god want her to value her health and life.</p>	<p>Tried to accept diabetes as part of her life and do whatever necessary to manage it in order to be healthier and have a happy life.</p>	<p>Being reminded about the complication by the doctor everytime she went for follow up - felt scared and increased her awareness to manage diabetes properly and follos the suggestion by HCPs.</p>
<p>15 : PT 2</p> <p>Age = 60-69 Duration of diagnosis = 11-15 years Gender = Male Treatment = Tablet</p>	<p>Strongly belief that the illness i.e. diabetes is a test from god - god is the one who give illness and will give the relief - need to always pray to god. Nevertheless, he still put confident on the doctors to treat his illness. Belief that as a human we need to try our best to manage it.</p>	<p>Had accepted diabetes positively - belief that he need to put effort to maintain his health condition. Aware that he need to try his best to manage it i.e. take the medication as instructed and have control on own body.</p>	<p>Feel scared of complication- had increased his awareness to manage the diabetes properly.</p>
<p>16 : PT 1</p> <p>Age = 60-69 Duration of diagnosis = 15- 20 years Gender = Female Treatment = Insulin</p>	<p>Just pray to god - don't want to think too much about the illness. Learn a lot about the acceptance of the illness from islamic television programme.</p>		

Appendix 23 – Process of classification and categorisation

Internal facilitator to self-care

Summary of data – charted in column 2.1.1 Religious beliefs	Elements/dimension	Categories/classes
PT 1. Just pray to god - don't want to think too much about the illness. Learn a lot about the acceptance of the illness from Islamic television programme.	Acceptance of diabetes influenced by the belief on the power of God.	Influence of religious belief towards acceptance.
PT 2. Strongly belief that the illness i.e. diabetes is a test from god - god is the one who give illness and will give the relief - need to always pray to god. Nevertheless, he still put confident on the doctors to treat his illness. Belief that as a human we need to try our best to manage it.	Diabetes is a test from God. Asked help from God- an ultimate helper. Strong believe – need to do whatever necessary and leave the rest to God.	Diabetes is a test from God to the believers. God is an ultimate helper – confident in God.
PT 3. Took diabetes as his fate that he needs to face it. Belief that only god can help in whatever situation thus he prayed to god a lot - had gave him strong confidence in life. Just do his pray and take the illness positively. Just keep his fingers crossed all the time.	Diabetes is fated. Asked help from God – believe God as an ultimate helper.	Diabetes is a fate. Positive influence of religious belief on coping.
PT 8. Belief that diabetes is a test that had determined to her - accepted it positively.	Diabetes is a fate – has been determine by God.	Fate.
PT 10. Pray and asked help from god - did it most of the time. Accepted it positively. Strong religious beliefs - help him to be calmer and patience to face the challenge which regarded as test from god. Although he believe that live and die is at god's hand but tried his best to live a better life with diabetes - need to move forward. Although unable to accept it at first but had realised that this is a test from god to him - started to accept it positively. Believe that by facing his fear i.e.	Believe God is an ultimate helper. Acceptance and coping with diabetes influenced by strong	Strong belief on the power of God. Positive influence of strong religious belief on coping.

needle/medication and involved actively in sports will helped him to manage his diabetes well.	religious beliefs.	
PT 11. Belief that diabetes as a test from god thus she has to accept it with pure heart. It had motivates her to change and cope with diabetes. Belief that god is a best planner and as a human we just need to accept our fate.	Diabetes is a fate. Strong believe in God – should not question what has been fated.	Fate. God is the creator and determine the life of the mankind.
PT 13. Accepted diabetes as a test from god. By accepting it, aware that he needs to find way to solve the problem and manage it properly.	Believe that diabetes is a fate/test from god to the believers. Religious beliefs become positive coping mechanism.	Positive coping.
PT 14. Accepted diabetes as a test from god. Always remember that whatever problem happened is a gift from god and belief that it is the way that god want her to value her health and life.	Regards diabetes as a test. Believes the illness is a blessing and as a reminder to improve the way of living.	Diabetes as reminder from God. Positive coping.
PT 15. Accepted diabetes as a test from god - need to accept it positively and try to manage it.	Acceptance of diabetes influenced by strong believe in God – positive coping.	Influence of religious beliefs in coping with diabetes.
PT 16. Took diabetes as a test from god and it had him a lot to accept the diabetes positively. Strong religious beliefs had helped him to be more patience and try to find the solution to the problem. Confident that Allah (god) is the best planner and he give the illness for a reason.	Positive acceptance – diabetes is a test that comes with mercy. God is an ultimate helper – pray and asked for help from God.	Test/fate. Confident in God.

