

**AN INVESTIGATION OF TYPE 2 DIABETES
SELF-MANAGEMENT IN TAIWAN**

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ABSTRACT

In Taiwan, as in other countries, type 2 diabetes is a major public health problem. Taiwanese nurses are being called upon to play an increasingly large role in diabetes care, but little is known about the factors that contribute to good or poor diabetes self-management in the Taiwanese context.

This study is an exploratory investigation of Taiwanese women's experiences of living with type 2 diabetes. Adopting an open-ended qualitative approach, the research aimed to discern personal characteristics, strategies, socio-cultural and health system factors that affected women's ability to manage their condition effectively. Thirty-eight women were interviewed. These included twenty women who were nominated by health professionals as being effective at diabetes self-management and eighteen who were considered to have difficulties, in controlling their HbA_{1c}. Five senior diabetes nurses were also interviewed. Data was analysed thematically.

The study found that for many women, their diabetes diagnosis was marked by profound shock and change in their sense of self. Learning to live with diabetes was an ongoing 'journey' in which women engaged in a range of strategies to acquire information and support, to gain a sense of control over their condition and to find a health care provider they could trust. The findings challenge the prevailing medical model that defines 'successful' self-management on the basis of clinical outcomes alone. Rather, self-management was found to be highly contingent upon individual life circumstances. From women's own perspectives, successful self-management involved coping with a context of severe social stigma and juggling their own self-

care alongside maintenance of multiple social gender roles and financial responsibilities, often in the face of social or economic difficulties.

The research points to a need for health professionals to adopt a non-judgemental, individualised and empowering philosophy in their approach to diabetes care whereby education and treatment is tailored to the specific and complex needs of individual patients.

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CHAPTER ONE – INTRODUCTION

This thesis explores factors influencing self-management of type 2 diabetes amongst the Taiwanese women aged forty to sixty. This topic has been intriguing to me for a long time since I took my first job as a nurse because the scenarios of sufferings amongst diabetic patients who developed into the end stage of the complications had always stricken me. Once, one of my classmates told me an inspiring story regarding diabetes self-management experienced by her stepfather. He was once suffering from a diabetic foot and it was suggested he have his foot amputated. However, it was hard for him to accept, and he decided to take self-management seriously; eventually, he saved his foot. From this story I have learned that the key persons in the team of diabetes care are the patients themselves because they decide how to cope with diabetes. Numbers of literature have been investigating the influential factors, both the barriers and the facilitators, to diabetes self-management. On the other hand, the influential factors to an individual are not fixed always but change over time; taking this case as an example, apart from the suggestion to have his foot amputated, his situation of living with diabetes seemed to change a little, and those objectively influential factors might still remain. One of the big differences was his changed motivation when he was eager to save his foot. It reveals the complexity of the knowledge of self-management. The behaviours are hardly observed by health professionals. Obtaining information relies heavily on the patients' descriptions because they are the very persons to deal with the diabetes in the real world, which could involve with great deal of cognitive activities, viewed as a black box. There has been very little research done on diabetes self-management in Taiwan; therefore, I

decided to explore the phenomenon of self-management, which has been commonly agreed as the centre of diabetes care in the context of Taiwanese society.

Diabetes: A global problem

The urgency of improving diabetes care results from its epidemic nature, which has been become one of the top healthcare issues (WHO, 1998). Currently, approximately 2.1% of the world's population is diagnosed with diabetes, but it could rise above 3.0% in 2010 (Zimmet, 2000). The number of diabetes sufferers is estimated to increase dramatically, from 135 million in 1995 to 171 million, 300 million, and 366 million in 2000, 2025, and 2030, respectively (King, Aubert, & Herman, 1998 ; Wild et al., 2004). India, China, and the United States will have the highest incidence of diabetes in the world by 2025 (WHO, 1998). The bulk of the increases are expected in the developing countries, with an estimated 170% increase from 84 million in 1995 to 228 million in 2025 (WHO, 1998). Most of the newly diagnosed diabetic patients will be seen in the Asia-Pacific region; and Taiwan, Hong Kong, Singapore, and Mauritius have been identified as higher prevalent areas (Zimmet, 2000).

Normally, the onset of type 2 diabetes occurs after the age of fifty in Europeans. However, among the Pacific islanders, the Chinese, and other groups (i.e. Micronesians, Polynesians, Australian Aborigines, North American Indians, Afro-Americans and other members of the Black population, Hispanics, and migrant Asian Indians) the number of cases, which occurs in the twenty-to-thirty-year age group, is increasing because of their genotype (Zimmet, 2000). Based on the differentiation of cultures, the emphasis on prevention or delaying the complications of diabetes

amongst those susceptible people with type 2 diabetes in the Asia-Pacific region deserves more attention.

Many of the behavioural and lifestyle trends, such as eating foods with high fat and sugar and living a sedentary lifestyle, are linked with the obesity epidemic, which has been strongly suggested as the major risk factor for developing type 2 diabetes (Haffner, 1998; UKPDS, 1988; Berger, 2001; Grubb, 2002; Pradhan, Skerrett, & Manson, 2002; Cleator and Wilding, 2003; ADA, 2008a). Evidence shows that obesity is associated with insulin resistance (ADA, 2008a). However, levels of obesity are rapidly rising in both developing and developed countries (WHO, 2002; Mokdad et al., 2001; Grubb, 2002; Pradhan, Skerrett, & Manson, 2002; Mokdad et al., 2003). With the continued increase in obesity, diabetes cases in excess of 366 million could be anticipated by 2030 (Wild et al., 2004).

The situation in Taiwan is even worse than this global picture indicates. Surveys investigating the prevalence of type 2 diabetes amongst adults in Taipei reported figures of 5.1%, 7.4% and 8.17%, in 1970, 1979, and 1985, respectively (Tai, 1996). Furthermore, approximately 17% of type 2 diabetes was found in the Penghu Islands located west of the Taiwan Island (Chen et al., 1999). Chang and his colleagues reviewed the prevalence of type 2 diabetes between 1985 and 1996 in Taiwan, and reported an overall result of type 2 diabetes between 4.9 and 9.2% (Chang et al., 2000). Other researches concerning the prevalence of diabetes in three major ethnic groups in Taiwan showed that the rates among the Hakaas, the Fukienese, and the aborigines were 17, 14, and 12%, respectively (Chen et al., 2001). After age adjustments in the aforementioned papers, the prevalence rates of diabetes ranged

from 2.2 to 6.9 percent, with undiagnosed diabetes at around 4.0 percent in Taiwan (Chou, Li and Tsai, 2001).

The number of the overall deaths toll caused by diabetes in Taiwan has gradually increased: the twelfth-leading cause of death in 1982, eighth in 1983, seventh from 1984 to 1987, fifth from 1988 to 2001, and fourth since 2002 (DoH of ROC, 2008). Together with its irreversible complications, diabetes mellitus finally leads to disability, mortality, and premature mortality; thus the burden to society is massive (WHO, 1998). Therefore, the rapidly increasing incidence of diabetes has been given priority by both the authorities and the health care professionals.

The major issue of diabetes care is focused on preventing or delaying longstanding complications, which is the major drain of health care. However, patients with type 2 diabetes, before developing into chronic complications, remain symptomless for years without urgent characteristics (Larme & Pugh, 1998), together with the increasing numbers of younger people suffering from the condition, the effect of type 2 diabetes, with its complex treatment procedures, has been devastating (ADA, 2000; Fagot-Campagna et al., 2000; Drake et al., 2002; Soltész, 2003; Wei et al., 2003). Thus, the earlier the onset of type 2 diabetes takes place, the more complications of diabetes will ensue, and the treatment costs will increase substantially (Fagot-Campagna et al., 2000; Jönsson, 1998; WHO, 1998).

The global cost of diabetes has been estimated at around 2-3 percent of the total expenditure of health care in each country (Jönsson, 1998). It costs an average of \$47,240 to manage complications over 30 years per diabetic patient, and this

expenditure is represented as the following: 52% for patients with macrovascular disease, 21% in nephropathy, 17% in neuropathy, and 10% in retinopathy (Caro, Ward, & O'Brien, 2002). In the United Kingdom, the cost for diabetes-related care was almost 9% of the total health care expenditure in 1996, and 14.6% in the United States in 1992 (Currie et al., 2004).

In Taiwan, the cost spent on diabetic patients was 4.3 times higher than those without diabetes, and represented 11.5%, 13.3%, 13.0% of total healthcare expenditure in 1997, 1998, 1999, respectively (Lin et al., 2001; Lin et al., 2004). The visits made by the diabetic patients to the outpatients' departments accounted for 25.2% of the total numbers of patients. In regard to hospitalization, diabetic patients accounted for 4,724,711 hospital inpatient days, 22.1% of the total inpatient days (Lin, et al., 2001). The expenditure was mostly incurred by the incidents of complications of diabetes, including congestive heart failure, neuropathy, ischemic heart disease, nephropathy, and cerebrovascular disease, which accounted for 32.9%, 31.3%, 18.7%, 14.1%, and 11.1%, respectively (Lin et al., 2004). The complications of renal disease secured the second highest percentage of patients with end-stage renal disease, and diabetic nephropathy claimed 20.3%, 24.8% of the total population of end-stage renal disease in 1990, 1997, respectively (Yang, et al., 2001). In addition, there are multiple indirect costs of diabetes that are hardly measured; these include mortality rates, premature mortality, and other factors, such as sick days, employment considerations, income, family home care, and transportation costs (Jönsson, 1998; Björk, 2001). Thus, to prevent the complications is the key to reduce the expenditure of health care.

The efforts of the authorities and the health professionals in Taiwan have mainly focussed on developing models of diabetes care to delay/prevent the complications. For example, the model of shared care, adopted from the United Kingdom, has been brought into practice since 1996 (Chiou et al., 2001); however, a survey that covered 25 diabetic care centres with 2,446 diabetic patients revealed that 59% of the participants had HbA_{1c} ¹ > 7.4%, and its mean was $8.1 \pm 1.6\%$ ² (Chuang et al., 2001). Similarly, Tsai's (2004) survey showed the mean of HbA_{1c} at 8.9%. This might explain the higher incident rate of the complications in Taiwan. Reducing the burden of health care from diabetes has become one of the main tasks of health policy in the country. To achieve the goal of HbA_{1c} values at less than 7% (DCCT, 1993; UKPDS, 1998), there is still large room for both the authorities and the health care professionals who are involved in diabetes care to elaborate more efforts.

Particular for the PhD study

To improve diabetes care, preventing or postponing the complications is the utmost goal to be achieved. However, apart from physiological conditions, the outcome of metabolic control is also influenced by medical treatment and self-management. After

¹ 'Glycated haemoglobin (GHb) is formed when haemoglobin molecules bind glucose. It is a process occurring both in diabetic and non-diabetic subjects. Because the average lifespan of red blood cells is 90–120 days, measuring the amount of GHb in the blood provides an indicator of the patient's average blood glucose level for the last 3–4 months. GHb occurs in several variants and can be measured using several different methods. Haemoglobin A (HbA) contributes to 90 percent of the total. Use of cation-exchange chromatography showed that HbA could be separated into at least three components: HbA_{1a} , HbA_{1b} and HbA_{1c} . Subsequent studies have found a particularly strong relationship between HbA_{1c} and fasting blood sugar over the preceding weeks in both diabetic and non-diabetic subjects. HbA_{1c} is the most frequently measured GHb in clinical practice, but some laboratories continue to use total GHb or HbA_1 assays.' (Coster et al., 2000).

² HbA_{1c} 6% = 135 mg/dl (7.5 mmol/l); 7% = 170 mg/dl (9.5 mmol/l); 8% = 205 mg/dl (11.5 mmol/l); 9% = 240 mg/dl (13.5 mmol/l); 10% = 275 mg/dl (15.5 mmol/l); 11% = 310 mg/dl (17.5 mmol/l); 12% = 345 mg/dl (19.5 mmol/l) (Goldstein et al., 2004). This recommends that most adults with either type 1 or type 2 diabetes target for preprandial plasma glucose levels (most glucose meters are calibrated to read as plasma glucose) of 70–130 mg/dl (3.9–7.2 mmol/l) and peak post-prandial plasma glucose levels of < 180 mg/dl (<10.0 mmol/l) (ADA, 2008b).

tremendous efforts, diabetes care has been described as ‘one of the most psychologically and behaviourally demanding of the chronic medical illnesses’ (Cox & Gonder-Frederick, 1992, p. 628), while the care of diabetes has been advocated as ‘at heart a self-management issue’ (Glasgow, 1999, p.833).

The research presented in this thesis arose out of my desire to better understand type 2 diabetes self-management. During my previous experience as a nurse and nurse educator working with patients and health professionals in experimental diabetes care, I observed the conflicting perspectives between patients and health care professionals while providing diabetes care.

A literature review of research that sought to examine issues related to diabetes care and diabetes self-care behaviours found that little literature focused on diabetes care in the context of Taiwan.

From the literature review, I became aware that there were multiple factors influencing self-management, which would change over time according to an individual’s life circumstances, such as social roles and gender (Maclean, 1991). In order to narrow down this endeavour, I decided to focus on a particular population, middle-aged women with type 2 diabetes.

This thesis seeks to fill a gap in knowledge about the self-management of women aged forty to sixty with type 2 diabetes in this group by interviewing thirty-eight patients and five nurse diabetes educators. Some of the women are considered exemplar self-managers, while others were identified as having poor control as

measured by HbA_{1c}. The aim of the study is to identify factors contributing to self-management of type 2 diabetes in Taiwan. The objectives focus on exploring the experience of self-management in the Taiwanese context, to investigate the patients' self-care strategies and factors that affect this, to specifically identify key factors in (1) the home/social environment, and (2) the hospitals, which facilitate or hinder self-management. An open-ended qualitative approach was utilized in this work, which allowed access to the perspectives of both the patients and the health care professionals.

The study is presented in chapters two to eight, which cover the literature review, context setting, methodology and methods, three data chapters, and the discussion chapter. In the data chapters, an analysis of the in-depth interviews identifies three themes that explain the patients' experiences of living with diabetes. These three themes are (1) 'a changed person,' (2) 'trying to restructure life,' and (3) 'helping hand.' They describe the patients' experiences of living with diabetes within their social context, their coping strategies in trying to resume their lives as normally as possible while living with diabetes, and the role that the health care professionals play in helping patients to cope with diabetes.

The first theme, 'a changed person,' revealed the situation in which having diabetes announced a devalued self, regardless of whether an individual experiences physical symptoms or not. In this situation, the integrity of the self is possibly jeopardized; and responding to this situation, patients have to take action with a range of health behaviours. The study found that the patients sought for help from a variety of sources, but with inadequate knowledge they were vulnerable to harmful suggestions. Due to

the stigma associated with diabetes, most of the patients decided to conceal their illness identity in public to reduce the negative impact, and such circumstances affected their ability to engage in self-management. The data showed that if the patients have adequate knowledge and perceive diabetes as a threat, which causes them to worry, it might potentially help them address the problem. The second theme, ‘trying to restructure life,’ reveals the process of integrating recommendations into their daily lives. Evidence from the data has shown how significant social roles are in people’s lives; that these are more important than their personal health. To live with diabetes, the patients are not simply dealing with the role of a diabetic patient, but they are playing many other social roles at the same time, and the performance of those social roles is the key element to remain the integrity of the self. However, people’s social lives are sometimes unpredictable and difficult, and their social situation influences their ability to manage their diabetes. The final theme, ‘helping hand,’ indicates that healthcare services play an important role in giving the patients support by providing information, education, and treatment; the support from either policy of insurance or facilities provided by institutions are significant for diabetes care.

The findings demonstrate that the current framework for evaluating ‘successful’ self-care between health care professionals and patients is based on different perspectives. For example, health care professionals consider that ‘successful’ self-care is associated with appropriate HbA_{1c} levels rather than the everyday strategies that people use to cope with a variety of situations. Under such a medicalised model, health professionals may fail to recognize and provide support to those patients who are confronted with the difficulties within the context of reality. In the final chapter, I

identify the implications of the research from a clinical, research, and theoretical perspective.

From a clinical perspective, diabetes self-management is largely influenced by cultural and social values, and the patients' perspective of diabetes is the key to self-management. From a research perspective, the aspects of the self, self-identity, and social roles in the Taiwanese context need more attention for a better understanding on diabetes self-management. From a theoretical perspective, the study synthesised is a conceptual framework of diabetes self-management, which links the influential factors with the process of diabetes self-management, providing a better understating of diabetes self-management. The study endeavours to explore diabetes self-management by examining the phenomenon with existing models and managing to extend the body of knowledge of diabetes self-management.

This thesis makes a unique contribution to the existing body of literature in three ways. First, it is the first time that a detailed investigation of diabetes self-management amongst women in Taiwan has been conducted. It yields important insights into the ways in which diabetes is viewed and managed. It has been identified that the content of diabetes educational programme has to be flexible enough to meet a variety of needs because their experiences and learned diabetes knowledge are based upon individuals' perspectives of their lives and context to achieve an effectively good 'diagnostic history taking.' This information will be useful for health care professionals. Secondly, the findings show that coping with the diagnosis and living with diabetes is affected by a complex constellation of factors, including life circumstance, social support, gender roles and economy. Finally, the findings

demonstrate a gap between professional practices, service provision (biomedical model) and the patients' lives and demonstrates the need for a non-judgmental 'group' relationship.

CHAPTER TWO – LITERATURE REVIEW

Introduction

In 1921, the discovery of insulin was once believed to be a breakthrough of regimen treatment, which could solve the problems of diabetes (Guthrie & Guthrie, 2002). As years passed by, the performance has not achieved its satisfactory level, even though extraordinary efforts have been paid off. Unlike the other chronic disease, the progress of diabetes mellitus has many possibilities, ranging from healthy normality to serious consequences, such as amputation, blindness, renal failure leading to required haemodialysis, heart diseases, and stroke, resulting in extreme burdens on individuals, families, and society. Therefore, efforts to prevent or delay the consequences of the disease are critical in diabetes care. Pharmacology treatment has its limit in good metabolic control, but self-management is the key to achieve the optimum outcome.

To gain a better understanding of diabetes self-management, the strategy of the literature review is the key element to achieving it. The first year, 2003, the literature reviewing began by using the key words of compliance, adherence, self-care, and self-management, and the databases involved with Ovid MEDLINE, PsycINFO, EMBASE, British Nursing Index, British Nursing Index and Archive, British Nursing Index Archive, Nottingham full text, AMED Allied and Complementary Medicine, International Pharmaceutical Abstracts, and Health Management Information Consortium. The following years, to deepen the understanding, further searches were undertaken using key words associated with concepts that existed in the study

regarding diabetes self-care or self-management such as the Health Belief Model, self-efficacy, locus of control, motivation, problem-solving empowerment, concordance, expert patient, doctor-patient relationship, and personality as well as its prevalence and the burden imposed to the society. Grey literature (such as unpublished conference papers, policy documents and websites) were also examined. I also hand searched the references lists at the end of each article. . The key word ‘chronic illness’ was also used to expand the boundary of knowledge by looking at selected research done in other clinical areas (e.g. Charmaz – Charmaz,1983; Charmaz, 1987; Charmaz, 1991). To examine the papers published by authors who have long dedicated their studies on diabetes self-management was another strategy used to help the development of the body of knowledge in the field, such as Russell E. Glasgow, Barbara L. Paterson, Robert M. Anderson, Martha M. Funnell, and Robin Whittemore. Regularly reviewing the content of the diabetes-related journals was another way to expand the scope of knowledge in the field, such as Diabetes Care, The Diabetes Educator, Patient Education and Counseling, and Diabetes Research and Clinical Practice. As I grew in my knowledge of diabetes management, the searching could be able to link other principles of care, such as the concepts of chronic illness, chronic care model, and sick role, which enabled the study to examine the relationship between diabetes self-management and healthcare system as well as policy.

Eventually, the literature review organised a broad concept to the understanding of self-management within the context of diabetic patients; therefore, this chapter is divided into four sections to provide the groundwork as follows: (1) overview diabetes mellitus and its disease-related management to gain the basic understanding about the disease management; (2) healthcare system and diabetes care, which

discusses the concepts of biomedical model, sick role, compliance/adherence, and empowerment; (3) factors that influence self-management and patients' experiences living with diabetes, revealing the progress of becoming satisfactory self-managers; and (4) a conceptual framework is developed from existing literature to show the process of diabetes self-management, and the gaps are then discussed.

Overview of diabetes mellitus

Diabetes mellitus (DM) is characterized by high levels of blood glucose resulting in abnormalities in insulin secretion, insulin action, or both (ADA, 2008a). There are four known subtypes of disease: type 1 diabetes, type 2 diabetes, other specific types of diabetes due to other causes, and gestational diabetes mellitus (ADA, 2008a; ADA, 2008b). Ninety to 95 percent of the total diabetes population are type 2 diabetes, followed by type 1 around 5-10 percent (ADA, 2008a). Type 1 diabetes is characterized by its β -cell destruction, which is caused by autoimmune procedure and non-autoimmune forms leading to absolute insulin deficiency (ADA, 2008a; WHO, 1999). Hence, the people with type 1 diabetes need to be treated with insulin. Type 2 diabetes is characterized by its inefficient insulin secretion, and the function of insulin is to help the body cells uptake glucose from the extra-cellular into the inner-cellular, with obesity leading to reduction in insulin sensitivity (Chilcott, Wight, Lloyd Jones, & Tappenden, 2001). The diagnosis of this type of diabetes is often delayed for many years because of its minor or asymptomatic condition (ADA, 2008a).

The major health burden of diabetes is caused by its concomitant complications (Leese, 1992; Jönsson, 1998; King, Aubert, & Herman 1998), which result in

premature death (Rose et al, 2002), especially chronic complications such as (1) microvascular diseases (Harris, 1998; Nazimek-Siewniak, Moczulski, and Grzeszczak, 2002; Strowig & Raskin, 1992) and (2) macrovascular diseases (Harris, 1998; Donahue & Orchard, 1992; Nazimek-Siewniak, Moczulski, and Grzeszczak, 2002) leading to retinopathy, nephropathy, neuropathy, and coronary heart disease and cardiovascular disease (Donahue & Orchard, 1992; Nazimek-Siewniak, Moczulski, and Grzeszczak, 2002; Strowig & Raskin, 1992). Hereto, the causes of development of macro and microvascular in diabetes mellitus diseases are still unknown (ADA, 2008a). As a result, previous diabetes care suffered from lack of guidance to prevent long-term complications, even though many had been suspicious of the positive relationship between chronic complications and high levels blood glucose (Donahue & Orchard, 1992; Strowig & Raskin, 1992). A notable, large-scale, longstanding and randomized sampling study, launched by the Diabetes Control and Complications Trial (DCCT, 1993), brought an answer to give diabetes care a clearer goal by showing that lower HbA_{1c} could benefit the prevention of long-term complications. Later, a number of studies showed similar results (Ohkubo et al., 1995; UKPDS, 1998) to make more convincing the relationship between values of HbA_{1c} and long-term complications of either type 1 or type 2. Furthermore, a ten-year data of the UK Prospective Diabetes Study (UKPDS) Group analyses the detailed relationship between high levels of blood glucose and complications, and indicates that for every 1% reduction in glycaemia measured as glycosylated haemoglobin (A1c), all-cause mortality, and myocardial infarction, diabetes-related death and microvascular disease has decreased by 14%, 21%, and 37% respectively (Stratton et al., 2000). On the other hand, every 1% increase in the value of HbA_{1c} is associated with a 7% increase in expected health care cost. As a result, to maintain the value of HbA_{1c} < 7% has then

become the golden standard of diabetes care (ADA, 2008b; Roberts, 2006), and some even take it much stringently, as to less than 6% (CDA, 2003; ADA, 2008b). However, the risk raised while adopting tight blood glucose control is of severe hypoglycaemia, which is about a two- to three-fold increase than those who do not receive tight blood glucose control (DCCT, 1993), and it poses a negative impact on diabetes control (Cryer, 2002; Davis & Alonso, 2004). To maintain blood glucose levels near normal range and also to prevent hypoglycaemia becomes challengeable, and diabetes care management has to include pharmacological, non-pharmacological, and also diabetes-related self-care activities (Dunning & Ward, 2008; ADA, 2008b; Cefalu, 1996; Warren, 2004). Apart from pharmacological treatment, the non-pharmacological focuses on lifestyle intervention, including physical exercise, dietary, and smoking cessation (Buysschaert & Hermans, 2004). In addition, some diabetes-related self-care behaviours are self-monitoring blood glucose, hygiene, and stress management (Guthrie & Guthrie, 2002). One phenomenon has been observed that the disease is expected to deteriorate by aging, even though the patients strictly follow the prescribed regimen (Guthrie & Guthrie, 2002; Ross, 2004; Warren, 2004). The effect is that blood glucose levels can be affected by the treatment regimen, physical conditions, and self-management behaviours (ADA, 2008b), thus adherence to self-management does not necessarily lead to good metabolic control, but overlooking self-management is likely to lead to poor metabolic control (Toljamo & Hentinen, 2001). It also makes the appraisal of diabetes care more complicated, when illness or perceived stress can raise blood glucose levels. As a result, it is arguable to judge whether the patients follow the recommendations or not as the only appraisal method while merely depending on the results of blood glucose. Indeed, maintaining blood glucose within a satisfactory level cannot be simply achieved by pharmacology, but it

involves the complexity of managing the disease holistically (WHO, 2002; WHO, 2003a; Buysschaert and Hermans, 2004). To ensure that an individual maintains a constant awareness of changing chemical conditions within his body is necessary, and it requires a relatively high level of knowledge and skills. Both the healthcare providers and healthcare system play pivotal roles in how patients can handle all these tasks at home by themselves.

Healthcare system and diabetes care

Nowadays, most of the healthcare systems in the world are dominated by the biomedical model (WHO, 2003b), which was originally designed for acute illness care (Anderson, 1995; Bury, 1997), and its major goal is to heal patients who are acutely ill and needed to be treated in hospitals (Anderson, 1995). The model adopts a paternalistic approach to guide the patients on the course of action (Tsoneva, 2004), and the patients are expected to follow orders. As a result, numbers of studies have been available regarding the development of methods to appraise compliance, techniques, and tactics to encourage adherence to medical treatments and advice (Funnell & Anderson, 2000).

The concept of the ‘sick role’ was originally identified by the sociologist Parsons (1951) and is an examination of the meaning of illness within the context of society, and the extent to which social norms and values affect how a person should behave in the stage of illness. His theory seeks to identify the meaning of illness within the context of Western society and extends to determine how a person should behave while in the stage of illness. The doctor-patient relationship is described as a part of

the social system, and they are both considered to have their own rights and obligations to perform. Parsons views illness as a form of deviance, and argues that patients are legitimately allowed to withdraw and suspend from their usual social obligations while being sick. It means that patients have to take the 'sick role' directly, with 'getting well' being their social obligation. As such, a sick person is not held responsible for his condition. A sick person is responsible to seek help from someone who can regain his health, and a doctor is responsible to restore the former's health and do the best to offer health care services. Ideal patients have to be either compliant or self-sufficient, and health professionals are viewed as experts (Thorne, Nyhlin, & Paterson, 2000; Tsoneva, 2004). Nevertheless, some argue that the notion of the sick role has overlooked the phenomenon of social stigma because the patients' fear of being stigmatised prevents them from taking the 'sick role' willingly (Walsh, 2004). Besides, women who are responsible for family care may prohibit her from her role's obligation. In addition, the action of the 'sick role' may not apply to other cultures and societies.

As the burden of health care has been shifted from acute illness to chronic illness (Bensing & Verhaak, 2004; Bury, 1997), the traditional model, which is physician-directed and compliance-oriented, has been recognised as inappropriate for chronic conditions (Adolfsson et al., 2004; Anderson, 1995; Arnold et al., 1995; Thorne, Nyhlin & Paterson, 2000; WHO, 2003b; Holman & Lorig, 2000). The health needs of patients between chronic and acute illness are not the same because chronically ill patients live in a community, and they require different patterns of health care. Living with chronic disease, the patients have to make decisions mostly outside of clinics. If

they want to satisfactorily perform health care, they are required to learn comparative knowledge and skills to cope with a variety of uncertainties by themselves with little possibility of getting instant help from health professionals (Beaser, Richardson & Hoolerworth, 1994). Under the biomedical model, the improvement of health care in chronically ill patients has its limitations, even though the strategies of healthcare services have made some improvements (Ferlie & Shortell, 2001). For example, many diabetic patients still suffer from serious complications after receiving health care from those systems that offer well-developed guidelines for diabetes management (Funnel & Anderson, 2004). Meeting the need of chronically ill patients, the World Health Organisation (2003b) once urged to develop innovative healthcare systems to ameliorate the problems.

Chronic illness management: A paradigm shift

To overcome the limitations of traditional caring approaches, numbers of innovations have endeavoured to satisfy the health care needs of chronically ill patients (Bodenheimer, Wagner, & Grumbach, 2002; Glasgow et al., 2001; Wolff & Boulton, 2005; Shetty & Brownson, 2007; Soubbi, 2007; Kirsh & Aron, 2008), and these designs are ‘patient-centred’ rather than ‘health-professional-centred’ (Wolpert & Anderson, 2001; Szecsenyi et al., 2008). To achieve this, reengineering the health care system to help patients has come to generate the patient-centred form of comprehensive health care services, which involves the redesigning of the delivery system, modernising the clinical information system, organising decision support, supporting self-management behaviours, and linking with the resources of the

community (Bodenheimer, Wagner, & Grumbach, 2002; Hroschikoski et al., 2006). The model is teamed up by multidisciplinary health care professionals who work together to educate, counsel, and empower patients with self-care skills for managing their chronic diseases (Wolff & Boulton, 2005). Furthermore, the health care relationship has been altered as patient empowerment replaces compliance in guiding the provider-patient interaction in the context of chronic illness (Aujoulat, d'Hoore, & Deccache, 2007) to shape the mode of health services. The concept places the patient in a partnership with health care professionals (Smith, 2004; Walker, 2003; Rodwell, 1996), in which patients need to be empowered to take on an active role in their own self-care.

Empowerment and partnership

Empowerment is defined as 'the discovery and development of one's inherent capacity to be responsible for one's own life' (Funnell & Anderson, 2003, p.454). The philosophy of empowering patients can be a philosophy or a process, and it is to foster their capability of disease management that enables them to deal with many situations in the context of a community (Anderson, 1995; MacKinnon, 2003; Alberts et al., 1998; Ma et al., 2006).

The empowerment approach to help patients achieve their self-management goals has been a focus since the 1990s (Anderson, 1996; Funnell & Anderson, 2003). As patients have to manage self-care largely by themselves, to empower patients by means of facilitating social support to make their task of coping easier (Feste & Anderson, 1995) would benefit the treatment's outcomes and increase the patients'

sense of self-efficacy (Tones, 1992; Donaldson, 2003; Anderson et al., 2005), which in turn results in improving the outcome of self-management to reduce the expenditure of health care (Lorig et al., 1996; Lorig et al., 1999; Anderson et al., 2005), essentially promoting better control of conditions (Lorig et al., 1996; Lorig et al., 1999; Jørgensen, Kristiansen & Kirketerp, 2001), and ameliorating the problems of consequences (Lorig et al., 1996; Cushen & Kruppa, 2004; Braun et al., 2003). To successfully carry out the concept of empowerment in clinical service, health professionals have to be trained for better communication skills; their roles would involve reshaping the mode of health interaction, and they have to encourage patients to be actively involved in the decision of health care instead of being passive recipients (Thorne, Nyhlin & Paterson, 2000).

The health care relationship in chronic care differs remarkably from the acute-care model (Thorne, Nyhlin, & Paterson, 2000; Funnell & Anderson, 2000). More than 95 percent of the primary providers of chronic care are the patients themselves at home (Funnell & Anderson, 2000). They know better of their experience of illness, social contexts, health beliefs, behaviours, and attitude regarding risks, values, and preferences (Anderson, 1995; Holman & Lorig, 2000; MacKinnon, 2003; Cushen & Kruppa, 2004; Donaldson, 2003). Furthermore, unlike acutely ill patients who can temporarily free themselves of their social obligations while being hospitalised (Parsons, 1951), they mostly have to engage in other goals, priorities, health issues, family health issues, family demands, and other personal concerns that make up their lives (Funnell & Anderson, 2000). Under such a complex environment, their right to plan and make decisions on how to live with disease is broadly recognised because they are the very persons to take action and live with the consequences (Funnell &

Anderson, 2000). On the other hand, health professionals have to share information, decision-making, evaluation, and responsibilities with their clients (Coulter, 1999; D'Ambrosia, 1999; Landro, 1999). To enable patients to practice self-management in reality, the concept of empowerment is adopted to equip the patients with specific knowledge and skills, as to foster the sense of 'self-efficacy beliefs' and 'perceived locus of control.' However, knowing is one thing, and taking action is another; only if the patients can realise that the learning is worthy, and after they take control over it and take real action (Tones, 1992) can self-management behaviours be performed.

Notwithstanding, the interventions of patient empowerment still encounter negative effects, such as the difficulties in converting their relationships with the patients towards this paradigm while they unconsciously use traditional approaches to interact with patients, and fail to share the power of decision while providing health care services (Pill et al., 1999; Thorne, Nyhlin & Paterson, 2000; Etu-Seppälä, 2001; Paterson, 2001; Henderson, 2003). Because of their experience and training background, health care professionals have been unconsciously affected by biomedical perspectives while offering health care (Russell et al., 2008), or they might misinterpret the concept and result in unsatisfied outcomes of chronic care (Rissel, 1994). Still, embracing the biomedical model unconsciously, some health care providers who have been equipped with guidelines may yet demonstrate their authority while interacting with patients (Herbert et al., 2007; Clark & Gong, 2000; Wolpert & Anderson, 2001; Thorne, Nyhlin, & Paterson, 2000). Some health professionals consider that empowerment is merely a 'politically correct' terminology, and some who employ a collaborative approach to manage disease have been frustrated because of lack of support from their colleagues and/or health care systems

(Anderson & Funnell, 2005). Nevertheless, evidence suggests that the chronic care model is more likely to offer patient-centre care, structured and collaborative care, and all these lead to better quality of care of diabetes (Szecsenyi et al., 2008; Russell et al., 2008; Solberg et al., 2006).

Whilst patient empowerment has been broadly adopted as a healthcare mode, the health care system in Taiwan has started to adopt the chronic care model in diabetes care. How to provide effective health service is the main concern of diabetes care. Based on a survey held by the Taiwan Diabetes Association in 2003, more than 5,000 diabetic patients were selected from the institutions of the Diabetes Shared Care Networks. However, the results are far too high above the expected goal, with the mean value of HbA_{1c} being 8.9% (Tsai, 2004). The data signals a warning that the diabetes care in Taiwan still has a large scope to improve.

Diabetes management

Diabetes care, similar to other chronic illnesses, has been focusing on the need to shift the traditional relationship between patients and healthcare professionals. As a growing burden of diabetes results in significant morbidity and mortality, diabetes care has been moved from provider-centred to patient-centred, such as from compliance/adherence to self-management (Lutfey & Wishner, 1999; Glasgow & Anderson, 1999). To improve self-management, empowerment is adopted as the major concept of health care (Anderson, 1995; Alberts et al., 1998). The chronic care model has been widely applied in health care organizations as a guide to transform

practice in collaborative quality improvement programs that have addressed concerns to diabetes (Bodenheimer, Wagner, & Grumbach, 2002; Hroschikoski et al., 2006). Based on this concept, numbers of studies have shown positive impacts on metabolic control while using innovated diabetes self-management programmes, but no study confirms that the strategy can be effective enough to sustain the necessary healthy-living life changes that diabetes requires (Norris, Engelgau, & Narayan, 2001). Thus, apart from facilitating the chronic care model, to incorporate principles of behaviour change into all aspects of diabetes care and link with community resources is to be taken into account while providing services (Fisher & Glasgow, 2007). However, to apply the principles of behavioural change is not common knowledge known among health care professionals, and as a result, they need to be trained properly.

To achieve optimal treatment outcome, type 2 diabetes in particular requires patients to be adapted to the often complex lifestyle changes and medical regimens diabetes mellitus; and by doing so they have to develop their own repertoires of self-management skills (Beaser, Richardson & Hoolerworth, 1994) because, in reality, immediate help from the health professionals is not enough. However, because the patients' health beliefs are unlike those of the doctors and nurses, this may prevent them from taking health-related advice, particularly when self-management is a greater burden than having asymptomatic disease. Thus having a better understanding of patient perceptions by health professionals may improve the therapeutic agreement. It is essential to understand what the patients experience while integrating diabetes in daily lives, as well as their thoughts and decision-making in the context of living with diabetes while making efforts to improve diabetes care.

Overview of diabetes self-management and key influential factors

Introduction

Self-management can be described as ‘a set of skilled behaviours engaged in to manage one’s own illness,’ influencing the outcomes of the treatment regimen (Goodall & Halford, 1991, p. 1). The skills needed to be known by the patients with diabetes are identified as diet, exercise, self-monitoring of blood glucose, foot care, travelling and sick-day management, and taking medicine; they are the very ones responsible for carrying out day-to-day self-care activities (Anderson & Funnell, 2000). After being diagnosed, diabetic patients are expected to follow the prescribed therapeutic regimen, in which a change of lifestyle is considered the most difficult goal to achieve (Whittemore, 2000). There are many factors that influence self-management. This section aims to gain a comprehensive understanding of these factors. It offers a solid platform for the study to be carried on further. The first part of the literature review of this section focuses on the factors that influence self-management. The second part reviews research on the patients’ experiences of carrying out diabetes self-management. Finally, I present a model of diabetes self-management that integrates the existing knowledge on this issue.

Factors that influence self-management

A number of studies have been conducted to investigate the factors influencing non-compliance/non-adherence (Wilson et al., 1986; Ary et al., 1986; Kyngäs, Hentinen

and Barlow, 1998; Kyngäs et al., 1996; Vermeire et al., 2003). The patients who do not meet the goals of treatment regimen, including taking medication, diet, exercise, self-monitoring of blood glucose, foot care, and disease-related health care, can have many reasons. These reasons are classified into four components: physiological, psychological, socio-cultural, and economic-environmental. Two of these components regard individual factors, including (1) physical condition, (2) cognitive situations, (3) psychological factors, and (4) emotional factors; they are different from individual to individual. Some influential factors are involved with social norm or perspectives of a collective of people and the environment; and these factors are shared by a group of people who live in the same environment. The following sections will discuss what has been explored amongst these components, including (1) physiological, (2) psychological, (3) socio-cultural, and (4) economic-environmental aspects.

The physiological component

Physical inability is a factor that affects self-management; it mainly focuses on exercise. Pain and disability, such as arthritis, hip problems, limb numbness, and amputation might prevent patients from taking regular exercise (Anderson et al., 1998; Hill-Briggs, 2003), and blurred vision can prevent patients from taking medicine (Anderson et al., 1998). These conditions, if serious enough, can also affect the preparation of diet for diabetes and self-monitoring on blood glucose. Physical tiredness, which can result from either poor metabolic control or simply overworking, could be a barrier (Samuel-Hodge et al., 2000) to exercise in particular (Jerant, von Friederichs-Fitzwater, & Moore, 2005). In Paterson and her colleagues' (1999) study, some people have been adapting to lower blood glucose, which may harm their body;

and under such situations, patients can develop hypoglycaemia unawareness, resulting in lack of physical warning signs to inform them to take self-care behaviours while needed. In contrast, some studies show that patients who are able to link the relationship between blood glucose levels and the emerging signs/symptoms of their body are more likely to carry out self-management as expected (Paterson & Sloan, 1994).

The psychological component

Great numbers of studies have contributed in building up the knowledge in this domain, and some even use concepts developed from other schools to explain the phenomenon of health behaviours to gain a better understanding of diabetes self-management. If specific knowledge that can affect diabetes self-management is the most often mentioned, some topics are also receiving attention from various studies, namely the problem-solving skills, health beliefs, personal traits, inner drive, and emotion (Hill-Briggs, 2003; Fisher et al., 1998; Paterson & Sloan, 1994). It is also recognised that knowledge alone does not necessarily translate into good self-management. Nevertheless, it is the foundation upon which strategies have to be built.

Knowledge and problem solving

It is widely accepted that a prerequisite for self-care is the knowledge about diabetes (Funnell et al., 2008). Although some studies report a positive relationship between knowledge and self-care, some debate that knowledge is not guaranteed for good metabolic glucose control (Coates & Boore, 1996; Herbert & Visser, 1996).

Nowadays, diabetes education not only imparts knowledge and skills, but also applies various strategies, such as facilitating the strategy of behavioural analysis to assist the patient in making behavioural changes that increase adherence and improve metabolic control (Boehm et al., 1993), providing lifestyle programmes that employ a tailored plan and use brief motivational interviewing to overcome barriers and encourage lifestyle change (Clark & Hampson, 2001), and with its major attempt focusing on behavioural change (Williams, 2001), such as facilitating nurse coaching intervention to improve self-management behaviour (Whittemore, Melkus, & Grey, 2005). The problem-solving skill is considered an essential ingredient of self-management, and significantly associates with metabolic control (Hill-Briggs, 2003; Hill-Briggs & Gemmell, 2007; Paterson & Thorne, 2000). Without relatively high domain-specific knowledge and experiences, patients may fail to enact self-care appropriately (Benner, 2001; Hill-Briggs 2003). The problem-solving skill should be attached to the knowledge sooner or later to facilitate suitable strategies for solving problems, otherwise the patients may have good problem-solving skills but are misdirected by misconceptions.

Lack of relative diabetes-specific knowledge might easily lead to misconception, which has a negative impact on self-care. This phenomenon is not uncommon among diabetes patients in Taiwan. Lai and colleagues' (2005) study describes that a participant's yi-guan-dao³ brother insists her taking no medicine because diabetes needs to be remedied by food. It indicates that lay-person could involve with the patient's self-management decision even though he has not yet totally understood how to deal with diabetes management. Therefore, the sufferers may simply accept the

³ Yi-guan-dao (or I-Kuan Tao): A new religion originates in twentieth-century China, and that incorporates much older elements from Confucianism, Taoism, and Chinese Buddhism.

suggestions from their friends or relatives who may lack diabetes knowledge (Keszthelyi & Blasszauer, 2003), which results in a vulnerable situation. There are few discussions on this topic, but the cues are obtained from the qualitative studies or clinical experiences. For example, some suffering from type 2 diabetes might refuse to take insulin in fear of damaging to his or her pancreas, of addiction, or of consideration that that is caused by the failure of treatment regimen (Mordenti, D'Angiolini & Murgia, 2000; Gentili et al., 2000; Skinner, 2004).

Health belief

Many studies have investigated the association between health beliefs and self-management, especially self-efficacy, locus of control, and perceived threat/serious (Coates & Boore, 1996; Fisher et al., 1998; Paterson & Sloan, 1994). Self-efficacy and locus of control are facilitated quite often by the diabetes educators to develop educational programmes for encouraging self-management behaviours, and those are adopted from the educational domain to improve self-care and learning outcomes in diabetes (Fisher et al., 1998; Bandura, 1997). Self-efficacy stems from Bandura's (1997) social cognitive theory, which is considered a central concept in self-management. Self-efficacy is defined as having confidence to carry out of behaviours that are necessary to achieve desired outcomes (Bodenheimer, Wagner & Grumbach, 2002). Some empirical evidences show that higher self-efficacy is linked to better outcomes (Chang & Lin, 1997; Guo, Tsay, & Yen, 2002; Littlefield et al., 1992; Wu et al., 2007; Chlebowy & Garvin, 2006; Senecal, Nouwen, & White, 2000; Aljaseem et al., 2001). Numbers of diabetes educational programmes or interventions have been designed to improve the patient's self-efficacy and self-management behaviours

leading to positive outcomes (Corbett, 1999; Lorig et al., 1999; Lorig et al., 2001; Whittemore, Melkus, & Grey, 2005; Wangberg, 2008). Many interventions are shown to have improved self-management behaviours, but there is still no one who could successfully retain the behaviours in a long period. In Sigurðardóttir's (2005) literature review, knowledge, physical skills, and emotions are the three basic elements that contribute to self-management activities and diabetes-related self-efficacy. Perceived threat/seriousness has been mentioned in many studies, which functions as a strongly influential factor to motivate the diabetics moving toward self-management (Nyhlin, Lithner & Norberg, 1987; Whittemore et al., 2002; Tan, 2004). Lack of knowledge causes patients difficulty in identifying further risks of their health (Tan, 2004); therefore, many health professionals emphasize heavily on the complications to induce their motivation. Hence, it needs to be managed carefully, or it might cause negative emotion to the patient that leads to avoidance of self-care behaviours.

Personal traits

Personal traits are the subjects of the study on the relationship between compliance and individual's personality traits (Gentili et al., 2000; Orlandini et al., 1997; Mordenti, D'Angiolini & Murgia, 2000). Ciechanowski and colleagues (2004) examined the characteristics of patient attachment style on self-care and outcomes in diabetes; the results show that dismissing attachment style⁴ is linked with lower levels of exercise, foot care, diet, and adherence to oral hypoglycaemic medications.

⁴ Four specific patterns of interpersonal attachment behaviours are identified in adults: secure and three insecure styles known as dismissing, preoccupied, and fearful. An adult that is identified as predominantly dismissing attachment style is stated to have experienced early care giving that was consistently emotionally unresponsive, and from an early age, they develop strategies in which they became highly self-reliant and uncomfortable trusting others (Ciechanowski et al., 2004, p.721).

Another study shows that greater opposition and ambiguity, less self-confidence, more inflexible, less demanding of the others, and more inclination to bargain would be great hindrances against insulin treatment (Mordenti, D'Angiolini & Murgia, 2000). Furthermore, many studies have discussed the issues of age, onset of age, duration of diabetes (Hepburn et al., 1994), hardiness personality (Ross, 1991), type A behaviour pattern (Sensky & Petty, 1989), gender (DeVries, Snoek & Heine, 2004), and so on. The results might be useful to predict self-care behaviours; yet it contributes little for nurses in conducting nursing care in the real-world practice because the lack of concrete guidelines could probably ameliorate their characters.

Inner drive

Inner drive is identified as the inner force for people to take action, such as motivation and needs. Motivation is one of the factors broadly believed to be linked to self-care or glycaemic control (DeVries, Snoek & Heine, 2004; Viner et al., 2003). The way to improve individuals' motivation is not well established, and the strategies used to improve blood glucose control has found only short-standing instead of long-standing improvement on self-care behaviours (Nurymberg, Kreitler & Weissler, 1996). It is believed that to improve motivation would ameliorate the problems of poor self-management or blood glycaemic control (DeVries, Snoek & Heine, 2004), such as motivational interviewing facilitated to ameliorate non-compliance or poor blood glucose control, and some of which have shown positive results (Trigwell, Grant & House, 1997; Senécal, Nouwen, & White, 2000; Channon, Smith, & Gregory, 2003; Viner et al., 2003). However, the mechanism of motivation might vary individually, and it is a tough challenge for the health care professionals to find out what the most

effective motivator or barrier is for the patient's self-care behaviours. There are still many puzzles left to be pieced together to understand the phenomenon.

Emotion

Many studies note that most of the chronically ill encounter strong emotional reactions whilst they are diagnosed with chronic disease (Price, 1993a; Charmaz, 1996; Beeney, Bakry & Dunn, 1996; Whittemore et al., 2002). These emotions might include fear, anxiety, helplessness, and depression (Bury, 1982; Nyhlin, Lithner & Norberg, 1987; Littlefield et al., 1992; Price, 1993a; Whittemore et al., 2002; DeVries, Snoek & Heine, 2004). Stress is believed to have negative effects on metabolic control (Surwit et al., 2002). If patients merely concentrate on tackling the problem itself, such as looking for the remedy of the disease rather than self-care, it would lead to aggravation of their conditions. Negative emotions can be raised while perceiving the vulnerability toward morbidity/mortality (Whittemore et al., 2002; Nyhlin, Lithner & Norberg, 1987); however, if health professionals provide information in a threatening way, it could increase the tendency to deny the disease and the meaning of it (Nyhlin, Lithner & Norberg, 1987). Having a sense of meaninglessness reduces the motivation to engage self in self-care behaviours (Nyhlin, Lithner & Norberg, 1987). People with type 2 diabetes tend to have a higher incident rate of depression than those who do not have diabetes (Eaton et al., 1996), and depression is found to be linked with poor metabolic control (Gary et al., 2000; McKellar, Humphreys, & Piette, 2004). However, to improve the symptoms of depression does not necessarily improve metabolic control (Lin et al., 2006). In addition, the family members under stress can affect the patients' self-care behaviours (Fisher et al., 1998); these are

mostly negative influences. Lower self-esteem also contributes to poor blood glucose control (Littlefield et al., 1992). Whilst the patients fear that hypoglycaemia could prevent them from keeping blood glucose levels within normal range, fear of long-term complications could motivate the patients to be cautious on the control of blood glucose levels (Paterson et al., 1999). The attempt to ‘want to be normal’ could motivate the sufferers either to perform good self-management (Nyhlin, Lithner & Norberg, 1987) or to ignore it (Paterson & Thorne, 2000), especially when they are in adolescence.

In summary, negative emotions might not always give negative impacts on self-management, and they could have different explanations or meanings to the patients. Carefully appraising the patients’ situation might help to provide health services properly.

Socio-cultural component

To carry out diabetes self-management inevitably involves being in a community and engaging in daily activities while surrounded by others. Interaction with others means that social and cultural norms have a major influence on health beliefs and behaviours, and that helps to understand culture as part of understanding diabetes self-management in Taiwan. Culture was defined as ‘the learned and shared beliefs, values, and lifeways of a designated or particular group that are generally transmitted intergenerationally and influence one’s thinking and actions modes’ (Leininger, 2002, p. 9). Kavanagh and Kennedy (1992) defined it as a group of people who share a system of beliefs and general worldview, and it affects the concepts of health and illness.

In the context of Taiwan, family is still embedded in the context of traditional Chinese culture and is heavily influenced by Confucianism. Together these lead to family and social relationships in a hierarchical society (Kim, Laroche, & Tomiuk, 2004; Smart, 1969). The relationships include father and son, elder brother and younger, husband and wife, elder and younger, and ruler and subject (Smart, 1969), and women have predisposed taking household task-role expectations and performance (Kim, Laroche, & Tomiuk, 2004). The social expectations of traditional family values foster strong family ties, filial expectations (Bond, 1993), and provide intergenerational care giving (Bond, 1993; Lee, 1997; Lee, 2007). Furthermore, females are expected to be the major caregivers of the family, and their performance is socially appraised by the roles they play as wife, mother, and daughter-in-law.

Arising from Confucianism, an influence on the behaviour of Chinese is that people are used to respecting their elder generations, as it is considered immoral not to (Smart, 1969). In addition, it affects the interaction between physician and patient, where the management of health and illness is constructed from biological, psychological, social, and cultural experiences (Shih, 1996). For example, even though a patient might not agree with advice given by the doctor, their reaction would remain silent. Instead, later they would take the opportunity to visit other doctors, resulting in repeatedly consuming health care resources. However, once a trust relationship is established, advice from a doctor becomes very persuasive, leading to positive influence on health care behaviours.

The influence of culture can be visible, invisible, or even in the subconscious/unconscious (Helman, 2000); therefore, sometimes it is hard to identify if the factors of culture come into play. Many researchers argue that a chronically ill person that is subject to physical discomfort tends to be vulnerable to cultural influence (Chi et al., 1996; Gregory et al., 1999; Goenka et al., 2004; Wood, Athwal & Panahloo, 2004). This means that in Taiwan, complementary medicine, traditional medicine or folk medicine need to be recognised alongside the increased use of biomedicine (Chacko, 2003). For example, a diabetic patient might hope to be cured and might believe that traditional remedies would take care of his body, leading him to ignore the importance of practicing self-management.

Ironically, most empirical studies related to Chinese culture and health care are published in Western countries (Gregory et al., 1999; Smart, 1969; Chen, 2001; Shih, 1996), and are seldom found in Taiwan. Nevertheless, the issues encountered in Western countries may not necessarily explain phenomena in Taiwan, but it can reflex the fundamental issues related to cultural issues. For example, dining together is the most significant social activity in Taiwan to interact with others, and this makes diet behaviour highly vulnerable to social influence (Sharma & Cruickshank, 2001; Gregory et al., 1999). Furthermore, it is common to the people who possess a culture different from nurses and this may result in problems if they have a taboo or ritual regarding their particular disease (Gregory et al., 1999). As a nurse, to respect the patient's culture is a way to establish rapport and requires that care is managed individually, not collectively.

The importance of social support has received much attention in diabetes care (Fukunishi et al., 1998; Kyngäs & Rissanen, 2001; Toljamo & Hentinen, 2001; Gallant, 2003), and health professionals need to take account of this in particular. Health care professionals providing health information and psychological support are vital to comfort people during their first experiences with a chronic disease diagnosis (Whittemore et al., 2002; Gallant, 2003). Patient's self-management behaviours appear to be susceptible to the health professionals' attitude (Hernandez, 1995; Paterson & Sloan, 1994; Ross, 2004), whether it is principle-oriented (Gregory et al., 1999), or using professional's power (Hernandez, 1995; Gregory et al., 1999) and this may similarly lead to a positive or negative effect. Similarly, individuals cannot carry out self-care properly when he or she is in a dysfunctional family (Fisher et al., 1998; Maharaj et al., 1998). Social stigma can prevent an individual from disclosing an illness-identity from the others, which may lead to avoiding self-care activities every time he or she cannot hide self-care activities from the public (Shiu, Kwan & Wong, 2003). An example is that many young diabetic adults tend to cover their illness-identity from others because if they disclose their disease, it might reduce their chances of getting married (Goenka et al., 2004). Also, different genders have different social support. Due to their role of caregivers to their own family, women tend to have less support from families, and multiple family members could hinder them from self-management (Samuel-Hodge et al., 2000). In contrast, men who are married tend to have their wife or partner to prepare proper food for them thus they tend to have better self-management (Koch, Kralik & Taylor 2000). Self-management extensively involves daily activities, thus carrying out self-management is influenced by many factors. As a result, it is necessary to consider a healthcare plan that is flexible enough to suit all the situations regarding self-care.

Economic-environmental component

Many studies suggest that the influence of the economic-environment to diabetic patients mainly lies in the access to facilities of exercise, healthcare services, and food. Some studies argue that several factors regarding economic-environment are found to hinder self-management activities, and these factors can apply to the context of the Taiwanese society, such as fear to exercise because of criminal concerns (Plescia & Groblewski, 2004; Brody et al., 2001) during the evening, lack of sidewalk, few facilities for exercise (Plescia & Groblewski, 2004; Brody et al., 2001), or easy access to energy-dense foods (Wing et al., 2001). In contrast, individuals who are actively involved in lifestyle change would try to explore the environment and restructure the environment to best support the changes (Whittemore et al., 2002).

Taiwan, Republic of China, is located in the subtropical climate zone, and the average temperature is around 22°C, and the lowest is 12–17 °C in winter, and the highest is above 30°C between May and August (Tourism Bureau, 2008), when the weather is sultry and oppressive. Not many people enjoy exercising under a scorching sun during the summer, especially the females. But things may start to change. Currently, the government is building cycling paths around Taiwan to encourage cycling since the fuel price is soaring to a historical height. This would create a better opportunity for changing lifestyles.

In summary, the factors that affect diabetes self-management cover the individual internal and external environment. Physiological and psychological components are classified as the internal environment, although both are strongly influenced by the

social environmental context. Some studies discover that the physiological condition could affect the patients' decision-making on diabetes self-management. If the behaviours of self-management are accompanied with uncomfortable feelings such as pain, non-adherence can be expected. On the other hand, if self-management improves the signs/symptoms that results in poor metabolic control, it would be more likely to be carried out. The psychological component is another internal environment of individuals to influence self-management behaviours. Sufficient knowledge and skills are essential to self-management, but do not necessarily lead to positive results. Yet, many other factors also contribute to self-management behaviours, including knowledge, problem-solving skills, health beliefs, personal traits, emotions, inner drive, socio-cultural, and environment.

The expertise diabetes self-management and the trajectory

Introduction

Apart from the study on the influential factors of diabetes self-management, there are some researchers endeavouring to examine the trajectory of diabetes self-management, from beginner to expert. For chronic disease, evidence of expertise in self-management could reduce the burden of health care as well as increase the quality of care (Thomas, 2001; Richardson et al., 2008). Learning from expert diabetes self-managers might provide valuable information to assist those diabetic patients who suffer from discontent diabetes self-management because it might unfold the decision-makings essential for becoming an expert self-manager. Attempts to gain deeper understanding about how patients cope with diabetes and integrate diabetes into their lives to become expert self-managers are the main purpose of this section.

Expertise in self-management

Living with diabetes may not be as easy as health care professionals have perceived. Farquhar (1995), who is a doctor, has suffered from type 1 diabetes for more than thirty years argued that individuals who have been highly motivated might still find it difficult to maintain blood glucose in constant levels because self-management is a complex and substantial daily task. He suggested that health care providers need to enhance patients' 'expertise and skills (p. 254)' to deal with day-to-day activities, which include learning how to make decisions of self-management, relying on the result of self-monitoring of blood glucose. The patients have to learn advanced diabetes-specific knowledge and need to be educated and empowered to develop the skills of self-management until achieving an expertise status. An increasing number of researches and evidences on the sociological and allied aspects of expert patients have now been accumulated (Lorig et al., 1999; Paterson & Thorne, 2000; Paterson, Thorne, & Dewis, 1998; Schoot et al., 2005; Wilson, Kendall, & Brooks, 2006). Furthermore, to assist patients in becoming expert patients, it has been integrated into the healthcare system in the United Kingdom — the Expert Patient Programme (DoH UK, 2001a). However, there were health care professionals that showed their doubts, especially the doctors (ABPI, 1999; Wilson, Kendall, & Brooks, 2006). The concept of expert patient still needs further investigation.

How to achieve the expertise status has drawn the attention of health professionals (Paterson, Thorne, & Dewis, 1998; Paterson & Thorne, 2000; Shimizu & Paterson, 2007), although the definition is yet to be clarified (Shaw & Baker, 2004; Fox, 2005;

Waterlow, 2005). The majority of information is obtained from those who live in Western countries, mainly the Caucasians, well-educated married women, specifically with type 1 diabetes (Paterson, Thorne, & Dewis, 1998; Kyngäs, 1999; Whittemore et al., 2002); thus, it needs further investigation from various diabetic populations. Given the different cultures, the philosophy of living with diabetes for the Chinese has been raised as an important issue to be concerned.

The trajectory of self-management

Qualitative research and in-depth information reveal how patients develop their own strategies to cope with myriad of situations until they are overcome. Paterson and Thorne (2000) define expert self-care as when patients have achieved the status of ‘awareness of their own bodies and what works best for them (p. 402)’; and to reach this status, time is a critical element (Paterson, Thorne, & Dewis, 1998; Price, 1993a). Price (1993a) presumes that five years are necessary for patients to learn, but Paterson and her colleagues (1998) believe at least 15 years are needed. The following stages have been identified from the existing research evidence.

Passive involvement — Stage one

Numbers of studies illuminate that follow a prescribed regimen is a common pattern of self-management in the early stage since diagnosed as diabetes, and patients are characterised as passive participants. This stage is identified as the first phenomenon of diabetes self-management process (Albright, 1994; Ellison & Rayman, 1998; Hernandez, 1996; Paterson & Thorne, 2000; Price, 1993a; Whittemore et al., 2002).

The patients in stage one are recognised as following the treatment regimen thoroughly or partially, a mere passive compliance to the regimen.

By following the regimen, good blood glucose control could be expected. It is clear that most health providers would expect patients to maintain the current condition, and this is referred to as compliance to the treatment regimen. But not all patients at this stage can follow the entire regimen or practise self-management. Whether the regimen could be carried out successfully depends on the patient's understanding of disease-specific knowledge and skilful decision-making, which are necessary for the patient to execute day-to-day self-care activities (Hill-Briggs, 2003).

The patients might attend an educational programme that introduces them to self-management in their daily lives. Upon completion of the programme, the patients are faced with their own self-care for the first time; negative feelings are common at this stage (Ellison & Rayman, 1998; Whittemore et al., 2002) such as fear and loneliness. Only when the patients reconcile their negative emotions can they become good decision-makers to deal effectively with self-care (Ellison & Rayman, 1998; Whittemore et al., 2002).

Medication is reported to have the most satisfying level of compliance when compared to the rest of the self-care activities. Actually, the patients mostly perceive the healthcare professionals as the authority for treating their diabetes. On the other hand, not every patient has the chance to attend an educational programme; only 35–58% of the patients attend such a program in the United States (Whittemore, 2000). In Taiwan, there is no data to show the percentage of patients attending the programme,

but attending diabetes self-management programme is part of the package of diabetes care by which the government provides an incentive payment scheme to improve the quality of diabetes care.

Salient experimental behaviour for assuming control — Stage two

Stage two is characterized by patients' beginning to actively practise their lifestyle as a diabetic, which involves a series of experimental activities or trial and error with the intention to take control of the disease. The reasons patients enter this stage vary, but include the following: the desire to live as a normal person (Paterson & Thorne, 2000), living like a mature person, being responsible for self-care and not merely following orders (Hernandez, 1996), and the desire to control diabetes (Paterson & Thorne, 2000; Paterson & Sloan, 1994).

While following the prescribed regimen, some patients with diabetes still experience the effects of the illness (Larme & Pugh, 1998; Paterson & Sloan, 1994) and are consequently blamed by health care providers for not following the regimen due to the apparent poor blood glucose control. Only when patients feel frustrated from the failure of the regimen and decide to assume self-control (Paterson & Sloan, 1994) do they start to experience different methods of diabetes care.

At this stage, some patients become actively involved in their own self-care activities, and learn to experience and even make mistakes (Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993a). They 'begin to interpret information, making

allowances in their management routines, and developing an increased awareness of their body' (Ellison & Rayman, 1998, p.328). In contrast to the adult patients, adolescents with type 1 diabetes moving to this stage might act differently. When taking over the responsibilities for self-care from their parents, these patients might attempt naïve experimentation due to some misconceptions; there might even be the denial of having diabetes in order to lead a life like a normal teenager (Paterson & Thorne, 2000).

During this stage, patients start by altering diet practice in accordance with their living environment because it has less effect than medication (Paterson et al., 1998). No two diabetes cases would have exactly the same experience and history; however, the majority of sufferers agree that the standardised knowledge offered by the health professionals is not thoroughly suitable for them (Pooley et al., 2001). Following a strict treatment regimen, such as medication and recommended lifestyle is not easy for all patients. However, once the patients start to know more about diabetes, the responses of their bodies and the need for self-control, the desire to fit diabetes into their own living environment motivates them to look for different self-care activities or strategies to enable self-control (Ellison & Rayman, 1998; Hernandez, 1996; Paterson & Thorne, 2000; Price, 1993a; Whittemore et al., 2002).

Among the self-care activities, dietary regimen is reported as the most difficult part to adhere to (Albright, 1994; Whittemore et al., 2002); it is also most vulnerable to social influences in particular (Gallant, 2003). Although patients might accept support from health care professionals providing disease-specific information, the massively detailed and in-depth printed material sometimes confuses the patients (Albright,

1994; Dietrich, 1996) due to a lack of reciprocal communication (Albright, 1994). In particular, the lists for meal planning might not realistically fit within the social and environmental context of the patient's life and thus lead to failures of compliance; that is, patients would try to find meals to suit them from the standardised menu (Albright, 1994). These trial-and-error attitudes, deviating temporarily from the treatment regimen, would result in a wider range of blood glucose levels (Paterson, Thorne & Dewis, 1998). Consequently, some patients were labelled as non-compliant simply due to their unstable blood glucose levels (Paterson, Thorne & Dewis, 1998). If abnormal blood glucose persists for a long period, this might increase the risk of diabetic complications or hospitalisation. The process of self-management is presumed to be dynamic, and patients might return to stage one if they encounter stressful events or fail to adapt their lives to diabetes, which would lead to complications.

A diabetic patient might experience a slightly different pattern of progress in self-management, depending on his particular level of human development. Social roles are still needed to be performed while living with the disease, and their roles are ever-changing, depending on their human developmental stage. Thus, Paterson and Thorne (2000) describe the phenomenon of rebellious behaviours among the adolescent diabetic patients while they are at a stage of developing their own self-identities; however, this may not be suitable for middle-aged patients. Each group needs to be identified separately to gain deeper understanding of the benefit of health service.

Knowing their bodies is essential for diabetic patients to assume self-control over the disease (Paterson, Thorne & Dewis, 1998). Body listening involves trying to listen to

the body closely and deciphering what certain cues mean, such as hypoglycaemia or hyperglycaemia; these should be validated with the results of blood glucose tests (Paterson & Sloan, 1994; Paterson, Thorne & Dewis, 1998). Continuing to compare the results of blood glucose with their body cues could accelerate and advance their skills (Paterson, Thorne & Dewis, 1998). Once the skills are completely developed, the final stage of becoming expert self-managers is achieved (Paterson & Sloan, 1994).

To increase the awareness of the relationship between the actual level of blood glucose and physical responses, it is essential to monitor blood glucose regularly. However, if the patients have financial problems, i.e. cannot afford to buy a blood glucose testing machine and strips, the skill of listening to body cues could be difficult to develop. To help patients advance to the stage of being expert self-managers, financial support might be an important factor.

After accumulation of disease-specific knowledge and experiences, an assumption is made that the problem-solving skills might be important factors at this stage because these skills could help patients sort out the problems more efficiently (Hill-Briggs, 2003).

Paterson and Sloan (1994) suggest that the stage of assuming internal control in the self-management process is based on the following characteristics: actively involved in self-management, incurring the risk of complications and confrontation with the professionals. The leading role of self-management is clearly with the patients

themselves; they decide what to do in their lives, even when ignoring recommendations from health care professionals.

Entering a status as an expert self-manager — Stage three

Stage three is characterised by the patients having succeeded in reshaping their lifestyles relative to diabetes, which leads to better blood glucose control. At this stage, they feel in control of the disease, and see themselves as a healthy person again. They have acquired a wide range of management strategies based on disease-specific knowledge and learned experiences, and can apply them to new situations (Paterson & Thorne, 2000). They accept themselves as successful self-managers. In their lives, diabetes is no longer considered the first priority because they feel more able to control diabetes; diabetes does not control them. Similar evidence was found by the other researchers (Ellison & Rayman, 1998; Hernandez, 1996; Price, 1993a; Whittemore et al., 2002; Whittemore & Roy, 2002). In addition, whilst diabetes has become part of their lives, living with it has no fear, which leads to better blood glucose control. When patients arrive at this stage, they are likely to become expert self-managers (Ellison & Rayman, 1998; Paterson & Thorne, 2000; Price, 1993a) and they consequently reach a high level of confidence in their decisions (Ellison & Rayman, 1998).

Salient features emerge, which include awareness of their own bodies, confidence in the decisions made for the disease, and knowledge of what is best suited to their bodies (Paterson, Thorne & Dewis, 1998). Some individuals even consider diabetes a

positive influencing factor, for it makes their lives healthier both physically and psychologically (Hunt, Pugh & Valenzuela, 1998).

The patients' view of blood glucose checking is obviously different from stage one. They feel that monitoring blood glucose means they know more about the relationship between self-care activities and blood glucose levels, which helps to set them free from diabetes (Paterson & Thorne, 2000).

Developing a conceptual framework

To understand these literatures, I have developed a conceptual framework that guides my research in terms of focusing on the process of diabetes self-management (see figure 1). The conceptual framework, the Process of Diabetes Self-Management, is synthesized from the existing literature. This shows people with diabetes managing to become expert self-managers, and the process in which they reach the status of expertise depending on certain variables, including the internal and external environment. The people with diabetes becoming expert self-managers are influenced by these factors, and all of the factors interact to push forward and backward the status of self-management. Diabetes self-management can be a constant learning process due to the ever-changing physical condition, including emotions, illness, and ageing. Whilst the influencing factor is facilitated as positive, it could be helpful to actively involve the patients with self-management rather than passively follow the prescriptions. While patients are able to get involved with their self-management actively, autonomy would arise. The more they are involved, the more they would learn from their physical responses to various situations or events, which then fosters

their unique knowledge about their own way of living with diabetes. Some may eventually move into expertise in diabetes self-management and become expert self-managers. The stage of active participant is not static, and patients could decline to passive participants by negative forces of many kinds. Once becoming an expert self-manager, the patient might be able to live with diabetes in harmony, turning self-care behaviours into habits.

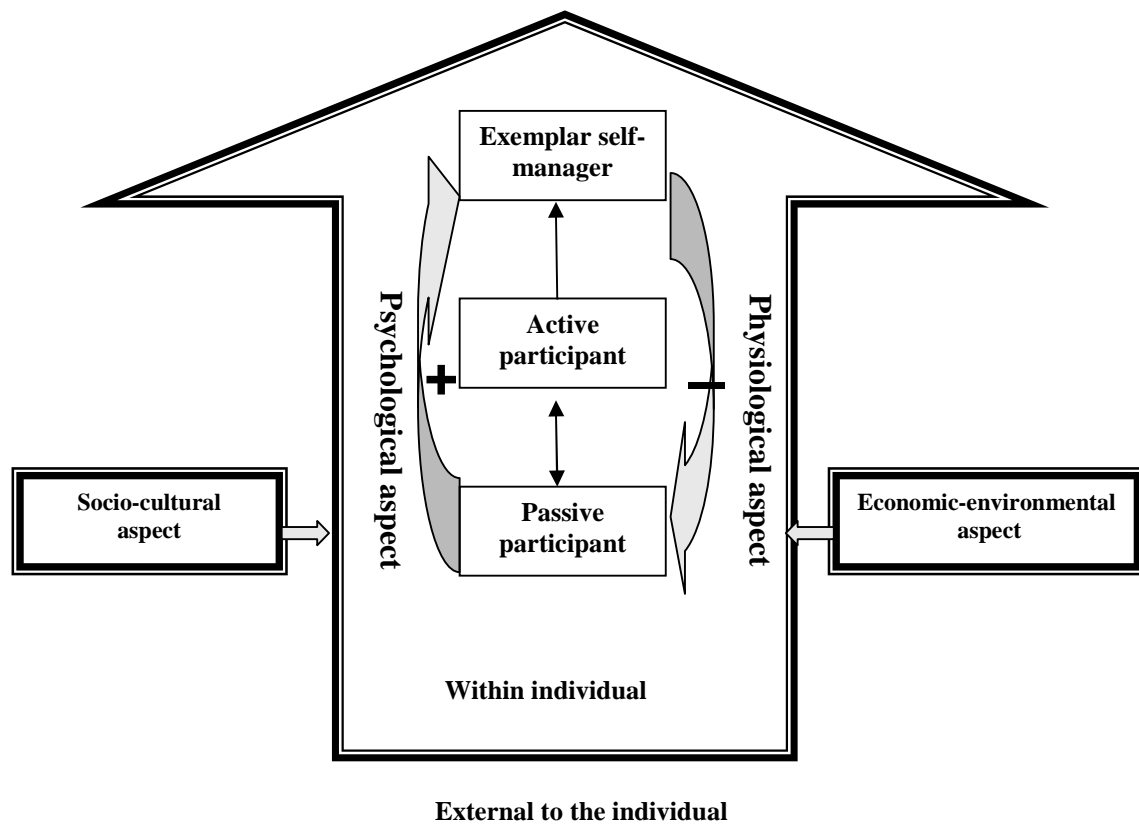


Figure 1 - Framework of the Process of Diabetes Self-Management

Roles of nurses in diabetes care

The human disease has made a transition, in which a dominant disease has shifted from acute to chronic (WHO, 2003b). A trend toward sharing power with patients means that the relationship between the two parties has to change. However, Henderson (2003) points out that the most difficult part to empower patients is when nurses have not yet prepared themselves to change, and to share their knowledge and decision-making powers with their patients. Thus, nurses need to learn how to let go of the professional power whilst interacting with patients, especially those who work on the ward. Moreover, nurses have to extend their knowledge of not only the disease itself but also those communication skills regarding how to deal with diabetic patients, family, and the environment as a whole. To achieve the goal of holistic care, nurses have to develop an assessment tool to detail a patient's information and personal needs (Coates & Boore, 1996). Encouraging patients to master self-management skills and develop into expertise status is a new era of diabetes care (DoH UK, 1999). However, to achieve this goal, there are gaps related to how they can achieve this status that need further investigation from every perspective. Understanding their decision-making on diabetes self-management is one of the avenues to achieve it.

Nurses will need to increasingly incorporate new technologies into the management of diabetes. On the other hand, while many other high-tech products have been facilitated into diabetes care, such as the trend of e-health including the Internet and personal digital assistant (PDA), there are many factors that would influence the mode of health care. Peters et al (2001) suggest that the role of the nurses in type 2 diabetes care involves clinical practice, responsibility, communication, knowledge,

education/experience, rewards, and the patient's roles. For example, with the revolution of medical information, many patients could learn self-management by using the Internet to interact with others (Landro, 1999). The health care provider could be the webmaster and carefully steer patients towards useful information. Nurses could be part of this role, and it might save time for both the health care providers and patients. Diabetes care extensively involves daily activities. Kesby (2002) argues that nurses of diabetes specialists need to engage in community health services to improve diabetes care.

Working as partners with the patients, the roles of nurses would focus on establishing equal relationship with patients, sharing related information and facilities, valuing patients' decisions, and guiding their own way in the complex health circumstances (Jonsdottir, Litchfield & Pharris, 2004). To remain in a long-term relationship with the patients, nurses have to develop strategies to reconcile with patients while needed because the lives of diabetic patients, like any normal person, are consisted to have both good and bad days. Supporting the patients to cope with negative emotions is critical to help them maintain satisfactory metabolic control (Lauritzen & Zoffmann, 2004; Snoek, 2002), as the goals of diabetes care are to prevent long-term complications and maintain the quality of life (Ross, 2004).

Considerable efforts have been made to motivate people with diabetes to adhere to a prescribed regimen. As type 2 diabetes is an asymptomatic chronic illness, patients fail to feel imminent needs to control blood glucose within an acceptable range (Loewe & Freeman, 2000; Ross, 2004). To foster the capability of behavioural change,

there is an increasing need to help patients sustain self-management behaviours (Fisher & Glasgow, 2007).

Conclusion

Diabetes mellitus is becoming an epidemic disease. With the increasing burden imposed on individuals, families, and societies, the improvement of diabetes care to reduce the consequences of the disease is necessary. The treatment regimen of diabetes involves pharmacological and non-pharmacological treatments. To reduce the incident rate of the consequences, the value of HbA_{1c} less than 7% becomes a golden rule for diabetes care. However, to achieve the goal, pharmacological treatment alone is hardly enough, and self-management is needed that requires patients to change their lifestyles. This issue has been a big hurdle in diabetes care because the patients' behaviours are difficult to be managed by the healthcare professionals alone. As a chronic illness, the traditional healthcare model in which most of the primary care has to be done by the patients themselves at home has been proved ineffective to provide good quality of diabetes care. Diabetic patients are the key persons for the expected outcome to be achieved. Thus, chronic care models are innovated to tackle the problems in which the relationship between health care providers and patients is different from the traditional one, as the former views patients as members of the health care team. How to improve self-management behaviours is the key element that influences the outcome of diabetes care; however, there is no common agreement on the measurement of the behaviours of self-management because of its complex nature of context. Numbers of studies that focus on either barriers or facilitators of diabetes self-management offer a background for

the current study to continue to explore the area not well defined or the unknown phenomenon to ameliorate the problem regarding self-management. From the studies, involvement with influential factors of diabetes self-management is divided into four components, which are physiological, physiological, socio-cultural, and environmental. The process of diabetes self-management has provided a primary framework for continuous exploration. The process of diabetes self-management consists of three stages, which are passive participant, active participant, and expert self-manager, and these processes are influenced by a great number of factors identified as four components. It provides a conceptual framework from the macro- and micro-dimension of view on diabetes self-management. Very few studies have been done in Taiwan, thus, there is definitely a need for more research.

Nurses are place into a consultant role to provide diabetic patients with holistic care, and one of the major tasks is to motivate patients for self-management practice. It is implicit that nurses learn more about diabetes regarding not only the treatment regimen but also the influential factors from the above four aspects. Little research studies the role performance or job satisfaction in Taiwan. In my personal experience, motivating patients for diabetes self-management remains frustrating for diabetes nurse educators and nurses. Unable to access to the patients' world, health professionals might somehow show their doubt toward the reasons given by patients, and this phenomenon illuminates an unsuccessful relationship resulting from poor communication. Having more information to understand how diabetic patients live with diabetes and practice self-management in the context of Taiwanese society is considered a way to increase mutual understanding while providing health services. It can only be possible for the patients to reveal their real world while a trusting

relationship is established, which can benefit in tailoring or planning a patient-centred care plan. Otherwise, the nurse role of diabetic counsel may fail to provide patient-centred health services, but rather the courses of diabetes education.

To fill up the gap, I decided to explore the experience of diabetes self-management, which focuses mainly on the perspectives of the diabetic patients. However, the professional perspectives may provide a deeper view in understanding the different perspectives between them, which might be useful for diabetes care.

The aim and objectives of the study

To consider the gap that current studies have left, the aim and objectives for this study are set as follows:

Aim

To investigate type 2 diabetes self-management in Taiwan.

Objectives

- To explore the experiences of self-management in type 2 diabetes in the Taiwanese context.
 - To investigate the patients' self-management strategies and factors that affects this.
 - To compare the patients' perspectives with professional views.
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CHAPTER THREE – CONTEXT SETTING

Introduction

The purpose of this chapter is to give a brief overview of the contextual setting to examine the data collection critically. The study aims to explore the nature of self-management of type 2 diabetes in Taiwan. The data collection comes from the participants with type 2 diabetes mellitus and the diabetes educators in Taiwan. This section starts with an overview of the health care system, diabetes care policy and diabetes care in Taiwan. An overview is necessary to offer a solid platform in which to begin the study.

Health care system and diabetes care in Taiwan

Introduction — A brief introduction to Taiwan

Taiwan, or the Republic of China (R.O.C.), consists of a chain of islands located off the southeast coast of mainland China. Taiwan had been a colony of Japan from 1895 to 1945. At the end of World War II, it was handed back to China, which was under the control of General Chiang Kai-Shek of the Kuomintang (nationalist). Due to the victory of the Communist Party in the civil war in China, the Kuomintang regime retreated to Taiwan in 1949. Taiwan had approximately 23 million inhabitants in 2008, more than 80 percent of whom were descendents of immigrants from the southeast provinces of China, 18 percent were descendents of those who retreated to Taiwan in 1949, and 2 percent were Aborigines (Liu, 1998; MoI, R.O.C., 2008).

Healthcare system in Taiwan

Before 1996, only 59 percent of the population was covered by 13 public health insurance plans. In 1995, the government of the R.O.C. launched a National Health Insurance Programme (NHIP), a single-payer system to replace the multi-payer system consisted of ten social health insurance programs, serving only 57 percent of the total population (Cheng, 2003). This general health insurance is a compulsory insurance, and citizens, permanent residents, those with working permits, or students in the country for more than four months are required to subscribe to it, otherwise one could receive a fine (DoH, ROC, 2005a). Under the scheme, each person receives health care by paying a premium per month, and the government-run Bureau of National Health Insurance (BNHI) will pay the cost. The premium has different rates according to the individual's status, e.g. government employees have to pay 40 percent, farmers and fishermen 30 percent, and the self-employed 100 percent. The BNHI is the body that handles the annual budget of national health care (Liu, 1998). Since then, over 96 percent of the population has benefited from this program, as well as those who might not stay in the country for more than six months, those who live in very remote areas, the near-poor people who could not afford to pay the premium, and the wealthy self-employed (Lu and Hsiao, 2003).

Once in the programme, the insured can attend the health care institutes that have a contract with the NHIP for health care services, and it is based on a global budget system (GB), which was modified from a fee-for-service scheme. By law, BNHI has to operate on a self-sustaining basis, and its revenues largely come from premiums paid by households (Cheng, 2003; Chang & Hung, 2008).

There are three sources provided by the premium, including the insured, the employees, and the government. The premium is collected per capital; each person can pay the premium for his or her dependents. The optimal number of dependents per capital is three, and from the fourth dependent, one will be insured gratis (Cheng, 2003). The rates of premium are divided into ten groups based on the individual's wage to pay the premium (DoH, R.O.C. 2005b).

Reflecting the market's economy, hospital owners are both public and private, and the proportion of hospital beds served from them are 35 percent and 65 percent, respectively. On average, every thousand people share 5.7 hospital beds, but more than 70 percent of the hospitals have less than 50 beds (Lu and Hsiao, 2003). Due to the BNHI control of expenditure of health care and the decrease of fees for health services, the doctors in Taiwan have to increase their volume of health service to make up the low-fee services (Chiang, 1997; Cheng, 2003). On the other hand, the doctors have to shorten the time of visiting, and it could cause some problems to the quality of health services.

There are more than 90 percent of Taiwan's health care providers contracted with the BNHI (Cheng, 2003). The insured, once in the programme, with no rationing of care, gain complete freedom to choose healthcare providers or therapies, as well as institutions. They can go directly to a tertiary-care institution in spite of the nature or severity of their conditions. In contrast to the British health care system, Taiwan's NHI is a market-oriented system based on the laws of demand and supply, thus the insured have little chance to queue for health services (Peabody et al., 1995; Cheng,

2003; Blendon et al., 2003). However, with little limitation on the system and with comprehensive coverage from the BNHI, the insured can easily go to the doctor or hospital navigation, and the function of the referral system among different levels of care almost comes to a halt.

Once the insured receive health services from contracted institutions in the country or from abroad, the BNHI will pay the cost (DoH, ROC, 2005b). The profit package is offered in a broad range, such as the payment for inpatient care, outpatient care, laboratory tests, diagnostic imaging, drugs, dental care, traditional Chinese medicine, long-term care, and certain preventive medicine (Cheng, 2003). Due to its characteristic of a single-payer entity, the BNHI can thus make s straightforward influence on moving the context of health care by means of shifting payment policy.

In Taiwan, traditional Chinese medicine and Western medicine co-exist within the health care system, and the BNHI would pay for the health service if the insured need it (Cheng, 2003). Chinese medicine has long been playing an important role in health services, especially while it is burgeoning amongst the Western society; thus, its influence becomes salient.

For example, the Taiwanese believe that the side effects of western drugs are more likely to happen than traditional herbs. Whilst the people are sick, they will not give up on the hope to seek for traditional treatment regimen together with Western medical care. It makes the treatment of complementary therapies very common among the Taiwanese (Chen, 2001). Actually, complementary therapies could be found in both Western and Chinese society. It was estimated that 25 and 30 percent of

people with diabetes used complementary therapies for their diabetes (Dunning, 2004). Nevertheless, the Chinese patients are more likely to seek help from complementary care than the Caucasians (Martinson et al., 1999). Complementary care includes acupuncture, herbs, Tai Chi, diet, Qi Gong (Dunning, 2004), and folk religion (Martinson et al., 1999). Acupuncture is usually facilitated to reduce body weight and improve blood glucose levels in the diabetes treatment regimen (Dunning, 2004). Yin/Yang is a major concept of traditional Chinese medicine (TCM), which involves balancing energy (Chi). Methods used by the TCM include herbs, diet, moxibustion, acupuncture, and exercise, i.e. Tai Chi, Qi Gong (Dunning, 2004). However, the studies on this area are less than enough, especially those on health behaviours. Even some studies do suggest paying attention between health behaviours and culture (Chen, 2001; Shih, 1996), lacking rigorous analysis, the concepts only provide knowledge. How the Chinese culture influences the behaviours of the Chinese is not well understood (Gregory et al., 1999).

As a personal experience, the Taiwanese prefer famous doctors because they believe it is better for their health. It creates a problem of blind faith on famous health care; people hang around hospitals, but the outcome of the treatment is usually not satisfactory. Therefore, many people hardly register themselves in a clinic managed by a famous doctor successfully even making an appointment in advance. The people tend to believe that the curing of their diseases depends on the doctor's experience. From a Chinese viewpoint, the responsibility of treatment should be taken by the doctor rather than by the patient herself. This might offend the essence of diabetes self-management. Looking for a famous or experienced doctor is a biggest issue while getting very sick. For extra care, some patients even pay a money-filled red envelope

to the doctor in private, especially before surgery. The phenomenon has gradually faded, for most of the institutions disclaim this behaviour. Gifts given by patients replace bribes with money. However, people believe that famous or experienced doctors are making differences in their health care.

Diabetes care in Taiwan

Before 2000, the budget for patient education of ailments and disease management was small. When a patient was first diagnosed with diabetes, the health care was mainly focused on the adherence to prescribed medication. Education and self-management by the diabetic patient were hardly implemented at all. Therefore, the diabetic patient had little sense of self-management as an important element in controlling the disease. Consequently there was a lack of information on self-management for the diabetic patients in Taiwan, although diabetes education could have positive influence in diabetes control (Tsai, 2004; NHIB, 2001).

Patient education plays a major role in diabetes care, and the content includes knowing the condition, the importance of exercise, how to eat, knowledge of medications, complications of diabetes, sick-day care, travelling care, how to manage with hypo- and hyperglycaemia, and foot care. How to eat properly is strongly influenced by Chinese culture, and it causes fewer problems in Taiwan than in those countries inhabited by huge numbers of immigrants, such as the United Kingdom and the United States.

From 1996 to 1999, the Bureau of Health of I-Lan County in Taiwan initiated a pilot study to develop the ‘Lan-Yang Diabetes Shared Care System’ with a multidisciplinary diabetes care team providing an integrated service for the diabetic patients in which a health care model through the shared care system used in the United Kingdom was adopted for diabetes care.

Shared or integrated care is a kind of care scheme that integrates primary and secondary health care. The programmes are ‘loosely characterised by joint participation of hospital consultants and general practitioners in the planned delivery of care and an enhanced exchange of information over and above routine discharge and referral letters’ (Sowden, Sheldon & Alberti, 1995, p.142).

Shared care was launched in 1996 and the efforts to improve diabetes care have been enormous. In 2001, the Bureau of Health Promotion was established and one of its major tasks is to prevent long-term complications diabetes. Besides, a specific diabetes care scheme called ‘The Improvement Programme of National Health Insurance Payment for Diabetes Medical Treatment’ was developed to increase the quality of diabetes care and reduce long-term complications (NHIB, 2001). The shared care network was spread all over the country in 2003 (Bureau of Health Promotion, 2008). In order to join the diabetes shared care network, the health care institute is required to pass local certification. Furthermore, the institutions need to hire health professionals who are qualified by obtaining the Certificates Diabetes Educator (CDE) from professional organizations to provide health care (Bureau of Health Promotion, 2008). In 2001, the NHIB launched a payment scheme called ‘pay-for-performance’ to improve health care, and diabetes is one of them. In this scheme,

diabetes care can receive extra payment from the NHIB as long as the institution enrolled, thus services for diabetic patients can have better funding. For example, the NHIB pays 1,845 points⁵ for an initial visit for new patient and 875 points for each repeat visit. The annual evaluation visit has 2,245 points and 200 points for repeat prescription. In addition, eye examination is a separate payment.

In the program, the diabetic patient receives Diabetes Care Notes, or a Diabetes Passport, which keep records of diabetes treatment and results of examinations. The information is useful for health care professionals to provide appropriate care. The pay-for-performance scheme for each diabetic patient is a three-year service package, which is considered crucial to foster a new lifestyle suited for diabetes mellitus. The package provides four follow-up consultations per year as part of the routine care. In the first year of the package, the newly diagnosed diabetes patient can receive physical/laboratory assessments and diabetes education. In the second year, the patient has three follow-up consultations including diabetes education, which focuses on the problem related to self-management. The care in the third year is managed in the same way as the second (NHIB, 2001).

Chiou and her colleagues (2001) launched a survey that showed the mean of HbA_{1c} from 700 registered diabetes patients had decreased from 8.7 percent in the first year to 7.9 percent in the third year. By the end of the study, Diabetes Shared Care System remains the mainstream of diabetes care in Taiwan, and the NHIB offers an insurance payment scheme, pay-for-performance, to encourage many institutions to join in the programme to improve the quality of diabetes care.

⁵ 1 point = NT\$ 1 = US\$ 0.03

CHAPTER FOUR – METHODOLOGY AND METHODS

Introduction

The aim of this chapter is to illuminate the research methodology underpinning the thesis. It begins with the process of finding a focus, outlining the research philosophy, and mapping out the study's guiding assumptions. The first section considers methodological issues and looks at the principles of reasoning behind the research, with a particular focus on interviews. The second section identifies the research strategies, including ethics approval, access, participants and analysis, and addressing the strengths and weaknesses of the design.

Literature review functions as a groundwork that enables the study design to sensitise the factors influencing diabetes self-management amongst the patients in the nature context of Taiwan.

Methodological considerations

Consideration of best answers to the research questions is the key focus of the research design. With decades of debates over the two paradigms — the quantitative and the qualitative (Playle, 1995; Letoumeau, & Allen, 1999; Clark, 1998) — it is not yet settled which method can best discover the truth (Flick, 2002; Clark, 1998), and these debates have somehow gradually withered (McPherson & Leydon, 2002) as the focus has moved to how best to ensure appropriate research methods rather than more theoretical debates.

Recognising the ‘truth’ as an area of debate in itself, quantitative methods — the positivistic paradigm — facilitate the examination of the ‘truth’ through the verification and duplication of observable findings directly regarding perceivable entities or procedures (Clark, 1998, p.1246), getting quantifiable information about the world (Porter & Carter, 2000). It involves indicators to test the hypotheses, and often aims to identify and explain causal relationships between events; thus, it is best suited for testing an existing theory, to examine cause-effect relationships, to predict and control, and to stress the importance of measurement and explanation (Schutz, 1954; Bryman, 2004). It is useful for examining phenomena through the application of random sampling in order to generate generalisable findings. By its characteristics, it has often been argued that its explanation is not suitable for the actions of humans (Smith, 2008; Porter, 2000; Porter & Carter, 2000). They argue that the meanings of behaviours in human beings are far more complex than they appear because there may be multiple meanings and interpretations behind the same behaviour.

Conversely, qualitative methods aim to understand how people perceive and interpret reality (Porter, 2000) by using words, either in the form of speech or writing, to interpret and understand the rationale behind the actions in terms of motives (Porter & Carter, 2000). The paradigm of the qualitative methods is to explore the nature of reality, which could have different interpretations from individual to individual depending on how one interprets the meaning of the interactions with the person involved (Porter, 2000).

Self-management behaviours involve day-to-day activities, which include taking medication, self-monitoring of blood sugar, dietary control, exercise, sick-day self-care, stress management, and monitoring and managing the complications, either chronically or acutely from the time of diagnosis. In this sense, how diabetic patients manage self-care in their daily lives is a subjective rather than objective issue, and is related not only to daily self-care activities, but also psychological, social and cultural factors. Concerning the strengths and weaknesses of the two paradigms (Denzin & Lincoln, 2005; Duffy, 1985; Clark, 1998; Carr, 1994; McPherson & Leydon, 2002), qualitative research is identified as an appropriate approach for the study (Strauss & Corbin, 1990; Bryman, 2004, p. 279; Streubert & Carpenter, 1995; Denzin & Lincoln, 2005; Speziale & Carpenter, 2003) as a means to investigate how patients experience and cope with the continuing effects of illness in their lives (Katz & Mishler, 2003; Lindseth & Norberg, 2004).

Baker and Stern (1993) suggest that meaning is a key concern for those carrying out self-care in chronic illness. To examine the meanings behind the actions might help to understand the nature of diabetes self-management, which inevitably involves social interaction because most of the behaviours are carried out in a social context. Some notions advocated by symbolic interactionists are useful in explaining the nature of diabetes self-management, such as the meaning, interaction, and social role. As a symbolic interactionist, Blumer (1969) looks at meaning, interaction, and social role and suggests that how people act at an event depends on what meaning they give to that event, and how it reflects the inner world of human behaviour. Using this insight as a ‘sensitising’ approach and knowing that evidence about self-management has been broadly covered both quantitatively and qualitatively, this study is considered as

a naturalistic inquiry, with the descriptive qualitative design as the appropriate method (Polit & Beck, 2004).

Having identified the qualitative methodology, the issue of how to develop appropriate research tools arise. The research question aims to explore the phenomenon of living with diabetes in terms of how diabetic patients are engaged in diabetes self-management in the social context of Taiwan, which covers patients' daily activities, including taking medication, diet control, exercising, stress and illness management, and even travelling. With the complex and nuanced situational interactions, the methods have to be flexible and fluid enough to cover a broad range of aspects, but also feasible to be taken within a limited time period. Taking into account these pragmatic issues, it is identified that some form of engagement with patients and health professionals would generate valuable insights into type 2 diabetes self-care management.

Identification of key methods

Interviews, direct observation, studying manuscripts and recorded speeches or behaviours (audio/video tapes) are the three major modes of data collection methods to explore people's subjective understandings of their daily lives (Pope & Mays, 2000b). Among them, observation is considered more time consuming than the other two methods in obtaining the patients' subjective understanding of daily lives, but it could identify their behaviours directly without questioning if the patients' sayings are equal to their doings (Pope & Mays, 2000a). However, it does not give the participants the opportunity to give information (Mcilfatric, 2008), making it difficult

to obtain information on past experiences. Ideally, to observe the patients' daily activities, the researcher has to live with them (Pope & Mays, 2000a). This invasion could make recruitment much more complicated because the patients might fear that their lives would be exposed. It is unrealistic to observe self-management behaviours that could begin before dawn while the patient gets up to exercise and has breakfast, and goes on until after midnight when the person goes to bed. Furthermore, some self-management behaviours could happen at any time, even during the night; for example, hypoglycaemia happens while sleeping. Furthermore, issues such as travelling management and dealing with working environment have to be taken into account. It would be unfeasible and inappropriate to undertake such intensive observation.

Conversation is a basic mode of human interaction, and through its activities people can get to know one another; however, the weakness of adopting interview methods is that participants may wish to please the interviewer (Flick, 2002). In contrast to observation, it is a better way to describe past events and experience of the social process directly (Warren & Karner, 2005). Mason (2002) also views the method of interview suitable to collect deep, nuanced, and complex data because it allows the interviewees to structure their own meanings with minimal pollution from the researcher's own structures and assumptions (Britten, 2000). Adopting face-to-face interviews can make it easier to clarify ambiguous statements by making prompt inquiries (Kvale, 1996; Mason, 2002), and also allows investigations into specific situations and action sequences, which lead to a better understanding of the real world (Kvale, 1996).

Qualitative research interviews have three well-developed modes: unstructured, semi-structured, and in-depth interviews. The unstructured is the least structured interview, followed by depth and then the semi-structured (Britten, 2000). Unstructured interviews are beneficial when the researcher knows little about what needs to be inquired (Morse & Field, 1996); it is characterised as a participant-guided approach (Jackson, Daly & Davidson, 2008). Depth is designed to answer one or two issues but with much more details while and semi-structured interviews are conducted on the basis of a loose structure consisting of open-ended questions that define the area to be explored, at least initially, from which the participant or researcher might diverge in order to pursue an idea or response in more detail (Britten, 2000). Besides, semi-structured interviews allows the interviewees freedom of responses and description to illustrate the concepts (Morse & Field, 1996), and together using an outline-interviewing guide can help not only to cover the necessary questions but also to encourage participants to develop their narratives in each interview (Bryman, 2001).

Documentation: medical records

Documentary analysis is suggested to be a meaningful and appropriate research approach in social research (Mason, 2002), with information obtained from documents helping to gain broader perspectives from different angles rather than merely collecting data from interviews. I was interested in whether the patients' demographic data are connected to decision-making of self-management, as well as whether the results of metabolic control could provide some kind of evidence to examine the relationship between self-management behaviours and metabolic control.

The value of HbA_{1c} is used to examine the outcome of metabolic control, which is valid for the period of the last three months.

In Taiwan, medical records include date of birth, education status, marriage status, occupation, values of HbA_{1c}, and years of diagnosed diabetes. All these are valuable because education status, marital status, and occupation might affect the outcome of learning the skills for diabetes self-care. Overall, these records could provide important evidence for the researcher about objective data related to the outcome of the subject's own self-management. Therefore, it is appropriate to collect information from medical records.

Fieldnotes

Warren and Karner (2005) suggest that writing fieldnotes is necessary to succeed in conducting field research. The interview method has its weaknesses of being unable to collect all the information in the field, as not all information can be tape recorded. To facilitate the use of observation, I recorded fieldnotes covering physical appearances, dress, mannerisms, body gestures, and facial expressions to enrich the information. The fieldnotes were taken immediately on the same day after the interview. While writing fieldnotes, I could reflect on the process of data collection, which was useful for the next data collection. Matters related to the way patients interacted with their family were also recorded to enrich the information in data collection.

Research diaries

Flick (2002) suggests that where more than one researcher is engaged, it is better to keep a research diary that can be used to reflect during the process data collection to increase the comparability of the empirical proceedings. To write a diary can help prevent forgetting ideas and observations that might be important to present a better understanding to the readers; it could also provide the ideas for the future direction of the study (Silverman, 2000). Thus, I decided to write a diary to reflect on the process of research and enable recording matters of major or minor importance I had perceived in the progress of the empirical proceedings, and to take hold of everyday activities in natural circumstances (see Appendix F).

Design decision

A diagrammatic representation of the final design is presented in figure 2.

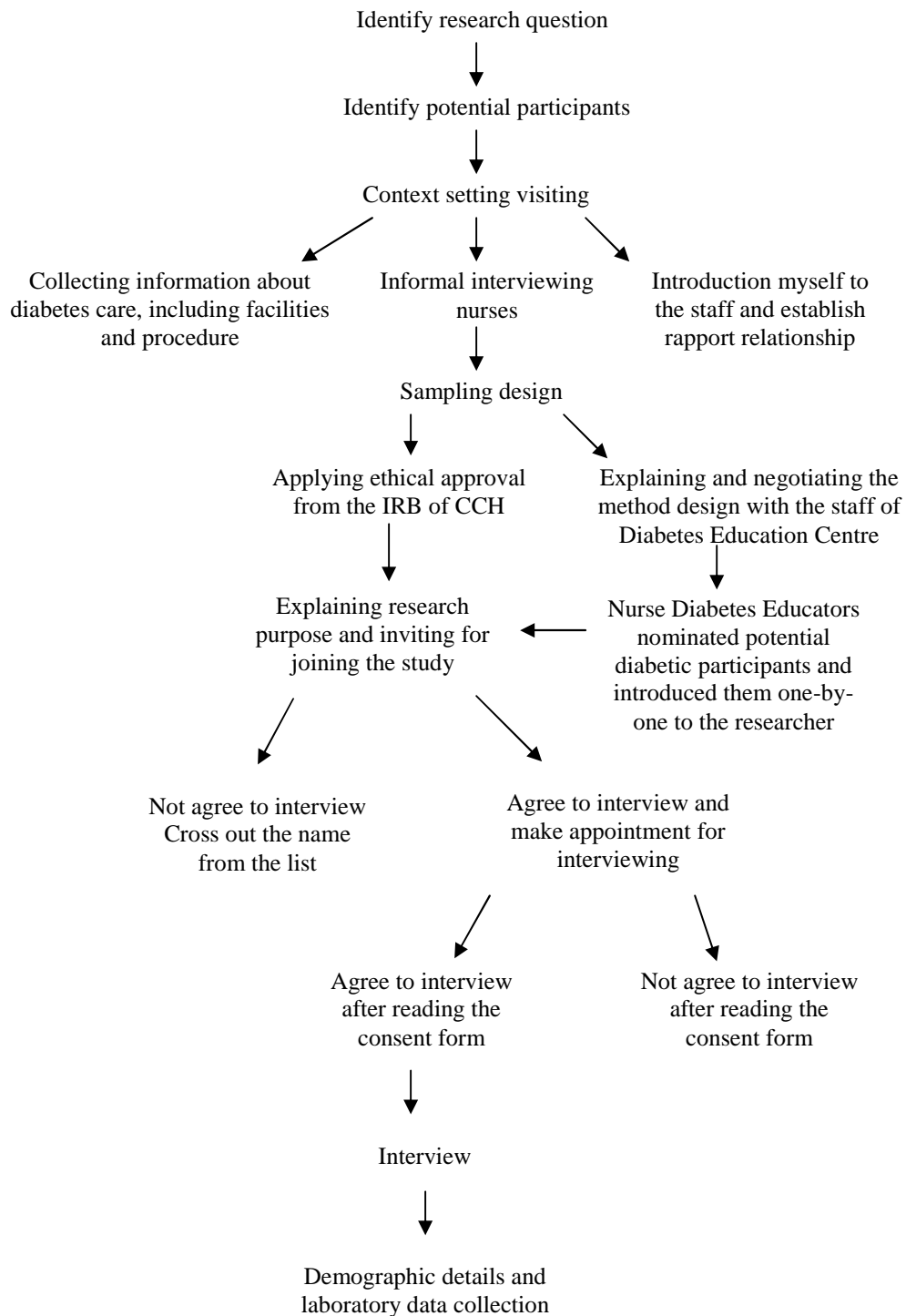


Figure 2 - Data collecting process

Negotiating access

Gaining access to the contextual setting is a key issue right after the research question is decided upon. The main purpose is to ensure a feasible sampling scheme. This requires numbers of contacts with the head of the endocrinology of the Changhua Christian Hospital (CCH) by email and telephone, which enables me to obtain the information I need to develop the research design. After accessing the contextual setting, the sampling scheme was promised.

Gaining access to participants

To recruit appropriate informants, it is necessary to find an institution where there are enough potential participants for sampling. The contact with the CCH, a leading institution of diabetes care in Taiwan, was initiated in December 2002. As the institution is affiliated with the Chang Jung Christian University where I work as a lecturer, I was introduced to the Head of the Section of Endocrinology, and he, an endocrinologist, had offered as much help as I needed, including all the information necessary for the study.

Its diabetes mellitus service reached 10,345 patients at the time of my visit to the Diabetes Education Centre (DEC) in September 2005, demonstrating the potential to offer subjects planned for the study. To gain a better understanding of how the centre runs its service to diabetic patients gives a practical view on planning the data collection to achieve the aim and objectives of the study.

Access to an appropriate setting

The CCH represents an outstanding performance of diabetes care in Taiwan, and the documents of the entire diabetes patients are built into the computer. It shows its advantage over the others in Taiwan: the great possibility to consist of self-management. Its built-in documentation is a great advantage for the researcher to facilitate sampling in any kind for the study.

The progress of being in touch with the setting

The Nanguo campus is located in Changhua City, and it is the major hospital of CCH. It consists of six hospitals and one clinic located in Nanto County, east to Changhua County (CCH, 2004). Its service is offered to the 236,000 residents living in Changhua City, as well as Changhua County of approximately 1.3 million residents, and some patients are also from southern Taichung County (MoI of R.O.C., 2007).

Diabetes care in CCH

In this research project, subjects were recruited from and experiments were conducted at the DEC of CCH located at Changhua City, Taiwan. CCH provides 1,840 beds for in-patient service, and has 52 divisions to provide out-patient service for approximately 5,500 patients each day and 10,000 patients from the emergency room per month. This hospital has been the highest-ranking medical centre in Taiwan since 2000, according to the Department of Health (CCH, 2004). Before 2003, the DEC had served approximately 15.7 thousand diabetic patients, including 6,100 patients who

were first-time visitors and 9,600 patients who had visited the centre more than once. In addition, records of the diabetic patients have been computerized and stored in the computer of the centre for easy access to the patients' profiles. The DEC is one of the biggest training centres of certificate diabetes educators in Taiwan. According to the statistics from the DEC of CCH, 97.8% of the 15.7 thousand diabetic patients were diagnosed with type 2 diabetes mellitus, with a mean age of 59.9 years old and a mean duration of 8.8 years since being diagnosed with diabetes. The diabetic patients visiting the centre for the first time had a mean value of HbA_{1c} at 8.4%, and the mean HbA_{1c} value was decreased to 7.7% following the second visit (CCH, 2004). The 7.7% mean HbA_{1c} value of diabetic patients from the DEC of CCH obtained from the diabetic patient in Taiwan in 2003 had been below 8.9% (Tsai, 2004).

Philosophy of the Diabetes Care Centre of CCH

The DEC provides a better level of care than anywhere else in Taiwan. The staff in the DEC believe that being conscious to the patients' needs and providing support can establish a relationship of trust. Consequently, they try to provide the patients with the best possible care and service. Once entering the centre, a patient would be approached by a volunteer who arranges the whole procedure of the educational programme to ensure that the process runs smoothly without keeping them waiting or ignored. Besides, to ensure the patients' safety from hypoglycaemia, providing food is part of the service, and it has been improved rapidly. The DEC in the CCH includes a showroom to display and provide information on diabetes; ten small offices, each equipped with a set of computers for patient education; and one room for annual examination including peripheral blood vessel examination and fundus examination.

The office is able to offer a private area, which provides the patient education on diabetes without disturbance. There are eleven certificate nursery educators and five staff responsible for the entire patient educational programs. In addition, there are six to eight nutritionists for nutritional education. In 2007, the centre was moved to a much more spatial area where diabetes care services are allowed to be completed in the same area, as well as returning check, examination to screen the complications of diabetes, and diabetes education from both the nurses and the nutritionists.

Before entering the field, I spent one week in the diabetes education centre to assess the possibility of the sampling scheme. The details will be presented in the following section to let readers understand the rationale behind each decision. The decision to visit the setting was based on the needs of planning data collection, including the establishment of rapport with health professionals to see whether they could possibly offer help to nominate the potential participants, how they manage the diabetes care, and what the regulation of the institution is that might influence the data collection process, such as the possibility of letting interviews be held in the hospital.

Sampling consideration

The literature chapter suggests that multiple factors, both internal and external to the individual, could affect decisions on self-management, and these factors might also change over time as individuals follow the timeline of biography. Drawing on my clinical experience, identifying ‘exemplar’ self-managers and ‘challenged’ self-managers might give some insight into how health professionals could support patients. This is supported by observations on a range from novice to expert in self-

management (Price, 1993a; Paterson & Thorne, 2000). In my experience, to become an expert self-manager is not a performance achieved by every diabetic patient; therefore, the information might be inadequate if I solely interview the exemplar self-managers without including those who struggle to manage their diabetes. The information from these two parties might provide valuable information to understand the phenomenon of diabetes self-management.

In addition to identifying exemplar and challenged self-managers, I need to narrow down the target diabetic subjects to ensure enough comparability and depth in the interview data.

The reason for doing so is based on the assumption that if five years is the shortest time to become an exemplar, to obtain rich information within this period might provide valuable information; therefore, the information obtained from this period might provide valuable information by extending the number of subjects. To obtain richer information, limiting the experience of living with diabetes for at least one year is based on the consideration that they could have richer information to share, but the period would be not long enough to be overlooked. The reason to divide participants by the years of experiencing diabetes self-management is to interview the participants who are in different stages of diabetes self-management, which is based on the assumption that time is the issue to learn diabetes self-management. The major definition of challenged self-managers depends on the opinions of the health professionals, with the hope that at least their nearest value of HbA_{1c} is greater than 8.5%.

Though good self-management might not necessarily lead to good metabolic control, good metabolic control mostly requires good self-management. As a result, the value of HbA_{1c} less than 7% during the last year is a key measure to reduce the risk of recruiting non-targeted population. Price (1993a) believes that it needs at least five years to foster an exemplar diabetic self-manager, and Paterson and Thorne (2000) suggest at least fifteen years. Based on their suggestions, I decided to choose five years as the least criteria in the group of exemplar self-manager. To understand whether different timelines of the biography would influence the decision-making of self-management, the target population was equally recruited from two groups, aged 40–50 and 50–60.

My criteria for selection are the following: (1) female, (2) being diagnosed as type 2 diabetes for more than 5 years, (3) age between 40 to 60 years old; 10 of 40–50; 10 of 50–60, (4) the value of HbA_{1c} less than 7% for the past year, and (5) being nominated as exemplar self-manager by the health care providers (see table 1).

In setting up a sampling frame, I decided on (see figure 3 and 4). To recruit diabetic participants, I relied heavily on the help of health professionals in the Changhua Christian Hospital (CCH). The lists of potential participants were generated by the nurse diabetes educators that worked in the CCH. The information on the list includes name of nominees, addresses, telephone numbers, and the date of check-ups. The information that allowed me to access potential participants by letter or telephone. The nurse diabetes educators suggested that I invite potential participants by telephone because the response rate could be low. This was explained as being the result of scams that happened every day in Taiwanese society, which made people

tend to give a negative response to any letter or telephone calls from someone they did not know. For this reason, the process started with a telephone call to invite a potential participant to join the study. If they agreed to join, an appointment was made for the interview, where they chose a place of their preference. The nurse educators also sometimes introduced potential participants to me when they were visiting the clinics and I was in the diabetes care centre. When there were no nominees left after making contact, the nurse diabetes educators provided another one until the numbers of participants were met. A face-to-face invitation was used to recruit nurse participants and stopped when numbers were met. An appointment followed after the invited one agreed to join the study.

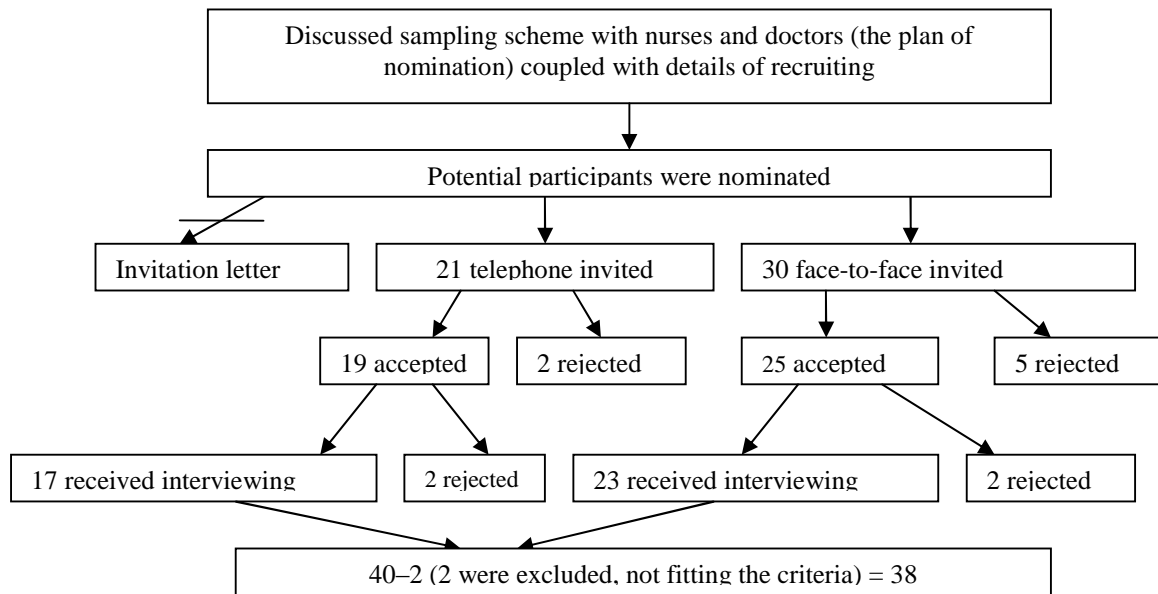


Figure 3 - The process of data collecting

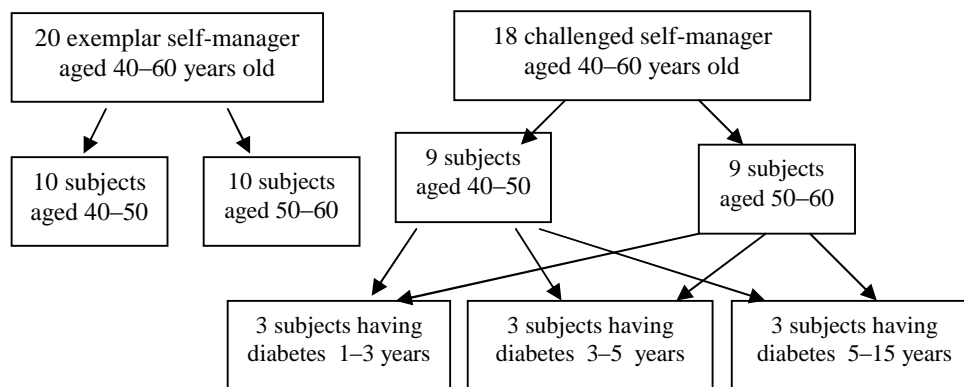


Figure 4 - Sampling scheme in diabetic subjects

Exemplar self-manager	Challenged self-manager	Nurse diabetes educator
(1) female (2) diagnosed as having type 2 diabetes over 5 years ago (3) aged between 40 and 60 years old – 10 were aged 40–50, and 10 were 50–60 (4) with a value of $HbA_{1c} < 7\%$ for the past year (5) were nominated as examples of self-managers by the health care providers.	(1) female (2) the last value of $HbA_{1c} > 8.5\%$ (3) aged between 40 and 60 years old – 9 were aged 40–50, and 9 were 50–60 (4) In each age group were divided into three subgroups based on the period of having diabetes as 1–3 years, 3–5 years, and 5–15 years, and each subgroup consists of 3 subjects (5) were nominated as poor self-managers by the healthcare providers.	(1) certificated diabetes nurses (2) working in diabetes care for at least the past 2 years

Table 1 - The criteria of sampling

9 of 40–50;

9 of 50–60, (4) being diagnosed as diabetes for 1–3, 3–5 years, and 5–15 years in the group of 40–50; being diagnosed as diabetes for 1–3, 3–5, and 5–15 years in the group of 50–60, (5) at least the latest value of $HbA_{1c} > 8.5\%$ before being recruited, and (6) being nominated by health professors. The challenged self-managers have the same criteria as the exemplar ones, such as female aged 40–60 in 40–50 and 50–60 two groups, and nominated by the health professionals. Each of the two age groups consists of participants who had been diagnosed with diabetes for 1–3 years, 3–5 years, and 5–15 years to increase the chance of getting information from various stages of self-management.

The recruitment of the right participants would require help, as I needed authorisation to access the necessary patient information. To recruit participants efficiently and ethically without violating their rights, I had them nominated by the health professionals because they had known the patients through counselling, which enabled them to provide good suggestions. This would then enable me to approach those patients identified for their individual consents.

Unlike the patients themselves, health professionals might have difficulties seeing the real life of self-management, but their perspectives of how these people had managed self-care are mainly shaped by hearing the stories from the diabetic patients together with integrating their own philosophy of diabetes care. For example, 11,269 diabetic patients were statistically counted as the first time receiving diabetes care in the Diabetes Education Centre of the CCH in 2006. As there were eleven nurse diabetes educators, the centre created a great chance for them to interact with diabetic patients, which could help them learn from the patients about how they had been managing self-care in many ways. Thus, their aspects of diabetes self-management could be analysed and compared to understand if there were any gaps between these parties, which could influence the quality of diabetes care. To enrich the information, the experience of interacting with diabetic patients was the main concern; therefore, I made a decision to set criteria that the potential participants of nurse diabetes educators were required to have at least two years of experience in diabetes care. Besides, the saturation of data was the sign to decide the number of nurse participants.

Research methods

Weighing their pros and cons, the qualitative research interview was decided as the suitable method to be adopted as the major data collection method, and the other methods such as fieldnotes, research diaries, documentation, and medical records are then used together to enrich data analysis. The purpose of accessing medical records was to gain the demographic and the laboratory data, which are related to the outcomes of metabolic control.

Interview

Appropriate data collection methods were the key elements to decide if the research questions could be answered properly. As the research questions aimed to explore the phenomenon of living with diabetes in terms of how they are engaged in diabetes self-management in the social context of Taiwan, it covers the patients' daily activities extensively, including taking medication, diet control, exercising, stress and illness management, and even travelling, thus the research method needed to be flexible and fluid enough to cover broad aspect of interests.

Issues of interview

Two major skills in qualitative research are the researcher's capability to obtain information, interview, and observation (Field & Morse, 1985). The purpose of the interview was to gain descriptions of the live experience of the interviewees to

interpret the meaning of the described phenomena. The main consideration of interview on this study is to find out if the subjects' pure experience is unpolluted by any leading questions. Conversation is a basic mode of human interaction, and through its activities people could get to know the others.

The duration of the interview was one of the concerns before entering the field to collect information, either to prevent the participants from feeling too tired to focus on the topic or the time was too short to collect the data needed. An interview of sixty minutes including introduction and conclusion was designed. During the interview, a comfortable situation was created to reduce possible tension.

Venues were another issue considered while interviewing, especially for those participants who were reluctant to receive interviews at home because of their fear to reveal their disease to either family or friends. The majority of the participants preferred to be interviewed at the hospital, especially when they came back for checkups, as they could receive the interview and check up together to save time. To negotiate for a proper place that was comfortable and without interruption was to ensure the interview was successful. There were several venues chosen, including diabetes education centre, unused clinics, and a faculty lounge room located in the institution but belonging to the Chang Jung Christian University where I work. Interestingly, no participants were interviewed at home as challenged self-managers, and those who grouped in exemplar ones also chose hospitals as the interview venue.

The kind of information expected to be collected was another concern, and a semi-structured interview was adopted, allowing participants to respond flexibly and

openly. The concept of interviewing was integrated into a semi-structured interview schedule to reach the goal of the study.

Structure of interview guide

From the above literature review, evidence reveals that decisions on practicing self-management are influenced by many factors, which could be from either within or without an individual. But the participants seemingly underwent a similar trajectory of diabetes self-management, presumably starting from passively to actively involved, and then they could become an expertise after a period of active involvement (Paterson & Thorne, 2000). Taking this in mind, a semi-structured interview was adopted to obtain a particular topic regarding self-management, but remained flexible for participants to address their experiences, providing direction but allowing the story to go by their ways (Morse & Field, 1996). The concept of interview guides was structured to cover general information regarding daily activities or social roles that could influence self-management, and it could allow the researcher to draw an overall picture of participants that is beneficial for gaining richer information. The next core concept focuses on their experience of living with diabetes, which is designed to follow the timeline of living with diabetes self-management, emphasising on the impact of diabetes, barriers and facilitators of self-management, and coping with diabetes. Self-evaluating of self-management could provide the information about their reflections on the process of diabetes self-management. To gain the perspectives of either health care system or policy in diabetic participants is to understand the role of health care systems in diabetes care; together with the last question, it can offer an opportunity for the participants to speak in their own ways (see figure 5).

The concept adopted for health professionals' interview guide follows the similar principle. General information of health professionals was obtained in the very beginning, and followed the question about what their perceptions of 'good diabetes self-management' was an attempt to gain their perception of diabetes self-management. The key interest of the interview was to explore health professionals' perception about the following: (1) the impact that diabetic patients have experienced; (2) barriers and facilitators that affect self-management behaviours; (3) the role that health professionals played in foster self-management behaviours; and (4) the important issues in diabetes care (see figure 5).

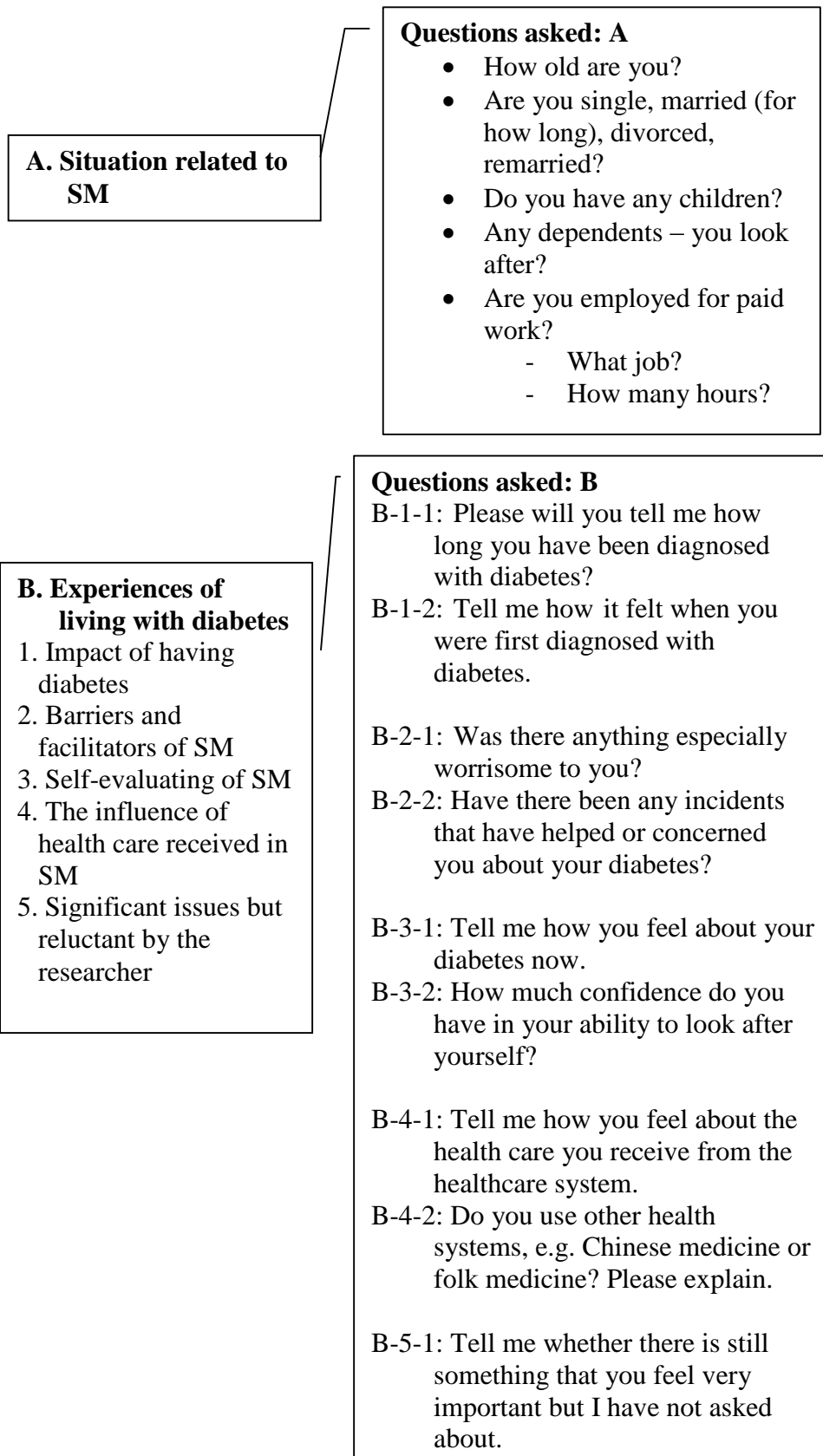


Figure 5 - The concept of interview and questions constructed in diabetic patients

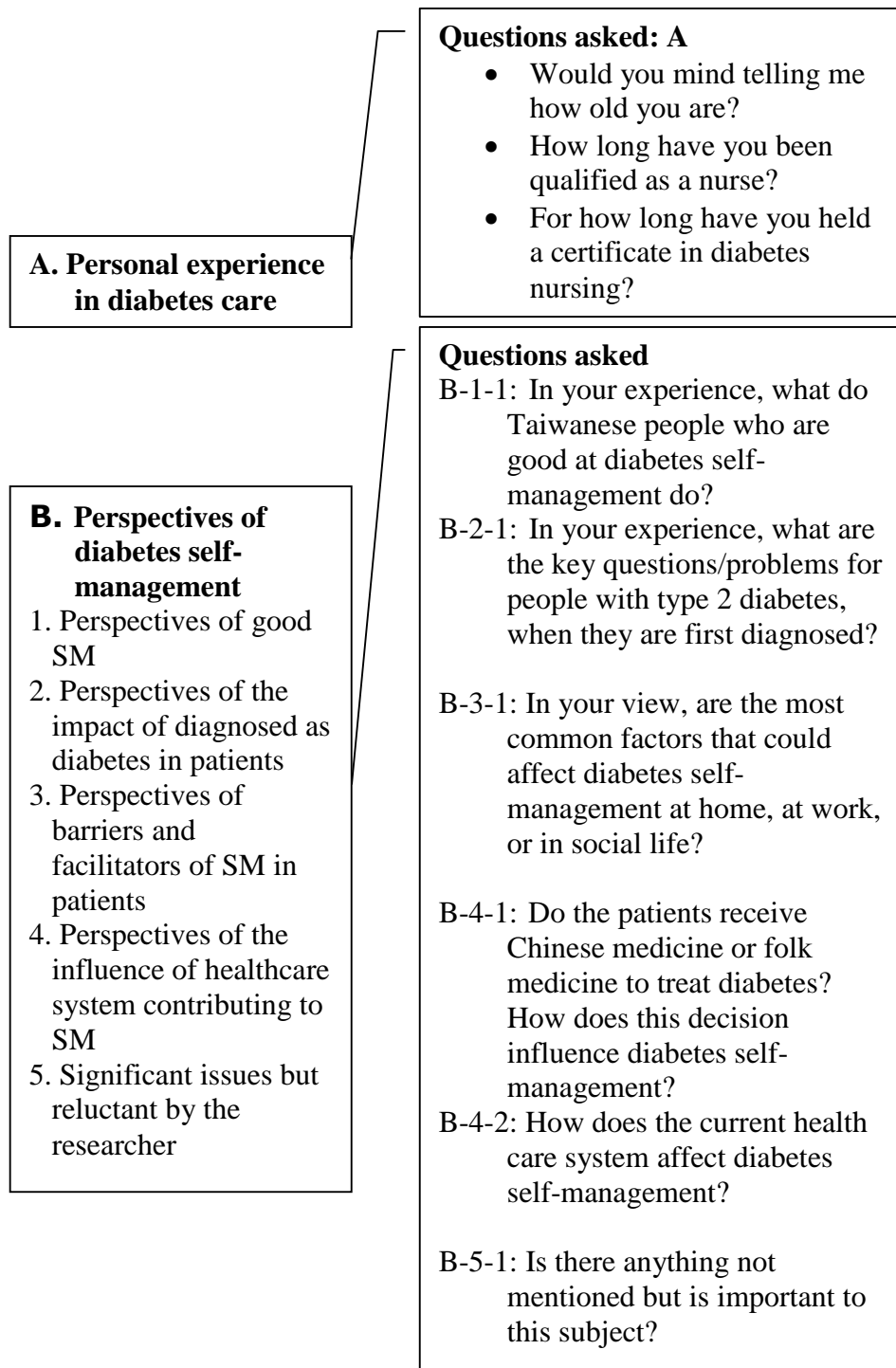


Figure 6 - Diagram of the concept of interview and questions constructed in health professionals

Data collection

When entering the field, the strategies of recruiting the target population is the key to achieve the goals of the study, and how to approach them would follow the steps of the sampling scheme, starting with the invitation by the researcher. The first contact with the potential participants made me change the scheme quickly to ensure the progress of the sampling. There were several strategies used in the process of the sampling while collecting data.

Issues raised while access to the field

After an informal contact with a few patients, from their indifferent responses I quickly recognised the problem. The society had been overflowed with fraud events that made the work of recruiting participants unlikely to progress as planned because the majority of patients were suspicious that their acceptance would bring them trouble without the health professionals' introduction in the hospital. After discussing the issue with the health professionals, they helped solve the problem. The staff helped me not only by offering a list of potential participants but also by calling them and giving a brief explanation about the study. It sounded promising for recruiting the participants, and I had successfully made three appointments with patients in the very beginning. On the day before the first appointment, I made a phone call to remind the potential participant about the visit, but a surprising and anxious voice said that her husband did not agree with it, and she hung up the phone. I realised that merely contacting potential participants by phone was not enough to convince them that we had given the true identity; they would remain feeling insecure to accept the invitation.

To solve this problem, the health professionals introduced me to the potential participants face-to-face in the centre. Therefore, the progress was largely dependent on the health professionals' help, such as the list of potential participants together with the dates when they would come back for a check up. Therefore, I could know when and which clinic the potential participants might show up, and then consider the possibility of holding an interview that could be prepared in advance. On the dates of their visits, I would visit the doctors and nurses before the clinics opened. Thus, the health professionals were able to notify my arrival while the patients were in the clinic. As I showed up in the clinics, the doctor could introduce them to me and left the rest for me to finish outside of the clinic. Before entering the field, understanding the society phenomenon is the key leading to the success of the sampling scheme.

The fifteen exemplar self-managers and five nurse diabetes educators were recruited between 27th February and 2nd May, 2006. Meanwhile, the supervisions were held twice while going back to the school on 4th–30th of May, 2006, for the evaluation of the sampling scheme. A change of the criteria of participants from non-exemplar self-managers to a challenged one was made after discussing a translated transcript obtained from an exemplar self-manager, which revealed that she had not yet totally reconciled from the shock of having diabetes since 1995. It was intriguing whether those assumed as challenged self-managers perceived diabetes differently; thus, the sampling scheme was shifted from non-exemplar self-managers to challenged self-managers who would be nominated by health professionals. As it was difficult to decide who was considered challenged self-managers, I set a minimum criteria of last value of HbA_{1c} greater than 8.5, and left the health professionals who might know the patients better to nominate the potential participants.

Due to the change, the study was required to have permission from the IRB of the CCH, and then it was granted on 5th July, 2006.

Interview and location

The decision about how to collect information from the participants, including diabetic patients, their family, and nurse diabetes educators, were based on two dimensions: general information about the patients and the family, and the patient's experience of diabetes, which mainly focuses on the home and health care system. As the patients were nominated as either exemplar or challenged self-managers, the perspectives of the patients were absent. Therefore, the measure of confidence score was designed to allow the perspectives of the patients' self-management to be presented. Interestingly, one of the exemplar self-managers denied that she was an exemplar self-manager, but insisted that she benefited from the medication, which she believed was quite strong to hold down her levels of blood sugar. In contrast, there were three challenged self-managers who were confident about self-management (see table 2). Health professionals did agree that they had problems evaluating the patients' behaviours of self-management, thus they had to evaluate if they were compliant to the suggested lifestyle by the results of blood sugars. The conflict might arise because health professionals believed in the results of blood sugar rather than what the patients had said to them.

The purpose of using a semi-structured interview was to research on the specific topic — diabetes self-management (Smith, 1995) — but it also allowed the

participants to give a fuller picture on self-management. Two interviewing guides were used to direct the interviews, which are presented in Appendix B. Most interviews followed the sequence of the pre-structured guide, but sometimes the patients started the interview in their own way. For example, Wan-Ling started with an apology saying that her slurred speech resulted from a stroke, and she continued to explain the suffering she had been through due to reluctance to take diabetes control into account. In this interview, I tried to provide a high priority of comfort for them to respond freely without interruption. The strategy was facilitated while participants failed to express clearly.

A semi-structured interview was conducted, and the interview guide was used to guide the context of the interview. Unlike the quantitative method, to require generalisation in qualitative method is arguable, but instead would desire the perception gained from the study would show useful in other contexts that had likeness (Yardley, 2008). Similarly, a hospital located in the middle of Taiwan should have problems to represent all populations of diabetic patients in Taiwan.

From the 25 exemplar self-managers, five (20 percent) agreed to be involved in the study, while six (25 percent) of the challenged ones out of 24 refused. A total of twenty exemplar and eighteen challenged self-managers, as well as five nurse diabetes educators gave their consent. There are two exemplar self-managers who received the interview but are excluded from the data, because one was over sixty-one years old and one's value of HbA_{1c} did not meet the criteria. The demographics of patients and confidence score regarding self-management is presented in table 2, and the nurses' ages and years of diabetes care are shown in table 3.

Those who rejected the invitation mostly showed their suspicion toward the study, and six out of eleven refused to be involved by phone. Five refused while invited in person. One of the patients said she was not used to talking to strangers, so she refused the invitation. Another one refused the study because she was undergoing enormous pressure from the family and needed to take care of a sick husband; family matters left her no time for returning checks. The rest of them refused to be involved or held an unconvinced attitude toward the study for no particular reason.

Data collected from the family was not an original part of the study design. In reality however, in some interview situations (n=7), the family members sat in on the interviews and seemed keen to add in their point of view. However, there was no interview guide used for the family members.

Seven participants were interviewed with their families, (see table 4), but only four of them provided information during the interview, mainly focusing on dietary management and the issue of complications. For example, Lan-Chun's husband showed his concern over the possibility of hypoglycaemia which might happen when she was alone. After listening to his concerns, Lan-Chun gave a detailed description of what strategy she had used for preventing hypoglycaemia. The interaction between participant and family could also provide valuable information which might be ignored if merely collected by interviewing the participant alone; such as Li-Hua, who had been observed having a changed attitude and emotion, including a higher-pitched voice while speaking and more smiles, since her sons were present during the interview. Her sons also told the researcher that it was their job to trim their mother's

toenails to ensure the quality of her foot care. Observing their interaction helped to identify why Li-Hua had a very strong will to keep herself healthy for carrying out the role of motherhood: as she said “I have to be healthy. I have to earn money. I have to raise my kids and feed my own” (cited in p. 170). In contrast, some of the family members knew little about participants’ self-management needs, such as Ssu-Hsaun and Ai-Chu, both nominated as challenged self-managers.

However, having family attending during the interview could also cause negative effects, such as giving selected information that was considered not suitable to be heard by her family, such as Shiou-Shiou gave little information about diet while she and her husband had no common agreement with diet control. With this in mind, thus, I had been paying attention to any nuanced changed between their interactions to enrich data collection.

characteristic	Exemplar self-manager	Challenged self-manager
Education		
Illiteracy	2 (10%)	1 (6%)
Primary school (6 years)	8 (40%)	13 (72%)
High school (6–12 years)	6 (30%)	4 (22%)
Junior College (14 years)	2 (10%)	
Undergraduate (16 years)	2 (10%)	
Marital Status		
Married	19 (95%)	16 (89%)
Widowed	1 (5%)	
Divorced		1 (6%)
Remarried (diabetes was the reason for being divorced)		1 (6%)
Children		
Yes	V (100%)	V (100%)
No		
Job		
Employed	7 (35%)	4 (22%)
Self-employed	3 (15%)	2 (11%)
Retired	6 (30%)	1 (6%)
Unemployed	4 (20%)	11 (61%)
Time of diagnosis		
5–10 years	10	
>10 years	10	
Confidence Score		
8–10	13 (65%)	3 (17%)
6–7.99	6 (30%)	4 (22%)
4–5.99	0	9 (50%)
2	1 (5%)	1 (6%)
0	0	1 (6%)

Table 2 - Patients' demographics and confidence score

	Aged	Years of diabetes care
Nurse participants	30–50y	3–13y

Table 3 - Basic data of nurse participants

Name	The family members who presented with participants while interviewing	Information provided
Lan-Chun	Her husband & sister	Yes, by her husband
Li-Hua	Her two sons	Yes, both of them
Tian-Tian	Her sister and niece	No
Ssu-Hsuan	Her daughter	No
Mei-Lien	Her son	Yes.
Shiou-Shiou	Her husband and youngest daughter, who was 8 years old	Yes, by her husband
Ai-Chu	Her daughter	No

Table 4 - The family members who participated in the interview

The years of receiving education between the two groups shows little difference while less than or equal or twelve years, but the patients receiving an education longer than fourteen years tended to have better metabolic control. They are likely to have more strategies to search for information needed for diabetes care. However, the patients who had problems reading could eventually become exemplar self-managers, as they learned diabetes control from the diabetes educational programme offered by the health professionals.

The result of confidence score indicates the different perspectives of self-management between health professionals and patients. Because of the lack of information to evaluate if patients could perform self-management as expected, the results of blood sugar become the major avenue to evaluate, which may explain why the participant, who was nominated as an exemplar self-manager, denied self as good as the health professional had expected. On the other hand, some patients perceived that they had done well in self-management, but health professionals might not agree with them. This difference somehow became the conflict between the two parties because the health professionals might blame the patients for failing to practice self-management. The measurement of confidence score is designed as a 0–10 scale to measure self-perceived confidence score of self-management. Some of the patients who were nominated as exemplar self-managers hardly agreed with the compliment; on the other hand, some of the patients grouped as challenged showed confidence about how to manage diabetes.

Ethical consideration

To protect the participants from harm, the research design had taken the ethic principles into account, which are autonomy, beneficence, non-maleficence, veracity, confidentiality, justice, and fidelity (Burkhardt & Nathaniel, 2002). It can be the respect for autonomy, and the principles of doing good and acting truthfully (Beauchamp & Childress, 2001; Polit, Beck, & Hungler, 2001). As the research was conducted in the CCH, the institution requested each study using their patients to be granted by the Institutional Review Board (IRB) of the CCH. The IRB, like the other ethical committees, had these principles integrated into the ready-designed consent forms (CCH, 2007), and I used these forms to design the sampling scheme. After the data were collected, all of the cases' documents had been kept confidentially. Each of the cases got a pseudonym to prevent the patient from being recognised.

Ethical issues in relation to gate keeping

Because Changhua Christian Hospital is the place where the study was based, the potential participants would be recruited from the institution. Therefore, this was where gate-keeping needed to be negotiated. The CCH is quite active in the research area, and the Institutional Review Board (IRB) was set up to protect the participants from any harm. Before starting the field work, obtaining permission from the board was essential (see Appendix A).

As the study was designed to gather participants in the CCH, before going to field, the study had to be granted by the IRB of CCH, otherwise the study could be prohibited to recruit subjects from the CCH. The committee had set up principles and offered ready-designed forms, which could be downloaded from its website, to ensure the study could meet their requirements. Before the approval was granted, the researcher had to download the forms offered by the CCH on its website, which includes an application form, proposal, resume of the researcher, and the participants' consent forms. The IRB required the researcher to submit three copies of these forms in well-organised folders. The first response from the IRB arrived twenty days after the submission. After the proposal was reviewed, the committee asked me to offer some documents such as the certificate of good clinical practice (GCP) to prove that before entering the field the researcher had been trained for carrying out the study properly. Because of the Chinese New Year, it took one month to look for the GCP programme held elsewhere in Taiwan. Eventually, I took two courses of GCP held by the Hospital of National Cheng Kun University and Chi-Mei Hospital, both of which were medical centres in Taiwan. It took about two months to be granted, but the committee also required a middle report and a final report of the study. The committee required me to send back copies of consent forms to ensure that each participant signed their name correctly while attending the study. Any correction needed the participant's name signed beside the cross-out mark to ensure they were totally informed. The purpose of the middle report was used to follow up if the participants were protected properly. The final report had to be completed to ensure the cases recruited followed the original plan.

Ethical issues of interviewing

As I approached the potential participants, they were suspicious about the study because I was a stranger to them. Therefore, I invited them to attend the study by phone or in person after briefly introduced by the health professionals. If the patients were interested in attending the study, I then made an appointment in the way they preferred. Most of them preferred to be interviewed at the hospital; it might be that it was a place they could check if the study was real rather than a scam. The recruitment of the nurses was the least difficult to achieve, and no one turned down the study. The very reason was a good relationship established between us by my frequent visits and working with them to recruit diabetic participants.

Before giving an interview, an address was given together with the consent form that included a full explanation of the nature of the study, their right to refuse participation, the researcher's responsibilities, and the likely risks and benefits that would be incurred (see Appendix C and D). Before the study, the participants were informed of the purpose of the study and the rights they have, and also that the interviews would be tape recorded. The interviews took place only when a consent form was signed by the participant; furthermore, some of the family members who accompanied the patients during the interview were to read the consent form and join the interview together (related forms please see Appendix A). During the interview, I remained as neutral, non-judgemental, approachable, and friendly as I could at all times, and I managed to pay attention to observing if the participants presented any emotional or physical stress, and allowed them to speak in their ways and at their own pace.

Although some participants could not help to show their emotion while sharing experiences, they seemingly felt better afterward, which was shown by talking non-stop or even being appreciative at the very end. At this point, I realised that my previous experiences as a nurse was the key that drove the process smoothly.

Data analysis methods

After data collection, thematic analysis was adopted for analysing data because the method was developed to meet the needs of investigating the experiences, meanings, and the reality of the participants (Braun & Clarke, 2006). Besides, the method allows the study to adopt the element from the constructionist notions — to investigate the ways in which events, realities, meanings, experiences, and so on are the effects of a range of discourses operating within a society. It makes meanings out of the participants' data of their experience, and in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of 'reality.' Its advantage is to untangle the surface of 'reality,' thus enable the data corpus to present in terms of the 'the world,' and 'reality' of diabetes self-management.

Five stages in this method are suggested, and it follows the sequence of familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (see figure 7).

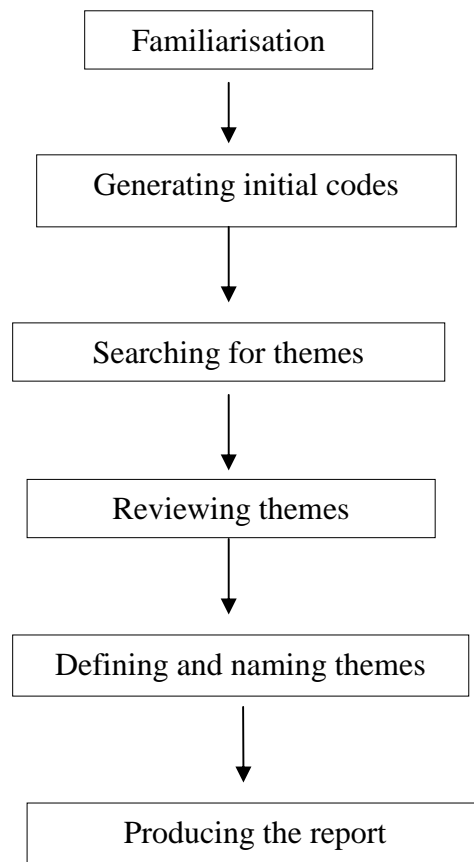


Figure 7 - The flowchart of thematic analysis

Familiarisation

The stage of familiarising data started with the collection of data, and then rechecked the transcripts to ensure accuracy, as well as translated the transcripts from Chinese into English. Before coding, it was useful to familiarise data by repeatedly listening to audio tapes, translation transcripts into English, reading transcripts, fieldnotes and laboratory data.

Generating initial codes

At this stage, each Chinese transcript was read and re-read before giving initial codes, and listening to video tapes assisted in catching nuanced meaning such as tone to ensure the meaning, which might be different from the words itself. While familiarising with the data, the initial codes were constructed manually using highlighters and underlines. The merits of NVivo include easy cutting and pasting, and all themes can be pooled together easily. But NVivo 2 has its weakness while importing the Chinese version of the transcripts, for some Chinese characters do not present properly; they are deformed and difficult to recognise. Without seeing any clue to solve the problem, most of the coding was done manually, and then saved as Word documents. Coding them manually allowed me to be close to the data, which presented the story as a whole rather than segmented information, and I also benefitted from the constantly applied comparison technique. Although the coding could be done without switching on the computer, it allowed me to code and abstract the themes in a much more casual position. The participants are sorted in three folders,

including exemplar self-manager, challenged self-manager, and nurse, which allowed easier access by pinning them down.

Each transcript was saved in the form of a Word document, leaving the right half of the page blank for coding, and printed out individually. The coded sentences are underlined for easy search. While a transcript is completely coded, all of these codes are typed onto one page and put on the front page of the transcript with the notes to indicate where they are located, such as ‘fear of complications: p.11, 13.’ A total of 193 codes (see Appendix E) were done at the very beginning, and the sub-categories were all put into one document, which makes constant comparison between cases or within case easier. Later, these sub-categories were sorted into piles of themes by using constant comparison to identify the relationship between codes, themes, and different levels of themes. After comparison and piling, the categories were formed, and the data that failed to enter any sub-categories were put in a temporary file.

Reviewing themes

At this stage, the sub-themes and codes were refined by reading and reviewing extracts until they sounded coherent. The unfitted codes and candidate themes were re-examined to see why they could not fit into the existing concept, and they might be refined. Meanwhile, the input from the supervisors, who read the transcripts in English, were helpful in refining them.

Defining and naming themes

In this stage, I tried to draw the themes together to examine the meaning behind them, and elaborated them to define and refine all of the themes until the coherence and internal consistency were achieved. The next step was to recognize the meaning of themes, from which a broad story was presented to describe how diabetic patients lived with diabetes. Three themes were identified to illuminate this broad story of living with diabetes, which are ‘a changed person,’ ‘trying to restructure life,’ and ‘helping hand.’ The framework is presented in table 5.

Themes	Category	Subcategory
Beginning the journey: A changed person	Meaning of having diabetes	<ul style="list-style-type: none"> • Bad name of diabetes • Anticipated burden to the family • Feeling inferior to others • Emotional response
	A glimmer of hope	<ul style="list-style-type: none"> • Searching for hope • Vulnerable to unrealistic comments or scam
	Leaning trip	<ul style="list-style-type: none"> • Essential learning • Experiential learning
Trying to restructure life	Weighing benefit and barrier	<ul style="list-style-type: none"> • Preferred lifestyle • Capability of self-management
	Family commitment	<ul style="list-style-type: none"> • Maintaining family integrity • Balance needs between family and self • Family problem
	Negotiating with living environment	<ul style="list-style-type: none"> • Social support • Adjusting advice to the realities of life circumstances
The journey with health care services: Helping hand	Content of information and education and treatment	<ul style="list-style-type: none"> • Integration of advice with other advice 'lay health system' • Relevance • Pragmatic evaluation of advice
	Process of information and education and treatment	<ul style="list-style-type: none"> • Didactic rather than active learning • Health profession's attitudes • Trust
	Context of health care provision	<ul style="list-style-type: none"> • Status/reputation • Services/insurance

Table 5 - The themes, categories, and subcategories

How the data to be used while doing data analysis

Interview was the main method of data collection, and semi-structured interviewing allowed the main topic, self-management, to be presented in an important position, but participants could speak about their way of self-management. I did not follow the strict order of the interview guide; the interview could depend on situations that the participant preferred to begin their story, such as Wan-Ling, who began by describing how she had a stroke and it influenced her speech. She was very concerned about the complications and feared it would occur again. It helped me to understand that it was a real issue that motivated her to remain satisfied with self-management.

The medical records include the outcomes of metabolic control, such as HbA_{1c}, the years of diagnosis, and demographic data. The medical records provided the sources for checking if participants were qualified for the study, because these were part of the criteria of data collection. Besides, simple statistic of the demographic data was an attempt to look for any relationship between them (see tables 2 & 3). During data analysis, field notes were used to observe the information which could not be videotaped, but it which could prove useful for data analysis. For example, the interaction between participants and families was relied on field notes to obtain more information to complement the information about family support, such as Li-Hua's changed attitude and emotion while her sons were present in the interview room. During the data collection, research diaries were used to record the plan and action of data collection, as well as the reflections and knowledge gained in implementing the actions. Through the real process of action and reflective practice, I was able to advance some strategies for data collection. For example, there were a number of

participants expressing their doubt about being interviewed, because of their fear that the study was a scam. By examining the strategy used and the way I talked to them, I managed to change the strategy for data collection. Thus, the progress of data collection was then on-track.

Producing the report

The final stage was to interpret the story of living with diabetes, which is to be presented in the data chapters and discussion chapter that aims to describe the rationale of decision-making of diabetes self-manager.

Rigour

Unlike the quantitative method, it is arguable to achieve objectivity, reliability, and generalisability in a qualitative research (Yardley, 2008). But it can be much more appropriate in considering the accuracy of the study. It means to ensure the trustworthiness of the study.

Trustworthiness

To ensure trustworthiness, several criteria were taken into account in order to try and accurately represent the reality of the participants' experiences (Holloway, 1997; Green & Thorogood, 2004; Morse & Field, 1996). To maximize validity and reliability, I elaborated to compare the data between and within cases in the data set as

well as compare the findings to other studies, and I also took the role of researcher carefully during the stage of data collection and analysis. To keep the study transparent a clear account of the procedures for allowing the others to follow was set forth in an attempt to meet this purpose. The issue of validity was addressed by by offering as rich a context about the participants as possible to allow the reader to judge the interpretation provided. To maximize reliability, the following actions were taken (1) taking as accurate transcriptions, field notes and diaries as possible to provide close attention in the field; (2) giving the simple statistics to present what percentage of participants were involved with the themes being identified; (3) analysing the whole data set by using a code book; (4) discussing the themes with two of my supervisors who had read the translated transcripts; and (5) considering the issue of language, which will be discussed later of this section. The themes were identified after a rigorous process of within and cross-case comparison. This also involved identifying ‘deviant cases’ (Yun-Yun was nominated as an exemplar self-manager, but she showed little confidence in practicing self-management as well as Ai-Hua who was quite confidence in diabetes self-management but being nominated as challenged one). The key themes were cross-checked with the study supervisors but also with one of the nurse key informants. Throughout the study I endeavoured to adopt a reflexive approach to my ongoing interpretations and research-related decisions. As a researcher having more than twenty years of experience of healthcare, I realised that there was a danger that my own preconceptions might dominate the data analysis, leading to a distorted view of the findings. Thus constant reflection was done throughout the process of data collection and data analysis. The following sections will give more detailed information about how I managed to ensure the trustworthiness of the study. It is organised by the sequences of study, including

sampling scheme, data collection, data management, data analysis, and data translation.

At the stage of sampling, it mainly concerned the collection of information from the people who could offer the information needed. Secondly, data collection was the next step to be carefully managed because the context would affect the rigour of the study. Careful not to violate the principles of ethical issues, I constantly reflected myself after each interview to stay in a neutral and non-judgement attitude, using words carefully to encourage them to share their experiences. Participants who were grouped in the challenged group seemed vulnerable to any opinion of diabetes from the outside world. Thus, the communication skills of invitation must be much more thoughtful, otherwise they might be hurt in the process of recruitment while explaining the reason to choose them as participants. I had used different sentences between the two parties. In the group of exemplar self-managers, they appeared quite proud of being selected; but I modified the sentences used for the challenged ones by showing them much more concerns about why they had difficulties in managing diabetes. This invitation conversation was the first step to establish trustworthy rapport between me and the participants, which was a helpful skill to encourage them to reveal their experience of living with diabetes. As a nurse and lecturer in the field for more than twenty years, all of these experiences contributed to sensitise on the process of interviewing by listening to possible hints behind the events, and prompt responses are the key to obtain rich information, which could hardly be planned in advance.

Thirdly, to ensure the accuracy of the data analysis, the results were brought to a clinical expertise, nurse diabetes educator, to be discussed. The themes were reviewed by both supervisors, using the English version, to compare the themes coded from the Chinese version to increase its validity.

The final stage was information processing. Each of the transcripts was verbatim in Chinese by a third party, but I rechecked them to secure its accuracy. Also, the richest, the transcription of Ai-Hua with 19,294 words as well as nurse 2 with 27,571 words and biased transcriptions, such as Yun-Yun whose confidence score was 2 but nominated as an exemplar self-manager, were chosen to be translated into English, and the works stopped at the point when both supervisors felt that saturation was achieved after 13 transcriptions were translated into English. During the coding process, the Chinese versions were read, but the English codes were produced by constantly reading and rereading the transcription and fieldnotes. The categories and themes were checked by both supervisors to increase its degree of accuracy, using different versions of transcriptions but coming up with agreement on themes. Besides, the excerpted transcripts were double checked by a Taiwanese, fluent in both Chinese and English, who has started formal education in the UK for nine years since high school.

In a qualitative research, it matters if the act of translation is identified or not (Temple & Young, 2004), and it is important to ensure that the units are identified to its very meaning. As the study was conducted by the researcher who shared the same culture and language with the participants, the translation issue did not exist during the process of research, but rather in its subsequent documentation in English.

Methodological issues might arise while the study has to employ a translator to translate or interpret the data (Temple, 2002) because it involves the understanding of meaning in two different worlds. This situation was not met by the study, and the Taiwanese participants shared the same culture and language with the researcher. Simon (1996) implicates that translation exists while people come from two different worlds, without sharing the same language and culture; thus, to remain ‘the same,’ meaning is the key of translation. This means that translation is hardly an issue while the researcher and participants share the same culture and language (Temple & Young, 2004). However, the issue could exist while the paper is presented in a different language that is not the mother tongue of the researcher. Thus, to ensure that the reader understands the texts during the act of reading, I decided to have translated quotations double checked by someone who masters in Chinese and English. This act allows the English-speaking readers to judge for themselves while reading ‘the same’ meaning as the researcher. During the process of data collection, data analysis, and interpretation, I used the original Chinese transcripts to capture the meaning directly; meanwhile, there was no translation during the process. Because the researcher and participants are all Taiwanese, there is no need for translation/interpretation during the process of study.

Transferability

The findings of the study have been found to consist of local beliefs about diabetes self-management, but they also reveal common elements with the studies which had been presented by the other ethnic groups in the world. From the perspectives of local beliefs, the findings can apply to the middle-aged women with diabetes who live in

Taiwan, because traditional Chinese culture has its influence on the decision-making process of diabetes self-management. To extend the findings, some of them share common themes among a diverse sample of Taiwanese, including social stigma (Lin et al., 2008), misconception (Lai, Chie, & Lew-Ting, 2007; Lai, Lew-Ting, & Chie, 2005), and particular health behaviours relating to disease management (Lin et al., 2008; Lai, Chie, & Lew-Ting, 2007; Lai, Lew-Ting, & Chie, 2005). Thus, these beliefs might be applicable to other people with diabetes in Taiwan. The conceptual framework of diabetes self-management provides a comprehensive understanding of diabetes self-management which could be applied to the other studies regarding diabetes self-management. The concepts of “the self,” “perceived threat,” and “worry” are common elements for examining the decision-making of self-management; therefore they can be transferred to those studies which focus on the decision-making of health behaviours, including people with diabetes or other chronic illnesses.

Strengths and weaknesses

Due to the limited time and expenditure, the small sample size cannot present all of the middle-aged diabetic females. Also, the patients who refused to attend the study failed to be identified of the rationales behind the decisions, and it could possibly show differentiation from those who were interviewed.

From their attitude, tone, and suspicious body language, I could only presume that they feared to meet cons while accepting someone they did not know; especially, signing the consent form would risk them into a situation that they were not sure

about. For example, one participant agreed to attend the study, but as I visited her at her house she hesitated to sign up the consent form. She confessed that she was not sure if the study was not a scam until she was convinced by her doctor, to whom she trusted the most. Another weakness of the study is that the participants were all located in the countryside of the middle part of Taiwan, where there might be different issues for carrying out self-management. The contextual setting was a renowned institution with the highest diabetes care in Taiwan, and not every patient could accept the diabetes care being offered in such a high-quality service facility as the CCH. As seen in the above literature review, the study of diabetes self-management has been structured into a broad concept, providing a general concept describing the influential factors in diabetes self-management, and also exploring its trajectory from novice to expert self-manager. However, such a broad concept has its weakness in deeper explanation on how such a great deal of information could be applied to each individual. It is too broad to identify every person's motives or needs, thus to pin down the focus and examine deeper information might help to unfold the yet-to-be-known information of self-management, as well as to focus on more specific service groups and understand what they need. As people lack the confidence to trust a stranger, to adopt a one-by-one interview rather than a focus group, the research's design could offer a more secured atmosphere to talk about selves without unfolding deeper concerns in front of the others, whom they are not familiar with. The interview could then provide a better understanding of whether diabetes self-management is involved with much more personal matters. To establish a good relationship with the staff is an important element to progress the study successfully, as their good relationship with diabetic patients could encourage the latter to attend the study.

The limitation can come from the researcher, even though the study is based on the patients' perspectives. During the interpretation process, as a health professional, my previous experience can probably come to dominate the process of interpretation, even though I tried very hard to reflect. Language is another limitation for the study. Although the transcripts have been checked by another bilingual person, the true meaning may not be perfectly translated into English.

Concluding summary

The thickness of the data from both diabetic patients and nurse diabetes educators renders a comprehensive picture on how middle-aged Taiwanese females live with type 2 diabetes. The journey of living with diabetes begins with feeling of the self as a changed person, and then self-identification of the need for change will be possible. The patients would then consider engaging in self-management to prevent themselves from future harm. The themes 'a challenged person,' 'trying to restructure life,' and 'helping hand' consisted of several categories that make up several sub-categories of data obtained from the transcripts of diabetic patients. The first theme comes before the second sequentially. It indicates that the journey of living with diabetes, including actual lifestyle changes, begins with the feeling of the self as a challenged person in terms of perceived vulnerability/threat. To fulfil their needs, the theme 'trying to restructure life' identifies the experiences while attempting to change the lifestyle. The intense motivation depends on many factors, which is influenced by their personal experiences, beliefs, goals of life, social roles, and living environments. Some influential factors appear to be common in many participants, but some

categories are unique in certain individuals, such as personal beliefs, social roles, and the capability to cope with stress. Finally, the theme of ‘helping hand’ describes the interaction between the patients and healthcare services offered, which is presented in chapter seven to demonstrate how health care helps the patients develop the concepts, knowledge, and skills in diabetic self-management. Giving a deeper view from their experiences, the rationale behind the decision-making of self-management is to dig out both the explicit and implicit meanings in order to unfold the conceptual framework of self-management behaviours.

CHAPTER FIVE – BEGINNING THE JOURNEY: A CHANGED PERSON

Introduction

This chapter focuses on people's experiences at the onset of being diagnosed with type 2 diabetes, illuminating the story of how they began the journey of diabetes. For the most part, the event of being diagnosed with diabetes seems to be claiming a gloomy future ahead, and with this perception brings much distress to them. When they are told of having diabetes, an incurable disease, they have to face the fact that they have to take medication and change their lifestyle for the rest of their lives. Being aware of these needs, their lives could no longer be the same as what they used to be, and they are more or less a changed person since that time. The theme 'A changed person' is abstracted and will be discussed in this chapter. Each individual might share common questions of having diabetes, but also the unique experience of one's own.

Beginning the journey: A changed person

The data are analysed from thirty-eight middle-aged females with type 2 diabetes, including twenty examples of self-mangers and eighteen challenged. Parts of the data regarding family concerns are obtained directly from the family members while they were accompanying the participants at the scene of interview venues. Those members include the participants' husbands, sons, daughters, and nieces. The characters of interview groups are listed in chapter four.

The theme of ‘A changed person’ is identified as the abstraction from three categories.

Each category consists of several subcategories; the details are presented in table 6.

Themes	Category	Subcategory
Beginning the journey: A changed person	Meaning of having diabetes	<ul style="list-style-type: none"> • Bad name of diabetes • Anticipated burden to the family • Feeling inferior to others • Emotional response
	A glimmer of hope	<ul style="list-style-type: none"> • Searching for hope • Vulnerable to unrealistic comments or scam
	Leaning trip	<ul style="list-style-type: none"> • Essential learning • Experiential learning

Table 6 - The theme, categories and subcategories

The theme is exerted from three categories. First of all, ‘meaning of having diabetes’ illuminates participants’ responses to the event of diagnosis. Their emotional responses range from extremely emotional distress to slightly psychologically affected; it depends on the background of their experiences and knowledge of diabetes. Most of the individuals who reveal extremely emotional distress in the very beginning are shocked by the social stigma of diabetes. Due to their distress, the second category is then identified as ‘a glimmer of hope,’ demonstrating how the participants sought health care, and quite a number of them had even showed unrealistic expectations — trying to get rid of it — after being told the disease was incurable. Their desire to be cured made them grip any chance that had been said to have cured the disease or better the condition. The final category is regarding the participants’ ‘learning trip,’ which is essential to prepare them for practicing self-management independently in the real world. The first step is essential learning, which is to build up a body of knowledge about how to perform self-management. Most of them learned from health

care providers, but the other resources such as media, books, or the experiences of other lay-persons are equally important. After being equipped with the specific knowledge and skills, they were able to practice them in the real world, and many of them started to examine what would suit them best through the awareness of the relationship between their physical responses and self-care activities. This process is identified as experiential learning, and this stage can be sustained through the rest of their lives. Depending on their learning process, the performance of participants vary in many ways. While some had developed themselves into the status of exemplar self-managers, some were yet on the way to achieve that status or they probably never will. Each of these categories is discussed in turn along with their associated subcategories. To bring vivid lives of these people, there are quotes excerpted from each subcategory, which allows them to read and judge for themselves.

Meaning of having diabetes

The responses to the event of diagnosis have somehow reflected their perspectives of diabetes at the onset, and it plays a crucial role in the decision-making of health-seeking behaviours in the first place. To those who responded little to the diagnosis because of inadequate knowledge, they may still have their chances to learn gradually from either formal or informal education, and would eventually be psychologically affected at large. No matter what they have learned from the very beginning or afterward, the event of having diabetes is not a very pleasant thing, especially with dreadful consequences that they have perceived in the context of the Taiwanese society.

Bad name of diabetes

In 2001, the National Health Insurance Bureau started to cover the fee of diabetes education, before which diabetes was an under-managed disease together with a higher prevalent rate. It has created a great chance for many patients to develop into chronic complications, and the disease was then getting a negative impression in Taiwanese society. Two quotations present the impact experienced by the participants while being diagnosed.

To hear that [having diabetes] felt like Chiang Ching-kuo [having a bad shape], [or] foot amputation....to amputate whatever part [of the body]. After hearing that, [I was] almost scared to death. What a terrible disease it was! (Tian-Tian)

[I] felt why [I] got it at such a young age. From my experience, my grandma died very soon since the diagnosis....So, at that moment [of being diagnosed diabetes], I thought it in that way.

I was very depressed. (Hui-Tzu)

The event of having diabetes, among many participants, means something awful to them. Lai and his co-worker's (2007) study reveals that patients' perspectives of diabetes are related to incurability and many chronic complication diseases, while the physical condition is expected to worsen. Diabetes have been perceived as quite negative; thus from their viewpoint, having diabetes announces a gloomy future ahead. The stress from its bad name results in most participants being quite reluctant to

divulge the disease to the people around them. This is not an exclusive phenomenon in Taiwan; it also happens in the Appalachia region of West Virginia in the United States (Tessaro, Smith, & Rye, 2005). There were two sorts of ‘meaning’ distinguished while having chronic illness (Bury, 1991, p453): ‘In the first place, the ‘meaning’ of illness lies in its *consequences* for the individual [...] Second, the meaning of chronic illness may be seen in terms of its significance.’ Therefore, the patient, under such stress, experienced a period of great difficult time and was unable to live normally. One of the participants expressed the process of her experiences:

I felt very depressed. I feared to go out there and make friends with other people, or be noticed having diabetes by anyone around me. (Lan-Chun)

The impact of the meaning of diabetes — the bad name — seems to be quite impressive, but the study regarding this area is scarce in Taiwan. It can become the reason for absence from diabetes education classes. One participant gave her concern:

They [healthcare professionals] have held it [diabetes education], but I have never taken it...Maybe my intention is not to expose my own identity [having diabetes]. Some people....because some of them are considering...diabetes, alas, it’s very awful. In general, many of them [feel in this way]. [They might say] ‘Diabetes, alas, why diabetes?’ Therefore, I would do my best....I will not let people know. (Tsui-Yu)

As a result, limited resources could affect their learning process and they would behave timidly, thus leading to lack of social support, which causes negative impact on their lives. The information need is unable to be fulfilled in the very beginning of diagnosis or even afterward; it can be expected that they are stressed out. The following excerpt shows the patients' concerns that may be beyond our understanding:

I don't know what notion I have had, and I just don't want to uncover it. I don't know. I just don't like the others to know it. I could merely unfold it to my children. My husband has a big mouth, and he will reveal it to some of [our] old friends and nephews. (Lin-Yen)

Many negative perspectives from society seem to indicate that diabetes bears a bad name, and the fact of having diabetes alone can be stressful enough to disturb their lives. Accordingly, concealing the conditions to the public seems to allow them to live with less stress until the disease becomes more acceptable by society.

Apart from the bad name of diabetes, the fear of unfolding the disease to the public might have another reason to enhance the patients to do so. Having diabetes itself could cause some symptoms, especially poor control, and it casts a negative image in many Taiwanese; thus, many of them feel like a devalued person in society. Facing this situation, patients could do nothing but be angry and hope that public health education could save them from feeling inferior to others (Lin et al., 2008).

Feeling inferior to others

The Chinese idiom ‘Kuan Iou Men Mei (光耀門楣)’ indicates that being able to devote one’s self to the family and glorifying it is something to be proud of. If one is still young but unable to work harder, he seems to be claiming that he is a less productive person within his family or society. The quote below illuminates the perspectives of having diabetes:

He [husband] said that ‘Alas, your disease is a sort of rich people’s disease.’ The rich people’s disease means that [you] cannot afford to be over exhausted, and cannot work very hard.
(Jia-Jia)

Fatigue is one of the symptoms caused by poor control, and viewing diabetes as a rich people’s disease is to presume that rich people used to have someone doing the donkey works for them. If one is not a rich person, it indicates a negative meaning, mocking his life more like that of a rich person while he does not deserve it. Having this concern, they would feel that claiming themselves as diabetics would be similar to admitting that they have less contribution to their family or society.

Albeit an increasing population is starting to know diabetes better, it seems not enough to ease their uncomfortable feelings to unfold their illness-identity in public; diabetes, from the depth of their hearts, is a name alone enough to embarrass them because of the social stigma.

(I) was worrying in the very beginning when I knew it [diagnosis], even felt embarrassed. Because I feared to be said to have diabetes in such a young age. Feeling embarrassed.

(Jia-Jia)

Fear of being discriminated is another concern; because of lack of knowledge, diabetes has been long misunderstood in many ways, being considered an infectious disease is one of them, which brings many negative emotions. The following description expresses the insecure feeling of having diabetes:

I intended....not to let the others know I got the symptoms [diabetes]. [I] felt that this symptom [diabetes] would make the others think [that whether diabetes is] good or bad. It is one of my mindsets....Not knowing [the others' thoughts] whether it could be contagious....or something else. (Tian-Tian)

This finding is in accordance with Lin et al.'s (2008) study. Although there is a different meaning of 'rich person's disease,' theirs is linked with the fallacy of contagious feature.

The social stigma of diabetes mellitus could even devalue their lives. As a result, the event of having diabetes could even bring unfortunate consequences to the patient. The quoted remark presents the situation the patient has experienced.

It was because of illness, I was divorced from him. He showed his dislike; because of diabetes....people said that a girl having diabetes could make it [vagina] a bit of sticky. It means that could be....he just disliked it. He said it is no good. My [ex] husband's friend also said exactly the same thing to him. (Ai-Hua)

From their subjective experiences, the event of having diabetes has seemingly brought them more psychological trauma than physical, or it may even worsen the negative impact on their family. Besides, the consequence of diabetes imposes them to face an uncertain future, which could probably cause great burden to their family, especially for the next generation.

Anticipated burden to the family

In Taiwan, most people view their family as the centre of their lives; how to maintain the family function is always vital. Even now, the family value is yet respected in most of the families; the grown-up children are obligated to take care of their elderly parents. If the parents are not fit enough to wait until their grandchildren grow up, the loading on their children's shoulders would be quite heavy. Under such circumstances, the extra efforts to care for the sick can bring the whole family into chaos. The meaning of having diabetes is seemingly expected to link the future life with fragility and sickness, while having this thought can cause patients to grow fearsome of the imposing burden to their family in the future. The concerns expressed below reflect their thoughts:

The most scary thing for me is to meet with the situation when I grow old and am unable to live well [healthily], but also unable to die soon. If it comes to a situation like that, we will be suffering and our children will be suffering as well. (Chiao-Yen)

The worry can grow even stronger if the family has been suffering from caring for any sick family member; the quote below describes the patient's concerns:

I fear that my husband has been sick, and it is already....I have been [living] under a very harsh condition. If I were also sick, the saddest person would have been my son....[He has to] take care of me, together with the financial problems. Later, he has to....double [the burden]....for his father and me. So, I am scared. (Mei-Hua)

Nevertheless, their desire to free themselves from the worries about imposing burden on their family has provided them the meaning to sustain self-management behaviours. A detailed discussion will be presented in Chapter 6 – Family commitment. Fear for imposing burdens on the family can also be found in other studies (Tessaro, Smith, & Rye, 2005).

In summary, once diabetes is interpreted as a dreadful disease, the impact of having diabetes has more of a psychological impact than physical. It depends on how the

patients interpret the meaning of having diabetes. Most patients have the problem of unfold their illness identity to the public because of social stigma, which is seemingly one of the major resources of stress. Besides, facing an uncertain future is another stress faced, but it might not be necessarily negative. Some patients had been psychologically preparing themselves that they would have diabetes one day in the future because of dispositioned heredity. Their emotions would be affected in various degrees, which depends on how they perceive the meaning of having diabetes.

Emotional response

The emotion elicited while being diagnosed is rather diverse, which is contingent upon their experiences and the knowledge of diabetes leading to different interpretations. Each subjective experience can vary widely, resulting in different responses of diagnosis, which range from no feeling to great panic. Two examples show their responses below, illuminating how they have responded to the situations:

Very scared indeed, thinking that how could it be possible to have it. Just couldn't accept it, even cried over it. (Ju-Hua)

During that period, it was quite hard for me to get some sleep, couldn't sleep. Lying in bed, I kept wandering 'Alas, what should I do? To have this disease, what should I do?' Whenever I thought of this, it made me quite anxious indeed. (Tian-Tian)

Negative emotions might influence not only the person involved but also her family, and the quoted statement below depicts this influence:

At that moment, very depressed....Because my husband told me that he saw me like that, and he got worrier than me. I thought it was awful. [While] he was worrier than me, he couldn't even work. (Tsui-Yu)

Not every patient is absolutely affected by the event of diagnosis, and some of them only experience little distress. Among them, some admit to having learned from their family before the diagnosis, especially from those who have had successful management. The lessons they learned from their family made them realise that diabetes could be controllable, and having diabetes would not be so dreadful; thus, they could recover quickly from the impact. Their experiences reveal one thing: once the patients have learned how diabetes care is managed successfully for some people, it tends to prevent them from being overwhelmed while diagnosed. The quote below depicts this situation:

While diagnosed, I knew...because my family all got it. Ah, I just said 'Why [I] have it at such young age? It's my turn to have it but why in my forties?' I was only forty-something at that moment....It didn't get much of my nerves indeed....My mum had it since I was at high school. (Lin-Yen)

It is helpful that the participants learn the knowledge of diabetes before the diagnosis because psychological preparations make the participants start the journey with diabetes more easily. The lesson learned from this group indicates that the learned knowledge of diabetes could work well for consolation, especially at the onset.

Conversely, some have experienced little stress, but it is because they knew little about the public view on diabetes while being diagnosed. In addition, newly diagnosed patients might believe that they are too young to have long-term complications, which are thought to be elderly diseases. Having this thought, the decision-making of self-management could be effective. The following quoted address illuminate these thoughts:

At that moment, I had diabetes and hypertension. It might be I was still young and it didn't make a great impact to me. It didn't really scare me you know. (Wan-Ling)

I didn't know the consequences of diabetes. I lacked common knowledge of health and medication, so [I] didn't care much about it. (Lin-Hsuan)

In summary, being young and lacking knowledge of diabetes could be the reasons for misleading the decision on self-management. As diabetes is an asymptomatic disease for years before developing chronic complications, patients could easily overlook the importance of self-management. The findings reveal that those participants, with little worry over the disease and its consequences, have a great chance of ignoring self-

management. In the finding, twelve out of eighteen participants whose metabolic controls were poor were slightly affected by psychological reasons while being diagnosed or later. In contrast, eighteen out of twenty participants nominated as exemplar self-managers showed their worry over the complications or diabetes-related matters while being diagnosed or later. Among these two groups of participants, one denied herself as an exemplar self-manager, and gave herself only 2 points on the 10-point scale of confidence of self-management. Another found herself as a diabetic patient while she had to undergo surgery for excision malignant tumour. She was diagnosed with diabetes while undergoing surgery for cancer. To restore her health, she devoted herself to religion, and took health care carefully. Desiring to be reconciled, they had shown stronger motivation to follow recommendations, and it is found to have affected their health-seeking behaviours.

A glimmer of hope

To ensure what situation she had encountered, the patient started to tackle the problem after the diagnosis, even though she was not yet facing the fact. Looking for a second opinion is common among these participants, but some have made the decision to accept the treatment straightaway. This section discusses how the patients managed to cope with diabetes in the beginning, and two subcategories are identified as ‘Searching for hope’ and ‘Vulnerable to scam.’

Searching for hope

After the diagnosis, the patients are found trying to find any possibility for treatment or information useful for their disease. Without any confidence, the patients might try to find a doctor who is the master in a particular field to treat them.

In Taiwan, the healthcare system is quite different from the Western countries, and people can go straightforward to any specialist of their choosing. It is not uncommon that people would find a good doctor for health care if they are quite sick. As a result, the so-called ‘good doctor’ is used to having many patients, and to register into the clinic they sometimes need to wait in a huge queue. Once successfully registered into the list of these doctors’ patients, they are reluctant to change them if the outcome is satisfactory. This hunting process dictated below demonstrates this phenomenon:

At the very beginning, I wanted to register into his clinic but it was not available....Later, I was eventually registered into his clinic, and then I was visiting Dr. Wang. He has been prescribing the medicine to me, and I have kept taking it. (I-Ting)

At the very beginning, information provided by those who have satisfactory results of diabetes control is important to show a glimmer of hope, and with this support they are able to feel confident in living with diabetes. Three out of twenty exemplar self-managers who have met someone with diabetes but are successful with managing their diabetes are then able to build up their confidence to manage diabetes effectively. The quoted interview below shows these kinds of experiences:

I met with the superintendent, who was about in his seventies, and told me he had diabetes for more than forty years. He has been living with diabetes, and encouraged me that I was diagnosed earlier, and still young. Therefore, everything would be fine to me; maybe I could be the person knowing how to take good care of myself. I felt he was, indeed, encouraging me. (Lan-Chun)

There are many mothers [who I know] who got diabetes, and [one of them] said she was [diabetic patient] since her forties. She has lived to eighties, and she still lives very healthily at eighty-five, even having a bit of foot ulcer. I could say it has been very nice being able to keep it in such a condition. Just like my uncle's wife, she is in her seventies, in good shape, even though she has had [diabetes] since very young, coming from her heredity. (Tian-Tian)

The newly diagnosed, convinced by the person who have dealt with diabetes successfully, could more likely render great comfort because they could be more confident that the future ahead is not as bad as what they thought before. It is understandable why it works perfectly in this way because these successful cases show the evidence that diabetes could be controllable, and the strategies they use could practically work out in the real world. Diabetes is not so dreadful a disease as they have thought. The quoted interview below addresses this kind of mindset:

I could comfort myself. It, at least, can be controlled by medicine. Now, it's okay for me. (Lan-Chun)

Moreover, if they start to find out that there are many people with diabetes, they are actually fighting together with loads of people — a feeling of not being alone, and the disease is not so dreadful. The address quoted below illuminates this thought:

The people would say 'diabetes at such a young age.' But later, I have been hearing [many of them] that it is quite a trend. (Jia-Jia)

Apart from these resources, the support from family is also important at the onset of diagnosis. An example of family support demonstrated below reveals the process:

[I] couldn't accept it while I got it, and even cried over it. And then my daughter would say to me to comfort me: 'Mum, in fact, you don't need to think it is quite serious, it is nothing indeed. The most important thing is you have to control the stuffs you eat. It's nothing.' And my husband together would be....all of them seem to have this sort of medical....knowledge. They seemed to rather understand it, and would tell me. My husband just did the same way. (Ju-Hua)

The information obtained is crucial for their decision on seeking health care. But not every patient was lucky enough to obtain the information useful to help them out of

gloomy days. There are numbers of participants who fail to be informed correctly. One of the most common misconceptions circulating around lay-people is with reference to the insulin shot. The quoted descriptions reveal this phenomenon:

Previously, because I heard from my older brother, and also someone else saying....Some people told me ‘After receiving insulin shots, it [life] could not make it before long. (Shu-Ju)

Because a lot of people told me....to receive insulin shot should be over....It would be the end of life when receiving insulin shot. (Lan-Chun)

As a result, some unfortunate patients are even misled into making wrong decisions that deteriorate their health condition. One of the participant’s experiences below shows this circumstance:

[I] had visited the clinic of family medicine for one or two years only. It was....I couldn’t have it [blood sugar level] reduced, and was required to have insulin shots. I was scared and didn’t dare to go back again. He [the doctor] did register me into the list for next visit, but I never went back since then. Had never went back again until....[I] had not visited it for four to five years, [until] the moment [I] became quite serious. (Shan-Shan)

From their experiences, information is very important at the onset; it is a crucial period, especially when they still know little about diabetes. Their anxiety of looking for a glimmer of hope could easily mislead them to making decisions that might be harmful to them.

Alternative remedies are also found in patients who have been desperate to find themselves more chances of controlling the disease. Looking for health care from Chinese medicine or folk remedies would be another alternative.

I went to a Chinese doctor. It was the highest level [of history] at that moment. It did work indeed....Had been taking the medication for a whole month, and I discontinued all of the Western medicine for one month, not taking any of those. At that moment, I got 300-somethings, and after taking that medicine it was reduced to 100- to 200-somethings. (Miao-Chun)

Most Chinese medicine is covered by the National Insurance Scheme, and the patients could easily access this health care facility. However, there are several disadvantages to push the patients back to receive a Western-style treatment regimen. The drawbacks of Chinese medical treatments include no facilities to check for blood glucose levels or other biochemical data, and also those medications are normally of quite awful taste, hardly tolerant in a long-standing treatment. If it is not covered by the health insurance, it could also be very expensive.

Some participants are somehow easily persuaded to try folk remedies because they still hope that something out there would be helpful for their disease. To seek any hope would hardly be swiped out from their minds. The quoted statement from an exemplar self-manager shows this desire:

Once he [cousin] unintentionally said that ‘Ah, do you eat something else at the usual time?’ I said, ‘No.’ He said, ‘You could eat this....Ah, it could be a sort of food remedy.’... ‘You eat this.....but you have to take your medicine as usual. Anyway, it cannot affect your body negatively.’ I took it, and went for examination. The doctor told me, ‘your blood sugar and blood pressure are both actually normal.’ (I-Jan)

Taking herbs and diet supplements in diabetes is not a unique phenomenon in Taiwan; it also happens in other countries (Yeh et al., 2003; Chacko, 2003). Patients might think the ingredients could do them no harm because they all come from herbs, vegetables, or fruits. They just do not want to give up any possibility to cure the disease. However, the hope could bring some negative results.

Vulnerable to unrealistic comments or scam

Although participants are told that diabetes is incurable, some of them might not come to terms with reality. They seem more likely to grip onto any possibility; even though it has little chance to succeed, they would give it a try. It makes individuals vulnerable to unrealistic comments or scams.

My father didn't control well....he shouldn't pass away at such a young age. He just listened to his friends, as A told him to buy this, he would go buy it; B told him this, he would do it, followed by C and D doing the same way. Each person suggested different medication, but all in vain; the kidneys was then damaged totally. (Jia-Li)

I reckoned that, particular in the process while you had shots, the people around you would say to you 'that has some privilege remedies. You have to give it a try.' I had been trying many of them. The more I tried the worse it was. Nothing it could do. (Ai-Hua)

Some might even try to be normal, thus they would appear to be eager to try anything claimed to have cured the disease; more attempts are also described in Lin et al.'s (2008) study. Having this desire, they are the markers of the hustlers, easily to become victims of scams.

When I started to visit the CCH, there was hustler outside, just in the patient's resting area....At that moment I thought 'why I got diabetes at such a young age, I have to be cured, I have to be cured. Just cannot become like my ancestors; every one of them died soon after having diabetes....I accepted it, and

bought and took it....it cost me twenty to thirty thousand dollars; later I found it useless. I felt I was coned. (Hui-Tzu)

In summary, learning about diabetes is necessary after the diagnosis. From lessons learned from their experiences, educating patients alone would be not enough. To increase public awareness could possibly decrease the negative information circulating among lay-persons; also it would help to reduce social stigma. It would be a way to block the information imparted by word of mouth. In fact, to educate people within people's lives might grab the chances to increase public awareness at large, such as television programmes. Apart from learning from the outer experiences, the patients might learn how to be aware of their physical conditions by means of observing the relationship between diabetes care and physical responses.

However, to ensure they could know how to manage diabetes, learning about diabetes and its care is quite common among these participants. They learn from professionals based on the scheme of diabetes education held by the National Health Insurance Bureau. Most participants were satisfied with the services offered, but a small amount of patients ticked the boxes of unsatisfied. This theme will be discussed in chapter 7.

Learning trip

Living with diabetes, diabetic patients have to learn specific knowledge and skills for practicing self-management. There are two kinds of learning being identified: essential learning and empirical learning. Essential learning is the information fundamentally required for practicing self-management, which could be obtained

from health professionals, books, media, or from others. After learning, the application of knowledge and skills to their real world is the beginning of empirical learning, if patients have started to observe how their physical conditions respond to their self-care activities. From empirical learning, they can then develop their own unique way of diabetes self-care behaviours, and the learning is necessary for them to become experts in their own lives with diabetes.

Essential learning

Apart from obtaining information from health professionals, in the finding, two out of twenty exemplar self-managers get the information from books concerning diabetes, and two others are taught by their children who have read from the books or on the Internet.

I have read a lot of books concerning diabetes since being diagnosed diabetic. Then, I have been very careful with taking care of daily activities and diet and exercise. (Lan-Chun)

As I knew I had diabetes, I went to buy books to read....Even more, I feared that my blood pressure might not be under good control, because obesity would lead to hypertension. I also bought some books related to hypertension. I also bought some recipes....That's it. Just to find some information from bookstores regarding it. (Tsui-Yu)

Reading diabetes-related books would be a positive tactic. The reason might be that these patients have much more motivation for their health issues, and also the knowledge from books would be rather rich and organised; and they could set up their own learning scheme based on their needs.

If the patients' family has a history of the disease, their learning could start earlier; however, the learning could be negative or positive depending on how their family perceives diabetes. If their family has good metabolic control, it would mostly lead to a positive influence. The following interview delineates this learning:

My mum had it since I was at senior high school....since then,
[I] had gradually learned a little....a little knowledge....And
then, my sisters all had it, and I just observed their diets.
Therefore, having a bit of concept about it, after I got it, I
hadn't been worrying too much. I just knew 'Ah, [I] just know
how to eat.' (Lin-Yen)

Hungry for the diabetes information, participants would easily draw their attention to any diabetes-related information. Media is one of the accessible resources, and even their family would be alert to any information regarding diabetes.

Sometime while he [husband] was reading newspaper, he
would said 'this one has to be cut off and kept. He has also paid
attention to me, though. He would copy it, and made them into
a book. He also discussed it with me. (Pei-Hsin)

However, some of the media would only advertise the products, which are somehow untrue, making them not quite positive resources. It might cause negative influences if patients are reluctant to consult with health professionals. The quoted statement shows their concerns:

Once read whatever specific report in the newspaper, I asked the doctor about it after it caught my attention twice. It was reported by the newspaper saying its fantastic effects, and I really wanted to give it a try, [which was said] to be able to cure it. (Yi-Fen)

In summary, information is needed at the onset as it is important to influence patients' decision-making of diabetes control. Due to negative emotions, diabetic patients are sensitive to diabetes-related information, and it makes them vulnerable to accept certain harmful suggestions. The need for information is demanding in many kinds (Peyrot & Rubin, 2008), and how to satisfy patients' needs is a big challenge.

Learning is one thing, but applying to the real world is another thing entirely. Diabetes, among other chronic diseases, has its particular characteristics. Even though blood sugar levels have changed, the patients might still not feel discomfort. Instead, patients still can get the results of blood sugar immediately by self-monitoring their blood sugar, and it could help patients to understand the causal effect among physical responses, blood sugar levels, and self-management behaviours. While the patients

start to link the result of laboratory data or body cues with the diabetes self-care activities, the learning could be more helpful in improving diabetes care skills.

Experiential learning

The stage of experiential learning is when participants start to observe the relationship between their self-care behaviours and blood sugar levels or signs and symptoms. If participants have limited knowledge, they could still learn by themselves. It mostly involves trial and error, and this kind of learning could be found from those who would like to try their own way of diabetes care. Two of the exemplar self-managers stopped the medication after they had received expected results to see how the blood glucose levels were:

At that time, I believed that I was quite good, and just took medication seriously a few days right before the clinic visit to convince the doctor that the blood sugar level did come down and there was no need to take medication regularly....On the moment of the onset, I didn't agree that I had diabetes. (Hui-Tzu)

Once I just didn't take medication, and it was measured as 170-to 180-something, and then I was scared....I just wanted to try it whether it would response. If not I would keep taking medication. (Tian-Tian)

If patients are vigilant to diabetes care, they could change to link their diabetes self-care activities with physical responses. The laboratory data is the most important reference for them to reflect on whether their self-care activities suit their bodies.

In Taiwan, the diabetes patients can have a whole package of laboratory and physical examination, and the value of HbA_{1c}, checked at a three-month interval, as well as blood glucose checked before and after meals. These are the major reference data for patients to learn. To check the blood glucose level is another resource that helps them to learn.

During the New Year, there would be more dishes cooked, we would eat more, and the blood sugar levels would go higher.
(Jia-Li)

Because I do feel that if I eat rice and noodle a bit less, the body weight would drop a bit; besides, that average value [HbA_{1c}] would be....six-point-something [%]. (Wan-Ling)

Through this learning, they started to develop the strategy to cope with this kind of situation. They would know how to avoid the risk of increasing blood glucose level.

People sent some wedding cakes here, and felt that would be wasted if they were not eaten; [I] just ate one more piece of cake. The coming tests would tell. It's quite sensitive in taking wedding feast and cakes. I had tested it out. Nowadays, any

more of that stuffs sent to me has better be sent off to someone else to eat them all, not for me. (Tian-Tian)

The benefit of exercise can also be proved by the laboratory data. They would start to understand how exercise is linked to cholesterol, and learning this could enhance their behaviours.

After being diagnosed, I had swum for the first ten years. I changed to take aerobic exercise since three, four years ago. That, because it's much intensive....About three years ago, I had a test in Australia. At that one whole year before the test, I had been taking rhythmic gymnastics four to five days a week. After getting the result the doctor told me, 'your cholesterol, good cholesterol, increases a lot, and, low density, the bad one is tremendously decreased. How did you do that?' 'I just keep exercising,' I said. (Lan-Chun)

They also notice the change of the pattern of lifestyle would disturb the blood glucose level; insomnia is mentioned by several participants.

Not enough sleep, [blood sugar level] would be very high indeed....if there is not enough sleep, the results would be very high. If I got enough sleep, the figures would be not so high. (Jia-Jia)

They also note that negative emotions would change the level of blood sugar, and from it they also learned how to respond to it by managing self-care.

I just knew that it [blood sugar level] would occur again
[soaring high up]....It would occur while [I was] worrying, I
could feel it. (Hsiao-Tsui)

As the patients start to become concerned about the outcomes, the tests can have another meaning rather than just the results, as they become references for them to modify self-management activities to improve metabolic control.

It could make me quite nervous, while having an examination
every three months. If it were every two months, I would have
been too scared to eat. I do feel that the interval of three months
could be only a moment, just as quick as the twinkling of my
eyes. My son always asked me ‘Mum, fancy something for
eating?’ I would say ‘no, it is about time for me to take
examination. I don’t want to eat.’ I would eat light food. I used
to think it this way. (Tian-Tian)

As they begin to know the relationship between self-care activities and blood sugar levels, they would be rather positive. Whether the institution can offer the service of examination would be an important factor for them to decide their treatment regimen.

For example, the patients feel hesitant to accept Chinese medical service as the only treatment because it offers no laboratory tests.

The most important is not only feeling the pulse, but just the [lab] data you have recently. It is said that it [Chinese medicine] has....no such medical service; and then, after receiving the service long enough, I might ignore it [blood sugar level]. (Yi-Fen)

In fact, the patients might facilitate a blood glucose monitoring machine to build up more advanced knowledge of metabolic control. One of the participants took experiments to obtain the information about how the medication worked inside her body, and then tried to estimate how her blood sugar would respond to the medication to learn more about diabetes care.

Sometime, I just intentionally....gave myself a shot. As I gave myself a shot at seven, and then I did not eat until eight o'clock, and nine o'clock, two hours later, I monitored it [blood sugar]. And the result was very near what I had expected. Then, that afternoon and evening, I ate some to reduce the effects of long-term's [medication]. After dinner, the results of blood sugar in each hour until the next morning, I could predict them quite precisely. It was only 5 [mg/dL] below or above the estimation. I could do it like this. (Lan-Chun)

After they have built up more knowledge about their own body's response to various situations, they would be capable of developing strategies to cope with different life events.

While the patients become more confident after their learning, even without the professionals' recommendations, they can make their own decision to tackle the problems encountered.

The doctor has changed the prescription for me....The 'quantity' seemed to be not enough for me. I had experienced dizziness, and the blood sugar was around 160–170 at that moment. One day I ate nothing, but the blood sugar was high up to 201. It made me feel anxious every time I went to bed.... Compared to the previous one, it is a mixture and consists of short-term and long-term insulin. I didn't know how to deal with it like I used to, by giving myself extra short-term insulin shots. But I did ask the doctor in his clinic just a moment ago, he explained it to me. Now, I have the idea. (Lan-Chun)

When I was depressed, the blood sugar would be higher than usual; when I feel light-hearted and have a nice sleep, the blood sugar level would be down to normal as if I am a healthy person again. The blood sugar would be maintained around more than 100, feeling very healthy, indeed. And then you

would need insulin less than what he had prescribed to you.

(Ai-Hua)

It would be a starting point for them, learning to prescribe themselves a proper dose of medication based on their unique physical response, which, in fact, has never been taught in such detail by the doctor. Apart from connecting the relationship between different lifestyles and blood sugar level responses, the patients also do some experimental studies to answer their own inquiries.

Patients with type 2 diabetes experience minor or even no symptoms, and this makes it difficult for the healthcare provider to motivate the patients for self-management. But some patients seem quite sensitive to the change of blood glucose. As they notice this phenomenon, the sign and symptoms would become a reminder that enhances their self-care behaviours, such as skin rashes. With less criticality, in personal concerns, it could also work to motivate them for self-care. The following quotes illustrate this consideration:

P: If having any finding....felt something happened in the skin,
previously found to be here [pointed at her abdomen].

R: At that moment, you got higher level of blood sugar, right?

P: Yeah, the level of blood sugar was higher at that moment.

R: About how much was that?

P: It was around 160 to 170 [mg/dL].

R: So you got skin problem, right?

P: Yes, yes, yes.

R: So, you might know your blood sugar level while you got skin symptoms, right?

P: Yes. Therefore I took a test using that one [machine], but it [skin symptom] hasn't been found. The skin isn't found to be like that. Now it is well-controlled, and it hasn't been found yet. (Chiao-Yen)

Some participants have been observing their body closely and even tried to understand whether it could be linked with their blood sugar levels. The quoted addresses below illustrate these experiences:

If I felt fatigue, as feeling fatigue, my eyes became very blur. At that moment, it would be around 148–150 [mg/dL] if [I] measured it. (Mei-Hua)

P: I would know it while the level of blood sugar control was not so good, feeling tightness on the neck.

R: How much is your blood sugar level when you felt that?

P: The data would be quite high.

R: Quite high? What's the level of that?

P: Approximately 190. (Hsiang-Yueh)

As they learn the relationship between the symptoms and blood sugar levels, they become vigilant when the symptoms appear. In the finding, there are four participants in the study having body cues appearing while their blood sugar soars, and those body

cues are identified as skin rashes, neck tightness, and blurred vision, although these signs and symptoms vary individually. All participants practice stringent self-care activities based on their knowledge of the relationship between physical responses and blood glucose levels. In Lin and her co-workers' (2008) study, their participants reveal similar awareness to their physical responses. It may explain why all the participants are classified in the group of exemplar self-managers. Flexible self-management relies on knowing one's physical responses and being able to handle them in an effective way (Paterson & Thorne, 2000). Bandura (1977) explains that the physiological state is one of four principal sources of information that is a threatening force that drives patients for persistent activities. Through physiological arousal, patients learn to know the relationship between physical response and metabolic control to increase their self-efficacy. All kinds of learning regarding their physiological response makes their self-management unique, and this kind of learning has a positive influence through the journey of living with diabetes. An increasing number of authors believe that experiential learning, linked with the physiological responses to self-care activities, is a necessary step to develop their own unique way of self-management (Price, 1993a, 1993b; Paterson & Thorne, 2000; Paterson, Thorne & Dewis, 1998; Paterson & Sloan, 1994; Lin et al., 2008). However, it still needs further investigation.

Conclusion summary

Only if patients can identify that they have been changed can they engage in self-management. Even though they do not agree with the diagnosis, they still have no choice but to set off on the journey with diabetes. Along the journey, they have to

learn how to manage the vehicle safely to remain healthy, or they have great a chance of developing long-term complications. It is similar to the trip they have but just more complicated.

Even when the appearance of the patient is not obviously changed, having diabetes would mark him in the heart as a diabetic patient. He becomes a changed person, and not a comfortable one, both psychologically and physiologically. Since being diagnosed, the event has influenced the patients more on a psychological level than the physical condition. The meaning of diabetes mostly focuses on the negative side, and how their suffering is raised depends on the perspectives on the meaning of diabetes they have. The public view of diabetes might cause them to feel inferior to others, even if they have the disease under control. They would still struggle with whether to unfold it to the public or not. The more they know about its negative side, the more tension they receive. Although they do not know much about diabetes, it does not mean patients can stay free from suffering the negative emotions. They have a great chance of developing long-term complications if they do not have good metabolic control. Once they have complications, the suffering they have can be more intense.

With this new identity, their lives need to be reorganised to live with diabetes, if they hope to resume healthier lifestyles. It depends on how they feel about the meaning of having diabetes. Social stigma or discrimination could lead to concealing the condition to avoid the stress of facing an unfriendly environment. As a result, it more or less increases the difficulty in changing their lifestyle.

Seeking professional help is considered a search for hope. As they learn from the successful self-managers who have been living healthily, having diabetes would no longer be so dreadful. It is a good way to offer the patients support. While the patients are in a vulnerable stage, it would be easier for them to accept unrealistic comments or become victims of scam to help them out of desperation.

Learning is essential to diabetes care. The capability to search for resources of diabetes could help them to advance their learning. If they start to learn from the relationship between physical responses and blood glucose levels, they will be able to know more in-depth information about diabetes care, which suits them well. Based on all of these experiences, it could advance the skills of self-management to become both practical and effective.

Human beings are part of the social context. To live with diabetes involves all kinds of living things, and it also involves the people around the patients. It is impossible that the patients stay unaffected by their social context. How they cope with it within the context of society will be discussed in chapter six.

CHAPTER SIX – TRYING TO RESTRUCTURE LIFE: SELF, FAMILY, COMMUNITY AND SOCIETY

Introduction

The theme ‘trying to restructure life’ is abstracted from three themes, which seemingly indicate that the patients are trying to restructure their lives within family, community, and society. These categories include ‘weighing benefits and barriers,’ ‘family commitment’ and ‘negotiate with living environment,’ and each category consists of subcategories. Table 6 listed below shows all of the categories with their subcategories.

This chapter concentrates on how the patients integrate diabetes self-care activities within their family, community, and society. The findings here show a number of influential factors contributing to the process of decision-making on diabetes self-management. This process appears to reflect that patients have to abandon some of their previous living habits and struggle to replace the newly suggested ideas on how to live with diabetes within their own environment. No matter how much they know about diabetes, the capability of being able to practice self-management within home, community, and society properly needs sophisticated negotiation with their preferred lifestyle and central values of living.

The suggestions from health professionals do not necessarily meet all the participants’ concerns because the time for diabetes education is not enough to cover all of them. Efforts to integrate the disease into all dimensions of life could be tremendous, as

immediate recommendations from health professionals are lacking. As daily activities could be trivial and complex, it is difficult to provide all the information needed for self-management through the standard self-management education. In fact, it depends on the patients themselves to deal with diabetes.

Themes	Category	Subcategory
Trying to restructure life	Weighing benefit and barrier	<ul style="list-style-type: none"> • Preferred lifestyle • Capability of self-management
	Family commitment	<ul style="list-style-type: none"> • Maintaining family integrity • Balance needs between family and self • Family problem
	Negotiating with living environment	<ul style="list-style-type: none"> • Social support • Adjusting advice to the realities of life circumstances

Table 7 - The theme, categories and subcategories

Trying to restructure life

The findings in this chapter are analysed from thirty-eight interview data, twenty of which are from a nominated exemplar group, with eighteen from the poorly controlled one. This chapter will draw their stories in order to understand how they made the decisions in living with diabetes.

The theme ‘Trying to restructure life’ describes how the patients live with diabetes in their own world — home, community, and society. Some subtle influences are revealed to have affected their decision-making on diabetes care, as they try to integrate diabetes care in their living environments.

Weighing benefit and barrier

The category ‘Weighing benefit and barrier’ is identified from two of the subcategories, ‘preferred lifestyle’ and ‘capability of self-care.’ Each of the subcategories will be discussed in turn, along with its consequences. ‘Weighing benefit and barrier’ is one of the categories emerging to construct the theme of ‘trying to restructure life.’ Through weighing benefit and barrier, the decision-making for diabetes control enables the patients to develop their own way of living with diabetes, which involves what they are more likely to accept without too much struggle, and also the appraisal they make based on their goals, situation, resources, and the capacity to decide what kind of life suits them best.

To integrate diabetes into life, the core issue is how the patients’ perspectives of their own lives join with their capacity for self-management, essentially leading to the various outcomes of metabolic control. If they have their own goal of life, it can encourage them to cope with diabetes, and capability of self-management could influence the result of metabolic control.

Preferred lifestyle

Following chapter five, the impact on the event of having diabetes could have different meanings. It depends upon the patients’ perspective of diabetes. An individual starts to recognise that he has to practice diabetes self-management in his daily life or would face the physical consequences, such as amputation, blindness, stroke, and renal failure. The issue of preferred lifestyle could be significant.

Decision-making involves the way in which an individual weighs the benefits of self-management against the barriers of practicing the necessary changes.

An example shows that how the occurrence of personal maturation relates to insulin. To some participants, being informed to receive insulin shots could cause great panic. An individual can be motivated to do everything just to avoid it. Avoiding the insulin shot becomes a goal, which motivates the individual to change their behaviours. Two nominated exemplar self-managers described how they made their previous decision on self-management while they had poor metabolic control. The event is related to the treatment regimen, as their doctors wanted to change medication from oral antidiabetic drugs to insulin shots. These quotes express their thoughts and responses to the prospect of insulin injections:

The doctor told me I had to start taking shots [insulin injection], for it did not work well only taking pills. To start taking shots! I said no, I didn't want it. It must be very painful. I didn't want to get shots. I decided to step down [from the post of manager]....Very troublesome, I have to bring it [insulin and syringes] everywhere, very troublesome indeed. My husband and I [both] like to travel abroad....bringing needles would be very exhausting. I decided to step down, for I don't want that much money. (Miao-Chun)

My previous doctor who took care of my diabetes said that if I don't have a good control, he would give me shots. I was scared, thus I have been taking exercise. (Hsiang-Yueh)

They each decided to change their work/exercise patterns to improve their diabetes control, and were both nominated as exemplar self-managers. On the date of the interview, both were still receiving oral antidiabetic drugs. The first participant had two daughters who were nurses, and they offered information regarding diabetes control. The second was a health professional, confident of her knowledge on diabetes. Each thought that having insulin shots would have more of an impact than practicing diabetes self-management. By changing their lifestyle, they noticed that the benefit from practicing self-management overcame their barriers. The first participant revealed that even if she had earned a handsome salary from her previous post, she would be unable to enjoy it because of the bad shape caused by poor metabolic control. Having this thought, she then decided to step down from the stressful post as a manager to work as a clerk, which allowed her time to manage diabetes. To be informed of having an insulin shot was a alarming sign that her physical condition was deteriorating; besides, it would affect her lifestyle immediately. From this decision-making, they obviously knew what they wanted their lives to be, and it turned out to motivate them to practice self-care.

While each of the patients still had a chance to reverse the need for insulin, they would appear to be highly motivated. The first case asked the doctor to give her one more month to see whether the self-management could work well enough to reverse

the situation; and the second had just chosen to change her doctor and restarted again, also earning herself a chance to reverse the situation.

To receive an insulin shot is similar to changing one's lifestyle — receiving shots every day. It is an immediate change although the chronic complications need longer time to be developed to affect the patients' future lives. If the patients picture a dismal life in the future, it could lead to psychological distress. Six out of eighteen nominated as challenged self-managers had experienced negative emotion since knowing the consequences of diabetes; in contrast, eighteen out of twenty nominated as exemplar self-managers were psychologically affected. It indicates that the patients who had less negative emotion toward long-term complications tend to have poor metabolic control.

There were five participants who experienced chronic complications of diabetes, including two who had a stroke, two who had numbness in their hands, and one person who had blurred vision. Having a stroke is stressful, especially while it happened in the patient's early forties. It caused great panic, but it altered the patient's self-management behaviours. The quoted interview below illuminates an exemplar self-manager's decision-making being affected by the complication:

I never thought that I could get a stroke so soon, but...after the stroke I found myself thinking 'eh, it's true, [I] can't move indeed.' I had always found myself some excuses. I would like to find some excuses for not wanting to do exercise. After that

moment [the stroke], I started to take exercise diligently. (Wan-Ling)

The patient experienced a stroke three years ago, and after recovering she had been strictly managing her diet and exercise. Even though she was not satisfied with her quality of life, the fear of having complications enabled her to tolerate her suffering:

Because, I like noodle pretty much. Noodles consist of carbohydrate, and I cannot eat too much. Besides, it's greasy. So, I was suffering. Why I got so bitter a life? Why? The others, at least, can take three meals with stomach stuffed. Sometime, thoughts of my situation would be very depressing. I then just thought that 'let it be though, my life is more important.' (Wan-Ling)

To manage diabetes is not a truly preferred lifestyle, but compared to risking oneself with another stroke, it is the best option. Wan-Ling realized that the desire to be alive enabled her to endure the suffering of craving her favourite food. In the interview, she said she did this for her only son, who was still young. Another participant grouped as a challenged self-manager found herself having eyes problems, and she started to consider diabetes care more seriously.

Now, it really harms the eyes. [I] feel not clear while looking at things. Besides, that examination....last year reported inner bleeding....the loss of vision would worry me....Have been

controlling it a bit, otherwise you....what can you do while one loses his eye sight. He [the doctor] said ‘[if not being controlled] the legs would not be able to walk.’ Eh, my legs were degenerated, too. (Shan-Shan)

Based on their experiences, if individuals understand the consequences of diabetes, it is possible for them to take action to change their lifestyles. Otherwise, they may have a great chance of suffering from physical incapability. The intensiveness of negative emotion could reflect their worry of gloomy lives. In the findings, if the patients had ever seen the other diabetics suffering from the consequences of diabetes, this could force them to face the possibility of a depressing future. Being afraid to live a life like that, they experienced tremendous stress, which also became a facilitator for them to take action to prevent them from becoming one of them. Two participants revealed their experiences and thoughts:

Like my second uncle, he passed away because of diabetes, and one of his legs was also amputated....Later, before he passed away, he was in the intensive care unit....Every time I went to see him, I always thought of myself. (Wan-Ling)

My sister had diabetes and passed away last year. She had neither taken exercise nor controlled her diet properly; therefore, her blood sugar used to be very high. During the last stage of her life, she needed haemodialysis. It’s quite a

terrifying thing to me, and I always keep my vigilance: ‘I must control my diet, and take exercise constantly as well.’ (I-Jen)

Numbers of studies agree that a perceived threat is a strong influencing factor to motivate the diabetics moving toward self-management (Nyhlin, Lithner and Norberg, 1987; Whittemore et al., 2002; Tan, 2004), and the findings in the study offer perspectives from the patients in some views to explain how it makes these influences. Also, the contribution of the study delineates how the patients make their decision, and what kind of lives they would like to live. As they could preview their possible future, they would have much more information to make the best decision for their own lives.

Despite that the threat might risk their future, it does not mean that the participants would choose to avoid taking risks. Instead, some patients preferred their lives remaining as happy as they could be, and might view that as a quality life. Before adapting their lives to living with diabetes, there might still be some problems in giving up their favourite lifestyles, which could undermine their health conditions. Unless they change their goals in life, it would be a challenge to persuade these patients to follow the recommendations. The dilemma is explained by Li-Ching:

In fact, I have one question, but you might not agree with me.
Human being should live happily in every single day....Ah, just like what you said, I can't eat this, I can't eat that either....control is quite strict....to last my life for some more years. Because of this [strict control] your life could last for

more years. If you have poor control, your life might have problem to last for some more years. But, why let your life become unhappy just for the sake of a few more years to live?

(Li-Ching)

Some patients are not afraid of death, but they lack the knowledge that the suffering brought from the chronic complications of diabetes could possibly last for a long period before they die. Being unafraid of chronic complications may result from lack of knowledge. The quoted conversation bellow presents the perspective of Hsiao-Tsui.

R: Do you know about the complications of diabetes? Do you worry about it?

P: Not at all. If it's time to go [die], and I shall go. Why shall it to be worried? Eventually, everyone has to die, nothing to be afraid of. Death to me....I have never worried about it. Why on earth [we] have to worry so much? Ah, that one [the complications], sooner or later, would come to get you.

(Hsiao-Tsui)

The findings indicate that to let the patients understand the consequences of diabetes is necessary, although it could possibly cause negative results leading to avoidance (Smari & Valtysdottir, 1997; Bombardier, D'Amico, & Jordan, 1990). Thus, how to manage perceived threats to motivate patients but not cause negative influences is an important issue and it needs further investigation.

The most common adjustment to self-care is the issue of diet. The findings suggest that enjoying food is part of life fulfilment on an everyday basis, and it is said to be the most difficult part to be achieved in diabetes control (Whittemore et al., 2002), influencing the perception of quality of life. It might be understandable that a patient's desire is to remain on his favourite diet; however, the health professionals do not encourage this. The quoted statements below delineate some participants' feelings about their perceptions on diet:

The nutritionist told me to fill it up to three quarters, but I used to fill it up to one bowl, as they were not looking....They said 'for the sake of your health, I would plead with you not to eat rice that much.' I said 'Okay, okay.' In fact, after I came back, I used to eat the same. [Laughs] (Tian-Tian)

In fact, I feel that the most difficult part for controlling diabetes is dietary. My personal experience shows that much, but I have no idea about the others....I feel that I have failed in controlling dietary, but the others might be fairly well-controlled though. (Li-Ching)

Change of lifestyles is difficult for many people, as one of the studies reveals the patient's perspective that it somewhat brings down the level of life (Smith et al., 2003). Among these participants, while starting the journey with diabetes, some had to play the game of tug of war — whether to practice self-management or not — in their everyday lives. The strength of the dragging force seems to be decided by their

feelings of fear and desire. All of these feelings are rooted from their perspectives of how they prefer their lives to be or the performance of their roles. This issue will be discussed further in the section on family commitment.

Motivation alone might not necessarily prove to have satisfactory results on diabetes care. Other influential factors within individuals are found regarding their capability of self-management, both intellectual and physical, which will be discussed in the next section.

Capability of self-management

The participants' responses suggest that personal capability in self-management influences the decision-making for self-management, which in turn affects the results of metabolic control. Living with diabetes, the patients have to build up confidence of diabetes self-management, which relates to their performance of restructuring a life with diabetes. Participants may know the benefit of self-management, but based on their physical limitation, they have to compromise their decision-making. In addition, inadequate knowledge could limit the quality of the decision on self-management; thus, the way they weight benefits and barriers could be different, but these decision-makings contribute to what life they will restructure.

When a participant fails to restructure his life with diabetes, it is mainly a result of lack of knowledge about the disease. After data analysis, it is found that if the patients misunderstand the information regarding diabetes, or the knowledge is incomplete,

they find it hard to practice self-management properly. The significance of this is illustrated below:

At that moment, for nearly one year, I was required to have dietary control. Maybe it was because I didn't care much about diet control at that moment. He [the doctor] didn't tell me how to control my diet. There was no nutritionist teaching me about it. (Lin-Hsuan)

Similarly, others have reported that with limited awareness of potential complications, the patients might ignore the importance of self-management because they focus on how to cure the disease (Helsel, Mochel, & Bauer, 2005). One of the participants grouped in the exemplar self-manager described how she suffered from hypoglycaemia without knowing how to deal with it:

At that moment, I didn't know yet that I had to eat sweet grubs whenever I got hungry. I didn't know that yet....He [the doctor] didn't even tell me a bit of this information, if my memory served me right....I was informed of nothing; otherwise I would have had no problem to prepare candy at any moment. (I-Jen)

It is not guaranteed that by attending similar diabetes education programmes the patients could know exactly what the health professionals are trying to teach. They could possibly misunderstand the information and do things in the wrong way. In Lai

et al.'s (2007) study, it has been found that there are misperceptions about taking medication, and it does affect the decision-making on self-care. As a result, the outcome of self-management could be affected. One of the participants' statements below reveals how she misinterpreted the recommendation from health professionals:

Based on the saying of the nutritionist, I did eat much more rice,
so it [the level of blood sugar] has been unable to be reduced. If
it's like this, some people said noodle, eating noodle would be
merely noodle; these are not [rice]. (Shan-Shan)

For some of patients, they might have difficulty learning about food substitution because it is complicated for them to carry out. With misunderstanding, the patients took the advice from the health care provider faithfully — not to eat too much rice — but she ate a lot of noodles instead. She failed to build up her knowledge of food of carbohydrates, even though she tried to restructure her life to live with diabetes. Similarly, in Lai and his co-workers' (2005) finding, patients are found to have some misconceptions of diabetes-related diet.

In my finding, some participants have little problems adopting suggestions once they are educated. However, it might be hard to apply this rule to all people with diabetes, especially to those with misconceptions of the disease. This is still a common misconception being found involved with medication, and one of the examples below demonstrates this phenomenon:

At that moment, I told my younger sister that I got diabetes. My younger sister said ‘you can’t take medication. After taking medication, it [taking medication itself] will last for a long, long time, and will never stop.’ (Lin-Hsuan)

For individuals with diabetes, their understanding of the disease would partially add some weight to their decision-making of how to receive health care; therefore, before knowing their thoughts, it could be difficult to ask them to follow the prescribed treatment. The quoted interview below illuminates how the participant is influenced by her health belief:

R: Is your mom under good control?

P: She is. She is not taking medication, either.

R: Eh, did she check her blood sugar?

P: No.

R: She didn’t check blood sugar. Did she go to the hospital to check it?

P: She was definitely not to going [regularly], she said....now I am not quite sure. I am not staying at home [with them] now, and I contact them merely by phone.

R: Oh, I see. So, you have learned from your mother, right?

P: Not definitely, because the air here is not quite clear [air pollution], though.

R: Hmm, you said the air here is not quite clear, so....

P: If it were, I would have taken it [medication]; but I always forget to take medication. It was forgotten because I was busy [Laughs].

R: Did you forget to take medication on purpose?

P: It was about that [Laughs]. (Ling-Hui)

Apart from intellectual limitations, physical problems also contribute to hinder them from restructuring their lives with diabetes. Physical incapability is the one limitation found with which they have been struggling while carrying out self-management, such as pain or teeth problems. Compromised to their physical condition, diabetic patients might not be able to carry out exercise as expected, even though they know it is important for diabetes control. It is easy to understand that if the patients are not yet enjoying the benefits from exercise but suffering from taking exercise, it would discourage them to do so. Two patients summed up examples below describing this situation:

Doctor said that I have....what it's called....tendon degeneration. Oh, I couldn't walk indeed. How can I take a stroll?....Previously, these areas [knees] were killing me, thus I had to sit down while cooking. (Fang-Fang)

I might not be able to exercise for half an hour. My legs have problem standing that long. As for exercise....mine [knees] have been degenerated....a sort of leg degeneration. Ah, sometime my heart wasn't good as well. Heart....if I

walked....sometime the pain was quite serious, and I didn't
dare to walk continually. (Shan-Shan)

Mental problems are also found to cause problems for self-management, especially the memory issue. Unless the problem is solved, it would otherwise affect the capability of self-management. Li-Li's serious problem with her parents-in-law, which induced her memory problem, and when her condition became worse she had problems to follow the recommendations from the health professionals. The quoted description below presents her experience:

R: So, you seem to be always forgetting to take medication,
right?

P: Now, it is happening quite often. Several days ago it would
also happen....Before coming here, I forgot two nights'
medications. This month, the frequency has been reduced.
But in the morning, I would have no idea how many times
indeed. Just very forgettable. Sometime I might remember
it [immediately] and made it up, but sometime not. (Li-Li)

In summary, to carry out self-management, participants have to know how to do it, and there should be no physical or mental problems to hinder them from doing so. The findings suggest that taking care of patients means to understand their limitations, and help them to conquer various problems by facilitating alternative methods to carry out self-management. Each patient might have different conditions, which might hinder self-management behaviours. These need to be carefully assessed.

Family commitment

Apart from individuals' characters, family issues are the factors involved with self-management because family is used to being the centre of women's life in the social context of Taiwan. From the data analysis, many concerns related to diabetes self-management are linked with family commitment. How to maintain the integrity of family would affect the decision-making of self-management.

In Taiwan, females are the major caregivers of a family, but they also need to work to financially support their family. The findings also reveal that family is their first priority, and the motivation is largely involved with the issues of how to fulfil family commitment.

A number of participants showed their concerns while they realised that the complications could impose a burden to their children. If their health conditions deteriorate into a status that needs someone to take care of, their children would suffer. To prevent them from this dismal future, the motivation of practicing self-management is seemingly integrated into part of their family commitment, and then it is strengthened as more meanings are added to it. One of the Chinese idioms 'Hsiang Fu Jiau Gia (相夫教子)' explains the role of a woman in the family, which specifies that the major mission of a married woman is to assist her husband and breed children. Any threat that would tear the family apart could probably become the first priority to be tackled. The following section will present the categories identified from the data.

Family integrity

Maintaining family integrity appears to be a very strong factor influencing self-management, while the participants realise the disease could probably risk their family integrity. If the disease can affect family integrity, it becomes a serious issue. If disease tears the family apart because of their health problem, how to maintain fitness will be linked with decision-making for diabetes self-management. The stronger need of the family to maintain integrity, the stronger motivation they may have for practicing self-management. It becomes a goal not only for one's self but also for the family. An exemplar self-manager shows her concern as follows:

My duty was quite heavy. I have a family to care for: children, husband, and business. How come it could be affected just because of you [being sick]....The business could never stop running because of your illness. What responsibility I had was work....For the sake of this family, my duty was still heavy. For the sake of myself, I had to listen to what the doctor said to me, and went out for exercise. (Hui-Tzu)

Because the participant was overwhelmed by the diagnosis, and this negative emotion infected her family, her husband was too worried to work, and the main financial support of the family was at risk. At that moment, she realised how the event of diagnosis could put her family in jeopardy before the disease becomes deteriorated from her worrying rather than the disease itself. To show their family that diabetes is

nothing to worry about, she hides her own negative emotions and pretends that she is fine. She also has to practice self-management faithfully because her husband has paid huge concerns on the result of examination from each check up. As she cried in the early, chilly winter morning due to exercise, she never thought to give it up. It becomes one of the responsibilities to become healthier for the sake of her family, and to retain the integrity of family. The meaning of practicing self-management has been much more than what it originally meant to the participant.

Similarly, the welfare of the children was listed as one of the major concerns, especially if the participant was the only one to provide support for her children. As a mother, the desire to be in good shape is found to be extremely strong because the behaviours could mean something not only to their own health issues, but family issues — being able to complete the role of a mother — as well. The two participants' husbands fail to support them and their children, thus they show a strong will to stay fit to take care of their kids.

I had been expecting it [to have diabetes], and what I thought [at the moment of diagnosis] was that it was still a long way ahead. My kids were all in their tender ages, and also needed to rely on me. I had to receive treatment. I had to convalesce myself into a good shape. At that moment, the only thought hit my head was 'I have to be healthy. I have to earn money. I have to raise my kids and feed my own.'....I had definitely followed whatever that doctor Wang had told me....I had thought that

‘my loading is still quite heavy. I cannot afford falling into sickness.’ (Li-Hua)

It was quite a harsh condition indeed. Especially when I was sick, I just couldn’t abandon these three kids. It is my beliefs that the kids are innocent in the event of their parents’ breaking up. You can’t just....I have been doing my best to make up for the event [of divorce]. I had thought of....if I wanted to be alive....then I should take good control over it. For if only it’s under a good control, then I could be possible to....take care of them (Ai-Hua).

From the findings, the participants show their concerns that retaining a healthy body is the only way to carry out their roles as a mother, or else the children would suffer from having no one to rely on. It adds a significant meaning to the matter of practicing diabetes self-management, and it presents an alternative way of caring. This motivation appears to be strong enough to conquer any temptation confronted, and the following interview demonstrates this phenomenon:

I had done whatever he [the doctor] wanted me to do. My thought was buzzing with ‘I have a lot of responsibilities indeed, and it’s not allowing me to be beaten by illness.’....I felt it [blood sugar level] was not so good during the stage of adjusting medicine. Therefore, I rejected eating any single foodstuff with sugar-bearing, and ate only a little bit of rice....I

had this episode [hypoglycaemia] happened for tens of times a day during that period (Li-Hua).

In the context of Taiwan, the responsibility of the parents could extend to the grown-up children. Therefore, apart from considerations of bringing up young children to reduce the burden of the family is another way of taking responsibility of their grown-up children. The quoted dictions below illustrate the more delicate concerns:

I have no worry. I thought that I have to take good care of myself for not to impose burden on my son....I always say that if I have a good shape my son will have no worry. (Mei-Hua)

Anyway, it should be definitely [good for] passing away comfortably [weeping]....Don't 'Tuo (拖)' [serious illness but unable to die soon]. 'Tuo' will put a burden upon the children, and they would have harsh lives as well. Albeit we [as people] personally might not feel it this way [the harsh lives as the children have], but it would be very depressing when we see them in such a harsh condition. (Chiao-Yen)

They have no intention to increase their children's burden while growing older because their children are expected to take care of them. If they fail to maintain their health while growing older, the burden could be huge. It could be a disadvantage for their grown-up children because they still have the obligation for their own family. To

avoid reaching this situation, self-management could benefit not only for their own health but their love for children in nature.

Financial concern is connected to the burden of a family while a member is sick. If the patients' financial status is good enough to support themselves, the issue of imposing burden on their grown-up children would be less affected. As a result, self-management that decreases the risk of complications would no longer be seen as an issue regarding the fulfilment of family commitment, and how to live with diabetes would then be back to their own perspectives of life. The quoted interview below shows this concern:

In fact, while the children grow up....in fact, even [I have] a bad shape later, it would be no matter. The children have all grown up. (Li-Ching)

Family is the centre of their lives, thus how to fulfil the family's need might always be beyond theirs. It could be beneficial to diabetes care to evaluate how the patients weigh the balance between the needs of them and their family.

Balance needs between family and self

In Taiwan, the goal of diabetes care in terms of the outcome of HbA_{1c} is expected to be less than 7 percent. However, receiving intensive diabetes treatment would increase the risk of hypoglycaemia, and this issue has been long discussed in various studies (Herman, 1999; Murata et al, 2004). From the patients' perspectives, severe

episodes of hypoglycaemia could cause panic to their family, and it might influence the quality of life of both the patients and their families.

As for her illness, she had experienced several episodes [hypoglycaemia] in the past decade, and it might happen again. But my family and I might not be around. This is the biggest worry for us. (Lan-Chun's husband)

My daughter always said that I looked insane. She said, 'mom, could you just skip the shot in the evening? When you had the shot in the evening, you lost your consciousness, and knew nothing even when people were moving you around.' (Ai-Hua)

Likewise, numbers of studies have found that the episode of hypoglycaemia can have negative influences on diabetes self-management (Lauritzen & Zoffmann, 2004; Davis & Alonso 2004), but there is little detail about the consequences regarding self-management in the context of family. A patient is more concerned about preventing hypoglycaemia, thus she develops her own strategy to cope with it. The quoted description below explains the process of coping:

[After begging for deleting one insulin shot] Doctor C also said, 'alright, alright, you could skip one shot in the evening.' I prefer to have a higher level of blood sugar. (Ai-Hua)

The participant greatly suffered from the episode of hypoglycaemia because it had been leading her family into chaos. Some patients try to negotiate with their doctors of the lives they want best, but some may choose non-compliance. However, Ai-Hua tried to persuade her doctor to agree with her, omitting one shot before going to bed, but it did not help her with metabolic control. Her values of HbA_{1c} were far higher than expected while recruited. Conversely, some did manage to cope with it and came out with satisfactory results. Two examples bellow tell the strategies used:

But I do feel, for some time, as I was going out for supervision, I would eat nothing but bring a cup of half-sugared cold green tea, 500 ml, just a quite small one. I feel this one works quite well....would be no cold sweating, no palpitation....[if] to achieve that condition, it would be too late, for at that moment [I] would inhale food with no limitation. No good, blood sugar would then soar high up. (Hsiang-Yueh)

If the blood sugar checked was below 100, I ate some before going to bed....If it was below or equal to 110, I would drink a glass of milk. Or just ate a bit of rice or noodle, or something else. If it was higher than 120, I would probably eat nothing. (Lan-Chun)

It is essential for them to feel controllable by using their own way of diabetes self-management. Once the patients could facilitate strategies successfully to control blood glucose, the confidence of self-management could be boosted. Through constant

learning, they understand the connection between blood glucose levels and self-care activities, thus they start to know their physical responses better. After benefiting from these experiences, they are quite convinced that self-monitoring blood sugar is the element to achieve good metabolic control.

Argh, while I felt something unusual, both in the morning and the evening I would definitely check it [blood sugar level]. Ah, to have a good control, you have to check your blood sugar level frequently. (Lan-Chun)

Women are the main caregivers in the family, and taking care of their family could consume lots of time and energy, which might even affect their self-management. Most women still have to take care of their family, and the roles they play might conflict with their own self-care activities. Living with grown-up children is not uncommon in Taiwanese society. Presumably, to live with a married son's family could receive financial support and be cared by his grown-up children, but it might not be the case for those of lower economic status. While both their son and daughter-in-law had to work, the patients might become babysitters for caring for their grandchild. As a result, their needs of self-management might then be sacrificed.

In the finding, numbers of the participants lived with their grown-up children, and there were seven out of thirty-eight sharing the responsibility of caring for their grandchildren; furthermore, they had to take care of their daughters or daughters-in-law while they were in the stage of confinement after delivery. Among them, six out of seven participants are in their fifties, and one just in her early forties, which means

that the women's role nowadays has been extended to taking care of their third generation. One participant was in her early forties; she had take care of her grandchildren, and it could mean that women have to be caregivers for a long period. The role of a woman and a grandmother used to be help in a family, but this kind of role is tough for them as they have to take care of their grandchildren. It could impose a huge physical burden and leave little time for the participants to practice self-management, and two statements quoted bellow address this situation:

Taking care of this one [granddaughter] couple with the responsibility of all of the chores of confinement [for her daughter-in-law], how could I take exercise....These two days, my grandchildren weren't going to bed while the clock passed two, they just kept running here and there. I am not an easy sleeper, and I couldn't sleep while they were running here and there. Besides, I had to get up at around five, six o'clock, because those youths [her grown-up children] had to work. (Jia-Jia)

R: Now, you have to take care of this six-month-old grandchild.

Does it affect your exercise?

P: Yeah, I just can't take exercise though. Previously, it would be rather possible [for me] to ride a bike, take a walk, or climb a mountain, but now it is not possible for me. (Ai-Hua)

Their roles also cover the caring of the sick family members, and in the finding they might even sacrifice their own care to satisfy their family's needs. There are three out of thirty-eight participants whose husbands had once suffered from serious diseases such as cancer and stroke. During the period, they failed to provide needs for themselves. The quoted descriptions below present their situations:

At that moment, my husband was sick, and I was busy as well. Therefore, I thought of not to take it [medication]. I was quite busy though....While my husband was sick and hospitalized, within that one whole month I hardly got even a little bit of sleep....It's true. At that moment, I had to offer him massage, and also cooked for him and poured him tea, and I hadn't even a bit of sleep. (Tian-Tian)

[My husband] had a stroke while he was thirty-nine years old.... Two years ago, in the morning after he woke up....and then....hit and then fell over. His leg was broken. Previously, for the sake of physical health, around half past five [I] would go to climb Pa-Kua Mountain. Ah, later, for the sake of my husband, (I) had to cook and also had to do so and so....It was too tired though, leading to discontinuity [of climbing mountain]. (Mei-Hua)

Furthermore, one of their roles is daughter-in-law, and they need to take care of their parents-in-law when the latter are old, fragile, or sick. Of thirty-eight participants, five

have taken responsibility to take care of their sick parents-in-laws. The tension might rise during the period of taking care of parents-in-law, and it could worsen their metabolic control. One example below shows the issue:

Have to take care of my mother-in-law. She just can't walk....just couldn't walk again since she fell....My mother-in-law used to scold people often since she was young....About one week of caring, it could already test you to the limit.
(Chun-Ju)

As the caregiver of the family, the participants are used to placing their needs next to their family members.' Two cases describe that they are the last ones to eat at the dining table after finishing cooking, and sometimes some particular food suggested by nutritionists might be eaten up while it is their turn to eat at the table.

I haven't eaten [meal] together with them....but after all of them have finished, I am the last one to eat. [Laughs]....veg, which I sometime ate quite a bit amount, sometime just....ate none. That might be all eaten up by those young persons.
(Chun-Ju)

Unless they develop some strategies to cope with it, they can hardly change their family's routine of life. Another example describes this kind of strategy:

Because I was the latest to eat, my husband and the children would eat first. Sometime, if that [dish] was their favourite, they ate it all up. I am a bit smarter now, I know to keep some for myself [before served on the table], or veg would be all gone at my turn. (Shan-Shan)

Ensuring that their families are all well-fed, they put themselves as the last person to eat. To withdraw one's self from dinner with the family might not be the golden standard in Taiwanese families, but it illuminates that the family's needs are somehow of higher priority than one's own. Even though they have diabetes, they have no intention to change it. Their families could also fail to recognise the participants' needs, as the family routine remained as usual since the participants are diagnosed as diabetic. Their interactions indicate that as caregivers, they seem to have little support from their families when their physical conditions are yet looking healthy; their families, while being cared for, have little obligation for other members' health, which leads to overlooking the health needs of the participants.

Diet and exercising self-care behaviours are closely linked to family behaviours (Wen, Shepherd & Parchman, 2004). Gregory (2005) argues that patients dealing with diet-related chronic disease need to juggle many things because the lifestyle involved is not simply seen as an individual matter, but rather it affects the whole family. To involve the family in the diabetes educational process can retain a longer and healthier behaviour by both exercise and dietary regimen (Foreyt & Poston, 1999). Women frequently, if not exclusively, are the persons to bear the caring of things in the family; and the task of preparing food is implicitly seen as an instrument to show being 'cared

about.’ Being a diabetic patient and caregiver of the family, there are dilemmas and conflicts. In fact, they might not always be happy to be the caregiver, especially if their family fails to understand them and go too far, or are over-demanding. That could cause negative emotion, and one of the participants explained how her youngest son is asking too much of her:

My little one [who was twenty-four years old], minutes later he will come to visit gastric-intestine clinic....Whenever he wanted to visit here [hospital] for ailments, he just asked me to bring him here...He had done every single scan, but nothing wrong was found with him...This kid just keeps bothering me, and keeps vexing me. Oh, recently I feel vexed, and then think ‘oh, I would rather die. (Jia-Jia)

Overwhelmed by the heavy workload, they are turning into helplessness and developing negative thoughts, which could have negative impacts on metabolic control. The finding shows that some of them had to struggle with the basic needs — having no enough time for rest or relaxation — because they were too exhausted to think of their own self-care. To sort out daily lives and keep the family in order could exhaust them if they were in an over-demanding family. Thus, together with developing a healthy lifestyle, it would be no easy task.

To offer children a normal family might be a married woman’s major goal in life, but things might run out of their control. If the family is not running as smoothly as she thought, it might worry her. Being unable to take control of this situation, she might

develop negative thoughts, which could literally affect her emotion and deteriorate her condition. At this moment, as a caregiver, the patient seems to have difficulties concentrating on her own diabetes care.

Family problem

The values of blood glucose are linked with stress; therefore, as the main caregiver of a family, any stressful event caused by family could lead to unstable conditions. While the family is unlike what an individual expects, it could develop stress within the family. If the event is tense enough to cause chaos within the family, it could cause negative emotions. In the finding, negative emotions could make a huge influence on the patients' self-management. Not only do negative emotions lead to higher blood sugar, but this sorrow could also distract them from keeping vigilant on their own self-care. Financial problems are the top issues disturbing the patients, and self-management activities seem quite vulnerable to this situation.

All living together....they [sons] all want to save money in order to get married....All my four sons are not married yet....It has been my eldest son supporting us. Ah, the oldest one would say 'ah, why among these four sons I am definitely the one that offers support? Everyone just pretends not knowing anything about it.' That is why I have financial

problem....Because of the lack of money, everyone would become serious on it [money]. (Ai-Chu)

The biggest worry is money....[Diabetes] isn't the thing to occupy my mind. Taking medication is the only thing told, just merely taking medication. Nothing [regarding diabetes] worries me. (Yueh-Ching)

Both of these participants are nominated as challenged self-managers, but they show least concern in discussing diabetes. During the interview, these participants repeatedly brought the issue back to their current situation of poverty rather than how to manage their diabetes.

As a female, facing a broken family or problematic children is the most traumatic event to them. Under such situations, patients could only pay little attention to their own self-management, and the outcomes of metabolic control would be unexpected. Ai-Hua, nominated as a challenged self-manager, had her first marriage ruined because of diabetes. When the divorce court gave her the custody over her children, she was rejected by her ex-husband's family to visit her own children. However, her husband did not care for their children properly, and her eldest son constantly ran into troubles. He went in and out of juvenile court many times because of drug problems, selling pirate CDs, and a car accident resulting in one death. Thus, she made great effort to help her son back to normal. Although her second marriage was great, she still had to deal with her son's trouble by herself. Under this situation, she had poor metabolic control because she kept struggling with family issues rather than taking

care of herself. Having stress is one factor to keep metabolic control poorly, but it could also be caused by poor self-management out of ignorance. Life to her was sometimes too stressful, thus following a treatment regimen was not her consideration when the thought of committing suicide flashed through her mind. Ai-Hua's description below shows the complexity of patient's decision influenced by many family matters in their own world:

Sometime, as I passed out [hypoglycaemia], I asked my husband, my son, my mom, all of them, saying that 'you all....if I am to pass out again, you all shall just let me die in peace.'....If your family wasn't in harmony, the kid was very troublesome. As there was still something that can't be sorted out, I was still feeling a twinge of sadness. (Ai-Hua)

Providing support can be more important than self-management at the moment when they encounter stressful life events. Taking care of Ai-Hua under such extremely stressful situations, health professionals need to consider that the outcome of metabolic control is not so important as to support the patient through the period of difficulties. From her lesson, one can learn that to focus on the outcome of metabolic control alone can easily treat patients with a non-sympathetic way of care, and to investigate every reason behind a poor metabolic control rather than judge or blame them can be much more important. Ssu-Hsuan, with poor metabolic control, is another case trapped in her family's problem:

At home, I just know that I am worrying about this and that.... Just because I kept worrying, it [high blood sugar level] then occurred. I do feel in this way....Just worry more about my husband only. [Laughs]...I was just upset about my husband spending money without planning....but it was just all my money, and he never thought to leave some for the kids....studying. Didn't want to let the kids study....Just worry about them (kids), I know that made it occur again. (Ssu-Hsuan)

Apart from family troubles, while the family lack the knowledge about diabetes, with little skill to express their concerns regarding the patients' self-management, it becomes an added negative factor for the patient to endeavour their self-management. For example, while families express their concerns in terms of their anxiety to the patients, its influences might not be as expected; instead, it imposes some emotional burden upon the patients. The way to offer support might not be necessarily helpful for the patients, especially when the family have no adequate knowledge to offer them help. Two example situations quoted below reveal this kind of relationship:

Sometime just..., off to have a feast with someone else. I didn't eat [on certain dishes], he [husband] would say 'Ah, [you] have to eat each one though. No problem!' He would say 'just eat each dish, but with little amount.' He meant that to take no partiality for a particular kind of food would be ok....While I only ate a little amount of rice, he always said 'you have better not to eat.' (Ying-Ju)

If he [husband] saw me giving myself a shot, he would say
‘Argh, you are nearly dying, you are nearly dying.’
[Laughs]....If he was there, I would go to another non-
populated place to take the shot. It would be ok though.
[Laughs] (Chun-Ju)

Improper responses or concerns by their family could make practicing self-management more difficult within daily life. From the finding, the participants consider that their families bear no ill-meanings; in fact, those behaviours show nothing to support, but discourage them instead.

Apart from family, social environment is another place closely involved with an individual's life, which includes interpersonal activities, community, and working environment. How the patients cope within their environment would be another factor that affects their self-management.

Negotiate with living environment

Community and society also play an important role in diabetic patients' lives, and to investigate how they live with diabetes in their society. The following section focuses on how they integrate diabetes care into the living environments. The categories are drawn out as social support and adjusting advice to the realities of life circumstances.

Social support

If the patients fear to reveal their disease to the public, it would be a disadvantage to carry out self-management while needed. They might have to make up many reasons to explain why they have to act differently. To insist on eating is viewed as hospitality at a friend's, but it could be the opposite for the people with diabetes.

The friends are really sort of, such as chocolate-coated ice cream lolly, chocolate, milk-made lolly. I would have no intention to eat these kinds of stuffs, but my friends would urge me [to eat it]. I did take one chocolate-coated ice cream lolly unnoticed. But after I took it, I was quite nervous and scared.

(Lin-Yen)

In Taiwan, food is the major theme in many occasions, such as friends' gathering, family events, and festive occasions. It would be hard to control if the patients attend such events involving eating.

We, a group of people, just went to have a meal together. We went to karaoke, and then went to eat (Li-Ching).

Because sometime [I] would drink some wine; sometime....so my HbA_{1c} would go higher....It was merely held on Saturday and Sunday. We do not drink during week days....Friends just gather together....We mostly drink beer....During the

weekends, [we] just want to have a chat, and [my friends] bring beer to my place. (Ling-Hui)

Because most of the participants lack the confidence to reveal the condition to their friends, they obviously suffer from lack of specific social support to prevent themselves from succumbing to temptation. Extended social networks contain risks to diet, as they still have to interact with friends. This finding is similar to some other studies (Gallant, 2003).

Travelling is another issue found to be difficult for patients to cope with. The patients feel vexed at handling self-management during the journey, if they treat metabolic control seriously. Giving up the journey might be one of their strategies, or they have to tolerate higher blood sugar levels than usual. Two quoted interviews below reveal different schemes used by both the exemplar and challenged self-managers:

She used to pay scrupulous attention to self-care. To say it more accurate, it might not affect the daily life; but, on the other hand, it causes some psychological effect, such as going outside - travelling. I think it affects her psychologically. She has to plan a trip in advance very seriously, considering the possibility of the plan; for she needs space for giving shots; especially she needs company. If not, she will give it up. I think it affects her psychologically. (Husband of Lan-Chun)

Like us, sometime just went abroad twice a year....about seven, eight days....Unconsciously, you would take more calories, and sometime forget to take medication. I believe it's the reason.... at night....I used to go to bed earlier, around half passed nine. When travelling, the life pace would be changed. (Li-Ching)

If the participants have to work, they might need to practice partial self-care activities at the work place. With the intention to conceal the condition, taking medication is not easy, especially the insulin shot. One of the challenged self-managers gave her concern below:

Sometime at work, people were around, I would not dare to take the shot there....Sometime I forgot, but most of the time I had my shots done. (Tsiu-Pin)

The major problem for the patients is that they have difficulty telling their friends about their dietary needs. In Taiwan, to share food with friends is a way to show their hospitality and friendship; thus how to turn down the other's kind invitation would be quite challengeable, especially without the understanding of their situation. The more extended social network has more chance to reach unexpected food, but this situation might not be the same with taking exercise.

Specific social support is found helpful to bolster the constancy of taking exercise. To take exercise is considered the second-hardest behaviour to be achieved (Whittemore et al., 2002). To stick to this activity might take some motivation. Keeping company

could make the activity itself more attractive to the individuals, and encourage them to go further. The quoted interview below reveals the phenomenon:

After five o'clock, [I] would go to the school's sport-field, just quite a big group of us. We, about the same age, just went there to take exercise, and it took about one hour. It's quite happy for me to go there....There are ten or more people in the group...and [if not going] they would say 'why didn't you come?' (Jia-Li)

If the patients are closely bonded with their fellow exercisers, the action itself could become more than just taking exercise but also a kind of social activity. As a result, taking exercise can become a pleasure of social life, and patients would have little struggle to do so.

Taiwan has a dense population. It is located within the tropical area with very high humidity and high temperature spreading throughout spring, summer and autumn seasons. All of these disadvantages easily discourage individuals from taking exercise.

Adjusting advice to the realities of life circumstances

The advice given might not perfectly suit the participants' lives, and they have to make subtle changes to be individualized. From their experiences, integrating the advice of taking exercise has various ways of being accomplished. The findings show that weather is the key influence on the patients' motivation. The weather in Taiwan

is hot and humid. During the summer time, from March to August, the average temperature is higher than 30°, which discourages people from going outside for exercise, except in the earlier morning. During the summer time, two kinds of weather days are most common: sunny spells or raining, and those are not good days for outdoor exercises.

Miss Y [diabetes educator] said I had no regular exercise, and should take exercise. I said ‘it is summer, and I cannot tolerate the hot weather. In winter, I cannot tolerate the cold.’ (Shan-Shan)

It’s very hot, how is it possible to practice any exercise? Do you like to go out there? It’s very hot out there; do you dare to go out there?....I will sweat a lot, as the weather is very hot....just sweating until....until....how is it possible to go out there? (Yueh-Ching)

The weather might not be so perfect for outdoor exercises, and the patients could grow unhappy while being advised to take exercise constantly. Except those who have been taking exercise for a long period of time and benefited from physical improvement, it would be very discouraging to take exercise under such unpleasant conditions. The quoted interview below reveals one of the participants’ thoughts in the very beginning:

During winter, I even cried though...I thought 'why everybody could hide under their duvets? Even when it is very cold, we still have to walk in the mountain....Now, I am getting used to it. [I] would feel something wrong if not doing it [mountain climbing]....Besides, my husband would like me to take some exercise. The physical condition has been improving constantly.

(Hui-Tzu)

Apart from the temperature issue, rainy days also keep the patients indoor. Normally, individuals do not go out for exercise during bad weather, but there is one exception found in the study. In a heavily rainy morning, one exemplar self-manager, who just finished her exercise, walked in with a raincoat held in her hand. She described her thoughts below:

I would definitely go to Pa-Kua Mountain for exercise, even when it was windy or rainy....I will definitely take exercise. Definitely want myself feeling burden-free [physically]. It must be in this way. My mind wants me just like this....If someone asks me for a trip, I will have the least intention to attend, for I can't take exercise in the morning. (Chiao-Yen)

To cope with weather, the health care professionals teach them about alternative methods, such as buying exercise equipment and exercise at home instead. For some it works well, but not the others. With a strong will, weather seems to be not so big an

issue to be concerned, but to the beginners, it could be difficult for them to take the first step forward or keep up with it.

Since I passed out, I felt that I would never have this episode happened again. I would feel that, I, myself, needed to have the determination to keep going. I definitely have to take exercise. I definitely want it [to be controlled] more than just taking medication. I definitely have to take exercise, together with dietary control. These two things I definitely have to do. So, I bought that walking machine. My son even said ‘Mum, you are very confident; you have taken exercise every day indeed.’ I said ‘once I bought it, I just want to use it every day, and then it would help my conditions.’ (I-Jen)

[Because it is] too hot, I would feel lazy to take a walk....My neighbourhood, quite diligent in taking a walk, invited me to walk with her. I just said ‘too lazy to walk.’....My son also has one sort of running equipment....of a good brand, [and I] just felt too lazy to use it....At the very beginning, I was interested in it, but not later. (Hsiao-Tsui)

Weather could be an influential factor for taking exercise in Taiwan, but it is still not significant enough to be a major one. Patients’ motivation could be much more important because weather issue may only be an excuse for not taking exercise.

To fulfil the needs of self-management somehow depends on whether the environment can support their needs. The quoted statement below demonstrates how it works for one of the participants:

I feel that the place where I grew up is really a nice one. The place I live in is called Chung-Hsing New Village, where there are many open grounds. My cousin just retired from her post, and she has diabetes but not a serious one. Therefore, we have been walking together since the episode of stroke I had. (Wan-Ling)

The exercise-friendly environment can support the patients with places for carrying out self-management. With partners, it makes the self-management behaviours less struggling. It could increase the chance to sustain the newly changed lifestyle.

Conclusion summary

To restructure the life to live with diabetes, the patients themselves are the major element to direct their own lives. Even if they have the sense to make the changes of their lives, they have their own preference of life to be considered. They rebuild their lives based on their needs — how they want their lives to be — and also compromise to their capability. The journey of living with diabetes is different from individual to individual.

Family commitment is the major concern in their lives. Juggling within their multi-role playing, the participants might either gain more strength from within to enhance the diabetes care, or the family would just hinder their way. As they want to make decisions on diabetes care, their concerns on children are pivotal to direct the process. Because family members might refuse to change their role as care-receivers, they might unconsciously make it more difficult for the patients to carry out diabetes care. Over-demanding families especially worsens the patients' conditions.

From the aspect of diet, the society is too food-friendly for the patients to have their diet controlled. Besides, when the patients fear to unfold their illness-identity, the situation has become more difficult to carry out self-care. In contrast, social support is important while exercising.

In the findings, each individual deals with different living conditions, and has different needs while living with diabetes. There might be good days, but there will also be bad days, and all the elements would contribute to the result of diabetes care. Amidst these complex situations, how the health care service has been contributing to their needs of diabetes care would play an important role.

CHAPTER SEVEN – THE JOURNEY WITH THE HEALTHCARE SERVICES: HELPING HAND

Introduction

This chapter concentrates on the experience of diabetes health care provisions, which is elaborated to not only the treatments of diabetes but also to foster patients' capability of diabetes self-management. Both the healthcare professionals and the healthcare policy could make profound influences on the patients' performance. With consideration of receiving good diabetes care, the patients have learned to find better sources for themselves and how the healthcare professionals and healthcare policy influenced their decision-making. The theme 'Helping hand' is used to describe this process of interactive relationship.

In Taiwan, apart from the specific project 'the Improvement Programme of National Health Insurance Payment for Diabetes Medical Treatment,' the pay-for-performance scheme has been launched to provide an incentive factor, with better payment, to encourage healthcare institutions to provide higher quality of diabetes care since 2001 (NHIB, 2001). If diabetic patients enrol in the project, which requires diabetes care to be managed by certified diabetes educators, they can accept a whole package of diabetes care. Take the Changhua Christian Hospital (CCH), for example, the package includes diabetes educational programmes, physical examination, laboratory evaluation, and evaluation of management plan. Diabetes education counselling is offered every three months, in which diabetic patients receive consultation from the nurse diabetes educators and nutritionists. Apart from nutrition counselling, nurse diabetes educators provide services of blood pressure checks, evaluation of the

performance of metabolic control and giving overall lifestyle change counselling, as well as foot examination. In laboratory evaluation, HbA_{1c} will be taken every three months or at least twice a year if the patient's condition is stable. Patients can receive physical examination, which includes ophthalmoscopic examination, thyroid palpation, cardiac examination, evaluation of pulse, foot examination, skin examination, neurological examination, oral examination, and sexual maturation (if peripubertal). In addition, like many of other services offered to various sufferers, a professional-led patient support group was launched to help the patients cope with diabetes. Through attending the group, patients can have a chance to know others who suffer from the same disease. They can interact with others, or provide more information needed for self-management, such as teaching strategies of how to eat in certain Chinese festival events.

Helping hand

The data analyses thirty-eight middle-aged females with type 2 diabetes and five nurse diabetes educators. The characters of interview groups are listed in chapter four.

After diagnosed, diabetic patients have to rely on the help of health professionals, both in understanding the treatment regimen and the diabetes education. Without diabetes education, patients may not understand the importance of diabetes self-management and may not have the knowledge and skills to carry out self-management because the traditional treatment of illness is heavily relied on medical treatment rather than self-management.

As a patient's diabetes control requires complex knowledge and skills together with continuously receiving treatment, to embark upon a process of being supported by health professionals is crucial for them. To illuminate this process of an interactive relationship, the theme 'Helping hand' is formed. Table 8 below presents the categories of data that are related to the patients' experiences of how the healthcare providers influence their decision-making in diabetes self-management.

Themes	Category	Subcategory
The journey with health care services: Helping hand	Content of information and education and treatment	<ul style="list-style-type: none"> • Integration of advice with other advice 'lay health system' • Relevance • Pragmatic evaluation of advice
	Process of information and education and treatment	<ul style="list-style-type: none"> • Didactic rather than active learning • Health profession's attitudes • Trust
	Context of health care provision	<ul style="list-style-type: none"> • Status/reputation • Services/insurance

Table 8 - The theme, categories and subcategories

Three categories were identified as the content of information, education, and treatment, the process, and the context of health care provision. The purpose of health care service in diabetes is to help patients in a long-standing trip to cope with diabetes. The information needed for diabetes care is imparted through formal and informal education, and healthcare provisions can provide support that influences the progression and content of diabetes care. The information could be obtained from multi-resources, health care system, or lay health system. Amidst the myriad of information, patients might not unconditionally accept the recommendations from health professionals, but they have their own ways to assess the information to be carried out in their reality.

The content of information, education, and treatment

The contents of information, education, and treatment are the key elements to diabetes care, which has been significantly influencing the outcomes of metabolic control. This section will discuss how patients receive advice from health professionals and lay-persons, together with their appraisal process of how to adopt recommendations in their own context of living. As many recommendations were given to them, they have to sieve out the ones that fit them best; if not, they would look for alternative ways for diabetes care.

Integration of advice with other advice ‘lay health system’

The research found that the information and advice from lay-people with diabetes are generally well respected. The purpose of diabetes education is to increase the patients’ knowledge and skills of diabetes to ensure the success of metabolic control. During diabetes educational programmes, the recommendations of diabetes control are given to the patients who are ultimately the key persons in deciding whether or not to take action. The research found that when the patients obtained information from lay-people they met by chance who had successful diabetes control experiences, it had a profound and positive influence on diabetes self-management behaviours. The findings reveal that the patients tend to have little question against someone who had been successfully managing diabetes, and advices from them mostly have profound influences. Jia-Li, one of the exemplar self-managers, described how she was helped by someone else who had diabetes with good control:

Because when I went to buy veg, a middle-aged man, who also has diabetes, told me that ‘diabetes is not a dreadful disease, but you have to believe in the doctor. Never listen to whatever those A, B, or C from radio, or cable telly telling about lots of stuffs, each of which is said to be very effective [to diabetes]. It [physical condition] will be deteriorating after taking that.’ Therefore, I did go to a doctor, and take the medication prescribed by him. (Jia-Li)

The best way to convince the patients is to show them the positive results from those who have similar experiences because of the golden rule ‘to believe is to see it by very eyes.’ The method used by some patients to decide whether the advice could work well for them is to see the results after the experience. This phenomenon has been observed by nurse 2 below that illuminates the awareness of health professionals:

Chinese people used to believe the thing seen with their very eyes, while after seeing a real case who had successfully achieved it; therefore, in the process of health care, I did find that to establish a patient support group would be quite positive. (Nurse 2)

The finding shows that the patients have little capability to judge if advice given from either health professionals or lay-persons are good for them. They need to judge by themselves, especially while some advice might be contradictory to each other. Therefore, how to appraise advices that could work well for themselves relies on

many factors, and the advice from health professionals may not necessarily be accepted unless they feel confident about it. Nurse 2 shared many of her experiences of how to communicate with patients. For example, one of her patients was quite confident about his knowledge on diabetes because he was a taxi driver having lots of chats with his customers while working. He was too confident to take advice from health professionals even though he had poor metabolic control. To solve the problem, nurse 2 facilitated her knowledge to point out what physical conditions the patients had experienced to convince them that health professionals understand their condition enough to help them. The quoted statement illuminates nurse 2's experiences:

During the teaching process....I kept facilitating [a strategy] which was that I agreed with your life experiences, and then....I let you compare with the bygone days' experiences, the ways you had been through, that place[....]For example, [saying to patient] 'you have problem to get to sleep at night. High blood sugar level would disturb your sleep, the truth is that as your blood sugar level is quite high, you would surely have neuropathy. You would definitely feel a little bit...numbness on the feet....or your hands lack muscle strength or feel the numbness during the night....' This....he did feel, but he didn't really know that [high blood sugar level linked with his symptoms][....]as you match these [symptoms] together....he would feel whatever [the signs and symptoms] you said was happening to him. He would start to take exercise.

(Nurse 2)

The communication between the health provider and the patient is very important; it is the key factor to collect information needed before giving suggestions or imparting information to encourage them to engage in diabetes self-management behaviours.

In the patient's view, each question raised indicates that an unsolved problem has been bothering the patient for some while, and he or she needs someone to help them solve the problem. This indicates that any question that might be seen as trivia or even stupid to someone's view can still be very important. My finding suggests that communication skills are fundamental for diabetes counselling; a better explanation from healthcare professionals could make different results of diabetes care. Once the diabetes educator could touch the core issue of the problem, the patients would be more likely to accept the advice.

Relevance

My research shows that standardised diabetes educational programmes could be beneficial to patients if they have little knowledge about diabetes; however, without constantly evaluating the educational scheme, the content might fail to meet the needs of the patients. One exemplar self-manager was annoyed with attending a compulsory educational programme, which had started several years ago since the patient first enrolled in the programme.

But sometime I felt quite bothered while needed to take lots of
courses, patient education....I felt it was alright in the very

beginning, but I have felt vexed by taking the courses. I do feel why it hasn't yet drawn to an end. (Yu-Lin)

For the course, to offer necessary information was much preferred by the patients. After taking the courses, the content of education might not be totally accepted by the patients, and whether they would take it or not depends on the patients' own decision-making, which is influenced by various factors. If the advice was not relevant to their daily lives, no matter how good the advice is it would be ignored or thought to be impossible. The quoted expression below illuminates this phenomenon:

She asked me to eat meat in some certain 'Lian (兩)' [unit of weight in Taiwan].... in fact, I ate more than that. To be honest, because of my workload....I have been consumed quite a lot [energy]. Definitely, [I] had to eat more. I just told the lady, nurse....told the head nurse saying 'I seem quite fond of stewed fat-lean pork.' [She] asked me to eat less, but I feel that I can never achieve it. (Tian-Tian)

A standardised diabetes educational programme designed by health care providers is a professional-centred educational scheme. It is an attempt to teach all kinds of patients with one standard. If diabetes educators are less experienced and skilled, the scheme might not be able to be best fitted for the patients. It can become a one-way communication, lack of consulting to patients who might have their own idea or specific experiences after years of practicing diabetes self-management. Negotiating

with patients before setting the goals could make the plan more feasible (Thiel de Bocanegra & Gany, 2004).

As for [the service which provides] the knowledge of dietary, it would be alright. Every one here just keeps offering similar information, even though the educator was different. They just keep saying, ‘You can’t eat lots of meat. Don’t eat greasy food, it needs to be boiled.’...Whenever you see these dishes, it could probably make you feel [not delicious]...The way they taught couldn’t be possible to achieve. (Ai-Hua)

The courses had lost its value in engaging them easily, and the patients would eventually hesitate to join in. In fact, the diabetes educator had sensed this situation, revealing their understanding of the patients’ perspectives:

He is one in good control, indeed, and also very enthusiastic. He would come occasionally to receive some classes regarding diabetes, but he would rather discard those courses full with sort of cliché. He only picked up the classes he thought fit him well. (Nurse 5)

The diabetes educators were aware of this issue and noticed their need to improve their skills to change lifestyle so that it would help them break through the bottleneck in diabetes education:

I feel that an important point of education is to learn something regarding behavioural change....I feel myself as an educator for so many years, even quite fond of it in the very beginning; I have been confronting a bottleneck after teaching them about diabetes every day. I would like to work like Mrs A⁶ [Nurse 2] because she can catch the critical issues that patients are concerned with, and understand their problems immediately.

(Nurse 4)

Diabetes self-management involves living matters, trivial and complex, which may matter a lot in patients' lives. It may be unrealistic for diabetes educators to be trained as an expert to tackle out a myriad of issues for patients and expect patients to carry out self-management faithfully by consultation. Health professionals have to learn from the patients, and need to come to terms that they are not the experts in the patients' lives. To negotiate with the patients on how to cope with the problem rather than overemphasising or persuading them to change their lifestyles may reduce the frustration caused by goal-oriented tasks.

Negotiation is a two-way communication, and the capacity to gain an insight into the patients' needs is an important skill to approach the patients and let them feel that they have been understood. Listening skills are crucial to improve the communication with patients. The interaction was described by the nurse educator in charge below, which illuminates the strategy she used:

⁶ Nurse 2 was a diabetes educator viewed as an expert in diabetes education because she could quickly recognise patients' needs and establish trust with patients.

After he entered our hospital, he would be also quite curious in saying ‘Eh, this one..., a failing treatment I had previously received, why are you still using it [on me]?’I explained it first that ‘as blood sugar level is high....’ I did think that he would have some self-awareness that something is wrong. I then told him ‘the water of your inner eye is all absorbed by this high blood sugar.’ He was a well-educated person, [so] I explained it as ‘it’s just like the focus of a camera, after adjustment, you would feel it quite blurred. But sometime later after the adjustment, you will see it clearly. Now, I just want to adjust your....focus; for the water is coming in, it’s why I have to readjust your focus. But you have to at least give me one more week to adjust this focus; otherwise your vision will start to become blurred after the injection [of insulin].’ For I knew he had repeatedly received insulin injections and it would be surely allowing him to experience this condition quite.... sensitively. As a result, he was quite touched, and he said ‘Lady, you are the very first nurse who can understand me. Because every time after shots I told them this, they would say I was nervous; I was mad. Only you could understand me.’ So, you need to have adequate professional knowledge and professional sensitivity to interact with this sort of patient. (Nurse 2)

The WHO (2003a) suggested that good communication can improve patient adherence; however, the meaning of good communication in this example is built

upon the professionals' expertise to impart information. Professional capability is a major element in earning trust from the patients. The skill of explaining things clearly and enabling the patients' understanding of why they have to receive the treatment is essential to diabetes education.

Pragmatic evaluation of advice

Once the patients accepted the advice from others, the findings suggest that they mostly evaluated the outcome of this advice in terms of its physical impact, which was usually felt very keenly. The study found that if the health care providers fail to relate the treatment regimen to their physical conditions, the patients have a great chance to cast doubt on the capacity of the health professionals. Only if the health professionals provide the information really needed by listening carefully, it would be hard to earn a trusted relationship with them. The advice has a great chance to be denied by the patients. The data suggest that the patients may not argue in the presence of the health care providers, but they are liable to change them, especially under Taiwan's healthcare system.

The appraisal of advice had been found in several forms, mostly physical responses, and some were their experiences after carrying out diabetes control. For example, Li-Ching, receiving insulin shots, gave a suggestion after recovering from her fear of having insulin shots. Lacking a clear explanation was the one to be blamed, and her address below illuminates that the content of information obtained needs more elaboration:

I feel that you as a nurse should tell the patients about the advantage and disadvantage of the shot. I feel that the fear could be caused because of their lack of understanding; therefore they fear it. Once knowing it well, one would accept it with no fear. I feel this is an important issue. (Li-Ching)

The finding accords with Campbell et al.'s (2003) that some patients tend to adjust their treatment based on their own observations:

I went to [a hospital located in] Huwei once, but they gave me the insulin...different [from here]. Thus, I didn't dare to give myself shots....I did give myself shots, but the result turned out to be not working very well. Not very well. Therefore, I decided not to go there. After a while of visiting, it is okay for me [to be treated here]. It's different [between the two hospitals]. Here is better performance on diabetes control. (Ai-Hua)

There was a case who bought a [insulin] pump just came here yesterday, and gave his thanks to us saying these last couple of months were the time he has been feeling the best. For he said his spirit were excellent, and then the physical strength was recovered quite a lot. While he came in and talked to us, he said 'you all would never know that how difficult it is for a person

who has high blood sugar levels.’ Yesterday, this was another word he spoke to us. (Nurse 2)

Patients could constantly learn from the relationship between physical responses and self-care behaviours. In Britten’s (1994) study, there are similar results as in my study, which suggest that patients are conscious of many reactions such as inappropriate prescription, adverse reactions, side effects, or knowing the disease has changed resulting in non-compliance to the medication. Patients take the advice based on their own beliefs and theories about health and illness (Vermeire, Hearnshaw, & Van Royen, 2001), and knowing what sense individuals make of the advice given to them is essential regarding their decision-making of taking action in diabetes self-management. Thus, with an increasing body of knowledge learned from their own experience, they can gradually know what works best for them.

If the patients have problems figuring out the relationship between the physical responses and self-care behaviours, their expectation could turn to health professionals. However, the services might not always fulfil their expectation, and it could lead to frustration for both the patients and the health professionals. The statement addressed below demonstrates the feeling of a nurse educator:

In fact, patients would like us to offer them some opinions, but we....could merely offer them knowledge. I feel that it’s quite superficial. Patients would feel like ‘Um, why it is the same content told every day, and it is all the same....The thing you mentioned is this, but what I can do is that. They [the

suggestions of lifestyle and real lives] have been quite different.

You don't understand me, and I will not tell you as well.' It is that. I do feel this way. (Nurse 4)

To be understood somehow needs time to be achieved; thus after this appraisal, the patients can learn that changing doctors constantly could affect the outcome of the treatment. To this learning, the patients could allow themselves to tolerate pressure coming from the doctor who was believed to have outstanding performance in the field. The quoted descriptions below illuminate the notions:

If you change the doctor, he would have no idea about our characteristics. Albeit, he could offer the same medications, and our question is...even though it's the same [medications], but the question is...not the same though. It's no difference though, and you just can't take it without considerations. I do not dare to go to another doctor indeed. (I-Ting)

I could examine the result about my effort of controlling it in the past whether it was satisfactory...There was not much change [of my physical condition], only if I come here every three months. [...]If the regular check is ignored, it could be possible to find complications suddenly when coming back to have a check again after a long absence. (I-Jen)

In summary, the content of diabetes care is important, but whether the content can be accepted depends on the patients' decision-making. They have a variety of avenues

available to appraise the information that could be obtained either from lay-person or health professionals and decide which information would be useful for them. If the recommendation were not relevant to their lives, it tends to be excluded. The content of diabetes care has to be relevant to their lives, and through constant evaluation to integrate advice into their treatment.

The process of information, education and treatment

The process of information, education, and treatment can enhance the success of diabetes care, such as the strategy of imparting information to diabetic patients and attitudes. An increasing number agree that empowering patients can improve patients' autonomy and benefit diabetes self-management. However, healthcare providers might not have successful transformation of their relationship with the patients while offering services. Passive learning style may fail to meet individual needs in particular.

Didactic rather than active learning

Didactic learning is based on the healthcare professionals' perspectives to decide what should be learned for self-management, and it lacks a mutual communication. Standardised care is developed to meet the basic information needs, but the patients may not be interested in the information provided. The quoted description of Fang-Fang, who was recruited in a group of challenged self-managers, revealed her experiences of diabetes education below:

It is a sort of just sitting there one by one....a person is giving a lesson enabling you to know about sort of that [diabetes]. What's the reason for this, what's the reason for that. It's more like a sort of speech, and then I never came back again. Each time they asked me to come, and I was feeling lazy to come....I felt very vexed after they talked about this and that....It's been all the same [content], and I just know it. (Fang-Fang)

As the patient felt that the advice was a kind of announcement of principles or expected lifestyle, without integrating her concerns the topics would be hard to draw her attention. Evidence shows that the improvement of diabetes self-management has to focus on good communication (Aikens, Bingham, & Piette, 2005).

Health profession's attitudes

A well-designed diabetes care plan can be ruined by bad attitudes while providing services; however, a good relationship can encourage patients to accept recommendations. Li-Li, a challenged self-manager, described why she was absent from the clinic for several months due to the attitude of the health professional who blamed her for her unsatisfactory outcome, which made her give up the treatment until her condition became worse. The quoted interview below shows the interaction between the diabetes educator and Li-Li:

She did ask me what I had eaten. I was quite honest to her, and told her about whatever I had eaten. As I got surgery for this

(breast cancer)...just said I had used to eat fried food, and caused me suffering for quite a while....She said 'you like to eat fried food, right?' I said 'no.' Cos, I just ate once or twice, (at that moment) I was quite honest to her. She said 'don't you think that your behaviour bring you to be this situation [having cancer], and why you want your son to be like you [to have cancer].' I was crying for quite a long time after I went back home. I just kept crying as I walked all the way home. (Li-Li)

If health professionals perceive the outcome of metabolic control as the only measurement to evaluate whether patients practice self-management properly, it can somehow be misleading. Physical conditions and stress can contribute to unsatisfied blood glucose levels. My findings show that patients have many roles to play rather than self-management. Blaming patients' poor performance may result in the frustration of health professionals when they view to achieve HbA_{1c} within satisfied level equal to diabetes quality care. It can be very frustrating when the outcome is uncontrollable. As the feeling of frustration floods out, it can damage the relationship between health professionals and patients. On the other hand, it has done no good for metabolic control, and instead, patients' conditions may become worse. Li-Li, for example, under such traumatic experience refused to come back. She was persuaded to come back by her family due to deteriorated conditions. Although blaming patients for their unsatisfactory results is not only a subject of concern in Taiwan, it had been reported in other countries.

Poor communication skills could be one of the reasons to be blamed because it also indicates that there is a lack of trust between health professionals and patients. As a result, patients could hardly share their personal concerns, which cause unsatisfied blood glucose levels.

Evidence suggests that the role of patient-provider communication is essentially important to influence diabetes self-management (Aikens Bingham and Peitte, 2005), and health care providers also need to be trained as good communicators (Dunn, 1995). Currently, the training of health care providers is yet to be improved to benefit the patients with a longer-term relationship.

Apart from blaming the patients, some doctors give the patients little chance to discuss their situations with them. In Taiwan, like many other countries (Herbert et al., 2007; Clark & Gong, 2000; Wolpert & Anderson, 2001), the relationship between the health care providers and patients is traditionally influenced by the biomedical model, which stresses on a paternalistic relationship rather than partnership. Under such a model, most of the patients are too timid to discuss the issues of treatment regimen with their doctor, thus the patients might take pills out of their prescription without consulting their doctors. I-Ting's statement quoted below reveals the interaction between them:

Ah, that doctor seems to be unable to allow too much question
[Laughs]. If asked too often he [became impatiently]....I also
dare not to ask (him), because no....oh very stern, indeed....I
have taken out (a pill) without his consent, and then I found the

data being fine though, but I have never told him. Anyway I just haven't been taking it. (I-Ting)

I-Ting did observe the physical condition since taking out the pill, and it signifies she evaluated the results by herself. She was grouped as an exemplar self-manager, and it means her decision had not gone wrong. Conversely, Yun-Yun had less control over self-management behaviours, but she was serious about the date of returning for a check up, unlikely to show total noncompliance on what was told by her doctor, who asked her to check her blood pressure frequently and record them for him. Her statement quoted below presents her way of self-management:

He was the only person treating my diabetes and hypertension. While visiting him, he would ask me to give him the records of blood pressure....Every time, two weeks before the appointment, I used to start checking my blood pressure....I used to have my blood pressure checked two weeks before the appointment, otherwise I would stow the sphygmomanometer away. (Yun-Yun)

Yun-Yun was grouped as an exemplar self-manager, and she was quite nervous when the time came to visit her doctor. She had feared over being scolded, thus the stress caused by checkups kept her vigilant on diabetes self-management. In order to avoid the negative emotions, she paid attention to diabetes self-management. Meeting with a demanding doctor may result in negative impacts on the patients' self-management behaviours, but the actual result is quite positive. For some patients, they could hardly push themselves to practice self-management without any stress. The expectation of

their doctors can serve as a driving force eking out self-management to satisfy their doctors. Jia-Li's description below reveals that the phenomenon is not uncommon:

Previously, when I got higher levels of blood sugar, he would say 'what had you been eating?' It would be quite a pressure to me. (Jia-Li)

On the other hand, the patients might hesitate to discuss with the seemingly untouchable doctors. In general, patients would prefer to receive warm concern from the doctors, and it might even become the very reason for visiting the latter.

As one of my friends, who was originally being treated by the other doctor, met with me on the other day and said that 'Doctor C is much approachable.' Thus I got the confidence to visit him constantly. Otherwise, I would not come if the doctor is sort of rigid to principle and not approachable. (Lin-Hsuan)

Heisler and his colleagues (2007) recommended that good communication between the doctor and the patient can make a positive impact on self-management behaviours. When a doctor or nurse changes his or her attitude, it is very much appreciated by the patients, especially when they admire his or her expertise in the field.

Since the beginning, I was feeling....quite annoyed while visiting him. Albeit being annoyed [I] still kept coming back. It was because my friend's experience that tells me to fix on only

one [doctor]. After being annoyed for quite a while, even my neighbours said ‘felt vexed while seeing him,’ but now everyone is praising him....Now, I heard from patients that he has changed a lot. I do agree that he has changed a lot. (Jia-Li)

To treat patients as partners in diabetes care is a concept advocated to ensure the quality of care. Health professionals respond to the unsatisfactory results of metabolic control with frustration, and they turn to blame the patients’ noncompliance. The reason may be the health care providers see the outcomes of metabolic control as their responsibility or performance rather than the patients’ and under such expectation, the sense of frustration leads to ineffective communication between them. If the health care professionals can change their relationship with patients, viewing them as partners, essentially sharing the responsibility together, it may help to reduce the sense of frustration. Remaining in a good relationship can benefit on improving diabetes self-management behaviours.

Trust

To get to know each other would be difficult. Without better understanding in the patients’ situation, a diabetes educator could be enveloped by frustration while the patients decline from telling what they want the most.

To solve this kind of problem, different explanations from the healthcare professional explained could lead to different results. The first quoted interview below reveals one aspect of being challenged by the patients’ suspicious attitude toward treatment:

Some people had some knowledge, but he might know it incompletely. He just criticised the doctor ‘why the doctor asked me to do it like this? Argh, it should be so and so.’ It’s caused by mistrust among people. I do feel that. (Nurse 4)

From this viewpoint, it could be explained as a lack of a trusted relationship, but another educator viewed it as a failure to access the patient’s need. For example, one of the diabetes educators dealt with this situation with a patient who challenged her about the repeated insulin shot prescription; the patient had failed with the insulin treatment from the other institutions, leading him to be there for help, but he turned out to have received a similar treatment.

For some patients, they explained that the doctor’s blame was good intention, hoping that the patients could have good results. Female participants with good metabolic control tend to have positive thinking, while they developed trusted relationships with their doctors. The quoted description illuminates this thinking process:

But I did see some patient who visited him [the doctor] before me. He didn’t follow the prescription, which the doctor had given him; and he even smoked and chewed betel nuts. The doctor was upset and told him directly ‘you have no need to visit me again, for I’m so worried about your condition, but you paid no attention to it.’When he scolded you, he must have

some reason. I was never scolded by him since I was here. (Li-Hua)

On the bright side, it might more or less reinforce the patients' self-care behaviours, particularly benefitting those who have a strong desire to continue to be treated by the doctor.

Context of health care provision

The support from health care institutions can improve the content of diabetes care, and the health care policy can make significant differences to improve the quality of diabetes care, especially the payment for diabetes education, which affects the capacity of diabetes self-management.

Status/reputation

The research found that to ensure the quality of diabetes care, the patients considered remaining in a long-term relationship with their health care providers; thus, the name of a renowned diabetes care institution would sound important to them. As the institution is famed, the patients would more likely trust the treatment they received. The quoted statement below reveals a patient's concern:

She is a sort of type 2 diabetes. It was because she knew something about the treatment here, having earned its name [in diabetes care]. She then came here and got Doctor B to treat her.

It was because she was bearing her second child at that time. So she was just cooperating with everything told to her; so she got very good control over her blood sugar level. (Nurse 5)

The fame of a professional doctor is still seemingly in a pivotal position in Taiwan, and many voices indicate the trend of patients' right being increased in current society. However, doctors somehow are still the authority and may be unchallengeable. Therefore, from the patients' perspective, a doctor's professional capability is more valuable than his or her attitude. Chiao-Yen described her experience with her doctor:

Once, I asked the doctor 'do I definitely have to take it?' and he replied elegantly 'you can leave it without taking it while you were dead. If you don't want to take it, you can wait for your death to come.' That is it. Oh, just answered me like that....But I cannot afford not to come....I definitely have to visit him for the sake of my health....He is the professional in this field.
(Chiao-Yen)

The data suggests that a doctor's professional capability is the main concern while seeking health care. As they benefit from high-quality care from a whole health care team, the patients learn that doctor's professional capability needs to combine with the facility and policy of the institution rather than exclusive consideration of diabetes care. The support from the health care institution is equally important for diabetes care because it offers a whole pack of healthcare services regarding the prevention

from the complications rather than providing medical treatment. The quoted statement below reflects their thoughts:

Because I feel this hospital is quite good. For....I live in Chi-Hu, Po-Shin. As Yuen-Lin got one, it is quite close for me to visit. He [my doctor] is responsible for a clinic there as well, but I just feel hesitate to be transferred there. I would prefer to come here even though it is much further....I do feel it's because of the facility installation. Besides....even the personnel [professionals] are the same. I do feel it's because of the facility installation. (Tsui-Yu)

Originally, [I] was treated in Wu-Luan hospital. I feel that there might be some gap between here and there in a way of medical treatment. Ah, just come here....that hospital could be the so-called educational hospital, but there is less advantage than here. In there, they merely check pre-meal blood sugar, and it seems that they do not offer retino and supersonic examinations. (Li-Ching)

The packed service includes examinations on HbA_{1c} every three months, and this service has profoundly influenced the patients' self-care behaviours, especially in the group of exemplar self-managers. There are eight out of twenty that mention they had paid attention to their results of HbA_{1c}, but it seemed not to be presented in the group of the challenged ones; no one was found to have mentioned it. On the day of the test,

the patients appeared to be anxious about the results of the examination, leading to various responses.

In summary, the finding suggests that a trusted relationship is essential to let the patients take advice seriously. With doubt toward the given advice, they are very likely to be turned down by the patients because they are the very persons to experience the result of the treatment. The data indicate that the key to building trust and promoting adherence to diabetes treatment lies not so much in the *content* of information provided but in the *process*.

Services/insurances

My findings show that health care delivery systems including health care facilities, policies, and insurance policies are related to decision-making of self-management, which influences the outcome of metabolic control. Health insurance can make a significant difference in diabetes care, especially its payment system, because it provides the content of health services. Before the government launched the National Health Insurance Programme in Taiwan, diabetes mellitus was under-managed because of lack of financial incentive and policy support of diabetes care. From a financial perspective, the NHIB provides incentive factors for the health care institution to take diabetes care seriously by providing an incentive payment system and standardised package of the payment of diabetes care. Financial issues among diabetic patients could be one influential factor to affect the outcome of diabetes care. During interviewing, a number of participants verbally appreciated the benefit from the insurance system because of their relief from financial burden upon being

diagnosed. The quoted statement from both the diabetic participant and the nurse below show similar perspectives toward the insurance system:

I feel it's a very good system indeed. As I have had this chronic disease, the cost....if it were not for the insurance [National Health Insurance], I would have been hopeless to find the money for my disease. (Li-Hua)

In fact, after the innovation of the scheme [diabetes care scheme] by the Taiwanese government....to be honest, previously, in the care of diabetic patients, there might be some patients never received even one blood sugar test within one year; just kept receiving shots, shots, shots. But under the programme of General Health Insurance, all the treatments [of diabetes] have been standardised....And then, the most important thing is the patients become more aware of how to take care of their own, because of joining in the healthcare team. (Nurse 2)

Although many show their appreciation, some participants still hope that the scheme could offer equipment needed for diabetes control, such as the strip of blood glucose test, which is considered a financial burden for some patients. It would be hard for patients to self-monitor their blood glucose if they can hardly afford it, and my findings show that could contribute to non-adherence to self-monitoring of blood

glucose. Lan-Chun showed her concerns over the policy of health insurance offered in Taiwan:

Such as the blood sugar strip, a box costs one thousand dollars or one thousand and two hundreds dollars. A box has only fifty strips. Yeah, one of my friends, an elderly person, said that the strip would be invalid if you do not put blood on the right spot. And the process only allows a few seconds to do that; if failed, it would cost twenty dollars [£ 0.33 pound] with no result.

(Lan-Chun)

As a chronic illness, patients have to spend money on illness management, which covers not only the material used for self-management but also time and transportation while visiting clinics. In the long-run, it can still impose a financial burden on the patients. Financial concern is still an issue for diabetes self-management.

The value of examining blood glucose can help the participants appraise their self-management behaviours during the process of lifestyle change. If the patients have little money for that, the progress of learning to live with diabetes can be hurdled. Fortunately, the data analysis demonstrates that the coverage of the test of HbA_{1c} every three months does somehow compensate for the disadvantage of measuring blood glucose themselves. Numbers of diabetic patients demonstrated how they have benefitted from their HbA_{1c} test every three months because the outcomes are used to evaluate self-management behaviours by providing clinical evidence that tell the

patients about the relationship between self-management behaviours and physical responses. It creates a chance for the diabetic patients to reflect their self-management behaviours within the past three months, and reminds them of self-management. Wan-Ling spoke of her aspect toward regular laboratory evaluations:

For example, we could see the reports, such as a report every three months. While it was higher, I would know that I had to take control a bit, just a bit, not allowing myself to be too relaxed. Cos, it could never lie to you, the data could never lie to you. (Wan-Ling)

The model of health care depends on the support from the healthcare system, and it affects not only the content of health services but also the process of giving the services. My data reveal that a standardised diabetes care programme could provide each patient with similar quality of health services, even though the health services are offered from less skilful health professionals. However, its limitation still remains if the health care service turns out to be routine, unconsciously losing the needs for individuals, especially while the loading is massive on healthcare professionals. Nurse 4 described her limitation in achieving the performance of helping patients with lifestyle change:

You could probably talk to him [her] for one or two minutes with something, and then the next patient would be waiting for you. And then you had to look at his data, go straight into his

point to understand his lifestyle, and [figure out] how to change his behaviours within these one to two minutes. (Nurse 4)

As diabetes care heavily relies on collaborative teamwork, the healthcare institution plays an important role in helping health services by its health policy and facilities provided. The context of health services could come to terms with the increasing amount of health services, which could sometimes be unpredictable, encountered by health professionals, in which their consideration might be hard to focus on achieving the goal but instead on finishing the work.

Conclusion

The theme of ‘helping hand’ indicates that helping patients develop self-management skills is exerted from three categories: (1) the content of information, education and, treatment; (2) the process of information, education, and treatment; and (3) the context of health care provision.

The first category indicates that patients do appraise the content of information, education, and treatment needed for diabetes control based on their own consideration of whether these advices are feasible to fit their situations. To equip the patients with specific knowledge and skills for diabetes care, healthcare providers need to consider how to conquer the limitation of the standardised diabetes care, and manage the process of diabetes care being flexible enough to satisfy each individual’s need in various situations and environments. Repeated content could fail to cover some specific topics that the patients might need. Theoretically, standardised content should

be flexible enough to offer versatile choices instead of one-fix-for-all educational programmes, which result in the failure of identifying individual needs.

Secondly, the category of ‘process of information, education, and treatment’ is abstracted from three sub-categories: didactic rather than active learning, health professional’s attitudes, and trust. The findings indicate the interaction between health professionals and patients affects the latter’s decision-making on diabetes self-management behaviours. During the process, to build up a trustworthy long-term relationship is essential to provide quality diabetes care.

While interacting with patients, health professionals have to listen to what they have said, and work with them for possible options in terms of dealing with the issues encountered in the real world, and to involve them as active objects rather than passive receivers of information. Improper attitudes would bring appalling trauma to patients, especially to criticise their behaviours while they fail to meet the expected goals. Health professionals could somehow contribute to the patients’ poor metabolic control because of inadequate discussion and negotiation with the patient; however, instead most patients are the very persons to be blamed. Offering services with a friendly and warm welcome is much more appreciated by the patients, and good communication skills is also essential to establish a trusted relationship, which is important to achieve the goal of diabetes care.

Finally, the data show that patients increasingly recognise that the quality of diabetes care involves the whole package of services (including education and physical monitoring) provided by the institution as well as the expertise of individual

professionals. To their understanding, health professionals alone could hardly meet a high quality of care, if the institution fails to provide the facilities needed; besides, it is not possible to achieve high-quality diabetes care without the support from both health institution and health policy by installing facilities needed and offering a comparable insurance payment scheme.

CHAPTER EIGHT – DISCUSSION: RATIONALES IN TYPE 2 DIABETES DECISION-MAKING

Introduction

My data analysis demonstrates that the process of lifestyle change, which is essential for metabolic control, is not an easy self-management task. The process of self-management begins with the sense of ‘a changed person,’ which requires individuals with diabetes to have at least the basic sense of viewing diabetes as a threat, which in turn leads them to engage in self-management to avoid future physical harm. It involves the concept of perceived threat. The theme ‘trying to restructure life’ illuminates the process of engaging self-management, which involves learning to practice management and also to conquer emotional distress while trying to resist temptation and engage in activities that might not be pleasing at the beginning. In my findings, apart from perceived threat, the concept of worry has a significant role to play in sustaining the unpleasant process of lifestyle change because worry results in the meaning an individual gives to the consequence of diabetes, which includes the self, self-identity, and social role. The theme of ‘helping hand’ in chapter 7 demonstrates how the role has been played by the health professionals to help patients practice self-management and sustain the newly established behaviours to cope with diabetes.

Health promotion theories in chronic illness management

For many years, the issue of how to improve diabetes self-management has been plaguing the healthcare professionals of diabetes care. Meanwhile, many other disciplines, such as social cognitive theory (Bandura, 1986), health belief model (Becker, 1974), and the transtheoretical model (Prochaska, & DiClemente 1983), are borrowed to examine and explain the phenomenon of self-management. It is known to be influenced by four constellations of factors: physiological, psychological, socio-cultural, and economic-environmental, which are presented in chapter two. Some topics, such as self-efficacy (Sigurðardóttir, 2005; Johnston-Brooks, Lewis, & Garg, 2002), self-esteem (Knecht et al., 2001), and locus of control (Knecht, Syrjala, & Knuuttila, 1999; Alogna, 1980) have been examined to predict diabetes self-management. In addition, as mentioned in chapter two, researchers such as Price (1993a), Paterson & Thorne (2000), and Ellison & Rayman (1998) made attempts to examine the process of self-management to understand how patients who are novice self-managers become experts in diabetes self-management. Due to its complexity and involvement of extensive change in daily activities, attempts to improve diabetes self-management have proved to be tremendously difficult.

Health promotion theories

To improve diabetes self-management tests, diet and exercise are recognised as the two most difficult parts for the diabetes health professionals to achieve. The management of diabetes self-management, like other chronic illness management, can be seen as a kind of secondary health promotion to prevent future physical harm before the disease develops into chronic complications (ADA, 2008b). There are many programmes based on health promotion models, such as explanatory theory and

change theory. Behavioural change is a complex process where positive health-related change comes about when people learn about risks and ways to enhance health to develop positive attitudes, social support, self-efficacy, and behavioural skills. Explanatory theory delineates the reasons behind an existing problem to guide the search for factors that contribute to a problem (e.g., a lack of knowledge, self-efficacy, or social support), and can be changed (Pentland, 1999). Health Belief Model (HBM) is one of the explanatory theories often used in diabetes self-management, considering that motivation results from a perceived threat and a hope to avert the possible harm (Weinstein, 1993; Floyd, Prentice-Dunn & Rogers, 2000).

The health belief model is one of the most popular models, probably the first formal model, used to illuminate health behaviours (McCaul & Mullens, 2003). The notion of a health belief model (Becker 1974) can be traced back to the 1950s (Prentice-Dunn & Rogers, 1986). By the 1970s, the concept was conceptualised into four components: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers to understand the preventive health behaviours (Prentice-Dunn & Rogers, 1986; Weinstein, 1993). The health belief model attempts to explain and predict health behaviours in terms of individual decision-making, which is done by focusing on individual attitudes and beliefs. It proposes that an individual will take a health-related action if a person's perception of both the threat of a health problem and his accompanying appraisal of the possibility of engaging in a recommended behaviour to prevent or manage the problem (Becker, 1974). During the decades, the model has proven to be weak for adoption in a disease, e.g. diabetes, which requires lifelong behavioural change, and the context of management is very complex. Firstly, HBM does not provide clear guidance for behavioural change, especially its

relationship. If aiming for preventing amputation of diabetic patients, it is to provide the knowledge to arouse perceived susceptibility, between actual knowledge of the risk factors for an amputation and education probably provided by healthcare professionals (Scollan-Koliopoulos, 2004). Secondly, it has been found to lack a consistent and predictive power for various behaviours, probably because its range is limited to predisposing factors (Harrison, Mullen, and Green, 1992). Thirdly, compared to the other models, the context of HBM takes smaller proportion of the variance in diet, exercise, and smoking behaviours (Mullen, Hersey, and Iverson, 1987). Finally, the model concerns little about the factor of affection, and it might not be able to fully explain why some diabetic patients reveal negative emotions, i.e. worrying. Since the 1990s, the BHM has been replaced of its frequency of application by the transtheoretical model of stages of change, although it is still a valuable guide for practitioners in planning the communication component of health education programmes. However, HBM and the transtheoretical model (TTM) are probably the most often used health promotion models in diabetes care.

In the clinical area, the transtheoretical model has been adapted to improve diabetes self-management in the Changhua Christian Hospital (CCH) where the participants were recruited, and probably contributes to the result of data analysis of the phenomenon of diabetes self-management. In the CCH, the intervention of behavioural change heavily relies on one-on-one diabetes education, and each patient could receive it up to four times per year. Meanwhile, physical examination and laboratory evaluation, such as the HbA_{1c} test, are taken every three months.

The Stages of Change concept from Prochaska and DiClemente's Transtheoretical model has been extensively used to examine a variety of health-related behaviours (Prochaska, & DiClemente, 1992; Littell, & Girvin, 2002). The model consists of four distinct stages, including precontemplation, contemplation, action/preparation for action, and maintenance (Prochaska, DiClemente, & Norcross, 1992). Precontemplation is the stage where a healthier lifestyle is not yet considered; contemplation stage is when an individual starts to think of change, and the need for cognitive approaches that will increase the motivation to engage in change. The preparation stage is when an individual intends to change his behaviours, with only preparatory action. Action is the stage when an individual modifies self-behaviours. At this stage, the patient makes specific interventions and uses concrete guidelines. The last stage is the maintenance stage, in which an individual achieves stable change and avoids reversion (Prochaska, DiClemente, & Norcross, 1992). Central to this idea is the notion of 'relapse,' which can occur at any stage.

Despite the extensive use of the TTM, the debates of the model arouse both negative and positive arguments (Adams & White, 2005; Brug et al., 2005; Povey et al., 1999). Applying TTM to physical activity and diet tends to be less successful than health promotion, such as smoking cessation, because the model oversimplifies the rationale behind behaviours, as the same behaviour, such as healthy diet, can have different interpretations, resulting in individuals' perceptions of pros and cons and holding a different self-efficacy belief for something (Povey et al., 1999; Brug et al., 2005). Furthermore, there is a lack of standardised staging algorithms, and no real determinants of activity change are being integrated into the model (Brug et al., 2005; Adams & White, 2005; Littell & Girvin, 2002). Overall, the TTM has been proven to

have short-term instead of long-term effects, which is a problem when people need behavioural change for a lifelong period (Adams & White, 2005; Brug et al., 2005).

Many studies have used HBM and TTM to examine the phenomenon of diabetes self-management, which requires an individual to change his lifestyle with great complexity, including medication, diet, exercise, and illness management (Scollan-Koliopoulos, 2004; Sigurðardóttir, 2005; Littell, & Girvin, 2002). Many studies show little evidence that using the stage-based intervention to improve behaviour change is more effective than usual care, such as in dietary intervention (Salmela et al., 2008). While perceived threat is an explicit factor for health promotion in the HBM (Becker, 1974), it is an implicit factor in the TTM, where the model has less explanation on why an individual will go on from the stage pre-contemplation to contemplation (Prochaska, DiClemente, & Norcross, 1992). If an individual fails to cope with a harmful event, he may avoid managing the situation, which tends to cause a negative effect (Rogers & Mewborn, 1976). It indicates that having a sense of perceived threat does not mean that an individual can automatically engage in health behaviours to avoid a negative effect; instead, he might escape. However, without a sense of threat, there is little impetus to motivate people to change their behaviour.

As shown in chapters five and six, women continue to focus on their family rather than themselves; self-management is about taking ‘self’ seriously. My findings reveal that perceived threat is an important factor to evoke motivation to focus on the self and thereby practice self-management. Initiating the motivation for self-management is necessary to begin lifestyle change; however, while the self-management behaviours are expected to be carried out for a lifelong period, it is arguable if the

perception of threat can possibly last this long to sustain the newly changed lifestyle. In my finding, changing lifestyle has been mostly perceived as a constant confrontation of distressful events, while an individual has to resist temptation on a daily basis. Negative emotions such as worry come to play an important role to help the patients focus on themselves, and somehow pull back from the psychological hunger for their favourite food. However, neither model has integrated effective factors in engaging in the process of behavioural change.

In addition, both models fail to explain why two individuals who face the same disease with similar knowledge may have different perceptions of threat. My data reveal that it involves how an individual gives the meaning to that situation, and that in turn involves many factors including the self-concept, social role, and self-identity, leading to different explanations in a similar situation. Therefore, these concepts will be discussed in this chapter to gain a better understanding of the rationale of decision-making in diabetes self-management, and these concepts include the self, threat, worry and social roles.

The self, threat, worry, and self-management

The self

Self-concept emerges in the social contact, and is (Mead, 1934; Epstein, 1973; Gecas, 1991; Ciambrone, 2001; Baumgartner, 2007) incapable of being detected by sensory organs; its development requires an individual's retrospection to apprehend how others react toward him (Epstein, 1973; Swann, Milton & Polzer, 2000; Ellemers, Spears & Doosje, 2002). The self is an open, ever-changing, multifaceted concept —

a process of continuous construction and reconstruction (Marks-Tarlow, 1999), that the individual holds about himself as an experiencing, functioning organism in communication with the world (Epstein, 1973). In Cooley's (1964) notion, the perception of the self is described as a 'looking-glass self,' which indicates that the perceptions of an individual are obtained from others, acting as a mirror to 'self,' from which an individual builds up his own self-structure and develops his own identity. The body of knowledge of self-concept is built up from two academic disciplines: psychological and sociological (Howard, 1991). Their viewpoints are useful to understand the motivation for health behaviour. The psychologists mainly focus on individual's 'internal processes,' and the sociologists on the causes of behaviours outside of the individual, including culture, social structure, and social situation (Gecas, 1991).

Chronic illness has long been concerned with its impact on the self (Corbin & Strauss, 1987; Charmaz, 1983; Charmaz, 1987; Goffman, 1990; Ciambrone, 2001; Baumgartner, 2007), leading to physical self and self-identity problem (Charmaz, 1987; Corbin & Strauss, 1987; Bury, 1991) because serious physical incapability can disrupt plans and alter lives (Charmaz, 1987). Bury (1991) argued that lack of physical confidence because of incapability can prevent an individual from social interaction with others. This implicates that physical incompetence results in the loss of self, which influences self-identity.

Some researchers argue that the chronically ill can lead to biographic disruption (Charmaz, 1987; Corbin & Strauss, 1987; Bury, 1991); thus, they have to experience a process of reconstruction of self to reach a sense of order of their past biography in

light of a new diagnosis (Bury, 1991; Williams, 1984). In Corbin and Strauss's (1987) notion, the deteriorating physical function in chronically ill people could lead to a devalued self-concept. They framed the theory of the Biographical Body Conception (BBC), which consists of three concepts — biographical time, body, and conceptions of self — to explain the phenomenon of living with chronic illness. By a continuous take-in-and-give-off process, the feature of self is constantly changed, which is beyond 'self-esteem but the views held of oneself, in relationship to the whole of identity' (p. 255). The body here is described as a medium through which an individual makes contact with the outside world, while biography represents an individual's perception of 'who I am' through the timeline of the process. The failure of the physical system causes debilitation, resulting in the inability to resume the self, losing his hope to be in the future. Unsuccessful communication with the outside world and an incompetent body system that fails to support social interactions would impose a negative impact on self-identity. Thus, to cope with chronic illness, it often contains a complex combination of individual values, perspective and social circumstance (Bury, 1991). Charmaz (1991) suggests that to live with chronic illness is not merely the task of daily living, but rather the whole manner of life to be experienced. She discusses that the treatment of chronic illness cannot only be the topic of interest, but as a whole set of issues that can be seen much more clearly when illness threatens to dominate the whole of one's life.

Many agree that the meaning of chronic illness is a key to reshape personal identity, but the meaning depends on how significant the influence is to an individual (Kralik, Brown & Koch, 2001). Bury (1991) identified two types of 'meaning' in chronic disease from the perspective of biographic disruption. The first meaning depends on

the effects of the onset disruptive symptoms on daily life either at home or at work, considering time consumption in the care of episode. The second focuses on how significant it is to an individual. It means that different conditions may bring individuals different implications and imagery, and these differences affect how individuals view themselves and recognize how others see them.

However, my data show that most people with diabetes were found to be eroded of confidence, which is linked with little physical confidence, even though they have shown little physical incompetence as a sense of fear, such as fear of haemodialysis, amputation, blindness, or physical incapability. The first theme, a changed person, shows that attempts not to unfold their illness identity to the public indicate their eroded confidence after being diagnosed as diabetes because of the meaning behind the disease, which causes great impact.

The consequences of diabetes are the major impact affecting patients' emotions, but based on their knowledge and experiences, they give different meaning to the event of being diagnosed, especially the meanings for the individual in relation to the stigma associated with diabetes, and the impact of the diagnosis on everyday life. It explains why some participants experience appalling pain while diagnosed, some have been scarcely affected, and some in-between. For example, Lan-Chun could not help weeping while explaining the reason why she was unwilling to unfold her identity as diabetes in public, saying 'it's awful.' But for Tian-Tian, the reason of covering identity was that she feared to be isolated because people might view diabetes as 'infectious.' From Jia-Jia's perception, diabetes was said to be a 'rich people's disease,' which means that a diabetic patient cannot afford to work hard, seemingly

implicating a devalued self. Similarly, the phenomenon was observed by the other authors (Lin et al., 2008).

Their concerns show that diabetes mellitus has its bad name from stigma, which affects the way one interacts with others. Because of their fear to be isolated or even feeling inferior to others, it explains the reason why they lack the confidence to disclose themselves as diabetic patients. As a result, only a few people could gain enough confidence to divulge their identity after being encouraged. It was reported to partially contribute to avoid self-management activities because of their fear to be disclosed in public when they have no place to hide the practices. Tsui-Pin, for example, lapsed an insulin shot once during midday in her working place because her office was filled with colleagues and it was not possible to hide her self-identity as diabetes from the others.

In order to cover self-identity, some might even react violently if the disease is unfolded without their consent. For example, Lan-Chun's husband said if he disclosed Lan-Chun's disease to his close friends or family members, his wife would suddenly 'throw a temper,' quite unlike her nature of soft characteristics. Another participant, Lin-Yen, told nothing to her husband for fear that he might not keep the secret for her. She admitted that she did not recognise what mindset she had but just did not like to reveal her disease to the others. Consequently, they might lose social support in some ways; Lan-Chun was told that she would give up travelling if no family went with her to cover her up while giving insulin shots; in Lin-Yen's situation, she did not only lack the support from her family but also had to cover self-identity from them. It makes the journey with diabetes much more difficult.

From their viewpoints, having diabetes is an embarrassment, and it implicates inferior feelings to the others. It might also imply their feeling of losing self. To prevent the loss, many participants who attended the study decided to conceal self-identity. In Lin's (2008) study, some patients even urged the health professionals to correct some of the misconceptions. The sense of being inferior makes them vulnerable to reveal the disease in public, even though their physical competences remain. The complications cast a shadow over their lives.

In sum, a great proportion of participants experience devalued self because of the meaning behind diabetes, and that meaning can be interpreted quite diversely from one individual to another. Their interpretation also affects their attitude to interact with the outside world, which can influence their attitude toward self-management. But my study suggests that negative emotions do not necessarily lead to negative results. Instead, this kind of negative emotion, fear-arousal response, can somehow motivate the participants for lifestyle change. It can be seen as a threat that motivates the participants to take action to avoid undesired consequences.

Threat

The concept of threat has long been used to explain health behaviours (Cava et al., 2005; Floyd, Prentice-Dunn and Rogers, 2000; Becker, 1974; Rogers, 1975; Rogers & Mewborn, 1976; Weinstein, 1993), but knowledge is involved with how it relates to behavioural change or coping (from cognitive to behavioural) is weak (McMath & Prentice-Dunn, 2005). Threat is defined as 'an expression of intention to inflict evil,

injury, or damage’ (Merriam-Webster, 2008). In Carpenter’s (2005) notion, a threat is described as (1) belonging to personal perception, influenced by culture and living environment; (2) based on the perception of some anticipated danger; and (3) being ‘derived from cognitive appraisal of an event or cue’ (p. 194). It also consists of two meanings, such as foreseeing of a future harm as well as involving cognitive process. Miller and his colleagues (1996) argue that people react to a threat differently; some people are apt to enlarge the threat cognitively and psychologically, and others manage to avoid it and psychologically ignore such cues. If individuals could have the perception of threat, they tend to increase health behaviours (Whittemore et al., 2002; Umeh & Rogan-Gibson, 2001). Likewise, Prentice-Dunn and Rogers (1986) suggest the existence of cue, which can be internal (e.g. symptoms) or external (e.g. mass media messages), is essential to trigger an action. Some studies show the relationship between perceived threat and compliance is weak, but some of these studies were considered as poor study design, or having patient population, and clinical problem (Carpenter, 2005). On the other hand, the issue has been observed by some authors who suggest that three tactics are being facilitated to cope with the threat, including avoidance, disavowal, and acceptance (Buetow, Goodyear-Smith & Coster, 2001). From the aspect of the defensive avoidance hypothesis, if individuals fail to cope with a harmful event, it could result in negative effects (Rogers & Mewborn, 1976). The data show that although perceived threat is significant in bringing about changes in health behaviour, it is not enough by itself because it can induce (negative) avoidance strategies as well as engagement in change.

Because diabetes deceives some patients with its asymptomatic characteristics before developing into long-term complications, whether they view diabetes as a threat or

not can vary quite significantly from one individual to another. For example, my data suggest that some of the participants perceived diabetes as nothing to worry about, some as a controllable disease, some a fatal disease, and some in between but in varied degrees. Many reasons could contribute to this diversity, such as background, experiences and health belief, where they obtain these resources, and how they appraise the impact of diabetes. For example, while Ju-Hua was informed to have diabetes, she said ‘very terrified, thought why I got it. I couldn’t accept it, even cried over it.’ The reason she feared having diabetes is because of her oldest brother, who had diabetes and developed into blindness, and the suffering he had experienced really terrified her. Thus, she described her feeling as ‘so I was scared.’ But after learning more about diabetes she considered that ‘diabetes is not a fatal disease but needs willpower. You have to control it, and then just relax yourself. It’s nothing [horrifying].’ After efforts of practicing self-management, the results of the metabolic control had remained at a satisfactory level, and then she could recover from a desperate situation, a feeling of uncertainty. Consequently, it enabled her to build up confidence, and life eventually came back to her hands again. Conversely, Yueh-Ching, who was nominated as a challenged self-manager, was surprised why diabetes needs to be concerned, and said, ‘I felt nothing. Particularly, it has done nothing wrong to me.’ Likewise, Lin-Hsuan, grouped as an exemplar self-manager, described how she felt while being diagnosed, ‘because I had no idea about the consequences of diabetes. Because [I] had no such medical knowledge whereas [I] was paying no attention [to it].’ Nevertheless, whether diabetes is a threat or not also depends on obtaining the adequate information, especially for the newly diagnosed.

Only if a patient can sense diabetes as a threat could lifestyle change begin because the concept of threat is considered as part of the stress process (Carpenter, 2005). To escape from this emotional state one has to engage in behavioural change (Rogers, 1976). Paterson and her co-workers (1999) argued that the drive for patients' transformation of illness experiences result in how the meaning of chronic illness is given; challenge is the key feature to making the transformation. Similarly, my findings show that only if patients can perceive diabetes as a threat to their lives can the drive to change their current situation be strong. My findings show that the participants, whose families were affected when they were diagnosed with diabetes, show stronger concerns on self-management than those whose family showed little influence on their diabetes. The perception of threat can be amplified when the event affects not only an individual per se, but also his family. These participants show much more concerns on self-management to prevent diabetes from hindering them to play their roles as either mother or wife. As a result, their engagement in diabetes self-management is not only for making themselves healthier, but also for the family, and their intentions explain that social performance in this study is one of the central concerns of the participants' self-management behaviours. This is the central issue that is discussed later under 'social role.'

Based on the data analysis, gaining a better understanding of social roles may shed light on how the performance of social roles can affect self-management. Self-management activities include not only medical treatment but also diet and exercise, and substantial involvement may encounter dilemmas between performing social roles and practicing self-management, which makes the task of self-care more complex and difficult to achieve. From the participants' perspectives, the lifestyle

recommended by health professionals could be far different from theirs, and they require great efforts to achieve. To get a better performance, an individual has to constantly be conscious of every single decision on the unwanted behaviours or wanted behaviours to sustain expected behaviours in the early stage. A comfortable lifestyle is not well suited for diabetes, and also it is hard to make people change, in regards to food in particular. However, among the recommended lifestyles, the limitation on food is listed in a high priority of diabetic education programme. Savouring favourite foods is considered as pleasant to life, thus to be limited claims the deprivation of the joy of life in some way. Besides, it has to be fixed on a daily basis. For example, a story told by a nurse educator regarding a child who was suffering from type 1 diabetes reveals how painful it can be, ‘Auntie [nurse educator], I determine to eat even though it will cost me my life.’ To the child, he might not totally understand what self-management means in his life, but the limitations on diet can cause immense torture. The evidence from my study provides important insights into this issue. Perceived threat is necessary to initiate behavioural change; otherwise, an individual can hardly endure stressful experiences while carrying out a healthy lifestyle without perceiving threat.

Apart from diet, taking exercise regularly, if not scheduled regularly in previous lifestyle, can be very disturbing, for routinely taking exercise might affect the routine activities or even be edged out from some of them. Before benefitting from its advantage, the participants have to endure its inconvenience or may suffer in the first place, such as physical discomfort after exercise, dealing with weather issues, venue issues, or even financial issues. Hui-Tzu’s story shows how she endured her suffering during the process of establishing regularly exercise with great effort. Even though

she got support from her family with her own strong motivation, she had hardly overcome the situation, waking up in the chilly winter mornings and leaving her warm duvet behind unwillingly, and setting off for exercise, which made her feel sad and even cry. However, she did not give up because the consequences of diabetes, as a threat, pushed her harder than the tiredness to wake up early. In fact, at that moment, the major threat to motivate her to exercise is not only her own health, but also to prevent her family from falling apart because of her disease. Again, this issue is discussed later under ‘social role.’ As years lapse, she expressed her feeling that after getting used to this newly established lifestyle and benefitting physically, she could hardly give self a thought of living without it. Most importantly, taking exercise made her know more fellow exercisers that had become part of her social life in terms of positive social support. When social activities are integrated as part of the patients’ lives, maintaining the activities becomes less of a struggle. From the experience they shared, to establish a new lifestyle is not easy even though they have great support from people surrounding them. Accordingly, the early stage of rebuilding a new lifestyle can be a critical period of diabetes care, until the newly established lifestyle can be carried out with less effort. It means that the new lifestyle is no longer new, and it has been integrated into their lives.

The task of changing lifestyle requires substantial efforts. While there is a lack of sense of need that might be caused by lack of knowledge to inspire oneself to change, it is unrealistic to expect them to practice self-management as suggested. It is also understandable if an individual cannot endure suffering caused by changes in lifestyle, as it may indicate the recommended lifestyle is not well-fitted in the situation. Since diabetes can remain asymptomatic years before reaching the end-stage complications,

combined with lack of knowledge, the importance of self-management can be easily overlooked. If diabetic patients fail to consider it as a self-demanding task, it would be quite challengeable to commence lifestyle change in terms of self-management. Numbers of researchers have agreed that dietary regimen is the most difficult to be achieved, followed by exercise (Whittemore et al., 2002).

Therefore, change of lifestyle in early stages is unlikely to move smoothly throughout the process if it lacks a pushing force to start running the vehicle of a new lifestyle. In the beginning of the behavioural change, many behaviours expected to be changed can appear unconsciously and automatically (Bargh & Chartrand, 1999); thus, to change a lifestyle is no easy task. In addition, diabetes self-management is both complex and demanding, which makes the tasks more difficult. My study suggest that many decision-making involving self-management are engaged in a mind game of tug of war between following the treatment regimen and following the heart, in which their desire, for example, craving food, and fear of having complication may hold each end of rope and pull each other. The stronger one wins the game. If an individual has a stronger force of fear, he could be more successful to resist temptation. From this viewpoint, during the restructuring of a new lifestyle, there must be a counterforce to inflict oneself on engaging self-management to avert future health harm because the current lifestyle is no longer well-fitted to the physical condition. However, because of its unpleasant nature, it is natural that the consequences must be much more disturbing than the change itself to initiate health behaviours. Only if they start to sense the potential harm can they then begin to restructure their new lifestyle. In my study, the perception of threat is significant in initiating a healthy lifestyle, and also maintaining it.

Having viewed diabetes as a threat to future physical harm, the participants start to think about their self-management to prevent the consequences of diabetes. Data in chapter 4 illuminates that the degree between two groups, exemplar and challenged, tend to differ. Conversely, less challenged self-managers, six out of eighteen, verbally concern the consequences. One even said diabetes is nothing to be worried about. From the data analysis, the patients who are grouped as exemplar self-managers tend to view diabetes as a threat more than those who are challenged.

As illustrated by the three-month review of HbA_{1c}, to obtain results of metabolic control is important to diabetic patients, even though it does not guarantee avoidance of future complications. However, the data suggests that a ‘good’ result can help build confidence in self-management. The data suggests that the exemplar group were able to use the HbA_{1c} results to reflect their self-management of diet and exercise better than the challenged group. It might be that, for them, to break down a long-term goal and to prevent the long-term complications into the short-term, enables them to set realistic short-term goals. To help them focus on a concrete goal, achieving expected blood sugar level. This is a concrete goal that prevents complications, rather than a concept.

Therefore, if participants view the achievement of a satisfied result of HbA_{1c} as their goals to prevent long-term complications, they appear to be very nervous while the date of returning check is drawing near. Rogers (1975) argues that while facing a threat, the feeling of fear, being framed as an emotional state protecting one against danger, can be aroused, and an attempt to enact health activities to avoid it can be

consequently followed. From Tian-Tian's experience, the sense of fear would become more intense as the date of returning check drew near because she should have her blood sugar, HbA_{1c}, checked a few days before visiting her doctor. And the result would be announced the moment she saw the doctor. She described the moment while she was listening to her doctor reading out the result was like hearing a verdict from a judge, which made her quite nervous. Actually, getting nervous on the returning check was shared by many in the study, and they had positively responded to the policy of diabetes care because regular blood sugar checks reminded them to keep vigilant on self-management. It also allowed them to reflect on the relationship between lifestyle and diabetes control in the past three months. Considering the quality of life, Tian-Tian suggested that it was the right period to have a returning check every three months for HbA_{1c} because it would make her more nervous to live with diabetes. But, if the returning check was longer than three months, she felt that would do no good for diabetes control because she would have become too relaxed to keep vigilant on diabetes self-management. Diabetic patients could examine the blood sugar levels to evaluate the connection between self-management and physical responses immediately or regularly in a three-month period to understand and modify health behaviours.

One the other hand, this kind of shadow could become a motivating factor for self-management activities, and help them conquer their inner desire, especially to those who had ever suffered the consequences or seen other people's suffering. Wan-Ling, an exemplar self-manager, followed a strict dietary regimen after a profound shock when the first episode of stroke happened in her forties. Attempts to reduce risks of another episode in the future prevented her from indulging in her favourite food —

noodles. She described her feelings over the process while resisting temptation, ‘I have been suffering a lot; how come I suffered this? Why? Unlike the others, who at least could have their meals to a full stomach. Sometime facing this situation made me feel very sorry and depressed....But later, I would think in this way: “just let it be. It’s more important to be alive.”’ Since the episode, she had been suffering during each meal while eating her favourite noodle because she could not allow herself to eat to her heart’s content. She also developed a strategy to resist the temptation by recalling the terrifying scenario — the scene of her uncle’s suffering from the consequences of diabetes — and it always worked successfully to put her temptation off her mind. From her experience, to avoid the complications is the most important thing to do because of her fear over the episode of stroke; thus, the consequence can be seen as a threat in her mind or become a worrying matter. To comfort herself, living a healthy lifestyle to avert the consequences might be more important than indulging in her desired food. A Chinese saying ‘to the people foodstuff is all-important’ reveals that changing the habit of food could be not only be an uneasy task but a suffering, unless it is recognised as a very important thing. In this case, it shows how the patient wrestled between the perception of threat and temptation. Interestingly, the participants who were grouped as exemplar self-managers tended to realise how vulnerable they were; thirteen out of twenty revealed their fear over the complications. But the challenged group were relatively less frightened of the complications, with a ratio of six out of eighteen. Where there was an overlap between the two groups in terms of sense of threat, the tense of fright in exemplar self-managers were stronger than the challenged. The perception of threat is one of the key elements to motivate self-management.

While some people used HbA_{1c} as their ‘goal’ to assess self-management, others were more aware of the reaction of their body to increased blood sugar level; for them, the physical response worked as a reminder to keep them vigilant in diabetes self-management. The physical responses, caused by a bit higher or lower level of blood glucose but having not yet reached a state of emergency, can exist as a threat in many forms, which has been discussed in other studies, such as body listening (Price, 1993b), body cues (Paterson & Sloan, 1994; Paterson, Thorne & Dewis, 1998), or body responses (Lin et al., 2008). In my study, using physical responses to remind oneself of self-management was reported only by those exemplar self-managers. They appeared to be quite vigilant to their physical conditions, resulting in concentrating their attention on the relationship between blood sugar levels and physical responses. They noticed that the appearance of particular symptoms is linked with various blood glucose levels. For example, the signs of hypoglycaemia include the feeling of fatigue or weakness in both legs, and hyperglycaemia with blurred eyes, skin rash, and neck tightness. As the patients noticed the caution of their bodies, they identified them as a sign of the soaring blood glucose level beyond expectation. This topic will be discussed again in the section of worry, as this fear-arousal stimulus involved with affection would result in motivation for self-management.

In summary, my findings show a significant relationship between perceived threat and the engagement of patients in self-management activities, while there was some overlapping proportion of participants who were nominated as exemplar self-managers to view diabetes as a threat than those who were in a challenged group. In addition, my data reveal that perceived threat is not a kind of sense that dominates their daily lives, but tends to become more and more intense when the time for the

checkup draws near. Body cues also function as a threat to remind self-management. Whether it can become a factor to assist diabetic sufferers to sustain a newly established lifestyle needs further investigation.

In addition, numbers of participants who perceived diabetes as a very serious threat tend to have negative emotions as worry, which plays an important role in the decision-making of self-management. As negative emotion is a natural context of an individual caused by a fear-arousal stimulus, which can create either a positive or negative impact on diabetes self-management.

Worry

A key theme emerging from the data is worry, which particularly functions to weaken the sense of temptation. Many participants who were nominated as exemplar self-managers admitted that whenever they were struggling with resisting favourite food, which is not recommended by the health professionals, their fear for complication tends to appear to stop them from eating. My findings show that the sense of negative emotion is like a force used to resist temptation. It indicates that negative emotion, such as the sense of fear, plays an important role to subdue one's desire, especially that of food.

Worry can be caused by the fear-arousal stimulus, and it is considered a core emotion different from others, such as fear (McCaul and Mullens, 2003). Borkovec and Inz (1990) give a definition to illuminate its characteristics:

Worry is a chain of thoughts and images, negatively affect-laden and relatively uncontrollable. The worry process represents an attempt to engage in mental problem-solving on an issue whose outcome is uncertain but contains the possibility of one or more negative outcomes. Consequently, worry relates closely to fear process (p.10).

Worry is the central defining feature of generalised anxiety disorder, and the mechanism is yet to be fully clarified. In 1992, Tallis and co-workers (1992) developed a questionnaire, Worry Domains Questionnaire (WDQ), but it failed to include the domain of 'illness and injury.' Eysenck and Van Berkum (1992) re-examined it and added the item of physical health or physical threat into the questionnaire. Furthermore, after re-framed by Aldrich and colleagues (2000), the concept of worry was then adopted in health issues by focusing on two tenets, vigilance and problem-solving, for the purpose of examining the phenomenon of chronic pain. Since then the concept of worry is mainly adopted in studying the phenomenon of chronic pain with little studies found in chronic fatigue syndrome (Eccleston et al., 2001; Bogaerts et al., 2007). The relationship between worrying and problem-solving is closely linked. While worrying, an individual tends to repeatedly seek various strategies to resolve the problem that caused worrying, but many of these are inefficient strategies leading to continuous recollection on the threatening events (Davey et al., 1992). However, while worrying, an individual tends to repeatedly make decisions rather than implement actual plans because worrying can debilitate an individual (Dugas et al., 1995). The worrying subject is suggested to mainly concern with the self in some ways (Aldrich, Eccleston & Crombez, 2000), and can occasionally happen to everyone in everyday life. The majority of things of worry are

the issues of finances, health, and social relationships (Wisocki, Handen, & Morse, 1986).

Worry can be stored in the memory, repeatedly affecting individuals when recalled (Borkovec, 1985; Borkovec & Inz, 1990; Foa & Kozak, 1986). Some authors argue that worriers are quite demanding with threat-related information leading to constantly seeking for information (Kelly et al., 2007). Worry could also be treated as risk perception to adjust on prompting crises (Hong, 2007). On the other hand, if the threat becomes inescapable, worry can be developed into a chronic condition (Aldrich, Eccleston, & Crombez, 2000).

Some authors argue that worry may encourage positive behaviours and assist analytic thinking (Davey, Tallis & Capuzzo, 1996). Some suggest that worry is more likely a structure of problem-focused coping (McCaul & Mullens, 2003). Also, the characteristics of worry, focusing on vigilant and problem-solving, could potentially resolve the problem (Szabó & Lovibond, 2002), which can shed light on the process of changing lifestyle, especially while confronting the dilemma between craving for something and worrying about the complications.

The concept of worry is recently adapted to understand how people with chronic lower back pain practice self-care, but no study has examined it in diabetes self-management. It requires further research to examine its influence on diabetes self-management.

My findings show that the concept of worry is a salient factor. For example, some exemplar self-managers showed that they used to turn their back on their favourite food because of their fear of complications. The negative emotion is strong enough for them to resist temptation and to maintain relatively satisfied metabolic control on a daily basis. It is more likely a mind game of tug of war while confronting the temptation each time, and worry and temptation hold one end of the rope against each other. If the sense of worry is strong enough to disturb an individual, he then gains a great chance to overcome his temptation — for example unhealthy food — and vice versa. Fortunately, the participants do not feel worried all the time while living with diabetes because worry is somehow stored in their brain to be recalled. The mechanism is still unknown. My findings also reveal that as patients have satisfied metabolic control, the sense of worry can be weakened; thus, many participants tend to be more relaxed and give themselves a break for savouring their favourite food.

For diabetes care, lifestyle change requires constant attention to the process. My data reveal that patients have to choose proper diet and know how many portions need to be taken in each group of food. They have to arrange for exercise, take medication, and take self-monitoring of blood glucose, and all of these tasks are quite demanding. Trying to have a better performance, these tasks have to be done consciously until a newly established lifestyle is integrated into the daily life. This requires an individual to be vigilant while practicing self-management.

Wan-Ling, who used to find excuses not to exercise before the first episode of stroke, said that ‘the major reason was because I was busy, thus....maybe it was just an excuse. I was unlikely to take exercise. Not until it (stroke) happened in 1993 that I

found that (I) had to do something. Then, I have started to take exercise.’ Because of worry, the patient would start to pay attention to the relationship between self-management and physical responses. Wan-Ling said, ‘I do have feel that if I ate less rice or noodle, my body weight would drop. Also, the average of that [HbA_{1c}] would be....6 point something. Just excellent, about 6.4 [%] though.’ Thus, satisfied results encourage the participants to keep an eye on the matter of self-management, and it also boosts their confidence to sustain the newly changed lifestyle.

Again, due to the worries over the complications, which can devalue self in many ways such as leading to unsatisfied performance of social roles, the patients become quite vigilant to the relationship between blood sugar levels and physical responses, which enhances their self-management activities. On the other hand, only if the patients are aware of diabetes control, knowing the relationship between self-management and physical responses, can the sense of worry help them to focus on remaining a healthy lifestyle. Some researchers argue that relatively adequate specific knowledge is the essential element to achieve the expectation (Tan, 2004; Vermeire et al., 2003). In diabetes self-management, diet is the most difficult part to achieve (Whittemore et al., 2002). Li-Ching, in the challenged group, also admitted that her biggest hurdle was to control diet; worry has the potential to solve the problem. Besides worry, fear-arousal stimulus can draw attention to the threatening event (Davey, Tallis & Capuzzo, 1996; McCaul & Mullens, 2003), which may keep an individual in self-management activities, many of which are trial daily activities. But without relatively adequate knowledge to realise diabetes, the patients, especially those who are symptomless, might not have the sense of worrying by realising potential health harm, which could probably lead to the failure of drawing attention to

self-management. It means that the patient is still not yet ready to live with diabetes, even though his physical condition has been changed. Thus, the major hurdle to embark on lifestyle change is being unaware of the need to change lifestyle.

In sum, the concept of worry is found to be significant when the participants try to conquer temptation or sustain an unpleasant lifestyle, which is considered to have more of a burden than diabetes itself. Worry is found to be a determinant to motivate the participants practicing self-management, especially in diet, which is considered as the most difficult part to achieve. Two characteristics of worry, repeatedly problem-solving and being vigilant, are beneficial in fostering a new lifestyle in terms of self-management; thus, the concept of worry is worthy of more attention. However, no study is found to explore this phenomenon and it requires further investigation.

Social roles and self-management

A great proportion of participants recruited were taking the role of caregiver in their family. As a married woman, to take care of family is highly valued in the Taiwanese society. Within the family, the major role of a married woman is to take care of the family members. The participants tend to sacrifice their own need of self-management if there is a conflict between performing social roles and self-management. Conversely, if practicing self-management means performing social roles, the motivation of practicing self-management becomes very strong.

Similarly, Charmaz (1987, 1991) echoes the value of social role, and she implicates that the chronically ill people cling to the valued lives and selves by means of

achieving satisfactory performance of social roles. Morse (1997) argues that attempts to remain the integrity of self can exist in the sufferers with all kinds of diseases. My material indicates that individuals place the performance of social roles before their own self-care, such as taking care of sick family members, and at the same time they have to deal with self-management. People with diabetes are convinced by the health professionals to take full responsibility of self-management; in fact, diabetic patients are not the only role the women in the sample played, but they have many other roles at the same time, such as daughter, daughter-in-law, wife, mother, and so on. Accordingly, the dilemma between their social roles and roles as patients could often be seen in their daily lives. For example, Shan-Shan needed to take care of her mother-in-law, who was in her nineties with a broken leg and required physical care. Shan-Shan was unable to leave her mother-in-law alone, and it hindered her from taking exercise. Under such situations, Anderson and Funnell (2000) argue that if providing self-management counselling fails to consider the patients' social roles, the patients could probably veto the suggestions because to perform their roles is considered a sense of preserving the autonomy of life.

The theme of family commitment is a significantly influential factor, closely linked to the decision-making of self-management. Amongst family commitments, the issues regarding children are highly concerned, and the meaning of self-management is closely linked to their own role. My material indicates that performing the role of a mother is posited in a higher priority than carrying out self-management. On the other hand, if an individual realises that he is healthier enough to perform his social role, motivation to practice self-management would become extremely strong. The reasons are found as needs to have a healthy body to take care of children, or to leave little

burden to the next generation when they grow old. Family integrity is also highly valued.

The social norm of filial piety is still valued by most Taiwanese. Children are expected to take care of parents while they grow old and are unable to take care of themselves. Thus, to stay healthy could have another meaning in Taiwan: not to burden the next generation physically, financially, and psychologically. They would be more likely to practice self-management to prevent their children from future suffering. This concern can be seen in Chiao-Yen's interview: 'Don't 'Tou' [拖: in a status that being chronically ill with debilitating condition not only incapable for self-care but also unable to die soon]. 'Tou' will impose a burden to the children, and their children's lives would be misery as well. Albeit we personally might not suffer in the same way, but it would be very depressing when we see them under such a harsh condition.' Furthermore, if their children are still in their tender age, the motivation to stay healthy became very strong while the patient is the only person left available to take responsibilities. Li-Hua, one of the exemplar self-managers, insisted on taking strict dietary control. The reason was because her husband betrayed her and brought a woman home to live with them. The woman had a drug problem. For some reason, the patient was not divorced from her husband, but had to tolerate them. She used to work at a small factory with a fixed night shift. She brought her children with her while she went to work during the night shift and settled them to sleep in the factory to protect them from the woman, for fear that she might feed her children drugs if she was not around. Later, she was diagnosed with diabetes, but she thought to herself 'I have to be healthy. I have to earn money. I have to raise my children up and feed myself.' For her, the meaning of practicing self-management is similar to the way of performing

the role of mother to nurture and protect her children; and it is found to be very powerful to sustain self-management. While being interviewed, even though her children had grown up and she was free from her responsibility of raising children, she was able to stick to her established strict lifestyle without much struggle.

In the context of Taiwanese society, taking care of family members is the major task for a woman. Thus, if patients' need to practice self-management conflicts with family needs, they tend to place family needs prior to theirs. For example, while Tian-Tian's husband was suffering from cancer and hospitalised, she had to keep him company in the hospital. During that period, she had no time to visit the clinic for her diabetes. It was after her husband's death when she had the time to start visiting the clinic and taking care of her own health again. From Tian-Tian's experiences, it indicates that the families' needs are of higher priority than theirs; thus, to consider the issue of providing healthcare to those married women, it is necessary to access their social roles and take them all into account to make the services more effective.

In addition, family crisis is found to be another important factor that influences individuals' self-management. The research shows that any family crisis can impose huge stress, which can make blood glucose soar, leading to poor metabolic control. Meanwhile, how to solve the problem under such stress is more important than practicing self-management, as this could result in ignoring/diminishing of self-management. My data reveal that it can impose more stress on patients when the health professionals concern more on the result of metabolic control than the care for the patients' distress. At this critical period, some individuals may even lose their will to live, thus to ask them to achieve expected outcomes set by the health professionals

is arguable. As the outcome of metabolic control is used to measure whether patients receive high-quality health care can result in oversimplifying the complexity of self-management. For example, Ai-Hua had experienced a series of family crises, including being divorced with her husband because of diabetes, and then her children constantly ran into trouble as the consequence of a broken family. These events might be considered as an unsuccessful performance of social roles, which evokes the sense of frustration and even shatters the meaning of her life. Under such situations, it is difficult to control the blood sugar levels within expectation. My data reveal that at that moment, to carry out self-management was not what she had in mind. How to cope with family crises inevitably became her urgent need, and the goal of health care can become unrealistic if it is still appraised by the outcome of metabolic control.

From their experience, I learned that if the patients' family could be involved with part of the self-management activities, they could be more understanding about the needs of the patients and reduce the possibility of stress raised from changing lifestyle. Also, if their family endeavoured to help them with diabetes control, to achieve expected performance must become the goal of the family rather than the patient per se. It could add meaning to diabetes self-management and motivate patients practicing self-management because it has one more meaning involving family commitment. Ju-Hua recorded every examination taken in the hospital and said that her husband and daughter would check them. They were very concerned with the outcomes of metabolic control, thus every returning check seemed to tell them how their efforts would turn out. The outcome of metabolic control would not be the personal goal but their families'. While family is involved with the actions, it might tie up the activities of self-management with family commitment. Family bond is a very powerful

strength to help the patients from the very beginning of lifestyle change. Once they have established the lifestyle, the journey of living with diabetes would be much easier. As a result, to involve family members in diabetes control could have positive influences.

In sum, the performance of social roles shapes self-identity, and it is mostly placed in a higher priority than self-management. Thus, if the consequences of diabetes are being recognised by the patients as a threat for further performance of their social roles, they tend to have stronger motivation for practicing self-management. Performing social roles tend to shape an individual's self-identity, and even become the meaning of his life. Therefore, while an individual has a dilemma between performing social role and self-management, self-management tends to be posited in a lower priority. Therefore, to provide high-quality diabetes care, health professionals have to obtain more in-depth information regarding the patients' social roles and disadvantages they may encounter before providing health counselling.

Revisit the conceptual framework of the process of self-management

Before coming to an end, I would like to revisit the conceptual framework mentioned in chapter 2, which was synthesised to provide a comprehensive view of self-management development (please see figure 8). An individual with diabetes may begin as a passive participant, probably because of lacking specific knowledge. The role of the health professional is more like a helping hand to provide information needed to practice diabetes self-management, also function as informer to diabetic patients for the process of self-management, and make them become exemplar self-

managers. Health professionals need to be aware of the influential factors that may cause negative impacts. They need, in particular, to weaken the impact of the negative influential factors. From the external environment, there are social stigmas, word of mouth, insurance system, health care facilities, health policy, and social roles that shape self-identity. The role of health professionals is to help diabetic patients. It helps to describe that patients have mainly received psychological impact while feeling the self as a changed person, in which without adequate knowledge to perceived threat is critical to feel an urgent need of learning self-management. However, the needs can be created because of their social role, such as anticipated burden to the family.

Apart from their strength of motivation, during the stage of restructuring their lives, they are heavily influenced by socio-cultural factors, such as social roles and social support; and their capability to carry out self-management behaviours are also important to them. Physiological conditions and adequate knowledge they learn can support them to develop self-management skills. During this period, socio-cultural, where they live, creates meaning for them to fight with diabetes. The meaning depends on the consequences of diabetes, and its impact is not only on the patients themselves but also on their families.

The meaning of life, which has been heavily influencing their social role, creates the meaning for them to live on and strength to cope with diabetes. They find their own meaning for their lives, depending on their relationship with others, to motivate them to carry out diabetes self-management. If people are free from the pressure given by

social roles, the motivation of self-management can depend on how they want their lives to be.

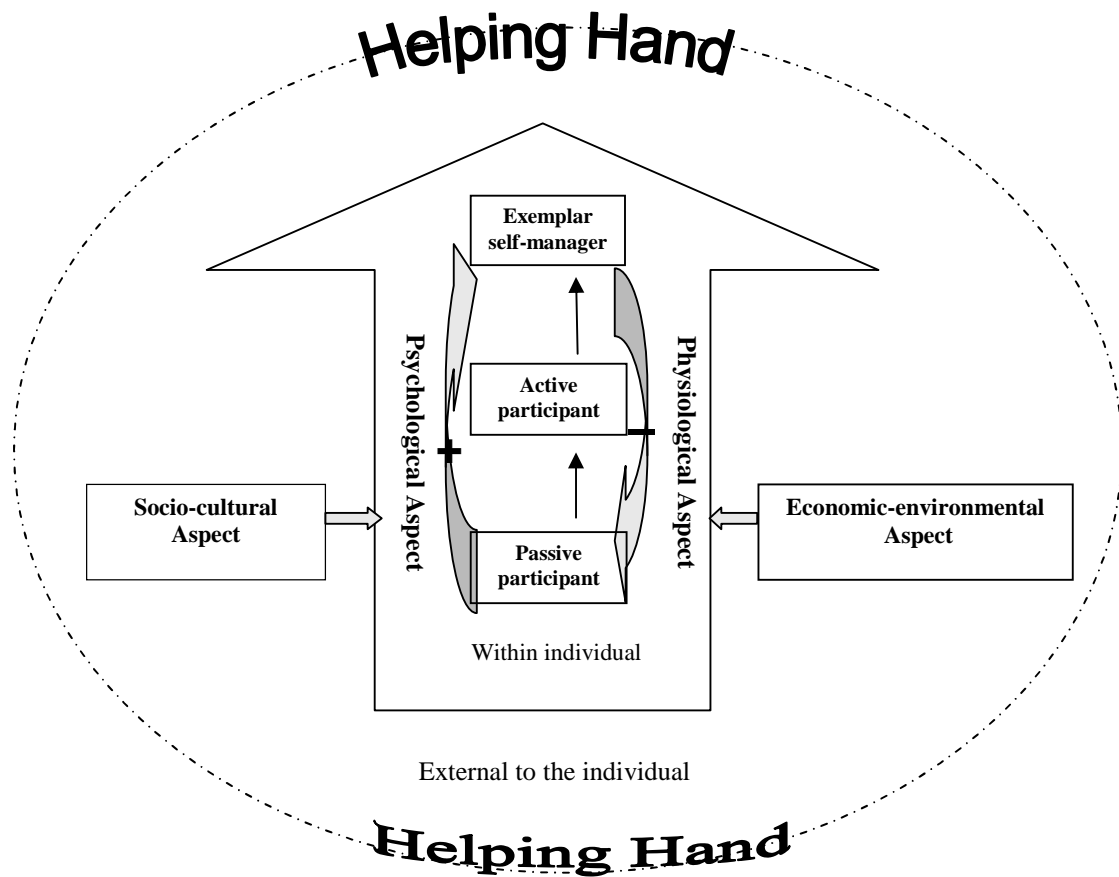


Figure 8 - Conceptual framework of diabetes self-management

In conclusion, this study has identified perceived threat as a determinant for diabetic patients to make decisions for self-management. It is not clearly identified from the transtheoretical model, which is adapted in many diabetes care institutions in Taiwan. Perceived threat is a necessary psychological preparation for diabetic patients to be aware of a need for change because the process of change can be very unpleasant.

The self, in terms of personal experience, health belief, value, as well as social role, are concepts directing the decision-making of self-management. The concept of perceived threat and worry can be used to understand how strong their needs are for a change. The stronger need they want, the more tolerance they can endure for unpleasant process of the change. If an individual feels the task of self-management is a greater burden than the diabetes itself, it is a hurdle for the patients to move on to self-management. While the patients are unaware of the need for change, they cannot actively involve in self-management, but remain passive participants.

Once they are able to perceive the self as a changed person, they start to actively involve in self-management. Their knowledge and problem-solving skills direct the way of developing self-management behaviours. As they manage to carry out self-management activities, they can start to learn from physical responses. The experiential learning is begun as they start to learn about their body in response to self-management, medical treatment, and physiological condition, in which the learning requires self-monitoring of blood glucose to understand physical responses to all of these treatments, personal emotions, and stress. During this period, they may even start to realise the minute change of their physiology, while their blood glucose achieves a particular level.

Implications of the study for health professionals working in diabetes care centre in Taiwan.

The participants experienced the impact of having diabetes, and sought help from many resources. While they were under stress, together with inadequate knowledge, some of them accepted harmful advice from lay-persons. At this stage, when they perceived having diabetes as a threat to them, and realised themselves as ‘a changed person,’ the help from health professionals is to provide them individual-tailored educational programme to fulfil their needs in essential learning. Meanwhile, establishing a trusted relationship is essential to assess more detailed information, which involves a patient’s then-situation of social role to provide proper education counselling. As patients have to play many other roles at the time of practicing self-management, the content of diabetes educational programme has to be flexible enough to meet various needs to achieve an effectively good ‘diagnostic history taking’ because their experiences and learned diabetes knowledge are based upon individual perspectives of their lives and the context of living environment. This information will be useful for health care professionals.

Helping patients to start with experiential learning can help them get actively involved with self-management, which includes how to observe the relationship between the physical responses and self-management activities, and the result of evaluation can be used to adjust self-management behaviours, to develop their unique way of self-management. Nurse diabetes educator could guide the patients to learn from their own body (experiential learning). While they achieve the stage of knowing what is best for their bodies, they could become exemplar self-managers. At this stage, a patient

support group can speed their learning, where they can learn from each other by observing what their bodies respond to various interventions or self-management.

Providing support is important to improve the quality of care. At the stage of restructuring life, it is essential to provide resources for newly diagnosed patients by introducing them to the exemplar self-managers, and provide peer support. Exemplar self-managers can comfort newly diagnosed patients by showing evidence that diabetes is controllable; furthermore, they can share their experiences and discuss and learn from each other.

Health professionals need to be careful while providing services because educating patients by telling them about negative impacts of diabetes may lead to adverse responses, since patients may adapt the strategy of avoidance to cope with stressful situations. In addition, health professionals have to be aware that the bigger the range of change is required, the more unpleasant perceptions will occur. To reduce the unpleasant feelings of change, health professionals have to support the patients and adjust the path of the process of change by accessing how much the patients could endure.

To reduce the stress of social stigma, the government has to consider public health education to reduce negative impact of word of mouth, and provide support to those people with diabetes, such as how to manage hypoglycaemia.

Looking for the future

This study provides a conceptual framework for a better understanding of the phenomenon of self-management in Taiwan. However, there are still more needed to be clarified in the future.

- To explore the phenomenon of living with type 2 diabetes in different population, such as children, adolescent, young adult female, and male in different age groups
 - To further examine the role of perceived threat in diabetes self-management
 - To examine the role of worry in the process of self-management
 - To examine the role of experiential learning in the process of self-management
 - To further examine the phenomenon of physical responses in diabetic patients
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APPENDIX A



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同意臨床試驗證明書

查吳秀麗、廖培鴻主持「探討台灣第二型糖尿病自我管理之過程模式」案（IRB編號：051236），經人體試驗委員會審查通過，特此證明。有效期限至九十六年二月十六日，且應接受本會之監督，同意臨床試驗證明書編號：CCH：2006-02-004

後續定期追蹤之程序及要求：

1. 期中報告：應於九十五年十二月十六日前繳交期中報告。核准有效期限屆滿，若尚未通過期中報告追蹤審查，不得繼續試驗。
2. 結案報告：試驗完成後，應將執行情形及結果以書面報告本會核備。

人體試驗委員會

主任委員

郭守仁

中 華 民 國 九 十 五 年 二 月 十 六 日

Protocol Title : Exploring type 2 diabetes self-management in Taiwan: A process model.

Protocol No : 051236

Protocol Version Date : Version 02.0 Jan 27, 2006

Informed Consent Forms : Version 03.3 Feb 15, 2006

Principle Investigators : Hsiu-Li Wu

Sub-investigator : Pei-Yung Liao

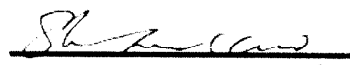
CCH : 2006-02-004

The above study was approved by the Institutional Review Board of the Changhua Christian Hospital on Feb 16, 2006 and valid till Feb 16, 2007 and accepts the monitoring of IRB

IRB用印：

Sincerely Yours
Shou-Jen Kuo, M.D.
Chairman
Institutional Review Board.
Changhua Christian Hospital, Taiwan




(signature, date) Feb. 16, 2006

本會組織與執行皆符合ICH-GCP

The Institutional Review Board performs its functions according to written
Operating procedures and complies with GCP and with the applicable regulatory requirements.



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E-mail: d9065@cch.org.tw
財團法人彰化基督教醫院人體試驗委員會

500 彰化市南校街 135 號
電話 : (04)723-8595 轉 1362
E-mail: d9065@cch.org.tw

同意臨床試驗證明書

壹吳秀麗、廖培湧主持「探討台灣第二型糖尿病自我管理之過程模式」變更案 (IRB 編號: 051236)，經人體試驗委員會審查通過，特此證明。有效期限至西元 2007 年 02 月 16 日，且應接受本會之監督，同意臨床試驗證明書編號：CCH：051236

後續定期追蹤之程序及要求：

1. 期中報告：應於西元 2006 年 12 月 16 日前繳交期中報告。核准有效期限屆滿，若尚未通過期中報告追蹤審查，不得繼續試驗。
2. 結案報告：試驗完成後，應將執行情形及結果以書面報告本會核備。

人體試驗委員會
主任委員
郭守仁

西 元 2 0 0 6 年 0 7 月 1 0 日

Protocol Title : Exploring type 2 diabetes self-management in Taiwan: A process model.

Protocol No : 051236

Protocol Version Date : Version 03.0 Jul 05, 2006

Informed Consent Forms : Version 04.0 Jul 05, 2006

Principle Investigators : Hsiu-Li Wu

Sub-investigator : Pei-Yung Liao

CCH : 051236

The above study was approved by the Institutional Review Board of the Changhua Christian Hospital on Jul 10, 2006 and valid till Feb 16, 2007 and accepts the monitoring of IRB.

IRB 用印：

Sincerely Yours
Shou-Jen Kuo, M.D.
Chairman
Institutional Review Board,
Changhua Christian Hospital, Taiwan



Shou-Jen Kuo

July 10, 2006 (signature, date)

本會組織與執行皆符合 ICH-GCP

The Institutional Review Board performs its functions according to written
Operating procedures and complies with GCP and with the applicable regulatory requirements.

APPENDIX B

Interview Guide (for type 2 diabetes)

Before I start the interview, I would like to thank you for being willing to take part in this study. All of the information you give will be kept confidential and remain anonymous, and will be used only for the academic purpose. During the interview, please don't hesitate to pause for a break. You can also withdraw from the study at any stage if you want to.

- a. This statement will be given before each interview.
- b. Permission to tape record will be obtained from the subject.
- c. Please will you fill out this form for me before we start? (4-5 minutes)

General information about you

1. To get us started I wonder if you could tell me about yourself and family? Please would you tell me:

- a) How old are you,
- b) Are you single, married (for how long), divorced, remarried,
- c) Any child you have,
- d) Any dependents – you look after
- e) Are you in paid employment?
 - what job
 - how many hours

Your experience of diabetes

2. Please will you tell me how long you have been diagnosed with diabetes?

. (15 minutes)

3. Tell me how it felt when you were first diagnosed diabetes?

<Prompts >

- What had you been feeling like before?
- What make you go to the doctor?
- After it was diagnosed – how did you cope with?
- How did your family feel about it?

4. Were there any things that were specially worrying you? (15 minutes)

5. Have there been any incidents which have especially helped or concerned you about your diabetes?

6. Tell me how do you feel about your diabetes now?

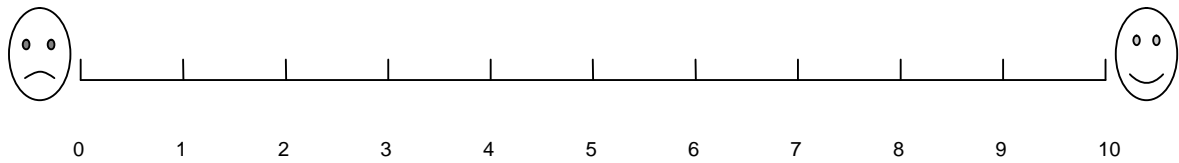
<Prompts >

- What do you do to stay healthy?
- Can you give me an example of a day or a period of time you managed really well?
- Can you give me an example of a day or a period of time you managed real difficulty?

8. How much confidence you have in your ability to look after yourself?

<Prompts >

- How you position yourself in this figure in terms of your ability to look after you?
-



- Why? You put yourself at this position.

9. Tell me how you feel about the health care you receive from the healthcare system?

<Prompts >

- Have you been to different doctors? If so, how many, why? (did they tell you different things)
- How do you feel about the healthcare service/support received from healthcare professionals?

10. Do you use other health systems, e.g. Chinese medicine or folk medicine? Please explain.

Others: regard with information not mentioned above

11. Tell me whether it is still something that you feel very important but I have not ask about. (1-10 minutes)

<Prompts >

- Thank you for taking time to answer these questions.
-

會談指引 (第二型糖尿病病人)

在會談開始之前，我要先謝謝您意願加入這個研究計畫。所有您所提供的資料將只作為學術用途，而且這些資料都將會保密，會用無名氏來顯示資料出處。在會談過程中，您隨時可以要求暫停休息，不必覺得不好意思。假如您不想參加研究，也可以在任何時候要求退出。

- a. 每次的會談前，上述這段申明都會被複述一遍。
- b. 會先徵詢參與者的同意，才使用錄音機錄下會談過程資料。
- c. 開始之前可否請您填寫這份表格？

與您有關的一般資訊

1. 一開始不知可否先告訴我關於您和您家裡的一些相關訊息？

(提示)

- 您幾歲了？
- 結婚狀況呢？(單身、已婚、離婚、再婚) 若結婚則有多久了？
- 有幾個小孩？
- 家中有沒有需要您照顧的人？有多少人？
- 您有在工作嗎？
 - 什麼樣的工作？
 - 每天要工作多少小時？

糖尿病的一些經驗

2. 可否請您告訴我得糖尿病有多久了？
 3. 當您剛被診斷為糖尿病那時有什麼感想？
-

(提示)

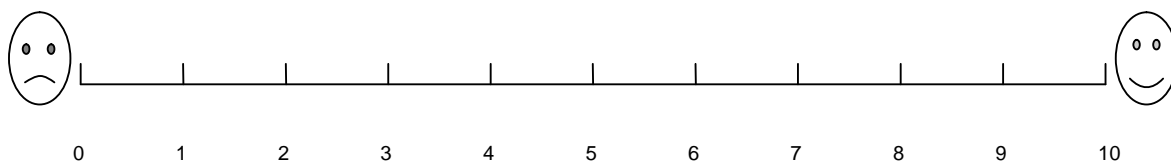
- 過去那段時間有什麼感想？
 - 那時是因為什麼原因去看醫師？
 - 得知診斷後那段時間您是怎麼撐過來的(調適)？
 - 同樣的您家人在那段時間的感覺呢？
4. 曾經有發生什麼比較特別的事，而讓您很煩惱？
5. 是否曾發生過一些事件，它對您照顧自己的糖尿病特別有幫忙，或使得您開始關心這件事？
6. 可否請您告訴我，現在的您對糖尿病有什麼感想？

(提示)

- 您如何讓自己維持在最佳健康狀況？
 - 您是否可以例舉您認為自我照顧做的最好的一天或一段時期？
 - 您是否可以例舉您認為自我照顧做的很不理想的一天或一段時期？
7. 可否告訴我您對照顧自己(的糖尿病)有多少信心？

(提示)

- 您可以用這個圖來顯示一下，您自己的信心會在什麼在位子上？



- 為什麼您覺得自己是在這個位子上？
8. 可否告訴我，您對目前這裡(的醫療系統)所提供的照顧，有怎麼樣的感覺？

(提示)

➤ 您有找過其他的醫生嗎？若有，有那些？爲什麼？〈他們告訴您的有沒有什麼不一樣？〉

➤ 您覺得這裡服務怎樣？覺得這些醫療專業人員給您的支援怎樣？

9. 您有沒有找過其他的醫療方法？比如說中醫或民俗療法？請您說明一下。

其它前面沒提到的資訊

10. 不知是否有一些跟自我照顧有關的資訊，您覺得蠻重要，但是我並沒有問到？

(提示)

➤ 謝謝您花這些時間幫忙回答這些問題。

Interview Guide (for nurses)

Before I start the interview, I would like to thank you for being willing to take part in this study. All of the information you give will be kept confidential and remain anonymous, and will be used only for the academic purpose. During the interview, please don't hesitate to pause for a break. You can also withdraw from the study at any stage if you want to.

- a. This statement will be given before each interview.
- b. Permission to tape record will be obtained from the subject.
- c. Please will you fill out this form for me before we start? (4-5 minutes)

General information about you

- 1. Would you mind telling me how old you are?
- 2. How long have you been qualified as a nurse?
- 3. How long had a certificate in diabetes nursing? (0.5 minutes)

Your experience of diabetes self-management

- 4. In your experience what do Taiwanese people who are good at diabetes self-management do.

<Prompts >

- Can you give me an example of each?
-

5. In your experience what are the key questions/problems for people with type 2 diabetes, when they are first diagnosed. (25 minutes)
6. Do the patients receive Chinese medicine or folk medicine to treat of diabetes?
How this decision influencing of diabetes self-management? (15 minutes)
7. In your view are the most common factors which could affect diabetes self-management at: home: work: in social life?
8. How does the current healthcare system affect diabetes self-management?

Others: regard with information not mentioned above

9. Does it anything not being mentioned but it is important to this subject? (1-10 minutes)

<Prompts >

- Thank you for taking time to answer these questions
-

會談指引 (護理人員)

在會談開始之前，我要先謝謝您意願加入這個研究計畫。所有您所提供的的資料將只作為學術用途，而且這些資料都將會保密，會用無名氏來顯示資料出處。在會談過程中，您隨時可以要求暫停休息，不必覺得不好意思。假如您不想參加研究，也可以在任何時候要求退出。

- a. 每次的會談前，上述這段申明都會被複述一遍。
- b. 會先徵詢參與者的同意，才使用錄音機錄下會談過程之所有對話。
- c. 開始之前可否請您填寫這份表格？

有關您的一般資訊.

- 1. 可否請問您幾歲？
- 2. 您成為有執照的護理人員有多久了？
- 3. 您在拿到糖尿病衛教學會的證書多久了？

您在糖尿病自我管理的工作經驗

- 4. 以您的個人在台灣照顧糖尿病病人的經驗，對於被稱為所謂有很好的糖尿病自我管理的人，他們是怎麼樣在做的？

(提示)

- 您可以舉個例子嗎？

- 5. 以您個人的經驗，第二型糖尿病病人在剛診斷初期，他們有那些主要的問題/困擾？

6. 他們會不會去看中醫，或一些民俗療法？這些對糖尿病自我管理有什麼影響？

7. 以您個人的觀點，那些是在執行自我照顧時，最普遍的一些影響因素？比如在家裡、工作、社交場所。

8. 以我們目前的健康照護制度，對糖尿病自我管理有那些影響？

其它前面沒提到的資訊

9. 不知是否有一些跟自我照顧有關的資訊，您覺得蠻重要，但是我並沒有問到？

(提示)

➤ 謝謝您花這些時間幫忙回答這些問題

APPENDIX C

Invitation Letter

Dear Madam:

We are working in the Diabetes Care Centre of Changhua Christian Hospital. We are interested in how you take care of your diabetes. The information from you could help provide health care professionals with a deeper understanding of how you adjust to diabetes in your daily life. The more, it could serve as fundamental knowledge for helping the people like you that may be diagnosed with diabetes in the future.

For better understanding we invite you to join our study and discuss how you look after yourself.

Doctor Liao, Director of the Endocrine Department and Diabetes Care Centre, and nurse Hsiu-Li Wu hope that you will study. Your support means a lot to both health care professionals and the academic development. Hsiu-Li Wu, a nurse and Ph.D. student in the University of Nottingham in the United Kingdom is in charge the project.

If you wish to find out more about the study, please read the information leaflet. If you are willing to help us with the study, please fill in the slip at the bottom of the form and put it – the envelope provided – and leave it in the Centre. Thank you for taking time reading through this letter and response it to us.

If you have any question, please don't feel hesitate to contact with us. The telephone number is as follow: 0922727022.

Yours Sincerely

Dr. Pei-Yung Liao

Director of the Endocrine Department

Hsiu-Li Wu

Diabetes Care Centre

邀 請 信

親愛的_____女士

我們是在彰化基督教糖尿病衛教中心工作的人員，我們對於您如何自我管理自己的糖尿病很有興趣，因此您所提供的資料，可提供一些有關，如何在日常生活中自我管理糖尿病的寶貴資訊，讓醫護人員能從您的角度，對調適糖尿病的過程有較深入的了解。這些資訊將可進一步成為專業的知識的一部份，並可用於未來幫助一些和您一樣的人。

為了進一步了解，我們需要您加入此研究，以提供資料 寶貴的如何自我管理資料。新陳代謝科 廖主任培勇和我〈吳秀麗〉，在此誠摯的邀請您加入這個研究，而您的加入對不論是健康照護人員或學術領域的發展都意義 非凡。而這份研究的主要負責人是，目前仍然在英國諾丁漢大學就讀博士學位的吳秀麗。若您有意願加入這個研究，請您填寫附於信件內的表格，並用回郵信封寄回彰化基督教醫院，我將會與您聯繫，也非常感謝您花時間給於我們的回應。

假如您有任何問題，隨時歡迎跟我聯絡，我的電話號碼是：0922727022

敬 祝 安 祺

內分泌新陳代謝科主任

廖培勇醫師

英國諾丁漢大學博士候選人

吳秀麗

Information Sheet

Hsiu-Li Wu, Qualifications

Study: Exploring self-management of type 2 diabetes in Taiwan: a process model

My name is Hsiu-Li Wu. I am a Taiwanese nurse who is currently studying for a PhD at the University of Nottingham School of Nursing in UK.

This information sheet is to tell you about my study and ask if you are willing to participate in it.

My study has been approved by an ethical committee at Changhua Christian Hospital. Your name was given to me by the Diabetes Care Centre. I was looking for woman, 40-60 years old, no comorbidities, and diagnosed with type 2 diabetes.

My study aims to explore how people live with diabetes. I am interested hearing you talk about:

- What you feel about your diabetes
- How you manage your diabetes
- What you think of your diabetes care

If you are willing to participate in the project, I will arrange a time to talk to you, either at home, or while you visit the clinic. Each interview will take about 1 hour. If you do not want to in the study it will not affect your care in any way.

With your permission, I will also look at the information kept in your clinical files and use that to help inform my study. This, and everything you say, will be kept confidential, and no-one will be able to identify you.

Please be aware that, if you agree to be interviewed, you can stop the interview at any time. This will not affect your care in the hospital in any way.

Information from the study will be written up in a thesis which will be submitted to the University of Nottingham to be examined for a PhD. It will also be used to write articles for publication in journals, to help other nurses understand diabetes care from a patient perspective.

If you are willing to help please complete the slip below and leave it in the clinic in the envelope provided. I will telephone you to arrange a meeting.

Thank you for your help. Please do not hesitate to contact me if you have any questions.

Hsiu-Li Wu

Contact number: 0922727022

Address: 432, No 82 section 1, Wen-Chang Road, Dadu Shiang, Taichung County.

25 November 2005

Name: _____

I am willing to help you with your study.

My contact details are:

Address: _____

Phone: _____

研究說明單張

吳秀麗

研究主題：探討台灣第二型糖尿病自我管理之過程模式

我的名字叫吳秀麗，是一位護理人員，目前在英國諾丁漢大學護理研究所就讀護理博士學位。此研究說明的主要目的，是要告訴您有關我的研究，和詢問您是否願意加入此研究，至於您的資料我是從彰化基督教醫院得到的。

我的研究目的主要是要探討如何與糖尿病一起生活，我希望能從您那兒聽到有關下列的訊息

- 您如何照顧自己的糖尿病
- 您如何將糖尿病的自己照顧融入日常生活中
- 您對自己如何看自己的糖尿病照顧

假如您願意參加這個研究，我會安排時間和您談，會談場地可以選在您家裡或者是您回到醫院看診的時間。每次會談時間約為一小時左右。

這些資料是用來撰寫博士論文，完成的論文會繳交到英國的諾丁漢大學，以決定可否通過博士學位的檢定。之後，也會用來發表在學術期刊上，以期幫助其他護理人員，能從病人的角度來思考糖尿病的照顧。

假如您樂意幫忙，請填寫最後之小單張，並依斜線撕下，裝在回函信封內，交到糖尿病衛教中心的臨時信箱裡。最後非常感謝您的協助，假如您有任何問題，隨時歡迎跟我聯絡。

這些資料是用來撰寫博士論文，完成的論文會繳交到英國的諾丁漢大學，以決定可否通過博士學位的檢定。之後，也會用來發表在學術期刊上，以期幫助其他護理人員，能從病人的角度來思考糖尿病的照顧。

最後非常感謝您的協助，假如您有任何問題，隨時歡迎跟我聯絡。

吳秀麗

電話號碼：0922727022

聯絡地址：台中縣大肚鄉文昌路一段 82 號 郵遞區號：432

吳秀麗

聯絡電話：0922727022

聯絡地址：台中縣大肚鄉文昌路一段 82 號 郵遞區號：432

姓名：_____

我非常樂意幫忙你和參與研究。

我的連絡資料如下：

地址：_____

電話：_____

APPENDIX D

EXPERIENCE OF TYPE 2 DIABETES SELF-MANAGEMENT

FORM OF CONSENT FOR PARTICIPATION IN RESEARCH

1. I have been given of information about the purpose of the study.
Yes/No (Circle as appropriate)
2. I have been given of information about of the INTERVIEW SCHEDULE.
Yes/No (Circle as appropriate)
3. I do understand that I have right to withdraw or take a rest during the study.
Yes/No (Circle as appropriate)
4. I do agree to take part in the study and to receive an interview from the researcher.
Yes/No (Circle as appropriate)
5. I give/do not give permission for the interview to be tape recorded.
Yes/No (Circle as appropriate)
6. I agree/do not agree that you can look at my clinical record at CCH.
Yes/No (Circle as appropriate)

Participant signature:.....

Name:Date:.....

Address:.....
.....
.....

Witness signature:.....

Name:Date:.....

Researcher signature:.....

Name:Date:.....

探討第二型糖尿病之自我管理經驗

研究同意書(FORM OF CONSENT FOR PARTICIPATION IN RESEARCH)

1. 我已經被告知這個研究的目的。

是/不是 (請圈選合適的答案)

2. 我已經被告知這個研究的研究過程。

是/不是 (請圈選合適的答案)

3. 我已經了解我有權力在參加研究時，可以中途決定要不要休息或者退出研究。

是/不是 (請圈選合適的答案)

4. 我同意參加研究，並接受研究者的會談。

是/不是 (請圈選合適的答案)

5. 我 允許/不允許 會談過程被錄音。

6. 我 同意/不同意 研究者可以看我的病歷資料。

參加者簽名:_____

姓 名:_____ 日 期:_____

地 址:_____

見證者簽名:_____

姓 名:_____ 日 期:_____

研究者簽名:_____

姓 名:_____ 日 期:_____

探討第二型糖尿病之自我管理經驗(護理人員)

研究同意書(FORM OF CONSENT FOR PARTICIPATION IN RESEARCH)

1. 我已經被告知這個研究的目的。

是/不是 (請圈選合適的答案)

2. 我已經被告知這個研究的研究過程。

是/不是 (請圈選合適的答案)

3. 我已經了解我有權力在參加研究時，可以中途決定要不要休息或者退出研究。

是/不是 (請圈選合適的答案)

4. 我同意參加研究，並接受研究者的會談。

是/不是 (請圈選合適的答案)

5. 我 允許/不允許 會談過程被錄音。

參加者簽名: _____

姓 名: _____ 日 期: _____


地 址: _____

見證者簽名: _____

姓 名: _____ 日 期: _____

研究者簽名: _____

姓 名: _____ 日 期: _____


 彰化基督教醫院 CHANGHUA CHRISTIAN HOSPITAL http://www.cch.org.tw	人體試驗委員會		編號	051236
	學術研究受試者同意書		版本	02.0
			日期	2006 January 26
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學術研究受試者同意書(護理人員)


本書表應向受試者說明詳細內容，並請受試者經過慎重考慮後方得簽名

您被邀請參與此研究，本表格提供您有關本研究之相關資訊。

<input type="checkbox"/> 藥品	<input type="checkbox"/> 醫療器材	<input type="checkbox"/> 醫療技術	<input type="checkbox"/> 其它
計畫編號		IRB 編號	051236
計畫名稱			
試驗委託者			
計畫主持人	吳 秀 麗	部門/職稱	
		電話/分機	0922727022
緊急連絡人	吳 秀 麗	部門/職稱	
		電話/分機	0922727022
主持人簽名		日期	年 月 日
受試者姓名		性別	年齡
聯絡電話		病歷號碼	不需要
通訊地址			
法定代理人		性別	年齡
通訊地址			
一、試驗目的	➤ 您的照顧第二型糖尿病病人的經驗 ➤ 您照顧第二型糖尿病病人的經驗，她們是如何將自己的照顧融入日常生活中 ➤ 您如何看第二型糖尿病病人自己的糖尿病照顧		
二、試驗方法與程序	甲、則透過面對面給予研究說明單章與邀請信，若潛在受試者有意願，可將回條放入回郵信封寄回糖尿病衛教中心。主持人再依據所留的資料，以電話連繫並安排簽訂受試者同意書、會談的時間與地點。 乙、所有會談安排，完全由研究主持人負責。 丙、會談性質則屬於深度會談 丁、會談時間約為 80 分鐘 戊、這研究過程與結果，有以下的情況需讓您了解： 1. 這過程將會錄音 2. 這些參考資料以及與您會談的相關資料，都會完全保密，所以沒人可以由所發表的文章中認出談的您。 3. 即使您已經答應要參加，任何時候您都可以要求退出。 4. 這些資料是用來撰寫博士論文，完成的論文會繳交到英國的諾丁漢大學，以決定可否通過博士學位的檢定。		

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	也請您放心，這並不會使您的治療品質受影響。 5. 這些資料是用來撰寫博士論文，完成的論文會繳交到英國的諾丁漢大學，以決定可否通過博士學位的檢定。之後，也會用來發表在學術期刊上，以期幫助其他護理人員，能從病人的角度來思考糖尿病的照顧。
三、身心上可能導致之副作用、不適或危險	對於罹病過程的不愉快情緒，可能被回憶起。
四、其他可能之損失或利益	無
五、預期試驗效果	無試驗
六、其他可能之治療方法選擇及說明	無任何治療會執行
七、參加本研究計畫受試者個人權益將受到保護	<p>(一). 若發生由依計畫執行引起之傷害時，<u>不負損害賠償責任</u>。</p> <p>(二). 研究過程中如有新資訊可能影響您繼續參與臨床試驗的意願，將即時告知您或法定代理人。</p> <p>(三). 如果受試者在研究過程中：</p> <ol style="list-style-type: none"> 1. 對研究工作性質產生疑問 2. 有任何問題或狀況 3. 因任何理由欲退出本研究 4. 對相關權益有疑問 <p>請隨時與計劃主持人：<u>吳秀麗</u>聯絡，電話為：0922727022 或 04-26999252。</p> <p>(四). 財團法人彰化基督教醫院將在法律所規範之程度內，視受試者之資料為機密。受試者亦瞭解衛生署與本院人體試驗委員會皆有權檢視受試者之資料。</p>
八、簽章	<p>(一). 經由說明後，本人已完全瞭解以上所有內容，並同意參加本研究，且將持有同意書副本。 受試者簽名：_____日期：__年__月__日</p> <p>(二). 我已向受試者解釋上述研究方法及其所可能產生之危險與利益。並且回答受試者有關本研究計畫之疑問。</p>

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	<input type="checkbox"/> 計劃主持人 <input type="checkbox"/> 協同主持人 <input type="checkbox"/> 研究代理人 簽名：_____日期：__年__月__日
	(三). 如您不是受試者，請用正楷書寫您的姓名：並指出您是受試者之： <input type="checkbox"/> 父母 <input type="checkbox"/> 監護人 <input type="checkbox"/> 法定代理人 <input type="checkbox"/> 受任人（需附委任書） <input type="checkbox"/> 其他：_____ 簽名：_____日期：__年__月__日 （醫療法第七十九條規定：受試者為無行為能力或限制行為能力人，應得其法定代理人之同意） (四). 如您是受試者，但無法親自簽名，請見證人 簽名：_____日期：__年__月__日

(本書表應向受試者說明詳細內容，並請受試者經過慎重考慮後方得簽名)


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學術研究受試者同意書 (糖尿病個案)

本書表應向受試者說明詳細內容，並請受試者經過慎重考慮後方得簽名

您被邀請參與此研究，本表格提供您有關本研究之相關資訊。

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聯絡電話		病歷號碼	
通訊地址			
法定代理人		性別	年齡
通訊地址			
一、試驗目的	<p>此研究主題為：探討台灣第二型糖尿病自我管理之過程模式，主要是想了解</p> <ul style="list-style-type: none"> ➢ 您如何照顧自己的糖尿病 ➢ 您如何將糖尿病的自己照顧融入日常生活中 ➢ 您對自己如何看自己的糖尿病照顧 		
二、試驗方法與程序	<ul style="list-style-type: none"> ➢ 則透過面對面給予研究說明單章與邀請信，若潛在受試者有意願，可將回條放入回郵信封寄回糖尿病衛教中心。主持人再依據所留的資料，以電話連繫並安排簽訂受試者同意書、會談的時間與地點。 ➢ 所有會談安排，完全由研究主持人負責。 ➢ 會談性質則屬於深度會談 ➢ 會談時間約為 80 分鐘 ➢ 這研究過程與結果，有以下的情況需讓您了解： <ol style="list-style-type: none"> 1. 這過程將會錄音 2. 會查看病歷中與糖尿病相關的資料：如檢驗糖化血色素、糖尿病可能引起的相關合併症資料。 3. 這些參考資料以及與您會談的相關資料，都會完全保密，所以沒人可以由所發表的文章中認出談的您。 		

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	<p>4. 即使您已經答應要參加，任何時候您都可以要求退出。也請您放心，這並不會使您的治療品質受影響。</p> <p>5. 這些資料是用來撰寫博士論文，完成的論文會繳交到英國的諾丁漢大學，以決定可否通過博士學位的檢定。之後，也會用來發表在學術期刊上，以期幫助其他護理人員，能從病人的角度來思考糖尿病的照顧。</p>
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七、參加本研究計畫受試者個人權益將受到保護	<p>(一). 若發生由依計畫執行可能引起之情緒無法負擔之傷害時，受試者有權利拒絕回答，若因之造成可能傷害，本研究<u>不負損害賠償責任</u>。</p> <p>(二). 研究過程中如有新資訊可能影響您繼續參與臨床試驗的意願，將即時告知您或法定代理人。</p> <p>(三). 如果受試者在研究過程中：</p> <ol style="list-style-type: none"> 1. 對研究工作性質產生疑問 2. 有任何問題或狀況 3. 因任何理由欲退出本研究 4. 對相關權益有疑問 <p>請隨時與計劃主持人：吳秀麗聯絡，電話為：0922727022 或 04-26999252。</p> <p>(四). 財團法人彰化基督教醫院將在法律所規範之程度內，視受試者之資料為機密。受試者亦瞭解衛生署與本院人體試驗委員會皆有權檢視受試者之資料。</p>
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	(二). 我已向受試者解釋上述研究方法及其所可能產生之危險與利益。並且回答受試者有關本研究計畫之疑問。 <input type="checkbox"/> 計劃主持人 <input type="checkbox"/> 協同主持人 <input type="checkbox"/> 研究代理人 簽名：_____日期：__年__月__日
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(本書表應向受試者說明詳細內容，並請受試者經過慎重考慮後方得簽名)

APPENDIX E

Primary Codes

Accept complementary treatment
Afraid of authority
Trying not to affect family
Accompany with more serious disease
Caregiver of family
Depression
Fear
Health insurance help
Independent
Main bread earner
Misconception
Negative emotion effects health
Not like of troublesome whilst visit
Passive self-care
Problem between family members
Reconcile of emotion
Remind self as a DM patient
Sodium intake control
Stress
Working let me feel good
Restrict self eating less but more times
Kept monitoring blood sugar (monitoring blood sugar work as standard of life)
Not like taking Chinese medicine
Not drinking soft drink
No habit for drinking soft drink
Not testing blood sugar
Not good doctor affect of self-care
Not affect of daily life
No fear
No complain
Diabetes is not a disease
No worry over the children
No trust with Chinese medicine
Deny
Don't worry too much
No mercy to forgive
Taking both Chinese and Western medicine
Trying to understand body's response to medicine, exercise and dietary
Kept reminding by the others
Hypoglycaemia and strategies
The treaty of Buddhist (need to be thrifty).
Trust in 'me' without following the things which is from word of mouth
Confidence
Self-beliefs (human being, having food is the best not definite requires dainty food.)
Never wrong doing
Wound hard to be healed
Strategies of conquer with temptation
Don't work too hard
Ancestor's experience
Crisis sensation
Not eating a lot
Vegetarian affect blood sugar
Reading sutra good for health
Understand it help to free from stress
Insulin shot means the end of life
Regular test on HbA1c
Working prevent taking medication regularly

Weather counts
Good doctor counts
Perceived threat
Family commitment
See diabetes as a friend
Religious having positive effect
Regular tests received from the hospital
Family attend in diabetes care
Family assist her to control diet
Affect family life
Positive Family support
Concern giving burden to the family
Can not resist to food while they are available
Exercise good for health
Trial and error
Searching for other resource
Not fancy in entertaining
Negative view to the disease
No know what to do about diabetes
Confidence in self-management
Set a short term goal for self to achieve good result
Less desire on food
Eating less but more times
Hard working affect of self-care
Working environment affect of self-care
Testing blood sugar often
Awful to have diabetes while in the young
Impedance travelling
Mindset
Tolerance
Fear insulin shot
Fear pain while testing blood sugar
Suppress emotion
Strategy of controlling
Eating food while craving for that
Benefit from exercise
Becoming part of life
Thrifty since young because of poor
Benefit from self-care, losing body weight and blood sugar decrease
Kept self hungry by resist self to eat food
Searching good doctor
Finding cured recipe
Receive insulin shot
Control it within low blood sugar
Unfold diabetes
Reminding
Fear of hypoglycaemia
Fear no one to assist while hypoglycaemia
Fear a situation of no capability for self-care
Government pay part of money for strip
'Yeh Chang' Buddhist's view of disease
Time different when travelling
Too much time left
Chinese medicine reducing blood sugar
Having place for taking exercise
Doctor giving pressure
Religious activities
Having job
Conscious control diet
"Huo-Tung (means want to be alive have to take exercise)

Fear having medication control should be ok
Having difficulty for diet control
Service attitude affect of receiving care
No feeling about having diabetes
Positive doctor-patient relationship
No job
Want to be alive is the motivation for self-care
Satisfied with health service
Family burden is not heavy
No pressure
Finding diabetes accidentally
Unable accept it
Change environment
Living simply
Lives could be controllable
Lifestyle changed
Lives regularly
Sick affect of taking exercise
Voluntary
Pain affect of exercise
Patient having heavy load
Lost weight
Anger
Seeing doctor while being seriously
Trust in authority
Trust in western treatment
Lack of knowledge
Hunger for knowledge
Trying to Control carbohydrate
Negative aspect form society
Cut down diet
Thrifty
Awful
Need to be careful all day long
Financial problem
Having previous experience benefit self care
Lack of exercise
Trust the lay-person's advice
Obesity
Knee problem affect of exercise
Fear to see healthcare provider's long face
It is self to control disease
Busy in own business (might not have time?)
Taking exercise with family
Not able to adapt it
Not self-monitoring of blood sugar is because the machine being not working well
Fraud event
Visiting big hospital rather than small one
Have to monitoring blood sugar for good control
The blood test strip is too expensive to afford it
Accept it while being diagnosed as diabetes
Knowing it's incurable
Adjust medicine
Feel self just like a normal person
Not happy to be critiqued (regarding with diabetes)
Negative emotion affect self-care
Blood sugar affected by sickness
Health fitness is more important
Withdraw from something do not like
Happy to have capability working

Exercise is a sort of happiness
Follow prescribed order
Follow prescribed medicine
Moving
Got this disease because being inherited from family
Prefer approachable doctor
Information need
Want to avoid hypoglycaemia
Sorrow
Noticed that having a job affect blood sugar
Face the problem
Start to eat less greasy food
The limitation on food to strict
Learn how to adjust self-care activities based on the blood sugar level
Encouraged from healthcare providers

APPENDIX F

1st March 2006

I called the Doctor A, who is a doctor with his professionals on diabetes treatment, and many of his patients are nominated by the DEC professionals, and it would be very helpful to have his encouragement to his patients to join in the study. He did tell me to visit him, and discussed the research face-to-face.

Whilst I arrived at outside of Dr A's clinic, he was not available at the moment. Meanwhile there was a potential participant who had appointment with Doctor Lin that morning. I did meet that potential participants and explained my study to her and gave her information sheet, from which she could be able to contact with me if she would agree to join in the study.

For I arranged a interview at 2 pm in the participant's home where I was not familiar with the area she lives, after lunch I set out immediately to FuSin Shiung to visit participant.

It took me 20 minutes to go there by car. I went out earlier in case I might have some unpredictable situation happened during the journey. It was 20 minutes earlier than the appointment time, and I waited inside my car, which parked outside of the potential participant's house a few yards away. I called the case before I visited her, and she told me where the house located. There was a long path, 50 meters, leading to the main entrance of the house, beside the path there were varied of plants planted in the pots ready to be sold. Whilst I walked along the path, and I could see 5-6 children and 3 adults looking at the direction where I was walking. One of two main doors of the house, or exactly two houses built together as one big house, came with the potential participant. Whilst I drew near to the main entrance, a young woman led me into the door which located on right side. She showed me to seat on the coach, and made me and the potential participant, her mother-in-law, a pot of tea, and introduced herself as the daughter-in-law of the participant. A small child, 2 years old, was in the room as well, and she was curious of my visiting. During the interviewing, this child did enter the living room, where we had interviewing just ongoing, once. The participant explained that she took care of this kid whilst her mother goes to work during day time. The participant's husband also came to say hello, and listened to the

explanation for the study, and the consent form. He was very open minded and felt that it could be fine for his wife to attend the study. He also signed the name on consent form together with her wife as a witness. The participant did show her interest to receive the feedback from me after all the data collected and analysed.

After went home, I completed fieldnote, and typed it into computer. There was another preparation for tomorrow's interviewing on 10 am. I have feel a bit of relax. Maybe the experiences of interviewing make me feel more confidence on the data collection in the field.

Translator's reference of

The exerted transcripts were checked by a bilingual Chinese person to ensure the rigour of translation. He has been in the United Kingdom for nine years. He started his degree from GCSE, and then to A-Level. Now he is doing MSc Marketing in the Nottingham Trend University.

After his permission, I will be able to put his name and contact number in the thesis.

Name: Ta-Hsiang Lin

Contact number: 07904619212
