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Zhao, Peng

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Swansea University
Prifysgol Abertawe

An Ethnographic Investigation of Self-management of Type-2 Diabetes Mellitus in Chinese People in China and Wales

Peng Zhao

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Abstract

The number of Chinese patients with type-2 diabetes in China and Wales has been increasing dramatically, which has been one of the most prominent health challenges in the two countries. Self-management provides an effective strategy to encourage patients with type-2 diabetes and their family carers to be involved in activities such as lifestyle modification, self-testing of blood glucose, and adherence to daily medication treatment to control their condition in daily lives. However, there is limited research that has explored the perspectives and practices of self-management among Chinese patients in China and Wales. The aim of this study was to investigate self-management of type-2 diabetes from the perspectives and practices of Chinese patients with type-2 diabetes and their family carers living in China and Wales.

Data were generated through the use of ethnography that entailed semi-structured interviews with a purposive sample of Chinese patients with type-2 diabetes in China (n=13) and their family carers (n=7) and Chinese patients with type-2 diabetes in Wales (n=13) and their family carers (n=7). Data generation also included a review of participants' own records of self-management, and observation of public diabetes education sessions in China and in Wales. After thematically analysing the data five key themes emerged: symptom perception and emotional responses to being diagnosed with type-2 diabetes, diabetes-related knowledge and information sources, the positive and negative consequences of type-2 diabetes, the practices of self-management, and barriers and facilitators of self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales.

The findings indicated that there was limited awareness and knowledge regarding type-2 diabetes and self-management among Chinese patients and their family carers in both China and Wales. This was mainly attributed to lack of financial support and access to reliable information sources in China and language barriers in Wales. Another important barrier to self-management among Chinese patients in Wales was lack of family support. In addition, this study has also identified the positive and negative influences of Chinese tradition cultural norms on self-management.

This study makes a significant contribution to the limited research on the perspectives and practices of self-management among Chinese patients and their family carers in China and Wales. In particular the findings provide an in depth understanding of the Chinese cultural influences on self-management of type-2 diabetes in two different contexts. Recommendations are provided for health care providers, diabetes educators, health policy makers, and research community.

Contents

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Chapter One Introduction

1.1 Introduction

The purpose of this study was to investigate self-management of type-2 diabetes from the perspectives and practices of Chinese patients with type-2 diabetes living in China and Wales and their family carers. A qualitative and ethnography methodology was considered to be appropriate to achieve the aim. This chapter will justify the conduct of this study and then provide definition of the key concepts of type-2 diabetes and self-management used in this study. An introduction to the research questions and research context is provided and finally an overview of the structure of the thesis is provided. Firstly, justification of conducting this study and definition of type-2 diabetes and self-management adopted in this study is presented.

1.2 Justification of conducting this study and definition of key concepts

Diabetes mellitus is a metabolic disorder that is characterised by chronic hyperglycaemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both, and a longstanding hyperglycaemia is associated with long-term damage, dysfunction and failure of various organs including heart, eyes, kidney, and nervous system (World Health Organisation, 1999). According to the new classification of diabetes mellitus published by the World Health Organisation (WHO) in 1999, diabetes mellitus was classified as type-1 diabetes mellitus, type-2 diabetes mellitus, other specific types, and gestational diabetes mellitus (WHO, 1999). This study focused only on people who are diagnosed clinically with type-2 diabetes.

Over the past two decades, the number of people living with type-2 diabetes mellitus (T2DM) has been increasing sharply throughout the world due to the prevalence of unhealthy lifestyles such as being overweight or obesity and physical inactivity and other unmodifiable factors including family heredity (Mokdad *et al.*, 2001; Zimmet *et al.*, 2001). WHO (2015) estimated that in 2014 approximately 347 million people globally were diagnosed with diabetes and type-2 diabetes comprised 90% of people with diabetes. The prevalence of diabetes mellitus is rising at a dramatic rate in the UK, as well as in China. In 2013, the number of diagnosed patients with diabetes was 3.2 million in the UK, and it is estimated that the number will approach five million by

2025 (Diabetes UK, 2014). In Wales, more than 170,000 people were diagnosed with diabetes in 2013 (Diabetes UK, 2014). In addition, in the UK, the prevalence rates of type-2 diabetes among Chinese people were 3%, which is nearly double the prevalence amongst white people (Diabetes UK, 2014). The latest study revealed that the number of people with diabetes in China is 92.4 million, and it has therefore overtaken the incidence rates of India and become the focus of a diabetes epidemic in the world (Yang *et al.*, 2010). Therefore, diabetes especially type-2 diabetes has been a great challenge for public health and health care in China, the UK, and Wales and the prevention and management of type-2 diabetes has been one of priorities of the health care system in these countries.

Although there is a high prevalence of type-2 diabetes in the world, the condition cannot be cured by existing medical techniques. There is increasing evidence to confirm the effectiveness of self-management on prevention and management of type-2 diabetes (Diabetes Prevention Program Research Group, 2005; Pan *et al.*, 1997). Cooper *et al.* (2003) defined self-management of diabetes as an evolutionary process of development of knowledge or awareness by learning to survive with the complex nature of the diabetes in a social and cultural context. Moreover, American Association of Diabetes Educators (2008) recommended seven essential self-management behaviours in people with diabetes which predict good outcomes. These are healthy eating, being physically active, monitoring of blood sugar, compliant with medications, good problem-solving skills, healthy coping skills and risk-reduction behaviours. Therefore, self-management of type-2 diabetes can be understood as individual behaviours to manage their condition which occurs in a social and cultural context. This understanding of self-management is adopted in this study.

As self-management of type-2 diabetes can be understood as individual behaviours to manage their condition which occurs in a social and cultural context, I explored if and how Chinese cultural traditions impacted on self-management of type-2 among Chinese patients in China and Wales. I also made a comparison regarding how these Chinese cultural norms influenced self-management of type-2 diabetes among Chinese patients in China and Wales. Redfield (1941) defines culture as conventional understandings, manifest in act and artefact. Napier *et al.* (2014, p.1610) develop Redfield's definition and redefined culture as:

> "The shared, overt and covert understandings that constitute conventions and practices, and the ideas, symbols, and concrete artefacts that sustain conventions and practices, and make them meaningful."

According to this definition, culture can be understood not only as shared habits and beliefs, but also as activities that are based on those habits and understandings and that understand beliefs held in common with others. This definition is also helpful because it clarifies that culture should not be understood neither as a group of people who have the same racial heritage nor as ethnic identity. Nevertheless, this definition fails to clarify that culture changes with development of society and why shared beliefs and practices do not spread automatically and evenly to every member within a society. Furthermore, for the people living in a world of others, although their perceptions are likely to be affected by others and the socio-cultural world in which they are located, they are not determined by others as they construct their own world independently (Csordas, 2002). Therefore, culture exists in the meanings that individuals construct in the context of their world rather than as an abstract set of rules which determines a group's behaviour. Additionally culture should also be viewed as a dynamic concept which reflects the complex contexts in which culture is negotiated (Fleming *et al.*, 2008).

China has 31 provinces and every place has its own cultural traditions so Chinese cultural norms described in this study were commonly shared beliefs and values amongst Chinese people, which were evaluated based on my understanding and experiences of being an "insider" within the Chinese cultural context. Therefore, I acknowledge that there may be different understandings regarding how these Chinese cultural norms mentioned in this study are prevalent among Chinese people. As reported by Napier *et al.* (2014, p1610), "...the hardest thing to know in a relative and comparative sense might be one's own culture." In addition, these beliefs and values are not fixed and they might keep changing with the development of society and economy in China. Thus, there may be different understandings of these beliefs and values over time.

My interest in type-2 diabetes stems from when I graduated from a medical college and gained a bachelor degree in medicine in China. Then I completed my master degree in chronic conditions management at Swansea University, which aroused my interest in the self-management of type-2 diabetes. However, when I conducted a literature search, limited research on self-management of type-2 diabetes among Chinese patients was found and most such research was conducted among American Chinese patients in the United States. Due to the different social and cultural context and health care system, the findings from such studies may not be directly transferred to other countries such as the China and UK. Furthermore, no research on self-management of type-2 diabetes among Chinese patients in Wales was found. There is a great need therefore to conduct a study to investigate self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales.

1.3 Research aim and questions

The aim of this study was to investigate self-management of type-2 diabetes from the perspectives and practices of Chinese patients with type-2 diabetes living in China and Wales and their family carers. The research questions posed to achieve this aim were:

- What do Chinese patients and their family carers understand about their condition and self-management?
- What sources of support and information on type-2 diabetes and self-management do Chinese patients and their family carers access?
- How does type-2 diabetes influence daily lives of Chinese patients and their family carers?
- What are the factors facilitating or hindering self-management among Chinese patients and their family carers?
- How do Chinese patients in China and Wales conduct self-management in the different social and cultural contexts and health care systems and how do Chinese cultural traditions influence self-management of type-2 diabetes among Chinese patients in China and Wales?

A qualitative methodology adopting an ethnographic approach was selected to achieve the research aim. Self-management can be understood as an individual activity and behaviour that happens in a social and cultural context and whist social and cultural context also may influence self-management. Thus, the understanding of self-management used in this study based on an ontological perspective that reality is constructed in a social and cultural context (Sale *et al.*, 2002). Ethnography provides the researcher with a method to investigate human events and behaviours in the natural context where they happened. The fundamental and core goal of ethnography is to understand a culture. Moreover, Morse (1987) points out that the focus of ethnography is on gaining an understanding of the phenomenon under study from the perspectives of the participants. It was therefore envisaged that a more detailed understanding of Chinese patients and their family carers' perspectives and practice regarding self-management of type-2 diabetes would be gained through adopting the ethnographic approach.

Being an ethnographer, I acknowledge that I am not only a researcher but also a part of the social world of those being researched (Hammersley & Atkinson, 2007). Thus, I acknowledge that my personal experience and medical knowledge will have influenced the conduct of this study and the interpretation of the findings (Aull Davies, 1999). Throughout this thesis I seek to demonstrate how my views, values, and feelings have influenced the interpretation of the data and will be writing in the first person. This process of "exploiting self-awareness as a source of insight" is known as reflexivity (Lipson, 1991, p.75). The context of this study is presented in the following section.

1.4 Context of the study

This study was conducted in China and Wales. Thus, the context of this study in China and Wales is discussed separately. First, a discussion of study site in China is presented.

1.4.1 Study site in China

In China, this study was carried out at a diabetes outpatient department of a large comprehensive regional hospital in Kunming, Yunnan province of China. Kunming is the capital and the largest city of Yunnan province with a population of nearly five million people, which is located in the southwest of China.

1.4.2 Brief introduction to diabetes care in China

As mentioned above, type-2 diabetes is one of the major chronic conditions among Chinese people, which causes a great health care burden in China. Due to lack of an effective primary care system, most patients seek diabetes care in hospitals, which results in an overstretched diabetes care system. In addition, although a countrywide medical insurance system has been established in China, there were still more than 300 million people living without any medical insurance at the end of 2008 (Dong, 2009). The medical insurance system is primarily targeted at hospitalisation and critical diseases, with the reimbursement rates for outpatients care capped at 40% for patients living in urban area (Dong, 2009). Therefore, the cost of diabetes care and self-management results in an increased financial burden for many patients and their family, especially for those patients with lower income.

Diabetes education plays an important role in diabetes care and self-management. Although many diabetes education programmes have been initiated in China, there are still barriers for implementation of the programmes, including lack of diabetes education programmes based on health promotion model, lack of standards of practice for diabetes educators, and lack of evaluation criteria to assess their performance (Wilson & Gyi, 2010). In addition, Chinese traditional medicine and Chinese cultural traditions in terms of family and social relationship and harmony greatly influences Chinese people including their perspectives on health and disease.

1.4.3 Study site in Wales

In Wales, this study was undertaken with the support of a Chinese charitable organisation in South Wales. Currently there are over 600 registered Chinese members with the organisation living across South Wales. The charitable organisation provides their members with a variety of services including translation and interpretation service, English training, and health education.

1.4.4 Brief introduction to Chinese immigrants and diabetes care in Wales

According to the 2011 census, the number of people of Chinese ethnicity was 13,638, which accounted for 0.4 % of the total population in Wales (Office for National Statistics, 2015a). Most Chinese immigrants originated from different parts of China, including mainland China and Hong Kong and a small number of them come from Malaysia, Singapore, and Taiwan (Office for National Statistics, 2015a). They moved to Wales mainly for business or family reunion (Zhou, 1992). In addition, as previously stated in 2013, there were approximately 170,000 people living with diabetes including type-2 diabetes in Wales (Diabetes UK, 2014). The prevalence rates of type-2 diabetes among Chinese people in the UK were 3.0 %, compared with the rates of 1.7 % among white people (Diabetes UK, 2014).

The Welsh Assembly Government (2008, 2013) has put in place a number of policies such as *Designed for the Management of Adult with Diabetes Mellitus across Wales* and

Together for Health-A Diabetes Delivery Plan and formulated *National Service Framework for Diabetes (Wales)* (Welsh Assembly Government, 2002) to manage the increasing prevalence of the condition. National Health Service Wales provides various and free services including prevention, early detection, and management based on a primary care system (Welsh Assembly Government, 2008). A structured and standard diabetes education programme called X-PERT Diabetes (Welsh Assembly Government, 2008) is being carried out in Wales to provide a range of information on type-2 diabetes and self-management for people living with type-2 diabetes or for those who care for someone with type-2 diabetes. Having orientated the reader to the study site, the layout and the structure of the thesis is presented in the following section.

1.5 The structure of the thesis

In Chapter two, a critical review of literature regarding the influencing factors on self-management of type-2 diabetes among patients from minority ethnic groups is provided. The literature review identified four key factors which affected minority ethnic-patients' self-management of type-2 diabetes, namely cultural traditions, culturally competent diabetes education, health literacy, and social support. However, it is noted that the majority of the research has been conducted among immigrants from minority ethnic groups such as African and Mexican Americans in the United States. As will be shown the literature focusing on Chinese patients with type-2 diabetes in China, UK and Wales was sparse.

In Chapter three, the methodology of this study is justified and detailed. My work and role during data collection and analysis and issues regarding evaluation of the findings are discussed and explained. Ethical considerations also are fully explained.

Chapter four is an introduction to the findings and discussion chapters. Firstly, demographic information and characteristics of the participants are aggregated and presented. After that, a number of sociological, psychological and health promotion theories were drawn upon to aid understanding of the complex issues which the data identified, which are explained in this chapter. The purpose of introducing these theories briefly prior to the presentation of the findings and discussion chapters is to aid the reader in understanding the interpretation of the data. These theories became relevant on analysing the data and were not predetermined.

The findings and related discussion are presented in Chapters five to nine. Chapter five explores the two routes that Chinese patients took to reach their diagnosis of type-2 diabetes, namely diabetes-related symptoms and an opportunistic route, and the factors influencing them on obtaining the diagnosis. In addition, the participants' including patients' and their carers' emotional responses at the time of being diagnosed and the influences of these emotional responses on Chinese patients and their carers are also presented and discussed.

Diabetes-related knowledge and information sources among Chinese patients and their carers are discussed in Chapter six. Most Chinese participants both in China and Wales demonstrated insufficient knowledge of type-2 diabetes and self-management due to lack of access to reliable information sources in China and due to language barriers in Wales. Besides demographic factors, good communication with health care professionals and family support played a crucial role on the level of knowledge of type-2 diabetes. As will be shown Chinese cultural norms also played an important role in the acquisition of type-2 diabetes information among Chinese patients and their family carers.

The negative and positive consequences of type-2 diabetes on Chinese patients and their family carers in China and Wales are discussed in Chapter seven. As an adversity, type-2 diabetes negatively impacted on many Chinese patients and their family carers in term of daily activities, employment, family relationship, and social life, which impeded the practice of self-management. However, as well as the negative effects, the positive effects of type-2 diabetes were also identified by over half of Chinese patients and their family carers including increased attention to health, the change of lifestyles, and enhanced family relationships.

A discussion on the practise of self-management of type-2 diabetes among Chinese patients and their carers is provided in Chapter eight. Modification of lifestyles including dietary change and exercise, adherence to a western medication regime and self-monitoring of blood glucose were common self-management behaviours reported among the Chinese patients interviewed. The positive roles of support from family carers in the patients' self-management behaviours were also identified. In addition, the influence of Chinese traditional medicine on self-management is discussed in this chapter.

The cultural barriers and facilitators to self-management of type-2 diabetes among Chinese patients and their carers are presented in Chapter nine. The cultural beliefs regarding traditional family roles and interpersonal relationships with wider social networks had a negative influence on self-management among Chinese patients and their carers both in China and Wales. However, cultural beliefs in terms of social and family harmony, human-heartedness and mutual support, and nurturance life derived from philosophy of Chinese traditional medicine had a positive influence on self-management in Chinese patients and carers. In addition, the application of salutogenesis to aid understanding the findings in this study is also discussed in this chapter.

Chapter ten includes evaluation and conclusion of the thesis. Limitations of the study are acknowledged and an evaluation of the methodological approach drawing on Hammersley's (1992) concepts of validity and relevance is provided. Finally, the study's main claims are presented and discussion of their relevance and recommendations for health care providers and diabetes educators, health policy makers, and research community are also provided.

1.6 Summary

In this chapter the need for the present study has been justified and my particular interest in the topic has been presented. The conceptual understanding of type-2 diabetes and self-management used throughout this study was explained. The research aim has been presented and the choice of an ethnographic approach has been briefly explained. The reader has been orientated to the research context and the two sites in China and Wales. Finally, an overview of the structure of the thesis was presented. A critical review of literature regarding the influencing factors on self-management of type-2 diabetes in people from minority ethnic groups is provided in the next chapter.

Chapter Two Literature review

2.1 Introduction

In this chapter previous research which has explored the influencing factors on self-management of type-2 diabetes is reviewed, synthesised and critically evaluated. The findings from 43 identified articles were synthesised with the aim of exploring and integrating contemporary research regarding the influencing factors on self-management among patients with type-2 diabetes from minority ethnic groups. Four influencing factors on self-management of type-2 diabetes were extracted from the analysis of the literatures. These were: (a) cultural traditions; (b) culturally competent education of type-2 diabetes; (c) health literacy; and (d) social support. Each factor will be elaborated on in the following sections. Firstly the literature search strategy is presented.

2.2 Literature search strategy

The main strategy used to search for relevant studies was the electronic search using keywords in five bibliographic databases: Medline (1990-2015), CINAHL (1990-2015), and Web of Knowledge (1990-2015), ASSIA (1990-2015), and Biomed Central Journals (1997-2015). The keywords used included "type-2 diabetes mellitus" or "type-2 diabetes" or "T2DM" or "non insulin dependent diabetes mellitus" or "impaired glucose tolerance" AND "self management" or "self care" or "home care" or "lifestyle intervention*" AND "influenc*" or "impact* factor*" AND "ethni*" AND "migrat*" AND "immigrat*". The contents of abstracts or full-text manuscripts identified by the literature search were completely reviewed in order to select studies which met the inclusion criteria. The inclusion criteria were:

- Original studies and literature reviews;
- Conducted in the last twenty-five years (1990-2015) and published in English;
- All relevant articles were investigated as full text;
- Assessed factors affecting diabetes self-management;
- Research participants were identified as patients with type-2 diabetes, and recruited from minority ethnic groups.

Additionally a manual search of articles was conducted if they were not available electronically. Moreover, additional studies were identified by searching all the reference lists of relevant trials, reviews and meta-syntheses.

The number of articles generated was 378. Their abstracts were checked for relevancy to the topic and 43 studies including four literature reviews m*et al*l the above criteria and were included in this review which included nine from Medline, eight from CINAHL, 22 from Web of Knowledge, two from ASSIA, and two from Biomed Central Journals. Having presented the literature search strategy, the four influencing factors on self-management of type-2 diabetes are now presented commencing with cultural traditions.

2.3 Themes

2.3.1 Cultural traditions

From reviewing the literature a key theme to emerge was cultural traditions. Within this theme key issues which have been explored included the effects of cultural factors on self-management of type-2 diabetes: the impact of family relationships and the impact of traditional beliefs on diet. Several of the studies identified the factors influencing the level of acculturation among patients with type-2 diabetes and the negative impact of social stigma and discrimination on self-management of type-2 diabetes. Each of these cultural influences is now discussed in detail.

2.3.1.1 Family relationships

Successful type-2 diabetes management requires that patients effectively conduct self-management in their daily lives and for most within a family context. Six studies examined the mutual influences of family relationships and self-management of type-2 diabetes (Chesla *et al.*, 2009; Chun & Chesla, 2004; Chun *et al.*, 2011; Nam *et al.*, 2013; Samuel-Hodge *et al.*, 2000; Vincent *et al.*, 2006). Three of the six studies discussed the impact of Chinese traditional family belief regarding maintaining family harmony on self-management of type-2 diabetes among Chinese American patients (Chesla *et al.*, 2009; Chun & Chesla, 2004; Chun *et al.*, 2011). The remaining three studies explored the mutual influences of traditional family responsibility and relationship and self-management among Mexican (Vincent *et al.*, 2006), Korean (Nam *et al.*, 2013), and African American patients with type-2 diabetes (Samuel-Hodge *et al.*, 2000).

Chesla *et al.* (2009) conducted an interpretive comparative interview study with 20 Chinese American couples (n=40) aged 35-75 years and living with type-2 diabetes for at least one year in order to identify cultural and family challenges to the management of type-2 diabetes among Chinese American patients and their spouses. Three main cultural beliefs, including family relationship, traditional beliefs on diet, and family role were identified which challenged diabetes self-management within Chinese American families. Chesla *et al.* (2009) found that family responsibilities and relationships were greatly challenged when Chinese patients and their family members had different expectations about what family members should learn about type-2 diabetes and what they should do to assist with the management of their spouse's type-2 diabetes. Meanwhile, family conflicts were triggered in negotiating the different role expectations. However, most Chinese patients in the study believed that family members had a reciprocal role responsibility to understand their condition and to help them conduct self-management, and they expected their family members to fully understand, to be highly sensitive to, and to anticipate their diabetes management needs. However, a convenience sample was used in the study. Moreover, all interviews were conducted in Cantonese but the use of interpreter and translator failed to be described in detail, which may impact on credibility of the findings.

Chesla *et al*'s (2009) findings were supported by another study conducted in Chinese Americans. Chun and Chesla's (2004) study focused on the culturally unique experiences and responses to type-2 diabetes in Chinese-American families. They recruited 13 Chinese-American patients with type-2 diabetes and seven spouses representing 16 families by purposive sampling. Chun and Chesla (2004) conducted a group interview, with two to five study participants per group, focused on participants' narratives about daily diabetes care and its effects on their personal and family life. Interpretive phenomenology was the method used for eliciting and analysing the participants' narratives. Chun and Chesla (2004) identified negative effects of type-2 diabetes on the family relationships, and found that many Chinese-American patients with type-2 diabetes attempted to maintain family roles and to avoid direct confrontation and conflict through presenting themselves as being very relaxed and happy in front of family members and suppressed expressions of unhappiness and pessimism out of concern for their family members. Therefore, Chun and Chesla (2004) stressed that a harmonious family relationship, which contributed to the conduct of self-management of type-2 diabetes, was the result of mutual understanding and joint efforts of the patients and their family members. Nevertheless, there were limitations which may impact on the credibility of the findings in the study. Seven Chinese American spouses involved in the study may not provide full concerns that Chinese American couples might express. Further, the conduct of a group interview may lead to a situation in which participants may hide their real feelings and experiences.

Additionally patients with type-2 diabetes from minority ethnic groups may encounter more family challenges in the self-management of type-2 diabetes as migrating to a new context greatly impacted on their family structure and relationships. Chun *et al.* (2011) conducted another study using interpretive phenomenology in order to explore how migration to the United States and family relationships affect management of type-2 diabetes among 40 Chinese American patients and their spouses aged 35-75 years. Chun *et al.* (2011) found that many Chinese American patients had a concern that their young generation may have lost traditional Chinese cultural values of respecting and taking care of elder parents, and expressed deep dissatisfaction with highly acculturated American-born Chinese youth. Moreover, many Chinese American patients also felt isolated and helpless due to the separation from their family members in China. Therefore, Chun *et al.* (2011) reported that lacking the care of their family members may be a main barrier to self-management amongst Chinese American patients. Nevertheless, this study focused only on Chinese American patients speaking Cantonese. Thus, their findings might not provide full perspectives regarding the influence of immigration and family relationships on Chinese American patients' self-management of type-2 diabetes because of growing numbers of Mandarin-speaking Chinese immigrants in the United States.

Moreover, further work on the mutual effect of traditional family relations and role and self-management of type-2 diabetes in other cultures has been undertaken. Nam *et al.* (2013) conducted a study using five focus groups with 23 Korean Americans with type-2 diabetes in order to explore challenges in self-management and found that women had to take more on responsibilities of feeding family due to the change of socioeconomic status after moving to the United States, which led to a change of traditional family relationships and role in Korean American families. Thus, male Korean American patients may receive reduced support from their female family carers and female patients may encounter multiple challenges to self-management as a result of such change in traditional family relationships and role. Similar findings were obtained from studies with African-American women living with type-2 diabetes. Samuel-Hodge *et al.*

(2000) conducted focus group interviews with 70 southern African American women living with type-2 diabetes for at least one year. In their study, the participants who had stable work and the responsibility of taking care of other family members had more stress than those who described themselves as retired and living alone. Therefore, the change in family responsibilities and relationships after having type-2 diabetes had greater influences on self-management of type-2 diabetes among female patients as women play a traditional role of care provider in their family in many cultures. Similar findings were obtained among Mexican-American patients.

Vincent *et al.* (2006) conducted focus group interviews with 20 Mexican American patients with type-2 diabetes and 20 family caregivers to describe factors that facilitate or hinder diabetes self-management and explore participants' preferences and recommendations about the essential components of a culturally competent diabetes self-management program among Mexican Americans. The findings demonstrated that patients' family traditions and relationships changed after having type-2 diabetes due to the needs of diet modification. In addition, psychological stress was prevalent among the patients due to a lack of information on how to conduct dietary management. Furthermore, the patients' family members were also stressed as they did not know how to support their relative with type-2 diabetes with respect to appropriate diet modification. Stress and lack of information on dietary management not only negatively influenced on their family relationships, but also may discourage their self-management. The main limitation of this study was related to its sampling, such as a relatively small sample size (n=40), a high proportion of female participants (68%). In addition, data collection was conducted at only one community clinic site and patient respondents were not asked about length of time since diagnosis with diabetes.

These studies identified how traditional family roles and relationships among patients with type-2 diabetes and their family carers from minority ethnic groups changed after having type-2 diabetes. These changes in traditional family roles and relationships had negative influences on self-management among patients especially among female patients. In addition, the findings stressed the importance of maintaining stable and good family relationships which supported patients in the self-management of their diabetes. The influences of traditional belief regarding diet are discussed in the following section.

2.3.1.2 Traditional beliefs regarding diet

Besides family relationship, Chesla *et al.* (2009), Chun & Chesla (2004), and Vincent *et al.* (2006) also explored the influences of traditional beliefs regarding diet on self-management among patients with type-2 diabetes from minority ethnic groups. In terms of dietary management, Chesla *et al.* (2009) found that Chinese-American patients with type-2 diabetes had a negative attitude to dietary restrictions as it was perceived as reducing their quality of life, and family and social relationships. Furthermore, Chun and Chesla (2004) also indicated that for Chinese-American patients with type-2 diabetes, dietary restrictions may potentially diminish the enjoyment and symbolic importance of a group meal, and adhering to food restrictions during social celebrations may conflict with collectivistic norms of respecting the wishes and desires of others in the group, thereby damaging their social interpersonal relationships. In the Chinese culture, food is not only considered simply as a form of sustenance but also viewed as an essential ingredient of quality of life and an important symbol of cultural values (Chun & Chesla, 2004). Thus, adhering to dietary restrictions may lead to cultural challenges for Chinese patients who insist that food abundance is central to the quality of life and maintaining social relationships. Besides Chinese-American patients, Mexican-American patients with type-2 diabetes and their family carers also had concern about dietary management. Vincent *et al.* (2006) found that Mexican-American patients and their family carers were confused as to what is appropriate diet for patients with type-2 diabetes and they had difficulties in overcoming the conflicts between maintaining traditional dietary beliefs and conducting daily diet modification. Therefore, the findings from these studies concurred that the plan of diet modification for patients with type-2 diabetes from minority ethnic groups and their family carers needed to be clear and tailored to their culture and traditions in order to ensure the conduct of an effective diet modification. Apart from traditional belief regarding diet, social stigma on type-2 diabetes and discrimination also might impact on self-management of patients from minority ethnic groups, which are discussed in the following section.

2.3.1.3 Social stigma and discrimination

The studies by Kohinor (2011), Liburd *et al.* (2007), and Nam *et al.* (2013) have revealed that there was social stigma regarding type-2 diabetes and discrimination which was prevalent in minority ethnic cultures they studied and had a negative influence on self-management of type-2 diabetes. Kohinor *et al.* (2011) conducted ethnographic study adopting semi-structured interviews with 32 Surinamese patients with type-2 diabetes in Netherlands in order to explore why Surinamese patients either share or do not share their condition with people in their wider social networks. After analysing the interview transcripts using grounded theory methods, Kohinor *et al.* (2011) found that Surinamese patients were not willing to expose their condition to people outside their family circle due to fears of discrimination unless they needed facilities and support for self-management of their diabetes. However, the participants in this study were limited to first-generation Surinamese migrants and most of them were women. Thus, they had lower intermediate socioeconomic status. Moreover, this study focused only on Surinamese patients. Thus, the disclosure of diabetes was not verified through seeking information from people they knew. These limitations related to sampling may reduce the credibility of this study's findings. Liburd *et al.* (2007) also conducted a qualitative study adopting an ethnographic approach with 16 African-American men with type-2 diabetes aged from 39-71 years in order to explore cultural influences of diabetes self-management amongst this ethnic group. Liburd *et al.* (2007) reported that African-American male patients kept silent about their condition and never shared their experiences and feelings of managing their condition in order to maintain their masculinity. Nevertheless, their findings might not be generalised to the other minority ethnic community due to its small sample size and limited meanings of its findings which were associated only with the experiences of black masculinity. Similar findings were obtained among Korean American patients. Nam *et al.* (2013) also found that most Korean American patients especially male patients were reluctant to talk about their type-2 diabetes to other people in order to avoid receiving unnecessary attention and injustice comments about their condition during social events, creating a social isolation, which was negatively related to their self-management by hindering them from an active care-seeking behaviour.

It would appear that social stigma and discrimination are barriers to expressing needs and asking for help and support in the course of conducting self-management among patients with type-2 diabetes from several minority ethnic groups. Therefore, there is a need for further studies to explore whether social stigma and discrimination to type-2 diabetes are also experienced by Chinese patients, which to date has been under explored both internationally and nationally. For patients with type-2 diabetes from minority ethnic groups, apart from coping with their own cultural barriers, the level of adaptation to western culture surrounding them may influence their self-management behaviours, which is discussed in the following section.

2.3.1.4 Acculturation

When people move to reside in different countries, people are expected to accept and acquire the values, practices, and beliefs of their new homelands. This adaptation to new social and cultural contexts has been found to be positively associated with the occurrence of type-2 diabetes (Kandula *et al.*, 2008) but its influence on self-management is not still clear. In this section, three studies (Chun *et al.*, 2011; Deng *et al.*, 2013; Xu *et al.*, 2011) in which the effect of adaptation to new social and cultural contexts on self-management among Chinese patients with type-2 diabetes in North America were evaluated.

Chun and colleagues (2011) investigated the influences of acculturation on diabetes self-management among Chinese American patients with type-2 diabetes and their spouses in the United States through conducting a study adopting phenomenology and identified three levels of acculturation experiences. These acculturation experiences included utilising the health care system, maintaining family relations and roles, and establishing community ties in the United States. Additionally they found that acculturation experiences among Chinese American patients and their spouses impacted on self-management and health in complex ways because of distinct individual's characteristics (e.g., age, gender, level of education, and socioeconomic status), repertoire of skills (e.g., language abilities and cultural knowledge), acculturation goals and motives (e.g., pursuing new educational opportunities, resettling in a healthier and more desirable living environment), acculturation demands (e.g., pressures to speak English and navigate the U.S. health care system), and coping resources (e.g., availability of culturally-appropriate health care services and government health care subsidies). Therefore, Chun and colleagues (2011) advocated developing culturally-appropriate diabetes management recommendations for Chinese immigrants and their families in the United States to improve their acculturation and self-management. This study investigated how the factors related to acculturation collectively and simultaneously impacted on self-management through using qualitative research approach, and then provided an abundant and holistic understanding regarding the relation between Chinese American patients' levels of acculturation and their self-management. Similar findings were also obtained in a cross-sectional study by Xu *et al.* (2011).

Xu *et al.* (2011) conducted a cross-sectional survey with 211 Chinese Americans people living with type-2 diabetes in order to examine the relationships between the level of acculturation and diabetes self-management behaviours. The study revealed that demographic characteristics such as gender, age, and socioeconomic status were associated closely with the level of acculturation. Women and older participants had a lower level of acculturation, and those who had higher socioeconomic status and lived in the United States for a longer period were more acculturated. In addition, the findings also supported the positive relationships between a high level of acculturation and diabetes self-management. This study had a high participation rate (90%) and culturally and linguistically data collection method was used. However, the majority of the participants were first-generation Chinese immigrants and they had small difference in acculturation scores. Moreover, the use of convenience sample and data based on self-report may increase bias of the findings.

The findings of above two studies indicated that acculturation to mainstream society contributed to self-management among Chinese Americans with type-2 diabetes probably because increased acculturation was associated with increased help seeking behaviours and increased use of professional services. Moreover, acculturation of Chinese Americans with type-2 diabetes was associated with their demographic characteristics such as gender, age, level of education, and socioeconomic status. However, this acculturation model was insufficient to explain a phenomenon that a high level of acculturation may be negatively associated with health behaviours, which was mentioned as the immigrant paradox by Alegría *et al.* (2008). The immigrant paradox in terms of dietary management among Chinese patients in North America was explored in a review of the literatures by Deng *et al.* (2013).

Deng *et al.* (2013) conducted a review of the literatures to evaluate the relationship between acculturation which was especially related to diet and diabetes self-management among Chinese patients in North America. They found that adapting to western diet, which contains a large amount of fat and calories may have a negative influence on the health status and dietary management of Chinese patients as it may result in an elevated risk for persistent hyperglycaemia. Therefore, maintaining a low level of dietary acculturation and retention of Chinese easting style may contribute to diabetes management among Chinese patients. However, a dependence on Chinese staple foods could be challenging to Chinese patients in western countries because these foods were not understood by western health care providers and educators. Therefore, the findings from this literature review indicated that full cultural considerations was needed when advising diets for the treatment of type-2 diabetes to Chinese patients in North America in order to increase diet acceptability and adherence to dietary modification. Yet, detail information regarding literature search strategy used, inclusion criteria, and the number of reviewed literatures was not explained clearly in this review.

In the current review, it is difficult to draw a definite conclusion that acculturation is positively or negatively associated with self-management of type-2 diabetes among Chinese patients in North America. The main critique of acculturation includes that its core concepts are still implicit and inconsistent due to insufficiency of a clear definition and conceptualisation of acculturation. Of three studies, only one study included a definition of acculturation (Xu *et al.*, 2011), namely acculturation can be understood as a process whereby the attitudes and behaviours of people from the original culture are modified over time as a result of contact with western culture. According to this definition, cultural change is a key element of the concept of acculturation. However, Hunt *et al.* (2004) found that the term "traditional culture" was commonly used to describe original culture of immigrants and "mainstream society" was used to described receiving culture of immigrants in their study but understanding in terms of "traditional culture" and "mainstream society" was quite widely presumed and various as culture is a concept which is dynamic and subjective and cultural values are not evenly distributed between all members of society (Napier *et al.*, 2014). Therefore, Crockett and Zamboanga (2009) stress that the interactional context in which acculturation happens must be understood first before understanding acculturation. This context includes characteristics of the immigrants themselves, the groups or countries from which they originate, their socioeconomic status and resources, the country and local community in which they settle. Moreover, in the three studies, the prevalence of cultural values which could have impacted on self-management of Chinese immigrants was not evaluated, thus it is unclear if and how widely these cultural beliefs and values are accepted in the original country of Chinese immigrants and mainstream society, which could impact on the generalisability of the findings of the three studies.

From reviewing the literature regarding the influence of culture on self-management of type-2 diabetes, four main cultural factors which have significant impacts on self-management in patients with type-2 diabetes from minority ethnic groups have been identified. These are family relationships, traditional belief regarding diet, social stigma and discrimination, and the level of acculturation. However, these four factors may have different influence on self-management in different social and cultural contexts. Furthermore most of the reviewed studies were conducted in the United States. The findings from the reviewed studies therefore may not be directly transferred to other countries such as the UK and China due to the different social and cultural context and health care systems. There is a need therefore for studies regarding the influences of Chinese culture on self-management among Chinese patients with type-2 diabetes and their family carers in the UK and China. In addition many of the reviewed studies advocated the need for culturally appropriate diabetes education to help patients from minority ethnic groups overcome cultural barriers to self-management. Thus, the effectiveness of culturally appropriate diabetes education in improving these patients' self-management is discussed in the next section.

2.3.2 Culturally appropriate diabetes education

Compared with patients with type-2 diabetes from the general population, patients and their family carers from minority ethnic groups living in developed countries experienced greater challenges during the conduct of self-management, which are related to their busy immigration life, language barriers, often low socioeconomic status, and cultural differences (Abate & Chandalia, 2003; Fischbacher *et al.*, 2009). As mentioned in the previous section, cultural traditions have a significant impact on self-management among patients with type-2 diabetes and their family carers in minority ethnic groups. Therefore, culturally appropriate diabetes education is advocated in order to help these patients conduct effective self-management (Nazroo, 1997).

This section provides a review of studies regarding the effectiveness of culturally appropriate diabetes education on self-management of patients from minority ethnic groups. Most studies were conducted in the United States America. Two studies were carried out in the UK. The minority ethnic groups studied included Chinese Americans, African Americans, Mexican Americans, South Asians in the UK, and Koreans in the USA. No studies were identified which had evaluated culturally appropriate diabetes education for Chinese patients in the UK.

The majority of studies were randomised controlled trials, with two studies using a one group pre/posttest quasi-experimental study (D'Eramo-Melkus *et al.*, 2004; Sun *et al.*, 2012). A wide range of sample sizes from 20 to 1486 was presented in the reviewed studies. Two studies only included female participants (D'Eramo-Melkus *et al.*, 2004; Keyserling *et al.*, 2002).The duration of interventions varied from a single session to 24 months. Interventions consisted of individual or group sessions, or a combination of both. Health care professionals delivering interventions included nurses, dieticians (nutritionists), diabetes educators, and podiatrists. Five studies used lay community health workers (CHWs), either for delivering education or in a supportive role (Bellary *et al.*, 2008; Brown *et al.*, 2002; Keyserling *et al.*, 2002; Rothschild *et al.*, 2014; Vincent, 2009). A control group was established in each of the trials and most participants in control groups were provided with usual care only. One study gave control groups the same treatment protocols as the intervention group, but not the extra resources (Bellary *et al.*, 2008). Length of follow-up ranged from 8 weeks to 24 months. Outcome measures included HbA1c as a measure of glycaemic control in six studies (Bellary *et al.*, 2008; Brown, *et al.*, 2002; D'Eramo Melkus *et al.*, 2004; Kim *et al.*, 2009; Rothschild *et al.*, 2014; Sun *et al.*, 2012), whilst Brown *et al.* (2002) and Baradaran, *et al.* (2006) recorded participants' diabetes knowledge score. Moreover Keyserling *et al.* (2002) and Rothschild *et al.* (2014) specifically evaluated the change of physical activity after interventions.

In terms of culturally appropriate interventions used in these reviewed studies, bilingual nurses, dieticians, diabetes educators, and CHWs were used in four studies (Brown *et al.*, 2002; Kim *et al.*, 2009; Sun *et al.*, 2012; Vincent, 2009). In Brown *et al*'s (2002) and Kim *et al.*'s (2009) study bilingual nurses, dieticians, and community workers were used to deliver an intensive and structured diabetes education programme. In addition, the bilingual CHWs' main responsibility was to deliver behavioural self-management training in Rothschild *et al*'s (2014) study. Additionally the interventions were culturally tailored by incorporating participants' traditional dietary preferences and recipes into dietary recommendations in five studies (Baradaran *et al.*, 2006; Brown *et* *al.*, 2002; D'Eramo Melkus *et al.*, 2004; Keyserling *et al.*, 2002; Vincent, 2009). Due to the importance of family in many cultures, participants were encouraged to bring a family member as a support person in two studies (Brown *et al.*, 2002; Vincent, 2009).

All the reviewed studies reported positive effects of culturally tailored diabetes education sessions on blood glucose control and self-management of type-2 diabetes. Six studies reported participants' level of blood glucose reduced significantly after attending culturally appropriate diabetes education (Bellary *et al.*, 2008; Brown *et al.*, 2002; D'Eramo Melkus *et al.*, 2004; Kim *et al.*, 2009; Rothschild *et al.*, 2014; Sun *et al.*, 2012). Two studies reported participants' increased awareness of type-2 diabetes and diabetes knowledge score after culturally appropriate diabetes education (Baradaran *et al.*, 2006; Brown *et al.*, 2002). In addition, the findings from two studies demonstrated that culturally tailored diabetes education promoted significantly participants' self-management especially in terms of physical activity (Keyserling *et al.*, 2002; Rothschild *et al.*, 2014).

Through completing this review of the effects of culturally tailored diabetes education sessions, the positive effects of culturally tailored diabetes education sessions on blood glucose control and self-management were identified. In addition three key aspects of culturally tailored diabetes education sessions including providing language support, incorporating traditional dietary preference into recommendations, and encouraging family involvement in self-management were also identified. However, no studies evaluating the effects of culturally tailored diabetes education on Chinese patients with type-2 diabetes in UK and Wales were obtained and evaluated in this review, and the majority of reviewed studies were conducted in the United States. Therefore, it may be difficult to directly apply the findings from these reviewed studies conducted in the United States to other countries such as the UK and China due to the different cultural and social context and health care systems. Therefore there is a shortfall in the literature and research is needed focusing on evaluating diabetes education for Chinese patients in the UK. Apart from culturally appropriate diabetes education, many of the reviewed studies also found that the level of health literacy of patients had an indirect influence on self-management of type-2 diabetes, which is now discussed.

2.3.3 Health literacy

This section provides a review of studies which evaluated the influence of level of health literacy of patients from minority ethnic groups on their type-2 diabetes and self-management. Most of the studies used quantitative approach, including cross-sectional study (Leung *et al.*, 2014b; Schillinger *et al.*, 2002), pilot study (Piatt *et al.*, 2014), and randomised controlled trial (Thabit *et al.*, 2009). In addition, ethnographic approach was used in two qualitative studies (Leung *et al.*, 2014a; Shaw *et al.*, 2012). Leung *et al.* (2014a, 2014b) assessed the health literacy on type-2 diabetes and self-management among Chinese American patients and Chinese patients in Hong Kong. Piatt *et al.*'s, (2014) and Schillinger *et al.*'s (2002) study evaluated the effect of health literacy on Spanish-speaking American patients' and African American patients' self-management, respectively. Thabit *et al.* (2009) and Shaw *et al.*, (2012) conducted their study among the patients from diverse minority ethnic groups such as Asian, African American, and Latino American.

Piatt *et al.* (2014) conducted a pilot study with 70 African American people with diabetes in order to examine the levels of functional health literacy among insulin-taking African Americans patients and to explore possible associations between functional health literacy levels and glycaemic control in the United States. The Newest Vital Sign (NVS) (Weiss *et al.*, 2005) was used to measure the level of functional health literacy. Self-reported demographic and diabetes background variables included age, gender, ethnicity, education and income level, insurance status, and type of diabetes were collected. HbA_{1c} was used to evaluate glycaemic control. The findings demonstrated that there were marginal associations between participants' demographic characteristics (e.g. gender, age, and retirement status) and the level of functional health literacy. 29.6% of male participants had a high likelihood of limited health literacy compared to 15.2% of females ($p=0.24$). Additionally there was a significant, positive, inverse association between age and the level of functional health literacy with older age being significantly associated with lower NVS scores ($r = -0.31$, $p= 0.01$). Largely a function of age, the same pattern was observed for retired participants. 29.6% of retired participants had a high likelihood of limited health literacy compared to 7.7% participants who were either employed fully or part time ($p=0.07$). Additionally inverse associations of the level of functional health literacy and glycaemic control were found in this study. Patients with a poor glycaemic control ($HbA_{1c}>8\%$) were 6.2 times (95%

CI, 1.4-28.3) more likely to have a high likelihood of limited functional health literacy than those patients who controlled the level of blood glucose well (HbA_{1c} <8%). This study determined patients' characteristics including age, gender, and retirement status were associated with low levels of health literacy and demonstrated an important relationship between health literacy levels and glycaemic control among African American patients with diabetes. However, a key limitation is the small sample size, which may limit the validity of the findings. In addition this study failed to establish causality of health literacy levels and glycaemic control due to the limitations of cross-sectional design. Similar findings were obtained among Spanish speaking American patients.

Schillinger *et al.* (2002) conducted cross-sectional observational study among patients with type-2 diabetes living in the United States which included 408 English and Spanish speaking patients aged more than 30 years in order to examine the relationship between health literacy and glycaemic control. The short-form test of functional health literacy in adults (S-TOFHLA) was used to assess the participants' health literacy. In addition, HbA_{1c} and self-reported diabetes complications were measured as outcomes of glycaemic control. This study identified health literacy as an independent factor affecting glycaemic control (HbA_{1c}) after adjustment for age, ethnicity, sex, education level, language proficiency, and social support. The findings demonstrated that patients with inadequate health literacy were less likely than patients with adequate health literacy to achieve optimum glycaemic control (adjusted OR, 0.57, 95% CI, 0.32-1.00, p=0.05), and were more likely than patients with adequate health literacy to have poor control (adjusted OR, 2.03, 95% CI, 1.11-3.73, p=0.02). Additionally this study also illustrated a significant relationship between health literacy and self-reported retinopathy related to type-2 diabetes, namely patients with inadequate health literacy were more likely to report the development of retinopathy (adjusted OR, 2.33, 95% CI, 1.19-4.57, p=0.01). However, the participants in this study were ethnically diverse, had low income levels and educational attainment, and were predominantly uninsured. Therefore, the relationships between participants' socioeconomic status and their level of health literacy were not established. In addition it is also difficult to generalise the findings of this study to a broader population. This study also failed to establish causal correlation between inadequate health literacy and poor glycaemic control due to the limitations of its cross-sectional design. In addition this study did not explicate mechanisms whereby low health literacy may result in worse glycaemic control as health literacy was only a marker for other factors affecting glycaemic control such as health care-seeking behaviours, psychological states and even cultural influences. However, this study provided a possible explanation for that, namely the poor health literacy may hinder the patients from gaining information on diabetes and its management by engaging in effective communication with health care providers. The indirect impact of health literacy on self-management of type-2 diabetes has been supported by the results in Leung *et al.*'s study (2014b).

Leung *et al.* (2014b) conducted a cross-sectional study with 137 Chinese patients with type-2 diabetes aged more than 65 years in Hong Kong in order to explore the relationships between health literacy, diabetes knowledge, health consultation, and self-management. Participants' level of health literacy was measured using the 34-item Chinese Health Literacy Scale for Diabetes (Leung *et al.*, 2013). Diabetes knowledge was measured using the 15-item Diabetes Knowledge Scale (Chan & Molassiotis, 1999). Perceived capacity for communication between patients and providers and self-management were also measured as latent variables. The study indicated that health literacy was not directly related to diabetes self-management; however health literacy had a direct effect on perceived communication capacity ($r=0.229$, $p<0.05$), and perceived communication capacity had a direct effect on diabetes self-management ($r=0.574$, $p<0.01$). Thus, health literacy had an indirect effect on diabetes self-management through perceived health consultation capacity. In addition, this study also mentioned the influences of Chinese culture of respecting authority on health literacy through reducing mutual communication between Chinese patients and health care providers. Therefore, understanding the impact of health literacy on self-management of type-2 diabetes needs to be situated in a social and cultural context. The effects of culture including family support on self-management and health literacy among immigrant patients have been explored by Thabit and colleagues (2009).

Thabit *et al.* (2009) carried out a randomised controlled trial with 52 randomly selected non-Irish-national patients with type-2 diabetes (immigrant patients IM) and 48 randomly selected Irish or Caucasian patients (IR) in order to compare the profile of self-management and to evaluate their differences in health literacy in the two groups of patients in Ireland. Diabetes Care Profile and Rapid Estimate of Adult Literacy in

Medicine (REALM) were used to assess the differences in self-management of type-2 diabetes and health literacy, respectively in both cohorts of participants. In addition all participants' plasma glucose, glycosylated haemoglobin (HbA_{1c}), plasma total cholesterol including high-density lipoprotein (HDL) cholesterol and low-density lipoprotein (LDL) cholesterol and triglycerides were measured to evaluate glycaemic control. The results illustrated that compare with IR group, IM group presented a lower level of health literacy when assessed using REALM (52.7 vs. 61.4, $p= 0.01$) and had poorer glycaemic control (HbA_{1c} 8.0 ± 1.9 vs. $6.9 \pm 1.4\%$, $p< 0.005$). In the IM group, 53% could understand simple or familiar questions about their diabetes care and 65.9% could provide information on simple or familiar topics about their diabetes which was related to their level of English proficiency. In addition the findings showed that as compared with IR patients, family support was more important among IM group than performing self-monitoring of blood glucose (75% vs. 47.7%, $p<0.05$), taking medications (81.7% vs. 42.2%, $p=0.01$) and following an appropriate meal plan (87.6% vs. 62.2%, $p<0.05$). However, this study failed to establish a correction of culture, health literacy, and self-management of type-2 diabetes, and it did not explicate how family support impacted on health literacy and the practice of self-management among immigrant patients with type-2 diabetes, which may be achieved through an emic approach with the integration of qualitative research instruments.

A ethnographic study using six focus groups and two individual interviews with 29 Chinese American people aged more than 45 years and diagnosed with type-2 diabetes for at least one year was conducted by Leung *et al.* (2014a) to explore the reasons why first-generation Chinese American people with type-2 diabetes encountered difficulty in obtaining, processing and understanding health information and communicating with others about their needs and preferences. Twenty-seven participants with type-2 diabetes were assigned to six focus groups with two to seven participants in each group, and two participants completed individual interviews due to their limited availability. This study identified eight themes which were found to potentially affect different components of health literacy among Chinese American people with type-2 diabetes. The eight themes can be categorised into cultural factors (three themes), structural barriers (three themes), and personal barriers (two themes). Three cultural factors, encompassed the high regard for authority, a desire to avoid being burdensome to others, and a desire to be together or follow a collective approach. Structural barriers included insurance, transportation issues and limited information in Chinese-speaking communities. Personal factors, included unawareness of self-care responsibility and age related limitations. The findings highlighted the cultural influences on health literacy and self-management through affecting patients' capacity to obtain, process, and understand diabetes related knowledge and health consultation. However, this study had some limitation related to its methodology. The majority of the samples were older, low income, and uncovered by health insurance, which may restrict the generalisation of the findings to all Chinese American people with type-2 diabetes, and the proportion of male participants in this study was much higher than female participants (62% vs 38%, respectively), which may reduce internal validity of the findings. Moreover, this study failed to determine how cultural belief impacted on health literacy as participants' level of health literacy was not evaluated. A final limitation was that this study specifically investigated Chinese culture in Chinese American people, thus it may be difficult to apply the findings of this study to other cultural contexts.

Another qualitative study adopting ethnographic approach among 296 patients with a variety of chronic conditions from four minority ethnic groups including Vietnamese, African American, White, and Latino was conducted by Shaw *et al.* (2012). The short-form test of functional health literacy in adults (S-TOFHLA) was used to measure participants' level of health literacy and S-TOFHLA was translated into Spanish and Vietnamese to matched participants' language of choice. Multiple data collection methods, including focus groups (n=47), in-depth interview (n=34), review of chronic disease diaries (n=15) were used to explore participants' understandings and experiences of living with their condition. The findings indicated that participants provided a wide range of understanding and interpretation of health literacy and self-management according to their own illness and health care experiences in a social and cultural context. In order to make response to participants' explanations for their health behaviours which were situated in a social and cultural context, health literacy could be reconceptualised as a socially and culturally influenced capacity. Therefore this study stressed health literacy and self-management were sensitive to social and cultural contexts. However, the Vietnamese translation of S-TOFHLA used in this study had been neither normed nor verified, which could impact on the evaluation of the level of health literacy among the Vietnamese participants. Therefore, their experiences also implied that the translation of health literacy instruments needs to be validated and adequate for evaluating the level of health literacy among minority ethnic groups.

After reviewing the literature, it is clear that health literacy has an indirect impact on self-management of type-2 diabetes among minority ethnic patients. The capacity for effective communication with health care providers and obtaining and understanding diabetes related knowledge play the role of mediator in the relationship between health literacy and self-management of type-2 diabetes. Furthermore, health literacy and self-management can be conceptualised as a socially and culturally influenced capacity. Therefore, the understanding of health literacy and self-management and their relationship needs to be situated in a social and cultural context. Social support has been identified as another key factor influencing self-management of type-2 diabetes among patients from minority ethnic groups, which is now discussed.

2.3.4 Social support

Previous studies have shown that the level of social support was closely associated with self-management among patients with type-2 diabetes (Gallant, 2003; Rosland *et al.*, 2008). The International Diabetes Federation (IDF) (2005) also supported that the lack of social support may result in a poor adherence to self-management and prescribed medical treatments in patients living with type-2 diabetes. There is therefore a consensus related to positive relations between social support and the conduct of self-management among patients with type-2 diabetes. Nevertheless it is still unclear if social support influences self-management in patients with type-2 diabetes from minority ethnic groups. 19 studies related to the impacts of social support on self-management among minority ethnic-patients were reviewed. Different types of social support were identified, including family support, peer support, and community health worker support. Firstly, family support is discussed in the next section.

2.3.4.1 Family support

A mix of quantitative (Kang *et al.*, 2010; Watanabe *et al.*, 2010; Wen *et al.*, 2004) and qualitative studies (Chesla *et al.*, 2009; Chesla & Chun, 2005; Jones *et al.*, 2008; Majeed-Ariss *et al.*, 2015) were identified and reviewed which explored the influences of family support on glycaemic control and self-management among minority ethnic-patients with type-2 diabetes. The key role of family support in the improvement of diabetes-related knowledge, dietary management, and psychological support was identified.

Kang *et al.* (2010) carried out a randomised controlled trial with 67 Chinese patients with type-2 diabetes with a mean age of 54.5 years, who presented with an unsatisfied glycaemic control ($HbA_{1C} > 7\%$) in the previous 12 months in Taiwan. The 67 participants were randomly assigned to the family partnership intervention care (FPIC) group and to the conventional care (CC) group. FPIC was defined as an intervention emphasising family participation and support, with a goal of assisting patients with poorly controlled type-2 diabetes to gain the knowledge and necessary skills to enhance their self-management and to improve glycaemic control. This intervention was only administered to the FPIC group and consisted of three brief individual educational sessions (IES), 2-day long group educational sessions (GES), and a monthly 25–30 minute telephone discussion. Moreover, all patients and family members also received diabetes handouts about diet, medication, physical activity and exercise, and eye and foot self-care. The patients in the conventional care (CC) group, without their family members, received regular care and monitored their glucose control during outpatient visits at the study hospital. 56 participants completed the study (attrition rate=16%). Baseline and 6-month follow-up scores were compared using the following outcome measures: (1) HbA_{1C}; (2) body mass index (BMI); (3) blood lipid profile; (4) family supportive behaviours; (5) knowledge of and attitudes toward diabetes; and (6) diabetes self-management behaviours. The findings demonstrated that there were no significant differences in the reduction of HbA_{1C} levels ($p=0.46$), blood lipid profile values ($p>0.05$), and improvement of diabetes self-management behaviours ($p=0.61$) between the groups at 6 months post-intervention. However, there were significant differences in the scores of family supportive behaviours ($p=0.031$) and patients' knowledge of and attitudes toward diabetes between the groups ($p<0.05$). Therefore, family support did not have a direct effect on glycaemic control but it contributed to the practice of self-management through improving family supportive behaviours and patients' knowledge of and attitudes toward type-2 diabetes. The main limitations of this study were related to its methodology, including small sample size, attrition rate of 16%, and follow-up of 6 months. In addition, socioeconomic information of the participants were not collected, which may lead to a bias for the internal validity if two study groups had a large differences in terms of these variables. Although this study failed to establish statistically a relation of family support and self-management of type-2 diabetes, its findings contributed to understanding the positive role of family support in obtaining diabetes-related information and improving level of knowledge among patients with type-2 diabetes. Moreover, the positive role of family support in dietary management of minority ethnic-patients was also verified by Wen and colleagues (2004).

Wen *et al.* (2004) conducted a cross-sectional survey with 138 older Hispanic people with type-2 diabetes at least for one year (mean age =64.1 years), living in a family environment in order to evaluate the role of family member in overcoming barriers to dietary management. In the course of the survey, the patients reported their perception of family functioning, family support for diet, and barriers to dietary self-care. The results showed that the level of family functioning was related to family support for dietary self-care, and family support for diet was related to perceived barriers to dietary self-care. Scores for family support were higher for those who perceived their family as functional compared to those who perceived their family as mildly dysfunctional or dysfunctional. As family support for diet increased, perceived barriers to dietary self-care decreased. Nevertheless, this study failed to establish a causality of family support and dietary self-care due to the limitation of a cross-sectional design. In addition, the family interactions, family support for diet, and barriers to dietary self-care were self-reported by participants so participants' attitude toward their family and condition may impact on the results of this study. The participants in this study were recruited among older people living with their family, which may limit generalisability of the findings.

Similar work was conducted by Watanabe and colleagues (2010) in Japan. However, their findings verified a significant relationship between family nutritional support and glycaemic control. Watanabe *et al.* (2010) conducted a cross-sectional study with 112 Japanese out-patients with type 2 diabetes in order to investigate the role of family support in glycaemic control by investigating nutritional self-care behaviour. All the participants were Japanese, predominantly male (60.7%), older aged (mean age 62.9 ±1.1 years), and had an average of 11.5 ± 0.8 years duration of type-2 diabetes. The survey was performed using the questionnaire designed for evaluation of the effects of Japanese family environment on out-patient diet therapy and glycaemic control. The questionnaire items assessed family diabetes enrolment, self-perception of diabetes nutritional management, frequency and kind of family support, and emotional response to the support. Moreover, HbA_{1c}, total cholesterol, triglyceride levels, and BMI were measured to evaluate the metabolic control of type-2 diabetes. The findings showed that family nutritional support was significantly related to HbA_{1c} levels. However, the relationship between family nutritional support and glycaemic control were affected by some factors such as age, gender, and the types of nutritional support. Family nutritional support showed a significant effect on level of HbA_{1c} among participants under 60 years old but in participants over 60 years of age, family support had little effect on HbA_{1c}. While most male participants had family nutritional support, significantly fewer female patients did. Additionally in male participants who were supported with cooking or buying light meals showed significantly lower HbA1c than those who were supported only by advice or encouragement. Therefore the findings of this study suggested that family support and glycaemic control may be profoundly related to culture and lifestyle. However, multiple dimensions of culture also may impede the roles and functions of the family and impact on patients' self-management behaviours.

Majeed-Ariss and colleagues (2015) conducted an explorative ethnographic study using face-to-face semi-structured interviews with 15 British-Pakistani women with type-2 diabetes to explore the effects of type-2 diabetes on British-Pakistani women's identity and its relationship with self-management and found that maintaining a traditional family role of supporting the family was a prominent barrier to conducting self-management of type-2 diabetes among British-Pakistani women. Similar findings were obtained among Chinese American patients with type-2 diabetes. Chesla *et al.* (2009) carried out an study with 20 Chinese American couples (n=40) living with type-2 diabetes in order to explore cultural and family challenges to self-management and found that self-management requirements such as diet modification changed Chinese traditional family role and responsibilities, which may trigger family conflicts and impede the conduct of self-management in Chinese American families living with type-2 diabetes. Another study regarding the influence of family on self-management of type-2 diabetes among Chinese American was conducted by Chesla and Chun (2005). They explored familial processes of response to type-2 diabetes with 20 Chinese Americans adopting interpretive phenomenology and found that longstanding family arguments and confrontations regarding type-2 diabetes and its management may reduce the abilities of Chinese Americans with type-2 diabetes to maintain their daily self-care behaviours and quality of life and to have adequate glycaemic control.

Jones *et al.* (2008) also carried out a ethnographic study with 21 African Americans with type-2 diabetes to examine the impact of family and friends on the management of type-2 diabetes among African American patients and found that African American patients with type-2 diabetes considered themselves as a burden to their family and had difficulty in maintaining good blood glucose levels when their family members had limited understandings of type-2 diabetes. With these inconsistent findings, it is clear that the effects of family interventions on self-management of type-2 diabetes and glycaemic control need to be situated in a social and cultural context to aid understanding. There is evidence to suggest that a culturally competent family support programme may help African Americans with type-2 diabetes and their family carers to overcome family challenges to self-management and glycaemic control. The main limitations of this study were related to a relatively small sample size (n=21) and more female participants (76.2%). Besides family support, support from peers was also identified as a factor influencing self-management, which is discussed next.

2.3.4.2 Peer support

In this section, findings are reported from four studies (Haltiwanger & Brutus, 2011; Long *et al.*, 2012; Philis-Tsimikas *et al.*, 2011; Smith *et al.*, 2011) and one systematic review (Simmons *et al.*, 2010) which explored the effectiveness of peer support in glycaemic control and self-management of type-2 diabetes among minority ethnic-patients living with type-2 diabetes.

Haltiwanger and Brutus (2011) carried out a pilot study using a combination of qualitative and quantitative methods with 42 older Mexican Americans type-2 diabetes aged from 60 to 85 years in order to determine the effectiveness of a peer-led diabetes support group intervention on the improvement of adherence to recommendations for type-2 diabetes self-management. Six participants withdrew from the study due to personal issues. The peer mentors recruited in the study were Mexican American patients with type-2 diabetes aged over 60 years, who had a good glycaemic control ($HbA_{1c}<8\%$) and followed dietary recommendations, exercised regularly, and tested blood glucose daily. There were three intervention groups, including one sustaining group composed of bilingual speakers who were led by two experienced peer mentors and two Spanish-speaking groups led by one experienced mentor and one novice mentor, and one control group of usual care. These three intervention groups used the

Bridges Diabetes Support Group Manual (BDSGM) and followed the programme structure outlined by the workbook. (The BDSGM was a workbook that guided group discussions with questions to be answered that triggered self-appraisal on topics important to developing adherence such as support, spirituality, health care beliefs, values, personal goals, stages of adjustment to the condition, assertiveness issues and mentoring others). Firstly, in terms of analysis the three intervention groups that all experienced a common intervention were considered as one group (n = 32) and compared with the control group (n = 10). After the 10-week intervention, compared to control group, the participants in the intervention groups displayed statistically significant improvements in blood glucose, self-efficacy, transformational change and personal resources. In addition, the levels of HbA_{1c} were compared between the three intervention groups. The levels of HbA_{1c} in the sustaining group were very significantly improved compared to the other two groups. Moreover, 60% of participants in the intervention groups showed an increased adherent behaviour through reviewing group logs. Secondly, qualitative data were obtained from audio-recordings of weekly group discussions in the three intervention groups for ten weeks. Each meeting was treated as a focus group that used semi-structured questions from the BDSGM. Qualitative themes were derived from the focus group meetings, including do not trust the system, choice + control = power, and the social cost of diabetes. The quantitative results suggested peer mentors were found to be effective in modelling and encouraging patients' behavioural changes, and the BDSGM intervention had a significant effect on glycaemic control and self-efficacy. The qualitative themes showed structural barriers such as lack of health care and mistrust of health professionals and social stigma and discrimination to type-2 diabetes, which may reduce Mexican American patients' willingness to conduct and adhere to self-management. The study was limited by a small sample size and a small control group. In addition, the discussions in the control group were not analysed using a qualitative approach. However, similar study was conducted in Mexican American people with type-2 diabetes by Philis-Tsimikas *et al.* (2011).

Philis-Tsimikas *et al.* (2011) also conducted a randomised controlled trial with 207 low income Mexican American people with type-2 diabetes with HbA_{1c} >8% in order to evaluate the effect of a culturally sensitive diabetes education programme in which a low-cost, peer-educator format (Project Dulce) was used as an educator on blood glucose control and metabolic parameters. The Project Dulce programme was delivered in the participants' and peer educators' native language (i.e., Spanish) and covered the basics of diabetes and its complications, diet, exercise, medication, blood glucose monitoring, and cultural beliefs that interfere with optimum self-management [e.g., fear of using insulin, fear of testing urine for sugar or eating nopales (Mexican prickly pear cactus used as a cure)]. Classes were interactive, providing opportunities for patients to discuss personal experiences and to convey support and advice to other group members. The programme focused on the standards of care established by the American Diabetes Association to achieve improvements in HbA_{1c}, blood pressure, lipids, and self-management behaviours. After the Project Dulce education programme, the intervention group exhibited significant improvements from baseline to four months in absolute levels of HbA_{1c} (−1.7%, P = 0.001) and HDL cholesterol (+1.4 mg/dL, P = 0.01) and from baseline to 10 months in absolute levels of HbA1c (−1.5%, P = 0.01), total cholesterol (−7.2 mg/dL, P = 0.04), HDL cholesterol (+1.6 mg/dL, P = 0.01), and LDL cholesterol (−8.1 mg/dL, P = 0.02), compared with the control group in which standard diabetes care was provided. The findings demonstrated that the Project Dulce model of culturally sensitive, peer-led education had a significant effect on glucose and metabolic control, and it was a low-cost and effective approach to self-management education for Mexican American people with type-2 diabetes. Apart from among Mexican American people with type-2 diabetes, the effectiveness of peer support on glycaemic control was also verified among African American patients by Long *et al.* (2012).

Long *et al.* (2012) conducted a 6-month randomised controlled trial with 118 African American veterans with type-2 diabetes (male participants=110) aged from 50 to 70 years with persistently poor blood glucose control in order to evaluate the effectiveness of mentors and financial incentives on improving glycaemic control among African American veterans. The 118 patients were randomly assigned to one of three groups: usual care, a peer mentoring group, and a financial incentives group. The participants in the peer mentoring group were matched to a peer mentor by sex and age. The peer mentors were all African American patients whose glucose control had previously been poor but currently was good. Peer mentors participated in an hour-long, one-on-one training session consisting of an interview, open-ended questions, goal setting, follow-up, and the assessment of progress, and they also were encouraged to share their experiences of diabetes management with the participants. Study participants randomly assigned to the financial incentive group were told that they could earn $100 at six months if their HbA_{1c} level decreased by 1% and $200 if it decreased by 2% or to 6.5% (HbA_{1c} level). The findings from the study showed that by the sixth month, the levels of HbA1c decreased from 9.9% to 9.8% in the control group, from 9.8% to 8.7% in the peer mentor group, and from 9.5% to 9.1% in the financial incentives group. Mean change in HbA1c level from baseline to six months relative to control was -1.07% (95% CI,-1.84% to -0.31%) in the peer mentor group and -0.45% (95% CI,-1.23% to 0.32%) in the financial incentive group. The results suggest that peer mentorship is an effective approach to improve glucose control among African American veterans with diabetes. However, the study included only African American veterans and lasted only six months. Although the effectiveness of peer-support on glycaemic control has been corroborated among Mexican and African American patients, it was still unclear whether peer-support was effective for other minority ethnic patients on glycaemic control. Smith *et al.* (2011) concluded that peer support was not effective on glycaemic control when it targeted at all patients with type-2 diabetes after conducting a cluster randomised controlled trial in Ireland with 395 patients with type-2 diabetes and 29 peer supporters with type-2 diabetes.

In Smith *et al.*'s (2011) study, 395 patients were assigned to intervention group (n=192) and to control group (n=203), respectively. All practices introduced a standardised diabetes care system. The peer support intervention ran over a two year period and contained four elements: the recruitment and training of peer supporters, nine group meetings led by peer supporters in participant's own general practice, and a retention plan for the peer supporters. HbA_{1c}, cholesterol concentration, systolic blood pressure and a wellbeing score were used as main outcome measures. All practices and 85% of participants were followed up. At two-year follow-up, there were no significant differences in HbA1c (mean difference: −0.08%, 95% CI−0.35% to 0.18%), systolic blood pressure (-3.9mmHg, -8.9 to 1.1mmHg), total cholesterol concentration (-0.03 mmol/L, -0.28 to 0.22 mmol/L), or wellbeing scores (-0.7, -2.3 to 0.8) between the peer support and control group. Therefore, peer support in a structured diabetes education was not effective in improving biophysical and psychosocial outcomes for all individuals with type-2 diabetes. The limitations of this study were related to its methodology such as inability to conceal allocation of the participants and lack of blinding of outcome data, which may impact on the internal validity of the findings.

Besides disputed effectiveness of peer-support, there were some barriers to conducting peer-support among patients, which was identified by Simmons *et al.* (2010).

Simmons *et al.* (2010) conducted a systematic review of diabetes peer support in New Zealand in order to review the different approaches to peer-to-peer support for people with, and at high risk of, type-2 diabetes in New Zealand. The systematic review was undertaken using all databases within the ISI Web of Knowledge using the keywords New Zealand, diabetes, 'peer support', 'self-help', 'support group', 'mutual support' or 'lay educator'. The literature review yielded 33 articles. Through analysing and evaluating the reviewed articles, the systematic review concluded that peer-to-peer support interventions had been widely used in New Zealand. However, a range of training, management, funding and organisational barriers existed in the implementation of these peer-to-peer support interventions.

In the main the evidence suggests that peer support has a positive effect on glycaemic control and self-management among minority ethnic-patients with type-2 diabetes, but its effectiveness is still controversial when it is conducted in a general practice setting for all patients with type-2 diabetes. Therefore, more attention needs to be given to widespread adoption of peer support in further studies. A further type of support identified in the literature as a factor influencing self-management of type-2 diabetes is that community health workers, which is discussed next

2.3.4.3 Support from community health workers

The effectiveness of support from community health workers (CHWs) on self-management of type-2 diabetes and education programme among minority ethnic-patients with type-2 diabetes was reported in five original studies (Gary *et al.*, 2004; Hawthorne & Tomlinson, 1997; Samuel-Hodge *et al.*, 2006; Spencer *et al.*, 2011; Two Feathers *et al.*, 2005) and two reviews (Hunt, *et al.*, 2011; Norris *et al.*, 2006). CHWs are defined as "community members who work almost exclusively in community settings and who serve as connectors between health care consumers and providers to promote health among groups that have traditionally lacked access to adequate health care" (Witmer *et al.*, 1995, p.1156). In addition in this review link workers used in some studies are characterised as community health workers.

Gary *et al.* (2004) conducted a randomised controlled trial with 542 urban African-Americans with type-2 diabetes with a mean age of 58 years in order to evaluate the effects of nurse case manager (NCM) and community health worker (CHW) team interventions on management of type-2 diabetes in urban African American patients. The participants were randomised to one of two intervention groups for a period of two years, namely usual medical care plus minimal telephone intervention implemented by a trained lay health educator (control group) or usual medical care plus intensive intervention implemented by a NCM/CHW team. The intensive NCM/CHW team delivered individual plans of care which focused on traditional diabetes self-management, screening and management of diabetes-related complications, and social issues surrounding diabetes care. Face-to-face NCM visits were conducted in the clinic once per year and CHW visits were conducted in the participant's home one to three times per year. The findings demonstrated that 80% of participants had at least one visit to an ophthalmologist and 85% of participants had a blood glucose self-monitoring machine to check their levels of blood glucose at home after NCM/CHW team interventions. Therefore support from NCM/CHW team was an effective and feasible approach to enhance self-management of type-2 diabetes in urban African-American patients. However, participants were 73% female and 72% participants were covered by capitated health insurance plans. Moreover, the majority of participants had a glucose self-monitoring machine to check their glucose at home (85%). These limitations on sample could impact on the internal validity of this study. Similar work has been conducted by Samuel-Hodge and colleagues (2006).

Samuel-Hodge *et al.* (2006) conducted a randomised controlled trial with 201 African Americans living with type-2 diabetes in 24 churches in North Carolina in order to evaluate the effectiveness of a culturally sensitive church-based intervention focused on improving a community resource to support self-management behaviours of type-2 diabetes and the community's health. 64% of the participants were women and on average, were aged 59 years, and had been diagnosed with type-2 diabetes for more than nine years. Baseline data included measures of weight, HbA_{1c}, blood pressure, physical activity, dietary and diabetes self-care practices, and psychosocial factors. Each church recruited patients with type-2 diabetes and designated a diabetes advisor, or peer counsellor, to be part of the intervention team. Participants were enrolled at each church and randomised as a unit to either the special intervention or the minimal intervention.

The special intervention included one individual counselling visit, twelve group sessions, three postcard messages from the participant's diabetes care provider, and twelve monthly telephone calls from a diabetes advisor. The minimal intervention involved a direct mailing to participants of two ADA pamphlets ("Healthy Eating" and "Staying Active") and three bimonthly newsletters that provided general health information and study updates. After 12 months, compared with the minimal intervention group, the participants in the special intervention had a significant improvement in HbA_{1c} and diabetes self-care practices including 85% of participants measured their blood glucose levels at home and about 75% did that once each day. The study concluded that a church-based diabetes self-management intervention program for African Americans with type-2 diabetes is effective and feasible.

Although there were some limitations related to their methodology such as slightly more female and younger participants in both of the studies, the two reviewed studies were good efforts to explore effective and feasible strategies to eliminate health disparities related to the need for culturally appropriate support and effective diabetes interventions which that address the individual's role in self-management and the community's role in supporting self-care. However, these two studies were conducted in the United States with African American patients. The findings of these studies may not be transferable to other social and cultural context especially to the Chinese cultural environment due to cultural differences. More studies are required to address the effectiveness of community based interventions involving community health workers.

Additionally several studies have evaluated the effectiveness of diabetes education performed exclusively by community health workers. Spencer *et al.* (2011) performed a randomised controlled trial with 164 African Americans and Latinos with type-2 diabetes in order to examine the effectiveness of a culturally tailored, behavioural theory-based diabetes education intervention performed by CHWs in the improvement of glycaemic control. The CHWs were recruited from the two participating communities, where they were ethnically matched with their assigned participants, underwent more than 80 hours of training, and conducted three primary activities, including diabetes education classes, two home visits of about 60 minutes each in length per month to address participants' specific self-management goals, and one clinic visit with the participant and his or her primary care provider during the intervention period of six months. The findings showed that the participants' mean level of HbA_{1c} was reduced from 8.6% at baseline to 7.8% at 6 month in the intervention group, and intervention participants also had significantly greater improvements in self-reported diabetes understanding compared with the control group. Therefore, the study confirmed the effectiveness of a diabetes education intervention conducted by CHWs on the improvement of diabetes self-management.

Two Feathers *et al.* (2005) conducted a non-randomised, one group, before and after design study with 151 African-American and Latino adults with type-2 diabetes in order to determine the effects of a community-based, culturally tailored diabetes education on diabetes complications delivered by trained community residents among African-American and Latino adults with type-2 diabetes. The diabetes education interventions provided knowledge and skills courses related to healthy eating, physical activity, and stress reduction through five 2-hour group meetings delivered every four weeks. The programme was delivered by trained community residents. The findings suggested that a culturally tailored, community-based healthy lifestyle intervention delivered by community residents over five sessions can significantly improve glycaemic control and reduce risk factors associated with diabetes complications. The unique feature of the study was that the intervention programme was delivered by trained community residents rather than health professionals so the recruitment, training, and retention of the community residents was a key aspect of the study, but these aspects failed to be reported upon clearly.

Specific challenges for patients with type-2 diabetes from minority ethnic groups such as language barriers and cultural differences, as well as low literacy have been shown to be threats to optimal management of type-2 diabetes (Molokhia & Oakeshott, 2000). Hawthorne and Tomlinson (1997) carried out a randomised controlled trial to explore how the effect of a structured one-to-one diabetes education programme using flashcards on the management of type-2 diabetes among 201 British Pakistanis. In this study, 76 of the 201 participants did not have a formal education background. Ten colour photographs were produced with the help of a dietician, link worker and professional photographer, enlarged to A3 size and laminated. Each was designed to cover one or more predetermined teaching objectives. Additionally a structured education package was conducted by the link worker. In the intervention group, the participants were shown the flashcards by the link worker, together with the structured education package. After six months, 192 subjects returned for follow-up. Compared with the control group, all parameters of knowledge were improved, for example, percentage scores for correctly identifying different food values increased from 57 % to 71%, and knowledge of one diabetic complication from 18% to 78 % in the intervention group. This study also has shown that pictorial flashcard education combined with a one-to-one teaching programme improved self-caring behaviours, with 92% of patients doing regular glucose tests at six months compared with 63% at the start. and HbA1c control by 0.34% (95% CI –0.8% to +0.1%). The biggest benefit of using flashcards was that these flashcards were easy to be understood and accepted by the participants. Flashcards could be an effective approach to deliver diabetes education among patients with a low literacy or language barrier. The findings of this study also suggested that besides traditional methods, novel and effective methods were necessarily required to help minority ethnic patients with type-2 diabetes overcome cultural and language barriers in the course of diabetes education.

Besides original studies, there are two reviews (Hunt *et al.*, 2011; Norris *et al.*, 2006) which focused on the effectiveness of CHWs in supporting the care of patients with type-2 diabetes. Norris *et al.* (2006) conducted a systematic review of 18 studies, including eight randomised controlled trials. Most reviewed studies focused on minority ethnic-patients in the USA which included African and Mexican Americans. The review identified various roles and responsibilities of CHWs in diabetes care from considerable participation in patient care to providing assistance with implementing education sessions taught by other health care professionals. Most participants in reviewed studies were satisfied with their contacts with community health workers. In terms of effectiveness of support from CHWs on management of diabetes, significant improvement in glycaemic control, levels of diabetes-related knowledge, and self-care practices were reported in a number of reviewed studies. In addition the review also identified a lack of information regarding the characteristics of CHWs was very common in the reviewed studies although all CHWs were recruited from their local community and were of the same ethnicity as the participants. Therefore the review pointed out that it was difficult to apply directly these reviewed studies' results to other settings and to broader populations so more research is needed to identify appropriate settings and optimal roles for CHWs in the care of people with type-2 diabetes. The review identified a variety of roles and duties of CHWs in effectively supporting of patient with diabetes management. However, it failed to explain the mechanism whereby the support of CHWs leads to positive effects of diabetes management and further research is needed with a wider range of ethnic minority groups outside of the United States.

Hunt *et al.* (2011) also conducted an integrative literature review to make an attempt to identify populations and settings served by community health advisors, which included 16 studies related to the effectiveness of support from community health advisors on self-management of type-2 diabetes. This review identified that community health advisors played multiple supportive roles including educator, care manager, advocate, and programme facilitator in diabetes education programme, health consultation, and peer support group on the basis of providing culturally competent diabetes care and resolution of health disparities among patients in minority ethnic groups. In addition, this review also identified that culturally appropriate diabetes intervention provided by community health advisors was effective in the improvement of the levels of diabetes-related knowledge, HbA_{1c}, level of blood lipid and blood pressure, and self-management behaviours among vulnerable and underserved patients with type-2 diabetes living in the community. However, this review failed to explain which people can be recruited and selected as community health advisors due to the characteristics of community health advisors being underreported in the most of the reviewed studies. In addition, it was difficult to identify a model of training that was available for all community health advisors in this review because of the use of a great variety of training strategies across reviewed studies, which was affected by the role expectations of community health advisors in diabetes interventions.

Overall, the positive effects of support from CHWs on glycaemic control and self-management of type-2 diabetes among minority ethnic patients with type-2 diabetes has been identified in the literatures. Nevertheless, some issues related to how to recruit, select and train CHWs need to be explored and discussed further in future research. Moreover, it is still unclear whether the findings of this review is available for a broader population and context as majority of reviewed studies in this section were conducted in the United States. Therefore more relevant research conducted among a broader population and outside the United States is required.

2.4 Overview of methodology of the reviewed studies

Through conducting a comprehensive search and review of the literature related to the factors influencing self-management of type-2 diabetes in patients from minority ethnic groups, 43 studies including 39 original studies and four literature reviews were identified. Four main factors affecting self-management of ethnic-patients with type-2 diabetes were identified, namely cultural traditions, culturally appropriate diabetes education, health literacy, and social support. The identification of the four factors demonstrates that the improvement of self-management of type-2 diabetes among minority ethnic patients requires comprehensive social support from family, peers, and the wider community and is sensitive to the social and cultural context in which self-management is conducted.

With respect to the methodology and quality of the 39 original studies reviewed, 13 used qualitative methods including ethnographic approach (nine), phenomenology (three), and grounded theory (one), and 26 used quantitative approaches such as cross-sectional study (six), randomised controlled trials (15), pilot study (one), and pre/posttest study (four). Most of data were collected from participants from diverse minority ethnic backgrounds including Chinese American, African American, Mexican American, Surinamese in the Netherlands, and Bangladesh in the UK. No studies were identified with Chinese patients with type-2 diabetes in the UK. Participants' understandings, feelings and past experiences in terms of self-management of type-2 diabetes were reported in the majority of reviewed qualitative studies. This is the main advantage of qualitative methods in studying self-management of type-2 diabetes compared with quantitative methods. However, the external validity of the findings from seven qualitative studies (Chesla & Chun, 2005; Chun & Chesla, 2004; Jones *et al.*, 2008; Liburd *et al.*, 2007; Majeed-Ariss *et al.*, 2015; Nam *et al.*, 2013; Sun *et al.*, 2012) might be affected due to a small sample size (n<25) although it is acknowledged that qualitative studies tend to have smaller sample sizes.

As previously stated, 26 studies used quantitative methods. Of the 15 randomised controlled trials, 12 studies stated their inclusion and exclusion criteria fully, only one study described the randomisation process and allocation concealment method adequately (Keyserling *et al.*, 2002). It was however impossible to blind participants to interventions in most of the reviewed randomised controlled trials due to the purpose of study. None of the reviewed quantitative studies however included an intention-to-treat analysis. The follow-up in most of the reviewed randomised controlled trials, cross-sectional surveys, and pre/posttest studies was less than one year so long-term effects of these studies remain unknown. 24 of the 26 reviewed quantitative studies reported follow up rates of which 23 studies had more than 80% follow up rates, but the attrition rate was nearly 33% in one study (Baradaran *et al.*, 2006), which may have affected the internal validity of this study.

In terms of the characteristics of the participants in the 39 reviewed original studies, most were aged over 35 years which reflect the age profile of type-2 diabetes, although children are now developing type-2 diabetes. Seven original studies and one literature review was related to Chinese Americans with type-2 diabetes. The majority of the studies in this review were conducted in the United States, with four studies conducted in the UK and one study in mainland China. The summary of reviewed studies is provided in **Table 1.**

It is acknowledged that most of the reviewed studies were conducted in the United States, therefore it may not be feasible to directly apply the findings from the reviewed studies conducted in the United States to other countries such as the UK and China due to the different social environment, financial situation, and health services systems. No study related to Chinese patients living in Wales or other places of the UK was found. Compared with Chinese patients living in China, those Chinese patients living in Wales may have different dietary habits, lifestyle, and health care, and their lifestyle and perception of their health and condition may be affected by migration. Therefore, there is a need to conduct a study to explore and evaluate whether these factors affecting self-management of type-2 diabetes identified in this review affect self-management of Chinese patients living in Wales and China, and explore whether there are new and specific factors which may influence Chinese patients' self-management.

2.5 Summary

In this chapter four factors influencing self-management of type-2 diabetes among patients from minority ethnic groups have been identified after reviewing 43 relevant studies. However, there is scarce literature that focused on Chinese patients' self-management in China and Wales. Therefore, I decided to conduct an exploratory study adopting an ethnographic approach to gain an understanding and perspectives of self-management among Chinese patients with type-2 diabetes living in China and Wales. First the methodology and methods used in my study is presented and discussed in the following chapter.

Table 1: Summary of reviewed studies

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Baradaran *et al.*, 2006	UK	RCT	299	To develop a culturally appropriate educational intervention programme for South Asians with Type 2 diabetes and then investigated the effect of this intervention could produce on their knowledge and attitudes towards type-2 diabetes and on practice of self-management.	South Asians	A culturally appropriate educational programme showed significant improvements in scores for Knowledge (+12.5%); attitudes toward seriousness (+13.5%), complications (+8.1%), practice of self-management (+20.0%) although there was no net benefit compared with the ethnic control group.	The effects of the translator on the non-English speaking participant's answers and subsequent knowledge were not explained clearly due to failure to assessing accuracy and validity of interpretation and translation process. Moreover, attrition rate was nearly 33%.
Bellary *et al.*, 2008	UK	RCT	1486	To investigate the effectiveness of a culturally sensitive, enhanced care package in general practices on improvement of risk factors in patients of south Asian origin with type 2 diabetes	South Asians	Compared with control group, a culturally sensitive, enhanced diabetes programme significantly contributed to improving participants' diastolic blood pressure (1. 91 [95% CI–2.88 to –0.94] mmHg, p=0.0001), mean arterial pressure (1.36 [–2.49 to –0.23] mmHg, p=0.018), and HbA1C (0.04% [–0.04 to 0.13]), p=0.29).	The main limitation of this study was to be unable to assess the relative contributions of individual components of the culturally sensitive, enhanced diabetes programme, which could affect the assessment of complex interventions.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Brown *et al.*, 2002	USA	RCT	256	To evaluate the effects of a culturally competent diabetes self-management intervention in Mexican Americans with type 2 diabetes	Mexican Americans	The finding demonstrated that the effectiveness of culturally competent diabetesself-management education on improving health outcomes of Mexican Americans, particularlyfor those individuals with poor glycaemic control (HbA1c levels>10%).	All participants of this study had few personal resources such as limited literacy, limited accessto health care providers, and having longstanding diabetes as well as longstanding lifestyle habits that negatively impact on their health.
Chesla & Chun, 2005	USA	Phenomenology	20	To explore and understand familial processes of response to type 2 diabetes in Chinese Americans	Chinese Americans	Unresolved family arguments and confrontations regarding type-2 diabetes and its management reduced the abilities to maintain their daily self-care behaviours and quality of life and to have adequate glycaemic control among Chinese Americans.	A small sample size.

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Chesla *et al.*, 2009	USA	Ethnography	40	To explore cultural and family challenges to management of type-2 diabetes in foreign-born Chinese American patients and their spouses	Chinese Americans	The findings demonstrated that diabetes symptoms impaired family harmony; dietary restrictions challenged food beliefs and practices, and diabetes management requirements changed established and traditional family role responsibilities within foreign-born Chinese American families.	Interviews were conducted only in Cantonese. Therefore, cultural variations beyond Cantonese speaking regions of Hong Kong and China were not represented. Moreover, a convenience sample was used in this study.
Chun & Chesla, 2004	USA	Phenomenology	20	To investigate cultural experiences and responses to type-2 diabetes among Chinese immigrant families in the United States.	Chinese Americans	This study illustrated five primary cultural factors influencing on diabetes management in Chinese immigrant families, including conceptualisation of diabetes, illness and health; significance and meaning of food; perceptions of Chinese and Western medicines; exercise and physical activity, and effects of the disease on family dynamics.	This study included a limited number of Chinese American couples, thus the cultural themes identified cannot completely represent the concerns that Chinese American couples might express. Moreover, group interviews were used in this study so there was a risk that some of the participants might have hidden certain types of information from other members in a group.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Chun *et al.*, 2011	USA	Phenomenology	40	To examine how acculturation affects type-2 diabetes management and perceived health for Chinese American immigrants.	Chinese Americans	This study identified three themes in participants' acculturation experiences including utilizing health care, maintaining family relations and roles, and establishing community ties and groundedness. The findings also showed that shifting family roles and evaluations of diabetes care and physical environment in the United States significantly affected diabetes management and health, but they were neglected in acculturation and health investigations. Moreover, the salience and impact of specific acculturation experiences respective to diabetes management and perceived health varied across participants due to individual, family, developmental, and environmental factors. In terms of salience, maintaining filial and interdependent family relations in the United States was of particular concern for older participants and coping with inadequate health insurance in the united States was especially distressing for self-described lower-middle to middle-class participants. In terms of impact, family separation and relocating to ethnically similar neighbourhoods in the United States differentially affected diabetes management and health due to participants' varied family relations and pre-migration family support levels and diverse cultural and linguistic backgrounds, respectively.	This study focused only on Cantonese speaking Chinese immigrants in the United States. Potential age-related differences in acculturation experiences were not fully explained in this study. Moreover, this study only included the patients and their spouses. Other family members such as parents, children, siblings and widowed or unmarried patients with type-2 diabetes were excluded.

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Deng *et al.*, 2013	Canada	Narrative review	Not mentioned	To explore acculturation and its effects on diabetes management in ethnic Chinese in North America	Chinese immigrants	Adapting to western diet, which contains a large amount of fat and calories might have a negative influence on the health status and diabetes management in Chinese patients as it might result in an elevated risk for persistent hyperglycaemia. Therefore, maintaining a low level of dietary acculturation may contribute to their diabetes management. However, a dependence on Chinese staple foods could be challenging to Chinese patients in western countries because these foods and recipes might not understood by western health care providers and educators.	Literature search strategy used, inclusion criteria, and the number of reviewed studies was not detailed in the review.
D'Eramo Melkus *et al.*, 2004	USA	pre/post-test quasi-experimental study	25	To develop and explore the effectiveness of a culturally competent intervention of education and care on black women with type-2 diabetes	Black women	The findings suggested that a culturally sensitive intervention of diabetes care and education was beneficial for black women with type-2 diabetes, resulting in program attendance, kept appointments, improved glycaemic control and weight, and decreased diabetes-related emotional distress.	There was absence of control group in this study due to the use of pre/post-test design. Moreover, this study only included black women with type-2 diabetes and they were a self-select group of volunteers who may represent black women with type-2 diabetes who would benefit the most from a self-management intervention of diabetes education and care.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Gary *et al.*, 2004	USA	RCT	542	To determine the effectiveness and cost-effectiveness of primary care and community-oriented interventions in managing type-2 diabetes among African-Americans.	African Americans	The findings demonstrated that 80% of participants had at least one visit to an ophthalmologist and 85% of participants had a blood glucose self-monitoring machine to check their levels of blood glucose at home after nurse case manager (NCM) and community health worker (CHW) team interventions. Therefore, support from NCM/CHW team was an effective and feasible approach to enhance self-management of type-2 diabetes in urban African-American patients.	Participants were 73% female and 72% participants were covered by capitated health insurance plans. Moreover, the majority of participants had a glucose self-monitoring machine to check their glucose at home (85%). These limitations on sample could impact on the internal validity of this study.
Haltiwanger & Brutus, 2011	USA	Pilot study	42	To determine the effectiveness of a peer-led diabetes support group intervention on the improvement of adherence to recommendations for type-2 diabetes self-management among Mexican Americans	Mexican Americans	The 10-week peer-led diabetes support programme was compared to usual care on five self-reported questionnaires and blood tests during four collection periods. Participants displayed statistically significant improvements in the levels of blood glucose, self-efficacy, transformational change and personal resources in peer-led diabetes support group. Qualitative themes were derived from 30 focus group meetings, including do not trust the system, choice + control = power, and the social cost of diabetes.	The study was limited by the small number of participants in a convenience sample and a small control group. The discussions in control group were not analysed using a qualitative approach such as thematic analysis.

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Hawthorne & Tomlinson, 1997	UK	RCT	201	To explore how the effect of a structured one-to-one diabetes education programme using flashcards on the management of type-2 diabetes among British Pakistanis	British Pakistanis	After six months of follow-up, compared with the control group, all parameters of knowledge were improved, for example, percentage scores for correctly identifying different food values increased from 57% to 71%, and knowledge of one diabetic complication from 18% to 78% in the intervention group. This study also has shown that pictorial flashcard education combined with a one-to-one teaching programme improved self-caring behaviours, with 92% of patients doing regular glucose tests at six months compared with 63% at the start and HbA1c control by 0.34% (95% CI –0.8% to +0.1%). This study demonstrated that the biggest benefit of using flashcards in diabetes education sessions was that these flashcards were easy to be understood and accepted by the participants.	One third participants had no understanding of English and 35% of participants had no formal education. Mean HbA1c level was 8.5% (95% CI 8.2–8.8%) among participants. Therefore, the findings might not be generalised to British Pakistanis with higher literacy and English proficiency levels and with good glycaemic control.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Hunt *et al.*, 2011	USA	Narrative review	16 (studies)	To identify roles of community health advisors (CHAs) and the effectiveness of interventions by CHAs on improving self-management of patients with type 2 diabetes	African Americans, Hispanics, Latinos, and Pacific Islanders	CHAs' theoretical interventions were based on providing culturally appropriate care and resolution of health disparities within minority populations. Typically CHAs were patients themselves living with type 2 diabetes. Identified major roles of CHAs included: supporter, educator, case manager, advocate, and program facilitator. Activities of CHAs were: coordinating educational programs, conducting educational courses for patients, serving as a link between patients and healthcare professionals, providing counselling, and leading peer support meetings. Moreover, the effectiveness of interventions by CHAs was mixed, including improvements in knowledge, HbA1C, levels of blood lipids and blood pressure, and physical activity	This review failed to explain which people can be recruited and selected as CHAs due to the characteristics of CHAs being underreported in the most of the reviewed studies. In addition, it was difficult to identify a model of training that was available for all CHAs in this review because of the use of a great variety of training strategies across reviewed studies, which was affected by the role expectations of CHAs in diabetes interventions.

Authors (year)	**Country**	**Type of research**	**Sample size**	**Aim of research**	**Ethnicity of participants**	**Major findings**	**Main limitations**
Jones *et al.*, 2008	USA	Ethnography	21	To examine the impact of family and friends on the management of persons with diabetes and their willingness to participate in a culturally tailored program among African Americans with type-2 diabetes	African Americans	The findings demonstrated that although family and friends may have been helpful at times, they also created moments of problems and an environment that made it more difficult to care for diabetes. Therefore, the effects of family interventions on self-management of type-2 diabetes and glycaemic control needed to be situated in a social and cultural context to aid understanding. The findings also suggested that a culturally competent family support programme may help African Americans with type-2 diabetes and their family carers to overcome family challenges to self-management and glycaemic control.	The main limitations of this study were related to small sample size and more female participants (76.2%).

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Kang *et al.*, 2010	Taiwan	RCT	67	To compare partnership intervention care (FPIC) with conventional care (CC) across a number of outcome measures in Chinese patients with poorly controlled type 2 diabetes.	Chinese	The findings demonstrated that there were no significant differences in the reduction of HbA1C levels (p=0.46), blood lipid profile values (p>0.05), and improvement of diabetes self-management behaviours (p=0.61) between FPIC and CC groups at 6 months post-intervention. However, there were significant differences in the scores of family supportive behaviours (p=0.031) and patients' knowledge of and attitudes toward diabetes between the groups (p<0.05). Therefore, family support did not have a direct effect on glycaemic control but it contributed to the practice of self-management through improving family supportive behaviours and patients' knowledge of and attitudes toward type-2 diabetes.	The main limitations of this study were related to its methodology, including small sample size, slightly high attrition rate of 16%, and short follow-up of 6 months. In addition, socioeconomic information of the participants were not collected, which might lead to a bias for the internal validity if two study groups had a large differences in terms of these variables

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Keyserling *et al.*, 2002	USA	RCT	200	To determine if a culturally appropriate clinic- and community-based intervention for African American women with type 2 diabetes will increase moderate-intensity physical activity (PA)	African Americans	200 African-American women were randomised to one of three treatment conditions: clinic and community (group A), clinic only (group B), or minimal intervention (group C). Totals of 175 (88%) and 167 (84%) participants completed PA assessment at 6 and 12 months, respectively. Comparing group A with C, the difference in the average adjusted mean for PA was 44.1 kcal/day (95% CI 13.1–75.1, P 0.0055). Comparing group B with C, the difference in the average adjusted mean was 33.1 kcal/day (95% CI 3.3– 62.8, P 0.029). Therefore, a culturally appropriate clinic- and community-based intervention was effective for the enhancement of PA among African American women with type-2 diabetes.	This study only included female African Americans with type-2 diabetes and had a high attrition rate of 12% and 16% at 6 and 12 months, respectively.
Kim *et al.*, 2009	USA	RCT	79	To assess the efficacy of a culturally tailored comprehensive type-2 diabetes management intervention for Korean Americans	Korean Americans	A culturally tailored comprehensive type 2 diabetes management intervention contributed to lowering HbA1C (<7%) and fasting glucose and to improving psychosocial outcomes among the participants	A relatively short follow up (30 weeks). Moreover, precise mechanism of the intervention, such as the complex interplay among psychobehavioural factors and physiological outcomes failed to be explained due to relatively small sample size (n=79).

Authors (year)	**Country**	**Type of research**	**Sample size**	**Aim of research**	**Ethnicity of participants**	**Major findings**	**Main limitations**
Kohinor *et al.*, 2011	Netherlands	Ground theory	32	To explore why Surinamese patients with type-2 diabetes either share or do not share their condition with people in their wider social networks in Netherlands.	Surinamese	Surinamese patients exposed their diabetes only to very close family members and most of them were not willing to expose their condition to people outside their family due to cultural taboo and fears of social stigma and discrimination unless they needed facilities and support for self-management of their diabetes.	The participants in this study were limited to first-generation Surinamese migrants and most of them were women (62%). Thus, they had lower to intermediate socioeconomic status. Moreover, this study focused only on Surinamese patients. Thus, the disclosure of diabetes was not verified through seeking information from people they knew.
Leung *et al.*, 2014a	USA	Ethnography	29	To explore the reasons why first-generation Chinese Americans with type-2 diabetes encountered difficulty in obtaining, processing and understanding health information and communicating with others about their needs and preferences	Chinese Americans	This study identified eight themes which were found to potentially affect different components of health literacy among Chinese American people with type-2 diabetes. The eight themes can be categorised into cultural factors (three themes), structural barriers (three themes), and personal barriers (two themes). Three cultural factors, encompassed the high regard for authority, a desire to avoid being burdensome to others, and a desire to be together or follow a collective approach. Structural barriers included insurance, transportation issues and limited information in Chinese-speaking communities. Personal factors, included unawareness of self-care responsibility and age related limitations.	The majority of the samples were older, low income, and uncovered by health insurance. The proportion of male participants was much higher than female participants (62% vs 38%, respectively). Moreover, participants' level of health literacy was not evaluated in this study.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Leung *et al.*, 2014b	Hong Kong	Cross-sectional study	137	To explore the relationships between health literacy, diabetes knowledge, health consultation, and self-management among Chinese patients.	Chinese	The findings illustrated that health literacy was not directly related to diabetes self-management; however health literacy had a direct effect on perceived communication capacity ($r=0.229$, $p<0.05$), and perceived communication capacity had a direct effect on diabetes self-management ($r=0.574$, $p<0.01$). Thus, health literacy had an indirect effect on diabetes self-management through perceived health consultation capacity. In addition, this study also showed the influences of Chinese culture of respecting authority on health literacy through reducing mutual communication between Chinese patients and health care providers.	The causational effect of health literacy, perceived communication capacity, and diabetes knowledge on diabetes self-care failed to be explained due to cross-sectional design used. Moreover, participants' levels of health literacy was measured by Chinese Health Literacy Scale for Diabetes, which may not be applicable to other cultures or contexts.
Liburd *et al.*, 2007	USA	Ethnography	16	To explore cultural influences of diabetes self-management amongst African American men with type-2 diabetes	African American	African-American male patients kept silent about their condition and never shared their experiences and feelings of managing their condition in order to maintain their masculinity. Moreover, the requirements of diabetes self-management often changed the traditional sex roles and learned behaviours of African-American men, and this can contribute to poor glycaemic control and adherence to medications. Therefore, gender identity was identified as a key cultural factor that impacted on health-related behaviours, including how African American men with type-2 diabetes engage with the health care services and management of their condition.	Small sample size and limited meanings of its findings which were associated only with the experiences of African American men with type-2 diabetes.

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Long *et al.*, 2012	USA	RCT	118	To evaluate the effectiveness of mentors and financial incentives on improving glycaemic control among African American veterans with type-2 diabetes.	African Americans	The findings from the study showed that by the sixth month, the levels of HbA1c decreased from 9.9% to 9.8% in the control group, from 9.8% to 8.7% in the peer mentor group, and from 9.5% to 9.1% in the financial incentives group. Mean change in HbA1c level from baseline to six months relative to control was -1.07% (95% CI,-1.84% to -0.31%) in the peer mentor group and -0.45% (95% CI,-1.23% to 0.32%) in the financial incentive group. The results suggested that peer mentorship was an effective approach to improve glucose control among African American veterans with type-2 diabetes.	The study included only African American veterans and lasted only six months. Most participants were male (n=110).
Majeed-Ariss *et al.*, 2015	UK	Ethnography	15	To explore the effects of type-2 diabetes on British-Pakistani women's identity and its relationship with self-management	British-Pakistani	Four themes emerged: Perceived change in self emphasised how British-Pakistani women underwent a conscious adaptation of identity following diagnosis; Familiarity with ill health reflected women's adjustment to their changed identity over time; Diagnosis improves social support enabled women to accept changes within themselves and Supporting family is a barrier to self-management demonstrated how family roles were an aspect of women's identities that was resilient to change. The over-arching theme Role re-alignment enables successful self-management encapsulated how self-management was a continuous process where achievements needed to be sustained.	Lack of a comparison group of majority population such as white British women. Furthermore, more than a third of participants were recruited from the same diabetes education class so these participants might be more highly motivated to self-manage than other patients because of their participation in diabetes education class.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Nam *et al.*, 2013	USA	Ethnography	23	To examine challenges in self-management of diabetes among Korean Americans.	Korean Americans	Most participants had limited knowledge about diabetes and its complications and they were reluctant to expose their condition to other people due to social stigma. Family obligations and financial stress due to their busy immigration life negatively impacted on their conduction of self-management. Women had to take more on responsibilities of feeding family due to the change of socioeconomic status after moving to the United States, which led to a change of traditional family relationships and role in Korean American families, which made them to be vulnerable to a lack of self-management. In addition, limited English proficiency also mentioned as barriers to access to mainstream health care among participants.	The use of a small convenience sample size limited the generalisability of findings. In addition, this study focused only on one single ethnic group in the United States.
Norris *et al.*, 2006	USA	Systematic review	18 (studies)	To examine the effectiveness of community health workers in supporting the care of people with diabetes	African Americans, British Pakistani, Hispanics, Latinos, and Zuni Indians	Eighteen studies were included, including eight RCTs. Most studies focused on minority ethnic populations in the United States. The roles and duties of community health workers (CWHs) in diabetes care were varied, ranging from substantial involvement in patient care to providing instrumental assistance in education sessions taught by other health professionals. Participants were generally satisfied with their contacts with CHWs and participant knowledge increased.	The applicability of these results to other settings and to broader populations was unclear.

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Philis-Tsimikas *et al.*, 2011	USA	RCT	207	To evaluate the effect of a culturally sensitive diabetes self-management education programme on glucose control and metabolic parameters Mexican Americans with type 2 diabetes	Mexican Americans	After education programme, the intervention group exhibited significant improvements from baseline to four months in absolute levels of HbA1c (−1.7%, P = 0.001) and HDL cholesterol (+1.4 mg/dL, P = 0.01) and from baseline to 10 months in absolute levels of HbA1c (−1.5%, P = 0.01), total cholesterol (−7.2 mg/dL, P = 0.04), HDL cholesterol (+1.6 mg/dL, P = 0.01), and LDL cholesterol (−8.1 mg/dL, P = 0.02), compared with the control group in which standard diabetes care was provided. The findings demonstrated that the culturally sensitive, peer-led education (Project Dulce model) had a significant effect on glucose and metabolic control, and it was a low-cost and effective approach to self-management education for Mexican American people with type-2 diabetes.	The majority of participants were low-income, obese, and middle aged Mexican American women, and they presented poor glycaemic control (HbA1c >10%). Moreover, the attrition rate was high at 25%, which may have affected the results of the analysis

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Piatt *et al.*, 2014	USA	Cross-sectional study	70	To explore possible associations between functional health literacy levels and glycaemic control among African Americans with type-2 diabetes	African Americans	The findings demonstrated that there were marginal associations between participants' demographic characteristics (e.g. gender, age, and retirement status) and the level of functional health literacy. 29.6% of male participants had a high likelihood of limited health literacy compared to 15.2% of females (p=0.24). Additionally there was a significant, positive, inverse association between age and the level of functional health literacy with older age being significantly associated with lower NVS scores (r = −0.31, p= 0.01). Largely a function of age, the same pattern was observed for retired participants. 29.6% of retired participants had a high likelihood of limited health literacy compared to 7.7% participants who were either employed fully or part time (p=0.07). Additionally inverse associations of the level of functional health literacy and glycaemic control were found in this study. Patients with a poor glycaemic control (HbA1c >8%) were 6.2 times (95% CI, 1.4-28.3) more likely to have a high likelihood of limited functional health literacy than those patients who controlled the level of blood glucose well (HbA1c <8%).	A small convenience sample was used. The demographic data were self-reported. Additionally, this study failed to establish causality of health literacy levels and glycaemic control due to the limitations of cross-sectional design.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Rothschild *et al*., 2014	USA	RCT	144	To assess if community health workers (CHWs) could contributed to improving glycaemic control among Mexican Americans with type-2 diabetes	Mexican Americans	Intervention participants illustrated significantly lower HbA1c levels than control participants at both year 1 ($D = -0.55$; $P = .021$) and year 2 ($D = -0.69$; $P = .005$). In addition, intervention participants increased physical activity from a mean of 1.63 days per week at baseline to 2.64 days per week after 2 years.	Failure to explain sustainability of benefits after the end of the intervention due to the limitations of study design.
Samuel-Hodge *et al*, 2000	USA	Ethnography	70	To identify if culturally relevant psychosocial issues and social context variables influencing lifestyle behaviours, specifically diet and physical activity among African American women with type-2 diabetes	African Americans	Three primary themes emerged from these focus groups. They were: 1) spirituality as an important factor in general health, disease adjustment, and coping; 2) general life stress and multi-caregiving responsibilities negatively impacted on daily disease management; and 3) the negative consequences of diabetes included dietary restriction, physical and emotional "tiredness," "worry" about complications due to diabetes.	This study only included female African Americans with type-2 diabetes. In addition, convenience sample was used to recruit participants.
Samuel-Hodge *et al*., 2006	USA	RCT	201	To evaluate the effectiveness of a culturally sensitive church-based intervention on improving a community resource to support self-management behaviours of type-2 diabetes and the community's health.	African Americans	After 12 months, compared with the minimal intervention group, the participants in the culturally sensitive intervention group had a significant improvement in HbA1c and diabetes self-care practices including 85% of participants measured their blood glucose levels at home and about 75% did that once each day.	Slightly more female (64%) and younger participants.

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Schillinger *et al.*, 2002	USA	Cross-sectional study	408	To examine the relationship between health literacy and glycaemic control among English- and Spanish-speaking patients with type-2 diabetes	Asians, Blacks, and Latinos	This study identified health literacy as an independent factor affecting glycaemic control (HbA1c) after adjustment for age, ethnicity, sex, education level, language proficiency, and social support. The findings demonstrated that patients with inadequate health literacy were less likely than patients with adequate health literacy to achieve optimum glycaemic control (adjusted OR, 0.57, 95% CI, 0.32-1.00, p=0.05), and were more likely than patients with adequate health literacy to have poor control (adjusted OR, 2.03, 95% CI, 1.11-3.73, p=0.02). Additionally this study also illustrated a significant relationship between health literacy and self-reported retinopathy related to type-2 diabetes, namely patients with inadequate health literacy were more likely to report the development of retinopathy (adjusted OR, 2.33. 95% CI, 1.19-4.57, p=0.01).	This study also failed to establish causal correlation between inadequate health literacy and poor glycaemic control due to the limitations of its cross-sectional design. In addition this study did not explicate mechanisms whereby low health literacy may result in worse glycaemic control as health literacy was only a marker for other factors affecting glycaemic control such as health care-seeking behaviours, psychological states and even cultural influences. The relationships between participants' socioeconomic status and their level of health literacy were not established as the participants were ethnically diverse, had low income levels and educational attainment, and were predominantly uninsured.

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Shaw *et al.*, 2012	USA	Ethnography	296	To explore the understanding of health literacy in the broader context of cultural beliefs and its influences on self-management of chronic conditions	Vietnamese, Blacks, and Latinos	The findings indicated that participants provided a wide range of understanding and interpretation of health literacy and self-management according to their own illness and health care experiences in a social and cultural context. In order to make response to participants' explanations for their health behaviours which were situated in a social and cultural context, health literacy could be reconceptualised as a socially and culturally influenced capacity. Therefore health literacy and self-management were sensitive to social and cultural contexts.	Vietnamese translation of measuring tool of health literacy (S-TOFHLA) used in this study had been neither normed nor verified, which could impact on the evaluation of the level of health literacy among the Vietnamese participants.
Simmons *et al.*, 2010	New Zealand	Systematic review	33 (studies)	To review the development of diabetes peer support initiatives in New Zealand	European New Zealanders and Maori	This review found that peer-to-peer support and education programmes in diabetes have been considered useful in New Zealand. However, a range of training, management, funding and organisational barriers existed in its implementation.	No quantitative evaluations were included.

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Smith *et al.*, 2011	Ireland	RCT	424	To test the effectiveness of peer support for patients with type 2 diabetes.	Irish	The findings demonstrated that at two-year follow-up, there were no significant differences in HbA1c (mean difference: −0.08%, 95% CI−0.35% to 0.18%), systolic blood pressure (-3.9mmHg, -8.9 to 1.1mmHg), total cholesterol concentration (-0.03 mmol/L, -0.28 to 0.22 mmol/L), or wellbeing scores (-0.7, -2.3 to 0.8) between the peer support and control group. Therefore, peer support in a structured diabetes education was not effective in improving biophysical and psychosocial outcomes for all individuals with type-2 diabetes.	The limitations of this study were related to its methodology such as inability to conceal allocation of the participants and lack of blinding of outcome data, which may impact on the internal validity of the findings.
Spencer *et al.*, 2011	USA	RCT	164	To test the effectiveness of a culturally tailored, behavioural theory–based community health worker intervention for improving glycaemic control among African Americans and Latinos with type-2 diabetes	African Americans and Latinos	The findings showed that the participants' mean level of HbA1c was reduced from 8.6% at baseline to 7.8% at 6 month in the intervention group, and intervention participants also had significantly greater improvements in self-reported diabetes understanding compared with the control group.	The sample size in the control group (n=92) was 28% more than that of the intervention group (n=72), so some within-group change might be significant in the control group but not in the intervention group. Moreover, self-reported data also were used for all behavioural measures, which might result in socially desirable responses.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Sun *et al.*, 2012	USA	Pre/post-test design	23	To test the feasibility and efficacy of a culturally tailored diabetes self-management education program for Chinese Americans in a support group format.	Chinese Americans	The findings indicated the statistically positive associations between high attendance of culturally tailored diabetes self-management program and increases in glycaemic control and diabetes knowledge among Chinese Americans.	The use of a convenience sample of currently insured patients subscribed to a local health care association that advertises itself as providing culturally competent health care to Chinese populations. In addition, the study was conducted in a setting with a high concentration of Chinese immigrants and access to high-quality health care and resources.
Thabit *et al.*, 2009	Ireland	RCT	100	To compare the diabetes self-care profile of non-Irish-national patients i.e. immigrant patients (IM) and Irish patients (IR) attending a hospital diabetes clinic and to evaluate differences in health literacy between the two groups	Non-Irish-national patients (South Americans, Eastern Europeans, Asians, and Blacks)	The results illustrated that compare with IR group, IM group presented a lower level of health literacy when assessed using REALM (52.7 vs. 61.4, $p= 0.01$) and had poorer glycaemic control (HbA1c 8.0 ± 1.9 vs. 6.9 ± 1.4%, $p< 0.005$). In the IM group, 53% could understand simple or familiar questions about their diabetes care and 65.9% could provide information on simple or familiar topics about their diabetes which was related to their level of English proficiency. In addition the findings showed that as compared with IR patients, family support was more important among IM group than performing self-monitoring of blood glucose (75% vs. 47.7%, $p<0.05$), taking medications (81.7% vs. 42.2%, $p=0.01$) and following an appropriate meal plan (87.6% vs. 62.2%, $p<0.05$).	This study failed to establish a correction of culture, health literacy, and self-management of type-2 diabetes, and to explicate how family support impacted on health literacy and the practice of self-management among immigrant patients with type-2 diabetes.

Authors (year)	Country	Type of research	Sample size	Aim of research	Ethnicity of participants	Major findings	Main limitations
Two Feathers *et al.*, 2005	USA	Pre/post test design	151	To determine the effects of a community-based, culturally tailored diabetes education on diabetes complications delivered by trained community residents among African-American and Latino adults with type-2 diabetes	African-Americans and Latinos	There were statistically significant improvements in postintervention dietary knowledge and behaviours and physical activity knowledge. A statistically significant improvement in HbA1C level was achieved among culturally tailored diabetes education program participants (P<.0001).	The unique feature of the study was that the intervention programme was delivered by trained community residents rather than health professionals so the recruitment, training, and retention of the community residents was a key aspect of the study, but these aspects failed to be reported upon clearly.
Vincent *et al.*, 2006	USA	Ethnography	40	To describe factors that facilitate or hinder diabetes self-management and elicit participants' preferences and recommendations about the essential components of a culturally competent diabetes self-management program among Mexican Americans.	Mexican Americans	The findings demonstrated that patients' family traditions and relationships changed after having type-2 diabetes due to the needs of diet modification. In addition, psychological stress was prevalent among the patients and their carers due to a lack of information on how to conduct dietary management. Patient and family caregiver participants wanted a self-management program to incorporate information on how to modify traditional foods, home remedies, and stress management.	This study included a relatively small sample size (n=40), with a high proportion of female participants (68%). Data collection was conducted at only one community clinic site. In addition, patient respondents were not asked about length of time since diagnosis with diabetes.

Authors (year)	**Country**	**Type of research**	**Sample size**	**Aim of research**	**Ethnicity of participants**	**Major findings**	**Main limitations**
Vincent *et al.*, 2009	USA	Pre/post-test control group design	20	To report the results of a culturally tailored diabetes intervention for Mexican Americans on lifestyle change such as physical activity	Mexican Americans	The intervention group had a significant decrease in weight and BMI. Mean weight loss was nearly 5 pounds and mean BMI decreased from 30.6 at baseline to 29.8 at 4 weeks postintervention. In addition, improvements were noticed for the intervention group in diabetes knowledge, self-efficacy, blood glucose, and HbA1C, but these did not reach statistical significance.	The limitations included small sample size (n=20) the 8-week intervention time period, and the use of a convenience sample.
Watanabe *et al.*, 2010	Japan	Cross-sectional study	112	To investigate the role of family support in glycaemic control by nutritional self-care behaviour among Japanese patients with type 2 diabetes	Japanese	The findings showed that family nutritional support was significantly related to HbA1c levels. However, the relationship between family nutritional support and glycaemic control were affected by some factors such as age, gender, and the types of nutritional support. Family nutritional support showed a significant effect on level of HbA1c among participants under 60 years old but in participants over 60 years of age, family support had little effect on HbA1c. While most male participants had family nutritional support, significantly fewer female patients did. Additionally in male participants who were supported with cooking or buying light meals showed significantly lower HbA1c than those who were supported only by advice or encouragement.	The interpretation of family function in self-management was limited due to the limitations of cross-sectional study.

Authors (year)	**Country**	**Type of research**	**Sample size**	**Aim of research**	**Ethnicity of participants**	**Major findings**	**Main limitations**
Wen *et al.*, 2004	USA	Cross-sectional study	138	To examine the role of the family in overcoming barriers to diet self-care among older Hispanic patients with diabetes	Hispanic Americans	The results showed that the level of family functioning was related to family support for dietary self-care, and family support for diet was related to perceived barriers to dietary self-care. Scores for family support were higher for those who perceived their family as functional compared to those who perceived their family as mildly dysfunctional or dysfunctional. As family support for diet increased, perceived barriers to dietary self-care decreased.	This study failed to establish a causality of family support and dietary self-care due to the limitation of a cross-sectional design. The family interactions, family support for diet, and barriers to dietary self-care were self-reported by participants. In addition, the participants in this study were recruited among older people living with their family, which might reduce generalisability of the findings
Xu *et al.*. 2011	USA	Cross-sectional study	211	To examine acculturation and its influences on diabetes self-management among Chinese Americans	Chinese Americans	The findings indicated that acculturation was significantly associated with self-management of diabetes, and more-acculturated individuals were more likely to conduct self-management than less-acculturated ones after controlling demographic characteristics.	The majority of the participants were first-generation immigrants and the variation of the acculturation scores was small. Other limitations included the use of the convenience sample and self-reported data.

Chapter Three Methods

3.1 Introduction

This chapter discusses the rationale for adopting the qualitative research approach of ethnography to explore a broader understanding of the perspectives and practices of self-management in Chinese patients with type-2 diabetes and their family carers living in China and Wales and their family carers. An account of the methods utilised and the conduct of the study to achieve the overall research aim is provided in this chapter. As a single researcher, my role in this study is reported and discussed along with the considerations of access to the research field and ethical considerations. Moreover, issues of rigour, including the reflexive approach adopted, audit trails, triangulation of data collection and analysis, and matter pertaining to interpretation and translation are also reported and evaluated. Firstly, the overall aim of the study and research questions are presented in the following section.

3.2 The research aim and questions

The aim of this study was to investigate self-management of type-2 diabetes from the perspectives and practices of Chinese patients with type-2 diabetes living in China and Wales and their family carers. The research questions of the study were to:

- Investigate perspectives, experiences, and practices of Chinese patients and their family carers regarding type-2 diabetes and self-management;
- Investigate the sources of support and information accessed by Chinese patients and their family carers regarding participants' diabetes and self-management;
- Explore the influence of type-2 diabetes on daily lives of Chinese patients and their family carers;
- Explore the factors which facilitate or hinder self-management in Chinese patients with type-2 diabetes;
- Investigate the conduct of self-management of type-2 diabetes in the different social and cultural contexts and health care systems and the influences of Chinese cultural traditions on self-management among Chinese patients in China and Wales.

- the influence of Chinese cultural norms on self-management of type-2 diabetes.

The initial research questions posed give focus to identification of the area to be studied and to the methods of data collection and subsequent analysis. The data collection methods used to address these questions are discussed in the following section. Moreover, justification for the methodological approach used and detailed information regarding the conduct of the study is also discussed.

3.3 A qualitative approach

This study was an exploratory study which sought to gain a broader understanding of type-2 diabetes and self-management in Chinese patients and their family carers in China and Wales. That is, the main aim of this study was to explore and understand the world of Chinese patients with type-2 diabetes and their family carers in China and Wales. In order to achieve this, a qualitative approach provided the most appropriate method to identify personal and even unique experiences and participants' interpretation of these experiences (Jones, 1995; Sarantakos, 1998). Moreover, Miller and Glassner (1997) note a qualitative approach is appropriate for research which is aimed at understanding and documenting others' understandings because it provides researchers with means for exploring the points of view of research participants, while granting these points of view the culturally honoured status of reality.

This study was inspired by an interest in the importance and necessity of self-management for patients with type-2 diabetes. Diabetes self-management is a dynamic, interactive, and daily process in which patients engage to manage their condition (Lorig & Holman, 2003). Self-management behaviours involve day-to-day activities, which include adherence to daily medication treatment, self-monitoring of blood glucose level, dietary control, physical activity, stress management, and monitoring and managing the complications, either chronically or acutely from the time of diagnosis (Diabetes UK, 2009). Hence, how patients with type-2 diabetes manage their condition by themselves in daily life is an issue related to personal perspectives and experience, which is closely associated with cognition, behaviour, and social and cultural context. In addition, Baker and Stern (1993) suggest that meaning is a key concern for those carrying out self-care in chronic illness. Thus, exploring the meanings behind the self-management behaviours might contribute to understanding the nature of diabetes self-management.

However, according to Silverman (1997, p.1), "there is a need to expand our conception of qualitative investigation beyond questions related with subjective meaning and towards issues of language, representation and social organisation." Therefore, qualitative research contributes not only to exploring the meanings of self-management but also to investigating into the influence of social and cultural context on self-management. Another characteristic of qualitative research is their interpretation, which allows the researcher to justify, elaborate or integrate the research results within a given theoretical framework (Malterud, 2001). In addition, the participants in qualitative research are investigated in their natural settings and are encouraged to speak for themselves and to approach their singular experience through the meanings and the vision of the world they possess by offering a dense description (Miles & Huberman, 1994). This contributes a deeper understanding of Chinese patients and their family carers' world. Another reason why this study was conducted was that questions about the factors that facilitate or hinder the conduct of self-management among Chinese patients in China and Wales have not been fully answered and the roles of the family carers in the patients' self-management have also not been clearly described in previous studies. Silverman (2011) indicates that qualitative approaches are particularly suitable to explore a social situation which has not been understood completely. A qualitative research strategy was therefore selected to use to achieve the aim of this study.

Historically, the qualitative tradition emerged as a result of the growing disillusionment and discontent with the products of the quantitative enquiry (Guba & Lincoln, 1994). Essentially, the basic assumption guiding the qualitative paradigm is that reality is socially constructed by active people in the research process (Pring, 2004; Schwandt, 1994). This paradigm emphasises that reality is a product of the values of researchers and researchers cannot be independent of it. People's action "...is inseparable from meaning, and experiences are classified and ordered through interpretive frames and pre-understandings mediated by tradition" (Scott & Usher, 1999, p.24). Qualitative research takes daily experiences and ordinary life as its subject matter and makes the assumption that meaning is constructed and interaction is negotiated in natural practices (Scott & Usher, 1999). I sought to explore the reality of self-management for Chinese patients as expressed by the participants themselves based on their daily experiences and social and cultural context. I intended to explore factors impacting on self-management behaviour and how these factors interact to improve or hinder self-management of Chinese patients in this study.

At the ontological level, the qualitative perspective asserts that there are multiple realities (Pring, 2004; Sale *et al.*, 2002). These multiplicities are based on the researchers' mental construction of what is considered to be true. There could be as many realities as there are researchers (Pring, 2004) but ultimately, reality is constructed in a social context (Sale *et al.*, 2002). Additionally Pring (2004) notes reality does not exist outside of the research activities. In contrast, qualitative researchers believe that the world exists but different people interpret it in very different ways and "organisations are invented reality" (Cohen *et al.*, 2000, p.9). Therefore, qualitative research is criticised for its subjectivity and lack of reliability, randomisation, and generalisability (Pope& Mays, 2000). However, qualitative research does not seek to be or to make claims to being objective, indexical, randomised, and generalisable. Indeed, the nature of qualitative research is interpretation and it is guided by a set of beliefs and feelings about the world and how it should be understood and studied (Denzin & Lincoln, 2001). If research focus only on what can be quantified reliably, factors that are significant in explaining important realities, complexities, and phenomena in natural settings may be missed (Peters *et al.*, 2002). Furthermore, qualitative research has been criticised for its relatively small samples. However, small samples enable in-depth analysis and the criticism is not relevant to the outcome and quality of the research providing the researcher has the skills to perform qualitative data collection and interpretative analysis. Pope *et al.* (2000) point out the qualitative researchers need to have knowledge about the relevant literature of the area of investigation and the methodology; a self-disciplined and informed approach to data collection and analysis; and a considerable degree of judgement and interactive and interpretative skills for cumbersome and often complex data analysis.

There are major differences of opinions amongst qualitative researchers on matters of ontology and epistemology as well as the methods to be used and the criteria of evaluation. In addition the divergences on the nature, purpose, status and practice of qualitative methods perplex qualitative researchers as well. However, many qualitative researchers take a predominantly method-based approach. Qualitative researchers such as Miles and Huberman (1994) and Patton (2002) stress data collection techniques.

Creswell (2007) and Denzin and Lincolin (2005) prefer the approach that has the advantage of being based on systematisation of knowledge providing a sense of order and orientation. Additionally, another approach is to classify qualitative research according to research traditions including grounded theory, phenomenology, and ethnography. But this approach has the disadvantage of oversimplification, ignoring the issues of the research question and conceptual frameworks used, and how these issues can shape the research process and the findings (Grbich, 1999). Finally, Miles and Huberman (1994) suggest that no study conforms exactly to a standard methodology and that the researcher bends the methodology to the peculiarities of the study.

There are critiques about qualitative work in health care due to the misguided separation of method from theory and of technique from the conceptual underpinnings (Lambert & McKevitt, 2002). However, the choice of method and how it is used can perfectly well be matched to what is being studied rather than to the methodological preferences of the researcher in a qualitative work (Mays & Pope, 1995). Additionally, researchers who are able to select and use qualitative methods as right as an expert are required in a qualitative research in order to ensure that the right methodology is used for answering the right questions. In fact, commentators claim that using qualitative methods in health-related research can result in substantial insight into health professionals' and patients' perceptions in health care and identification of barriers to changing healthcare practice (Al-Busaidi, 2008).

Other qualitative approaches other than ethnography were reviewed prior to conducting this study, particularly the utility of the approach of grounded theory and phenomenology. The justification why these two approaches were not selected to use in this study is presented below.

3.3.1 Grounded theory

Grounded theory method was developed in the 1960s by two American sociologists, Barney Glaser and Anselm Strauss. The two originators described the research process as the discovery of theory through the rigors of social research. A more detailed definition forwarded by Strauss and Corbin (1990, p.23) is as follows:

> "A grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed and provisionally

> verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis and theory stand in reciprocal relationship to one another."

Grounded theory is a creative process which is appropriate to use when there is insufficient knowledge or theory of a topic (Glaser & Strauss, 1967), where existing theory fails to resolve the problems (Chenitz & Swanson, 1986) or for modifying existing theory. Grounded theory was developed to refute the arguments of lack of rigour in qualitative research (Glaser & Strauss, 1967) such as a flexible plan of inquiry (Avis, 2005) and a comparable approach to data analysis (Silverman, 2001). Therefore, grounded theory approach requires a prescribed method of data collection and analysis and emphasises steps and procedures for connecting induction and deduction through the identification of a broad research area with progressive focusing, simultaneous data collection and data analysis, theoretical sampling, and saturation of categories (Corbin & Strauss 2008). Thus, grounded theory approach was not appropriate to achieve the aim and research questions of this study as in this study I intended to explain and understand a reality of self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales. Although grounded theory was not selected for this study, an inductive approach which is similar with grounded theory approach was used, namely theory, data generation and analysis were developed simultaneously.

3.3.2 Phenomenology

Phenomenology is another qualitative approach used commonly in the social and human sciences including sociology, nursing, and human and health sciences (Creswell, 2007). Phenomenology is used to explore how human beings make sense of experience and the meaning they give to these experiences (Creswell, 2007). Phenomenologists are interested in how people put together the phenomena they experience in such a way as to make sense of the world and develop a worldview. There is a focus on meaning-making as the essence of human experience (Moustakas, 1994). As phenomenology concentrates on seeking understanding of the meaning and the essence of a particular human experience, adopting this approach would have addressed some of the research questions in terms of understanding Chinese patients and their family carers experiences of self-management of type-2 diabetes, but would not address all of the research questions particularly in terms of exploring the social and cultural context in which Chinese patients lived and their influence on self-management of Chinese patients.

Therefore, compared with these two alternative qualitative approaches, an ethnographic approach was considered to be more appropriate to achieve this study's aim of understanding Chinese patients and their family carers' perspectives and practices of self-management of type-2 diabetes.

3.4 Ethnography

The aim of this study is to explore and understand self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales. Self-management of type-2 diabetes is a process by which patients take activities to manage their condition in their daily lives (Diabetes UK, 2009). Moreover, Chinese patients are living in a social and cultural context that may be dynamic and complicated, thus my interest was what Chinese patients and their family carers understand type-2 diabetes and self-management and how social and cultural context in which they lived influenced their self-management in this study. Ethnography is a qualitative research design aimed at exploring human culture or human phenomenon (Geertz, 1973; Philipsen, 1992) and was considered the most appropriate approach to achieve the aim of this study due to its distinct and fundamental goal to explore and understand a culture.

Ethnography is not only a research methodology but also a written account of the culture investigated (Morse & Field, 1996). Brewer (2000) also contends that ethnography is not only a particular method of data collection but also a style of research that is distinguished by its goal to understand the social and cultural meanings and activities of people in a given field or setting. Williams (1995) also suggests that ethnography is both a method of data collection and a theoretical or philosophical framework by which to explore how people interpret their experiences of the world. Therefore, ethnography is defined (Brewer, 2000, p.10) as:

> "The study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally".

The distinct advantage of ethnography is that the researcher can identify human events and behaviours by observing (participant observation) and then exploring the meanings of these events and behaviours through questioning (interview). That is, ethnography provides the researcher with a way to witness human events and behaviours in the natural context where they happen. Hammersly and Atkinson (1983, p.2) describe the role of researcher(s) in detail in an ethnographic research as:

> "The ethnographer participates overtly or covertly in people's daily lives for extended periods of time watching what happens, listening to what is said, asking questions. In fact collecting whatever data are available to throw light on issues with which he or she is concerned."

Being a young researcher using ethnography, I may obtain some helpful inspirations and experiences of how to conduct an ethnographic research from the early pioneers' work through reviewing the development of ethnography. Early ethnographic studies sought to explore unique and disappearing cultures through spending several years living with and experiencing the real life of the participants. The earliest ethnographic work was traced to Malinowski's fieldwork among Trobriand Islanders in 1914 (Ellen, 1984). His ethnography of the Trobriand Islands described the complex institution of the Kula exchange and became foundational for subsequent theories of reciprocity and exchange (Ellen, 1984). His approach to social theory was characterised by functionalism emphasising how social and cultural institutions serve basic human needs, which was opposed to Radcliffe-Brown's structural functionalism that stressed the ways in which social institutions function in relation to society as a whole (Ellen, 1984). Radcliffe-Brown brought French sociology to British anthropology, constructing a rigorous series of concepts to frame ethnography (Kuper, 1973). He contributed extensively to the anthropological ideas on kinship and produced structural analyses of myths, including on the basis of the concept of binary distinctions and dialectical opposition on the basis of his extensive fieldwork in the Andaman Islands and Australia (Radcliffe-Brown, 1951). However, these early ethnographic researchers such as Malinowski were greatly affected by the modern positivist paradigm and tried to confirm objectivity of culture by investigating other cultures that were different from their own (Brewer, 2000). Although there are criticisms related to such early ethnographic research due to their association with British colonialism and religious expansionism (Brewer, 2000), there is no doubt that this early ethnographic research can provide young researchers of today with valuable experiences and help them to have a better understanding of essence and nature of ethnography and so guide the conduct of their research.

Besides an intellectual development of ethnography in Britain, there is another development in North America. The intellectual development of the two schools of ethnography is completely independent. The development in North America was the work of the Chicago School in sociology, which explored groups on the margins of urban industrial society in the United States in the early of twentieth century through using observational techniques (Brewer, 2000). The Chicago School refers to a specific group of sociologists at the University of Chicago during the first half of this century. Their way of thinking about social relations was heavily qualitative, rigorous in data analysis, and focused on the city as a social laboratory (Deegan, 2012). The Chicago School developed a set of standard assumptions and themes in their work (Bulmer, 1984). From the 1960s onwards, forms of sociological work influenced by the Chicago School, spread across many sub-fields of the discipline, and into other disciplines and areas of inquiry; and they also migrated from the United States to Europe and to other parts of the world (Hammersly & Atkinson, 2007). However, the concerns of the Chicago School were of their day, their situation resonated with the study of many more modern social systems. Many of their methods and themes were not directly applicable to the study of electronic social spaces, but their approach to studying complex, rapidly evolving social environments was helpful for current endeavours (Bulmer, 1984). Theirs was a call to be sensitive to context, careful with appropriate methodologies and immersive in study.

With the development of ethnography, anthropologists grew more interested in less tangible aspects of culture, such as values, worldview and what Geertz (1973) termed the ethos of the culture. Meanwhile, there were a slew of theoretical and practical changes in ethnographic technique. The great changes took place in the 1980s. First, Geertz's (1973) interpretive anthropology and his focus on the "anthropologist as author" had convinced a number of anthropologists that there was as much art as science to ethnography. Second, poststructuralism, postmodernism, feminism, and neo-Marxism had disturbed a number of the epistemological and ethical foundations of traditional ethnography (Brewer, 2000). Third, the world was changing. New models of travel and communication, medical breakthroughs, political movements, religious shifts, global economic patterns, and the general collapse of the colonial world order meant that the social and cultural ordering of the world was fundamentally different from what it had been in the days of Malinowski (Hammersly & Atkinson, 2007). The relationship between researchers, audiences, and participants has become a central tenet of contemporary anthropological and ethnographic practice wherein active collaboration between the researcher(s) and participant(s) has helped blend, in certain instances, the practice of collaboration in ethnographic fieldwork with the process of creating the actual ethnographic product that emerges from the research itself (Luke, 2005). Ethnography is a detailed way of witnessing human events and human behaviours in the context in which they happen, which can be used to investigate and resolve problems that cannot be worked out by quantitative approaches (Brewer, 2000). However, the improvement of awareness of human rights and protecting participants in research increases ethical concerns in the conduct of ethnographic research.

Much early ethnographic research has been criticised for their ethical shortcomings such as lack of informed consent and invasion of privacy (Brewer, 2000). In addition some ethnographic researchers observed participants covertly and have defended their discourteous behaviours by claims that there were no other options due to limited access or fear of revenge. For instances, Homan's (1978) work on old-time pentecostalists, Scheper-Hughes's (2004) study of organ-traffickers, and Humphreys's (1970) research among homosexual encounters. These studies have been criticised widely by academic fellows for their invasion of the participants' privacy and the potential risk for those participants to suffer from harm and psychological stress (Brewer, 2000). Hammersly and Atkinson (2007, p.209) state that "...there are ethical issues surrounding social research, just as there are with any other form of human activity." Therefore, ethical issues in this study are discussed in detail in the section 3.8.

There are two major critiques of ethnography within social sciences. These are the natural sciences critique and the postmodern critique of ethnography (Brewer, 2000). The natural science critique accuses ethnography of falling below the standards of science and advocates constructing the natural science model of social research through forming the proper measure for the social sciences (Brewer, 2000). The postmodern critique tries to deconstruct ethnography to its constituent processes and accuses ethnography of nothingness (Brewer, 2000). Moreover, ethnography is bedevilled by ambivalence: caught in a conceptual and methodological confusion surfacing in two competing strands of practice, namely naïve realism, a modern approach that claims that a truth has been found by objective approaches, and critical realism, which asserts multiple reality and negates accepting the existence of a one and incontestable truth (Banfield, 2004). Therefore, Hammersley (1992) calls for a subtle realism to deal with the confusion. Hamersley's subtle realism contains three key elements. Firstly, truth can be constructed as "beliefs about which whose validity we are reasonably confident" (Hammersley, 1992, p.50); secondly, phenomena exist independent of human knowledge of them; thirdly, social research represents rather than creates reality and that phenomena can be represented by multiple perspectives (Hammersley, 1992). The first two elements represent epistemological and ontological claims whilst the third one refers to the application of those positions to ethnographic research. I accepted and acknowledged Hammersley's (1992) subtle realism as my philosophical and methodological standpoint in this study as the aim of this study is to explore a reality of self-management of type-2 diabetes, which may be multiple from the perspectives of Chinese patients and their family carers.

Hammersly and Atkinson (2007) point out that ethnography always focuses on understanding social and cultural events and behaviours, and that observation takes place in the participants' natural environment. The role that the researcher plays in identifying human events and behaviours by participant observation and then exploring the meanings of these events and behaviours through questioning is an important strength of ethnography. Observation is therefore a brand of ethnography (Brink & Edgecombe, 2003). Nevertheless, increasing numbers of ethnographic research has been carried out without the use of participant observation. For example, Corbin and Strauss (1988) conducted a classic sociological study in terms of living at home with chronic illness based mainly on interviews rather than direct observation. Such study did not stress contextual understanding that required the use of participant observation. Additionally the absence of participant observation is increasingly accepted in interpretative ethnographic research, which aims to chart the network of shared meanings that constitute reality within a community (Smart, 1998). In such studies, the primary data source is people and their interpretations are based on a "thick description" (Geertz, 1973, p.6) of a community's "interworked systems of construable signs" (Geertz, 1973, p.14) gained by the use of approaches such as interviewing (Blaikie, 2000). Further, Savage (2005) explains that today the term of ethnography can be applied to any small-scale social research carried out in everyday settings and uses several methods evolving in design and focusing on an individual's meanings and explanations.

Ethnography provides the researcher with a method to investigate human events and behaviours in the natural context where they happen. Therefore, ethnography has been used in exploring topics related to health beliefs and practices, allowing these issues to be viewed in the context in which they occur and therefore helping broaden the understanding of people's perceptions and behaviours related to health and illness (Burden, 1998; Rapport & Maggs, 1997; Savage, 2005). Ethnography within the health care context is also valuable for the exploration of the influences of social and cultural context on health and illness (Meyer, 2000). In addition, there is a growing interest in the application of ethnographic approaches in nursing. Mulhall (1996) suggests that a true understanding of culture is necessary before it is possible to fully integrate the discipline into a nursing knowledge base. Ethnography also has been the method of choice in previous studies into how people lived with type-2 diabetes and why self-management was challenging for patients and their families. One example is Hinder and Greenhalgh's (2012) ethnography of exploring understanding of self-management and support needs in a community among 30 patients with type-2 diabetes using interviews. Additionally Lundberg and Thrakul's (2011) ethnography of exploring and describing Thai Muslim women's self-management of type-2 diabetes at their home using qualitative interviews and participant observation. In addition, there has been an increase in the amount of cross-cultural and short-term ethnographic research, for example, the studies sponsored by the international development agencies or student exchange projects (Al-Busaidi, 2008). Overall ethnography is being increasingly used as a research strategy in health care disciplines such as nursing and chronic conditions management.

Nowadays, increasing numbers of ethnographers conduct their research in a relatively short period of time and based on a single community instead of spending many years in integrating into a fieldwork to collect data as did those early ethnographic pioneers (Brewer, 2000). The development of modern science and technology and rapid changes of human society also greatly affects ethnography as an important social research strategy investigating into human society and culture. Hence, a researcher's ontological and epistemological stance may impact on the conduct and development of ethnographic research (Brewer, 2000). Nevertheless, the distinct and essential value of ethnography is its core aim to explore and understand a culture. Hammersley and Atkinson (2007) emphasise that understanding of a culture can be achieved through investigating people's daily behaviours and events in a natural environment in which they occur, with using various and flexible approaches to collect data, and analysis to explore interpretative understanding of human behaviours and contexts. I acknowledge that ethnography has its limitations and criticisms including subjectivity of findings, ethical concerns, and researcher's role conflict, and the negotiation of role in the field work (Brewer, 2000). How to solve these issues in my study is discussed in detail in the subsequent sections. Additionally I also acknowledge potential influences of my views, strands, education, and life experiences on this study (Aull Davies, 1999). Moreover, I only can explore a reality based on narratives provided by the participants in this study. However, ethnography was the most appropriate methodology to explore, to interpret, and to understand Chinese patients and their family carers' perspectives regarding self-management of type-2 diabetes. The conduct of this study is discussed in detail in the subsequent sections. First the location and access of this study is presented next.

3.5 Location and access

The field of this study in China was located at a diabetes outpatients department of a regional comprehensive hospital in Kunming, which is the capital city of Yunnan Province in the southwest of China with a population of nearly five million people. Hammersley and Atkinson (2007) suggest that the selection of research field should consider its availability and accessibility. Therefore, criteria for the selection of this diabetes outpatient department to conduct this study in China included transportation convenience; the familiarity to myself having been educated and trained there for two years previously as a medical student and an intern; existing relationships as my previous mentors and classmates in medical school were still working there; and supportive and encouraging attitude toward my research held by the staff within the diabetes department. However, I must emphasise that none of the participants were known to me prior to the study.

Nevertheless, pragmatism was not most important when I selected the study field in China. The most important consideration was that the diabetes outpatient department can provide abundant resources and opportunities to access to Chinese patients with type-2 diabetes and their family carers. Around 50 people and their carers visit the diabetes outpatient department every day. In addition, the diabetes outpatient department provides patients not only with medical treatments for type-2 diabetes but also with diabetes education lectures. Thus, conducting this study in the diabetes department facilitated not only recruitment of participants who had various characteristics and experiences of living with type-2 diabetes and but also observation of diabetes education lectures. Therefore, conducting this study in the diabetes outpatient department can obtain abundant "opportunity to learn" (Stake, 1994, p.244).

In Wales, this study was undertaken at a Chinese charitable organisation in South Wales. Criteria for the selection of this field to conduct this study in Wales included transportation convenience; its existing cooperation relationships with Swansea University; and positive and supportive attitude to research held by the staff in the Chinese organisation. More importantly, currently there are over 600 registered Chinese members living in South Wales in the organisation. These Chinese members immigrated to Wales originally from the mainland China and Hong Kong. Moreover, most working staff in the organisation is fluent bilingual speakers of Mandarin, Cantonese, and English. They have been trained to provide their members with Cantonese-English interpretation services. Thus, I can obtain Cantonese interpretation service from the staff when the participants prefer to completing the interviews in Cantonese (as I am only able to speak Mandarin). Overall, conducting this study in the Chinese organisation in Wales ensured the recruitment of the Chinese participants in Wales and facilitated to access to Cantonese interpretation service provided by the staff in the organisation.

3.5.1 Obtaining permission from the managers of the diabetes outpatient department and the Chinese charitable organisation

While I embarked on the application of ethical approval from the Ethics Committee in the College of Human and Health Sciences (ECCHHS) in Swansea University, I contacted the manager and sister of the diabetes outpatient department in the Chinese hospital by telephone and email to explain purpose of this study and the research approach. After that, an oral permission was obtained from the manager and sister. They agreed in principle to patients and staff including doctors and nurses in the department being approached for this study. Moreover, they accepted the ethical approval granted by the ECCHHS. Thus, I did not need to apply for an additional ethical approval in the Chinese hospital. Meanwhile, the permission of the manager of the Chinese charitable organisation in South Wales was also obtained after introducing and explaining the purpose of this study and the research approach. I conversed with a staff in the charitable organisation who had experience of providing Cantonese interpretation service after being permitted to approach their staff and members for this study directly. The staff agreed to provide me with Cantonese interpretation service on a voluntary basis. All approached were helpful, accessible, and no barriers were presented. Therefore, the conditions to be satisfied were that I had obtained permissions of the managers of both the diabetes outpatient department and the Chinese charitable organisation before I submitted ethical approval application to ECCHHS formally.

3.5.2 Gaining approval from the Ethics Committee in the College of Human and Health Sciences (ECCHHS) in Swansea University

As this study included vulnerable people including patients with type-2 diabetes and old people (aged over 60 years), I was required to submit completed application forms attached with a detailed research proposal for approval to the ECCHHS. The proposal was approved and the permission was given to progress to data collection including formal semi-structure interviews, observation of diabetes education sessions, and reviewing participants' self-management records (Appendix 1). A key concern of the ECCHHS was the venue of conducting interviews. The ECCHHS suggested that participants' interviews should not be conducted in a private space such as participant's home on the basis of consideration of safety. Therefore, I amended my research proposal and restricted the venue of participants' interviews on a quiet public place. The health consultation room in the hospital and staff office in the charitable organisation was considered to be ideal place for participants' interview. In addition, I was required to submit a permission from the diabetes outpatient department to the ECCHHS when I started to conduct this study in China. This requirement was complied with. Participant recruitment and selection is detailed next.

3.6 Participants recruitment and selection

The participants for this study included Chinese patients with type-2 diabetes and their family carers in China and Wales. Firstly, the terms used throughout this study are defined here.

In the study, Chinese patients with type-2 diabetes in China refer to those people diagnosed clinically with type-2 diabetes who identify themselves as having Chinese ethnicity and live permanently in the territory of mainland China. Moreover, to explore the impact of immigration on self-management of type-2 diabetes, Chinese patients with type-2 diabetes in Wales refer to those people diagnosed clinically with type-2 diabetes who identify themselves as having Chinese ethnicity and who immigrated to Wales from mainland China or Hong Kong and live in Wales permanently now.

The family carer is the person whom the Chinese participant with type-2 diabetes identifies as the person who takes the most responsibility or is most knowledgeable about their condition. This could be parents, a spouse, brother(s), sister(s), adult offspring or other relative.

Patient with type-2 diabetes refers to people who have been diagnosed with type-2 diabetes mellitus according to the accepted medical diagnosis standards such as the Definition, Diagnosis and Classification of Diabetes Mellitus and its Complications published by the World Health Organisation (WHO) in 1999.

3.6.1 Participants recruitment

In China, the recruitment of participants was undertaken at a diabetes outpatient department of a regional hospital in Kunming. Before the recruitment, I provided health professionals working in the department with detailed information about this study including inclusion criteria, study information packets in which Participant Invitation Letter (Appendix 2), Participant Information Sheet (Appendix 3), and Consent Form (Appendix 4) were enclosed, and invited them to participate in the recruitment by providing an introductory presentation. After that, these health professionals introduced this study to their patients and family carers who accompanied the patients, who met the inclusion criteria. If these patients and their family carers were interested in participating in the study, they took a study information pack from the public information counter of the department, which was located outside of the working area of health professionals. Moreover, the health professionals were required to introduce the study to potential participants in an understandable language in order to make sure these potential participants understood the study clearly, and stressed that participation in the study was absolutely optional in order to avoid the situation that potential participants could feel coerced to accept the participation because they were worried that the health professionals could be offended if they refused to participate. In addition, the assistance from the diabetes department was also on a voluntary basis, the health professionals who helped in recruitment did not receive any incentives from the study. Therefore, it was unnecessary for them to force the distribution of the information about the study. Additionally, posters containing the main information about the study were made and placed on the notice board in the department with the permission of the hospital staff to aid recruitment and to raise awareness of this study.

In Wales, the recruitment was conducted with assistance from the Chinese charitable organisation in South Wales. First, I introduced the study including inclusion criteria to the staff and left the study information packets in which Participant Invitation Letter (Appendix 2), Participant Information Sheet (Appendix 3), and Consent Form (Appendix 4) including a stamped addressed envelope and reply slip were enclosed in the organisation. The staff introduced the study to their members with type-2 diabetes and their family carers who met the inclusion criteria. If they were interested in participating in the study, they took a study information packet from the reception counter of the organisation. The staff in the organisation was required to introduce the study to potential participants in an understandable language in order to make sure these potential participants understood the study clearly, and stressed that participation in the study was absolutely optional. In addition, the study information packet were put in a public place such as the reception counter in the organisation so that potential participants made an independent decision as to whether or not to take the information packet. The assistance from the Chinese charitable organisation was on a voluntary basis, and the staff in the organisation did not receive any incentives from the study. Moreover, posters were displayed in the organisation with their permission of the staff to aid recruitment and raise awareness of the study.

On receipt of the potential participants' reply slip which indicated their interest in the study. Then I contacted them to introduce the study more in detail, to answer their questions, and to confirm their contact information and willingness to participate. Finally, I arranged a mutually convenient time to interview them in a local public venue.

3.6.2 Participants selection

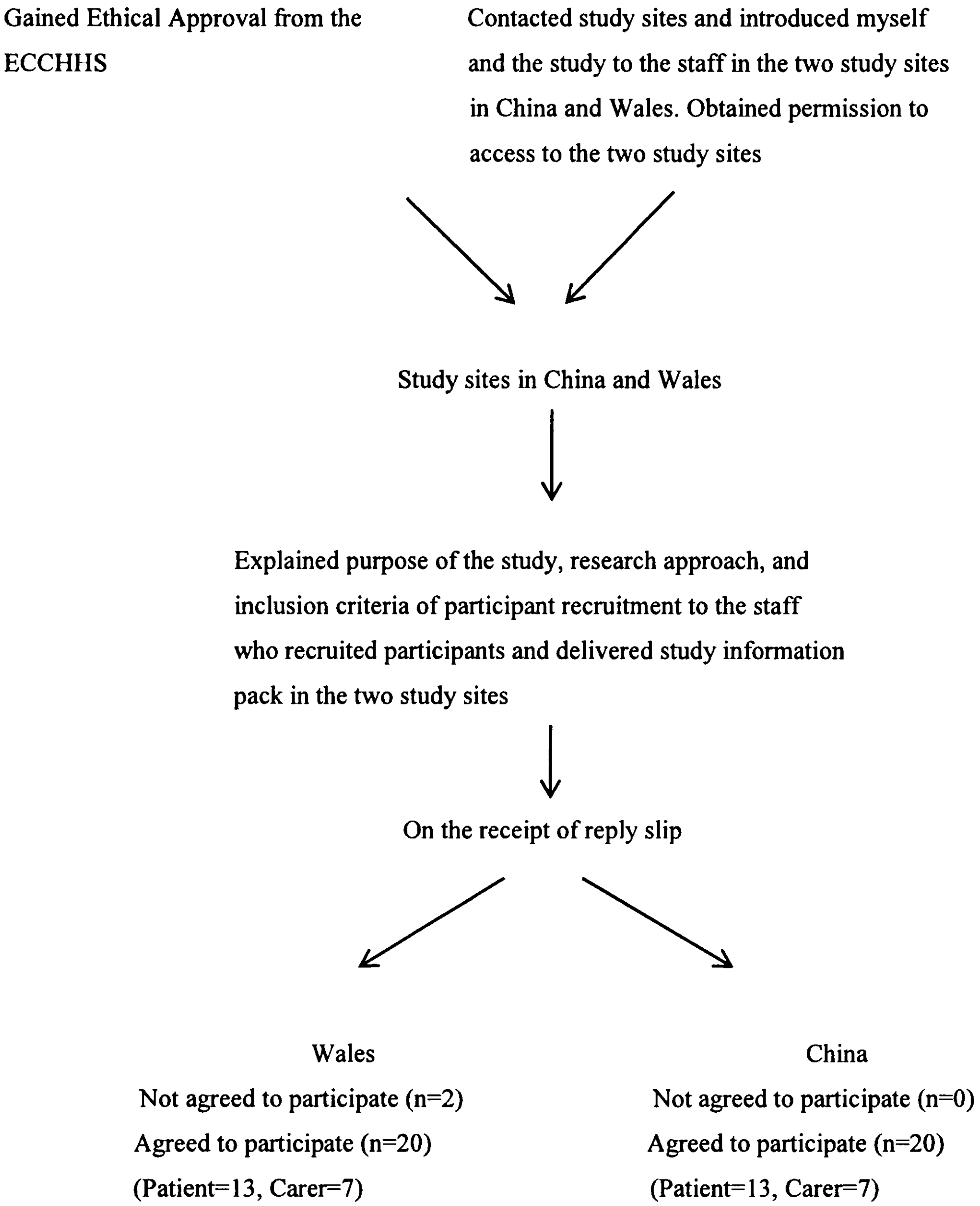
Purposive sampling was employed in the recruitment of participants. The purposive sampling technique is a type of non-probability sampling and is based on the belief that researcher's knowledge about population. It is most effective when researcher needs to study a certain cultural domain with knowledgeable experts within (Tongco, 2007).

Eligible Chinese patients with type-2 diabetes were: (1) over 18 years of age; (2) had been diagnosed with type-2 diabetes for at least 6 months; (3) of Chinese ethnicity, speak English, Cantonese or Mandarin; (4) lived in urban and rural areas within a 30 mile radius of a large city in South Wales, or Kunming city in Yunnan province in China; (5) willing to talk about their illness experiences; (6) did not have serious health problems affecting the completion of one-hour interview; (7) and were able to give informed consent.

Whilst eligible family carers were: (1) over 18 years of age; (2) looking after their Chinese kin with type-2 diabetes; (3) lived in urban and rural areas within a 30 mile radius of a large city in South Wales, or Kunming city in Yunnan province in China; (4) willing to talk about experiences of looking after their kin with type-2 diabetes; (5) did not have serious health problems affecting the completion of one-hour interview; (6) and were able to give informed consent.

Two individuals in Wales indicated on the reply slip that they did not agree to participate. 40 eligible participants including Chinese patients with type-2 diabetes (n=26) and family carers (n=14) participated in this study. 20 out of the 40 participants including 13 patients with type-2 diabetes and seven family carers were recruited in China. The remaining 20 participants including 13 patients with type-2 diabetes and seven family carers were recruited in Wales. The number of participants was determined by information saturation (no longer learning anything new) (Morse, 2000). The process of participant recruitment and selection in China and Wales is summarised in **Figure 1**, and the data collection and analysis is presented in the next section.

Figure 1: The process of participant recruitment and selection



Gained Ethical Approval from the ECCHHS

Contacted study sites and introduced myself and the study to the staff in the two study sites in China and Wales. Obtained permission to access to the two study sites

Study sites in China and Wales

Explained purpose of the study, research approach, and inclusion criteria of participant recruitment to the staff who recruited participants and delivered study information pack in the two study sites

On the receipt of reply slip

Wales
Not agreed to participate (n=2)
Agreed to participate (n=20)
(Patient=13, Carer=7)

China
Not agreed to participate (n=0)
Agreed to participate (n=20)
(Patient=13, Carer=7)

3.7 Data collection

3.7.1 The methods of data collection

Ethnography is not a particular method of data collection but a style of research which is featured by its objectives of understanding the social meanings and people's activities in a given setting (Brewer, 2000). Thus, multiple methods of data collection are appropriate, including interviewing, observation, and reviewing personal documents in order to explore social meanings, observe activities, and work closely with informants (Brewer, 2000). In this study, data collection methods comprised semi-structured interviews, observation, and reviewing personal self-management documents.

The main method of data collection used in this study was semi-structured individual interviews conducted both in China and Wales. The first part of data collection commenced in October 2012 in China lasting for seven months. The second period of data collection commenced in March 2013 in South Wales and lasted for eight months. A discussion about semi-structured individual interviews conducted both in China and Wales is presented first in next section.

3.7.1.1 Semi-structured interviews

Interviews are discussions between an interviewer and an individual, with the purpose of gathering information on a specific set of topics (Harrell & Bradley, 2009). Interviews are common methods to collect primary data in scientific studies. First, interviews are ideal methods to collect information from individuals about their own practices, beliefs, or opinions, and they also can be used to gather information on past or present behaviours or experiences (Warren & Karner, 2005). Second, the method of interview is suitable to gather 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). According to how much control the interviewer will have over the interaction, interviews can be categorised as unstructured, semi-structured, and structured interview. There are benefits to each of these kinds of interviews. In unstructured interviews, the researcher has a clear plan and topic, but minimum control over how the respondent answers (Harrell & Bradley, 2009). Collecting information in this manner might lead to very rich and nuanced data but it can take a long time (Harrell & Bradley, 2009). Therefore, unstructured interviews are really most suitable when researchers have a great deal of time to spend with the community they are studying. Structured interview is the most controlled. In structured interviews, the questions are fixed and they are asked in a specific order (Harrell & Bradley, 2009). These interviews are often used in quantitative research and when the researcher has very large samples and is looking for data that can be generalised to a large population (Harrell & Bradley, 2009). Semi-structured interviews are used often in ethnographic studies. In semi-structured interviewing, a guide is used, with questions and topics that must be covered. Additionally, 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). Semi-structured interviews allow 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). Hence, the method of semi-structured interviews can help the researcher to delve deeply into a topic and to understand thoroughly the answers provided. However, semi-structured interviews may reduce the researcher's control over the interview situation and requires considerable amounts of time and energy for information management and review. Moreover, face-to-face interviews contributes to making 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). Therefore, face-to-face semi-structured interview was considered suitable for data collection in this study on the basis of consideration of achieving the study aim of exploring and understanding self-management of type-2 diabetes from the perspectives of Chinese patients and their family carers.

All 40 participants participated in a face-to-face semi-structured interview lasting approximately 45 minutes to an hour in a consultation room or an office in the diabetes outpatient department in China or in the Chinese organisation in South Wales. With the permission of the participants, each interview was audio recorded using a digital recorder. The interviews followed a prepared topic guide (Appendix 5, 6) which was designed according to the research questions of this study and developed from themes derived from the literature review, and further developed and refined with the development of the interviews. Moreover, in order to prevent participants hiding their real feelings, for example, possibly feelings of unhappiness and pessimism in front of their family members and to collect participants' own views, feelings, and experiences (Chun & Chesla, 2004; Chun *et al.*, 2011), most interviews were undertaken with Chinese patients with type-2 diabetes and their family carers separately. However, four participants wished to be interviewed with their family carers together, and then that was accommodated.

32 out of the 40 participant interviews were carried out in Mandarin in China and Wales, and the remaining eight interviews were conducted in Cantonese in Wales. A same Cantonese- Mandarin interpreter from the Chinese charitable organisation was invited to participate in the interviews to provide oral translation service when eight participants in Wales preferred completing their interviews in Cantonese. The Cantonese-Mandarin interpreter was a trained and experienced interpreter as she had experience of accompanying Chinese people to hospital appointments. Moreover, the interpreter had successfully completed her degree courses in a university in Wales, thus she was also able to speak English fluently. Before attending the eight interviews, I clearly introduced and explained the purpose of this study and research approach to the interpreter and orientated her to the interview topic guide. Additionally I also explained the medical terminologies relating to type-2 diabetes to her in order to improve her ability to explain the terms of type-2 diabetes. Therefore, the interpreter was fully prepared for participating in this study. However, there are still concerns of using interpreters in data collection, which is discussed below.

A significant concern with using interpreters and translators in cross-language qualitative studies is that the quality of data of interpretation and translation can affect the accuracy and validity of the findings (Schultz, 2004; Temple, 2002). Squires (2009) stresses language is a methodological challenge when conducting a cross-language research. Jandt (2003, p.3) points out that interpreters and translators should provide a technically and conceptually accurate translated communication of a concept spoken by the study's participants, namely achieving "conceptual equivalence" during interpretation and translation. In order to ensure conceptual equivalence, interpreters or translators should have a minimum of sociolinguistic language competence, namely the ability to communicate between languages using complex sentences structures, a high level of vocabulary, and the ability to describe uncommon concepts or words when providing translation services (Danesi, 1996; Sauvignon, 1997).

In addition, Temple and Young (2004) emphasise that qualitative researchers should acknowledge the epistemological role of the interpreter and translator in the conduct of research. Failure to recognise their epistemological role in the research process can lead to bias of the results as it does not realise their potential effects on data. The Cantonese interpreter used in this study was a working staff member from the Chinese organisation where this study was conducted. The selection of the Cantonese interpreter was based on the consideration of her adequate skill and experience of providing Cantonese interpretation services. In addition, a qualified Cantonese-English translator was employed from a language service company to ensure the accuracy of interpretation and translation. The main purpose of using the interpreter and translator was to obtain the most technically correct interpretation and translation. I acknowledged the influences of personal experiences and perspectives and attitudes to this study of the interpreter and translator on data collection. I therefore maintained a reflexive stance to seek understandings of these influences. In addition, my supervisors and I were able to use personal experiences and knowledge of Chinese and English and cultures to discuss difficult and complicated passages to reduce the potential influences of the interpreter and translator on this study. Furthermore, the use of interpreter in data collection may also lead to an ethical concern about how to prevent the risk of breaches of confidentiality (Ghandor, Yasmine, & El-Kak, 2013). These issues in terms of how to ensure the quality of data of interpretation and translation and the participants' confidentiality in this study are discussed in detail in the section 3.7.2 and 3.8.2, respectively.

Field notes were taken during each interview, which recorded (1) basic information of the interview such as location, date, and basic demographic and personal information about the participant; (2) new issues that have been coming up repeatedly that were not covered in the interview schedules; (3) issues that should be developed and explored in subsequent interviews; and (4) issues that should be taken into account during data analysis, for example, participants' particular countenance, actions, and gestures during answering questions.

In addition, Brewer (2000) stresses reflexivity by researchers is important to ensure that they are aware of the situated understandings that interview data represent and that they convey this to the reader when writing up. Thus, I maintained reflexive notes after each interview, where I recorded how I felt the interview had gone, any problems, views, or insights, and these recordings were my personal insights (Spradley, 1979), which were helpful in informing analysis of the interview data. Besides semi-structured interviews, observation was also used as a method of data collection in this study, which is discussed in the next section.

3.7.1.2 Observation of diabetes education programme

Brewer (2000, p.59) states that social research involves "observation of people in their natural and social environment." Marshall and Rossman (1989, p.79) define observation as "the systematic description of events, behaviours, and artefacts in the social setting chosen for study". In addition, Merriam (1998) suggests that the most important factor in determining what a researcher should observe is the researcher's purpose for conducting the study in the first place. The aim of this study is to explore and understand self-management of type-2 diabetes from perspectives of Chinese patients and their family cares in China and Wales, and one of the research questions is to explore the sources of support and information accessed by Chinese patients and their family carers regarding type-2 diabetes and self-management. In addition, the findings of the literature review I have conducted in Chapter two demonstrated that the diabetes education programme had a positive and direct influence on self-management of patients with type-2 diabetes from minority ethnic groups. Moreover, some participants also mentioned their experience of attending diabetes education lectures in the interviews. Therefore, I realised it necessary to observe how diabetes education sessions were conducted in China and Wales, what information Chinese patients and their family carers obtained by participating in these diabetes education sessions, and how these diabetes education sessions influenced their understanding regarding type-2 diabetes and self-management. Observing diabetes education sessions provided me with an approach to be immersed in the diabetes education setting to obtain direct experience and information on diabetes education in China and Wales (Mason, 2002).

In China, as the diabetes outpatient department in which I conducted my study took an additional responsibility to provide their patients and local residents with diabetes education lecture, I gained a permission to attend their diabetes education lecture. There was no intention to conduct observation of the diabetes education lecture in a covert manner and it was made clear that the participation of the diabetes education lecture sought to understand how the diabetes education lecture was conducted and what information relating to type-2 diabetes were delivered in the lecture. Therefore, at the beginning of the diabetes education lecture, the lecture provider introduced my participation to all the participants.

I also obtained an opportunity to participate in the X-PERT Diabetes in South Wales, which is a structured and standard diabetes education programme consisting of six sessions and being conducted across Wales. An X-PERT Diabetes educator was informed about this study and my intention to participate, and then my participation was accepted by this educator. There was no intention to conduct the observation of the X-PERT Diabetes in a covert manner and it was made clear that the participation of the programme sought to understand how X-PERT Diabetes was conducted in Wales and what information relating to type-2 diabetes were delivered in the sessions. In the first session of the programme, the diabetes educator introduced my participation to all the participants.

Conducting observation in social research was found to be a complex task and the roles of the researcher in the observation required to be deliberated. Gold (1958) presented a classic classification of the roles that the researcher adopted in the observation, namely complete participant, participant-as-observer, observer-as-participant, and complete observer. In the complete participant role, the researcher's activities are wholly concealed. In contrast to the complete participant, the complete observer has no contact at all with those he or she is observing. Participant-as-observer and observer-as-participant are two midway positions. In the both roles, the researcher's activities are overt, but the participant-as-observer presents more interaction with those he or she is observing than observer-as-participant.

In China, the diabetes education lecture was ad hoc, thus I just attended once. Nearly 50 people including patients with type-2 diabetes and their carers attended the lecture, and the lecture lasted about two hours. The role that I initially developed in the observation was an observer-as-participant because I had little time and chance to interact with the participants within two hours. Therefore, I focused mainly on listening and watching how the diabetes education lecture was conducted. In contrast, in the Wales, I attended a whole X-PERT Diabetes consisting six sessions, 2.5 hours for each session and once a week. It lasted six weeks. 15 patients with type-2 diabetes and their carers attended the sessions. Therefore, I had more chance and time to meet with the group for a period of six weeks. The role that I developed in the X-PERT Diabetes was a participant-as-observer. Therefore, eventually my roles in the observation of diabetes education moved between participant-as-observer and observer-as-participant as Gold (1958) noted.

Brewer (2000) stresses that a proper balance is required between being an insider and outsider, which provides observers the opportunity to be both "inside" and "outside" the setting, to be simultaneously member and non-member, and to participate while also reflecting critically on what is observed and gathered while doing so. Burgess (1982) suggests that personal abilities are important for achieving the balance, including the ability to share, to learn, to remember and to interact with other people Thus, I always kept a friendly and negotiating attitude when I participated in the observations.

Fieldnotes were taken during the observations. Merriam (1998) developed an observation guide in which she compiled various elements to be recorded in field notes, including description of the context, participants, activities and interactions that occur in the setting, frequency and duration of those activities/interactions and other subtle factors, such as informal, unplanned activities, symbolic meanings, nonverbal communication, physical clues, and what should happen that has not happened. Therefore, the fieldnotes taken during the observations included time and location, information about the diabetes educators and the participants, teaching manner and content, the interaction between the educators, participants, and myself. An example of fieldnotes taken in the observation is provided in Appendix 8. Moreover, I also collected data by reviewing participants' self-management records, which is discussed in the next section.

3.7.1.3 Review of self-management records

Much type-2 diabetes self-management was undertaken by people at their homes so it was difficult for me to enter into the setting in which self-management occurred. In addition it was not feasible for me to move into the participants' home and to live with them and then to observe how they conduct self-management every day because it may trigger a series of complicated ethical and legislative problems. However, six participants provided their self-management diaries or records in which daily actions of self-care such as self-testing of blood glucose were recorded after the interviews. By reviewing these diaries or records, I gained information about the participants' documented self-management behaviour and how they looked after themselves at home. Moreover, it was also difficult to undertake observation within any patient-doctor consultation so I did not know whether or how self-care was discussed or not discussed between participants and health care providers although I did collect participants' views on their consultations with health care providers. Therefore, what I have done was to look at where these participants were able to access information about diabetes self-management through reviewing their self-management records such as self-testing blood glucose to gain an insight into how they understood and conducted self-management in their daily lives.

In summary, the data collected in this study included interview transcripts and fieldnotes made in the interviews, observations of diabetes education programme, and self-management records review. Data handing and analysis was conducted after data collection, which is discussed next.

3.7.2 Data handling and analysis

The data collected in this study included:

- Interview transcripts and fieldnotes made in interviews;
- Observations of diabetes education programme;
- Self-management records review.

3.7.2.1 The transcription and translation of the interviews

Of the 40 interviews, 32 were carried out in Mandarin in China and Wales, and the remaining eight interviews were conducted in Cantonese in Wales. All the 40 interviews were transcribed verbatim and then translated into English by myself. The English translations of four out of eight Cantonese interviews were selected randomly and sent back to the interpreter. Then the interpreter reviewed and checked the English translations of the four Cantonese interviews according to their raw audio recording. In addition, to establish rigour, an external qualified Cantonese-English translator formally employed checked the English translations of the four Cantonese interviews according to their raw audio recording again. Therefore, the external qualified translator checked the interpreter's oral translations in the four Cantonese interviews and my English translations. Moreover, English translations of all 40 interviews were checked by my two academic supervisors who are English native speakers. All the data were saved in the form of Word documents. Descriptive statistics of participants' demographics were computed. The qualitative data from the interviews, observational fieldnotes, and the documentary review were thematically analysed.

3.7.2.2 Thematic analysis

Thematic analysis is a method for identifying, analysing, and reporting themes within data, which is used widely in qualitative research. Thematic analysis is essentially independent of theory and epistemology and can be applied across a range of theoretical and epistemological approaches (Braun & Clarke, 2006). Through its theoretical freedom, thematic analysis provides a flexible and useful tool for analysing qualitative data, which can provide a rich and detailed account of the phenomenon under study. Therefore, thematic analysis can be used as a method reporting reality, meanings and experiences of self-management among Chinese patients and their carers, and as a constructionist method, which examines the ways in which the realities, meanings, experiences in terms of self-management are the effects of a range of discourses operating within society and context (Braun & Clarke, 2006). Moreover, thematic analysis moves beyond counting explicit words or phrases and focuses on identifying and describing both implicit and explicit ideas within the data (Braun & Clarke, 2006). However, reliability is a greater concern with thematic analysis than with word-based analysis as more interpretation goes into defining the data items such as codes as well as applying the codes to chunks of text (Braun & Clarke, 2006).

To maximise reliability, the following steps were taken in the analytic process: first, familiarisation with the data was completed through transcribing interviews word for word from the audio records and translating the interviews into English. The transcription process was also assisted with the fieldnotes made in the interviews in order to decipher non-verbal information such as voice tone, countenance, and movements, which provided valuable cues to understanding the emotional status of the participants (Silverman, 2000). Additionally, repeatedly listening to the audio recordings, reading and re-reading the transcripts and fieldnotes, and translating the interview transcripts from Chinese into English were conducted by myself, which also contributed to familiarisation of the data. Second, the initial codes were constructed manually using highlighters and underlining. Qualitative data analysis software such as NVIVO 8 (a software assisting analysing qualitative data) was used to assist with the storage and retrieval of the data. All actual data extracts were coded, and then collated together within each code. Moreover, I compared the codes of the new transcripts with existing codes until no new codes emerged (data saturation). Meanwhile, samples of coded transcripts were reviewed and coded by my supervisors to check the consistency of the coding, and discrepancies were resolved by discussion with the supervisors and comparison of the raw data. Third, different codes were combined to form an overarching theme and then I collated all the relevant coded data extracts within the identified themes. Meanwhile, I created a temporary theme of miscellaneous quotes to accommodate those codes that did not seem to fit into the main themes. At the end of the stage, I had devised a set of potential themes. Fourth, I read all the collated extracts for each theme to examine whether they appeared to form a coherent pattern. In addition, I re-read the entire data set in order to ascertain validity of individual themes in relation to the entire data set and to code any additional data within themes that had been missed in earlier coding stages. After this stage, I reviewed collated data extracts for each theme, and organised them into a coherent and internally consistent account in order to identify the essence of the themes and to determine what aspect of the data each theme captured, and I checked how each theme was relevant to research questions and the relationships between each theme to ensure there was not too much overlap between them. As part of the refinement, I checked whether a theme contained any sub-themes, which were essentially themes-within-a theme and were useful for giving structure to a particularly large and complex theme, and also for demonstrating the hierarchy of meaning within the data. Finally I had a set of fully worked-out themes, and the final analysis pertaining to self-management among Chinese patients and their family carers. An example that demonstrated how a theme was developed by using thematic analysis was provided. (Appendix 10) Many important ethical issues should be considered when conducting an ethnographic study with patients in a health care setting. The following section focuses on these ethical considerations.

3.8 Ethical considerations

Ethical issues should be considered in any sort of research, including ethnography (Hammersley & Atkinson, 2007). The social research process has the potential to create conflict between the aim of research and the rights of participants to maintain privacy and confidentiality (Orb *et al.*, 2000). Ethics pertains to doing good and avoiding harm (Hammersley & Atkinson, 2007). Harm can be prevented or reduced through the application of appropriate ethical principles. Thus, the protection of participants in any social research study is imperative. I paid careful attention to considering and dealing with ethical issues in the specific context of this study. A series of ethical issues related to participants' rights in terms of personal autonomy including informed consent, rights to maintain privacy, rights to keep confidentiality (Hammersley & Atkinson, 2007), which are discussed in the following sections.

3.8.1 Autonomy and informed consent

Capron (2006) states that any research should be guided by the principles of respect for participants, beneficence, and justice. Protection of participants' right to autonomy is a mandate for qualitative research in term of health care (Dresser, 1998; Kvale, 1996; Raudonis, 1992). In addition, Hammersley and Atkinson (2007, p.210) also points out that:

> "...people must consent to being researched in an unconstrained way, making their decision on the basis of comprehensive and accurate information about it; and that they should be free to withdraw at any time."

Therefore, a consent sheet should include clear information about the study in a non-technical and understandable manner so that participants were able to understand the information and their right to make a decision voluntarily to accept or refuse to participate in this study (Royal College of Nursing, 2004). I subsequently developed a consent sheet (Appendix 4) following this advice before conducting fieldwork.

Every potential participant was asked to complete the reply slip which formed part of Participant Invitation Letter (Appendix 2) and return it in the stamped pre-addressed envelope provided. They were not coerced to make a decision immediately as it was important for them to have enough time to make an informed decision. A period of two weeks was allowed for a decision, and I ensured that all potential participants had my contact details so that they could ask any further questions about the study before deciding to participate. Two individuals who indicated on the reply slip that they did not wish to take part were reassured that I would no longer contact them.

Written consent including permission for the interview to be audio recorded was sought from all participants after they had an opportunity to ask questions about the study and prior to their participation in the study starting. It was clearly explained that participation was on a voluntary basis and even if consent was given participants would withdraw from the study at any time without giving an explanation for their decision and with no adverse consequences. With participants with type-2 diabetes it was emphasised that refusal or withdrawal of consent would not lead to any negative effects on their future health care. The second ethical principle was maintaining confidentiality which was an important ethical issue in this study, which is discussed in the next section.

3.8.2 Confidentiality

The risk of breach of confidentiality was carefully considered. All participants were provided with clear information in Chinese (written in traditional and simplified Chinese in the Participant Information Sheet) about the confidential nature of this study.

Confidentiality in the interviews with Cantonese-speaking participants required specific consideration due to the involvement of a Cantonese interpreter. Participants' information and the content of the interview would be accessible to the interpreter. Therefore, as the principal investigator of this study, I ensured a commitment to guarantee confidentiality of participants and a confidentiality agreement form (Appendix 7) was signed by the interpreter before the conduction of interviews in order to ensure that the interpreter was fully aware of the requirement to treat the interviews as confidential. Moreover, the confidentiality agreement was also signed by the external qualified translator to prevent the risk of breaches of confidentiality of participants' information in verifying of English translation of the four Cantonese interviews.

I acknowledged full anonymity of participants was not achieved because the Cantonese interpreter met them face to face and more than likely may have even known them as the Chinese charitable organisation in South Wales is quite close knit. However, overseeing the potential consequences of revealing participants' identities was a moral obligation. Therefore, the following measures were taken in order to maintain confidentiality:

- A commitment to ensure confidentiality of participants and data was signed by the Cantonese interpreter before the conduct of any interviews and by the qualified translator;
- The Cantonese interpreter and the qualified translator were not allowed to keep participants' information, interview record, and notes taken during the interviews, which were submitted to me after the interviews;
- A de-briefing session with the interpreter who was the same interpreter throughout all the Cantonese interviews was conducted after each interview. This provided the opportunity to discuss any issues that may have arisen during the interview and further aided in ensuring that the content of the interview remained confidential;
- Everything discussed in the interviews was treated in the strictest confidence;
- All data collected and participants' contact information were stored in a locked filing cabinet, and on my password protected computer;
- All participants' real name was replaced by pseudonyms during the transcription of all interviews.

Apart from above two main ethical issues, other ethical issues such as the risk of harm, potential benefits for the participants of participating in this study, and the storage and disposal of data also were carefully considered and are discussed below.

3.8.3 Potential benefits and risks to participants

3.8.3.1 Potential benefits to participants

The study did not have any therapeutic benefits for the participants personally. However, I provided the participants with helpful local sources of information on type-2 diabetes and self-management after the interview. Moreover, participation in this study provided the participants with an opportunity to share their feelings and experiences of living with type-2 diabetes, which might be beneficial for other Chinese patients and their family carers and future research.

3.8.3.2 Inconvenience of participation

All participants were interviewed at a venue and time convenient to them in order to reduce any inconveniences for them, for example, avoiding the need to take time away from their work and the need to take too much time to travel to the interview venue.

3.8.3.3 Risk in participant interviews

This study was undertaken "with" the participants and not "on" them, which means that final product of this study being a co-construction between myself and the participants. Throughout the study, I remained aware of my responsibility to ensure that the participants were aware of the purpose of this study and not harmed physically and psychologically due to their involvement in this study. It is acknowledged that the topic and nature of the study which explored participants' understandings, feelings, individual experiences, and challenges of self-management had the potential for the participants to become upset or anxious in the course of the interview. During the interviews, I therefore remained non-judgemental, approachable, and friendly as I could at all times, and I paid attention to observing when the participants presented any signs of physical anxiety or upset. In the event one participant did become upset and nervous, I immediately stopped the interview and supported and consoled her and offering her a list of contact names and details of services which would be able to provide further support, including local health care professionals, health institutions, charitable organisations, and contact helpline and websites. The lady recovered from the negative emotions after obtaining the list and details of services so we continued to the interview. The storage and disposal of data also were carefully considered and are discussed below.

3.8.3.4 Arrangements for storing and disposal of data

All confidential data collected was stored in a locked filing cabinet, and on a secure password protected personal computer. All data was fully transcribed and anonymised with identifiers known only me. In accordance with the conditions of ethical approval, all confidential data including audio recordings, fieldnotes, and transcripts will be destroyed within five years after completion of the study.

One of the biggest challenges confronting qualitative researchers is how to assure the rigour and trustworthiness of their research. The following section provides a discussion regarding how the trustworthiness and methodological rigour of this study is assured.

3.9 Rigor in qualitative research

The trustworthiness and methodological rigour of qualitative research needs to be evaluated and justified against established criteria otherwise qualitative researchers may lay themselves open to criticism from those of the positivist persuasion who regard qualitative research as "merely subjective assertion supported by unscientific method" (Ballinger, 2006, p.235). There is held widely agreement amongst qualitative researchers about the importance of the critical evaluation of research by the application of criteria. However, there is lack of consensus on what kind of evaluation criteria are used to assess qualitative research (Willig, 2001). Qualitative researchers such as Lincoln and Guba (1985) contest and reject the positivist criteria of reliability, validity and generalisability, which provide a basic framework for conducting and evaluating traditional quantitative research. Lincoln and Guba (1985) propose four criteria for naturalistic research, namely credibility, transferability, dependability, and confirmability. Their work to formalise rigour has been particularly influential in social science and they also offer a further dimension of authenticity. Additionally Henwood and Pidgeon (1992) identify seven attributes which characterise good qualitative research. These are the importance of fit, integration of theory, reflexivity, documentation, theoretical sampling and negative case analysis, sensitivity to negotiated realities, and transferability. Madill *et al.* (2000) applying a radical constructionist viewpoint, argue that criteria concerned with confirmability and accuracy are meaningless. They offer three alternatives: internal coherence, deviant case analysis, and reader evaluation. However, the central aim of qualitative research is to provide privilege to the perspectives of research participants and to "illuminate the subjective meaning, actions and context of those being researched" (Popay *et al.*, 1998, p.345). Thus, there are two core criteria to assess the quality of qualitative research, namely whether participants' perspectives have been authentically represented in the research procedures and the interpretations made from information collected, and whether the findings are coherent in the sense that they fit the data and social context from which they were derived.

Padgett (2008, p.1) describes qualitative research as a "family of methods" deriving from a variety of traditions. Denzin and Lincoln (2008, p.4) also explicate "qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them". Increasing number of qualitative researchers will implicitly include or identify a philosophical stance or paradigm to construct their work, for example, social constructivist, post-positivist, and critical theory (Creswell & Miller, 2000; Morrow, 2007). Understanding the theoretical perspectives or paradigm used to guide the study will help the reader to understand the epistemological position of the researchers and the methods utilised to resolve the research question (Drisko, 1997). Thus, Caelli *et al.* (2003) contend that qualitative research should be appraised in a manner which is consistent with its epistemological and methodological perspectives.

As discussed previously, Hammersley's discussion of ontological and epistemological nature of qualitative research particularly of ethnography using the construction of subtle realism is positioned between the stance of naive realism and critical realism. Hammersley (1992), in a discussion of evaluative criteria suitable for ethnography, argues that ethnographic writing should be judged in terms of, firstly, its validity and, secondly, its relevance. Hammersley (1992) also notes that the intensity of application of such criteria may need to be adjusted to the intended audience. Hammersley's (1992) interpretation of the concepts of validity and relevance as criteria to evaluate qualitative research seem the most appropriate for assessing the rigor of this study and is now discussed in the following section.

3.9.1 Validity

Hammersley (1992) conceptualises validity as adopting a position of subtle realism, and he uses "validity" as a synonym of "truth", which has become a taboo word for many social researchers. Additionally, Hammersley (1992, p.69) notes "an account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise." Therefore, validity can be defined as "truth: interpreted as the extent to which an account accurately represents the social phenomena to which it refers" (Hammersley, 1992, p.57). Subtle realism also recognises it is impossible to know with certainty whether an account is true because of the inexistence of independent, immediate, and utterly reliable access to reality (Hammersley, 1992). Nonetheless, the validity of claims on the basis of the adequacy of the evidence offered in support of them must be judged. With respect to the evaluation of validity, Hammersley (1992) suggests that the assessment of validity involves identifying the main claims made by a research, and then comparing the evidence provided for each claim with what is judged to be necessary. Additionally the strategies to increase validity in a qualitative research have been discussed by other authors. For instance, Sandlelowski (1986) argues that a clear description giving details of methodology used including data collection, data coding, and categorisation, and conclusion development can increase validity. Sandlelowski (1996) also suggests that if the decision trail of the researcher can be clearly followed, and another researcher could gain the same or comparable, but not contradictory conclusions given the previous researcher's data, perspectives, and context, validity can be improved. In addition, Lincoln and Guba (1985) discuss the use of an audit trail, which can be defined as an external auditor can judge the trustworthiness of the data and the interpretative processes involved in the analysis, contributes to enhancing validity. Therefore, this requires that decision-making processes of philosophical, theoretical, methodological, and analytical choices should be detailed and justified by the researcher in the presentation of the study. Throughout the thesis I intended to discuss and justify the decision made throughout the conduct of the study. Additionally the presence of the researcher has an immediate and long-term effect on the social phenomena they are studying, and the problem is ubiquitous and the influences of the researcher cannot be eliminated in the majority of ethnographic research (Clammer, 1984). Thus, increased contemporary ethnographic research advocates acknowledging and explicating the effects of researcher influence through the use of reflexivity, which also contributes to increase validity.

3.9.1.1 Reflexivity

Hammersley and Atkinson (2007) advocate researchers adopt the concept of reflexivity because it is impossible to dispel completely the presence or effect of the research process or the researchers' preconception in ethnography. The concept of reflexivity acknowledges that "the orientations of researchers are shaped by their socio-historical locations, including the values and interests that these locations confer on them." (Hammersley & Atkinson, 2007, p.15). Reflexivity is rather more than merely reflection. Horsburgh (2003, p.308) explains reflexivity as "active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation". Reflexivity requires researchers to improve their awareness of personal prejudices, to reflect on actions taken, their roles and emerging understandings, whilst engaged in the research process (Rice & Ezzy, 1999). Reflexivity is also seen as an appropriate strategy to enhance credibility in any qualitative research including ethnographic research (Creswell & Miller, 2000). Reflexivity is therefore not an activity that occurs at one point in time, but it is a process that is carried out throughout the entire research process (Guillemin & Gillam, 2004). The maintaining of reflexivity in this study is discussed in detail in the following section.

Reflexivity was used throughout this study from the formulation of the study questions to the writing up of the study. To improve my reflexive awareness throughout this study, I maintained a reflexive diary, which recorded my reflexive insights, and the ways in which the study findings will have been influenced by my personal sociocultural background, existing worldviews, subjective experiences, and pre-understandings (Aull Davies, 1999). The diary also recorded some analytical memos, and unexpected incidents which happened during the study. The reflexive diary was significant for me because it provided an outline of my thinking, and inspired me when I was unhappy with the study progress, and reminded me of what I had achieved and what I needed to do more. In addition, in the write up of the study, I drew on notes from the diary to aid in justifying all decisions made throughout the conduct of the study and in so doing provide an audit trail for readers. Two examples of reflexive diary written after participants interviews are provided in Appendix 9. Moreover, the use of reflexivity also aided me identifying my "insider" and "outsider" perspectives in this study, which is discussed in the next section.

"Insider" and "outsider" perspectives are consequential for social research because they have impact on the process and findings of a study, and the arguments made by the researcher about the implications of findings. "Insider" perspectives are those taken by a researcher who is a member of the social groups being studied. "Outsider" perspectives are those taken by a researcher who is an outsider to the social groups being studied (Dwyer & Buckle, 2009). Therefore, as I have a Chinese background I was in one sense an "insider" because of our shared ethnicity but in another sense I was not especially with the participants who immigrated to Wales because we lived in a different cultural and social context and even spoke different language (Mandarin and Cantonese). Thus, the boundaries between "insider" and "outsider" may be blurred and are not as clear cut as the literature espouses. In China, I felt it easier to establish a good relationship with the participants as we lived in a same social and cultural context and the participants were more willing to share their feelings and experiences because we had a good communication with shared accent. Therefore, I was able to identify more with the participants in China than those in Wales. However, I had to be mindful that I maintained reflexivity and a critical stance and did not take at face value what the participants in China described because of my familiarity with social context, cultural beliefs, and health care system.

Apart from reflexivity, audit trails based on a good presentation of this study was used to enhance the validity of this study, which is discussed in the next section.

3.9.1.2 Audit trails

The origins of audit trails in qualitative research appear to reside in the work of Lincoln and Guba (1985). Lincoln and Guba (1985) regard audit trails as one of the principal techniques for establishing the confirmability of qualitative findings. Koch (2006) suggests that a study's trustworthiness may be established if a reader is able to audit the events, influences and actions of the researcher. Additionally Akkerman *et al.* (2006) suggest that audit trails represent a means of assuring quality in qualitative studies. An audit trail is a written account regarding the research process that includes a reporting of what occurred throughout the research project along with a demonstration of reflexivity (Lincoln & Guba, 1985). In developing an audit trail, a researcher provides an account of all research decisions and activities throughout the study. A researcher makes explicit all decisions taken about theoretical, methodological and analytic choices (Koch, 2006). Therefore, an audit trail is based on a good presentation of a study. In the presentation of this study, I described the study throughout from the formulation of the research questions to writing up of the study, and the decision-making process regarding philosophical, theoretical, methodological and analytic choices was also detailed. Moreover, Creswell and Millar (2000) point out in order to develop a detailed audit trail, the researcher needs to maintain a log of all research activities, develop memos, maintain research journals, and document all data collection and analysis procedures throughout the study. Therefore, I maintained a reflexive diary, recorded fieldnotes, and the notes of data analysis in order to present an audit trail. An audit trail also requires clarification and self-reflection on the researcher's part (Akkerman *et al.*, 2006). Thus, I consistently evaluated whether the findings were grounded in the data, and whether inferences were logical. In addition, the audit trail helps readers to follow each stage of the process and helps other researchers determine whether the study's findings may be relied upon as a platform for further research and as a basis for decision making. Moreover, triangulation was also used to achieve reliability, which is discussed below.

3.9.1.3 Triangulation of data sources and analysis

Triangulation is the utilisation of "two or more sources to achieve a comprehensive picture of a fixed point of reference" (Padgett, 2008, p.186). Drisko (1997) also points out that qualitative researcher are capable of achieving "completeness" or an exhaustive response to the research question through collecting data from multiple sources (data triangulation) or using multiple analysts to review the data (observer triangulation). Three methods including participant interviews, observation of diabetes education programme, and self-management records review were used in order to gain a full picture of Chinese patients and their family carers' understanding and experiences of self-management of type-2 diabetes. In addition, transcripts and English translations of all interviews were reviewed by my supervisors and I also verified the accuracy of my coding with my supervisors. Therefore, I and my supervisors were involved in the analytical process. Therefore, the completeness of this study was achieved through triangulation of data collection and analysis.

Overall, validity was enhanced through maintaining reflexivity throughout the study and using audit trails and triangulation of data collection and analysis. The second criterion to appraise qualitative research proposed by Hammersley (1992) is relevance and it is now discussed in the context of this study.

3.9.2 Relevance

Hammersley (1992, p.73) identifies two core aspects of relevance, namely "Importance of topic" and "Contribution to the literature". An evaluation can be made in terms of the importance of the studied topic to a substantive field and its relevance to wider societal values and contexts. Moreover, the relevance of a research is judged by its contribution to the literature. Hammersley (1992, p.73) stresses that "research that confirms what is already known well is of little value." A research must achieve a significant contribution to what is established knowledge, namely completing an innovation and theoretical development (Lofland, 1974, Athens, 1984). Although qualitative research does not seek generalisability due to a lack of probability sampling, if the findings and analytical insights are found meaningful and to have potential to fit situations outside of the study then a contribution to theoretical development can be made. Hammersley (1992) also acknowledges that as differentiation of social research community in terms of its specific research problems and methodological and theoretical approaches the assessment of relevance of a research may vary among different audiences. Thus, a research may be judged relevant or irrelevant "not only in terms of its relation to some topic of interest but also on the basis of its exemplification of some methodological or theoretical paradigm" (Hammersley, 1992, p.73).

I completely agree that the relevance of this study can be achieved if the study's findings are demonstrated to fit with other situation outside the study and readers judge that these findings are meaningful and applicable according to their own experiences (Sandelowski, 1986). Devers (1999, p. 1165) points out that in order to achieve the transferability of findings,

> "...the contexts must be similar. Therefore, it is the role of the researcher to identify key aspects of the context from which the findings emerge and the extent to which they may be applicable to other contexts."

Thus, I have sought to provide sufficient information regarding the locations and settings of the study whilst maintaining the participants' confidentiality to enable the readers to judge the transferability of the findings. The validity and relevance of this study is discussed and assessed in the Chapter ten.

3.10 Summary

In this chapter the research methods and methodology used in this study have been described and the decision-making process for all stages of the research process including data collection and analysis has been justified. Prior to the presentation of the findings and discussion chapters I provide an introduction to the theories used to interpret the findings which now follows.

Chapter Four Introduction to findings

4.1 Introduction to the analysis

An introduction to the analysis of the findings of this study is presented in this chapter. Firstly, an overview of the characteristics of the participants is provided. This is followed by a brief discussion of the main theoretical frameworks that were drawn on to aid analysis and understanding of the data and therefore to explore the perspectives and practices of self-management from Chinese patients and their family carers in China and Wales. A number of theoretical perspectives have been drawn upon to make sense of the data. These included psychophysiological comparison theory (PCT) (Cacioppo *et al.*, 1989), sociological approach (Zola, 1973), social comparison theory (Festinger, 1954), health locus of control (Wallston & Wallston, 1982), theory of planned behaviour (TPB) (Ajzen & Madden, 1986), health belief model (HBM) (Becker, 1974), cognitive adaptation theory (CAT) (Taylor, 1983), theory of social stigma (Goffman, 1968), self-determination theory (SDT) (Deci & Ryan, 1985). In addition, salutogenesis (Antonovsky, 1979) as a primary theoretical insight was used throughout this study to interpret and understand the findings. According to Hammersley (1992), the core aspect of relevance of the findings in an ethnographic study is their potential contribution to development of existing theoretical concepts. The application of salutogenesis (Antonovsky, 1979) not only embedded the findings with theoretical significance but also contributed to its development as a theoretical framework by promoting understanding of the self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales. This is then followed by an outline of the key themes from this study which constitutes the five findings and discussion chapters. Firstly, the characteristics of the participants are detailed.

4.2 The demographic characteristics of the participants

The sample comprised 40 Chinese patients with type-2 diabetes and their family carers from China and Wales. Of the sample, 20 out of the 40 participants, including 13 patients with type-2 diabetes and seven family carers were recruited in China. The remaining 20 participants, 13 Chinese patients with type-2 diabetes and seven family carers were recruited in Wales. The amount of female participants was more than male (23 vs 17). The age range of the participants was between 47 to 81 years (mean = 62.4

years). In China, the participants had diverse occupational backgrounds, including health care professionals, teachers, governmental officials, agricultural workers, and retired pensioners. Most participants in Wales were retired manual workers and waitresses, and were working in catering. Compared with the participants in China, they had less diversity of occupational backgrounds.

In terms of the level of income among the participants, according to the Statistics Bureau of Kunming (SBK), the average disposable annual income (ADAI) in Kunming was ¥ 51,100 (equal to £5,110) (¥: Chinese Currency Sign) in 2014 (SBK, 2015), but the ADAI was ¥ 68, 953.80 (equal to £6,895.38) among patients and was ¥ 38,571.48 (equal to £3857.15) among family carers in this study in China. In Wales, the ADAI was £14,623 in 2014 (Office for National Statistics, 2015b), but the ADAI among patients and family carers in this study was £11,314.20 and £10,800, respectively. Therefore, the patients in China had an above average annual income whereas in Wales they had a lower annual income. This may be attributed to the higher number of the participants in Wales who were retired and therefore reliant on pension or benefit.

In China, the mean years in education were 7.75 in the patients and 9.00 in family carers, and eight out of the 20 participants had a degree or a diploma whilst two participants reported that they had never been educated in school. In Wales, the mean years in education were 9.46 and 10.29 in the patients and family carers, respectively. All participants had education background, with 12 out of the 20 participants reporting school education for 12 years. None reported that they had a degree or a diploma. Therefore, both patients and their family carers in Wales had more years of education than the patients and their family carers in China. The possible explanation was that most patients and their family carers in Wales were first generation immigrants from Hong Kong where there is better public education system than mainland China. Moreover, both in China and Wales, family carers had better level of education than the patients.

All participants in China were married and all 13 patients reported they were living with their family carers, primarily their spouse. Whilst seven out of 13 patients in Wales lived with their family carer, and the remaining six patients lived without a family carer due to an unmarried or widowed status or no family members in Wales. All patients in

China reported they were covered by the Basic Social Medical Insurance (BSMI), and all patients in Wales also reported they were eligible to access National Health Services (NHS), which provides patients with medical care services free of charge.

In addition, 11 out of the 26 patients both in China and Wales reported a family history of type-2 diabetes. Moreover, all 20 participants in Wales mentioned their immigration history, with finance and reunion of family as the most common reasons for moving to Wales. 10 out of the 20 participants have been resident in Wales for more than 20 years, and all patients had developed their type-2 diabetes after settling in Wales. The detailed demographic characteristics of participants are summarised in **Table 2**.

Table 2: Characteristics of the participants

Characteristics	**Patients (n=26)**		**Carers (n=14)**	
	living in China, n (%)	**living in Wales, n (%)**	**living in China, n (%)**	**living in Wales, n (%)**
Gender				
Male	6 (23.08)	5 (19.23)	3 (21.43)	3 (21.43)
Female	7 (26.92)	8 (30.77)	4 (28.57)	4 (28.57)
Age (years)				
Mean	61.83	63.46	64.29	60.00
40-50	2 (7.69)	0	1 (7.14)	2 (14.29)
51-60	4 (15.38)	5 (19.23)	1 (7.14)	1 (7.14)
61-70	4 (15.38)	5 (19.23)	4 (28.57)	3 (21.43)
71-80	3 (11.55)	2 (7.69)	1 (7.15)	1 (7.14)
> 81	0	1 (3.85)	0	0
Yearly income (Yuan/GBP)				
Mean	68, 953.80	11,314.20	38,571.48	10,800.00
12,000-36,000 / 1,200-3,600	3 (11.54)	0	4 (28.57)	0
36,001-60,000 / 3,601-6,000	5 (19.23)	1 (3.85)	3 (21.43)	1 (7.14)
60,001-84,000 / 6,001-8,400	2 (7.69)	1 (3.85)	0	0
84,001-120,000 / 8,401-12,000	2 (7.69)	9 (34.61)	0	2 (14.29)
>120,001 / >12,001	1 (3.85)	2 (7.69)	0	4 (28.57)
Marriage Status				
Married	13 (50.00)	9 (69.24)	7 (50.00)	7 (50.00)
Single	0	2 (15.38)		
Widowed	0	2 (15.38)		
Years in Education				
Mean	7.75	9.46	9.00	10.29
0-9	5 (19.24)	5 (19.23)	1 (7.14)	3 (21.43)
10-15	4 (15.38)	8 (30.77)	4 (28.57)	4 (28.57)
>16	4 (15.38)	0	2 (14.29)	0
Yeas of living with type-2 diabetes				
Mean	5.23	6.17		
0-5	7 (26.93)	5 (19.23)		
6-10	2 (7.69)	4 (15.38)		
>11	4 (15.38)	4 (15.38)		
Living with family carer				
Yes	13 (50.00)	7 (26.92)	7 (50.00)	7 (50.00)
No	0	6 (23.08)		
Family history of type-2 diabetes				
Yes	4 (15.38)	7 (26.92)		
No	9 (34.62)	6 (23.08)		
Years of living in Wales				
Mean		20.69		21.00
0-10		2 (7.69)		0
11-20		5 (19.23)		3 (21.43)
>21		6 (23.08)		4 (28.57)
Covered by BSMI				
Yes	13 (100)			
No				
Access to NHS in Wales				
Yes		13 (100)		
No				

4.3 Main theoretical frameworks used in this study

The findings of the study demonstrated that Chinese patients' self-management of type-2 diabetes happened in a social and cultural context which was dynamic and complicated. It might be impossible to fully explain and understand Chinese patients' self-management by drawing upon one or two theories. Therefore, a number of sociological, psychological and health promotion theories were drawn on to gain a full understanding of Chinese patients' self-management in this study. The purpose of introducing these theories briefly prior to the presentation of the findings and discussion chapters is to aid the reader in understanding the interpretation of the data. These theories became relevant to analysing the data and were not predetermined

In Chapter five, I discuss the Chinese patients' medical care-seeking behaviour. According to the psychophysiological comparison theory (PCT) (Cacioppo *et al.*, 1989), the detection of unexplained signs and symptoms can motivate individuals to evaluate their physiological condition by biological disposition. Therefore, this theory was drawn on to aid understanding of medical care-seeking behaviour of the Chinese patients in relation to serious and novel physical signs and symptoms. However, PCT did not aid understanding of the role of family and social help in Chinese patients' medical care-seeking behaviour which was highlighted by the data. Thus, Zola's (1973) theory of sociological approach helped to illuminate this finding.

Zola's (1973) model identified five different types of incident which can trigger the decision to seek help, including interpersonal crisis, perceived interference with work activity, perceived interference with social and leisure activity, pressure from other people who insist help be sought, and symptoms persist beyond arbitrary time limit set by the individual. In addition, this model also identified the importance of lay referral system for seeking help among people after they perceived physical symptoms. Moreover, in Chapter five, the findings also showed that although most Chinese patients presented a negative emotional response to their condition, several patients had relatively positive attitude toward their diagnosis of type-2 diabetes, which can be explained by Festinger's (1954) social comparison theory.

According to social comparison theory (Festinger, 1954), individuals are motivated to gain accurate assessments of their opinions and abilities and do so by comparing them with the opinion and ability of similar others. Comparison with others worse off than oneself is referred to as downward social comparison, which contributes to improving one's self-esteem and to self-enhancement. This theory has been used in previous work to explain patients' positive perceptions regarding their condition. For example, Wood *et al.* (1985) examine patients' references to social comparison process among 78 patients with breast cancer and found that the downward comparison processes were conductive to increasing perception of positive consequences of illness among patients. Nevertheless, social comparison theory (Festinger, 1954) cannot fully explain the impact of such positive attitudes to type-2 diabetes on self-management. Thus, health locus control (Wallston & Wallston, 1982) was drawn on to aid understanding this impact.

The concept of locus of control was developed by Rotter (1966) in order to investigate aspect of personality. Rotter originally considered individuals to have either an internal locus of control orientation or an external orientation. The internal and external dimension of attribution theory has been specially applied to health in term of the concept of a health locus of control. Wallston and Wallston (1982) develop a measure of the health locus of control which evaluates whether an individual believes his /her health as controllable by himself/herself (internal), whether an individual considers his /her health is not controllable by himself/herself and in the hands of fate (external), or whether an individual regards his /her health as under the control of powerful others. Therefore, health locus control (Wallston & Wallston, 1982) contributes to understanding the negative impact of overreliance on family carers and health care providers on their self-management, which are presented and discussed in Chapter five. However, Ajzen and Madden (1986) develop the theory of planned behaviour (TPB) which can be used to explain and understand how to improve self-management among Chinese patients.

The TPB conceptualises behavioural intentions as plans of action in pursuit of behavioural goals (Ajzen & Madden, 1986), and are a result of a combination of the three beliefs including attitude to a behaviour, subjective norm, and perceived behavioural control. This theory has been used to promote self-management of diabetes through stressing the importance of understanding of diabetes and lifestyle change and family and social support in the control of blood glucose. This theory has been applied to aid understanding self-management of patients with diabetes. For instance, White *et al.* (2012) conducted a randomised controlled trial (RCT) evaluated the effectiveness of a four-week extended TPB intervention to improve regular physical activity and healthy eating among older people diagnosed with type-2 diabetes or cardiovascular diseases (n=183) and found TPB-based interventions including planning strategies contributed to promoting physical activity among older people with type-2 diabetes and cardiovascular diseases. In addition, Hwu and Yu (2006) conducted a study with 36 Taiwanese people with various chronic conditions to identify the determinants of attitude affecting adoption of health behaviours by using TPB and found social support including family members, social networks, and health professionals were major referents that influenced health behaviour adoption. Therefore, TPB helped to make sense of the importance of family and social support in self-management of type-2 diabetes for the Chinese patients in this study. Besides family and social support, the level of knowledge on type-2 diabetes also had positive influence on Chinese patients' self-management. Therefore, health belief model (HBM) (Becker, 1974) was drawn on to explain why a family history of type-2 diabetes can influence Chinese patients' level of knowledge on type-2 diabetes

Becker (1974) developed the HBM in order to predict preventive health behaviour and the behavioural responses to treatment in acutely and chronically ill patients. The components of the HBM include the individual's perception of their susceptibility to the illness, the severity of the illness, the costs involved in carrying out the behaviour, the benefits involved in carrying out the behaviour, and internal or external cues to action (Becker, 1974). Therefore, HBM contributed to understanding why Chinese patients were more likely to be motived to obtain information and change behaviour when they obtained information regarding type-2 diabetes and its complication from their family members' real experience of living with type-2 diabetes, which is presented and discussed in Chapter six.

The findings in Chapter seven demonstrated that although most Chinese patients considered type-2 diabetes as an adversity for their life and family, some patients realised the positive influence of type-2 diabetes on their life. This finding can be explained by drawing on the cognitive adaptation theory (CAT) (Taylor, 1983). According to CAT (Taylor, 1983), successful adaptation to victimisation is accomplished through engagement in a series of positive self-relevant cognitive distortions. That is, the adjustment process in response to a threatening event involves: a search for meaning where the individual tries to achieve or maintain an optimistic attitude towards the event or towards life in general, an attempt to regain mastery over the event or over one's life in general, and a process of self-enhancement. These three processes are central to developing and maintaining illusions, which are necessarily consistent with reality and are positive interpretations of that reality, and that these illusions constitute a process of cognitive adaptation. Therefore, CAT was used in this study as an approach to explore and understand Chinese patients' psychological adjustment process in response to having type-2 diabetes and its influence on self-management. Furthermore, several Chinese patients reported that they encountered social stigma and discrimination in their communities, which negatively impacted on their social activities and the conduct of self-management. Therefore, Goffman's (1968) theory of social stigma was drawn on to understanding this issue.

Goffman (1968, p.14) defines stigma as "a special kind of relationship" between virtual social identity, that is, the stereotyped imputation we make in everyday life, and actual social identity, namely those attributions which an individual does actually possess. According to Goffman (1968), there are four factors influencing the likelihood of stigmatisation, including the extent to which the signs or symptoms of a condition are recognised by other people, the extent to which others are aware of an illness, the extent to which the flow of interaction is impeded, and the perception that others have about an individual's ability to participate fully and normally. Goffman's theory of social stigma provides a theoretical model to explain and understand the causes of stigma related to type-2 diabetes among Chinese patients and also contributes to identifying strategies to address diabetes-related stigma in Chinese communities. Besides eliminating stigma and discrimination and establishing a supportive social context, motivations were important factors which influenced Chinese patients' self-management which was illuminated by self-determination theory (SDT) (Deci & Ryan, 1985).

SDT is an approach to human motivation and personality that uses traditional empirical methods while employing an organismic metatheory that highlights the importance of humans' evolved inner resources for personality development and behavioural self-regulation (Ryan *et al.*, 1997). In SDT (Deci & Ryan, 1985), two different types of motivation based on the different reasons or goals that give rise to an action were distinguished. These are intrinsic and extrinsic motivation. Intrinsic motivation is defined as doing of an activity for its inherent satisfaction rather than for extrinsic consequences. When intrinsically motivated a person conduct an activity for the fun or challenge entailed instead of for external prods or pressure. In contrast, extrinsic motivation is a construct that pertains whenever an activity is conducted in order to attain separable outcomes. Although intrinsic motivations is an important type of motivation, much of what people do is not intrinsically motivated, especially when the freedom to be intrinsically motivated is increasingly curtailed by social pressures to do activities that are not interesting and to assume a variety of new responsibilities (Ryan & La Guardia, 2000). Additionally according to SDT (Deci & Ryan, 1985), there are three psychological needs which motivate the self to initiate behaviour and specify nutriments that are essential for psychological health and well-being of an individual. These needs are competence, autonomy, and relatedness, which are characterised to be universal, innate and psychological.

SDT has been used in the research into self-care behaviour among patients with type-2 diabetes. Seo and Choi (2011) conducted a study with 218 patients with type-2 diabetes mellitus to develop a model which explains self-care behaviour in patients with type-2 diabetes based on SDT and found that competence and autonomous motivation were the strong factors influencing self-care behaviour among participants, and so stressed support from health care provider for autonomy was a significant indirect factor on self-care behaviour. Therefore, the use of SDT also contributes to explaining and understanding the importance of social support from health care professionals, family carers and other social resources in Chinese patients' self-management, which is presented and discussed in Chapter eight. Nine theories were used in this study in order to aid understanding of a different aspect which was not fully explained through applying just one or two theories. However, salutogensis (Antonovsky, 1979) helped to bring these theories together and provide an overarching framework to aid understanding the findings, which is discussed in next section.

4.4 Salutogenesis

Salutogenesis is a concept derived from the work of Antonovsky (1979), which considers the experience of health as movement along a continuum of ease/dis-ease.

The salutogenic approach focuses on factors that support human health and well-being. Some fundamental concepts came out of Antonovsky's primary research and these have been investigated further in recent years. These core salutogenic concepts include generalised resistance resources (GRRs) and a sense of coherence (SOC) (Antonovsky, 1979).

GRRs are biological, material and psychosocial factors which make it easier for people to understand and structure their lives (Antonovsky, 1979). Typical GRRs include material and emotional factors such as money, knowledge, experience, self-esteem, healthy behaviour, commitment, social support, cultural capital, intelligence, cultural traditions and one's view of life (Antonovsky, 1996). Self-management of type-2 diabetes stresses patients' knowledge and skills to make changes in lifestyle and to manage the symptoms, daily treatment, physical and psychological consequences in daily lives. Therefore, an effective and enduring self-management is closely associated with a variety of support from family, health care providers, and other social resources. GRRs provide a theoretical concept to aid understanding of the importance of support resources in self-management of type-2 diabetes.

Whilst GRRs identify important resources, a sense of coherence (SOC) provides the capability to use them. That is, SOC explains how GRRs work to help people to cope with challenges. SOC is a positive method of looking at life alongside an ability to successfully manage the challenges encountered throughout life. Three types of life experiences shape the SOC, namely, comprehensibility (challenges have a certain predictability and can be understood), manageability (resources to cope are available and accessible) and meaningfulness (having willingness and motivation to cope) (Antonovsky, 1996).

Antonovsky (1993) developed a scale of SOC, which has been widely tested across different population groups and settings in order to confirm these components of SOC more widely in terms of their relationship to health. In addition, Eriksson and Lindström (2006) conducted a systematic review and concluded that the salutogenic model was a health promoting resource in which it provides means by which individual resilience might be enhanced and people may be helped to feel physically and mentally healthy, with a good quality of life and sense of well-being. However, although salutogenesis provides a different and unique approach to understanding the relationship between health and illness, studies which explore Chinese patients' understanding of self-management of type-2 diabetes on the basis of salutogenesis (Antonovsky, 1979) were not found. Additionally Antonovsky (1996) contends that people's understandings in terms of health and coping resources may greatly vary in different cultural and social contexts. Therefore, as will be shown the self-management of type-2 diabetes as experienced by Chinese patients and their family carers in two different contexts of China and Wales, the influence of Chinese culture on self-management was illuminated by drawing on the model of salutogenesis (Antonovsky, 1979). In the next section the themes of the thesis are introduced.

4.5 Key themes

After a rigorous analysis of the data, five key themes were generated which capture the complexity of experiences of Chinese patients and their family carers regarding self-management of type-2 diabetes.

The first theme, "Symptom perception and emotional responses to being diagnosed with type-2 diabetes" is presented and discussed in Chapter five. In this theme it will be shown that there were two main routes by which Chinese patients were diagnosed with type-2 diabetes. The second theme is presented in Chapter six and explores the level of diabetes-related knowledge of Chinese patients and their family carers both in China and Wales and the factors influencing their level of diabetes-related knowledge. In addition, the third theme is about what diabetes information sources Chinese patients and their family carers in China and Wales have access to and any barriers to accessing reliable information sources. In Chapter seven the positive and negative influences of type-2 diabetes on Chinese patients and their family carers lives are discussed. It will be shown that for some patients being diagnosed with type-2 diabetes yielded unanticipated benefits. A key finding of this study related to the importance of family support which is presented and discussed in Chapter eight. This chapter provides a discussion about how Chinese patients in China and Wales conducted self-management of type-2 diabetes in their daily lives, helped and supported by family carers. It will be shown that for those patients who did not have family carers that this posed challenges. In the final theme in Chapter nine, I discuss the barriers and facilitators of self-management of type-2 diabetes among Chinese patients and their family carers. In addition there is a focus upon Chinese cultural norms and how Chinese cultural beliefs influenced Chinese patients' self-management and how moving to a different cultural context influenced self-management specifically among Chinese patients in Wales, both negatively and positively. A discussion on the application of salutogenesis (Antonovsky, 1979) to aid understanding of self-management in Chinese patients and their carers is also presented in Chapter nine. The sub-themes and themes are summarised in **Table 3 (1-2)**.

Before commencement of the presentation of findings, the abbreviations used in the quotations need to be clarified. In the abbreviations for participants, the first letter W (Wales) or C (China) indicates the place where the participants come from, the second letter F (female) or M (male) denotes the gender of the participants. DP means the participant is a patient with type-2 diabetes, and DPC means the participant is a carer living with a patient with type-2 diabetes. The last number indicates the participants instead of their real name.

Moreover, this study includes Chinese patients and their family carers. Thus, I used the term of patient to differentiate from carer in the text. I recognise that the participants may not view themselves as patient. However, participant is appropriate when I refer to both patient and carer.

Table 3-1: Summary of sub-themes and themes

Categories	Sub-themes	Themes
Characteristics of physical sensations	Diabetes-related symptoms route to diagnosis	The detection of type-2 diabetes
Emotional responses to physical sensations		
Social triggers		
Symptomless	Opportunistic route to diagnosis	
The lack of awareness of symptoms		
Perception of severity	Negative emotional responses	Emotional responses to the diagnosis of type-2 diabetes
Worry about the cost of diabetes care		
Worry about losing traditional role in the family		
Optimistic outlook on type-2 diabetes	Positive emotional responses	
Ignorance bliss		
Diabetes is a “long-term disease”	Diabetes-related knowledge	Diabetes-related knowledge and information sources
Causes of type-2 diabetes		
Complications of type-2 diabetes		
Socioeconomic status and education level	The factors influencing level of knowledge of type-2 diabetes	
Communication with health care professionals		
Family support		
Health care professionals	Information sources	
The media		
Lay interpersonal sources		
Public health lectures		
Daily activities	Negative consequences	The consequences of type-2 diabetes
Employment		
Family relationships		
Social activities		
Improved attention to health	Positive consequences	
Changes in lifestyles		
Enhanced family relationships: “True love”		

Table 3-2: Summary of sub-themes and themes

Categories	Sub-themes	Themes
Daily dietary change Increase in exercise	Modifying lifestyles	The practices of self-management
Self-monitoring of blood glucose levels		
Perceived need: “medication was beneficial” Trust in health care professionals Family support	Adherence to daily medication treatment	
Maintaining traditional family role Maintaining good interpersonal relationships with wider social networks Low level of acculturation	Cultural barriers to self-management	Barriers and facilitators of self-management, cultural perspectives
Family harmony and social mutual support Philosophy of Chinese traditional medicine	Cultural facilitators of self-management	

4.6 Summary

In this chapter the demographic characteristics of participants was detailed. A number of different theories that have been drawn on to explain and aid understanding of the findings in terms of self-management of type-2 diabetes among Chinese patients and their family carers have been presented and described. In addition, salutogenesis (Antonovsky, 1979) which was used throughout the findings and discussion chapters as a primary theoretical model to explicate and understand the findings has also been introduced. In the final section, an overview of the five themes of the study was provided.

The following chapters present the findings and discussion and commences with the first theme, namely, symptom perception and participants' emotional responses to being clinically diagnosed with type-2 diabetes.

Chapter Five Symptom perception and emotional responses to type-2 diabetes

5.1 Introduction

In this chapter, I present data from Chinese patients with type-2 diabetes and their carers in China and Wales which indicates how their condition was detected and their emotional responses to the diagnosis. Firstly, the detection of type-2 diabetes among Chinese patients is presented and discussed in the following section.

5.2 The detection of type-2 diabetes

Type-2 diabetes onsets mostly among adults over aged 40 years (Krentz & Bailey 2001). The early physical sensations caused by type-2 diabetes including tiredness, frequent thirst and urination, increasing appetite, and weight loss are untypical and mild and even transient (Krentz & Bailey 2001). It is therefore important for patients with type-2 diabetes to identify these physical sensations as medical symptoms which lead to medical seeking behaviour in order to detect their condition at an early stage. In this study, two main routes of detection of type-2 diabetes among Chinese patients were identified. 17 out of 26 patients with type-2 diabetes in this study were motivated to seek medical help after they had experienced some initial physical sensations such as tiredness, frequent thirst and urination, increasing appetite, weight loss, sweating, and dizziness. Having identified symptoms they were clinically diagnosed with type-2 diabetes in hospital after completing blood glucose tests. I have termed this route as the "diabetes-related symptoms route to diagnosis". The remaining nine patients detected their type-2 diabetes opportunistically during routine physical examinations or when seeking medical help for other health reasons. I have named this route as the "opportunistic route to diagnosis". The identification of the two routes to diagnosis contributes to understanding the Chinese patients' diabetes-related symptom perception and medical help-seeking behaviours and to exploring the factors influencing their symptom perception and medical help-seeking behaviours.

The majority of patients from both China and Wales in this study were tested and diagnosed for type-2 diabetes because of reported physical sensations. A typical comment was:

> "About 20 years ago, I started feeling fatigue, sweating, thirst, and weight loss and so I went to hospital to see a doctor and the doctor tested my blood sugar and then he told me the result was very bad, more than 19 (mmol/L). So I was asked to stay in the hospital to receive full blood sugar assessments in order to explore the reason for increase in blood sugar and confirm the diagnosis of diabetes. After finished the full blood sugar tests, the doctor told me I had been diagnosed with type-2 diabetes."
>
> (CFDP6)

Whilst in Wales, a female patient reported going to the GP due to perceived weight loss but her GP detected potential signs of diabetes:

> "In 2008, I found my weight had decreased by five kilograms **sharply**. I was **very** nervous about it so I went to see my GP. The GP tested my blood sugar and found my blood sugar had increased to 12 (mmol/L) so the GP asked me to go to hospital to have a further blood sugar tests. When the results of the blood sugar tests come back to my GP, the GP told me I had been diagnosed with type-2 diabetes."
>
> (WFDP1)

These two Chinese patients described a normative route of experiencing physical sensations which prompted their contact with health services either directly to a hospital in China or via primary care service mainly GP in Wales. Therefore, subjectively experienced physical sensations, which may be associated with type-2 diabetes were important triggers for medical care-seeking behaviour among the Chinese patients both in China and Wales.

On the other hand nine patients in this study were diagnosed with type-2 diabetes opportunistically. A male patient from China described his opportunistic experience of being diagnosed with type-2 diabetes:

> "Two years ago, I attended a yearly physical examination in a health centre organised by my employer, my blood sugar was found to be increased in the examination. After that, I went to hospital to see a diabetic specialist and then the doctor asked me to do a series of blood sugar tests. Unfortunately, the results of the blood sugar tests were abnormal as well and the doctor told me I had got type-2 diabetes."
>
> (CMDP1)

In addition, a male patient from Wales reported that although he had experienced some physical sensations, he sought medical help due to a persistent unhealed thumb injury rather than those physical sensations, which suggested that he failed to identify the physical sensations as medical symptoms.

> "My disease was found out opportunistically three years ago. My left thumb was injured by a kitchen knife when I made food. The wound was not very serious so I cleaned it using clean water and wrapped it around using a plaster. However, three week later, the injury had not healed and it was getting worse and worse, my left thumb became very painful and swollen so I made an appointment to see my GP. My GP checked my left thumb and told me it would be infected, and then my GP tested my blood sugar, and it indicated 9.5 (mmol/L). My GP told me I needed further blood sugar tests after the injury of left thumb had healed in order to confirm the diagnosis of type-2 diabetes. **Frankly,** I used to have bad feelings such as thirst, tiredness, sweating, headache but I did not pay more attention to them because I have too much work to do every day. Eventually, when I finished the blood sugar tests and then I was diagnosed with type-2 diabetes."
>
> (WMDP3)

The findings support the notion that there are two reasons why patients found out their condition opportunistically, namely symptomless or failure to identify the physical sensations as medical symptoms. However, it is difficult to judge whether those patients who were detected opportunistically were previously symptomless or alternatively failed to identify physical sensations as medical symptoms. Nevertheless from reading their reported illness experiences, it is proposed that for those patients who were diagnosed opportunistically, there was a common failure to identify the physical sensations as medical symptoms. Therefore, it is important to explore the reasons for failure to identify the physical sensations as medical symptoms. However, firstly, the first route most patients took to gain a diagnosis of type-2 diabetes is discussed in detail in the following section.

5.2.1 Diabetes-related symptoms route to diagnosis

In the study, 17 out of 26 patients took the diabetes-related symptoms route to arrive at their diagnosis, including four male and 13 female patients. Seven patients were from China and the remaining ten were from Wales. In this route to diagnosis, the patients identified physical sensations as medical symptoms, which motivated their medical help-seeking behaviours and so contributed to detection of their type-2 diabetes. It is therefore necessary to explore and discuss what factors had impacted on the patients' identification of symptoms which in turn initiated obtaining a diagnosis.

5.2.1.1 Characteristics of physical sensations

5.2.1.1.1 Severity

As mentioned above, 17 patients in the study were clinically diagnosed with type-2 diabetes after they experienced physical sensations. Eight out of 17 patients reported that severe or acute physical sensations were the triggers which resulted in their type-2 diabetes being diagnosed. For example, a female patient from China sought medical help after experiencing severe deterioration in vision, which had greatly impacted on her life.

> "Five years ago, I found my eyesight went down and I could not see anything clearly and even I could not recognise the people's face [regret] so I went hospital to see an oculist. The oculist tested my sight and eyes and then he told me I have got a disease of the retina and he suspected the disease of the retina may be caused due to diabetes. Therefore, I was sent to the Diabetes Department to have a full blood sugar assessment in order to confirm the diagnosis of type-2 diabetes. After I finished the full blood sugar assessments, the results indicated my blood sugar level was very high, more than 20 (mmol/L). The doctor from the diabetes department told me I was diagnosed with type-2 diabetes and I had to stay in the hospital a few days to receive a full treatment for the disease."
>
> (CFDP5)

Compared with the early physical sensations caused by type-2 diabetes including tiredness, increasing appetite, frequent thirst and urination, a deterioration in vision due to type-2 diabetes is more noticeable and severe. As the patient could not see anything clearly, this had greatly impacted upon her life and so she went to hospital to seek medical help. However, although she did not mention if she had early physical sensations before she experienced symptoms related to her vision, she could have had uncontrolled type-2 diabetes for quite some time because her deterioration in vision was caused by retinopathy, which may be caused by uncontrollable and long-lasting hyperglycaemia (Krentz & Bailey, 2001). Although she may have been relatively symptomless, it may be that she did not recognise any changes in her health status and the significance of any physical sensations before her vision deteriorated. Therefore, there are some factors which may influence the judgement of the severity of early physical sensations as indicated in the following extract:

> "...fourteen years ago, I felt very fatigued, sweating, and having difficulty in walking and climbing stairs so I thought I could get type-2 diabetes because I used to be a doctor and I know the symptoms of type-2 diabetes too much so I went to the hospital to see a doctor and the doctor tested my blood sugar and then the result indicated 14 (mmol/L). After that, the doctor asked me to have full blood sugar assessments in order to confirm the diagnosis of type-2 diabetes.

> After completing the full blood sugar assessments, I was diagnosed with type-2 diabetes. I was diagnosed with type-2 diabetes at 63 years of age. So far this year, I have been living with type-2 diabetes for 14 years [sighs]."
>
> (CFDP2)

This patient perceived the severity of physical sensations because they impacted on her daily activities of walking and climbing stairs, which increased her focus on her physical self. In addition, the patient was able to perceive immediately the severity of the physical sensations and identified them as symptoms related to diabetes because of her occupational background as a retired health professional. Having medical knowledge may have heightened her awareness and sensitivity to any physical changes and sensations, and made her more internally focused (Pennebaker, 1982). This resonates with an earlier study which supports the notion that increased medical knowledge can alter people's attention to physical sensation, and make them more internally focused. This has been termed "Medical Student Disease". Where the increased knowledge about disease-specific symptoms gained from medical books made most medical students internally focused and increased the self-reported experience of these symptoms (Mechanic, 1962). Therefore, increasing the level of knowledge about type-2 diabetes may contribute to improving Chinese patients' attention to their health and type-2 diabetes.

Furthermore, according to the psychophysiological comparison theory (PCT) (Cacioppo, *et al.*, 1989), individuals are motivated by biological disposition and by social learning to maintain an understanding of their bodily (i.e. physiological) condition. Therefore, the detection of physical sensations and symptoms can motivate individuals to appraise their physiological condition. The strength of the motivation to understand and evaluate one's physical sensations and symptoms is a function of factors, such as their probability of occurrence, salience, severity, personal relevance, and potential restriction of freedom. Therefore, these Chinese patients were more likely to be motivated to seek help from medical professionals when physical sensations had a great impact on their daily activities.

5.2.1.1.2 Persistence

Apart from severity of physical sensations, the persistence of physical sensations was also a trigger to medical seeking-behaviour among six patients as indicated in the following extract:

> "About twenty years ago, I found I had some symptoms such as very fatigued, sweating, irritability, thirst, and having difficulty in walking and climbing the stairs **for quite a long time** so I went to hospital to see a doctor and the doctor tested my blood sugar and then the blood sugar test indicated more than 19 (mmol/L)..."
>
> (CFDP6)

The patient stressed the persistence of physical sensations "for quite a long time" in her comments rather than providing an accurate duration of the persistence. However, different patients could have different understanding regarding the persistence of the physical sensations. Morrison and Bennett (2012) defined the persistence of physical sensations as those which had been perceived for longer than is considered usual or had persisted without relief in spite of self-care. This articulation also emphasised that persistence refers to physical sensations which persist for longer than is considered usual rather than for an accurate duration. Therefore, the judgement of persistence of physical sensations is also subjective and may vary from individual to individual. However, according to the psychophysiological comparison theory (Cacioppo, *et al.*, 1989), the persistence increases the salience of physical sensations, which can mobilise patients to evaluate their physiological condition through medical services.

5.2.1.1.3 Novelty

Additionally, some novel findings and physical changes can increase motivation to medical help-seeking behaviour. A male patient from China reported his novel finding, which motivated him to be diagnosed with type-2 diabetes:

> "I am a forest protector and I often patrol in the forests. I once found that my urine could attract ants or insects. I was anxious about it. And so I went to hospital last year, my fasting blood sugar was found to be increased to 8.4(mmol/L) there. The doctor suspected I had got type-2 diabetes so I was advised to see a diabetes specialist in order to confirm the diagnosis of type-2 diabetes."
>
> (CMDP5)

Some patients with type-2 diabetes can discharge urine containing a high level of glucose when their level of blood glucose exceeds the renal glucose threshold (RGT) (Harmel & Mathur, 2004). Ants or insects can be attracted to feed on the urine if urinating in the field. So this novel experience which was of specific significance for a forestry worker. According to the Psychophysiological Comparison Theory (Cacioppo, *et al.*, 1989), novel findings are likely to be considered indicative of something rare and serious so people who have novel findings in the body are more likely to seek medical help actively in order to maintain an explicable physiological condition.

In this section, the characteristics of physical sensations including severity, persistence and novelty were identified, which increased the likelihood of symptom perception and motivation for medical-seeking behaviour in Chinese patients with type-2 diabetes. Besides these physical symptoms, the data indicated that emotional responses to physical sensations may impact on symptom perception and medical help-seeking behaviour, which are discussed in detail below.

5.2.1.2 Emotional responses to physical sensations

Three out of 17 patients in the study reported their emotional responses when they initially had physical sensations. All three patients were from Wales. The following extract is one female patient's descriptions about her emotional responses:

> "18 years ago, I often felt dizzy, tiredness and had left foot pain. I was **very nervous and anxious** about them and worried about my health condition so I went to see my GP **promptly**. The GP tested my blood sugar and told me my blood sugar had increased to about 8.0 (mmol/L) and then I was sent to a regional hospital to have a further blood sugar tests. When my GP received the results of the blood sugar tests, I was told I have been diagnosed with type-2 diabetes.
>
> (WFDP2)

The patient stressed her negative emotional responses of feeling "very nervous and anxious" due to physical sensations in her descriptions, and the worry about her health condition directly and "promptly" motivated her to seek medical help. Therefore, this finding illustrated that the impact of negative emotions on symptom perception may be perceived as being positive for some Chinese patients. Previous studies also support the positive role of negative emotions in improving symptom perception and medical help-seeking behaviour. Chen *et al.* (2006) conducted a quantitative study among 86 participants diagnosed with mild or moderate asthma to test the relationship of anxiety and asthma severity to symptom perception and found that symptom perception was affected by both anxiety and asthma severity status, and anxiety was associated with heightened perception of symptoms, particularly during times when asthma was mild. Moreover, Kressin *et al.* (2000) investigated the relationship between negative affectivity (NA; a general disposition to experience negative mood states) and health-related quality of life. They drew the same conclusion that apart from actual blood glucose levels, for patients with type-2 diabetes, symptom perception was determined by cognitive and emotional response, particularly negative affectivity. However, excessive negative moods can result in more symptoms and impact on patients' mental health as indicated in the following extract:

> "In the beginning of 2007, I felt very stressful and nervous after having some symptoms such as no energy, sweating, thirst, and often feeling hungry so I went to hospital to see a doctor and the doctor tested my blood sugar. The first blood sugar test indicated 8.4(mmol/L), and the second test indicated 3.3 (mmol/L). The doctor said that I needed to often test my blood sugar and I might have a high risk of developing diabetes. After that I felt more stressful and nervous, and I did not feel very well in the whole body, such as headache, no energy, muscle pain…"
>
> (CFDP4)

Similar finding was obtained in previous study. Leventhal *et al.*, (1996) explored the impact of mood on symptom perception, and concluded that people who have more positive mood have been found to consider themselves as more healthy and report fewer symptoms, but people who have more negative mood report more symptoms and even could exaggerate their symptoms, which may impact on their mental health and diagnosis of their illness.

Further evidence supports that hypothesis that emotion can trigger executive attentional control (Norman & Shallice, 1986). Kanske and Kotz (2012) conducted a study among 142 participants to test whether temperament and subclinical anxiety or depression can influence the emotional modulation of executive attention. The results confirmed the original hypothesis. They found that detection of negative emotional stimuli occurred significantly faster among participants with negative emotions such as stress, anxiety or depression. Meanwhile those people with negative emotions also oriented their attention to these negative stimuli quicker and had more time extricating their attention from these stimuli (Kanske & Kotz, 2012). Processing of negative emotional stimuli was altered for these people, leading to an increased sensitivity towards these stimuli (Kanske & Kotz, 2012). Therefore, according to the findings from the Kanske and Kotz's (2012) study, symptom perceptions are strongly influenced by negative emotional states, specifically a fixation on such symptoms. Besides negative moods, the data indicated that social support also may play an important role in Chinese patients' symptom perception and medical care-seeking behaviour, which is presented and discussed in the next section.

5.2.1.3 Social triggers

14 family carers participated in the study who were all spouses with the exception of one sister. Six out of the 14 family carers were men, the remaining eight were women. Seven family carers were from China and seven from Wales. Four family carers, including three men and one woman reported their responses and actions when their relatives informed them about their physical sensations. The other ten carers reported that they were not told of any physical sensations or lack of responses to this information. Most carers verbally urged or suggested their wife or husband to visit the doctor when they were told physical sensations. Typical comments from carers included:

> "I **urged** my wife to go to hospital to see a doctor and to find out the causes of the symptoms after she told me she was suffering from fatigue, sweating, irritability, thirst because I worried about her health condition. Then she went to the hospital and was diagnosed with diabetes there. It happened 20 years ago."
>
> (CFDPC6)

Whilst another typical example from a carer Wales was:

> "About ten years ago, my wife started having some symptoms such as headache, tiredness, feeling sick and dizziness so I suggested her going to see the GP. Her GP tested her blood sugar and he found her blood sugar had increased over the normal level and then she was sent to the hospital and her type-2 diabetes was diagnosed there."
>
> (WFDPC5)

As soon as the two carers knew their wives' experienced physical sensation, they urged or suggested they sought medical care immediately. The wives also followed their spouses' suggestion regarding seeking medical care so that their type-2 diabetes was diagnosed. Besides verbal encouragement or suggestion, one of the four carers took direct action, namely driving his wife to the surgery as soon as he knew his wife was suffering from symptoms.

> "My wife told me she often had headache, tiredness, and dizziness then I drove her to the surgery the next day. The GP in the surgery tested her blood pressure and he found her blood pressure was very high, and then my wife was sent to have further examinations then she was diagnosed with type-2 diabetes and high blood pressure."
>
> (WFDPC7)

This finding regarding the influence of family carers may be partly explained by using Zola's (1973) sociological approach to help seeking behaviour. According to Zola (1973), people's responses to physical sensations are subject to their cultural values and beliefs concerning health. Accordingly, the decision to seek professional medical help is either promoted or delayed by social factors. Zola (1973) identified five factors that trigger the decision to seek help. These are interpersonal crisis, perceived interference with work activity, perceived interference with social and leisure activity, pressure from other people who insist help be sought, and symptoms persist beyond arbitrary time limit set by the individual. In this study, it is apparent that family carers' promotion and assistance was an important motivation for some Chinese patients to seek medical help.

Previous work supports the positive role of family motivation in maintaining individual's health and the detection of diseases. Franks *et al.* (1992) found that compared with people who were divorced, separated, single, or widowed, married people had a better overall state of well-being. One of the ways that family can improve health is by improving mutual attention and support between family members to detect disease early on. In addition, Neale *et al.* (1986) explored the link between marital status and delay in seeking treatment and survival from cancer among married and widowed Caucasian women and found that people living with their family were more likely to see the doctor for screening, examinations and other early detection than people living alone with the same symptoms, functioning, and general level of health. In terms of the role of the family in detection of chronic conditions, Kaugars *et al.* (2004) conducted a literature view regarding the influence of family on the detection and management of asthma and they found that family functioning contributes to improving diagnosis of asthma and to reducing mortality through the detection and identification of early asthma symptoms.

In addition in my study, two Chinese patients from Wales were also motivated to seek help by social connections outside of their family such as neighbours, friends, or working colleagues when they disclosed their physical sensations. A female patient from Wales reported:

> "Three years ago, I often felt extremely thirsty, and then drank too much water every day. I told that my Chinese neighbour Mrs. XXX. Mrs. XXX suggested me seeing my GP so I went to the surgery to see my GP...."
>
> (WFDP3)

Whilst a male patient commented:

> "About thirteen years ago, I often felt so tired and sleepy that I did not have energy to do work. I told this to my working colleague and friend Mr. XXX. He is a Chinese. He told me I need to pay more attention to the symptoms and then he suggested me asking for help from my doctor."
>
> (WMDP5)

These findings illustrated that some Chinese patients accessed their social networks, including families, neighbours, friends, and working colleagues to obtain advice and help before seeking medical help, which was termed as lay referral in Zola's (1973) model. The use of lay referral system among Chinese patients may be associated with the Chinese cultural norm that stresses collectivism and mutual help and support within a community. In addition, both the two Chinese patients who reported the use of lay referral system to obtain help in the study were from Wales, and they sought help mainly from their Chinese neighbour and friend, which implied that Chinese patients in Wales may prefer seeking help and information from Chinese community and sources when they perceived physical symptoms.

This finding is consonant with previous work. Oh *et al.* (2014) conducted a cross-sectional survey in both South Korean and the United States to examine the influence of immigration status on Korean Americans' trust in health information sources and health information seeking behaviours with 208 native Koreans and 254 Korean Americans. They found that compared with native Korean, immigration status had a profound influence on Korean Americans health information seeking behaviours and they more trusted the information from printed Korean language magazines or newspapers. In addition, Cristancho *et al.* (2014) also found that workshops in Spanish at community settings were the most preferred health information source among Hispanic immigrants in the United States in their study in which 894 adult Hispanics were investigated to explore factors affecting their preference to gain information regarding health and illness. Therefore, culturally appropriate and acculturation-sensitive approaches are required when health organisations and practitioners in Wales implement to address Chinese patients' needs of information regarding type-2 diabetes. Moreover, the data indicated that although most Chinese patients sought medical care after perceiving physical sensations and symptoms, some patients reported delaying seeking medical help after perceiving physical sensations and symptoms, which is discussed now.

5.2.1.4 Delay in medical help seeking

Four male patients reported delay in seeking medical help, including three patients from Wales and one from China. Of note is that no female patients reported delaying seeking help. A male patient from Wales reported that:

> "I am working in a Chinese take-away. Since 2009, I often felt weakness and thirsty. About three years ago, one day I suddenly got dizziness and weakness in my legs and then I collapsed while I was working in the Chinese take-away. About a couple of minutes later, I woke up automatically. My colleague gave me a cup of hot water, and I felt better after drinking it. After that, the symptom of dizziness no longer happened but weakness and thirst were persistent. My colleagues once suggested me going to a clinic or hospital to see a doctor, but I did not do that because I was extremely nervous and I was fearful of being diagnosed with a serious illness and I could lose my job due to the illness. In addition, my work was busy and my English is not good so I do not know how to talk to doctors in XXX (name of town). In 2010, I went back to China and eventually I went to hospital to see a doctor. The doctor tested my blood sugar, and it indicated more than 12 or 13. I cannot remember it clearly. After that, I got a lot of physical tests, and then the doctor told me I have got type-2 diabetes."
> (WMDP2)

According to the patient's comments, there were four main reasons why he failed to seek medical help immediately after having physical sensations and collapsing. Firstly, his physical sensations relieved through self-remedy behaviours, such as drinking water or disappeared automatically. Secondly, after suffering from the severe symptom of collapsing, he was afraid of being diagnosed with serious illness and losing his current job as a result of the diagnosis. Thirdly, his busy work distracted him, and lastly, language barrier hindered his medical help seeking in Wales. Therefore, the patient's delay in seeking medical help was due to the interaction of various factors related to symptom type, negative mood, cognition and social context, which is consistent with the findings from previous research. Scott *et al.* (2009) carried out an investigation to improve understanding of patients' delay to inform the development of interventions to encourage early presentation of oral cancer among 57 participants with potentially malignant oral symptoms and found that patients' delay to seeking help related to beliefs about symptoms, the health care system, and an individual's circumstances.

Besides WMDP2, another two male patients also mentioned their experiences of delay in seeking medical help due to alleviation of perceived symptoms by self-remedy behaviours. Typical comment included:

> "Seventeen years ago, I found I had a good appetite and always wanted to eat foods and to drink water but my weight did not increase. However, these symptoms did not make me very uncomfortable and they could be relieved after drinking water and eating food so I ignored them. But I still remember, one day, when I gave a lecture to my students, I suddenly felt very uncomfortable, nauseous, weakness and sweating so I suspended the lecture and then went to the hospital to have examinations and treatments. After that I was diagnosed with type-2 diabetes."
>
> (CMDP2)

Some early and mild physical sensations due to hyperglycaemia such as weakness, thirst, frequent urination and increasing appetite can be alleviated through self-care behaviours including drinking water or other beverages, eating food and sleeping. Thus, partial patients with type-2 diabetes preferred taking the self-remedy strategies to deal with the physical sensations when they initially experienced them rather than through seeking medical care immediately. The relief of physical sensations through self-remedy reduced the patients' attention to the physical sensations. Pennebaker (1983) clarified that symptom perception is related to an individual's attentional state and sensitivity and that boredom and the absence of environmental stimuli may result in over-reporting, but distraction and attention diversion may lead to under-reporting. Therefore, diagnosis and treatment of type-2 diabetes could be prolonged as a result of self-remedy behaviours. Karimi Moonaghi *et al.* (2014) conducted a qualitative study to explore the subjective experiences of health care-seeking behaviour among Iranian patients with type-2 diabetes mellitus among 15 participants. Their findings also supported that the alleviation of the symptoms after the self-remedy behaviours was associated with reduced symptom perception and postponed medical help-seeking behaviours. It is apparent that the alleviation of the symptoms after self-remedy behaviours did not indicate the patients' type-2 diabetes was in remission because the causes of symptoms were not eliminated completely by these self-remedy behaviours. This is the reason why the patient CMDP2 suffered suddenly from an attack of hyperglycaemia (high blood glucose). Therefore, although self-remedy behaviours can relieve physical symptoms due to type-2 diabetes, it may result in a prolonged diagnosis and increase health risk.

Furthermore, none of the female patients in China and Wales reported delay in seeking medical help after suffering from symptoms. The findings demonstrate that there may be gender differences in seeking medical help, namely male Chinese patients were more likely to delay seeking medical help than the female Chinese patients. Another male patient from Wales explained why he delayed in seeking medical help after perceiving physical sensations:

> "Since three years ago, I often felt tired and thirsty, and frequent sweating and urination. However, I did not think these problems were caused by an illness because I was always healthy and rarely went to hospital, and seeing doctor was a sign of weakness... I am a **man**...so I did not see the GP until I could not walk..."
>
> (WMDP4)

The male patient failed to seek medical help immediately after having initial physical sensations because he thought seeing the doctor was a sign of weakness, which could reduce his masculinity. Courtenay (2000) provids an explanation for the gender differences in seeking medical help, and pointed out that gender differences in seeking medical help may happen as a result of different meanings given to health-related behaviour by the two sexes. The differences reflect the association between health and masculinity, femininity, and power. Courtenay (2000) contends that men are more likely to engage in health-risking behaviour and to avoid signs of weakness, even when ill in order to show their masculinity. Therefore, male Chinese patients may need more help and support in seeking medical help.

In summary, the positive factors influencing Chinese patients' symptom recognition and medical care-seeking behaviours in the diabetes-related symptoms route to diagnosis have been identified. These are characteristics of physical sensations, negative emotional responses, and social triggers. However, individual circumstances, social context, and self-care of symptoms can reduce the perception of symptoms and then result in delay seeking medical care among the Chinese patients in the study. Moreover, some Chinese patients in the study arrived at their diagnosis of type-2 took via the opportunistic route, which is discussed in the following section.

5.2.2 Opportunistic route to diagnosis

Nine out of 26 Chinese patients were diagnosed with type-2 diabetes opportunistically. Seven patients were men who all lived in China, and two were woman who lived in Wales. In this route, the patients' condition was detected opportunistically in a routine physical examination or by a blood glucose test before receiving surgery or consulting doctors for other health reasons. In the following section, the reasons how these patients gained their diagnosis through this route are presented and discussed.

5.2.2.1 Symptomless

Six out of the nine patients mentioned they never experienced any physical sensations before being diagnosed including five patients from China and one from Wales. I refer to these participants as being symptomless. Being symptomless is not uncommon in the early stage of type-2 diabetes as indicated in the following extract:

> "Two years ago, I attended a yearly physical examination in a health centre organised by my company, my blood sugar was found to be increased in the examination. After that, I went to hospital to see a diabetic specialist and then the doctor asked me to do a series of blood sugar tests. Unfortunately, the results of the blood sugar tests were abnormal as well and the doctor told me I had got type-2 diabetes...I never experienced any discomforts before I was diagnosed with type-2 diabetes."
>
> (CMDP1)

This patient was symptomless as he denied he had suffered from any physical sensations before being diagnosed with type-2 diabetes. The lack of symptoms was the main reason why the patient's hyperglycaemia was not detected until he attended for a regular physical examination. Approximately 15% of newly established patients with type-2 diabetes never report diabetes-related symptoms before being diagnosed clinically (Nathan *et al.*, 2007). Moreover, current estimates indicate that up to 70% of individuals whose type-2 diabetes is in an asymptomatic state eventually develop clinically diagnosed type-2 diabetes (Vendrame & Gottlieb, 2004).

In addition, CMDP1's type-2 diabetes was detected in a regular physical examination organised by his employer. Currently in China some employers including commercial companies, government departments, and schools arrange for their employees to attend a regular physical examination usually once a year as a work benefit and is free of charge. Such free regular physical examinations organised and backed by employers is helpful for the detection of patients' condition at the stage of being symptomless. Almost none of the patients from Wales reported he had attended a routine physical examination, which was organised and paid for by their employer because most patients from Wales in the study were retired or self-employed. Just one patient from Wales reported he had participated in a health check as a requirement of a motor insurance company, and his elevated blood glucose was found:

> "...I bought insurance for my car in 1996. The insurance company required me to have a MOT in a private hospital in Cardiff. My blood sugar had been found to be increased in the MOT so I went to see my GP. The GP tested my blood sugar and also found my blood sugar had increased to more than 11 (mmol/L) and then he sent me to a hospital to confirm the diagnosis of type-2 diabetes... before being diagnosed type-2."
>
> (WMDP1)

Compared with symptomatic patients, the detriment due to being symptomless is greater because people tend to take action only when they experience unpleasant and unexplained symptoms (Pennebaker, 1982) while the risk of complications of uncontrolled type-2 diabetes, which are the cause of major morbidity and mortality, are ongoing during the asymptomatic period (Coutinho *et al.*, 1999; Levitan *et al.*, 2004). Attending for regular physical examination including blood glucose tests may be helpful to detect the individual with hyperglycaemia even in the asymptomatic phase (Krentz & Bailey, 2001). Although most patients from Wales did not have access to a routine physical examination through their employment, they did have access to GP and other primary care facilities to detect diabetes early and quickly (Welsh Assembly Government, 2013). In addition, screening for those at high risk of developing type-2 diabetes may be also undertaken to identify those who may not know they have the condition. Many investigators suggested that screening programmes targeting people with multiple type-2 diabetes risk factors including advanced age, obesity, and a family history of diabetes are worthwhile to detect type-2 diabetes patients early and quickly (Lee *et al.*, 2000; Lindahl *et al.*, 1999). In China, as actively attending a routine physical examination including blood glucose test is recommended by the Chinese Diabetes Association as an alternative method for detecting diabetes early in the context of lack of effective primary care services for prevention, management and treatment of diabetes

(Chinese Diabetes Association, 2010), it is suggested that a routine physical examination including blood glucose tests needs to be covered by the medical insurance system so that more Chinese patients regardless of their employment status can detect their type-2 diabetes at an early stage through participating in physical examination regularly.

Apart from being symptomless, lack of awareness of symptoms is a main reason for opportunistic detection of type-2 diabetes among Chinese patients, which is discussed in the following section.

5.2.2.2 The lack of awareness of symptoms

Three out of the nine patients in the study reported that their type-2 diabetes was detected after seeking medical help for other health reasons rather than for diabetes-related physical sensations or symptoms. All the three patients were from Wales. As already mentioned the patient WMDP3, his type-2 diabetes was diagnosed when he attended his GP with an injured thumb which would not heal. He revealed that he had experienced some physical sensations, which may be associated with diabetes, but he ignored them due to being busy with work. In addition, a female patient from Wales reported similar experience:

> "About ten years ago, I started feeling headache, dizziness, and tiredness but I did not give them more attention because I worked in a Chinese takeaway…I had to work every day…I did not see GP until I got a serious cold. GP tested my blood pressure and he found out my blood pressure increased to 150/90 (mmHg), and heart rate was 101 (beats per minute), then he asked me to have a further tests including ECG, blood cells, blood sugar, and urine test. In the blood sugar tests, my blood sugar was found out increasing to 13 as well and then I was referred to the hospital to see diabetes and cardiology specialist and I was eventually diagnosed with type-2 diabetes and high blood pressure there. "
>
> (WFDP7)

The patient's type-2 diabetes was discovered after seeking medical help for a serious cold. Although she had experienced some symptoms beforehand, she ignored them due to work stress. Her experiences are similar to the patient WMDP3, and they both have similar demographic backgrounds as Chinese migrants working in the catering business. They both stated that they ignored their diabetes-related symptoms because of having a large amount of work. Their experiences also represented many Chinese migrants' reality of living in Wales. They work in the catering business which involves long hours and hard work often seven days a week to earn sufficient income to support their families. The finding illustrated that an intensive immigration life had impacted on the awareness of symptoms of Chinese patients in Wales. The similar finding is obtained in the Lee *et al.* (2001)'s study. They conducted research in which 50 Chinese immigrant patients in Canada with medically unexplained fatigue and weakness were investigated by semi-structured interview and found that migration had a prominent impact on Chinese immigrants' perspectives of health and illness, and Chinese immigrants had relied mainly on self-help rather than seeking help from health care providers after perceiving symptoms. Therefore, health care providers in Wales need to create a friendly health care environment based on mutual respect and understanding and to provide Chinese patients and their family with more support and help that is tailed to their culture and life and working circumstance.

In this section, I have discussed the two routes that Chinese patients took to reach their diagnosis, namely the diabetes-related symptoms and opportunistic route, and the factors influencing them in obtaining the diagnosis. In the following section, I will discuss the participants' emotional responses to their diagnosis and the cause and effect of these emotional responses on self-management of their condition.

5.3 Emotional responses to the diagnosis of type-2 diabetes

All 40 participants including 26 patients and 14 carers in the study described their responses to their or their relative's diagnosis of type-2 diabetes. 30 out of the 40 participants reported negative toned emotions such as anxiety, depression, surprise and fear, whilst seven participants reported positive emotions such as peace, hopefulness and optimism. The remaining three participants reported few emotional responses because of a lack of knowledge of type-2 diabetes. 13 out of the 30 participants who reported negative emotions to diagnosis were from China, the other 17 participants were from Wales indicating that the participants living in Wales reported more negative emotional responses. By contrast with respect to reporting positive emotions, five participants lived in China and two in Wales. Firstly, negative emotional responses are discussed in the following section.

5.3.1 Negative emotional responses

The most frequently reported negative emotions related to diagnosis included anxiety, depression, worry, fear, and disbelief. The negative emotions were on a continuum from mild anxiety and surprise to extreme negative response such as viewing type-2 diabetes as serious as cancer or even as a sign of death. Typical responses on the mild end of the continuum included:

> "I felt a little bit nervous and surprised about the diagnosis. I used to be a doctor and I looked after patients previously but now I have been a patient who needs other's care. "
>
> (CFDP2)

> "I was surprised and nervous when I got the news that I have been diagnosed with type-2 diabetes from the GP, but not too much, just a little bit."
>
> (WFDP3)

Whilst the following two participants reported stronger emotional responses:

> "I started worrying about my health and stomach since I was diagnosed with type-2 diabetes. Although I was told my stomach was fine after the gastric endoscopy examination, I often get stomach ache so I am **extremely** anxious and worried if type-2 diabetes can cause stomach cancer."
>
> (WFDP6)
>
> "I was very nervous and anxious. I thought I had got a serious disease and was going to die so I made my will after I was diagnosed."
>
> (CFDP5)

The findings show that negative emotions related to diagnosis were prevalent among the Chinese participants. Many previous studies also supported that negative emotional reaction to diagnosis were common among people diagnosed with chronic conditions, for example, heart disease (Lane *et al.*, 2002; Polsky *et al.*, 2005), stroke (Aström, 1996), and long-term lower back pain (Hall *et al.*, 2011). Patients with type-2 diabetes also experienced emotional distresses when they were diagnosed, as shown by a systematic review of studies with a combined population of over 2500 adults with diabetes and almost 1500 control subjects. The authors found that compared with the 3-4% prevalence of generalised anxiety disorder among control subjects, the prevalence of anxiety was 14% among those with type-2 diabetes, and 40% displayed elevated anxiety symptoms (Grigsby, *et al.*, 2002). Moreover, depression is twice as likely in adults with type-2 diabetes as those people without (Anderson, *et al.*, 2001).

Apart from anxiety, worry, and fear, one male patient from China reported he did not believe that he was diagnosed with type-2 diabetes:

> "When I got the news that I have been diagnosed with type-2 diabetes from the doctor, I was so surprised and I asked the doctors to review my blood tests report [surprised] because I am **always very** well and I did not have any diabetes-related symptoms before the diagnosis so I cannot believe that.
>
> (CMDP1)

The finding demonstrates that some newly diagnosed patients especially asymptomatic patients did have difficulty in accepting their diagnosis. The male patient stressed his previous health state in order to minimise the health threat, and then he questioned the practice of the health professional to try to repudiate the diagnosis. Wiebe and Korbel (2003) described this type of response as reality based defensive denial, a set of subconscious defensive processes that help to understand threatening information while simultaneously alleviating emotional distress. These rational processes include minimising the health threat, using self-serving social comparisons, and biased processing of health information.

Hearing news of a medical diagnosis can bring about a lot of negative feelings in most newly-diagnosed patients with type-2 diabetes. Therefore, further exploration of the causes of the negative emotions related to diagnosis may contribute to minimising the effects of the negative emotions on patients and their management of their condition, which is now presented.

5.3.1.1 Perception of severity

Five patients in the study reported that they felt very nervous and anxious when they heard of their diagnosis because of their existing perception of type-2 diabetes in terms of its severity and incurability. A female patient from China reported she viewed type-2 diabetes as serious a condition as cancer:

> "I thought I would die and felt **very** anxious and nervous when I got news that I have been diagnosed with type-2 diabetes from the doctor because I knew diabetes was also regarded as 'incurable cancer' and it could not be cured **completely**. My weight has decreased by three kilograms, and I felt very stressful and anxious, and had difficulty in falling asleep since I have been diagnosed with diabetes."
>
> (CFDP1)

This patient's experience illustrates that people may have minimal information about their condition when they first receive their diagnosis, or erroneous information, or a vague awareness of the condition but not enough of the facts to evaluate it in terms of the implications for their lives. These perceptions or even misperceptions, for example viewing type-2 diabetes as serious a condition as cancer, may lead to an emotional reaction that is not consistent with reality. Therefore, the existing perceptions or misperceptions of the severity of type-2 diabetes have a direct stimulation to patients' emotions. However, information and explanation from health professionals could have a positive effect on undermining or eliminating the perceptions or misperceptions of severity and then contributes to reducing the negative emotions as indicated in the following extract:

> "When the specialist told me I had been diagnosed with diabetes, I was **so** nervous because the condition could not be cured [sighs]. But I returned to peace after the specialist explained the condition for me and told me the condition can be controlled completely through modifying lifestyles and taking medications."
>
> (CMDP3)

> "I felt fearful and nervous when I got the news that I have been diagnosed with diabetes from the GP but I felt better after the GP told me my diabetes was not very serious but I had to control diet."
>
> (WFDP2)

In addition, the negative emotions were also attributed to worry about the potential negative consequences related to work, family and life as a result of the diagnosis, which are now presented.

5.3.1.2 Worry about the costs of diabetes care

As type-2 diabetes is a chronic incurable condition, most patients need an ongoing treatments and regular examinations so the costs of care are a realistic concern. This is particularly so for those with low income living in countries such as China in which the majority of the population are not entitled to free diabetes care services. A female patient from China with type-2 diabetes reported her worry about the costs of diabetes care:

> "I was very nervous and anxious when I was diagnosed with type-2 diabetes. In my family, my mother, aunt and uncle are diabetic patients so I knew diabetes was a long-term and incurable disease and I needed to pay much money for the treatments for the condition. My son was still young and studying at a school

> and he needed my financial support in education so I felt stressed and anxious due to the diagnosis..."
>
> (CFDP4)

Most patients with type-2 diabetes living in China have to confront a realistic and unavoidable problem of the costs of diabetes care. Although an increasing number of the Chinese population have been involved in the Basic Social Medical Insurance (BSMI), Chinese patients' negative moods toward type-2 diabetes and diabetes-care costs are partially attributable to flaws in the medical insurance system. Firstly, at the end of 2008, there were still more than 300 million people living without any medical insurance in China (Dong, 2009). Secondly, BSMI is primarily targeted at hospitalisation and critical diseases so most of the costs of outpatient care cannot be covered by the scheme. Although patients with chronic conditions such as type-2 diabetes can get extra compensation, for example the extra compensation is less than 3,000.00 Yuan (equal to £300.00) each year in Kunming. However, for diabetes care in outpatient, the average cost for the patient excluding self-monitoring of blood glucose is 12,000.00 Yuan (equal to £1,200.00) per year (Kunming Medical Insurance Centre, 2012). In addition, in the last five years the growth rate of medical care spending is 13.6% in China, but average income among the Chinese population has been increasing at the rate of approximately 6% in China (Hou and Li, 2011). Therefore, many patients especially those who have a lower income level in China have a financial challenge when being diagnosed with type-2 diabetes.

Moreover, the financial burden contributes not only to increasing patients' negative emotion but also to impeding subsequent self-management behaviours. Shen *et al.* (2013) have reported that many Chinese patients with type-2 diabetes gave up self-monitoring of blood glucose due to consideration of cost of blood glucose meter and disposable strips, which are not reimbursed by BSMI. The negative impacts of financial burden on self-care among participants will be discussed in detail in the subsequent Chapter nine.

Compared with patients living in China, the patients living in Wales who are eligible for healthcare under the National Health Service (NHS) had less financial apprehension regarding diabetes care and self-management because of the provision of free medical care and support in self-management at the point of delivery through the NHS in Wales. A typical response from a patient living in Wales is illustrated in the following quote:

> "Yes, health care in XXX (name of town) is good and I can get full free care and support for type-2 diabetes."
>
> (WMDP5)

Besides worry about the costs of diabetes care, the data indicated that the fear of losing work capacity is another trigger for negative emotions.

5.3.1.3 Worry about losing traditional role in the family

Two male patients from Wales in the study reported their worry caused by the diagnosis of type-2 diabetes.

> "I do not know what type-2 diabetes is. I do not understand why I have this condition. I was just 48 years when I was diagnosed with type-2 diabetes. I have to work for money. I am extremely worried I cannot work anymore due to the condition."
>
> (WMDP2)

Whilst another commented:

> "...I was **very** depressed by the diagnosis because I **worried** that I could lose my job due to the condition. No job means no money. It is embarrassing and unacceptable for me to live relying on my family."
>
> (WMDP5)

None of the patients in China reported being worried about losing work capacity due to type-2 diabetes because firstly seven out of the 13 patients were retired and they no longer had responsibility to work and were living on a pension. In addition, four patients were working in public departments such as a school, governmental departments, or commercial companies so they had few worries about losing their job due to type-2 diabetes because dismissing employers due to ill health is not allowed in public departments in China (Baker & Mckenzie, 2013). But most of the patients from Wales in the study were Chinese migrants working in catering businesses. Working in Chinese restaurants or managing their own Chinese restaurants were the main sources of income. Therefore, loss of work capacity due to illness may directly impact on their financial status and life condition, namely "no job means no money".

In addition, men are usually the breadwinners in Chinese families and men have a greater cultural responsibility for supporting their families. Loss of status as a breadwinner was described as "embarrassing and unacceptable" for a Chinese man as it goes against the Chinese cultural norm. Chun and Chesla (2004) studied the influence of culture on diabetes management for Chinese Americans with type-2 diabetes. They also reported that many male Chinese Americans with type-2 diabetes worry about the loss of machismo due to their condition much more than their worry about the medical outcomes of type-2 diabetes. Due to the gendered nature of roles in Chinese families, Chinese women have more responsibility for looking after the family and children. Thus, female patients reported their worries about losing any capacity to look after their family due to type-2 diabetes:

> "Being diagnosed with diabetes happened 14 years ago, I cannot remember. But I was nervous because I was looking after my grandson when I was diagnosed with type-2 diabetes. I quite worried that I could lose the ability of looking after family and grandson due to the disease because my daughter had to work every day and she did not have much time to take care of her son. I just want to help my daughter. "
>
> (WFDP8)

Older Chinese people especially women tend to take care of adult children and/or grandchildren who live in the home or spend extended periods of time there. Meanwhile older parents sacrifice themselves for their young children, including providing care to grandchildren, in order to help their young children who have to work to improve their life chances and lifestyles. In addition, women play more of a role of caregiver and supporter within Chinese families. Losing their capacity for looking after their family due to disease changes their traditional role within the family. Thus, Chinese female patients may have more challenges than males in terms of self-management after being diagnosed with type-2 diabetes because they need to look after not only themselves but also their family. Chun, *et al.* (2011) in their study regarding acculturation experiences affecting diabetes management and perceived health among Chinese American immigrants also reported that shifting traditional family role significantly affected diabetes management and health. In other culture, similar findings have also been reported. Nam *et al.* (2013) conducted a qualitative study using five focus group with 23 Korean American with type-2 diabetes to explore challenges in diabetes self-management and found that Korean women with type-2 diabetes living in the United States were particularly vulnerable to a serious lack of self-management due to the stresses of life associated with immigration.

To sum up, most patients' reported initial responses to their diagnosis of type-2 diabetes were emotional in the study. The negative emotions were produced due to fear of the disease. In addition, the negative emotions were also situated in a certain social and cultural context so social and cultural factors need to be fully considered in the course of seeking to address and control the negative emotions. Although most participants in the study presented negative emotional responses to the diagnosis of type-2 diabetes, some participants reported comparatively positive emotional responses to their condition, which are discussed in the next section.

5.3.2 Positive emotional responses

Compared with the 30 participants' negative emotional responses, seven participants including five patients and two carers reported more positive responses to their or their relative's diagnosis of type-2 diabetes. Five out of the seven participants were from China, and two from Wales. Five were men and two were women.

Two female patients expressed their positive and optimistic outlook on their condition as indicated in the following extracts:

> "I **did not** have too many negative emotions such as anxiety, stress or even insomnia. I accepted the diagnosis peacefully because I trust doctors and the science of medicine. Modern medicine has developed more than before so my condition can be controlled and I can still live as a healthy person if I obey doctors' care. "
>
> (CFDP6)

> "I was Ok when I was diagnosed. Everybody could get diseases in life. It is wise to see doctor and to take tablets after getting any discomforts or disease. "
>
> (WFDP7)

Whilst a male patient from China also expressed similar views as indicated in the following comments:

> "I **was Ok** when the doctor told me I have got diabetes. I **did not** have tension, anxiety, depression, and not any difficulties in falling asleep in the night since I have been diagnosed with diabetes. There are a large number of diabetic patients in the world so I am not alone [laughs]. Nowadays medical science has been developed and I trust medicine science and doctor. I am **quite** optimistic about the treatment for diabetes."
>
> (CMDP4)

These three patients reported relatively positive emotions such as an optimistic outlook and trusting doctors and medicine when they were diagnosed. They believed that their condition can be controlled through medical care provided by doctors. In other words, they considered that external factors such as doctors and medical care play an important role of in the management of their type-2 diabetes. On the one hand, such positive attitudes to their condition contribute to promoting their psychological equilibrium through protecting them from the consequences of prolonged negative emotions and to gaining more effectiveness from medical treatment because of adherence to advice and treatments provided by medical professionals (Fredrickson, 1998). On the other hand, the participants could pay less attention to their role and responsibilities and behaviours in the control of their type-2 diabetes because controlling their condition is considered a doctor's responsibility, which may militate against their self-management (Wallston & Wallston, 1982). Moreover, the participants also could play a passive role in the performance of self-management because they only do what their doctor tells them to do rather than negotiating with the doctor and playing an active role in information and support seeking. When a female patient from China was asked if and why she tested her blood sugar by herself at home, she answered:

> "Yes. The doctor in the hospital asked me to test blood sugar by myself at home so I obey his advice and do that every day."
>
> (CFDP6)

CMDP4 also mentioned he did not feel "alone" after being diagnosed with type-2 diabetes because he have realised that "there are a large number of diabetic patients in the world." He laughed after saying that. His optimistic response and outlook to the diagnosis of type-2 diabetes and treatment was a result of comparison with other people with type-2 diabetes. According to the social comparison theory (Festinger, 1954), individuals are motivated to gain accurate assessments of their opinions and abilities and do so by comparing them with the opinion and ability of similar others. Comparison with others worse off than oneself is referred to as downward social comparison, which contributes to improving one's self-esteem and to reducing negative emotions (Schachter, 1959). Wood *et al.* (1985) examined patients' references to social comparison process among 78 patients with breast cancer and found that the downward comparison processes were conductive to increasing perception among patients of positive consequences of illness.

Positive emotions to diagnosis were based not only on the positive belief of the effectiveness of medical care and social comparison, but also on individual's prior experiences:

> "I was quite calm when I was diagnosed with diabetes. I used to be a military official and joined the army at the age of 18 years. I have participated in many battles and eliminated a lot of enemies so I will not be beaten by diabetes."
>
> (CMDP6)

As the above extract shows, personal experiences impact on how illness and threats to health were perceived. The above patient's experiences of engaging in battles enhanced his courage and confidence to cope with his own type-2 diabetes. Moreover, he drew on his previous experience of coping with risks and dangers and used this experience to face type-2 diabetes which he perceived as a lesser threat to his life than what he had previously experienced. I referred this to be as self-comparison. Self-comparison can be used as a coping strategy for dispelling negative emotions when people encounter new challenges. Contrada and Coups (2003) point out that patients have individual different social experiences and such experiences often play an important role in determining their adjustment to a condition. Therefore, exploring coping strategies patients have used in the past could be helpful when providing them with support to cope with challenges due to type-2 diabetes.

All 14 carers also mentioned their emotional responses when they knew their family member was diagnosed with type-2 diabetes. Compared with patients with type-2 diabetes, most carers' emotions were more moderate as indicated below:

> "I accepted her diagnosis peacefully. I told her do not worry about it too much but no matter what happened I always stand with her."
>
> (CFDPC2)

> "I was fine but my wife was surprised and nervous too much. I reassured her she would get well soon as long as she could obey doctor's advice."
>
> (WFDPC5)

In addition, some carers felt mild nervousness and anxiety about their family's diagnosis, but they controlled their emotions to comfort their relative as indicated in the following extracts:

> "I was a little nervous and anxious when my wife was diagnosed with type-2 diabetes. However, I did my best to comfort her and encourage her to overcome the condition."
>
> (CFDPC6)

> "When my husband told me he had been diagnosed with diabetes, I was nervous and surprised [sighs]. But I knew he could be more nervous and surprised than me so I tried my best to hold my feelings to comfort him. I told him do not worry, whatever difficulties he encountered I always stand with him."
>
> (CMDPC3)

Although the carers also experienced some negative emotions when their family member was diagnosed, they were acutely aware that their negative emotions could upset or worsen their relative's distress. Consequently, they went against any self-expression of negative emotion and made an effort to "comfort" their relative. Such comforts from the family may contribute to lessening patients' negative emotions at the moment of hearing news of a medical diagnosis. A female patient from Wales reported her emotional distress was reduced after her husband comforted her:

> "......I was surprised and nervous too much because it was an incurable disease but I felt better after my husband comforted me."
>
> (WFDP5)

Social support including family care has been shown as an important strategy to cope with negative emotions due to illnesses. (Kiecolt-Glaser & Newton, 2001). The people with social support believe they are loved and cared for, esteemed and valued. People who perceive support levels as high are likely to appraise events as less stressful than individuals who do not perceive they have any support (Lazarus, 1993). Social support acts as a buffer against negative emotions. Supporting family members with illness in coping with physical and emotional distress is another cultural issue that emerged from the narratives. Some carers stressed "no matter what happened I always stand with her" in their comments. This is consistent with the Chinese cultural belief that mutual help between family members is the cornerstone of maintaining union and harmony of family especially during difficult periods such as suffering from illness or encountering disasters. In addition, mutual respect and support between spouses is also considered as a moral norm in Chinese families. Therefore, it is valuable to explore and discuss the significance of support from family in the management of type-2 diabetes especially for patients living with their family, which is presented in detail in Chapter nine.

Besides negative and positive emotions, three participants reported being at peace when they or their relative were diagnosed. I refer to this as being ignorant bliss, which is discussed in the following section.

5.3.3 Ignorance bliss

Three participants including two patients with type-2 diabetes from China and one carer from Wales reported being at peace when they knew their or their relative's diagnosis.

> "I was Ok when I was diagnosed with type-2 diabetes because I did not know what diabetes was at that time and I just hoped the doctors could help me cure the condition as quickly as possible."
>
> (CFDP3)

> "Yeah, I accepted my brother's diagnosis peacefully because I really did not know what type-2 diabetes was. I think it was a mild disease like cold."
>
> (WMDPC2)

The peace reported by the two participants was based on their lack of knowledge of type-2 diabetes and their expectation of medical care. However, such psychological peace may not be actual bliss and could become a negative emotion with the increased information about type-2 diabetes as indicated in the following extract:

> "When the consultant told me I had been diagnosed with type-2 diabetes, I was **quite** peaceful, and no fear because I really did not know what diabetes was. But after being diagnosed with diabetes, I have got a lot of information from the consultant and I also have read some books about diabetes, and I have known diabetes is a chronic condition, which will cause many severe complications. Nowadays, I am **worried** about the condition."
>
> (CMDP2)

The above patient's comments raise the issue of the impact and role of access to health information and health literacy on patients with type-2 diabetes and their self-management. Dietrich (1996) found that the attitude doctors displayed toward patients and patients' perception of their information needs at the time of type-2 diabetes diagnosis crucially impacted on their subsequent self-management and adherence. Data related to the level of knowledge of type-2 diabetes among the participants and the provision and accessibility of information about type-2 diabetes in China and Wales, and its impact on self-management is discussed in the next chapter,.

5.4 Summary

In this chapter, I have discussed the two routes that Chinese patients took to reach their diagnosis of type-2 diabetes, namely diabetes-related symptoms and the opportunistic route, and the factors influencing them obtaining the diagnosis. In addition, the participants' including patients' and their carers' emotional responses to diagnosis have also been presented and discussed. Negative emotions such as anxiety, stress and worry were reported as being prevalent among three quarters of the participants at the time of diagnosis, which were triggered by perception of severity and worry about the negative impacts of type-2 diabetes on their work, life, and family role. A quarter of the participants expressed a relatively positive emotion such as optimism and confidence in medical care and advancing knowledge which also included a few who expressed a type of ignorant bliss to diagnosis. The latter emotion was underpinned by a lack of information. Such relatively positive emotions could have positive effects on their or their relative's subsequent treatments and self-management. However, ignorance is not actual bliss and may be short lived, as demonstrated by a lack of knowledge about type-2 diabetes among some participants. Therefore, the following chapter presents and discusses the findings related to the participants' level of knowledge regarding type-2 diabetes and their information sources.

Chapter Six Diabetes-related knowledge and information sources

6.1 Introduction

In Chapter five, I discussed the Chinese patients' perception of diabetes-related symptoms and their and their family carers' emotional responses to their diagnosis of type-2 diabetes. The findings illustrate that many Chinese patients and their family carers failed to immediately seek medical care after perceiving physical sensations and symptoms to detect and diagnose their condition due to an insufficiency of knowledge about type-2 diabetes and its symptoms. In this chapter, I will present data from the participants including Chinese patients and their carers in China and Wales which further indicate their level of knowledge of type-2 diabetes and factors influencing their level of knowledge of type-2 diabetes. Moreover, findings related to sources of information on type-2 diabetes in China and Wales are also presented and discussed. Firstly, findings and discussion regarding the level of knowledge of type-2 diabetes and its influencing factors among Chinese patients with type-2 diabetes and their carers in China and Wales are presented.

6.2 Diabetes-related knowledge

6.2.1 Diabetes is a "long-term disease"

When all participants in the study were asked about their understandings of type-2 diabetes, none were able to provide full and clear information regarding type-2 diabetes and its symptoms, risk factors, complications, and management. Most participants both in China and Wales expressed a general or summarised understanding as indicated below:

> "Diabetes is also regarded as incurable cancer and it could not be cured completely."
>
> (CFDP1)
>
> "I have little knowledge about diabetes. I just know diabetes is a kind of serious and incurable disease."
>
> (CFDPC6)
>
> "I know type-2 diabetes is a kind of long-term and incurable disease because my old brother has been living with the disease for nearly 20 years as well."
>
> (WFDP5)

> "I do not know what type-2 diabetes is until my wife was diagnosed with type-2 diabetes. We were told type-2 diabetes is a kind of long-term and incurable disease but it is controllable through tablets or insulin."
>
> (WFDPC5)

The findings demonstrate that most participants have realised that type-2 diabetes was "a kind of long-term disease" or "an incurable disease". However, type-2 diabetes was still regarded as "incurable cancer", which suggested that several misunderstandings of the causes of type-2 diabetes, of management, and of prognosis, existed among the participants.

6.2.2 Causes of type-2 diabetes

Although eight participants including six participants from China and two from Wales mentioned fragmentary information about aetiology of type-2 diabetes such as impairment of function of the pancreas and lack of insulin, how it worked seemed to be unclear to them:

> "…diabetes is a kind of long-term and incurable disease, which is caused by lack of insulin."
>
> (CFDP4)
>
> "…I am not sure diabetes could occur when pancreas on longer produce enough insulin to reduce blood sugar… …"
>
> (WFDP7)

Besides impairment of the pancreas and lack of insulin, four patients guessed that family heredity could be a possible reason for their type-2 diabetes. Three patients were from China and one was from Wales. Typical comments included:

> "I think my diabetes is associated with family heredity. There are three people who have been diagnosed with type-2 diabetes in my family."
>
> (CFDP4)
>
> "My type-2 diabetes could be closely linked with my family history of diabetes and overweight because my two brothers have also been diagnosed with type-2 diabetes five years ago."
>
> (WMDP5)

Furthermore, 12 participants reported that type-2 diabetes could be associated with their previous lifestyles, especially with their eating behaviour. There were limited differences in reported awareness of lifestyle factors by country. Typical examples from the patients' accounts from both China and Wales respectively included:

> "I just know diabetes is caused because I eat too much food in daily meals, thereby increasing the level of sugar in my blood."
>
> (CFDP3)

Whilst another female patient from Wales also reported that her type-2 diabetes was attributable to an improper eating behaviour:

> "I guessed the reason why I got the disease is that I eat too much food and snacks in daily life because I like eating sweetmeats very much."
>
> (WFDP1)

Whilst eating is an important component within most people's daily lives for Chinese people having three regular meals within a day and an appropriate intake in every meal is also traditionally regarded as healthy and a reasonable eating behaviour. However, with the increase in quality and quantity of food both in China and Wales, Chinese people tend to omit the traditional eating habits and are increasing their daily dietary intake. A male patient from Wales reported:

> "...not sure...my diabetes could be closely associated with eating because I heard of fat people had a high risk of diabetes. When I was young, I liked to eat meat and fried food such as ham, sausage, and chips. I used to eat two bowls of rice or noodle, about three Liang (weight unit used in China, equal to 300g) in lunch and dinner every day. This is also one of the probable reasons why I got type-2 diabetes, I guessed. But now I have realised such eating style is not healthy enough so I must change it."
>
> (WMDP3)

Whilst a patient's wife from China also said:

> "His (her husband) diabetes may be caused by eating too much food and long-standing sedentary lifestyle and working style. My husband used to be a bus driver before retirement. He had to work five days a week and eight hours a day. After retirement, he rarely takes part in any outside activities and just playing computer games or watching TV while eating food at home every day [sighs]."
>
> (CMDPC1)

Moreover, three out of the 20 participants in Wales including two patients and one female carer assumed that their or her relative's condition was closely associated with a stressful life following immigration. When most Chinese immigrants came to Wales, they ran small businesses or worked in Chinese take aways and restaurants. They worked day and night to earn and save money for a better business and life in Wales (Zhou, 1992). For example, a male patient from Wales attributed his condition to intensive work and "irregular" eating behaviour after moving to Wales:

> "I did not have a regular diet and lifestyle when I was young. I have been living in Wales for 30 years and I used to manage a lot of Chinese restaurants so I had to work for more than 10 hours a day from Monday to Sunday. My meal time was not fixed. I did not eat meals until I felt hungry so eventually such busy work and irregular diet resulted in diabetes. "
>
> (WMDP1)

Such a stressful life and excessive workload also aroused their family carers' concern over their health and condition. A female carer in Wales reported:

> "...my husband's diabetes may be caused by working too hard [sighs]. He always works from 7 am. to 10pm. or 11pm every day so now I often remind him do not work too hard and have a rest during work."
>
> (WMDPC2)

After being diagnosed with type-2 diabetes, the patients started reviewing their life, diet, and working experiences and then assumed that there was a relationship between their condition and their previous lifestyles and working circumstance. Moreover, carers also realised the potential association between their relative's previous lifestyles and working circumstance and their type-2 diabetes. I refer to this process to be "self-reflection". Self-reflection is an active process of reviewing, analysing and evaluating experiences in order to inform future actions. Self-reflection contributed not only to motivating the patients to conduct lifestyles change but also to motivating the carers to help their relatives to conduct lifestyles changes, which is supported by a previous study. Heisler *et al.* (2003) conducted a study to explore the association between reflection of self-management and glycaemic control among 2,000 patients with type-2 diabetes and found that reflection contributed not only to promoting self-management itself but also to improving their glycaemic control.

Although most participants both in China and Wales lacked a full understanding of the association between their lifestyles and their type-2 diabetes, they had realised that type-2 diabetes was a condition which may be associated with lifestyles. More importantly, they were aware of the importance of changing lifestyles in the management of type-2 diabetes. According to the theories of planned behaviour (TPB) addressing the links between beliefs and behaviour, those participants who had a positive realisation to behaviour change and perceived support from family carers were more likely to modify their behaviour (Ajzen & Madden, 1986). Nevertheless, behaviour change is one of the most difficult tasks in self-management of type-2 diabetes (Van der ven *et al.*, 2002). Therefore, diabetes education is necessarily required in order to help Chinese patients and their family carers to gain a full understanding of the relationship between lifestyles and type-2 diabetes and to conduct lifestyles modification.

6.2.3 Complications of type-2 diabetes

12 of 40 participants including seven patients and five carers reported their knowledge of complications caused by type-2 diabetes. Ten was from China, and two was from Wales. However, the remaining 28 participants failed to report their knowledge of complications due to type-2 diabetes. A female patient from China reported her understanding of amputation due to type-2 diabetes:

> "I have a close friend who has got diabetes for ten years, and her left foot was amputated due to a serious infection caused by diabetes last year. I am very sad about it. She is not able to take care of herself now. I cannot imagine what my life will be going to be if I lose my feet due to diabetes like her...so I have to take actions to control my blood sugar well."
>
> (CFDP7)

Whilst a female carer from Wales also remarked her understandings of complications associated with type-2 diabetes:

> "I do not know too much about diabetes until my husband was diagnosed with diabetes. My husband's GP and a diabetic consultant told us diabetes was a kind of long-term and incurable disease, which could cause a lot of serious complications such as blindness, heart attack, and stoke and so on. Last year, my husband got a problem with his left eye. We were told the problem was likely to be caused by my husband's diabetes because his blood sugar was not controlled well in a long period [sighs]."
>
> (WMDPC1)

These two quotes are typical of the 12 participants who reported knowledge of complications due to type-2 diabetes. They illustrate that the participants both in China and Wales obtained knowledge about complications due to type-2 diabetes mainly from their friend's or relative's real experiences. Thus, social support may have important effect on the participants' awareness of complications due to type-2 diabetes both in China and Wales. However, the data indicated that nearly 70 % participants were lack of knowledge of complications related to type-2 diabetes. The knowledge of complications due to type-2 diabetes can be regarded as risk perception, which is an essential concept in a number of theoretical models addressing health-protective behaviour. Perceived risk is considered to be the primary motive to take actions and change behaviour within the health belief model (HBM) (Becker, 1974). The HBM was designed to understand why people at risk to a disease did not contribute in the disease diagnosis program. According to the HBM, people are more likely to take a health action if they perceive: they are at risk; the disease and its consequences are severe; health action is beneficial; there are few barriers to health action and receives a cue to take health action (Chapman *et al.*, 1995). Therefore, those participants who realised that type-2 diabetes can lead to serious complications and consequences were more likely to follow medical recommendations and to take actions to manage or help their relatives to manage their condition. Dehghani-Tafti *et al.* (2015) conducted a cross-sectional study in Iran with 110 patients with diabetes to determine self-care predictors among patients with diabetes based on the HBM. They found that the HBM constructs including perceived benefits, barriers, severity, susceptibility, self-efficacy and social support predicted 33.5% of the observed variance of self-care behaviours and perceived severity, susceptibility and self-efficacy had a positive effect on self-care behaviour among patients with diabetes. In addition, Jalilian *et al.* (2014) also carried out a study in which randomised pre-and post-test approach was used to evaluate the efficiency of self-management promotion educational program intervention based on the HBM with 120 patients with type-2 diabetes and they concluded that education program based on the HBM contributed to improving self-management among patients with type-2 diabetes. Therefore, conducting diabetes education based on the HBM may contribute not only to increasing understanding of complication due to type-2 diabetes but also to improving the conduct of self-management among Chinese patients and their carers although further research is needed.

In summary, the findings demonstrate that there was a lack of abundant knowledge of type-2 diabetes and its complications among most participants. There is therefore a need to explore the factors influencing the level of knowledge of type-2 diabetes among the participants, which are now discussed.

6.3 The factors influencing level of knowledge of type-2 diabetes

Data from the participants indicated that there were multiple factors which influenced their level of knowledge of type-2 diabetes, including socioeconomic status and education level, communication with health care professionals, and family support. In

Wales, the participants' level of knowledge of type-2 diabetes was also associated with their competence in understanding English. These factors are now presented and discussed.

6.3.1 Socioeconomic status and education level

Of the 20 participants in China, eight had a degree or diploma whilst two reported that they never studied in school. The remaining ten participants reported their education history, which ranged from three to 12 years. In Wales, of the 20 participants, none had a degree or diploma. 12 reported that they had studied in school for 12 years, the remaining eight reported their education background, which ranged from three to nine years.

A noticeable disparity in the level of knowledge related to type-2 diabetes between the participants with different socioeconomic status and education level in China. Compared with the participants who had a low socioeconomic status and education level, those participants who had a high socioeconomic status and education level demonstrated a higher level of diabetes-related knowledge. For example, when an agricultural worker who was educated for three years in a school was asked her understanding of type-2 diabetes, she commented:

> "I was born in a poor family and my parents were peasants. I only studied at a primary school for three years and I only can write my name and few Chinese characters. It is very difficult for me to read and understand those papers and books about diabetes so I do not know too much about diabetes. "
>
> (CFDP3)

In comparison, a retired obstetrician from China provided more information about her condition:

> "After being diagnosed with type-2 diabetes, I have read a lot of medical books such as endocrinology and gerontology and I know type-2 diabetes is mainly caused due to the impairment of pancreatic secretion of insulin and lack of insulin. I also know effective diabetes management contains five main tasks, namely diabetes education, diet modification, physical activity, self-monitor of blood sugar, and medical treatments. "
>
> (CFDP2)

Additionally, a university lecturer with type-2 diabetes from China also demonstrated a good level of knowledge regarding type-2 diabetes:

> "After being diagnosed with type-2 diabetes, I have read some books about the condition so I have got a lot of knowledge of diabetes. Type-2 diabetes is mainly caused due to insufficient pancreatic secretion of insulin. The lack of insulin will

> result in the elevation of blood sugar, and long-term high blood sugar could impair the structure and function of many vital organs such as brain, eyes, heart, and kidneys, eventually."
>
> (CMDP2)

Compared with CFDP3, both CFDP2 and CMDP2 demonstrated a better understanding about their condition, which could be associated with their high socioeconomic status and education level and active information seeking including access to resources such as books. Previous studies have also found that demographic characteristics such as occupational background and educational level were associated closely with knowledge of diabetes. He and Wharrad (2007) conducted a cross-sectional study in order to explore the factors that could enhance the quality of Chinese diabetes self-management education programmes among 100 Chinese patients with type-2 diabetes in China and found that compared with manual workers, white-collar workers had more knowledge of type-2 diabetes. Additionally a similar finding was obtained from another study conducted by Al Shafaee *et al.* (2008) with 563 adults in Oman. They concluded that the level of education was the most significant predictor of knowledge regarding risk factors, complications and the prevention of diabetes. A likely explanation is that those of a higher academic level (and hence of higher socio-economic status) may have more active information-seeking behaviour and they may have more resources to do this active seeking, such as access to the mass media, books including professional books, and the Internet.

Karimi Moonaghi, *et al.* (2014) carried out a qualitative study to explore the subjective experiences of health care-seeking behaviour among 15 Iranian patients with type-2 diabetes mellitus also supported that sources of sharing and acquisition of information were affected by education level and economic status, and those patients who were highly educated actively searched for information in magazines and online. Moreover, Wang *et al.* (2013) conducted a survey to monitor family health and information use among 4553 Chinese subjects in Hong Kong and found that 33.2% participants sought health information monthly from the internet, and lower education attainment, lower household income were associated with less frequent health information seeking. Besides an active information-seeking behaviour, the participants with a good education level also demonstrated a better ability to understand the information they accessed. A typical example is indicated below:

> "...I graduated from a medical college and got a degree in medicine about 55 years ago. After graduation, I worked in the maternal and child care service centre in Kunming as an obstetrician till retirement. I am certainly able to understand these medical books such as endocrinology and gerontology (speaks medical terms)."
>
> (CFDP2)

I am unable to judge whether the level of diabetes-related knowledge of participants in Wales is better or not compared with participants in China because the assessment of level of diabetes-related knowledge was based on participants' self-report and a measurement tool of level of knowledge was not used in this study. Moreover, the impact of socioeconomic status and education level on level of diabetes-related knowledge was not found among the participants in Wales because of lack of noticeable differences in socioeconomic status and education background among the participants in Wales. Nevertheless, competence in understanding English was an important factor that influenced the level of knowledge of type-2 diabetes among the participants in Wales. A female patient with self-reported proficiency in English from Wales reported plenty of knowledge on type-2 diabetes and its management as indicated:

> "...my GP told me type-2 diabetes is not cured completely currently. However, taking tablets is an effective way to control the development of the disease. I also know that the number of people with diabetes has been increasing dramatically in the world so I am interested in the reasons for type-2 diabetes, and I was informed I needed to change my diet and to do more exercise, which was beneficial for my blood sugar and health state ."
>
> (WFDP4)

The finding demonstrates that those Chinese patients who were able to communicate with health care providers in English in Wales had ample knowledge about their condition. This finding is also supported by previous studies. Hsu *et al.* (2006) conducted a pilot study with 52 Chinese Americans with diabetes to identify linguistic barriers to diabetes knowledge and glycaemic control. They found that compared with Chinese American patients with limited English fluency, English-speaking Chinese-American patients had higher level of knowledge of diabetes and less barriers to achieving optimal diabetes outcomes. Moreover, English fluency was identified as a factor independently associated with better diabetes knowledge in Bruce *et al.*'s (2003) study in which 1264 patients with type-2 diabetes with diverse ethnic backgrounds such as Northern European, Southern European, Asian, and African were asked to complete

15 standard multiple-choice questions about diabetes and its management to assess the association between diabetes knowledge and attendance at diabetes education programme. Therefore, English competence is an important and fundamental factor which influenced the level of knowledge of type-2 diabetes among Chinese participants in Wales. As will be shown in the next section this had a direct impact on obtaining information from other sources such as health consultation.

6.3.2 Communication with health care professionals

All participants reported how they communicated with health care professionals such as mainly diabetic specialists in hospitals in China and mainly GPs in Wales, and acquired knowledge of their condition. Their experiences illustrate that active and good communication with health care professionals aided their understanding of their condition and improved their level of diabetes-related knowledge. A female patient from China reported she had acquired much information about her condition through consultation with her doctor:

> "I never studied medicine so I have little knowledge of diabetes before I was diagnosed. But when I stayed in hospital, I had talked to my physician-in-charge several times. He told me type-2 diabetes is a kind of common disease among Chinese people aged over 40 years. And the causes of diabetes are still indefinite, which may be associated with defects of pancreas and unhealthy lifestyles and obesity. In addition, he stressed diabetes can be controlled well and I can live as a healthy people if I have proper treatments."
>
> (CFDP6)

Whilst another female participant from Wales also reported her experiences of communicating with her GP:

> "I have been living in UK for 28 years. I am able to speak English …so I liked to talk to my GP and I had asked my GP what causes of diabetes were. My GP told me type-2 diabetes is caused due to the lack of insulin in the body or insulin does not work properly."
>
> (WFDP2)

The findings demonstrate that the two participants' understanding of type-2 diabetes was improved through an active and effective communication with health care professionals. The findings are consistent with previous work. Hu *et al.* (2013a) who investigated diabetes knowledge among 108 older adults with type-2 diabetes in China using face-to-face interviews found that effective communication with health care professionals was related to higher diabetes knowledge scores. According to salutogenesis (Antonovsky, 1979), participants who perceived health care professionals as an important source of health information and tried to obtain information about their condition actively through effective communications with health care professionals may have an strong sense of coherence. The patients with type-2 diabetes with a strong sense of coherence are more likely to take actions to manage their condition (Nilsen *et al.*, 2015). Therefore, there may be a positive relationship between self-management and patients' sense of coherence. However, for most Chinese participants in Wales, good communication with their health care professionals was mostly subject to their ability to speak and understand English. The majority of participants from Wales reported they had difficulties in communication with health care professionals without Mandarin or Cantonese interpretation service, and five participants had self-reported English proficiency. Compared with the participants who were able to speak English, those who were not able to communicate with health professionals in English displayed less knowledge of type-2 diabetes:

> "I do not know too much about diabetes. I was not able to speak and understand English and Mandarin so it was quite difficult for me to communicate with my GP and nurses. I did not understand what they said and I also could not tell them what I needed."
>
> (WFDP1)

Nam *et al.* (2013) who conducted a qualitative study using five focus groups to explore the challenges of diabetes management in 23 Korean Americans with type-2 diabetes found that language barriers not only resulted in ineffective communication with health professionals but also impeded immigrants from accessing other information resources such as diabetes education. Therefore, language barriers had direct and negative impact on the participants in Wales in the acquisition of knowledge of type-2 diabetes. Besides communication with health care professionals, the data indicated that family support also plays an important role in obtaining knowledge of type-2 diabetes, which is discussed in the following section.

6.3.3 Family support

An interesting finding among the participants in China was that there was a mutual effect on the level of knowledge of type-2 diabetes between the patients and their carer. The carers' level of knowledge of type-2 diabetes was positively associated with patients' level of knowledge. If patients had a high level of knowledge, their carers displayed more knowledge than other carers and vice versa. A male patient's wife reported that she obtained knowledge by reading her husband's books regarding type-2 diabetes:

> "Since my husband was diagnosed with type-2 diabetes, he has got and read a lot of books about his condition. I sometimes also read his books because I would like to have information on how to help him control blood sugar."
>
> (CMDPC3)

Additionally, another female patient's husband also reported that he obtained information on type-2 diabetes from her wife:

> "Before my wife was diagnosed with type-2 diabetes, I really did not know what diabetes was. But after my wife was diagnosed, I have got a lot about diabetes from her, for example diabetes occurs when insufficiency of the pancreatic secretion of insulin, and diabetes can cause a lot of serious complications such as blindness, heart attack, and stroke. "
>
> (CFDPC2)

The two carers' experiences demonstrate that information related to type-2 diabetes spread within their family. The patients' level of knowledge of type-2 diabetes positively impacted on their carers' level of knowledge through easy access to information and verbal communication. Moreover, visiting the doctor or attending diabetes education sessions together is another important factor influencing the conformity in the level of knowledge of type-2 diabetes between patients and their carers in China. Typical examples included:

> "When he goes to hospital or community health centre to see doctors or nurses I always accompany him. The doctors had told us obesity and lack of exercise is high risk factors for diabetes."
>
> (CMDPC1)
>
> "...we have taken part in the public health lectures about diabetes organised by hospital a few times. I think they are very helpful for me. I have got a lot of knowledge about diabetes from the lectures."
>
> (CFDPC2)

In Wales, this mutual effect on the level of knowledge of type-2 diabetes between patients and their carers was also found as indicated in the following extracts which are typical examples of this issue:

> "My wife told me that doctor said diabetes is a kind of long-term and incurable disease, which can cause a lot of serious complications. My trouble with left eye

> was likely to be caused by my diabetes because my blood sugar was not controlled well."
>
> (WMDP1)

> "I did not know diabetes until my husband was diagnosed with diabetes. My husband's GP and a diabetic consultant told us diabetes is a kind of long-term and incurable disease, which can cause a lot of serious complications such as blindness, heart attack, and stoke and so on. Last year, my husband had a problem with his left eye. Doctor told us the problem with my husband's left eye was likely to be caused by my husband's diabetes because his blood sugar was not controlled well. After that, I knew diabetes was a kind of extremely terrible disease. "
>
> (WMDPC1)

Patients who lived with their family in Wales were more likely to be accompanied by their carers when they visited health professionals because carers who were able to speak English not only accompanied their spouse when visiting the doctor but also played the role of English interpreter during consultations. In Wales, five out of the seven carers reported that they had attended a consultation or diabetes education with their relative. A common response is indicated in the following quote from a female carer from Wales:

> "I always accompany my husband when he goes to see doctors. I play the role of English interpreter during the meeting because my English is better than my husband's [laughs]."
>
> (WMDPC4)

However, in China, although all 20 participants including seven carers lived with their relative who had diabetes, two of the seven carers reported their attendance at consultations or diabetes education. A female carer from China reported the reason why she was absent when her husband went to hospital to visit a doctor:

> "No, he usually goes to the hospital alone. I have to work so do not have time to accompany him to the hospital."
>
> (CMDPC5)

Besides some pragmatic barriers such as a clash between work and attending doctor's appointments, the data indicated that the absence of carers during consultation was also related to cultural values such as machismo and family responsibilities. Most Chinese men confidently consider that they have full capability to deal with any troubles in their family so several Chinese patients especially men emphasised their own ability to solve their condition and were reluctant to add additional tasks to other members in their family. Moreover, female carers in Chinese families usually have various commitments including care of grandchildren so sometimes it is difficult for them to spare their time as indicated in the following extracts:

> "My husband is very macho and he asserted he was able to sort his own business out by himself so he did not let me go to the hospital with him."
>
> (CMDPC6)
>
> "He thought he can sort his own problems out by himself. In addition, I am very busy every day and I need to look after my grandson."
>
> (CMDPC3)

As mentioned above, five carers from Wales and two from China reported their attendance in health consultations and diabetes education programme. Of these seven carers, six were female, and one was male, which demonstrates the gendered nature of family roles in Chinese culture. Women usually play the role of a care giver in Chinese families. Therefore, Chinese female carers take more responsibility to look after their male family members when they are ill including attendance at health consultation and diabetes education programmes, providing an interpretation service, and learning health knowledge in order to maintain the cultural norm and role so that Chinese male patients could obtain more and better support and care from their female family carers. In contrast, Chinese female patients could have more cultural challenges in self-management and less support from their male family carers.

The other form of family support is to obtain information from other family members with type-2 diabetes. 11 of the 20 Chinese patients including four from China and seven from Wales reported their family history of type-2 diabetes. Patients with a family history of type-2 diabetes presented a better understanding of type-2 diabetes and its treatments as they acquired information on type-2 diabetes from other family members with type-2 diabetes. A female patient from Wales reported:

> "I have known that type-2 diabetes is a kind of long-term and incurable disease because my older brother has been living with the disease for nearly 20 years as well. He has to take a lot of tablets every day and he was blind in left eye due to the disease two years ago."
>
> (WFDP5)

This finding supports the previous studies. Berhe *et al.* (2014) conducted a study to assess diabetes knowledge level and associated factors among 310 adults with type-2 diabetes in Northern Ethiopia and found that there was significant association between family history of diabetes and level of diabetes-related knowledge. Similarly, Al-Adsani *et al.* (2009) conducted a cross-sectional survey with 24 diabetes clinics and 5114 adults with type-2 diabetes in Kuwait and also found the positive association between level of knowledge of type-2 diabetes and family history of type-2 diabetes.

Understanding the positive effect of family support on the participants' level of knowledge of type-2 diabetes can be explained by applying the model of salutogenesis (Antonovsky, 1979). The information from other family members with type-2 diabetes can help the Chinese patients to have a better understanding of their condition and to perceive their condition as predictable and manageable, which contributes to improving their sense of coherence. In addition, the Chinese patients perceived that they can access family resources to manage their condition through obtaining information from other family members with type-2 diabetes, which is consistent with the concept of generalised resistance resources (GRRs) in salutogenesis (Antonovsky, 1979). This helps to understand why those Chinese patients with a family history of type-2 diabetes had a higher level of knowledge of the condition.

In this section, three factors associated with the level of knowledge of type-2 diabetes among the Chinese participants both in China and Wales were identified, namely socioeconomic status and education level, communication with health care professionals, and family support. This finding is associated with the development of concept of health literacy. Health literacy is defined as the degree to which an individual has the capacity to obtain, communicate, process and understand basic health information and services to make appropriate health decisions (Ratzan & Parker, 2000). In diabetes, health literacy is related to diabetes knowledge, self-efficacy and self-care behaviours and glycaemic control (Cavanaugh, 2011). According to the definition, there are four components in health literacy, namely obtaining health information and services, communicating with others about their needs and preferences and responding to the received information, processing the meaning and usefulness of the information and services, and understanding the choices, consequences and context of the information and services (Institute of Medicine, 2004). Health literacy is a broad concept including more than individual levels of intelligence, but rather a specific skillset that involves a variety of methods to communicate and interpret health information with unique demands, depending upon the person and their setting (Cavanaugh, 2011). The committee on health literacy developed a framework which illustrates the three major factors influencing health literacy, including educational systems, health systems, and cultural and social factors (Institute of Medicine, 2004). Therefore, the improvement of level of knowledge of type-2 diabetes among Chinese patients and their family carers is related not only to individual ability and intelligence but also is affected by multiple factors such as health care systems and the social and cultural context. Moreover, sources of information on type-2 diabetes may play an important role, which is now presented and discussed.

6.4 Information sources

The data indicated that Chinese participants obtained information related to type-2 diabetes from four sources, including health care professionals, media, lay interpersonal sources, and public health lectures, which are discussed in the following sections.

6.4.1 Health care professionals

26 out of the 40 participants including 14 participants from China and 12 from Wales stated health care professionals, such as diabetic specialists in hospitals in China and GPs in Wales, as their principal information source. 19 out of the 26 participants were patients, and the remaining seven were carers.

Generally, health care professionals were among the most frequently mentioned sources of information, both immediately after the diagnosis and over a lifetime of treatment. Typical examples included:

> "I got information about my condition mainly from doctor in hospital after I was diagnosed with diabetes."
>
> (CMDP6)

> "...my information about diabetes was mainly from my husband's GP because I often accompanied him when he went to see GP..."
>
> (WMDPC4)

The reason why health care professionals were the most important source of information among many participants is that they were regarded as the most reliable information sources as indicated in the following extract:

> "The information from doctors is most reliable. When I went to hospital to see a doctor, I asked a lot of questions about my condition, for example how to control blood sugar in the consultation."
>
> (CFDP1)

Perceived as the most reliable source of information, the participants in China acquired information related to their condition and its management through good communication with health care professionals, but in public hospitals the participants usually failed to obtain sufficient knowledge they needed due to the limited length of time of the health consultation as indicated by the following two comments from two patients in China.

> "...those doctors [in diabetes outpatient department] are usually **very** busy, and they have to see a lot of patients a day so they do not have time to give me a lot of information in the consultation."
>
> (CMDP2)
>
> "I was given a little time to talk to a doctor in the outpatient department. The doctor sat at her desk, asking me some questions very quickly. I tried to answer carefully, but she told me to be concise... I wanted to ask her some questions ... but she was quite busy with medical records and prescriptions; then she stopped that I could leave. From start to finish, the encounter just lasted less than 10 minutes...but I spent more than three hours waiting to see her."
>
> (CFDP7)

These typical examples illustrate that Chinese patients failed to acquire necessary and sufficient information on their condition during health consultations due to restricted time with health care professionals, which also seems to suggest that the health service in China is overstretched. The current health service system in China is a hospital-based service and so most patients seek medical care in hospitals due to a lack of an effective primary care system. With the increase in demands on health care and population size, Chinese doctors have been overloaded. In China, the ratio of doctors to the general population is 1:735, which is considerably lower than that of western countries (1:280–1:640) (Li, 2007). In addition, according to statistics from the Ministry of Health of the People's Republic of China, a doctor in a health centre treats an average of 24.1 patients daily in Shanghai, China (Ministry of Health of the People's Republic of China, 2010). Therefore, it is difficult for patients in China to gain sufficient health information through health consultations in hospitals as a consequence of an overstretched health care system, which may be a great challenge for patients' self-management in China.

In order to have more time and opportunities to get information from health care professionals, a male patient from China increased the frequency of visits to the doctor:

> "...doctors cannot give me much time to ask questions in every consultation so I go to the hospital frequently to see and talk to them to get information about how to take medicines, how to change eating style and how to increase exercise since I have been diagnosed with diabetes."
>
> (CMDP3)

These additional visits contributed to obtaining more information from health care professionals. However, the financial cost for accessing this information may increase as a result of these additional health consultations because most people in China are not eligible to free health consultations in the public hospitals. Moreover, the spending on travelling to hospital may result in greater financial burden, which may reduce health information-seeking behaviour for some participants who do not have the finical means to pay these additional costs. Richardson *et al.* (2012) used data from the 2007 Health Information National Trends Survey (HINTS) to assess the effects of ethnicity, education, and income on health information-seeking, confidence in obtaining health information, and trust of information sources and found that people with lower incomes had decreased health information-seeking and confidence in their ability to obtain health information due to the consideration of finance.

Moreover, the minority of participants with high socioeconomic status started seeking help from private clinics to gain better consultation services as indicated by the retired obstetrician with type-2 diabetes from China:

> "Six years ago, when I lived in Beijing with my first son, I had talked to a diabetic specialist from Germany for one hour, who established a private clinic in Beijing. The German specialist gave me a lot of information about diabetes and its management and treatments during the meeting. I still keep in touch with the German doctor now and ask for his help when I have some problems in diabetes management."
>
> (CFDP2)

Private clinics usually provide patients with sufficient time in the health consultation so that patients could obtain more information in the private clinic than in public hospitals.

However, expensive consultation fees are charged in the private clinic, which may be a reason why private clinics were not an option for most participants in this study, and even for those who had high socioeconomic status, this was still a concern as indicated by CFDP2 in the following extract:

> "But, you know, the consultation was **very** expensive (in the private clinic). It is not affordable for me if I need to have a frequent encounter there."
>
> (CFDP2)

Besides these limitations of health care system, physical impairments and low level of literacy were barriers to acquiring information from health care professionals for older participants in China. An illiterate female patient aged 65 years with a visual impairment reported her difficulties when she talked to her doctor:

> "I have got a problem with my eyes so it is hard for me to read something. I am also illiterate so I would like to talk to the doctors but you know sometimes I am not able to understand what the doctors say completely."
>
> (CFDP5)

Health information on diabetes is equally important for every patient and their carers. It is therefore crucial to ensure this information is accessible for every patient and their carers. However, this finding demonstrates that the participants with physical disability and a low level of literacy preferred accepting verbal information. Williams *et al.* (1998) conducted a cross-sectional survey with 516 participants with hypertension and diabetes to examine the relationship between functional health literacy level and knowledge of chronic disease and treatment among patients with hypertension or diabetes and confirmed that low-literate participants had great difficulties in having full understanding of medical information and advice using standard patient education methods. Whilst Plimpton and Root (1994) also point out that the most poorly educated adults, those with the lowest literacy levels, suffer the highest rates of morbidity and mortality from chronic conditions. The fact that they cannot either read or understand the information necessary to improve their health would seem to be an important contributing factor. Although there are many difficulties in educating patients with a low level of literacy, endeavours to increase level of knowledge related to their condition among less educated patients have shown some success. Winkleby *et al.* (1992) performed four cross-sectional surveys (n=6,580) to explore trends in cardiovascular disease risk factors by educational level and found that persons from all educational levels were able to modify their risk for cardiovascular disease after a broad-based, multisource health education intervention. Moreover, Hussey (1994) investigated medication knowledge and compliance with 80 year old people with low-literacy and suggested that successfully communicating medical advice to patients with chronic illnesses who had inadequate or marginal literacy required providing appropriately written materials, using oral communication, and improving visual presentation. Therefore, these previous work provides effective methods and experiences in terms of how to educate patients with low level of literacy or physical impairments. These methods also may be effective for Chinese patients with low level of literacy or physical impairments although further study is required.

In Wales, several participants also reported similar experiences, namely they were not allocated enough time to obtain information from health care professionals at the health consultation. Unlike China, most participants in Wales usually visited their GP for their type-2 diabetes instead of attending the diabetic specialists in hospital therefore their GP was their main source of information for type-2 diabetes. However, long waiting times and limited time during consultations with GPs impeded them accessing adequate information. A typical comment exemplified this issue when she described her GP as a "trustworthy but limited" information source:

> "Since being diagnosed with diabetes, I have got some information from my GP. But you know if I want to see my GP, I need to make an appointment in advance and probably I need to wait a couple of days before seeing him. In the clinic, there is usually a long queue in the waiting area. I usually just have a couple of minutes to talk to my GP. I would like to talk to him more but I know if I talk to him more I could occupy other people's time so although I have got some information from the GP, it is not enough for me. The information provided by GP is trustworthy but limited."
>
> (WFDP2)

Both in China and Wales, , health care professionals were the main information sources and regarded as the most reliable information sources by most participants. Nevertheless, due to the limitations of the health care systems, most participants reported that they failed to obtain abundant knowledge on type-2 diabetes from health care providers. Therefore, the use of health booklets and public diabetes lecture may be helpful to solve the problem. A Chinese diabetic consultant, who also supported providing patients with increased information through additional approaches, was interviewed during my observation of a public diabetes lecture in China. He stated:

> "We received many complaints from patients and their family members because our doctors failed to provide enough information about their condition during consultations. I understand patients' needs but we do have a lot of realistic difficulties. It is really difficult for our doctors to provide enough information as a diabetes educator while performing clinic treatments. Five doctors in outpatient department have to see more than two hundred patients every day, less than 10 minutes for each patient. Of course, we fully know our responsibilities as doctors so we are making efforts to find out feasible alternatives such as setting up a dedicated telephone line to answer patients' questions, compiling and dispatching booklets and increasing public diabetes lectures in order to meet patients' needs for information of their condition."
>
> (Fieldnotes)

In Wales, besides limited time of the health consultation, language barriers were greater obstacles to accessing information from their GP for most participants, who had limited competence in understanding English:

> "GP told me there is a link between diabetes and stroke so I need to control my blood sugar to a normal level to prevent stroke. Probably my GP could tell me more about my diabetes but I was not able to fully understand them because I do not speak English very well and sometimes he spoke too fast."
>
> (WFDP8)

As this above quote illustrates that there is a need for health care professionals to improve cross-language communication skills including slowing speech speed down, simplifying expression, and using common and understandable terms and to provide a Chinese interpretation service. On the other hand, Chinese patients and their family members also need to improve their English language competence as the acquisition of information and effective communication with health care providers is one of key components of self-management of type-2 diabetes (Diabetes UK, 2009). Moreover, a structured diabetes education programme, namely the X-PERT Diabetes programme, which can be complementary to accessing information from health professionals, is being provided for diagnosed patients with type-2 diabetes and their carers across Wales. Nevertheless, few Chinese patients and their carers access this programme as it is currently delivered in English. I was able to observe an X-PERT Diabetes programme over a period of six weeks, which is discussed in the subsequent section of public diabetes lectures.

As mentioned above, health booklets can be feasible additions to obtaining information from health professionals and 18 participants also reported they had acquired information about type-2 diabetes from the media such as from health booklets, books, TV programme, and the Internet, which are discussed in the following section.

6.4.2 The media

18 participants including nine from China and nine from Wales reported that they had gained information about diabetes and its management from the traditional media including printed local newspapers, medical books, health booklets, TV programmes, radio, and new technological media such as the Internet. In Wales, six out of the nine participants had acquired information related to type-2 diabetes through a single media source, namely health booklets from health care professionals, and another two participants had received the booklets but they were not able to understand them due to a language barrier. Only one participant from Wales reported her experience of using the Internet to get information on type-2 diabetes. By comparison, besides health booklets, the nine participants from China had obtained information through a wider range of media sources including printed local newspapers, medical books, advertisements, TV programmes, radio, and the Internet. A female patient from China reported her various sources of information from the media:

> "I like reading newspaper every day, and well, you know there is so much information about health so I had got a lot of information about diabetes from the health column of City Times (name of a local newspaper). Additionally, I had got some information regarding controlling blood sugar from the TV health programmes, health booklets, pharmaceutical advertisements, and the instructions for health products related to diabetes."
>
> (CFDP1)

Several participants from Wales also reported that they had received health booklets about type-2 diabetes from the GP, which were important and "reliable" sources:

> "...after being diagnosed with diabetes, I had received some English booklets from GP, and well there was a lot of information about type-2 diabetes, including recipes, exercises, medicine, and insulin."
>
> (WMDP3)

> "Yeah, I like the booklets from my GP, which provide me with a lot of credible information about type-2 diabetes and particularly the information telling me how to make recipes to help me control blood sugar."
>
> (WFDP4)

The findings demonstrate that patients in China had access to information on type-2 diabetes through multiple media sources, such as newspapers, television, and advertisements. In Wales, patients reported fewer options to obtain information regarding diabetes through media sources, which may be attributed to the fact that most information through the media is provided in English. Health booklets provided by health care professionals was their most important media source although not all could understand booklets provided in English or did not have a relative who could translate the information as indicated in the following extracts from two patients from Wales:

> "I had received some booklets about diabetes from my GP. But I am not able to understand them because they were written in English. "
>
> (WMDP2)
>
> "...my GP has given me some health booklet about diabetes and high blood pressure but I am not able to understand them because they are written in English, and nobody could help me to translate them into Chinese in my family so if he [GP] can give me some Chinese booklets, it could be more helpful for me. ...so that I could not need to see him frequently...[sighs]."
>
> (WFDP3)

Provision of interpreting service and more information on diabetes in Chinese languages which is available from sources such as Diabetes UK seems to be needed, which may facilitate health information-seeking behaviour among Chinese patients and their carers in Wales. Being provided with health booklets by the health care professional is illustrative of the concept of passive receipt of health information (Longo *et al.*, 2010); that is, individuals who may not be actively engaged in information-seeking behavior come across relevant health information about type-2 diabetes during the course of such daily activities as reading newspapers or surfing television channels or reading advertisements, or are provided health information by health care professionals during consultation or through media such as posters or health booklets.

TV and radio are traditionally viewed as more passive media outlets for health information. There is an assumption that these outlets may be considered the primary source of health information for individuals who have less interest in health. Moreover, Carlsson (2000) conducted a study among 192 Swedish cancer patients to examine the degree to which cancer patients seek information from sources outside the health care system and found that a passive information seeking strategy was common among Swedish cancer patients, especially among those with lower educational levels.

However, the association between demographic factors and passive receipt of information was not found in the current study. It is predicted that with the development of mass media, passive receipt of health information will become more common among patients, which may contribute to increasing patients' level of health knowledge.

In contrast, a small number of participants both in China and Wales reported active information-seeking through using media sources such as medical books from the library and the Internet as indicated by a male patient from China, who was working in university as a lecturer:

> "After being diagnosed with type-2 diabetes, I often go to our university's library to read some medical books regarding endocrinology and metabolism. Although sometimes I am not able to fully understand those medical terms, I can get reliable knowledge about diabetes through reading such books. In addition, nowadays, the internet has been developed very well. I often use the internet in my spare time to get some latest information and development about diabetes and its treatments."
>
> (CMDP2)

In addition, a female patient from Wales with a self-reported good level of English reported:

> "...actually I do not use Internet very well [laughs] but sometimes I use it to get news about health and diabetes, for example surfing health columns of the BBC webpage."
>
> (WFDP4)

This finding demonstrates that active information seeking was associated with the participant's socioeconomic status and education level. It was also related to their level of English proficiency among the participants in Wales. This finding also echoes previous findings of a positive association between socioeconomic status and education level and level of knowledge of type-2 diabetes among participants. Longo *et al.* (2010) conducted a qualitative study among 46 people with diabetes to identify how individuals with diabetes seek and use health care information and found that patients with higher education level had more active health information-seeking behaviour. Additionally, Kalantzi *et al.* (2015) carried out a cross-sectional study to examine the information behaviour of 203 patients with diabetes from Greece and found a positive association between patients' socioeconomic status and education level and health seeking information behaviour. Moreover, applying the model of salutogenesis (Antonovsky, 1979) may further aid interpretation of this findings. The participants perceived that they were able to obtain information on type-2 diabetes from the media sources through active information seeking, which contributed to improving their sense of manageability. Moreover, an increased sense of manageability also contributed to improving their active information seeking through strengthening their sense of meaningfulness (Antonovsky, 1996).

However, the credibility of information from media sources was an important concern among nearly half of patients and their carers in China:

> "No, no. [waves her hands] I do not believe the Chinese media. The local newspapers, radio, and TV programmes are being filled with a large number of commercial advertisements, especially those advertisements of products related to diabetes, which actually claimed that diabetes can be eradicated in order to promote their products."
>
> (CFDP7)
>
> "Previously, I had watched some TV programmes on diabetes, but I thought those TV programmes were not helpful for me because these programmes were often interrupted by exaggerated, perplex and **even deceptive** commercial advertisements. I once was frustrated by an advertisement, which stated diabetes can be cured after using their products. It was absolutely a **big deceit** so I currently **no longer** watch any TV programmes on diabetes."
>
> (CMDP2)

A carer from China also reported his dislike of those advertisements, which claim diabetes can be cured:

> "I like listening to the local radio every morning, but currently most radio programmes about diabetes are occupied by those exaggerated commercial advertisements, which claim diabetes can be cured. I do not believe that. "
>
> (CFDPC5)

These participants did not trust the information on diabetes from mass media such as newspapers, television or radio especially when it was associated with commercial advertisement. They had the feeling that the information was thus only given to promote products. There is therefore a need for information about credible information sources among Chinese participants.

> "In addition, there are a large number of information and advisements about diabetes in media such as TV, newspapers, radio and the Internet, but I do not know about diabetes as much as doctors...after all... I am not able to distinguish what kind of information is right or not so now I do not know where I can get reliable information on diabetes except doctors [sighs]. "
>
> (CMDP5)

By comparison, no participants from Wales reported that they had received any commercial advertisements related to type-2 diabetes and its medicine treatment in media such as TV, newspapers, and radio, which may be associated with a strict regulation in terms of advertising medicine to public in the UK. In the UK, advertising prescription-only medicines (POMs) or any medicine that is not licensed by the Medicines and Healthcare products Regulatory Agency (MHRA) or the European Commission to general population is not allowed (MHRA, 2015), which protects patients with type-2 diabetes from those overstating and even false commercial information related to type-2 diabetes and its medicine treatment.

To summarise, in China, nearly half of participants obtained information related to type-2 diabetes from a wider range of media sources but the credibility of the information was a concern. Thus, health care professionals need to provide patients with information about credible information sources especially when using the media. In contrast, participants from Wales accessed mainly a single media source, namely health booklets from health care professionals. However, most health booklets were written in English. Thus, language barrier was a great obstacle for those patients in Wales who had limited competence in English to gain information from the health booklet. Therefore, health care professionals' and patients' awareness of the availability of health booklets provided in Chinese languages needs to be raised. Also there is a need to ensure that health care professionals offer patients who are not able to understand English the choice of an interpreter or language line and for Chinese patients to be made aware that these services are available and which they can request.

Beside the health care professionals and the media, nearly half of participants also turned to their family, friends, working colleagues, and neighbours, who had been diagnosed with type-2 diabetes in order to gain insights into their diabetes and its management. Although these people have been living with type-2 diabetes, they may not have a health professional background and so for this reason they are described as lay people and the findings related to use of the lay referral network as an information source are discussed in the next section.

6.4.3 Lay interpersonal sources

19 participants including ten participants from China and nine from Wales had received information about type-2 diabetes and its management through lay interpersonal sources including family, friends, working colleagues, and neighbours, who had been diagnosed with type-2 diabetes. Five out of the 19 participants were carers, and the remainder were patients.

The information provided by lay people was mainly related to general information on type-2 diabetes and personal experiences of self-management. Examples of typical comments included:

> "I have a lot of friends living with type-2 diabetes, and they often tell me some knowledge and their experiences about diabetes and its treatments, for example, they told me if the medicine they are using is effective to reduce blood sugar."
>
> (CMDP1)

> "...sometimes I like to talk about my condition to my friend Mr. XXX, who is also a Chinese patient with type-2 diabetes. He gave me some valuable and understandable information about type-2 diabetes and what I need to do in daily diet and life. He told me what kind of food and exercises are good for me according to his personal experiences of managing type-2 diabetes. For example, he suggests me going to swim with him every week because his blood sugar was controlled by swimming twice a week."
>
> (WMDP5)

In addition, lay people's experiences were also cited as important information sources of complications due to type-2 diabetes as indicated below:

> "I have a friend, who has type-2 diabetes for long time, and he lost vision last year due to the condition [sighs]."
>
> (CMDP1)

> "I have a close friend who has got diabetes for ten years, and her left foot was amputated due to a serious infection caused by diabetes last year."
>
> (CFDP7)

These findings demonstrate that participants were able to obtain "understandable" information in terms of type-2 diabetes and its complications, of self-management, and of personal beliefs and experiences of living with type-2 diabetes from lay interpersonal sources. This may be a main reason why lay people were mentioned as an important diabetes information source by nearly half of the participants. Moreover, information regarding complications of type-2 diabetes and self-management from lay people was identified as being "valuable" because it derived from personal real feelings and experiences, which shows the important role that lay people may have on decision-making through sharing of personal feelings and experiences. Kjos *et al.* (2011) conducted an exploratory qualitative study with 40 patients to determine how patients communicate within social networks to seek medication information. They found that compared with health care professionals, lay social contacts played a more important role in providing information on personal experiences, beliefs and attitudes towards health and illness. Moreover, patients' sense of manageability (Antonovsky, 1996) can be increased by obtaining information from their lay sources and wider social networks, which may contribute to improving their self-management. However, this information from lay people may lack accuracy. A female patient from Wales reported her concern:

> "...my brother's knowledge could be less accurate and professional than information provided by GP..."
>
> (WFDP5)

Moreover, the data also indicated that the patients with lower education level and newly diagnosed patients in China preferred using lay people as their main information sources. A female patient who was illiterate from China remarked:

> "I never studied at school. When I talked to the doctors but you know I was not able to fully understand them so I prefer talking about my condition to my neighbour, who has got diabetes for a longer time, I can understand her..."
>
> (CFDP5)

A male newly diagnosed patient from China reported:

> "My boss has got diabetes for more than ten years... I asked him some questions about diabetes and he told me his knowledge and experience of living with diabetes. I just was diagnosed less than one year... and have little knowledge of diabetes so his information was helpful for me... "
>
> (CMDP4)

In Wales, the patients whose level of English was limited relied more on lay information. A female patient from Wales commented:

> "My old brother has been living with the disease for nearly 20 years... I often talk to him to learn his experiences living with diabetes. We talk in our own language... my English is not very good so actually I do not like to see GP..."
>
> (WFDP5)

These findings indicate that those who have a lower educational level or poor proficiency in English rely more on sources of information which may not be reliable and for these participants may be their main source of information. These findings are congruent with previous studies. Cotton and Gupta (2004) investigated factors that differentiate between online and offline health information seekers with 385 adults in the United States and found that reported lay interpersonal sources was particularly important for individuals with fewer years of education and lower income levels due to less use of other information resources such as printing health booklets or the Internet. Additionally, Ford and Kaphingst (2009) examined the relationship between beliefs about causation for lung, colon, and skin cancer and the use of lay interpersonal sources of health information with 5,119 adults and found individuals with lower educational attainment was associated with more use of lay interpersonal sources for health information. Besides less use of other information resources, another possible explanation for the finding may be that for those patients with low education level and newly diagnosed patients whose diabetes knowledge was insufficient, lay interpersonal sources such as family, friends, or working colleagues were easy to understand and accessible. Ford and Kaphingst (2009) also found that individuals with lower educational attainment would be less likely to use health information if it was provided in print because some printed materials require a good educational and reading level to understand the information.

However, a small number of patients in China with higher education level also gained information from their lay interpersonal sources. A male patient working in a university as a lecturer in China reported his experiences of using lay interpersonal sources to gain information related to type-2 diabetes:

> “I have many friends who have diabetes. I also like to talk to them in order to exchange the experiences of diabetes management. I would like to talk to the friends whose blood sugar is controlled well to know how they control blood sugar well. On the other hand, I also would like to talk to the friends whose blood sugar is not controlled well to know why their blood sugar is controlled badly. I think their merits and shortcomings of diabetes management are helpful for me. Such mutual study and help between the friends I think is **very** helpful for me.”
>
> (CMDP2)

These findings are associated with Chinese cultural norms, which support mutual understanding, consolation and help among patients with the same condition. Therefore, the effect of this cultural norm is that Chinese patients were more likely to disclose and talk about their condition to other people who had the same condition as theirs in order to gain more mutual understanding and support, which coincides with the idea of peer support as a promising approach to diabetes management as recognised by the World Health Organisation (WHO) (World Health Organisation, 2008).

Dennis (2003, p.323) defined peer support as "support from a person who has experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population." The purpose of a peer support programme in diabetes is that:

> "People with diabetes and those affected by the condition are able to help other people with diabetes and their family to cope effectively with a range of demands and challenges involved in diabetes management, and in their struggle against discrimination."
>
> (Wientjens, 2008, p.45)

Peer support has occurred formally in many parts of the world for example, as part of diabetes education and support programmes, and informally among friends living with the same condition who offer each other advice and support. Besides acquisition of health information, the key functions of effective peer support include assistance in daily management, social and emotional support, linkage to clinical care, and ongoing availability of support. Qi *et al.* (2015) conducted a literature review using meta-analysis, in which 13 randomised control trials (RCTs) assessing the effects of peer support at improving glycaemic control in patients with type 2 diabetes were included and concluded that peer support had a significant impact on glycaemic control (HbA_{1c} levels) among patients with type-2 diabetes. Additionally, Fisher *et al.* (2012) conducted projects in Cameroon, South Africa, Thailand, and Uganda, respectively in order to evaluate and then develop peer support interventions for adults with diabetes in international settings and found peer support contributed to the improvements in symptom management, diet, blood pressure, body mass index, and blood sugar levels for those taking part in the programmes in the four countries.

In China currently peer support in diabetes is only being conducted in a few communities of economic developed regions such as Beijing, Shanghai, and Nanjing

(Peers for Progress Program Development Centre, 2012). However, increasing awareness of health behaviour and the importance of primary care in chronic conditions prevention and management in China provides a dynamic context for conducting health education and support activities among Chinese patients. In this environment, peer support has risen as a practical approach to aid health promotion and chronic conditions management, which is applicable to the primary care model of care and the Chinese culture and health care system. Due to the disparity in economic development, the level of health care, and even cultural belief, China seems to be one country with many systems, which underscores the concept that there is no one size fits all model for peer support programmes. While cultural adaptations and tailoring could be needed, the four key functions of peer support are able to serve as an important framework for programme development in China.

As mentioned above, culture is another important factor influencing how patients and their carers acquire information through lay interpersonal sources. Chinese culture encourages patients to tell their family members about their condition in order to gain more help and support. Due to the influence of culture, patients often inform their family members of their condition and knowledge is passed to their family members. Therefore some carers gained information about type-2 diabetes from their relative with type-2 diabetes:

> "My wife told me this information of diabetes when we talked. She knows more about diabetes than me."
>
> (CFDPC6)
>
> "...He (her husband) has read some books about diabetes so he has got a lot of knowledge of diabetes. When we talked about his condition, he passed this knowledge to me."
>
> (CMDPC3)

In addition, the Chinese cultural norm of advocating mutual understanding, consolation and help among patients with the same condition also played an important role in how patients reduced their apprehension and gained information from lay people:

> "I would not like to talk my diabetes to other people especially people outside of my family because I think I could lose my face when many people know my condition particularly when they mention me as an example of patient with diabetes. But I have a working colleague, who has got diabetes for ten years. I think we are easy to be understood each other because of suffering from same

> condition so we frequently exchange information and experiences about what I need to do to control blood sugar in daily life."
>
> (CMDP5)

Many Chinese patients especially male patients were reluctant to disclose and talk about their type-2 diabetes to other people especially people outside of the family because they thought they could lose "face" due to their diabetes. Face is an important Chinese cultural norm, which is linked to self-perception of being integral social members and having self-respect in interpersonal communication (Zane & Mak, 2003). Thus, the patients may be very sensitive to their perceived role as a patient in seeking health information from other people. Disclosing their identity as a patient to other people would thus breach such interpersonal norms and risk loss of face. Face concerns are crucial in all social communication but can be attenuated in situations where patients and other people are also patients with type-2 diabetes because of the effect of another cultural belief, namely advocating mutual understanding, consolation and help among patients with the same condition. Ho *et al.* (2012) discussed the effect of the Chinese cultural norm of face on health communication among Chinese American with type-2 diabetes and found the cultural norm not only affected the patients' health communication with non-experts but also could result in the concealment of real views and feelings among the patients in health consultations. Therefore, health communication is not only an issue related to language but also needs to be matched culturally.

In this section, lay interpersonal sources were discussed as sources of health information. I have explored and discussed what kind of information was acquired through lay interpersonal sources and factors influencing participants acquiring information from lay interpersonal sources. Besides education and language level, Chinese cultural norms played an important role in how participants gained information via lay interpersonal sources, which could inform future diabetes education and support activities such as peer support groups among Chinese patients and their family in China and Wales. Public health lectures were mentioned by six participants as another source of information related to type-2 diabetes, which are discussed in the next section.

6.4.4 Public health lectures

Of the 40 participants, six participants including three participants from China and three from Wales had received information about diabetes and its management through attending public health lectures. One participant was a carer, and the remaining five participants were patients. The remaining 34 participants reported that they never participated in any diabetes education sessions.

In China, only three participants including one carer reported that they had once attended public diabetes lectures organised by the diabetes department of the hospital, and provided by diabetic medical specialists. One of the participants who was a university lecturer reported his attendance at the public diabetes lectures:

> "...I had once taken part in free health lectures about diabetes organised by hospital and I had got a lot of helpful information about diabetes and its management during the lectures. The lecture was provided by an experienced doctor from diabetes department of the hospital so the information he provided was **very** credible and **very** helpful for me."
>
> (CMDP3)

Whilst a retired doctor and her husband also reported their participation at public diabetes lectures organised by the hospital:

> "I had taken part in the public lectures about diabetes organised by the hospital a few times. But now I no longer attend because the content of the lectures was superficial for me, and the lecturer always repeated same topic and no new things were offered."
>
> (CFDP2)

> "...I and my wife used to take part in the diabetes lectures in the hospital together. These lectures were very helpful for us because I had got a lot of basic knowledge of diabetes during the lectures. Moreover, I made a lot of friends with other participants in the lectures. They were patients with diabetes or patients' family...it was very helpful to talk to them as well. But now my wife does not want to take part in these lectures and I also have difficulty in walking with the increase of age so we have not been there for a long time. "
>
> (CFDPC2)

These findings illustrate that public diabetes lectures provided by diabetes care professionals in the hospital were accepted by a small number of participants with a higher education level and socioeconomic status as an important and reliable source of information related to type-2 diabetes in China. The possible reason for this finding is that participants with a higher education level and socioeconomic status were able to acquire more information about these public health lectures through more communication with diabetes care professionals and had the resources to attend. The university lecturer reported where his information on public diabetes lectures came from:

> "I keep in touch with diabetic specialists in the hospital and they gave me information about the free health lectures about diabetes."
>
> (CMDP3)

In contrast, most participants reported that lack of information on public diabetes lectures was the main reason why they did not attend:

> "I had never attended public diabetes lecture in the hospital because I had not received any information about these lectures."
>
> (CFDP1)

> "...I and my wife never being informed about the public health lectures organised by community health centre or hospital."
>
> (CFDPC5)

Nevertheless, many participants who reported they never attend diabetes education lectures expressed their strong willingness to participate in the lectures if they were informed:

> "...I would like to participate in (the lectures) if I was informed because I think I can get a lot of useful and credible information about my condition from the lectures."
>
> (CFDP5)

> "Sure, I would like to attend (the lectures) if I know where and when they happen. I think they must be **very** helpful for me."
>
> (CMDP2)

This finding demonstrates that a lack of information has been an obstacle for most participants to attend public diabetes lectures in the hospital in China. However, having a good relationship and effective communication with diabetes care professionals contributed to obtaining this information on diabetes education. In addition, many participants reported a strong willingness to attend public diabetes lectures in the hospital, which demonstrated that there was a demand for professional diabetes education among Chinese patients and their carers who participated in this study.

Education of patients with type-2 diabetes and their carers is considered a fundamental aspect of diabetes care because patients and their carers are responsible for the day-to-day control of their condition (National Institute for Clinical Excellence, 2003). The aim of diabetes education is to empower patients by improving knowledge, skills, and confidence, enabling them to take increasing control of their condition (Assal *et al.*, 1985). In China, public diabetes lectures based in the health care setting are currently the main form of diabetes education. From observing these lectures it was apparent during the lectures, educators informed participants about medical information but also management skills around diet, exercise, self-monitoring and medication use. Although reliable and useful information was provided, there were drawbacks to this model of diabetes education such as limited access due to lack of information among patients, lack of individualised information, and repetition of teaching content.

I attended a public diabetes lecture in the hospital as a member of the audience. The lecture was held in a conference hall on a Saturday from 2pm to 4 pm. The lecturer was a diabetic consultant and head of the diabetes department in the hospital. The topic was type-2 diabetes and its management. Almost 50 people attended the lecture including patients with type-2 diabetes and their family carers, junior doctors and nurses, and medical students. The lecture lasted for two hours and some audio and visual resources such as projector, audio speaker, and laptop were used during the lecture. At the end of the lecture, the audience were provided with about 20 minutes to ask their questions but the question time was not enough so the lecturer was still surrounded by members of the audience to answer their questions after the lecture ended, which indicated that there was great demand for professional and individualised information among the members.

The lecture focused mainly on increasing knowledge of type-2 diabetes and its applications and medical care. Due to the limited time, all provided information was general in nature. Meanwhile the lecturer paid more attention to delivering accurate medical information about type-2 diabetes but the information about daily management such as nutrition, exercise, blood sugar monitoring was mentioned briefly. The delivery of information during the lecture relied mainly on verbal communication, and the audience was not provided with any printed materials such as leaflets and booklets to refer to at a later date. However, taking notes and audio recording the lecture were allowed, although how good the quality of recording would have been was unclear. In addition, there was little time given to enabling the audience to discuss issues with the lecturer or for the audience to discuss issues amongst themselves. Many members of the audience complained to me that they had few chances to raise their questions and that they had a lot of problems regarding their condition, which may have been solved with the assistance of diabetes professionals.

After the lecture, I had the chance to have a short conversation with the lecturer. He told me the difficulties they had encountered in conducting public diabetes education:

> "We still have a lot of difficulties in conducting public diabetes lecture. Firstly, there are no full-time and trained diabetes educators in the hospital. Currently all diabetes educators are provided by clinical doctors or senior nurses so they usually provide diabetes lecture in their spare time, which is a reason why we cannot make a routine timetable for the lecture. In addition, we are lacking guidelines for diabetes education. You have seen we did not have a textbook to use during the lecture. All topic and contents were decided by lecturers themselves so our teaching was not systematic. We have received a lot of complaints from patients that our lectures always repeat the same topics and content so they cannot get new or more individualised information. Moreover, lack of funding to support diabetes education. Our clinical doctors or nurses usually provide lectures without extra remuneration. We also cannot improve dissemination of the diabetes lectures through mass media or other ways due to the lack of funding so we just send information of diabetes lectures within the hospital through posters or oral announcement, which greatly impedes the transmission of information of diabetes lectures among patients."
>
> (Fieldnotes)

From this extract it is evident that diabetes education is not seen as a core activity of either doctors or nurses as is an additional voluntary role. Moreover, the content of the lecture and the way it was delivered with the audience primarily being passive recipients also demonstrate that the medical model and pathogenesis is the focus of the diabetes care in China and that adopting a salutogenic approach (Antonovsky, 1979) would reinforce the need for more individual or small group health promotion in terms of promoting self-management and building on the knowledge and experiences of the individual or small group. In so doing this may reduce the number of medical consultations patients require as patients and their carers become more knowledgeable about self-management which they were keen to do and their diabetes may be better controlled. In addition, the diabetes consultant also acknowledged the limitations in the diabetes education being provided in China but seemed to be powerless to address the situation. Without more support from government in terms of finance and human resources, it seemed that the effectiveness and quality of public diabetes lectures would not be improved. More importantly, a shortfall in terms of systematic and structured guidelines for diabetes education was identified. Yet there are some good examples of evidence based and structured diabetes education programmes in developed countries such as the X-PERT Diabetes programme in the UK which I was able to participate in , which China could adapt and follow.

In Wales, three participants reported they had once attended a public health lecture, which was organised by charitable organisations or the church, and provided by people related to health care such as retired GPs, or nurses, or staff from charitable organisations connected to health.

> "I had attended health lectures about diabetes and high blood pressure held at the Chinese Centre (a charity organisation). These lectures were very good and I can understand (the lectures) because most lectures were provided in Cantonese. If some lecturers cannot speak Cantonese, Mrs. XXX translated what they said immediately into Cantonese."
>
> (WFDP3)
>
> "I had once attended a health lecture about the prevention of heart attack provided by a retired Chinese doctor in a Chinese church last year. I very much liked such lecture because we talked easily and the information he provided was very helpful especially for old people like me."
>
> (WFDP7)

In the public health lectures which were organised by Chinese charitable organisations or the church, most of the audience were Chinese people, which facilitated mutual communication among the audience without any language barriers. These lectures were provided in Chinese including Mandarin or Cantonese. Chinese interpretation services were also provided during the lectures when the lectures were not able to speak Chinese. Therefore, such public health lectures were accepted by Chinese patients as a valuable health information source. However, these public health lectures were organised on an ad hoc basis so they did not provide participants with structured and systematic knowledge of type-2 diabetes. Moreover, there may be a risk of the provision of inconsistent information due to the diverse background of the lecture providers. Although health fairs for patients with type-2 diabetes and a structured diabetes educational session, namely X-PERT Diabetes is being conducted in local hospitals across Wales, no participants from Wales reported that they had ever attended the X-

PERT Diabetes programme. When questioned about this most had no awareness about the diabetes education programme and therefore had not participated. Many participants also indicated that they could not participate even if they were informed because of limited English proficiency:

> "...diabetes education programme in Wales, X-PERT...Diabetes (tries to say it in English) ...sorry, no idea about that..."
>
> (WFDP1)

> "I never received any information about the diabetes education programme in Wales. Even if I know it, I could not go because my English is not good so I could not understand what they say. "
>
> (WMDP2)

As an observer, I attended the X-PERT Diabetes educational sessions at a diabetes centre in a hospital in South Wales. The X-PERT Diabetes is an award-winning initiative based on theories of empowerment and discovery learning (Department of Health, UK, 2005a). The programme was developed systematically over five years and has been evaluated through a randomly controlled study (Deakin *et al.*, 2006), in which 314 patients with type-2 diabetes were randomised to either individual appointments (control group) (n=157) or the X-PERT Programme (n=157). X-PERT patients were invited to attend six 2hrs group sessions on self-management education and the findings confirmed the positive impact of the X-PERT programme of self-management education on clinical, lifestyle, and psychosocial outcomes.

The X-PERT programme consists of six weekly sessions, and each session lasts 2.5 hours. The programme covers an extensive range of topics to improve knowledge and understanding regarding type-2 diabetes and the skills of self-care. The programme is free of charge for all participants. Patients with type-2 diabetes and their carers can access the programme through health care providers' referral or self-referral in Wales. A dietician hosted the programme I attended in collaboration with a diabetes nurse and the dietician provided participants with a lecture every week with the assistance of flash cards, pictures, and teaching models in a bright and warm classroom located at the diabetes centre. At the beginning of the first week session, every participant was registered and given a handbook. The handbook was printed clearly and bound fully and written in understandable terms. The content of the handbook covered all topics of the whole X-PERT programme which included introduction to type-2 diabetes, weight management, carbohydrate awareness, understanding food labels and possible complications. In the last session, a summary of the last five sessions and some important information regarding helpful resources and self-management were provided.

13 participants including eight men and five women attended the X-PERT programme. They took part in the programme for the first time. All 13 participants were aged over 40 years, and had been diagnosed with type-2 diabetes from three months to 10 years. 11 of the 13 participants were being treated by taking tablets or injecting insulin, and two of the 13 participants were being treated through lifestyle modifications alone. All 13 participants were local residents and no participants were from minority ethnic communities, and no Chinese patients with type-2 diabetes attended the programme.

Compared with the public diabetes lectures in China, there were fewer participants in the X-PERT Diabetes programme so that the participants were allocated more time to have one-to-one conversations with educators and individualised guidance. In addition, besides providing basic medical information about type-2 diabetes, the X-PERT Diabetes programme focused more on providing skills and a guide to conducting self-management such as diet control, exercise, and self-monitoring of blood sugar. Structured sessions and provision of systematic knowledge were important features and advantages of the X-PERT Diabetes programme so that participants were able to acquire full information about type-2 diabetes and its self-management through attending a whole programme. A male participant provided his comments about the programme:

> "...you know I had little knowledge about diabetes before attending the programme although I have been living with it for nearly three years. But I have got a lot and I can understand the nutrition label on the food packages after the sessions...it's quite helpful for me..."
>
> (Fieldnotes)

Whilst another female participant also commented:

> "I was happy with it as I have got a lot of useful information about my condition. Before I participated in the sessions, I was always confused how much food I can eat a day, how much exercise I need to do a day. All these questions have been sorted out in the sessions. They were really nice and helpful courses."
>
> (Fieldnotes)

Moreover, all participants needed to be registered before the commencement of the programme so that educators were able to keep in contact with the participants to obtain their feedback, to follow up their self-management, and then to help them solve problems they encounter in self-management. However, few Chinese patients and their carers had attended the programme. An educator from the X-PERT programme was interviewed:

> "Since 2006, I would say just two Chinese people (had attended the programme) in XXX (name of town)"
>
> (Fieldnotes)

When questioned why few Chinese patients had attended the programme, she replied:

> "Probably the programme may not be well known among Chinese communities, and their GP or other health care providers may not do enough work to deliver the information about the programme among their Chinese patients... and we do not offer interpretation services during the programme so if the Chinese patients cannot understand English, it would be very difficult to follow us."
>
> (Fieldnotes)

Therefore, in order to improve accessibility of the X-PERT Diabetes in Wales among Chinese patients and their carers, there is a need to improve awareness of the programme working in collaboration with GPs, other health care providers and the local Chinese community. Moreover, the comments from the X-PERT Diabetes educator demonstrated that adopting a salutogenic approach (Antonovsky, 1979) would increase the need for Chinese language interpretation and translation services to recruit more Chinese patients including those with limited English proficiency to participate in the X-PERT Diabetes sessions. There is a consensus that it is important that structured education programmes are flexible and responsive to the needs of individuals and their communities (Loveman *et al.*, 2008). Additionally, concerns have been raised that the X-PERT programme may not meet the needs of different communities, which may be better served by programmes tailored to their specific requirements. Therefore, a structured education programme exclusively for black and minority ethnic groups is being undertaken by the Royal London Hospital, focusing on Bangladeshi communities [Bangladeshi Initiative for Prevention of Diabetes (BIPOD)] (Loveman *et al.*, 2008). Despite the initiative, more research is required to assess its quality and effectiveness to ensure the programme meets the requirements established as part of the National Service Framework (NSF) for diabetes (Department of Health UK, 2001). However, the

London programme could be a valuable attempt at providing structured diabetes education for minority ethnic groups or other groups who have special needs and which may have relevance for Wales. It seems that those who may have the greatest need for diabetes education due to lower levels of education, poor proficiency in English and limited income have the least access to such services which Tudor Hart (1971) a GP in Wales identified many years ago and coined the term the Inverse Care law which is as pertinent today as it was then.

6.5 Summary

Most Chinese participants in both China and Wales had insufficient knowledge of type-2 diabetes and even misunderstandings were prevalent among them. Besides demographic factors such as socioeconomic status and education level, communication with health care professionals, and family support were viewed as important factors influencing the level of knowledge of type-2 diabetes among the participants. Although health care professionals were recognised as important, credible and reliable sources of information on type-2 diabetes for most participants in China and Wales, the limitations of health care systems in both countries and language barriers resulted in many participants not acquiring sufficient information on type-2 diabetes from health care professionals. In addition, the media has been traditionally viewed as a method to deliver health information, and it could play a more important role in the promoting the level of knowledge among the participants, but the media in China as the participants reported was deluged with a large number of commercial advertisements and inaccurate information related to type-2 diabetes, which greatly impaired its credibility and effectiveness as a source of health information. In Wales, the language barrier was significant obstacle to accessing information, which impeded those with limited proficiency in English acquiring information from either health care professionals or the media. Therefore, there is an increasing need for more Chinese language interpretation and translation services during the provision of diabetes care and delivery of information on type-2 diabetes. Additionally, this study also has shown that nearly half of participants obtained information on type-2 diabetes from lay interpersonal sources which may be associated with Chinese cultural norm of encouraging mutual understanding and help between people with same condition. Although public diabetes education sessions are considered as an important information sources, a small number of participants reported their participation. In China despite not all participants being aware of the public health lectures on type-2 diabetes there was a significant demand which was not being met through the provision of one off public lecture. In Wales as none of the participants were aware of the X-PERT sessions and X-PERT sessions as provided were not accessible in terms of meeting language needs it could be perceived by health care providers that there was no demand for the service and therefore no need. However as my findings have shown participants in Wales as in China had insufficient knowledge about type-2 diabetes especially in terms of self-management and were willing to learn more so there was evidence of unmet needs in both countries

Having explored the information sources which participants accessed, a further key finding identified from analysing the data was how the condition affects patients and their family, which is presented in the next chapter.

Chapter Seven The consequences of type-2 diabetes

7.1 Introduction

In the last chapter, I discussed the level of diabetes-related knowledge among the participants and their information sources. The findings illustrate that there was a deficit of diabetes-related knowledge among most participants in China and Wales. This was attributable to the lack of reliable and professional sources of information on diabetes in China or to limited accessibility to local diabetes information sources and education programmes due to language barriers in Wales. Therefore, type-2 diabetes, which is currently an incurable and chronic condition, may have more widespread impact on Chinese patients and their family carers when they have scant knowledge of their condition. In this chapter, I present data from the participants in China and Wales which indicates how type-2 diabetes influenced their lives both negatively and positively. Firstly, the negative consequences of type-2 diabetes on the participants in terms of daily activities, employment, family relationships, and social contacts are presented and discussed in the following section.

7.2 Negative consequences

7.2.1 Daily activities

The negative effects of type-2 diabetes on day-to-day living were reported by eight patients including four patients from China and four from Wales. Three out of the eight patients reported that they had lost the ability to do some daily activities such as cooking, doing housework, and looking after the family due to type-2 diabetes and its complications, and that they needed help and care from their family members. As a female patient from China said:

> "...diabetes and the disease of the retina had a great impact on my daily life. I now cannot see anything clearly so I am not able to look after myself and my family, including cooking and doing housework [sighs]... I need my husband's care to live now."
>
> (CFDP5)

Whilst a female patient from Wales also reported:

> "...diabetes and stroke impacted greatly on my and my family's life at the beginning of getting the disease. I could do nothing including going to toilet independently and washing face because of stoke."
>
> (WFDP8)

These two patients' comments demonstrate that the complications due to type-2 diabetes such as impairment of vision and stroke were the main reasons for losing the ability to live independently among Chinese patients in China and Wales. Type-2 diabetes is a strong independent predictor of risk of stroke. Patients with type-2 diabetes have a higher risk of stroke, with an increased risk of 150–400% (Lehto *et al.*, 1996). Risk of stroke-related dementia and paralysis, as well as stroke-related mortality, is also elevated in patients with type-2 diabetes (Beckman *et al.*, 2002). Moreover, the two comments also show that these two patients needed more care from their family carers in daily life as a result of type-2 diabetes and its complications so that their carers had to expend much time and energy to look after them. During the process, traditional Chinese family roles had changed. A female patient from China described the impact of her type-2 diabetes on her family's life:

> "My son and my husband looked after me every day and they hardly had spare time to do things they wanted. For my son, he had quit his job and had to be with be all the time to care for me. He even did not have time to date with his girlfriend [sighs]."
>
> (CFDP5)

Whilst a female patient from Wales also reported how her type-2 diabetes influenced her family's lives:

> "My husband and daughter and grandson looked after me in turn. I had occupied much of their time, especially my daughter and grandson had their own work and life and family but they sacrificed all their spare time to care for me so that they spend less time with other family members."
>
> (WFDP8)

CFDP5's husband described his role in the family as a "house man" after his wife had a problem with vision due to type-2 diabetes:

> "My wife has a problem with her eyes so I have to spend much time and energy to look after her life every day. I cook for her and do all housework. I have become a house man [laughs]...when she goes to hospital, I also have to accompany her...she cannot live without my help now... [sighs]."
>
> (CFDPC5)

In Chinese traditional culture, as in many other cultures, women mostly are the caregivers in the family. They are ascribed traditionally with responsibility to look after their family including cooking, doing housework, and educating young children. Once they lose this responsibility due to illness, other family members have to replace their role, which adds a burden on to other family members. In most Chinese families, husbands assume the traditional responsibility of breadwinner. If their wives lose the ability to look after the family, the males have to take on more family responsibilities. The change in family roles and the burden of care for the carer is one of the main consequences of the illness. This greatly affected carers' own personal life and health state as indicated in the following comments from WFDP8's husband:

> "...after she got diabetes and stroke, she could not do anything without my help so I had to help her to do everything in daily life. I hardly had spare time and freedom to do the things I wanted...I felt very tired, helpless and depressed, and my health condition got worse and worse since she got the diseases."
>
> (WFDPC8)

This finding supports the work of Golics, Basra, Salek, & Finlay (2013) who conducted a qualitative study in which 133 participants were investigated to explore the impact of patients' chronic disease on family members' quality of life and found that the quality of life of family members was hugely reduced in terms of daily activities, family relationships, and social life by the patient's chronic disease. Previously, much attention has been paid to the impact of chronic conditions on the patient's life. Currently an increasing number of studies focus on the impact of chronic conditions on the live of family carers of patients because the importance of the support provided by carers in successful patient care and self-management has been proved and accepted widely (Baig, *et al.*, 2015). Therefore, more attention by health care providers is expected to be paid to the negative impact of Chinese patients' type-2 diabetes on their carers' life because it may impact on quality of care. As CFDP5's husband described his concerns:

> "...life is very hard for my wife without my help but I am 70 years old this year...I feel very tired every day...I do not have adequate energy and ability to provide her with good care... I am a patient with high blood pressure sometimes I also need other's care...my blood pressure is not stable recently because of the burden of care..."
>
> (CFDPC5)

Baanders and Heijmans (2007) conducted a qualitative study in the Netherlands with 1093 partners of patients with chronic disease to explore the impact of their relatives' condition on their daily lives and work and found that more than half of the partners reported personal life strain due to the increased burden of care after their family members were diagnosed with a chronic condition. In addition, they also found that this impact on female partners was higher than on male partners. Similar findings were obtained in another two studies conducted by Glasdam *et al.* (2010) and by Soubhi *et al.*

(2006). They also found that the impact of chronic conditions including type-2 diabetes on female caregivers were greater than on male caregivers. The likely explanation for this finding was that female carers assume more responsibility for providing care in families and male caregivers more readily accepted help from other family members. However, it is difficult to make a judgment in terms of the differences in the effects of Chinese patients' type-2 diabetes on their female or male carers in the present study, which may be because the male carers are fewer than female carers included in the study.

The findings indicate that carers played an important role in assisting their relative in managing their type-2 diabetes. However, not all patients have family members to support them. All 13 patients in China lived with their family carer, but six out of 13 patients in Wales lived alone. Those patients who lived alone in Wales encountered more difficulties when they needed help and care. A female patient from Wales who lived alone reported:

> "I once collapsed at home due to diabetes but nobody knew that because I live alone…[sighs]…I woke up by myself later. Sometimes I cried at home because I felt helpless and isolated…" [sighs].
>
> (WFDP1)

Whilst another two patient from Wales who lived alone commented:

> "Sometime I felt depressed especially when I need help and care so it is more difficult for me to control diabetes as I live alone here…"
>
> (WFDP2)
>
> "I am living here alone so I have to do everything by myself but sometimes I cannot manage everything well, sometimes everything is hard for me…stressful...very stressful...[speaks them in English]…"
>
> (WMDP3)

These comments reflect how the patients who lived alone had difficulties in daily life and were prone to experience psychological distress. This finding is supported by the work of Schiøtz *et al.* (2012) who conducted a cross-sectional survey with 2572 patients with type-2 diabetes to investigate the relationship between structural and functional social support, diabetes-related emotional distress, perceived diabetes care, self-management behaviour, and glycaemic control. They found that a poor functional social network, especially lack of family care was significantly associated with greater emotional distress, negative assessment of care, and less health-promoting eating habits.

Additionally, Vaccaro *et al.* (2014) also carried out a cross-sectional study to investigate the impact of type-2 diabetes on patients from minority ethnic communities with 405 participants in United States and found that the participants with less family support had more difficulties in diabetes self-management and poorer glycaemic control. Therefore, there is need to help those Chinese patients who live alone to overcome the potential negative effects of type-2 diabetes on their daily lives, self-management, and mental health. Moreover, those Chinese patients who live alone also required more care and support from health care providers, Chinese communities, and wider social workers to help them to control their condition as indicated by the following comments:

> "…so I really need more care from other people…such as doctors, other Chinese people, and social workers…"
>
> (WFDP1)
>
> "I live alone so I have to do everything by my own. If I can get more help and support from other people and community, it would be very beneficial for my diabetes."
>
> (WFDP6)

More social support from friends, Chinese communities, and social worker may facilitate these patients to carry out daily care and self-management. More importantly, health care professionals need to endeavour to understand the greater impact of type-2 diabetes and its complications on Chinese patients who live alone which may mean closer monitoring of these patients. Health care professionals also need to be aware of the support and resources available to meet the needs of these Chinese patients. In addition, inconvenience to daily lives was reported as a negative consequent of type-2 diabetes by five patients. A typical example of the inconvenience expressed included:

> "After being diagnosed with diabetes, I have to take medicine every day so I have to take medicine with me wherever I go…it was annoying and inconvenient... so I often forgot to take medicine on time especially when I focused on doing something…"
>
> (WMDP3)

Another female patient from China also felt that she had less freedom to enjoy her interests because of the extra tasks and inconveniences caused by self-management of type-2 diabetes:

> "I like to travel with my husband but it is annoying that I have to take various stuff including medicine, insulin, injector, and blood sugar and pressure meter when I go to travel now. In addition, during travelling, sometimes I had to stop visiting to find a quiet place to inject insulin, sometimes I had to test my blood

> sugar and pressure on the coach or train. I felt I had less freedom to enjoy my travelling than before I got diabetes…"
>
> (CFDP2)

In addition, CFDP2's husband also reported that their travelling was affected by these extra tasks and inconveniences:

> "…when we went out for travelling together, I often reminded her to take medicine and sometimes I needed to help her to test blood sugar and pressure…you know there were more inconveniences to do that during travelling than at home so we had less fun during travelling than before…"
>
> (CFDPC2)

For patients with type-2 diabetes, self-management activities need to be conducted consistently. Patients need to complete day-to-day tasks, which as some patients reported caused a lot of inconveniences in their and their carers' life. A recent survey conducted by the Department of Health UK, which examined public attitudes to self-care, reported that personal inconvenience was one of the most important barriers to self-care (Department of Health UK, 2005b). In addition, personal inconvenience is commonly endorsed as a barrier to self-management among patients with type-2 diabetes. Ong *et al.* (2014) carried out a qualitative study to explore barriers to self-monitoring of blood glucose with 15 people with type-2 diabetes using insulin in Malaysia and reported that inconvenience caused by self-management activities can lead to poor adherence to self-management. Therefore it is important to explore and understand patients' and their carers' lives including interests, hobbies, and individual needs in the course of promoting self-management and providing support. Moreover, the advancement of technology is required to improve and simplify self-management activities such as injection of insulin and self-monitoring of blood glucose to minimise the inconvenience to patients' and their carers' daily life. Besides daily activities, nine participants reported that their employment was affected by their or their relatives' type-2 diabetes, which is discussed in the following section.

7.2.2 Employment

Six patients including four patients from China and two from Wales described how their job was affected by their condition. Most of these patients reported that they had to change their work or reduce their workload because of having type-2 diabetes and its complications. Moreover, two patients completely gave up their job in order to focus on their treatments, which had a significant financial impact on their families as indicated in the following extracts from patients from both China and Wales, respectively:

> "My work had been impacted hugely by my condition. I used to work as a sophisticated optical equipment inspector and my responsibility was to ensure the quality of the optical equipment using a microscope so I used my eyes too much. My work was very intensive and stressful and any tiny error was not allowed because these sophisticated optical equipment were usually very expensive and any tiny error could cause serious consequences and great financial loss. However, I was not able to do my job since my sight became impaired due to diabetes. Although I could take time off work to have medical treatments, it caused difficulties with my working colleagues so I had to change my work, which mostly reduced my income as well..."
>
> (CFDP4)

> "Last year, I had got a problem with my left eye, and doctor told me it was caused by my diabetes so I gave up my work and sold my all restaurants to concentrate on treating my condition. Although I had lost my main financial source, health was more important than money."
>
> (WMDP1)

Deterioration in sight as a result of complications due to type-2 diabetes had a profound effect on these two Chinese patients' capacity to work in paid employment. They had to change their responsibility or completely quit their job after suffering from this complication due to type-2 diabetes to focus more on treatment of their condition, which directly impacted on family income. This finding suggests that once complications develop, patients with type-2 diabetes may choose to take themselves out of the labour force and not seek other work, which may worsen their financial stress. Kraut *et al.* (2001) carried out a cohort study based in Canada, consisting of 25,554 individuals without diabetes and 608 with diabetes, of whom 242 had a complication of the disease to compare employment and income of people with and without diabetes and found that diabetic participants without complications had incomes similar to those of non-diabetic individuals, and diabetic patients with complications were twice as likely not to be in the labour force than non-diabetic individuals.

This finding of the impact on employment and income among Chinese patients with diabetic complications may provide useful information for diabetes education. This information could be applied both in career advice for patients with type-2 diabetes and in the provision of explanation about how the complications of type-2 diabetes affect patients' employment and income. It is evident that in order to limit the negative effects of poorly controlled type-2 diabetes on employment and subsequent potential financial hardship if no longer able to work in paid employment, the priority is to prevent or prolong the development of complications of type-2 diabetes through early diagnosis and effective control of blood glucose levels. Furthermore, carers' employment was also affected by their relatives' type-2 diabetes and its complications. CFDP4 reported the impact of her condition on her son's job:

> "My son had quitted his job which is good in XXX (name of town) and then came back home to take care of me."
>
> (CFDP4)

In addition, three carers both in China and Wales reported they had to change their job or reduce their paid work time to spend more time on caring for their family member with type-2 diabetes. Typical examples of the views expressed included:

> "...since my wife had got type-2 diabetes, I closed my restaurant early every day because I had to spend more time to care her."
>
> (WFDPC7)
>
> "Since my husband was diagnosed with diabetes, I needed to spend more time on looking after him so I quit my previous full time job and then got a part time job in a supermarket...consequently, my current income is lower than before."
>
> (CMDPC5)

This finding demonstrates that type-2 diabetes negatively affected not only Chinese patients' employment opportunities and income but also their carers' employment. The most obvious effect occurred when complications due to type-2 diabetes limited the patients' ability to be employed. Robinson *et al.*, (1990) carried out a survey of employment problems in a random sample of patients with diabetes and a group of control subjects in the UK and found that patients with diabetes aged 17-65 years were more likely to report difficulties in obtaining employment or had to change their jobs due to their condition. Moreover, the carers also had to change or reduce or even quit their job because they needed to take on more responsibilities to look after their family with type-2 diabetes and its complications. Consequently, the income of the patients and their carers was reduced. The finding that patients with diabetes and their family carers had reduced incomes is consistent with the statistical data. Recent data from the United States has shown that individuals with diabetes have significantly lower predicted earnings, resulting in 4.7 million US dollars loss in earnings in 1987 (Mayfiel *et al.*, 1999). In addition, data from Sweden revealed that people with diabetes and their family had lower mean disposable incomes and a higher rate of disability pension than either hypertensive or healthy people and their family (Wändell *et al.*, 1997). The reduction of income not only directly impacts on the financial situation of patients and their carers but also subsequently impacts on self-management type-2 diabetes. CFDP4 described how the reduction of income impacted on her self-management:

> "After changing the work, my income reduced. Additionally, my son also had quit his job to care for me so the financial situation was not very good in my family. Doctor asked me to test blood sugar at least once a day but the strips were expensive so I tested blood sugar once every two days to save strips. If I cannot afford the strips in the future, I could quit testing blood sugar by myself... "
>
> (CFDP4)

Whilst a Chinese couple also commented how financial barrier impacted on their self-management of type-2 diabetes:

> "In addition, financial problem is another big barrier to managing my conditions at home. I am an agriculture worker, my monthly income is just about 1500 RMB (=£150). The doctor asked me to test blood sugar at home. Although I have been involved in medical insurance, it is ridiculous that blood sugar meter and strips are not compensated by the medical insurance...I do need them...I **really** do not understand...I assume those health policy makers really did not understand what diabetic patients need...[sighs]. In addition, I have to use insulin, you know, the insulin was very expensive for me as well. I once asked doctor to stop prescribing insulin and replace it by tablets in consideration of the cost, but doctor said no so now I need to spend nearly half of my monthly income on insulin so it is unaffordable for me and my family to test blood sugar at home without compensation from the medical insurance..."
>
> (CFDP5)

This patient's husband also reported:

> "I and my wife are both agriculture workers, we live on planting and selling vegetables. Our earnings are very tiny every month and my wife was diagnosed with type-2 diabetes and she needs to use insulin every day and we spend most of our money on her treatment. I hope she can get good medical care but we do not have enough money to afford that...[sighs]"
>
> (CFDPC5)

It is evident that financial constraint due to a lower level of income limited cost-related self-management practice such as daily medication treatment and self-monitoring of blood glucose (SMBG). In addition, several patients with lower-incomes in China reported their dissatisfaction with the Chinese Basic Social Medical Insurance System (BSMIS). Although these patients were covered by the BSMIS, most spending on self-management of type-2 diabetes was not compensated by the BSMIS, which impeded their self-management. BSMIS is the countrywide government system for health-care financing whose primary goal is to ensure every Chinese person can have access to basic medical care. Therefore, the medical insurance system is currently primarily targeted at hospitalisation and acute diseases because of the disparity between the numerous demands for health care and limited insurance funding. The majority of patients who need outpatient services for type-2 diabetes in China can have access to limited financial support from this medical insurance system, which is main reason why several patients from China in this study complained that the blood sugar meter and testing strips were not covered by the BSMIS even if they were prescribed for self-testing of blood glucose levels.

Similar findings were obtained in previous work. Shen *et al.* (2013) performed a qualitative study to investigate facilitators and barriers to self-management among community dwellers with type-2 diabetes in China and found that economic stress decreased the motivation for self-management and patients were more likely to give up self-management such as self-monitoring of blood glucose (SMBG) owing to financial considerations. In addition, Chen *et al.* (2012) conducted a qualitative study using semi-structured interview with 40 patients with type-2 diabetes in China to understand the cues and barriers to engagement in self-management and also found that financial stress was one of the barriers to self-management among these patients. It is possible that with adequate social support some of the Chinese patients and their carers might have been able to continue work so that they could have maintained a stable financial income to support their self-management.

The National Health Service (NHS) provides universal coverage and there is a well-established and extensive system of social security in Wales. Thus, Chinese patients in Wales had fewer financial barrier to conducting self-management compared to the patients in China. A female patient from Wales commented:

> "Diabetes care is free for me including medication and blood sugar meter so I do not need to spend too much money on managing my condition at home."
> (WFDP1)

This finding shows that access to free diabetes care provided by the NHS in Wales significantly reduced patients' financial burden on performing daily medication management and SMBG. It also suggests that decreased individual financial spending on medication treatment and SMBG may contribute to promoting adherence to medication treatment and SMBG. Barnard *et al.* (2010) conducted a survey in the UK among 555 Diabetes UK members with type-2 diabetes who use SMBG and found that 80% of respondents reported high satisfaction with SMBG, and reported feeling more 'in control' of their diabetes management using it, which may be associated with the free provision of equipment for SMBG. In addition, two studies conducted in Australia reported that more than 80% patients with diabetes using insulin practiced SMBG (Bruce *et al.*, 2003; Chubb *et al.*, 2011). Such high prevalence of SMBG use may be attributed to the subsidies for test strips provided by the Australian federal government since 1987 (Bruce *et al.*, 2003). The long-term cost savings to be made from supporting self-management are considerable, both in reducing the frequency of support needed from primary care and by preventing patients with type-2 diabetes from needing more and longer hospital treatment due to emergencies or long-term complications caused by uncontrolled type-2 diabetes. Although it is currently difficult to achieve fully funded financial support for self-management from the medical insurance system in China, these is a strong recommendation based on the experiences in Wales that patients with type-2 diabetes in China should have financially supported self-management, based on their individual clinical need rather than on their or the medical insurance system's ability to pay.

Besides daily medication treatment and SMBG, economic constraints also impacted where Chinese patients were able to afford to live, resulting in barriers in relation to access to appropriate food and transport. A female patient from Wales identified difficulties in accessing some of the recommended foods due to financial hardship:

> "I was told to eat more vegetables and fruit in my diet. If I stay in China or Hong Kong, I could afford to eat vegetables every day, but in UK, you know, vegetables are usually quite expensive so it is unaffordable for me to eat vegetables every day. "
>
> (WFDP6)

Whilst a female patient from China reported the high cost of transport from home to hospital or the community health centre every month which meant she reduced her health appointments and frequency of blood glucose monitoring in order to save money:

> "I was told I needed to see the doctor regularly, at least twice a month. My home is far away from hospital and I usually spend too much money on transport when I go to hospital. In addition, I needed to go to community health centre by

> bus to test blood sugar every day. Consequently, I spend much money on transport every month so I now do not attend consultations and blood sugar tests to save money..."
>
> (CFDP3)

Moreover, several patients also identified other less obvious costs which are not subsidised, but which arise directly from their type-2 diabetes care. For one male patient from China, the cost of purchasing lotion to prevent dry skin and skin infections was identified as an extra cost of living spending caused by type-2 diabetes:

> "Before diabetes, I never used and bought any personal care products, but I was told I needed to use lotion to protect my skin from irritation and infection every day so I have got extra living expenses for lotion after having diabetes."
>
> (CMDP1)

Whilst a patient from Wales also reported that the cost of buying soft and comfortable shoes to protect her feet was identified as an additional financial burden:

> "My GP said to me I needed to wear soft and comfortable shoes in order to avoid injury of feet . . . so I bought leather ones and they cost me nearly 100 pounds... I am not sure how many leather shoes I need a year...I live on a pension so it was very expensive for me."
>
> (WFDP3)

Self-management of type-2 diabetes not only requires essential resources such as a blood glucose meter and strips and medication but also requires maintaining a healthy lifestyle and having regular consultations with health care providers (American Association of Diabetes Educators, 2009). It is evident that financial constraints not only hinder the practice of self-management due to limited access to necessary resources and medication, but also impacted on the establishment and maintenance of a healthy lifestyle including appropriate diet, personal care and regular consultations between the patient and his/her health care provider. Marcy *et al.* (2011) carried out a cross-sectional study to identify barriers to appropriate dietary behaviour with 98 type-2 diabetic patients with low-incomes and found that "healthy food being too expensive" was one of the most frequently reported barriers to having healthy eating behaviour. Additionally, Jerant *et al.* (2005) conducted a qualitative study with 54 patients with more than one chronic condition and reported that patients would omit their medical appointments due to lack of transportation and lack of funds required to take the bus or a cab. Therefore, financial support for self-management needs to encompass not only medication and SMBG but also on the additional requirements with respect to appropriate lifestyle choices.

Whilst it is evident that living with a chronic condition such as diabetes places additional responsibilities and challenges on both the person with diabetes and their carer, it was also apparent that this had an influence on family relationships for 13 participants both in China and Wales, which is now discussed in the following section.

7.2.3 Family relationships

13 participants including four patients and three carers from China and three patients and three carers from Wales reported affected relationships among family members attributed to type-2 diabetes. Ten out of the 13 participants reported family arguments about diet and lifestyle changes. The remaining three participants also reported type-2 diabetes had impacted on their family life. A female patient from China reported arguments between her and her husband relating to changing eating behaviour:

> "I and my husband had more arguments about changing diet since I had got diabetes. Because I rarely ate meat after diabetes but my husband did not like vegetarian diet because he thought the nutritional ingredients from meat were necessary for maintaining health. However, now he supports me to change eating habits because he has understood that vegetarian diet is very important for my health. "
>
> (CFDP6)

Whilst her husband also reported:

> "We used to argue what kind of food we should eat more or less…and she was responsible for making food in family but I really did not like the food she made so I used to go out for dinner."
>
> (CFDPC6)

Another male patient from Wales also reported arguments in terms of diet between him and his wife:

> "Sometimes I and my wife had some divergences about diet. I insisted I ate this food more, but she disagreed with me. Sometimes, she asked me to eat more of those foods but I did not think I should so there were more arguments about what kind of food I should eat more or less between us."
>
> (WMDP4)

His wife also remarked:

> "I make food for him every day but it is really a difficult task for me because I am not sure what kind of food he can eat or not or what kind of food he should eat more or less…so we often have arguments about it since he has got diabetes."
>
> (WMDPC4)

These findings demonstrate that family arguments between Chinese patients and their carers in both China and Wales focused on dietary modifications. The main reason for the arguments was that they did not know how to support each other in dietary management, which suggested that they did not have adequate and necessary knowledge about dietary management and how to support dietary management in the family. In Chinese culture as in many South Asian cultures, diet is an important element. Making food for the family and having meals with the family is not only a highly significant part of family life but also a good way to promote family relationships and to strengthen affection among family members in Chinese families. Nevertheless, arguments and conflicts in terms of dietary management were triggered between Chinese patients and their carers especially when they had disagreement about who should create, observe, and enforce dietary management and whose philosophy of diet should prevail. Moreover, conflicts also arose when carers were inflexible about their own dietary preferences. A patient from China reported he had quarrels with his wife in terms of diet, and described the impairment of family relationship after the quarrels as "family cold war":

> "Since I had been diagnosed with type-2 diabetes, diet became a big problem for me as well as for my family [sighs]. My wife preferred eating sweet dishes so she liked to put much sugar when she cooked, but I had been told I should not eat too much sweet food and dishes so we often quarreled about that [sighs]. I felt my wife did not pay enough attention to my condition...After the quarrels, we had not talked to each other for a long time. I called it family cold war."
>
> (CMDP1)

His wife also described their quarrels:

> "We often quarrelled about dishes I made...actually not once but **many times**. I liked to put some sugar into dishes when I cooked. But my husband was not happy with that and complained the food I made tasted very sweet and his blood sugar increased after eating the food; he even said the main reason why he got diabetes was eating the food I made, which was too sweet ...I was **extremely** angry when he put the blame on me..."
>
> (CMDPC1)

The Chinese couple's comments demonstrate that they were not only lack of information about dietary management but also had little knowledge regarding type-2 diabetes and its cause, which led to family conflict and the inappropriate attribution of blame for causing the condition. Hu *et al.* (2013b) conducted a qualitative study using five focus groups with 36 Hispanic immigrants with type-2 diabetes and their family members (n=37) in the United States to explore perceived barriers among Hispanic immigrants with diabetes and their family members and found that dietary constraints were the main causes of family conflict in many participants' families and many participants experienced a lack of family support, particularly with dietary changes due to a lack of understanding of what diabetes entails. In addition, Kapur *et al.* (2008) carried out a study amongst 350 adults with type-2 diabetes in South India to explore barriers to changing dietary behaviour and found that the lack of information on type-2 diabetes and changes in eating behaviour were the main reasons for less family support in diet and family conflict over dietary management.

Moreover, this finding also demonstrates that family harmony was additionally challenged when patients and their carers had different expectations about what carers should know about type-2 diabetes and dietary management. The patients felt neglected because their carers did not "pay enough attention" to their condition and demands. Meanwhile, their carers also felt injustice especially when they were unreasonably blamed by the patients. Therefore, the lack of understanding of type-2 diabetes and accommodation in the Chinese family resulted in apportioning blame, which aggravated family conflict. Chesla and Chun (2005) conducted a qualitative study with 20 participants representing 16 Chinese American families to describe family responses to type-2 diabetes in Chinese Americans and found that patients needed to keep balance of attention and concern for the disease requirements with attention to the entire family's needs in order to maintain family harmony. Moreover, family carers also needed to develop shared diabetes care practices and negotiable approaches to disagreements about diabetes management. In addition, Chesla *et al.* (2009) called for reciprocal responsibilities and interdependent relationships based on mutual understanding and respect between Chinese patients and their carers to maintain the family's well-being and to promote disease management.

Furthermore, diabetes education plays important role on the alleviation of family conflict. With the increase of knowledge of type-2 diabetes and self-management, family carers can change attitude and adopt more supportive behaviour. A carer from China reported his change of his attitude to his wife's dietary management after gaining information on type-2 diabetes and its management:

> "...but after I got some information about diabetes, I understood it was very important for my wife to change diet so now I support her and have dinner with her and no longer complain about the food she makes."
>
> (CFDPC6)

A similar finding was obtained in previous work by Maillet *et al.* (1996) who conducted a qualitative study using focus groups in order to characterise the health beliefs, self-care practices, diabetes education needs, weight-loss issues, and facilitators and barriers to diabetes health care in black women with non-insulin-dependent diabetes. They found that family carers were generally regarded as supportive in the assistance with self-management after gaining information on type-2 diabetes and its management. Glasgow and Eakin (1998) also supported the notion that the patient's family environment must be taken into account in order to produce enduring behaviour change, and plans made for ongoing support of self-management behaviours. Chesla *et al.*' study (2009) also stressed the importance of diabetes education in the elimination of family conflict. In addition, Tsiouli *et al.* (2013) conducted a literature review including six cohort studies, three cross-sectional studies, and one qualitative review to investigate the influences of diabetes-related family stress on glycaemic control in patients with type-1 diabetes and found that family stress was negatively correlated with patients' glycaemic control in all the reviewed studies. Therefore, they suggested that participation of the entire family in educational programmes on disease management and psychotherapeutic programmes for stress management would help young patients deal with the stress of treatment and achieve good glycaemic control. Whilst this review focused on people with type-1 diabetes who may be of a younger age than those with type-2 diabetes, the findings of the importance of engagement of the whole family in diabetic educational programmes has resonance with my findings and may be transferable to patients with type-2 diabetes and their family carers. Thus, Chinese patients as well as their family carers need to be facilitated to be involved in diabetes education programme and their participation may be promoted through the provision of interpreting services and bilingual educational leaflets in English and both Mandarin and Cantonese. Furthermore, as my findings indicate more attention needs to be paid to family influences on dietary regimens because diet is especially vulnerable to family influences especially in cultures where communal eating is the norm. This requires diabetes education programmes not only to deliver sufficient and necessary information on type-2 diabetes and dietary management, but also to provide skills and strategies to minimise the potential negative impact on family relationship related to dietary management.

Besides diet modification, the change of lifestyle and unhealthy behaviours also triggered arguments and even conflicts within Chinese patients' families. This was compounded by patients' change in mood after being diagnosed with type-2 diabetes, which increased the risk of family conflict. As a male patient from China reported:

> "After being diagnosed with diabetes, I became frustrated and irritable. I often had arguments with my wife about trifles. For example, I liked smoking because it made me relaxed but my wife often asked me to quit smoking, and said smoking could worsen diabetes. I did not think there was any association between smoking and diabetes so we always argued about that..."
>
> (CMDP5)

This extract shows that this male patient used smoking as a coping mechanism in a stressful situation due being diagnosed with type-2 diabetes. However, his stressful situation had not been completely solved by using this strategy and smoking resulted in more family arguments. Type-2 diabetes can influence patients' emotions and increasing evidence demonstrates that people with type-2 diabetes are susceptible to negative emotions such as stress, anxiety, irritation, and depression. Zhang *et al.* (2009) carried out a study with 304 Chinese patients with type-2 diabetes to explore possible interactive effects of coping styles and psychological stress on depression and anxiety symptoms and found that negative coping strategies for psychological stress significantly increased the level of both anxiety and depressive symptoms among Chinese patients. It is therefore important for Chinese patients with type-2 diabetes to gain positive and effective strategies to cope with their psychological stress due to type-2 diabetes, which may contribute to reducing the risk of family conflicts due to negative emotions related to type-2 diabetes.

Moreover, this finding also indicates that this patient's wife tried to help her husband to cope with type-2 diabetes. However, she had no idea about what her husband needed and what difficulties her husband encountered. Her misunderstanding of risk factors of type-2 diabetes aggravated the family conflict. More importantly, they did not know how to emotionally support each other as indicated the extract from CMDP5's wife:

> "...however, sometimes my husband looked very stressful and then smoked too much but I thought smoking would not be good for his diabetes so sometimes we had some arguments about smoking. I did not know what I needed to do to help him get relaxation so I often felt stressful as well..."
>
> (CMDPC5)

This finding echoes the previous work of Rook *et al.* (2015) who conducted a study with 129 patients with type-2 diabetes to examine whether individual differences in emotional stress were associated with fasting blood glucose and whether emotional support provided by spouses moderated this association. They found that emotional support from spouses contributed not only to relieving psychological stress and but also to reducing the level of fasting blood glucose among patients. Therefore, not only practical skills for self-management but also strategies to improve emotional support within Chinese families would seem to be an important part of diabetes education programme for Chinese patients and their carers. 12 out of 40 participants both in China and Wales raised the issue of the effects of type-2 diabetes on their social activities, which is discussed in the following section.

7.2.4 Social activities

12 participants reported type-2 diabetes impacted negatively on their social activities including five patients and one carer from China and five patients and one carer from Wales. Four out of the 12 participants reported physical impairments caused by type-2 diabetes and its complications reduced their ability to attend social events. As a female patient from China reported:

> "Since I had got diabetes and the disease of the retina, I could not see anything clearly so I hardly took part in social events such as friends' gatherings and dinner and I spent most of my time at home."
>
> (CFDP5)

Her husband also reported his social life was impaired by his wife's condition because he had to spend much time caring for her instead of with other family members and friends:

> "Since my wife lost her sight, I had to look after her every day so I hardly had spare time to go out with my friends. Sometimes my friends invited me to attend gathering or to have dinner together, I usually said no because I could not leave my wife alone at home."
>
> (CFDPC5)

This finding reveals how patients' physical disability caused by type-2 diabetes and its complications not only reduced their capability to attend social events but also impacted their family carers' social life due to increased responsibility to care for their relative. Additionally four other patients also reported they reduced the chances to have dinner or to drink with their friends in restaurants due to dietary restrictions. A male patient from China reported:

> "I had reduced chances to go to restaurants for dinner with my friends because it was not easy to control the intake of food in restaurants because I usually had to eat much food otherwise my friends thought I disliked the food, which could offend them. Afterwards, my blood sugar level went up immediately..."
>
> (CMDP2)

Whilst a male patient from Wales reported:

> "I used to go out with my friends for a pint or dinner after work… but now I cannot do that because it was not polite for Chinese people to refuse the food my friend gave me during dinner…so I often ate too much and drank too much in restaurants…it was not good for my blood sugar..."
>
> (WMDP2)

Food has multiple connotations in Chinese culture. Eating food is not only viewed as a means of sustenance but also regarded as a method to maintain social relationships. The above narratives suggest that for Chinese patients, adhering to dietary restrictions during social gatherings could go against the collectivistic norms of considering and respecting the wishes and desires of other people and avoiding conflict in the group. Therefore, the four Chinese patients reduced the chances to attend social gathering to avoid awkwardness. This raises another issue that self-management that focuses on dietary restrictions presents unique cultural challenges for those Chinese patients who do not want to sacrifice social relationships for their condition. However, a small number of Chinese patients attempted to break tradition and to achieve an optimal balance between maintaining social relationships and dietary management. For example, a male patient from China reported how he avoided any awkwardness regarding attending restaurants for meals with friends by adopting his strategy for gaining an optimal balance between maintaining social relationship and dietary management:

> "…but apart from having dinner in restaurants together, there are a lot of alternative ways to improve social communication such as drinking tea together, doing exercise together, and making an excursion together so I now prefer inviting my friends to drink tea or coffee together to having dinner together in order to strengthen our ties and affection."
>
> (CMDP2)

Additionally, three patients mentioned the cultural and social stigma of having type-2 diabetes as the main reasons why they reduced their social communication as indicated in the following extract from a male patient from China:

> "...I had reduced chances to gather with friends and work colleagues because it was embarrassing to take medicine in front of them so I preferred staying at home after work after developing diabetes."
>
> (CMDP5)

Everyday medical adherence is one of the main tasks of self-management for patients with type-2 diabetes. Taking medications during social gatherings has the risk of disclosing the condition to other people. In Chinese culture, taking medications usually suggests weakness and an unwell status, which may reduce machismo among male patients. Thus, this male patient reduced his chances to attend social gatherings to avoid exposing his condition to other people outside of the family in order to maintain his machismo, which could lead to a social isolation (Cacioppo *et al.*, 2002).

Other reported reasons for reduced social contacts among Chinese patients were that they did not want to receive unnecessary and additional attention from other people or they perceived prejudices toward patients with type-2 diabetes in their communities. As two female patients from Wales remarked:

> "I used to do some work as a volunteer in a charity organisation but now I do not do it because I was concerned how my colleagues or other people react to my condition because I sometimes need to take medicine in front of them. If they do not know diabetes too much, they could worry about my health. I do not want to receive unnecessary and additional attention from other people in the social exchange."
>
> (WFDP5)
>
> "After having diabetes, I attended less social events because there were still some personal prejudices to patients with diabetes. Some friends once said to me that the cause of my condition was that I failed to control my mouth (eating behaviour) by myself. Additionally, other friends even accused me that diabetes was retribution I deserved it because I had done a lot of bad things. It really upset me. "
>
> (WFDP7)

These findings demonstrate that there is still diabetes-related social stigma and prejudice in Chinese communities, which impacted on Chinese patients' social activities or contacts. Similar findings have been reported in previous work conducted with Chinese patients with type-2 diabetes. Shiu and Wong (2002) carried out a qualitative study to investigate the perceptions, experiences and concerns of 13 insulin dependent Chinese patients in Hong Kong and found that many Chinese patients perceived that the public had contempt for them and mistook them as being either intravenous drug users or self-inflicting the disease as a result of over-indulgence with food when they carried out self-administration of insulin in public places. In another qualitative study in which 12 Chinese patients with type-2 diabetes were investigated to explore the perceptions and experiences of using insulin therapy in Hong Kong, it was found that ten out of the 12 participants initially refused insulin therapy due to anxiety about social stigma in terms of strange looks from other people, that it was a sign of personal weakness or a critical state of health, and that they would be perceived as a burden on society (Kwan, 2001).

Health-related stigma and prejudice is the negative social judgement on the grounds of a feature of a condition or its management that results in perceived or experienced exclusion, rejection, blame, and stereotyping and/or status loss (Weiss *et al.*, 2006). This is a deleterious social phenomenon, which has been observed and investigated widely in many conditions such as HIV/AIDS (Brown *et al.*, 2003), obesity (Agerström & Rooth, 2011), and mental illness (Hayward & Bright, 1997). The International Diabetes Federation (IDF) (2013, p.10) has identified diabetes-related stigma as a problem that needs increased attention, and one of the organisation's priorities is to "champion a world free from discrimination and stigma for people with diabetes."

According to Goffman's theory of stigma (1968), stigma is established due to a distinction between virtual social identity, that is, the stereotyped imputations we make in everyday life, and actual social identity, namely, those attributes which an individual does actually possess. Stigma occurs when virtual identity is not consistent with actual identity. Goffman (1968, p.14) therefore defined stigma as "a special kind of relationship between attribute and stereotype". Goffman's theory of social stigma has been used in the study of experience of chronic illnesses (Jacoby, *et al.*, 2005; Joachim, & Acorn, 2000). According to Goffman (1968), there are four factors influencing the likelihood of stigmatisation, including the extent to which the signs or symptoms of a condition are recognised by other people, the extent to which others are aware of an illness, the extent to which the flow of interaction is impeded, and the perception that others have about an individual's ability to participate fully and normally.

My findings with respect to participants' concerns expressed regarding prejudice and how others may view them can be explained by applying Goffman's (1968) theory of stigma. For WFDP5, taking tablets in the workplace aroused other people's attention to her health state, which led to stereotyping. Although type-2 diabetes is still not curable, it is manageable and controllable through the use of medication and self-management. Therefore, WFDP5 perceived unnecessary and additional attention, when other people were not aware of the importance of medication in management of type-2 diabetes. In addition, for WFDP7, other Chinese people criticised her lack of self-discipline and even blamed her for having type-2 diabetes as her retribution when she participated in social events, which is an example of stereotyping. The occurrence and development of type-2 diabetes is related to diet, but it also can be affected by non-modifiable factors such as heredity and ethnicity, which are attributes. Therefore, stigma occurred when other Chinese people did not understand the relationship between these non-modifiable factors and type-2 diabetes. Therefore, misconceptions and a lack of accurate knowledge of type-2 diabetes and its management among the general population and in particular the Chinese community is a main cause of social stigma related to type-2 diabetes. My findings support those of Shiu and Wong (2002) and Kwan (2001) conducted in Hong Kong who attributed social stigma related to type-2 diabetes and insulin therapy to public misunderstanding about self-administered injections and the nature of diabetes as a chronic condition. Additionally, my findings indicate that social stigma is an issue not only for Chinese people with diabetes who are controlled by insulin but also for those who are controlled by medication and lifestyle modification,

In terms of the consequences of social stigma, both patients reduced their social activity in terms of either giving up voluntary work or reducing social contact as a result of the diabetes-related stigma, which may increase the likelihood of lack of social support in the course of self-management and suffering from psychological distress as a result of social isolation. Lin *et al.* (2008) reported similar findings in their study using focus groups with 41 patients with type-2 diabetes in Taiwan to understand and document the perspectives of Taiwanese patients in terms of the processes and strategies for self-management. They found that social exchange and help-seeking behaviour from social resources was limited and reduced among participants due to social stigmatisation associated with having diabetes.

In order to eliminate social stigma and public prejudice for patients with type-2 diabetes, the most important intervention is to improve public awareness of type-2 diabetes and its management through widespread diabetes education among the general population and specifically within the Chinese population. For example, mass media campaigns that target the general public and attempt to clarify the aetiology, importance and types of treatment of type-2 diabetes may help dispel misconceptions related to type-2 diabetes. Moreover, in terms of diabetes education among patients, an aim of such programmes is to educate patients and their carers to enhance their assertiveness and self-efficacy to help resist social stress (Tak-Ying Shiu *et al.*, 2003), which may facilitate appropriate self-management despite perceptions of social stigma.

As well as the negative effects, 26 participants reported positive effects, which are now presented and discussed.

7.3 Positive consequences

In Chinese tradition and culture, illness is usually regarded as an aversive event. When illness particularly incurable and chronic illness occurs, most people focus on its negative consequences and few people are aware of its positive aspects (Zeng *et al.*, 2015). However, by comparison in my study over half of the participants (n=26) including 13 patients and 13 carers reported the positive effects of type-2 diabetes. Nine out of the 13 patients were from China, and the remainder were from Wales. Whilst seven out of the 13 carers were from Wales, and the remaining six were from China. The main positive changes mentioned by participants were the improvement of awareness of health and changes in lifestyles. Moreover, enhanced family ties after the diagnosis of type-2 diabetes was reported by five participants. Therefore, the focus of this section is on the positive effects of type-2 diabetes reported by Chinese patients and their carers.

7.3.1 Improved attention to health

Six patients including three patients from China and three from Wales reported that they started paying more attention to their health after being diagnosed with type-2 diabetes. Moreover, three carers including two from China and one from Wales described that how they had noticed that their relative gave more attention to their health and as a result they also improved their awareness of their own health. As a female patient from China reported:

> "...previously I paid scant attention to my health status, but after having diabetes, I realised I must pay more attention to my health because I was no longer a healthy person."
>
> (CFDP6)

Her husband also remarked about her improved awareness of health:

> "Since my wife was diagnosed with diabetes, she was very careful about her health... paid more attention to her diet and shape of body, and often asked me if she became fatter or not... and she asked me to do exercise with her so I did as well..."
>
> (CFDPC6)

Whilst a female patient attributed her diabetes to a previous lack of attention to her health:

> "...after being diagnosed with diabetes, I paid more attention to my health, and I looked after myself carefully...because I realised lack of attention to my health may be one of reasons for my diabetes... "
>
> (WFDP3)

And a carer from Wales reported:

> "I had noticed that after being diagnosed with type-2 diabetes, my wife paid more attention to her and my health... and was very careful for any changes in her body such as weight... and she followed doctor's advice strictly and had made a lot of changes in diet. Sometimes I helped her test her blood pressure at home, after that she also helped me to test my blood pressure but I was fine and I did not have high blood pressure but she said preventative test was necessary for me ..."
>
> (WFDPC7)

These findings indicate how a diagnosis of type-2 diabetes was viewed as a health warning among some Chinese patients, which motivated them to pay more attention to their health state. With the improvement of awareness of health, these patients were sensitive to their health state including body shape, weight, blood sugar level and blood pressure and paid more attention to their lifestyle such as diet and exercise. Furthermore, these patients' carers were also involved in their lifestyle modifications and participated in primary prevention as a result of their improved awareness of health.

According to Taylor's (1983) theory of cognitive adaptation, this improvement of attention to health after having type-2 diabetes among some Chinese patients is a result of searching for meaning in their type-2 diabetes, which is the first process in cognitive adaptation. Most previous work focused mainly on the relationship between cognition adaptation and treatment adherence among patients with type-2 diabetes. For example, Azar *et al.* (2012) conducted a cross-sectional study with 480 patients with type-2 diabetes in Iran to assess the cognitive adaptation to treatment adherence and its relative factors in coping with disease among patients with type-2 diabetes and found there was a significant relationship between cognitive adaptation and treatment adherence. There are few studies which have sought to explain the positive effects of type-2 diabetes on Chinese patients according to Taylor's (1983) theory of cognitive adaptation. Applying the theory of cognitive adaptation helps to aid understanding of the positive influences of type-2 diabetes on Chinese patients as identified in my study.

In Taylor's (1983) theory of cognitive adaptation, in the face of threatening events such as illness, individuals engage in a process of cognitive adaptation in order to gain meaning, to gain mastery, and to restore self-esteem through self-enhancing evaluations. These three processes are central to developing and maintaining adaptive illusions, which constitute a process of cognitive adaptation. Essentially, illusions are perceptual biases, which form the core of cognitive adaptation theory as the ability to sustain illusions is proposed to help individuals view the aversive situation from a positive perspective (Taylor, 1983). Such illusions are not necessarily in contradiction to reality but are positive interpretations of this reality. Taylor (1983) also points out that these illusions are an important and necessary component of cognitive adaption.

After being diagnosed with type-2 diabetes, many of my Chinese patients went through a process of self-reflection about their previous level of attention to their own health. Afterwards, they realised that they "did not care about health status" before having type-2 diabetes, and then they developed their illusion that the lack of attention to health was the cause of their type-2 diabetes. Although there may be little evidence for the specific causes of type-2 diabetes (Harmel & Mathur, 2004), the illusion is not contradictory to reality. For example, there is scant evidence to support diet is a causation of type-2 diabetes, but the importance of modification of diet in blood glucose control has been proved (Knowler *et al.*, 2002). Moreover, the illusion is beneficial not only for Chinese patients themselves but also for their family carers. For Chinese patients, the illusion was helpful to better understand the cause of type-2 diabetes and to promote the implementation of self-management because understanding the cause of type-2 diabetes and developing an insight into the implications of type-2 diabetes provided type-2 diabetes with a specific meaning, and a sense of meaning contributed to the process of coping and cognitive adaptation (Taylor, 1983). In addition, more attention has also been paid to their carer's health as a consequence of the improved attention to health among the patients, which may contribute to family mutual support in self-management (Rosland, 2009).

Therefore, I suggest that the increased attention to health following type-2 diabetes resulted from a cognitive process in which Chinese patients found a positive meaning from being diagnosed with type-2 diabetes. The implications for participants of applying a positive meaning to their type 2 diabetes was evident in terms of positive changes to their lifestyles, an improved family relationships, and their philosophy of life, which are discussed in the next section.

7.3.2 Changes in lifestyles

Ten patients including six patients from China and four from Wales reported that they started changing their lifestyles such as diet, exercise, and living habits after being diagnosed with type-2 diabetes. A female patient from China stated:

> "...after diabetes, I changed my eating habits. Previously, I liked to eat sweet food such as Tang Yuan (汤圆) (Note: it is a Chinese traditional food, which is made from glutinous rice, peanut, sesame, and plenty of sugar) and rice cake, but now I no longer eat these sweet foods and just eat a small bowl of rice in three meals but eat more vegetables..."
>
> (CFDP3)

Whilst a male patient from Wales also reported increased awareness of his diet and made changes to his diet about being diagnosed with type-2 diabetes:

> "...I paid more attention to what I eat in meals every day since I was diagnosed with type-2 diabetes. Previously, I had only one meal a day and ate too much junk food such as chips in the meals. After eating, I lay on the sofa and watched TV and then slept. After having type-2 diabetes, I have changed the unhealthy lifestyle so now I have three meals a day and no longer eat fried food..."
>
> (WMDP1)

Besides the change in eating habits, patients also mentioned increased physical activities after having type-2 diabetes. A female patient from China reported:

> "...I did more exercises such as dancing, Tai Chi and walking after having diabetes. I liked Tai Chi very much because it was a kind of mild exercise and it was very suitable for old people like me. I do Tai Chi every morning for one hour now.
>
> (CFDP6)

Whilst a female patient from Wales reported her daily exercise schedule after being diagnosed with type-2 diabetes as:

> "...I included more exercise in my spare time after diabetes. For example, now I do Yoga three times a week, and each time for one hour. Although Yoga is very peaceful and mild, my energy is being consumed while I am doing it. I like it too much..."
>
> (WFDP4)

Furthermore, a small number of patients especially male also reported that they had abandoned previous unhealthy behaviours such as smoking and drinking after being diagnosed with type-2 diabetes as indicated in the following extract from a male patient from China:

> "...I had quit cigarettes and alcohol since I have been diagnosed with diabetes...."
>
> (CMDP3)

These finding show that 10 Chinese patients both in China and Wales realised the importance of lifestyle modification in the management of type-2 diabetes and made efforts to change their lifestyle in terms of diet, physical activity, and forsaking unhealthy behaviours after having type-2 diabetes. This finding is consistent with the findings in other previous studies regarding patients with myocardial infarction (MI). In a study conducted by Hutton and Perkins (2008), ten male patients with (MI) were interviewed and found that all participants reported perceived positive effects of MI, making healthy lifestyle changes were considered the most important positive effect. In addition, Petrie *et al.* (1999) found that over two thirds of first time patients with MI reported positive changes as a result of their condition and the most common was healthy lifestyle change. Although type-2 diabetes and MI are two different diseases, they have similar risk factors and healthy lifestyle changes are the most important components in self-management of both diseases (Harmel & Mathur, 2004). Thus, the findings from the above two studies provide insight and support for the present study findings.

Being diagnosed with type-2 diabetes motivated 10 Chinese patients to change their previous lifestyle so they developed and maintained a healthier lifestyle, which is also explainable through applying Taylor's (1983) theory of cognitive adaptation. Based on this theory, illusion was established when the Chinese patients understood the negative association between their previous lifestyle and type-2 diabetes so they tried to control their condition by changing their previous lifestyle and developing a healthier lifestyle. These processes contribute to a sense of mastery, which is central to the progression to a state of cognitive adaptation (Taylor, 1983). Indeed, patients with type-2 diabetes necessarily make changes in lifestyle to optimise their blood glucose level so the illusion is consistent with the reality and it contributes towards a positive interpretation of reality.

Moreover, 10 carers including five carers from China and five from Wales reported that they had noticed that their relatives changed their previous lifestyles and they had been involved in the self-management of type-2 diabetes. A female carer from China reported:

> "My husband paid more attention to his condition since he was diagnosed with diabetes. He takes two medicines to reduce blood sugar every day and tests blood sugar twice a week in the community health centre. Moreover, my husband has changed his lifestyles. Now he has meals regularly every day and reduces the intake of food in every meal, does not eat any sweet food and eats more vegetables than before diabetes. Every morning, he wakes up at 7:00. After breakfast, he goes outside our home and does some exercises including jogging and fast walking for more than one hour…I do exercise along with him…I also paid more attention to my blood sugar. When my husband tested blood sugar at community health centre, I asked for a blood sugar test as well…sometimes my husband forgot to take medicines so now I have another job to remind him to take medicines on time."
>
> (CMDPC3)

Whilst a female carer from Wales also commented:

> "…since my husband had got diabetes, he started paying more attention to his condition and he reduced the amount of work and got more time to rest. Moreover, his weight has reduced as well because he often participated in exercises such as swimming so both his health condition and blood sugar are good at the moment. For me, I was also careful for my health and blood sugar since my husband has got diabetes, and I changed eating styles with my husband and sometimes we swam together. In addition, I plan to have a blood sugar meter so that we can test blood sugar at home...I think…probably…my husband's diabetes is not absolutely bad thing to my husband and me because we paid more attention to health and changed previous unhealthy living habits after diabetes... "
>
> (WMDPC5)

These findings illustrate that type-2 diabetes positively impacted not only on patients, but also on their carers. These carers not only noticed that the patients changed their previous lifestyles but also had participated in lifestyle changes and in the primary prevention of diabetes such as having their blood sugar level tested. More importantly, they also provided help and support in the course of their relative's lifestyle change. As the patients involved their family carers as equal partners in self-management activities, the family carers perceived these self-management activities as being more valuable and worthy of commitment and had a stronger willingness to help their relatives to conduct self-management, which is consistent with the definition of meaningfulness as applied in salutogenesis (Antonovsky, 1979). Meaningful activities may enhance Chinese patients' motivation to conduct self-management and may improve their family carers' willingness to provide support in self-management as the data indicated:

> "I am his secretary at home [laughs]. I have two important tasks at home, one is looking after our grandson, the other is reminding my husband taking medicine and testing blood sugar, and sometimes I tested blood sugar for him. I thought what I have done for him was very helpful and valuable..."
>
> (CMDPC3)

> "I should give him more care and support. It is my responsibility as being his wife. Whatever he did, I did not oppose if these things were beneficial for his condition. I would like to try my best to help him control his condition and look after his daily lives... my care was I thought beneficial for my husband's recovery."
>
> (WMDPC1)

In addition, Chinese patients and their family carers may have common lifestyles and risk factors for type-2 diabetes, and the diagnosis of type-2 diabetes in one members of the family can arouse a group perspective which motivates other family members to change their common lifestyles and risk factors in order to prevent the development of type-2 diabetes in other family members (Burke *et al.*, 1997), which may also contribute to enhancing ties between family members.

7.3.3 Enhanced family relationships: "True love"

Five participants including three patients and two carers mentioned enhanced relationships among family members after acquiring type-2 diabetes. Three out of the five participants were from China and the remainder were from Wales. A female patient from China reported that she found her family had become more "united" and "harmonious" after she got type-2 diabetes:

> "...after acquiring diabetes, my husband gave me more care in daily life and took more responsibilities to look after our family... and he did not let me do much farm work and housework. My children used to be very wayward so they

> had a lot of conflicts with their father, but now they changed attitude to their father in order to avoid making me upset and they call me every day to ask about my health and condition. Other relatives visit me frequently with a lot of gifts and food… I found our family more united and harmonious after diabetes…" [laughs]
>
> (CFDP3)

Whilst a male carer from China also mentioned that he valued his family and his wife more since his wife was diagnosed with type-2 diabetes:

> "I and my wife got married 34 years ago. There was never quarrel and fight between us. After she got diabetes, I realised we were getting older and older and our life time was getting less and less so I treasure my family more and my wife by giving her more care and support. "
>
> (CFDPC2)

Such enhanced relationships between spouse and family members after having type-2 diabetes were reported not only by participants from China but also by participants in Wales. A male patient from Wales reported that he perceived increased "true love" between him and his wife after acquiring type-2 diabetes:

> "…we (he and his wife) loved and supported each other more after I developed diabetes. My wife gave me much more care in daily life and treatments… she spent more time with me since I got diabetes. There is a proverb in Chinese, namely true love can be felt during the difficult time… I felt such true love from my wife after diabetes. "
>
> (WMDP1)

His wife also reported a strengthened spousal relationship after her husband developed type-2 diabetes:

> "We have been living together for more than 30 years. My husband was the closest person in the world. He got the condition (type-2 diabetes) and his condition was worse and worse. I love him more after he got diabetes because I felt he is the most important person in my life and I could not lose him. "
>
> （WMDPC1）

Type-2 diabetes had facilitated the five participants to have better family relationships. This finding is endorsed by previous studies. Mahrer-Imhof *et al.* (2007) conducted a phenomenological study with 24 couples to investigate the impact of heart disease on the couples' relationship and found that some couples assessed the illness as a positive, transformative experience in their lives, bringing them closer together. In addition, the positive effect of chronic disease on family relationship was also found in the study conducted by Golics *et al.* (2013). This study indicated that family members felt closer to the patient through supporting each other in difficult times and making more effort to spend time as a family.

It is widely accepted that type-2 diabetes is regarded as a family disease since the necessity to comply with therapy instructions and self-management requires changes not only in the functioning of the patient but also in the functioning of the entire family (de Grauw, *et al.*, 1999; Heropolitańska-Janik & Ukleja, 2004). Apart from appropriate medical therapy, in the everyday struggle with the type-2 diabetes, patients need the help and support from their family, which can increase the patient's motivation to adhere to therapy recommendations and self-management (de Grauw, *et al.*, 1999). According to attachment theory (Hunter & Maunder, 2001), these Chinese patients and their carers who felt closer family relationship after type-2 diabetes might be securely attached to each other and therefore believe that more care and support from family is effective in conquering the threat. In addition, these Chinese patients and their carers could have reinforced mutual understanding and thus avoid direct confrontation and conflict while coping with type-2 diabetes.

Additionally, enhanced family relationships among the five Chinese patients and their carers after type-2 diabetes was affected by Chinese culture. Chinese culture stresses family harmony and mutual support among family members especially in difficult times. When one family member is diagnosed with type-2 diabetes, spouses or other family members usually take on more family responsibilities and avoid confrontation and conflicts in order to fulfill mutual support and to maintain family harmony so that patients feel more loved, cared and supported.

The positive consequences of type-2 diabetes merit more attention not only for conceptual completeness but also for aiding understanding and exploring concordance in self-management. These findings help to provide a more complete picture of the issues confronting Chinese patients and their carers following the onset of type-2 diabetes and are helpful in developing Chinese patient education programme to promote more effective long-term self-management of type-2 diabetes.

7.4 Summary

In this chapter, I discussed the consequences of type-2 diabetes on Chinese patients and their families in China and Wales. As an adversity, type-2 diabetes negatively impacted on many participants in terms of daily activities, employment, family relationships, and social life, which could impede the practice of self-management. On the other hand, as well as the negative effects, the positive effects of type-2 diabetes were also identified among 26 participants including increased attention to health, positive changes in lifestyle, and enhanced family relationships. The identification of both negative and positive effects adds to the existing limited body of knowledge regarding the consequences of type-2 diabetes for Chinese patients and their family carers. In addition, insight into the effects of type-2 diabetes on Chinese patients and their family carers is important for two particular reasons. Firstly, this knowledge is helpful in developing a diabetes education programme targeted to meet the needs of Chinese patients and their carers. Secondly, they are also helpful in better understanding the practices of self-management among Chinese patients, which is now presented and discussed in the next chapter.

Chapter Eight The practices of self-management

8.1 Introduction

In the last chapter, I discussed negative as well as positive consequences of type-2 diabetes for Chinese patients and their carers in China and Wales. Over half of participants mentioned that main positive consequences of type-2 diabetes was to increase their awareness of health and to motivate them to modify their previous lifestyles in terms of diet, exercise, and other living habits in daily lives. In order to present a complete picture of self-management of type-2 diabetes among Chinese patients and their carers, I present data which indicates how the participants understood and practised self-management in their daily lives in this chapter. The key issues identified from the data and explored include modifying lifestyles, self-monitoring of blood glucose level, and adherence to western medication treatment. Firstly, a discussion about modifying lifestyles among Chinese patients and their carers is provided in the following section.

8.2 Modifying lifestyles

20 patients including 11 patients from China and nine from Wales reported that they changed their previous lifestyles including dietary modifications and increased physical activity after developing type-2 diabetes. Furthermore, five carers including three carers from China and two from Wales reported that they also were involved in lifestyle changes in order to support their relatives with type-2 diabetes. In totally 25 participants including 20 Chinese patients and five carers reported making lifestyle changes. Firstly, as the most frequently reported change in lifestyle, daily dietary change is discussed in the following section.

8.2.1 Daily dietary change

23 out of the 25 participants including 18 patients and five carers reported dietary changes in their daily lives after being diagnosed with type-2 diabetes. Of the 23 participants, 12 were from China and 11 from Wales which indicates that in terms of this issue there were marked similarities between the two groups. A female patient from China reported on changes she had made to her diets after acquiring type-2 diabetes:

> "After having diabetes, I ate more beans and vegetables and less oily food in daily meals. My breakfast recipes changed. Now I eat one boiled egg and drink a

> cup of skim milk without sugar every morning. In lunch and supper, I eat a small bowl of rice, some vegetables and a little bit of lean meat. Particularly, I like to eat Mu Er (木耳) (Note: a kind of mushroom growing in China) as it has a lot of fibre, which may be good for my blood sugar level. "
>
> (CFDP1)

In Wales, a male patient explained how he now ate three regular meals a day and incorporated foods that he did not like before having type-2 diabetes such as vegetables and fruits into his current diet:

> "I have changed my eating behaviour and I pay more attention to what I eat in meals every day after having diabetes. Before diabetes, I only had one meal a day and ate too much meat in a meal. I used to hate eating vegetables and fruits. But now I have three meals a day regularly and eat less meat and foods which are sweet such as cake and biscuit than before...additionally I did not like to eat vegetable and fruits, but I have to eat them more every day, which are not too sweet..., which made me a little bit frustrated...anyway...I know they are good for my blood sugar... "
>
> (WMDP1)

After having type-2 diabetes, patients commonly tried to make significant overall changes in eating behaviour, such as reducing the amount of certain foods such as sugary foods, fats, and animal products, and increasing the intake of vegetables, fruits, and other foods containing much fibre. Moreover, another major change patients reportedly made concerned fat and meat. Although the nutritional value of fat and meat in the daily diet was accepted by many patients, they were no longer the centrepiece of the meal. A male patient from Wales mentioned that he previously ate "plenty of " meat, but now meat is no longer his main dish in the meals:

> "Before diabetes, I used to eat plenty of meat and fat such as ham, sausage, and chips, and I did not want to have meals without meat. But after diabetes, I reduced the amount of meat and fat in daily diet but I could not quit them completely because they were still valuable to health... "
>
> (WMDP3)

Furthermore, a female patient from China reported she had a lighter meal with a greater emphasis on rice, grains and vegetables after having type-2 diabetes:

> "I made some changes in my eating behaviour after diabetes. Previously, I used to eat meat and oily foods, especially I used to have a main dish of pork or beef for every dinner... Now I eat a small bowl of porridge, rice or noodle, about two Liangs (两) (=200g Note: *Liang* is unit of weight used in China, 1Liang = 100 g) in each meal, but I still eat a little bit of lean meat because I think it is necessary for my health..."
>
> (CFDP7)

The findings demonstrate that many Chinese patients began the dietary changes immediately after diagnosis. But several patients experienced discomfort from the changes in diet, which may attenuate the modification of their diet. Corbin and Strauss (1991) developed trajectory phasing (TP), which is a major concept of the trajectory framework. The concept explains that a chronic condition has a course that varies and changes over time and that this condition course can be shaped and managed (Corbin & Strauss, 1991). The trajectory phasing illustrates the many different changes in status that a chronic condition can undergo over the course of an illness (Corbin & Strauss, 1991), which can be applied specifically to explain the changes in diet among Chinese patients.

According to the trajectory phasing (Corbin & Strauss, 1991), three stages were identified during the changes in eating behaviour, namely initial, accommodation-adaptation (self-modification), and crisis. The initial stage usually begins when the diagnosis is confirmed by health care professionals and the patient makes the first attempts to control food intake. The main feature of this stage is that the patient begins to experience a conflict between taking pleasure from food and performing the change in diet as indicated in the extract from WMDP1 who reported feeling "frustrated" by having to eat more vegetables.

After the stage of initial changes in diet, Chinese patients no longer experienced great discomfort and conflict, and continued to carry out their dietary changes independently, which is consistent with the second stage of self-modification. However, a small number of patients compromised between the accustomed diet before type-2 diabetes and modified diet after type-2 diabetes as indicated in the following extract from a female patient from China:

> "Although I changed my diet after diabetes, I liked to eat sweet foods such as cake and biscuit. They were very nice…it is difficult for me to give them up completely so now I just eat them once a week, and just eat some, not too many, I not think it is too bad for my blood sugar…
>
> (CFDP2)

However, the use of compromised solution through shifting the accustomed diet before having type-2 diabetes and the modified diet after having type-2 diabetes in order to deal with the conflict between personal desire and dietary requirements may increase the risk to adherence to the modification of diet (Corbin & Strauss, 1991). Although trajectory phasing (Corbin & Strauss, 1991) identified different stages during the changes in eating behaviour, the boundary of different stages was usually not distinct among Chinese patients. The overlap of initial stage and self-modification was demonstrated commonly among the Chinese patients. The use of trajectory phasing (Corbin & Strauss, 1991) contributed to having a better understanding about how personal eating behaviour and food preferences were modified after having type-2 diabetes in Chinese patients.

In addition, changes in the Chinese patients' di*et al*so resulted in dietary changes for those who eat with them. A male carer from China reported dietary changes in his family after his wife was diagnosed with type-2 diabetes:

> "In my family, I rarely went to the kitchen and my wife dominated the kitchen; my wife decided what we ate. After she was diagnosed with type-2 diabetes, she changed her eating behaviour and cooking manner. Previously, she used to make roasted pork or fried chicken in evening dinner but now she just made some light dishes, for example, steamed egg, soup, and various vegetables so I was also obliged to change my eating behaviour alongside her..."
>
> (CFDPC2)

Most Chinese women are culturally ascribed the role of the controller in the kitchen, and they usually make food for their entire family. This finding demonstrates that some Chinese women with type-2 diabetes changed their eating behavior and that of the whole family without negotiation with their family. Therefore, their carers changed their eating behaviour passively and even reluctantly. Furthermore, a female carer from Wales also reported that she changed family recipes without negotiation with her brother with type-2 diabetes:

> "I understand my brother cannot eat too much sugar, and sweet and oily foods so I now just make some light dishes for him such as soup and vegetables. I also like such light dishes so they are ok for me as well... but sometimes my brother did not control his appetite and I told him eating too much that was bad for your blood sugar; just have a little taste..."
>
> (WMDPC2)

It is evident that Chinese women usually played an active role during the changes in eating behaviour regardless of whether they were patients or carers, and Chinese men were relatively passive in the management of diet in Chinese families. The likely explanation for this finding is that Chinese men and women have different gender roles in the families as a consequence of Chinese cultural norms related to gender. In China, women usually take on more responsibility to prepare, cook and serve food for their families. In addition, Chinese women were not only active participants but also surveillants in the course of dietary management in their families as the data indicated:

> "...my wife controlled the portion size of foods by using smaller plates and bowls. Sometimes if she found I ate some food too much, she shouted to me and asked me to stop eating that..."
>
> (CFDPC2)

The probable explanation for this finding is that Chinese women may have better awareness and knowledge of dietary management than Chinese men, which might be closely associated with their long-term experience of making food for their families. Mathew *et al.* (2012) carried out a study with 35 participants including 17 men and 18 women to explore men and women's experiences of diabetes self-management in Canada and found that compared with men, women had much more prominent self-care behaviour in terms of dietary management and women demonstrated better awareness and knowledge of nutrition. In addition, Wong *et al.* (2005) also conducted a study with 12 married clients (six female and six male) and seven spouses of clients (three female, four male) to understand how the sharing of household labour influences adherence to nutrition guidelines in type-2 diabetes and found that male clients were more likely to be actively supported by their wives in the form of meal preparation and verbal encouragement, while female clients were supported less in dietary management by their husbands.

This gender difference in dietary management could be viewed as being a facilitator of self-management among Chinese male patients because they may obtain more and better care and support from their female family carers in dietary management. On the other hand, it suggests that Chinese female patients could encounter more challenges in managing dietary changes as they may acquire less support from their male family members. Therefore, it may indicate the need for male carers to be involved with consultations with health care providers and diabetes education programme to improve their awareness and skills of dietary management, which may also be conducive to overcome some of the challenges in dietary management identified among Chinese female patients with type-2 diabetes.

Besides the changes in eating behaviour, many participants also reported increased exercise as a part of their lifestyles modification after developing type-2 diabetes, which is discussed in the following section.

8.2.2 Increase in exercise

20 out of the 25 participants including 16 patients and four carers mentioned increased exercise in their daily lives after being diagnosed with type-2 diabetes. Of the 20 participants, 13 were from China and seven from Wales. The participants, including patients and their carers, reported participating in a wide range of physical activities and there was great variation in the level of physical activity between individuals. Walking, jogging, Tai Chi, swimming, and doing exercises in gym were the most commonly reported activities. Moreover, physical activities that the participants engaged in differed by gender. Many of the male participants preferred outside or aerobics exercises such as jogging, swimming, and badminton. Moderate physical activities such as walking, dancing, and Tai Chi were more popular among female participants. A male patient from Wales reported:

> "I like swimming and playing badminton...I went to swim three times a week and played badminton with my friends once a week... It was very enjoyable and I thought they were beneficial for my blood sugar as well as health ..."
>
> (WMDP1)

Whilst a female patient from China reported her favorite physical activities after having type-2 diabetes were:

> "I did more exercises such as dancing, Tai Chi, and walking after I got diabetes. I liked Tai Chi most because it was a kind of moderate exercise and was very suitable for old people like me. I now do Tai Chi every morning for one hour..."
>
> (CFDP3)

This finding reveals that when the patients perceived doing exercises they like as being "beneficial" for their "blood sugar as well as health", they were more likely to perceive these exercises as being worthy of doing, which is consistent with the definition of meaningfulness (Antonovsky 1979). Meaningful exercises can enhance patients' pleasure and motivation (Vernooij-Dassen, 2007). In addition, this finding also raised the issue of exercise being appropriate for physical ability. The importance of appropriate exercise in self-management of type-2 diabetes has been supported in previous studies. Nelson *et al.* (2002) analysed data from 1,480 American adults with a self-reported diagnosis of type-2 diabetes in the Third National Health and Nutrition Examination Survey (NHANES III) to describe diet and exercise practices among patients with type-2 diabetes and found appropriate exercise was not only beneficial for glycaemic control but also conducive to maintain regular physical activity among patients with type-2 diabetes. In addition, Oftedal *et al.* (2011) carried out a cross-sectional study to investigate diet and exercise management and how indicators of intrinsic motivation such as ability expectations and values are associated with diet and exercise management with 425 adults with type-2 diabetes and found that positive expectations concerning their ability to perform exercise was associated with sustaining regular physical activity in self-management. Moreover, according to self-determination theory (SDT) (Deci & Ryan, 1985), patients are more likely to be motivated to conduct exercises when they perceive that they have the ability to complete these exercises. Therefore, to maximise Chinese patients' participation in exercise, the sort of exercises that patients can manage and enjoy needs to be considered on an individual basis.

In terms of motivation for physical activities among Chinese patients besides having the capacity to exercise, the perceived psychological and physical benefits of physical activity were commonly mentioned as a motivator, for example:

> "I was told I needed more exercise after diabetes so now I go to work by bicycle and ride about 15 kilometres every day. In addition, I often go to climb mountain with my friends on Saturday or Sunday. After exercise I felt very comfortable and relaxed...my stress and anxiety had gone away, and my blood sugar seemed to be better than before exercise...so now I favour these exercises very much and I will keep doing them. "
>
> (CFDP1)

Similarly, a male patient from Wales also remarked:

> "In addition, I took part in some exercises every week such as swimming and walking. Such exercises were very good for my health and blood sugar. I felt better after exercise...last month, my doctor tested my blood sugar after meal and it showed 7.2 (mmol/L)...it is very fine for me...so I will stick to exercise."
>
> (WMDP5)

Many Chinese patients presented the increase in self-efficacy associated with participating in physical activity. They became much more confident in the management of their blood glucose level through regular physical activity because they perceived the benefits of participating in exercise in terms of their mental health status and blood glucose level, which contributed to adherence to exercise and to maintaining healthier lifestyles. The positive role of self-efficacy in adherence to exercise was supported in the study conducted by Sniehotta *et al.* (2005) with 307 patients who were participating in cardiac rehabilitation. Their findings verified that self-efficacy was an essential mediator between intention to exercise and actual and consistent exercise at four months follow-up.

In addition, several male patients mentioned enjoying team physical activities including playing badminton, basketball, and walking with friends and family as indicated in the following quote from a male patient from Wales:

> "...sometimes I play basketball and badminton with my Chinese friends together...I do not like doing exercise alone because I feel very bored but these social exercise programmes are very interesting for me..."
>
> (WMDP3)

Female patients talked of dancing or doing Tai Chi with friends and neighbours together at a public square. However, walking with the family was the most preferred activity that Chinese female patients engaged in both in China and Wales. A female patient from China commented:

> "I like walking with my husband and my dog for one hour in the morning. We are talking and playing with the dog while walking. Moreover, I dance with my friends at a public square every evening after dinner."
>
> (CFDP7)

Whilst a female patient from Wales also reported:

> "I walk with my husband in the park for an hour in the morning as long as weather is good."
>
> (WFDP7)

These findings demonstrate that there was a preference for taking part in physical activity with one or more friends rather than exercising alone among both Chinese men and women. Team exercises such as badminton, basketball and dance offered the opportunity for social interaction, which was one of the key motivators for participating in exercise among Chinese patients. This finding support the study of Jepson *et al.* (2012) who conducted a qualitative study using focus groups and in-depth interviews in order to explore motivations and facilitators of physical activities among 59 South Asians in the UK and found that the main motivators for taking part in physical activity were external motivators, for example participating in physical activity as a means to an end, which included the opportunities that physical activity provided for social activity and enjoyment. Moreover, Hardy and Grogan (2009) conducted a qualitative study adopting ground theory analysis to explore the reasons for exercise among older adults (n=48) and found that although they did exercises to prevent a decline in their health status or to meet requirement of managing a health condition, other key factors such as the social aspects and the role of other people who helped keep them motivated were important.

Besides social communication, enjoyment of exercise was another commonly mentioned motivator for Chinese patients especially when it was combined with a social element.

> "It was very fabulous that more than thirty women danced together while playing music. We dance together until 9 o'clock every evening. I am always very enjoyable, very nice…bedsides dancing, we talked and chatted together which increased our friendship."
>
> (CFDP7)

> "I have got more chances to communicate with my Chinese friends by taking part in these team sports (basketball and badminton). In addition, I also met a lot of local people and made friend with them in the playground, which increased my social connections with local communities."
>
> (WMDP3)

Furthermore, several patients regarded their work or family responsibilities as a kind of physical activity. A male patient from Wales described his everyday work as "exercise which people did in gym":

> "…I would like to do some exercises every day but I do not have much time to do that because my work is very busy. However, I think my work is also a kind of exercise, which people did in gym because I have a lot of tasks such as shelf-stacking and the lifting and carrying of heavy boxes and so on every day… I feel tired after work every evening…"
>
> (WMDP2)

Whilst a female patient from China also remarked she regarded her family tasks as exercises:

> "Although I did not take part in specific physical exercises, I had a lot of tasks to do at home every day. I do some housework such as washing clothes and cleaning kitchen, bathroom, and floor. After finishing the housework, I start preparing for dinner for my family… every day is the same…. when I finished these family tasks, I felt very tired so I did not want to do additional exercise… they were exercises as well…"
>
> (CFDP6)

The reasons that Chinese patients gave for what motivated them to participate in physical activities were identified, including perceived psychological and physical benefits, social interaction, achievement of work and family responsibilities, enjoyment and pleasure of exercise. Chinese patients perceived benefits and pleasure of physical activity so they accepted the value of physical activity and then they were willing to keep doing exercise and even regarded exercise as a necessary part of their life, which is consistent with the concept of internalisation and integration in the theory of self-determination (SDT) (Deci & Ryan, 1985). With the increase of internalisation, Chinese patients may have greater persistence, more positive self-perception, and better quality of engagement in physical activity.

Family carers also played an important role in the process of internalisation and integration through participation in physical activity with patients as indicated in the following extract form a female patient's husband from China:

> "I take a walk with my wife every evening after dinner for one or two hours after she got type-2 diabetes."
>
> (CFDPC2)

Whilst a female patient's husband from Wales also commented that:

> "...after my wife was diagnosed with type-2 diabetes and we were told she needed more outside exercises so now we often walk along the beach together for about one or two hours in the morning or evening as long as the weather is nice. "
>
> (WFDPC5)

Moreover, carers also played a role of promoter in their relative's physical activity. A typical comment included:

> "After my husband was diagnosed with diabetes, I often persuade him to do more exercise. For example, when we went shopping together, I always said no bus or taxi, we walked to shopping mall. "
>
> (CMDPC5)

This finding shows that carers played a role of companion or promoter during physical activity for Chinese patients. This role contributes to improve Chinese patients' sense of relatedness in self-determination theory (SDT) (Deci & Ryan, 1985). A sense of relatedness can be understood as individuals' views about themselves as connected to important others and worthy of love and support from others (Deci & Ryan, 1985). People with a strong sense of relatedness are more likely to be autonomously self-regulated around the behaviours. Therefore, Chinese patients who have obtained support and encouragement from their carers have a strong willingness to engage in physical activity as data indicated:

> “Moreover, my wife also encouraged me to do more exercise. She often asked me to stop watching TV and to go outside of home to do more exercise. We also did exercise together. She likes dancing and singing so now I also join their team and dance and sing with them every evening as long as weather is good.”
>
> (CMDP6)

Besides dietary modification and physical activity, 14 Chinese patients reported that they conducted self-monitoring of blood glucose, which is discussed in the next section.

8.3 Self-monitoring of blood glucose levels

Of the 26 patients, 14 Chinese patients including 10 patients from China and four patients from Wales reported that they conducted monitoring of blood glucose at home or at a community health centre. The remaining 12 patients did not conduct self-monitoring of blood glucose as they were not advised to do that by health care providers or lacked financial support as discussed in last chapter. A female patient from China reported her experience of self-monitoring of blood glucose at home:

> “…I tested blood sugar by myself once a day at home using my own blood sugar meter and recorded the results of the tests…”
>
> (CFDP6)

Whilst a male patient from Wales also reported:

> “Yes. I tested my blood sugar before or after meal once a day by myself every day because my blood sugar was not stable recently so I was told I needed to do that.”
>
> (WMDP1)

Self-monitoring of blood glucose (SMBG) is an important component of self-management for type-2 diabetes. The benefits of self-monitoring of blood glucose have been accepted widely including achieving a specific level of glycaemic control and preventing hypoglycaemia or hyperglycaemia (Welschen *et al.*, 2005). The goal of monitoring is to collect detailed information about blood glucose levels at many time points to enable maintenance of a more constant glucose level by more precise regimens. It also can be used to aid in the adjustment of a therapeutic regimen in response to blood glucose values and to help patients adjust their dietary intake, physical activity, and tablets and insulin doses to optimise glycaemic management on a day-to-day basis.

In order to promote self-monitoring of blood glucose among Chinese patients, it is important to understand the motivation for self-monitoring of blood glucose among Chinese patients first. The 14 Chinese patients reported the reason why they performed self-monitoring of blood glucose at home was to follow doctor's advice. Typical comments included:

> "My doctor asked me to test blood sugar before eating three times a week at home so I did it."
>
> (CFDP1)
>
> "My GP asked me to test my blood sugar before meal by myself at least twice a week."
>
> (WFDP1)

Moreover, the health care providers' attention in responding to the blood glucose readings was one of the reasons several participants gave for continuing self-monitoring of blood glucose. A female patient from China reported:

> "...I tested my blood sugar at home by myself and I recorded the results after testing. When I saw the doctor, I took these blood sugar records with me. The doctor looked at my records and said my work was very helpful for my further treatments and suggested I keep doing that..."
>
> (CFDP4)

Whilst a male patient from Wales also reported that he recorded his blood glucose tests and then his GP approved of his work during health consultation:

> "Yes I recorded every blood sugar test and took them along when I saw my GP. My GP read them carefully and then discussed them with me. He praised my work and encouraged me to keep doing that. He told me my work was very helpful for my condition and treatments."
>
> (WMDP1)

This finding illustrates that recommendation and approval provided by health care professionals played an important role in the motivation for self-monitoring of blood glucose among Chinese patients. I have termed this health care professional motivation. The recommendation from health care professionals was an initial motivator. After that, the approval and positive feedback from the health care professionals created further interest in continuing self-monitoring of blood glucose, which is consistent with the concept of a sense of relatedness in self-determination theory (SDT) (Deci & Ryan, 1985). Health care professionals' advice, encouragement and support can motivate Chinese patients to accept and internalise the value of self-monitoring of blood glucose through increasing their sense of relatedness. This increased sense of relatedness was illustrated in patients' records of self-monitoring of blood glucose.

Six patients including four patients from China and two from Wales provided their records of self-monitoring of blood glucose to review. The records from the four patients in China recorded their levels of blood glucose in the past three months. Their frequency of testing blood glucose was various from three times a day to three times a week. In addition, they also recorded additional tests when they had physical symptoms such as palpitation, sweat, shaking, and dizziness. All results of blood glucose tests of over 7 (mmol/L) or below 3 (mmol/L) were highlighted in red or underline and their feelings at that time were also recorded. Two of the four records had doctors' comments telling the two patients how to use medication and insulin properly. The records from two patients in Wales recorded their levels of blood glucose in the past one month. Their frequency of testing blood glucose was also various including one time a day and four times a week. They also indicated the results of over 7 (mmol/L) by underline or bold. However, no additional information about physical symptoms and doctors' comments were seen on the two records. I obtained information on how Chinese patients in China and Wales understood and conducted self-monitoring of blood glucose in their daily lives and how self-monitoring of blood glucose was discussed between the patients and their health care providers by reviewing these records. In addition, the patients had a better understanding about their condition and self-management through completing these records as indicated by this extract from a female patient from China:

> "The doctor told me I needed to test my blood sugar by myself at home and record the results of these tests. These records are very important and helpful for treatments for my diabetes as they can know my blood sugar levels in a period of one or two months by reviewing these records. I thought I can do that. It is a good thing for my condition so I keep doing it."
>
> (CFDP3)

Besides encouragement and support from health care professionals, family carers also played a key role in motivating their relatives to conduct self-monitoring of blood glucose as indicated in the following extract from a carer in China:

> "...doctor recommended my wife to test blood sugar at home so I bought a blood sugar meter for her. Every day I reminded her about taking medicine and

> testing blood sugar on time. My wife has presbyopia so sometimes I helped her to test and record blood sugar and inject insulin at home..."
>
> (CFDPC6)

This finding shows that encouragement and assistance from carers motivated self-monitoring of blood glucose practice among Chinese patients. I have termed this carer motivation. Similarly, carers' encouragement and support can promote the conduct of self-monitoring of blood glucose among Chinese patients through enhancing their sense of relatedness (Deci & Ryan, 1985). This finding supports the work of Park *et al.* (2004) who conducted a study with 168 patients with diabetes to investigate risk factors associated with poor self-care behaviours and found that those subjects with diabetes who had family support were more likely to conduct self-monitoring of blood glucose level. Nagelkerk *et al.* (2006) conducted an exploratory and descriptive study incorporating focus groups with 24 adults diagnosed with type-2 diabetes in the United States to investigate perceived barriers and effective strategies for self-management and found that there was a supportive person in the family who offered encouragement and assistance was instrumental for patients in adhering to their plan of self-care including self-monitoring of blood glucose. Therefore, social support networks including health care professionals and family carers played important roles in encouraging and promoting self-monitoring of blood glucose among Chinese patients.

However, whilst support from carers is beneficial for self-monitoring of blood glucose, a minority of Chinese patients entrusted their own responsibility for self-monitoring of blood glucose to their carers, who then became directly responsible for their relative's self-monitoring of blood glucose. For those patients with visual impairments this was a necessity but for others it could be viewed as a delegation of responsibility as a female carer from Wales reported:

> "I reminded my husband about taking medicine, testing blood sugar, and injecting insulin on time every day. Sometimes my husband was lazy to test blood sugar and then I helped him to do that... now my husband asked me to test blood sugar for him most times...I assume he may not do that without me..."
>
> (WMDPC1)

This female carer complained that her husband delegated his own responsibility for self-monitoring of blood glucose to her and expressed her concern that her husband may not conduct the test by himself without her assistance. This demonstrates that an over-reliance on support from a carer which could reduce autonomous performance, and adherence to self-monitoring of blood glucose may be attenuated when responsibility for the diabetes management is shifted back from the family carer towards the patient. However, once responsibility for this task has been taken on by family carers it may be difficult to relinquish.

In addition, Chinese traditional family roles need to be taken into account in interpreting this finding. In China, women may take on the role of caregivers to the family and are granted culturally more responsibilities to take care of male family members especially ill male family members. Therefore, Chinese male patients are more likely to rely on their female carer to conduct self-monitoring of blood glucose at home, and over-reliance and dependence could happen more among Chinese male patients.

Additionally, a small number of Chinese patients regularly tested their blood glucose at a community health centre, which was performed by health care professionals instead of themselves. Typical examples of comments which reflect this practice included:

> "...no, actually, I do not test blood sugar at home. I go to the community health centre to test blood sugar twice a week. The community health centre was close to my place, and the nurses in the community health centre were very friendly and skilled, and they recorded my, each visit and blood sugar test...I think they can do it better than myself."
>
> (CMDP3)

Similarly, a Chinese patient from Wales also had her blood glucose level tested regularly at a community clinic:

> "No, I did not test my blood sugar by myself because my blood sugar was fine after taking the tablets of metformin, and I visited my GP every two weeks and my GP helped me test my blood sugar so it was Ok for me..."
>
> (WFDP5)

These Chinese patients tested blood glucose at community health centre instead of at home in consideration of convenience. Moreover, as CMDP3 reported that he felt that the nurses were more skilled in conducting the test which may lead to more reliance on support from health care professionals in monitoring of blood glucose level, which could weaken adherence to monitoring of blood glucose when health care professionals are no longer accessible. Reliance on powerful others such as health care professionals has been shown to indirectly affect patients' health awareness and in turn negatively influenced their adoption of self-care behaviours like self-monitoring of blood glucose (Wallston & Wallston, 1982).

Besides self-monitoring of blood glucose, adherence to daily medication treatment was reported among most of the Chinese patients interviewed as another important component of their self-management, which is now discussed.

8.4 Adherence to daily medication treatment

23 out of the 26 Chinese patients including 11 patients from China and 12 patients from Wales reported that they used one or multiple western medications daily to treat their type-2 diabetes. The remaining three patients reported that according to doctor's advice, they controlled their blood glucose level daily mainly through lifestyle modifications such as diet restriction and physical activity instead of medications. A female patient from China commented adherence to medication treatment to control his blood glucose level:

> "I also control my blood sugar by taking medication. I take two tablets of metformin before meals every day since I was diagnosed with type-2 diabetes."
>
> (CFDP7)

Whilst a female patient from Wales also reported medication compliance to control her blood glucose level:

> "I take five different tablets to control my blood sugar every day, including two tablets to maintain my mental health...I take these medications regularly every day following doctor's prescription."
>
> (WFDP1)

Daily medication treatment was the most commonly reported self-management practice among Chinese patients in China and Wales. Adherence to medication treatment seems to be high in Chinese patients. Zhou *et al.* (2013) used a descriptive study approach to investigate the self-care practices among 163 patients with type-2 diabetes in China. They also found that the majority of participants were aware of the importance of medication in managing diabetes and had adherence to hypoglycaemic agents (OHAs; 60.1%) in daily treatment. It is therefore interesting and important to explore what motivates Chinese patients to adhere to medication treatment in their daily self-management practices, which is discussed in the following section.

8.4.1 Perceived need: "medication was beneficial"

All 23 Chinese patients, who reported adherence to daily medication treatment, were aware of the importance of medication treatment in the control of blood glucose levels. A male patient from China reported:

> "…I am a diagnosed patient with type-2 diabetes so it is no doubt that I have to take medication to treat my condition... everybody including even kids know that."
>
> (CMDP4)

Whilst other male patient from China also commented:

> "…my blood sugar was controlled well after taking medication and the level of blood sugar before eating was less than 7 (mmol/L) in the recent tests so medication was beneficial for my blood sugar level and I would stick to it."
>
> (CMDP5)

The two patients' awareness of the importance of medication in the treatment of their condition was based on common sense that medication is often necessary to control type-2 diabetes and its effectiveness on controlling levels of blood glucose. In addition, Chinese patients' perception that medication is essential in the management of type-2 diabetes was also influenced by Chinese traditional beliefs about illness and its treatment. A male patient from China commented:

> "In Chinese culture, everybody knows it unquestionable that if I get ill, I have to take medication…so I take medication to reduce my blood sugar regularly following the doctor's suggestions every day. …"
>
> (CMDP5)

Chinese traditional beliefs on illness and its treatment stress the importance of medication in treatment for illness. This patient considered daily medication treatment as a personal responsibility as a result of this traditional belief, which contributed to establishing a strong internal belief that I can manage my condition by adherence to medication regimen (Wallston & Wallston, 1982). Moreover, the beliefs about medication have been identified as a positive factor influencing adherence to medication treatment among patients with type-2 diabetes in previous studies. Farmer *et al.* (2006) conducted an exploratory survey among 121 patients with type-2 diabetes to identify patients' beliefs about taking medication and found that the vast majority of respondents agreed with statements about the positive behavioural beliefs of taking medication, and over 85% of people agreed that taking medication regularly would be beneficial for their condition.

Although Chinese traditional beliefs about medication treatment is conducive to adherence to medication treatment among Chinese patients, there may be a risk that Chinese patients might be over-reliant on medication treatment in the course of self-management and pay less attention to other activities such as diet management and exercise as a consequence of this traditional belief. A female patient from Wales expressed her doubt over whether blood glucose could be controlled well without medication:

> "I have to take seven medications to reduce my blood sugar and blood pressure every day. But I was surprised that some patients controlled their blood sugar well without medications...only by diet or exercise alone. I did not believe that any disease can be treated well without medications. Medication may be more crucial and necessary for a patient with diabetes than diet and exercise... "
>
> (WFDP3)

This extract indicates that medication was viewed by this patient as being central to the effective management of type-2 diabetes which reinforces an earlier finding that many patients had inaccurate knowledge about their condition. It also reinforces the medical model of health which may undermine self-management activities in terms of lifestyle changes as indicated by the extract from a patient from China:

> "I am not sure I can manage my condition by myself. I am not a doctor. I think doctor knows best how to help me manage my condition well. I control my blood sugar mainly by taking tablets every day."
>
> (CMDP4)

Whilst a female patient from Wales also reported in terms of self-management:

> "I just take tablets on time every day following the doctor's prescription."
>
> (WFDP5)

Trust in medication resulted in six patients not perceiving the need for lifestyle changes in this study. Therefore, diabetes education needs to help Chinese patients eliminate misunderstandings of self-management as a consequence of Chinese traditional beliefs about medication treatment to optimise control of blood glucose levels through effective and appropriate self-management strategy although the data indicates a small number of Chinese patients were lack of awareness of self-management.

8.4.2 Trust in health care professionals

Although several Chinese patients mentioned their concern about adverse effects of Western medications if they used them for a long time, they still adhered to Western medication treatment as a result of trust in health care professionals. Examples of typical comments which reflect this view included:

> "I am taking metformin three times a day and injecting insulin by myself at home. But I had a concern about adverse effects of insulin. I got news that it was not very good and I could have addiction or over-reliance on insulin if I use it for a long time. But I still would keep using it because I trust western medicine…if they were not safe, the doctor would not give me."
>
> (WMDP1)

Whilst a female patient from Wales reported although she experienced low blood sugar caused by the side effects of medications, she insisted that medications were the most effective and safe way to treat her type-2 diabetes following her doctor's advice:

> "…I used to suffer from attack of low blood sugar probably caused by side effects of medications, but I still used them because I know any medications have side effects…if I used them under instruction of doctor, they were still safe…medications were most effective way to treat my condition…"
>
> (WFDP1)

These findings illustrate that the importance of mutual trust and support between health care professionals and patients in medication adherence. Health care professionals play an essential role in educating patients about methods for properly managing their disease and advising patients in terms of adverse effects of medication to help ensure that patient care is optimised (Sisson & Kuhn, 2009). In addition, health care professionals have expertise and knowledge to answer questions regarding medications. Therefore, the key role of trust in health care professionals is the facilitator for medication adherence among patients. A male patient from China reported his experience of discussing the use of medications with a diabetic specialist:

> "I go to the hospital to see a diabetic specialist once a month and then get the medications I need from the pharmacy in the hospital. After getting these medications, I would like to go back to this specialist's office and asked him some questions about how to use these medications properly, how much I need to take every day, whether these medications can cause side effects, if so what these side effects are and how to prevent their occurrence so I believed adherence to medication treatment is safe and necessary for me after talking to the specialist."
>
> (CMDP1)

Whilst other female patient from China also reported that she kept connection with her doctor to obtain guide when she used medications to treat her type-2 diabetes:

> "I kept in touch with the doctor and I would like to call him to ask for some advice when I used medication to treat my condition at home especially when I used this medication first time and was not sure its potential side effects."
> (CFDP2)

Mutual trust and good communication between the health care professional and patient has been shown to be associated with greater diabetes medication adherence in a survey conducted by Larkin *et al.* (2015) with 807 people with diabetes which evaluated the extent to which a variety of factors influence diabetes medication adherence. Furthermore, Schoenthaler *et al.* (2012) conducted a study to examine the influence of patient and physician psychosocial, sociodemographic, and disease-related factors on diabetes medication adherence with 41 physicians and 608 of their patients with type-2 diabetes and found a positive association between trustful patient-physician relationship and medication adherence.

Although WFDP1 experienced an attack of low blood glucose, which is one of common adverse effects due to anti-diabetic medications, she still reported a good adherence to medication treatment. However, this finding refutes that of Larkin *et al.* (2015) who reported that patients were more likely to fail to adhere to medication treatment as a result of worries about medication side effects. The likely explanation for this conflicting finding is that support from health care professionals plays an important role in helping patients cope with the adverse effects of medication and adhere to treatment as WFDP1 stressed due to the advice, trust and support provided by health care professionals in averting adverse effects. Insufficient support provided by health care professionals has been shown to contribute to patients' poor adherence when they experience adverse effects of medication (Osterberg and Blaschke 2005). It is therefore evident that robust support from health care providers plays important role in the adherence to medication treatment among Chinese patients. Furthermore, the data indicate that family support is also an important factor promoting Chinese patients' adherence to daily medication treatment, which is now presented and discussed.

8.4.3 Family support

15 Chinese patients living with their family carer reported good medication adherence with the assistance of their carer, including 10 patients from China and five from Wales. For example, a male patient from China attributed good medication adherence to the support he received from his wife:

> "I have to take four medications to reduce my blood sugar every day. But I was always confused which one I had to take before or after eating, and how much I had to take. My wife put the medications every morning into separate boxes and put labels on the boxes telling me what time and how much I had to take these tablets. She has been doing that for seven years so I never missed medication treatment since I was diagnosed with diabetes."
>
> (CMDP6)

Whilst family carers mostly reported their role as a reminder to Chinese patients to take their daily medication. A carer from China commented that:

> "...my husband often forgets to take medicines on time due to decreased memory so now I remind him about taking medications on time every day
>
> (CMDPC3)

Whilst a female carer from Wales also reported:

> "Every day, I remind my husband to take his tablets..."
>
> (WMDPC4)

The findings illustrate that family carers played a supportive role in daily medication adherence among the Chinese patients. It is important to note that family support could not change the course and development of the patients' type-2 diabetes, but family support may influence the way the patients might perceive their condition and self-management. The patients felt supported through obtaining a reminder to take their tablets from their family carers. Therefore, one of the most important roles of family support in the patients' self-management is to enhance the patients' feeling of being supported, and trying to preserve this as a resource, which is consistent with the definition of manageability within the model of salutogensis (Antonovsky, 1979). According to the salutogensis, this feeling and perception of being supported may be sufficient to develop and strengthen the patients' sense of coherence (Antonovsky, 1987), which may enhance the practice of self-management. These findings are also supported by work of Khosravizade Tabasi *et al.* (2014) who conducted a randomised controlled trial to determine the impact of family supportive behaviour on diabetic medication persistence and cognition among patients with type-2 diabetes and concluded that family support was conducive to improved medication adherence and cognitive status. Additionally, social support including family members was also identified as a positive factor affecting good adherence to medication in Borgsteede *et al*'s (2011) study which was conducted to explore factors related to adherence that patients with type-2 diabetes experienced in their medication use.

In contrast, those Chinese patients from Wales who lived without a family carer attributed their poor medication adherence to lack of support from a carer. A female Chinese patient from Wales remarked:

> "I was told I had to take medications regularly every day but I often forgot to take them due to decreased memory [sighs]... I live alone...If there was a carer living with me, who can remind me to take tablets every day, I may have persisted and have a more effective medication treatment..."
>
> (WFDP6)

Whilst another male patient from Wales commented:

> "My wife and family still live in Hong Kong and I live and work in Wales alone. My work is very busy every day so I frequently forget to take medication on time. In addition, I sometime feel quite lonely because nobody can talk to me at home after work... I think it is better if I live with my wife, at least she would remind me to take medication on time..."
>
> (WMDP3)

In the present study, all 13 Chinese patients from China lived with their carer, but six out of the 13 Chinese patients from Wales lived without a family carer. Decreased memory, a high workload and lack of carer support were commonly reported as barriers to medication adherence among those Chinese patients who lived alone in Wales. Insufficient family support has been shown to be a significant factor associated with low medication adherence by Srinivas *et al.* (2002) who conducted a study in rural South India among patients with diabetes. They reported that lack of family cooperation was one of the reasons for non-adherence to medication. Therefore, the solution to help those Chinese patients who lived without a family carer to minimise the negative influences of lack of carer support on adherence to medication is requested as indicated by the following comments from a female patient who also lived alone in Wales:

> "In addition, I have to take seven medications to control my blood sugar and blood pressure and use two eye drops to treat cataracts. But I often failed to take them properly and on time due to decreased memory and poor sight [sighs]...I live alone...If there is anybody, who can help me to take the tablets and to use the eye drops every day, I may have better medical outcomes..."

(WFDP3)

Many Chinese immigrants left their family in China and then came to Wales alone to live and work so they usually live without their family in Wales, which was a barrier to self-management. This finding demonstrates that lack of family support was a prominent barrier to adherence to daily medication treatment among those Chinese patients in Wales who lived alone. This finding is consistent with other studies reporting that social support directly influences diabetic patients' practice of self-management and indirectly affects their glycaemic control. Mayberry and Osborn (2012) conducted research using mixed methods with 106 patients with type-2 diabetes in the United States to explore the relationships between participants' perceptions of family members' diabetes self-care knowledge, family members' diabetes specific supportive and non-supportive behaviours, and participants' medication adherence and glycaemic control and found that lack of support from family carers was associated with being less adherent to patient's diabetes medication regimen, and less adherence was associated with poor glycaemic control. Similarly, Zeng *et al.*, (2014) explored the factors that may influence self-management of type-2 diabetes among Chinese immigrants in the United States and the potential health outcomes and concluded that general support from patient's family was related to improved subjective health, while family separation undermined management of type-2 diabetes amongst Chinese immigrants.

In fact, family care is one of components of social care, which can be defined as "an interaction involving two or more people whose purpose is to provide awareness and education, to provide emotional, instrumental and financial support, and assist with problem-solving skills" (Baken & Akyol, 2008, p.599). Therefore, if there is a difficulty in resolving the pragmatic barrier of lack of family support, other relevant social resources including friends, social workers, peers, and health care providers may combine collaboratively in order to provide those patients without family care with assistance with self-management. A female patient living alone in Wales stated what joint help she had received with self-management from various social support sources including a social worker and a Chinese community charitable organisation:

> "I live alone here (Wales), my family and relatives are still living in China...my diabetes is serious as well as I have some mental problems such as depression. I do need family care, but I cannot have it because nobody lives with me. Fortunately, a female social worker visits me once a week. But she cannot speak

> Cantonese and I cannot speak English as well. Although we have limited communication due to language barrier, she still gives me a lot of help. For example she reminds me about taking medications on time every day by telephone. When I need to see doctors, she often helps me make an appointment in the clinic or hospital. In addition, when I see the doctors, she accompanies me as well. She is a very nice lady…I no longer feel isolated and helpless at XXX (name of town) since I have got help from the social worker. Furthermore, I am not able to speak and understand English and Mandarin so it is very difficult for me to talk to my GP and other diabetes specialists so I often ask for help from the Chinese centre. The staff at the Chinese centre are very enthusiastic and kind, more importantly, they are bilingual in English and Cantonese. Now when I see the doctors, one member of staff from the Chinese centre accompanies me as a Cantonese interpreter. I do appreciate them. It is easier for me to manage my condition with their help. "
>
> (WFDP1)

This finding demonstrates how collaborative social support contributed to reduce the negative impact of the lack of family care on self-management, which is consistent with the value of integrated diabetes care. Integrated diabetes care is about designing a system that focuses on the diabetic patient's perspective of care. The delivery of integrated care is facilitated by integration of the processes, methods and tools which enable patients with diabetes to move between services according to need (Shaw *et al.*, 2011). Integrated diabetes care works in many forms. Here integrated care refers to collaborative work between different social care providers and patients with type-2 diabetes to support shared decision-making and self-management. Previous work also supported the effectiveness of social integration on self-management of type2-diabetes. Arcury *et al.* (2012) evaluated the association of social integration and diabetes management among 563 rural older adults with type-2 diabetes and found that participants who had high levels of social integration (social network, relatives, telephone contact) were associated with increased monitoring of blood glucose and examining feet and then they concluded that social integration had a small but significant association with self-management behaviours. Furthermore, Shaw and colleagues in their study which included over 200 patients with diabetes in which sources of support for diabetes self-care in underserved communities was assessed. They found that support from family and friends, as well as from community organisations were important for self-management, which also suggested that one source of social support may not necessarily improve self-management behaviours and related health outcomes (Shaw *et al.*, 2006). In addition, as outlined in the NHS Wales

White Paper "Quality Care and Clinical Excellence", the National Service Framework also stressed the importance of integrated social care to provide a systematic approach to driving up standards to improve quality across health care sectors, in partnership with social care and other organisations (Welsh Assembly Government, 2002). Hence, the collaborated social support including friends, social worker, community organisations, peers, and health care providers may be effective as a strategy to help Chinese patients, especially those who live without family care in Wales to conduct self-management.

These findings regarding adherence to medication treatment in Chinese patients support the medication adherence model (MAM) which was developed by Johnson (2002) based on cognitive theories such as the health belief model (HBM) (Becker, 1974) to understand patients' medication adherence and the factors influencing this adherence. This model identified three core concepts that contribute to the degree to which an individual takes medications as prescribed. These are purposeful action, patterned behaviour, and feedback (Johnson, 2002; Lehane & McCarthy, 2007). As data indicated, Chinese patients adhered to their medication treatment when they realised that medication was necessary and effective for their type-2 diabetes. This is consistent with the first concept of purposeful action, which refers to the degree to which individuals cognitively or intentionally decide to take their medications based on perceived need, effectiveness and safety. In addition, Chinese patients initiated and persisted in daily medication treatment after accessing to medication they need. This is consistent with the second concept of patterned behaviour which refers to the degree to which patients initiate and establish a behavioural routine, habit, or pattern of taking their medications through medication access and routine. The identified important role of support from health care provider and family carer in Chinese patients' adherence to medication supports the third concept of feedback which is the degree to which information, remembering, cues or events reinforce adherence or modify medication-taking. Therefore, on the one hand, this model contributes to establishing a better understanding in terms of Chinese patients' adherence to medication. On the other hand, the findings in the study develop this model and extend its applicability to Chinese patients.

Apart from western medication, the use of Chinese traditional herbs was reported in daily practice of self-management among a minority of Chinese patients. Although most Chinese patients reported a relatively negative attitude towards the effectiveness of

Chinese herbal medications on reducing blood glucose level, positive beliefs derived from Chinese traditional medicine had a great influence on Chinese patients' understanding and practice of self-management, which is presented and discussed in detail in the next chapter.

8.5 Summary

In this chapter, I presented and discussed the practice of self-management of type-2 diabetes among Chinese patients and their carers in China and Wales. Modification of lifestyles including dietary change and physical activity, self-monitoring of blood glucose, and adherence to western medication regime were common self-management behaviours reported among Chinese patients. Moreover, the key roles of support from health care providers and family carers in the Chinese patients' self-management behaviours have also been identified in the chapter. Cultural facilitators and barriers to the conduct of self-management among Chinese patients and their carers is presented and discussed in the following chapter.

Chapter Nine Barriers and facilitators of self-management, cultural perspectives

9.1 Introduction

In the previous chapter, I discussed how Chinese patients and their carers in China and Wales conducted self-management in their daily lives. Most Chinese patients conducted self-management, including modification of lifestyles, self-monitoring of blood glucose, and adherence to medication treatment. Carers also provided help and support. However, there were barriers to self-management in terms of financial hardship, lack of information, and lack of social support. In this chapter I present findings which indicate how Chinese cultural beliefs regarding family responsibility and interpersonal relationships with wider social networks impact on Chinese patients' self-management. Moreover, the data indicated that other cultural beliefs in terms of family harmony, human-heartedness and mutual support, and nurturance life, along with the philosophy of Chinese traditional medicine, facilitated to Chinese patients' self-management, which is also discussed. In the last section, a discussion regarding how salutogenesis was applied in this study to illuminate the findings is provided. First, a brief introduction to Chinese cultural beliefs is presented.

9.2 A brief introduction to Chinese cultural beliefs

China has nearly five thousand years of history and culture, which affects Chinese people's life in every aspect, including their health awareness and attitude to disease and its treatment. Chinese cultural values are greatly influenced by Confucianism whose core concepts are human-heartedness and love (Bao, 2003). Human-heartedness and love are regarded as virtues emphasising mutual and altruistic help and support between people (Bao, 2003). In addition, Confucianism also stresses the significance of family and social harmony which is thought to be a prerequisite of development of a country (Bao, 2003). This focus on family and social harmony is the basis of maintaining traditional family roles and good social interpersonal relationships with wider social networks (Bao, 2003). Therefore, any change to traditional family roles and interpersonal relationships may threat family and social harmony.

Chinese people's perspective of health is also influenced by Confucianism. Confucianism contends that "Chung" and "Yung" are two basic concepts of health and longevity (Chin, 2005). "Chung" refers to "equilibrium" or "being without inclination to either side". Confucianism does not encourage people to refrain from the pleasures of life, such as eating. However, it stresses the importance of maintaining balance between the extremes and avoiding excess. "Yung" can be understood as "persistence" or "continuing without change". Confucianism points out that the pursuit of good health and longevity is on the basis of establishing regular habits of healthy living, including exercise, diet, and meditation (Chin, 2005). In addition, health practices need to be persistent as it is difficult to reap their beneficial effects on a particular occasion or after a short period of practices (Chin, 2005). The perspectives of health from Confucianism are consistent with the ideology of the balance of "Yin" and "Yang" in Chinese traditional medicine. Their interaction affects Chinese people's perspectives of health and illness. Therefore, I present and discuss how these Chinese cultural beliefs influence Chinese patients' self-management, negatively and positively in the following sections.

9.3 Cultural barriers

The data indicated that maintaining traditional family roles and interpersonal relationships with wider social networks had a negative impact on Chinese patients' self-management, which is now presented and discussed.

9.3.1 Maintaining traditional family role

Four patients including two from China and two from Wales highlighted that attempting to maintain traditional family roles impacted on their self-management. A female patient from China explained why she did not persist with Tai Chi and walking:

> "I used to do Tai Chi and dance in the morning but I no longer do that since I had a grandchild...I was not free... I had to help my daughter manage everything at home. The child was very young. I must keep watching and look after him. Sometimes I even hardly have time for a walk with my husband after dinner."
>
> (CFDP5)

Similarly, a male patient from Wales explained that he failed to persist with regular exercise in the gym due to his responsibility as a breadwinner:

> "Sometimes I go to gym to do some strength exercises for an hour. I would like to do some exercises every day but I do not have much time to do that because I have to work...I have to earn money to feed myself and my family."
>
> (WMDP3)

In Chinese culture, men and women have highly differentiated family roles. Men usually take on more responsibility to work to feed their family, and women assume the role of looking after their family. The data demonstrates that although attending Tai Chi or the gym was not required by self-management, Chinese patients reduced or even sacrificed their personal need of having a regular physical activity in their daily lives, which may be beneficial for their glycaemic control, in favour of maintaining their family role because of the influence of Chinese traditional culture. This finding supports the study of Shen and colleagues (2013) who conducted a qualitative study using four focus groups with 17 patients with type-2 diabetes to explore perceived barriers and facilitators to diabetes self-management for patients in China and found that older Chinese patients with type-2 diabetes gave their needs a lower priority than caring for their family including providing grandchildren care and making meals, which was viewed as an inescapable responsibility by them.

In addition, maintaining traditional family roles may also undermine patients' autonomy in the practice of self-management especially for male patients. A male patient from China reported:

> "In our family, making food is not my business. I just gave my wife money and told her what I wanted to eat and then she went to market to buy the foods so my wife was responsible for managing my diet, I did not worry about that."
>
> (CMDP6)

> "My wife is very able and she knows how to look after me very well so I do not need to worry anything about my life and diet. I think as being a man, the priority is to work hard and make money and let your wife and child have a good life."
>
> (CMDP4)

This finding demonstrates that several male patients transferred their responsibility to look after themselves and to manage their condition to their wife in order to maintain tradition family role of being a breadwinner in the family. Their carers assumed the decision-making role for what and how foods were prepared for the relatives, which may undermine the relatives' motivation to conduct self-management especially dietary management. In addition, Chinese people show a greater passion for enjoying food and "eating" are endowed with more important meanings in Chinese culture although cuisine is an important aspect in many cultures. Therefore, Chinese patients especially older patients encounter a cultural dilemma when they have to make a decision for self-management, for example they have to make a choice between freedom to enjoy food and a dietary restriction for health. A lady aged 72 years from China said:

> "Indeed, I feel frustrated because I have to give up a lot of my favourite foods; sometimes I think there is no quality in my life. I may be going to die tomorrow, I wish I can eat anything I like without any restriction, and I would not like to be a starving ghost after I die...[sighs] It is best if scientists can find out a way to treat diabetes without diet constraint..."
>
> (CFDP6)

The regimen of type-2 diabetes required Chinese patients to distance themselves from familiar and favourite food habits. They reported that culturally meaningful, familiar, and comforting foods had to be foregone or drastically reduced, which discouraged self-management efforts. Moreover, as food embodies social meanings and importance in Chinese culture, the cultural dilemma was also demonstrated during social communication related to eating such as easily participating in a social dinner due to dietary restrictions, which is discussed in the following section.

9.3.2 Maintaining good interpersonal relationships with wider social networks

The required dietary management due to type-2 diabetes complicated shared social experiences of meals and celebrations with family and friends, which was discussed in Chapter seven. Several Chinese patients' reported difficulties in following an appropriate diet at Chinese restaurants which led them to withdraw from socialising over meals so that their social communication was reduced. However, several patients mainly male patients would not breach the cultural belief of maintaining interpersonal relationships in social networks. Thus, they compromised dietary restriction in the course of social events. A male Chinese patient from China said that:

> "I know I should not eat out with my friends and working colleagues and boss regularly because I had diabetes...but you know I have to have dinner with them frequently in restaurant in order to keep a good interpersonal relationship otherwise it is difficult for me to be promoted in the company I work for. This is Chinese culture...we can do nothing for it but adaptation..."
>
> (CMDP4)

Whilst a male patient from Wales also reported that:

> "...my friend complained that I was always absent at gatherings. It is considered to be rude to refuse to attend social gathering in Chinese culture so now I attend gathering in restaurant when invited. I usually eat and drink a lot during the gathering because you know in Chinese culture it is discourteous to refuse the foods and alcohol friends give me in the gathering...so I take more tablets after the gathering to reduce blood sugar."
>
> (WMDP2)

These two narratives suggested that refusing to attend social gatherings and adhering to food restrictions during social gatherings was in conflict with the strong traditional belief of maintaining good interpersonal relationships in social networks and being courteous, which is one of the core norms of Chinese culture (Lee *et al.*, 2012). In addition, this finding implies that Chinese male patients were more likely to compromise dietary restriction when it is inconsistent with traditional cultural beliefs compared to Chinese women. The possible explanation for that is that Chinese men usually assume more responsibility to maintain traditional culture. Therefore, Chinese male patients may encounter more significant cultural challenges in dietary management especially when they have to follow the cultural norms in social events.

Providing information about coping strategies would help Chinese patients and their carers to keep a balance between social expectation and self-management requirements without unduly sacrificing their own health. For example, the presence of their family in social gathering reminded patients of their responsibility to observe diabetes restrictions, as a duty to their family. Additionally, although the uniqueness of Chinese culture is emphasised, the existence of cultural similarities contributes to seeking solutions for Chinese cultural barriers to self-management from other studies carried out in diverse cultures. For example, family and peer reinforcement to encourage appropriate diabetes management behaviours was also suggested by Hallgren *et al.* (2015) who conducted a community-based participatory research using focus groups to investigate the beliefs and perceptions related to type-2 diabetes that influence self-management behaviours with 28 Marshallese adults in the United States. Besides Chinese traditional cultural beliefs, Chinese patients in Wales may encounter additional cultural barriers to self-management as they live in a different social and cultural context, which is discussed in the next section.

9.3.3 Low level of acculturation

In Wales, all 13 Chinese patients reported that their type-2 diabetes was diagnosed after moving to Wales and they also reported their limited communication with local communities as indicated by the following two extracts from three patients:

> "I have been living in XXX (name of town) since 1985, nearly for 28 years. But I think I am still a typical Chinese. I make and eat Chinese food every day. I do not like British food, very oily. I also had few communications with local people but my GP. But I often come in the Chinese organisation to meet and talk to other Chinese people."
>
> (WFDP2)

> "Since I moved to XXX (name of town), I focus mainly on my work every day from day to night, from Monday to Sunday. I do not have much spare time to communicate with local people, to travel to other place in the UK, and not to have many entertainments."
>
> (WMDP4)

This finding illustrates that Chinese patients in Wales had a low level of acculturation, which refers to a process by which the attitudes and behaviours of people from the original culture are modified over time as a result of contact with Western culture (Suinn, 2009). The low level of acculturation among Chinese patients was associated closely with their limited competence in understanding English as data indicated:

> "I have been living in XXX (name of town) for five years, I am mainly living in Chinese community and I prefer asking help from other Chinese people when I need because my English is not very good and I feel it easier to talk with other Chinese...I rarely talk to local people except the people who came to buy Chinese food. But everything is ok but it is difficult to talk to the doctor because I cannot speak English very well."
>
> (WMDP2)

This finding supports the work of Chun and colleagues (2010) who conducted a qualitative study using interpretive phenomenology to examine how acculturation affected type-2 diabetes self-management and perceived health for Chinese American immigrants. They found that low English language proficiency was identified as a salient acculturation stressor that limited access to health care services for Chinese immigrant participants. It not only inhibited participants' communication with health care providers, but also complicated their capability to accomplish diabetes self-management tasks in daily lives such as scheduling medical appointments and purchasing over-the counter diabetes care products.

In addition, all 13 Chinese patients in Wales reported the impact of moving to Wales on their self-management. Besides language barriers and lack of family care which were discussed in previous chapters, several patients reported that there was a lack of a social network as wide as they had in China or Hong Kong. They could not obtain help and support from a wider social resources when they conducted self-management as indicated by the following extracts from a male patient:

> "...in China, I had a lot of friends, relatives, working colleagues, and former classmates so I could get a lot of help from them if I needed. But I do not have many friends and acquaintances in XXX (name of town) so sometime it is difficult for me to get help from other people."
>
> (WMDP2)

In addition, WMDP2's carer also reported lack of a wide social network impacted her brother's self-management of type-2 diabetes:

> "We do not have relatives and friends here, our many relatives are still living in China, and there few Chinese people in the place where we are living so sometimes if I am very busy or go back to China, few people can look after and help him. I still remember, last year I went back to China for a couple of months. My brother did not see doctor and repeat his prescriptions until I came back."
>
> (WMDPC2)

Therefore, these findings illustrate that there are three main factors which undermine acculturation of Chinese patients. These are language barriers, lack of family care, and lack of a wide social network or social capital. Therefore, a low level of acculturation had a negative impact on Chinese patients' self-management through reducing effectiveness of communication with health care providers and their motivation to obtain information on type-2 diabetes from other sources and limiting access to a wide social support network. Moreover, a low level of acculturation in Chinese patients also suggests that Chinese traditional cultural beliefs still have a great impact on their daily lives and perspectives of health and their condition although they have been living in Wales for many years. The study of Xu *et al.* (2011) who carried out a cross-sectional survey with 211 Chinese Americans with type-2 diabetes to examine acculturation, and its relationship with diabetes self-management found that those Chinese Americans with type-2 diabetes who were more acculturated to mainstream society increased their help seeking behaviours and the use of professional services. Therefore, there is a need to develop outreach programmes, which help and encourage Chinese patients in Wales to be involved in their local communities and to obtain wider social support from different sources as data indicated:

> "I would like to have more communication with local communities and make more friends not only with Chinese people but also with local people. However, it is not easy for me as I do not know how to do that and I have few chances to contact local community and local people so I hope I can get help and support in the involvement of local society. It may be also good for managing my condition as I may get more help from other people."
>
> (WMDP5)

These findings demonstrate that Chinese traditional cultural beliefs regarding family role and interpersonal relationship in social networks have a negative impact on Chinese patients' self-management. Moreover, in Wales, a low level of acculturation to local social and cultural context due to a language barriers and lack of family and social support also undermined Chinese patients' self-management. However, the influences of cultural factors on self-management are not separate and static but interwoven and dynamic as culture is negotiated and re-created in association with the shifting context of patients' lives. When cultural values were not consistent with the requirements of self-management, patients were faced with the dilemma of either following cultural beliefs and undermining self-management or breaching cultural traditions and adhering to self-management, which had a negative impact on their self-management. Therefore, there is a need to help patients to overcome cultural barriers to self-management as traditional models of promoting self-management focuses only on medical knowledge and skills and seems not to meet patients' needs as the data indicated:

> "It was difficult for me to make a choice between keeping a good interpersonal relationship or dietary management in social gatherings. I really need help to solve the problem, but I really do not know where I can get help. I used to try to ask my doctor but he failed to give me a good answer."
>
> (CMDP1)

In addition, the identification of cultural barriers to diabetes self-management requires that health care providers and diabetes education need to take account into the impact of cultural factors on Chinese patients' self-management and provide them with culturally sensitive diabetes care and information regarding type-2 diabetes. If a regard for culture is not evident the promoting self-management among Chinese patients especially those in Wales may be limited as indicated by the following extract from a male patient in Wales:

> "I had once got some Chinese health booklets from GP and nurses. They could be read and understood easily. But those suggestions about how to make changes in diet and living habits were not quite useful for me because it was mostly related to local people's food preference and living habits. The people who wrote the booklet could not understand Chinese people's diet and daily lives so those information was not very helpful for me."
>
> (WMDP1)

This finding is consistent with the development of concept of cultural competence. Cultural competence is defined by the American Medical Association (1999) as the knowledge and interpersonal skills that allow providers to understand, appreciate, and work with individuals from cultures other than their own. It involves an awareness and acceptance of cultural differences, self-awareness, knowledge of the patient's culture, and adaptation of skills. An increasing volume of evidence demonstrates that cultural competent diabetes care has positive effects not only on type-2 diabetes control and/or its complications, but also on the implementation and adherence to self-management among patients with type-2 diabetes through improving mutual trust and communication between health care providers and patients. For example, Nam *et al.* (2012) conducted a meta-analysis of 12 studies to evaluate the effectiveness of cultural competent diabetes education on glycaemic control in ethnic minorities with type-2 diabetes and found that participants' level of HbA1c significantly reduced after six months of attending diabetes education with cultural competence. In addition, Caballero (2007) conducted a literature review in order to explore and evaluate the most common social and cultural factors that may influence the progression of type-2 diabetes, and adherence to treatment plans in patients from culturally diverse populations. They concluded that improving cultural competence in diabetes care may help improve the quality of care provided to minority groups and may ultimately reduce health care disparities, and increased cultural competence may help patients adhere to treatment and self-management plans. It is therefore proposed that diabetes care and education which incorporates Chinese culture is more likely to be accepted by Chinese patients and their carers and may have an increased positive effect on self-management.

9.4 Cultural facilitators

The data also showed that other Chinese cultural beliefs regarding family harmony, heartedness and mutual support, and nurturance life derived from the philosophy of

Chinese traditional medicine have a positive effect on self-management in Chinese patients. A discussion of these cultural facilitators is presented in the next sections.

9.4.1 Family harmony and social mutual support

The majority of Chinese patients mentioned support from their family carers in the course of self-management and most Chinese family carers also reported their willingness to help their family with type-2 diabetes. Despite this, the picture was slightly different in Wales with six patients reporting a lack of family support due to living alone. Reported family support was varied including financial support for medicine costs, care in daily life including diet, exercise, and housework, constant reminders, and psychological consolation. In Wales, family support also meant family members acting as translators and has been discussed in Chapters six. The family support within Chinese patients' families may be associated with the effect of the Chinese cultural norm in terms of family harmony.

The Chinese traditional family value of harmony is significantly affected by Confucianism, which advocates and promotes social harmony in human relationships, including family relationships (Chang & Holt, 1991). To reach a state of harmony within the context of the family, involves mutual respect, understanding, and care between family members and the role and responsibilities of each individual. Therefore, under the influence of Chinese family values, explicit conflict within the family may be avoided because personal relationships are understood centrally in terms of roles and role responsibilities instead of in terms of personal traits (Markus & Kitayama, 1991). For example, a male patient from China reported:

> "It was annoying when my wife nagged…"you cannot do this, you cannot eat that." However, when I calmed down, I often apologised to her because I realised she did these because she cared about my health and she wanted to look after me very well."
>
> (CMDP5)

Family monitoring was forgiven and family conflict was also diffused because such behaviours were viewed as role behaviours rather than inherent personality traits. In addition, Chinese traditional family values also stressed family members' responsibility to care and help ill members, which derives directly from Confucian ideology of human-heartedness and love (仁爱). A carer from Wales remarked:

> "I must look after her because I am her husband. It was my responsibility based on love. If I get disease later probably, I am firmly sure she will look after me as well. We have responsibility to look after each other in the family."
>
> (WFDPC8)

Markus and Kitayama (1991) also expounded that personal relationships within Chinese families are understood centrally in terms of roles and role responsibilities rather than in terms of personal traits. Thus, family conflict might be avoided and Chinese patients were more likely to be supported by their family members as a consequence of this cultural belief. Additionally, Liu (2012) found in a review of literature in terms of analysis of self-efficacy in older people with diabetes in China that a mutually supportive relationship, particularly from the spouse and adult children to the ill family member, can provide adequate resources and facilitate diabetes management as a result of strong family bonds in Chinese culture. Therefore, Chinese traditional family values contribute to building mutual care and support within Chinese families based on family responsibilities instead of personal characteristics, which is important to having consistent family care in diabetes self-management among Chinese patients.

Family support was also frequently mentioned together with other sources of support such as relatives, friends, neighbours, working colleagues, and other patients, which was described as an opportunity to share information and gain knowledge on type-2 diabetes and its management among Chinese patients. In Wales, four out of 13 Chinese patients also mentioned that they were able to access a language interpreting service from the local Chinese voluntary organisation for when they met health professionals. A female patient from Wales reported that:

> "...I often ask for help from the Chinese centre...The staff at the Chinese centre are very enthusiastic and friendly. More importantly, they are able to speak English as well as Cantonese. So now when I need to see the doctors, she accompanies me as an interpreter. They do give me a lot of helps..."
>
> (WFDP1)

Several Chinese patients also emphasised that support from other patients with type-2 diabetes was important and irreplaceable because sometimes healthy people including spouses did not completely understand patients' feeling and needs. In addition, the positive effect of peer support was also valued. A male Chinese patient from China remarked:

> "I have a working colleague who has diabetes for more than ten years and he was blind due to diabetes after he retired [sighs]. His tragic experience tells me diabetes is a quite severe condition and I must make the effort to manage the condition otherwise I could be blind like him."
>
> (CMDP3)

Therefore, these findings illustrate the influence of a wider network of social support outside the Chinese patient's family, which may be associated with Chinese cultural norms in terms of commiseration. The Chinese belief of commiseration stresses extensive and multiple social care and support is provided when an individual encounters misfortunes or illness (一方有难，八方支援). In addition, Chinese patients are more likely to seek help and support from other patients with type-2 diabetes as a result of this cultural belief because they deem that other patients with type-2 diabetes can understand better the suffering of one another (同病相怜), which contributes to building social support networks. Leung *et al.* (2014a) conducted a qualitative study to investigate the barriers and facilitators to understanding information related to diabetes among first-generation Chinese Americans. They found that peer learning experiences and group learning environments are crucial and lead to success in diabetes management due to the influence of collectivism. In addition, Lee *et al.* (2012) found that Chinese participants preferred learning in a peer group not only because they can gain empirical self-management skills from others, but also due to their willingness to help peers by discussing their personal experiences regarding social support and networks among Chinese Americans.

Besides the influence of the cultural belief of commiseration, building and maintaining a good relationship with health care providers is important for enhancing social support networks. Five Chinese patients including three from China and two from Wales mentioned friendship with health care professionals and a relaxed atmosphere in health consultations as a facilitator to managing their condition. A male patient from China reported:

> "…the nurses in the community health centre are very friendly and skilled. They helped me a lot… we have become friends now [smiles]. They tested blood sugar and blood pressure and then they record them…they were familiar with my blood sugar and my health state…if I have any questions about diabetes, I would like to ask them and they always respond to me seriously and patiently…"
>
> (CMDP3)

Whilst a male patient from Wales also stated:

> "...my GP was very friendly and helpful. I felt relaxed when we talked...he always spoke slowly and he did not let me leave his office until he confirmed I had fully understood his prescription..."
>
> (WMDP2)

These findings illustrate that the collaboration between health care providers and Chinese patients was based on mutual understanding, trust, and respect. As mentioned above, an overloaded health care system in China and language barriers in Wales were disincentives to establishing good relationships between Chinese patients and their health care providers in the two countries. However, this finding demonstrates that health care providers were also reported as creating a relaxed and friendly atmosphere and displayed good skills in caring for patients, a humble and patient attitude of listening to and answering patients' enquiries, and strong willingness to help patients during the health consultation, which contributed to negating the shortfalls in health care systems and language to establishing collaborative relationships between Chinese patients and health care providers.

As mentioned previously, social support including family support could not change the course and development of the patients' type-2 diabetes, but this support from family and other social sources may influence the way the patients might perceive their condition and self-management. The model of salutogenesis (Antonovsky, 1987) contends that resources exist within individuals. What the Chinese patients have seen, felt, heard, or read in the social and cultural context in which they live may contribute to increasing their life and self-management experiences. These experiences may help Chinese patients to see the world as "making sense" cognitively and instrumentally, which may result in an increased sense of coherence (Antonovsky, 1996). It may be thus easier for the Chinese patients with a strong sense of coherence to participate in the management of their type-2 diabetes although further research is required to substantiate this claim.

9.4.2 Philosophy of Chinese traditional medicine

All 26 Chinese patients in the study both in China and Wales were asked about their attitudes towards Chinese traditional medicine in the self-management of type-2 diabetes. 24 out of the 26 Chinese patients expressed relatively negative attitudes towards the effectiveness of Chinese herbal medications on reducing levels of blood glucose. The common criticisms among these Chinese patients included no effect, time consuming to make up the medicine, and no specific way to control blood glucose. Typical comments included:

> "No. I never believed Chinese herbal medications were effective for diabetes..."
>
> (CFDP2)
>
> "...I just used Chinese herbal medications to treat cold or sore throat but never used them for diabetes and high blood pressure. I do not think Chinese herbs have special or better effectiveness to reduce blood sugar than Western medicine so I still preferred using Western medicine to control blood sugar."
>
> (WFDP7)

Although the majority of Chinese patients did not consider Chinese herbal medications as effective methods to control blood glucose level, they believed in the modifying function of Chinese traditional medicine in the relief of symptoms due to type-2 diabetes and in the improvement of health status as indicated by the following extract from a female patient in China:

> "The doctors had prescribed Western tablets along with the tablets of Huan Di Ji Xian (name of a kind of Chinese herbal medication) when I stayed in the Department of Chinese traditional medicine in the hospital. They told me that it was the Western medicine that controlled the blood glucose level, and Chinese herbs had a supporting function. After taking the Chinese herbal medications, my symptoms such as sweating, bitter taste, and thirst were relieved."
>
> (CFDP1)
>
> "I think that Chinese traditional medicine may play some complementary role if blood glucose was not very high. Its main role was to modulate and improve the function of the whole body. For example, I often made some pork or chicken soup with Chinese herbs, which was called Yao Shan (药膳). After eating it, I felt comfortable and energetic."
>
> (WFDP2)

Chinese traditional medicine as a health practice originated in ancient China and has a history of over five thousand years. It includes the use of herbs, acupuncture, massage, and other methods including healthy and nutritious diet and regular exercise aiming to maintain and promote or modify the balance and harmony of the human body, which is regarded as the foundation of health (Kong & Hsieh, 2012). It also focuses on the relationship between health and environmental, social, and geographical factors (Chang & Kemp, 2004; Liu, 2004; Spector, 1996) and stresses the effect of individual behaviours, lifestyles, and harmony with family and other social connections on the management of disease. In terms of diabetes, more than two thousand years ago, ancient Chinese physicians started treating diabetes with mixed herbs. This was recorded as Xiao Ke (消渴) in ancient Chinese medical documents. According to the theories of Chinese traditional medicine, every part of the body was considered to be integrated by Yin (negative energy) and Yang (positive energy), and Qi (gas), and the balance and stability of Yin and Yang and circulation of Qi were crucial for the maintenance of health status. Xiao Ke was characterised by the deficiency of Yin in the kidney and the lungs, and the block of Re Qi (hot gas) in the stomach (Li *et al.*, 2004). Even though there were efforts to explore evidence supporting the theories of Chinese traditional medicine through the examination of western medicine in recent years, the theories of Chinese traditional medicine failed to explain diabetes in terms of physiology, pathophysiology, and aetiology. Therefore, the effectiveness of Chinese traditional medicine on treatment for hyperglycaemia has not been confirmed and accepted clinically.

Nevertheless, there is increasing empirical evidence which supports the modifying and supporting function of Chinese traditional medicine in the relief of symptoms caused by hyperglycaemia and also the improvement of body functions. Furthermore, the supporting function may be more apparent when there is a combination of western medicine and Chinese traditional medicine. Covington (2001) concluded that Chinese traditional medicine did not offer a cure for diabetes, but it was beneficial for optimising the body's ability to function normally which reflected the views of the Chinese patients in this study. In addition, Xie *et al.* (2011) in their review of the literature also confirmed the supporting function of Chinese traditional medicine such as improvement of symptoms among patients with type-2 diabetes. Similarly, Wang and colleagues conducted a qualitative study using focus groups, with 24 Chinese Americans with type-2 diabetes, and found that participants identified a uniform desire to incorporate traditional Chinese medicine or herbal remedies into their diabetes treatment regimen because they showed strong interest in supporting the role of Chinese traditional medicine (Wang *et al.*, 2012).

Chinese traditional medicine not only provided Chinese patients with a complementary method to cope with the challenges of type-2 diabetes, but its ingredients and ideology had been incorporated into Chinese patients' everyday lives especially when they engaged in activities of managing their condition. As a female patient from China said:

> "According to the saying of Chinese traditional medicine, to cure a disease like diabetes, we should rely on 30% medical treatments and on 70% nurturance life, namely I have to look after myself carefully every day in terms of diet, exercise, and living habits."
>
> (CFDP5)

The ideology of Chinese traditional medicine as part of Chinese culture has been influencing Chinese people for thousands of years through its infusion with Chinese people's daily lives. Nurturance life (养生) is a fundamental and well-known concept in Chinese traditional medicine, which stresses the importance of maintaining a harmonious balance in everyday life through a nutritious diet, regular exercise, and good living habits. Therefore, Chinese traditional medicine provides the ideology guiding Chinese people how to manage a condition and how to live healthily.

Moreover, the ideology is consistent with the value of advocated self-management of type-2 diabetes, which confirms that patients with type-2 diabetes can have an impact on the progression and development of their disease by participating in their own care including following a diet plan, increased exercise, self-monitoring of blood glucose, and foot care (American Association of Diabetes Educators, 2009). Therefore, besides being considered as a complementary method to overcome type-2 diabetes, Chinese traditional medicine may impact on self-management of Chinese patients as a cultural and ideological value system. "Culture is not something that irrationally limits science, but is the very basis for value systems on which the effectiveness of science depends." (Napier, *et al.*, 2014, p.1630). It is therefore advisable to incorporate cultural and ideological values of Chinese traditional medicine into promoting self-management of Chinese patients so that Chinese patients and their carers are more likely to accept and to be involved in the practice of self-management.

Overall, when Chinese cultural norms in terms of family harmony, human-heartedness and mutual support, and the philosophy of Chinese traditional medicine, are consistent with the value of self-management, Chinese patients obtained more help and support from the social and cultural context they lived, which is consistent with the concept of manageability in salutogenesis (Antonovsky, 1979). Therefore, Chinese cultural beliefs which are consistent with the value of self-management can be considered as facilitators to increase a sense of coherence and then practice of self-management in Chinese patients and their carers. A discussion with respect to the application of salutogenesis (Antonovsky, 1979) to aid understanding of findings is presented in the next section.

9.5 The application of salutogenesis to aid understanding of self-management in Chinese patients and their carers

I have presented and discussed the data in Chapters six to nine. In these chapters I presented a picture of self-management of type-2 diabetes as reported and experienced by the Chinese patients and their family carers in China and Wales. Salutogenesis (Antonovsky, 1979) was helpful in aiding understanding and explaining the patients' understanding and experiences of living with type-2 diabetes and conducting self-management. In addition, salutogenesis (Antonovsky, 1979) was also useful in identifying areas that can be considered when promoting self-management among Chinese patients, which is discussed in detail in the following section.

One of most important findings in this study is that most Chinese patients and their family carers had limited awareness and knowledge of type-2 diabetes and self-management although they had a summarised understanding of type-2 diabetes as "a kind of long-term and incurable disease". However, the findings demonstrated that Chinese patients were highly motivated to conduct self-management. Moreover, four main sources were accessed by Chinese patients and their carers to obtain information and support regarding type-2 diabetes, including health care providers, the media, lay people, and public health lectures. These four information and support sources can be considered as what Antonovsky (1979) termed generalised resistance resources (GRRs) in salutogenesis. Antonovsky (1979) points out that GRRs can be understood as biological, material and psychosocial factors which make it easier for people to understand and structure their lives. These factors include knowledge and skills, life experience, healthy behaviour, social and financial support, cultural traditions and capital. GRRs identify important resources. A sense of coherence (SOC) explains how GRRs work to help people to cope with challenges. Moreover, the findings also showed how Chinese patients and their carers obtained health information and help from these sources (communicating with health care providers, with family members and other people in social networks, seeking and obtaining health information from TV, radio, books, health booklets, and the Internet, and participating in health lectures), which is consistent with the concepts of manageability and meaningfulness in salutogenesis (Antonovsky, 1979).

Nevertheless, the findings also identified systematic and instrumental barriers, which hindered Chinese patients and their carers from obtaining health information and support from these sources, such as an overstretched health care system, lack of reliable information sources, diabetes education based on a pathogenic model in China, and a lack of Chinese interpretation and translation services and communication with the local community in Wales. These systematic and instrumental barriers may reduce Chinese patients' sense of manageability and impede their sense of coherence. Furthermore, some personal factors such as a low level of income and education were also identified as barriers to obtaining health information and support from these sources. These personal factors may also impact on their sense of manageability and coherence. Although having family members with type-2 diabetes links with comprehensibility in salutogenesis (Antonovsky, 1979) and they shared information on the condition amongst the family, salutogenesis failed to explain why Chinese patients were motivated by this information. Health belief model (Becker, 1974) provides a concept of risk perception which can be used to better understand why Chinese patients were highly motivated to take actions to manage their condition after obtaining information about complications due to type-2 diabetes and its other negative consequences from other family members with type-2 diabetes.

In addition, the findings illustrated that type-2 diabetes had significant consequences on Chinese patients and their family. These consequences can be understood as the interference and interruption to experiences of living with type-2 diabetes. What Chinese patients saw, felt, and perceived in their daily lives contributed to increasing their life experiences of living with diabetes and helped shape their beliefs about type-2 diabetes and self-management. These experiences and beliefs may help Chinese patients to see the world as "making sense" cognitively and instrumentally (Antonovsky, 1996) although they may not be consistent with accepted medical understanding of type-2 diabetes and self-management. I propose that those who reported negative consequences of diabetes which related to an increased family burden, financial stress, family confrontation and conflict, and social isolation and stigma may have an impaired sense of coherence. Nevertheless, salutogenesis fails to provide a full explanation for the findings in terms of social stigma for type-2 diabetes and its impact on self-management. Therefore, Goffman's (1968) theory of social stigma was drawn on to aid in explaining possible reason why Chinese patients were stigmatised and how social stigma of type-2 diabetes impacted on their self-management. In addition, it is also difficult to explain the positive consequences of type-2 diabetes such as increased health attention only using salutogenesis. Thus, cognitive adaptation theory (CAT) (Taylor, 1983), which stresses cognitive adjustment process in response to a threatening event was drawn upon to aid in understanding the positive consequences of type-2 diabetes on Chinese patients.

The data indicated that most Chinese patients reported that they conducted self-management after being diagnosed with type-2 diabetes, including lifestyle modification, self-monitoring of blood glucose, and adherence to medication treatment. The involvement of family carers and support from health care providers and wider social networks in the conduct of self-management contributed to increasing Chinese patients' perception that type-2 diabetes was manageable and self-management was meaningful. Indeed, the findings demonstrate that consistent support from family, health care providers, and wider social networks played an important role in Chinese patients' medical care seeking after perceiving diabetes-related symptoms, seeking and obtaining health information, and the practice of self-management. Antonovsky (1996) contends that a consistent life experience is important to shape a sense of coherence. However, although there is a motivational component of meaningfulness in salutogenesis (Antonovsky, 1979), it fails to completely explain Chinese patients' self-management behaviour. For example, several Chinese patients reported that they exercised regularly because of personal interest and enjoyment. Therefore, self-determination theory (SDT) (Deci & Ryan, 1985), which emphasises the importance of evolved inner resources such as inherent satisfaction for behavioural self-regulation was drawn on to explain this data. Furthermore, although manageability in salutogenesis (Antonovsky, 1979) can explain positive role of family carers and health care providers in Chinese patients' self-management, it cannot provide a good explanation for the findings related to the negative influence of overdependence on family carers and health care providers on Chinese patients' conduct of self-management. Thus, the concept of powerful others in health locus control (Wallston & Wallston, 1982) was incorporated under the aspect of manageability to aid in understanding of this negative influence.

The data also revealed that Chinese traditional cultural beliefs regarding family harmony, heartedness and mutual support, and an ideology of nurturance life had a positive effect on self-management as they corresponded with the values of self-management. The identification of positive effects of Chinese culture on self-management explains why Chinese patients were able to obtain support from their family carers and wider social networks. This finding supports the notion of GRRs.

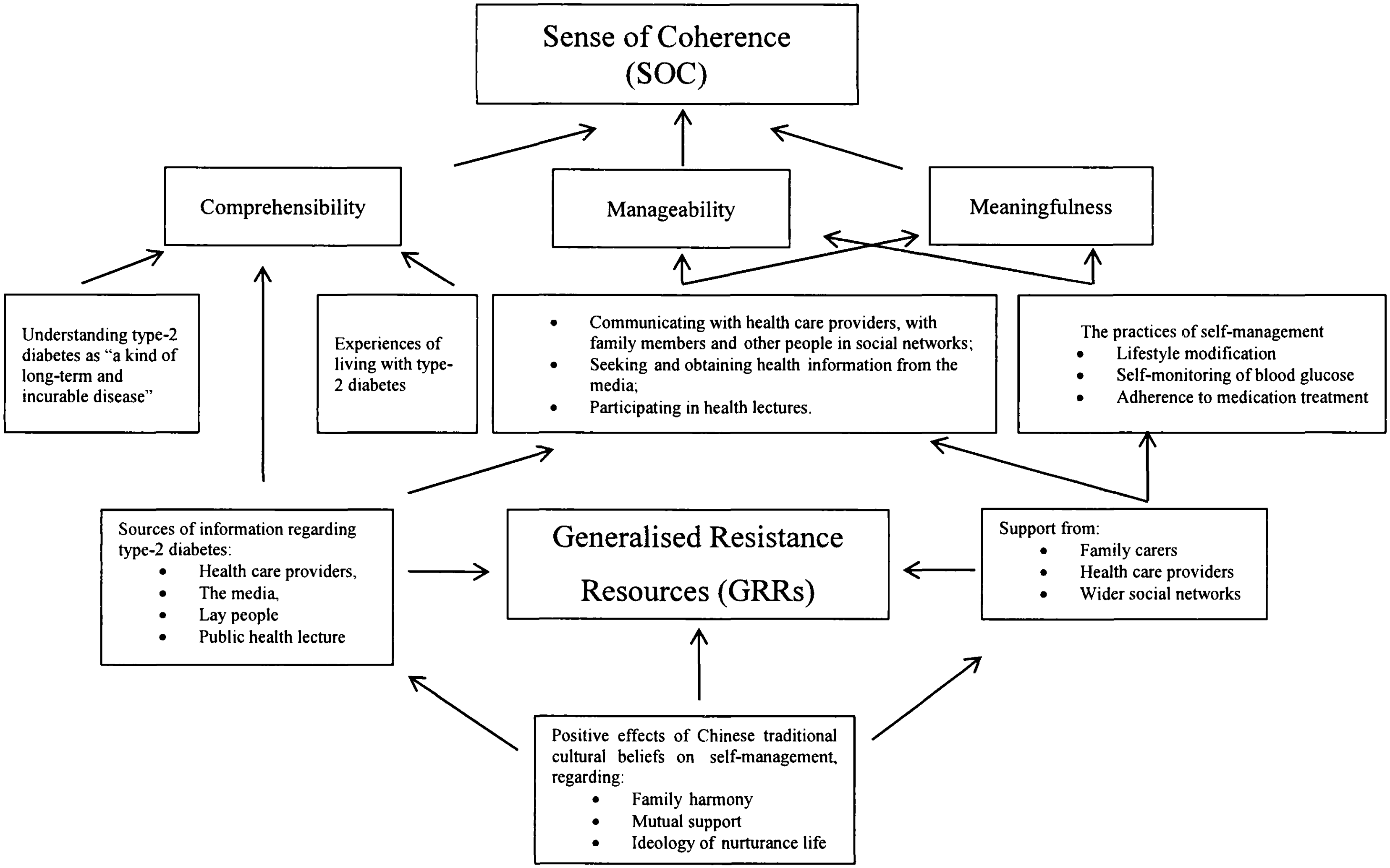
I propose that salutogenesis (Antonovsky, 1979) is as an overarching model to illuminate the findings related to sources of health information and support and to the importance of support from family carers, health care providers, and wider social networks in the self-management of diabetes by Chinese patients. Moreover, salutogenesis (Antonovsky, 1979) also contributes to understanding the positive effect of Chinese cultural beliefs regarding family harmony, heartedness and mutual support, and an ideology of nurturance life on self-management. Nevertheless, as pointed out salutogenesis (Antonovsky, 1979) has limitations when explaining the subjective and social mechanisms to health and self-management and the influence of individual characteristics and personality on self-management. Therefore, other sociological and psychological theories such as the health belief model (Becker, 1974), health locus control (Wallston & Wallston, 1982), cognitive adaptation theory (Taylor, 1983), self-determination theory (Deci & Ryan, 1985), and theory of social stigma (Goffman, 1968) were also drawn on to fully explain the complexity of the findings related to Chinese patients and their careers perceptions and experiences of self-management of type-2 diabetes.

This study has shown that salutogenesis (Antonovsky, 1979) may aid in understanding of Chinese patients' self-management in China and Wales. The findings demonstrate that lack of knowledge of type-2 diabetes and self-management and professional guidance were the main barriers to self-management as reported by Chinese patients both in China and Wales. Moreover, a low level of income and education, cultural barriers, living alone and language barriers in Wales also had a negative impact on self-management in Chinese patients. Although there were ad hoc and voluntary diabetes education sessions in China, they focused mainly on delivering medical knowledge and information regarding type-2 diabetes to patients and their carers. Chinese patients accessed these education sessions and in part they contributed to the sense of comprehensibility (Antonovsky, 1979) but the full potential of these education sessions in aiding self-management was not fulfilled because of the pathogenic approach which was taken. Therefore, within the context of the salutogenic model, I suggest that there is a need for a shift from ad hoc diabetes education sessions in China which adopts a pathogenic approach of focusing mainly on aetiology and medical treatment of type-2 diabetes to a salutogenic approach to diabetes health promotion. The purpose of the salutogenic approach is to provide Chinese patients with wider resistance resources and support and to improve their perception that type-2 diabetes is understandable and manageable and facilitate meaningful self-management so as to control the development of type-2 diabetes. In comparison in Wales, although diabetes education programmes are provided in primary care, a lack of Chinese language interpretation and translation services illustrates poor cultural sensitivity and competence, which restricted Chinese patients to engage with this programme. Therefore, Chinese interpretation and translation services and health information and resources tailored to Chinese culture are needed in diabetes education sessions and health promotion in Wales, which may contribute to providing wider resistance resources and to improving Chinese patients and their carers comprehension and participation in self-management. The application of salutogenesis to aid understanding the findings is summarised in **Figure 2**.

9.6 Summary

In this chapter, I presented and discussed the barriers and facilitators to self-management of type-2 diabetes among Chinese patients and their carers in China and Wales with an emphasis on Chinese cultural beliefs. The beliefs regarding traditional family roles and interpersonal relationships with wider social networks had a negative influence on self-management among Chinese patients and their carers both in China and Wales. This was due to highly traditional roles being difficult to maintain in the context of diabetes. However, cultural beliefs in terms of social and family harmony and human-heartedness and mutual support had a positive effect on self-management through creating a supportive climate in the family and community. Moreover, although there is little evidence to support the effectiveness of Chinese traditional herbs on type-2 diabetes, the philosophy of Chinese traditional medicine is consistent with the value of self-management. Thus, it may contribute to the promotion of self-management in Chinese patients and their carers when it is incorporated into diabetes education and other promotion programmes. In the last section, a discussion which demonstrated how salutogenesis (Antonovsky, 1979) was applied in this study to illuminate the findings is provided. In the next chapter, an evaluation and conclusion is discussed and presented.

Figure 2: The application of salutogenesis to aid understanding of self-management in Chinese patients and their carers



Chapter Ten Evaluation and Conclusion

10.1 Introduction

The purpose of this study was to explore and explain the perspectives and practices of self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales. This understanding and interpretation was established and developed by the utilisation of a qualitative approach employing an ethnographic approach. Through interviewing 40 Chinese patients and their family carers in China and Wales, the perspectives and practices of self-management among Chinese patients and their family carers in both countries were investigated and the social and cultural influences on self-management were identified. In this chapter, the limitations of this study are provided first. Drawing on Hammersley's (1992) criteria of credibility for evaluating qualitative research which has been discussed in Chapter three, the validity of claims made for this study are discussed subsequently. The relevance of this study's main findings are considered for Chinese patients and their family carers, health care providers and diabetes educators, health policy makers, and the research community is presented in the last section. Firstly, the limitations of this study are discussed.

10.2 Limitations of this study

There are many sources of possible quality concerns in ethnographic research, including influence of researcher, lack of rigor, and inadequate analysis of data. I therefore acknowledge that there are limitations of this study although I am confident that a substantial study has been completed as three strategies were used to ensure validity in this study as discussed in Chapter three.

One unavoidable limitation is that the perspectives and practices of self-management of type-2 diabetes among Chinese patients and their family carers were investigated in one capital city of a province of the 31 provinces in China and in South Wales. It is therefore clear that the findings from this study will not present all the perspectives and practices of self-management among Chinese patients throughout China and Wales. In addition, no claim is made that the findings from Chinese patients can be generalised and transferred to other cultures as this study focused only on the influences of Chinese cultural traditions on self-management.

Another potential limitation concerns the way data have been produced. In this study, data collection and transcription was complicated by the additional step of interpreting and translating. Eight interviews were conducted with assistance from a Cantonese interpreter and the remaining 32 interviews were conducted in Mandarin, and then all 40 interviews were translated from Chinese into English by myself, which increased amount of work and the possibility of errors. Words that seem to be equivalent can take on different meanings in different cultures (Patton, 1990). It requires interpreters and translators to translate not only the literal meaning of the words, but also how the words relate conceptually in the context (Gee, 1990). Therefore, interpreters and translators need to provide a technically and conceptually accurate translated communication of a concept spoken by the study's participant (Jandt, 2003). Although I used an experienced and skilled Cantonese interpreter and a qualified English translator, and I and my supervisors were able to use personal experiences and knowledge of Chinese and English and cultures to discuss difficult paragraph to reduce the problem, I acknowledge that the problem may not have been completely eliminated as I, the Cantonese interpreter and the English translator may bring a personal cultural perspective to the interpretation and translation process (Avruch & Black, 1993). The same Cantonese interpreter was used for all the eight Cantonese interviews and was briefed by myself before and after the interviews. Verification of interpretation and translation was also independently conducted on 50 % of the interviews. However it is acknowledged that there may not be a single correct interpretation and translation of data (Bassnet, 1994), and that the translation choices may result in biases. Additionally data analysis and writing-up in English also added an additional level of complexity.

The limitations in terms of sampling are also acknowledged. This study was conducted in the setting of a diabetes outpatient department in a hospital in Kunming, China, which facilitated recruiting participants with various demographic backgrounds and providing good gender representation. In Wales, this study was conducted in the setting of a Chinese charitable organisation in a city in South Wales. The majority of registered members at the organisation were retired older people who lived mainly on benefits or pension and people who were working in catering businesses. Therefore, there was lack of diversity of demographic backgrounds and characteristics among the participants in Wales. Despite this limitation, I deem that the sample of participants was appropriate and adequate because I focused on exploring and understanding of a social reality of self-management among Chinese patients and their family carers. My sampling strategy was used on the basis of consideration of recruiting participants who can provide information and experience of living with type-2 diabetes rather than of obtaining a representative sample of a total population (Mason, 2002). In addition, a further limitation is that it was reported behaviour not observed behaviour regarding self-management practice although I sought to verify this through reviewing participants' own records regarding monitoring of blood glucose and observation of diabetes education sessions. Furthermore, both in China and Wales, informal conversation in the observation of diabetes education sessions with diabetes educators informed the analysis and the subsequent findings of this study.

Overall, although there are several limitations of this study, the aim of this study was achieved successfully and the research questions posed were addressed. An advantage of this study is that this study was conducted in China and Wales, which contributed to exploring understandings of self-management of type-2 diabetes among Chinese patients and their family carers in different social and cultural contexts. Therefore, the findings from this study can provide a starting point for research questions related to self-management of type-2 diabetes in a cross-cultural context. A discussion on the evaluation of the validity of this study is presented in the following section.

10.3 Validity of this study

This study accepted the criterion of validity from Hammersley's (1992) perspective of subtle realism which acknowledges the fallibility of human knowledge. As discussed in Chapter three, validity was perceived as "to what degree can ethnographic accounts legitimately claim to represent an independent social reality" (Hammersley, 1992, p.2). This study focused on exploring and explaining the perspectives and practices of self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales. The conduct of this study was discussed and a discussion about the application of Hammersley's (1992) criteria to the conduct of this study was also provided in Chapter three. In findings and discussion chapters five to nine, the evidential support for the claims made have been provided and discussed. In this section, the main claims made by this study are presented and discussed according to the criteria of credibility from Hammersley (1992). Firstly, the validity of this study is evaluated.

In Chapter three, the strategies adopted to maximise the validity of the study were discussed. These were the use of a reflexive approach, presentation of the conduct of the research which provided an audit trail, and triangulation of data sources and analysis. Firstly, a discussion of the effect of reflexivity on the conduct of the study is discussed.

This study was conducted in China and Wales due to an increased interest about self-management of type-2 diabetes among Chinese patients and their family carers in different social and cultural contexts. Due to my education background of medicine and chronic condition management, I commenced this study with pre-existing knowledge and attitude to type-2 diabetes and self-management. Moreover, I conducted a personal revision of theoretical and professional views on health promotion and disease management before conducting this study, which was helpful for reflexivity when recording data and interpreting findings. Throughout this study, I always tried to maintain a critical stance to the data being generated. Reflection was related not only to process and content of this study, but also to existing and presupposed perspectives. Through investigating the understandings and practices of self-management of type-2 diabetes among Chinese patients, a new understanding in terms of cultural influences on self-management was developed. I used to consider self-management as individual behaviour and paid more attention to the influences of individual internal factors such as cognition and belief on self-management, and tried to understand and explain self-management by the use of the theories of behaviour modification. However, daily self-management happens in a social and cultural context and this social and cultural context can also influence self-management behaviour. The understanding that these external factors can influence on self-management was known and discussed in behaviour modification theories, for example, the health action process approach (Schwarzer, 1992), but they have been considered as of peripheral importance in most behaviour modification models.

Although I have studied type-2 diabetes and its management for many years, it was the first time for me to converse with patients with type-2 diabetes and their family carers face to face about their feelings and experiences of living with type-2 diabetes. I considered that conducting this study was also a learning process in which I was no longer studying type-2 diabetes from textbooks and literatures but from real patients' world including their feelings, distress, experiences, and endeavours to live with their condition. As a Chinese researcher, I and participants have same cultural background so that it was easier for me to approach and understand their world. In addition, as a Chinese student living and studying in Wales for nearly six years, I also can better understand the difficulties Chinese patients in Wales and their family carers have encountered due to living in a different social, cultural, and language context. I did not attempt to conceal and even eliminate my feelings but rather "set about understanding them" (Hammersley & Atkinson, 2007, p.16) and considered them as part of my interpretation and construction. Although I provided my interpretations and understandings in this study, I recognise that different readers may have their own understandings of the findings when they read this study as a result of different sense-making capacities. I accepted Hammersley's (1992) subtle realism which emphasises the fallibility of human knowledge as my epistemological position. Therefore, my reflexive and interpretative process was influenced by subtle realism. I did not seek objectivity of the findings and what is called truth in naïve realism (positivism) but represent a reality by presenting and interpreting the findings. I used reflexive notes to record my views, feelings, and experiences and sought to describe the values and interests that may affect my position and interpretation as a single researcher. These reflexive notes were utilised throughout the conduct of the study, in particular I made reflexive notes when I completed an interview, which was not only helpful for subsequent analysis and interpretation but also significant for conducting subsequent interviews.

Semi-structured interviews provided an opportunity to communicate with the participants face to face. This allowed me to obtain information not only through verbal communication but also by the capture of non-verbal information such as countenances, actions, gesture, and tone. Additionally, face to face interviews enabled rapport and mutual trust to establish between participants and myself. Besides semi-structured interviews, observation of diabetes education sessions provided an opportunity to explore how diabetes education sessions was conducted in China and Wales, what information Chinese patients and their family carers can obtain from these sessions, and how these sessions influenced their understanding regarding type-2 diabetes and self-management. Moreover, observation of diabetes education sessions also provided a chance to communicate with diabetes educators and to explore self-management from their perspectives. As it was difficult for me to observe Chinese patients' self-management in their daily lives and their communication with health care providers, reviewing their records was best method to know how they conducted self-management and how they communicated with health care providers. Therefore, I collected data through flexible and multiple approaches including semi-structured interviews with participants, observation of diabetes education sessions, and reviewing participants' records of self-management. The triangulation of data sources and methods used in this study provided rich and in-depth data and a variety of perspectives to develop interpretative insights into Chinese patients' self-management.

I also sought to comprehend the influences of Chinese culture on self-management of type-2 diabetes. However, being a researcher with Chinese cultural background, I was conscious of the risk of the influences of my cultural perspectives and experiences on this study. On the one hand, I encouraged the participants to explain their feelings and experiences fully. On the other hand I endeavoured to maintain a fieldwork role that sought a balance between ethical considerations and the needs of the research. Additionally, I maintained a reflection on my researcher role and the research aim throughout the conduct of data collection and analysis. A Cantonese interpreter and qualified Cantonese-English translator were used in this study. Reflection on their role in this study was also conducted and regular supervision with my supervisors where issues pertaining to data collection and analysis were discussed also aided in reducing the risk that I may "go native" (Hammersley & Atkinson, 2007).

In Chapter three, the research decisions made were detailed and the rationale was also provided so that readers are able to follow an audit trail that helps support the validity of the findings from this study. In addition, I have provided sufficient information about the different settings and policy contexts of the study without compromising the anonymity of these settings so that readers can judge whether the findings are transferable. In the following section, the main claims made by this study are presented and discussed.

10.4 Claims made by this study

This study described and explicated the perspectives and practices of self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales and provided a significant understanding of the Chinese traditional cultural influences on self-management of type-2 diabetes in two different contexts. Five themes emerged, namely symptom perception and emotional responses to type-2 diabetes, diabetes-related knowledge and information sources, positive and negative consequences of type-2 diabetes, the practices of self-management, and cultural barriers and facilitators of self-management. These themes contributed to establishing the three main claims of this study. These claims included limited awareness and knowledge about type-2 diabetes and self-management, lack of professional guidance in the practice of self-management, and the influences of Chinese traditional culture on self-management. The first main claim is now discussed.

10.4.1 Limited awareness and professional knowledge about type-2 diabetes and self-management

Although self-management of type-2 diabetes has been encouraged and advocated for more than twenty years among patients with type-2 diabetes, self-management is still perceived as a new concept and strategy in the control of type-2 diabetes among Chinese patients and their family carers, which subverts the traditional view that the management of type-2 diabetes relies mainly on health care providers and medication. There are therefore few studies which have explored self-management from the perspectives of Chinese patients and their family carers in China and Wales. This study has therefore made an important contribution to the existing limited body of knowledge regarding self-management among Chinese patients and their family carers and has revealed a lack of awareness and knowledge of type-2 diabetes and self-management. Moreover, salutogensis (Antonovsky, 1979) has been applied for first time to help develop understanding of the influences of lack of information related to type-2 diabetes and self-management on self-management among Chinese patients and their family carers. Salutogensis (Antonovsky, 1979) provides an insightful and novel way of understanding the importance of accessible information related to type-2 diabetes and self-management as a booster of self-management. According to salutogensis (Antonovsky, 1979), the stronger the sense of coherence, including meaningfulness, comprehensibility, and manageability, the more likely an individual is able to select appropriate coping strategies including self-management behaviours. Although previous studies have concluded that a sense of coherence contributes to improving self-management among patients with type-2 diabetes, the concept has not previously been applied to Chinese patients. For example, Sandén-Eriksson (2000) conducted a study to test the relationship between sense of coherence, treatment results and an index of patients' participation in active management and emotional state with 88 patients with type-2 diabetes and concluded that patients with high sense of coherence were capable of managing their diabetes.

In this study, self-management promoting aspects, based on the salutogenesis, are connected to the coping resources. Coping strategies can be seen as trying to manage a situation or avoid the anxiety it causes (Gåfvels & Wändell, 2006), thus, coping resources can also be characterised by problem solving and social support. As this study has demonstrated, the majority of Chinese patients in China and Wales actively sought medical help after perceiving physical symptoms. Moreover, although most Chinese patients and their family carers had little knowledge about type-2 diabetes and its management, they had an accepting and positive attitude to their condition. In addition, family carers also expressed their strong willingness to look after their relatives with type-2 diabetes and help them conduct self-management in their daily lives. An accepting and positive attitude to type-2 diabetes and self-management can be regarded as a coping resource.

Accessible professional information on type-2 diabetes and self-management is an important coping resource, However, this study illustrated that although most Chinese patients and their family carers expected to acquire more diabetes-related information encompassing from aetiology of type-2 diabetes to its everyday management, they reported that they still had insufficient professional knowledge about type 2 diabetes and its management due to limitations of health care system, lack of reliable information sources in China and language barriers in Wales. Most participants actively sought out and acquired information based on their own initiative from different information sources such as public media and social networks including friends, relatives, and working colleagues, but expressed concerns about the credibility of information derived through the media. Therefore, providing Chinese patients and their family carers with reliable information sources in China and with Chinese interpretation and translation services when they seek information on type-2 diabetes in Wales, can increase their coping resources, which contributes to improving their sense of coherence and their practice of self-management.

What are needed are health promotion sessions whereas currently in china there is provision of is diabetes education sessions which adopt a pathogenic approach of focusing mainly on aetiology and medical treatment of diabetes. In addition, these education sessions usually are conducted on a large group basis which is not conducive to meeting the needs of individuals. Although structured and standard diabetes education sessions, namely X-PERT Diabetes on a small group basis (10-15 people) are being conducted across Wales, few Chinese patients and their family carers participated in the programme in which I participated which had a catchment area which included a high proportion of Chinese people because of language barriers and a lack of Chinese interpretation and translation services in the sessions. Therefore, diabetes education sessions which focus not only on medical knowledge of type-2 diabetes but also on information and skills of self-management on a small group basis are necessarily required in China. In Wales, Chinese interpretation and translation services need to be offered in the diabetes education sessions in order to facilitate the participation of Chinese patients and their family.

In summary, the first claim from this study is that there limited awareness of type-2 diabetes and lack of professional knowledge on self-management was identified among the Chinese patients and their family carers interviewed in China and Wales, which was mainly attributed to limitations of health care system and lack of reliable information sources in China and language barriers in Wales. Limited knowledge of type-2 diabetes and self-management as a result of overstretched health care system, lack of reliable information sources, and language barriers can impact on the conduct of self-management. The second claim of lack of professional guidance in the practice of self-management is discussed next.

10.4.2 Lack of professional guidance in the practice of self-management

Self-management of type-2 diabetes is the process by which patients acquire knowledge and develop the skills to manage their condition (Diabetes UK, 2009). Successful self-management of type-2 diabetes requires knowledge about the condition, how it needs to be treated and what needs to be completed, and skills of behaviour changes and problem-solving (Diabetes UK, 2009). Therefore, self-management does not mean that patients are left to do everything on their own, but stresses the collaboration between patients and health care providers in order to obtain professional guidance and support.

According to salutogensis (Antonovsky, 1979), guidance and support from health care providers is an important coping resource in self-management which can augment the sense of coherence. However, as this study has demonstrated, most Chinese patients in China and Wales have been conducting self-management in terms of dietary management, exercise, and changes in living habits in their daily lives with insufficient support from health care providers. This was as a result of an overstretched health care system, lack of reliable and professional information sources and diabetes education programmes in China and language barriers in Wales. Additionally health care providers, mainly doctors and to a lesser extent nurses were regarded as the most trustworthy sources of information and support among Chinese patients and their family carers in this study. Self-management is not only a product of certain traits and skills that the patients bring to the illness situation but also a consequence of the patients' context (Ryan & Sawin, 2009). Therefore, support from health care providers in self-management is supposed to be informational, emotional, and instrumental (Bardach, *et al.*, 2011). Health care providers have expertise of type-2 diabetes and self-management so one of the appropriate roles of health care providers in self-management is to deliver expert knowledge to the patients at a time and in a manner which it is most likely to be accepted and applied. Patient education model deems that there is a linear relationship between appropriate and accurate information delivered by the health care providers, a trusting relationship between patient and health care providers, and effective self-care management decision making by the patients (Loveman *et al.*, 2003). Thus, the roles of health care providers in self-management should not be confined to informational support.

As this study has illuminated, support by health care providers should be not only respectful communication and expressing comfort but also enable the establishment of long-term mutual trust between the patients and health care providers. Moreover, this study also illuminated that the activities of self-management were conducted by Chinese patients in a complex social and cultural context, and that the social and cultural factors deeply influenced the conduct of self-management. Therefore, health care providers especially those in Wales require a good cultural competence in order to provide Chinese patients with help and support which matches to their culture. However, the findings from this study demonstrated that health care providers in Wales had limited cultural competence. For instance, they did not use Chinese interpretation services or

Language Line which is readily accessible to all NHS staff and GPs, they did not provide health promotion leaflets in Chinese languages but instead in English only, and they offered advice regarding changes in diet and lifestyle which did not reflect Chinese cuisine and lifestyles therefore was not relevant to individual patients. Therefore, there is a need to improve cultural competence of health care providers in Wales. In China, health care providers, especially doctors could usefully adopt a salutogenic approach to the care of patients with type-2 diabetes so that health promotion is viewed as a core aspect of the management of patients and not as a voluntary, ad hoc and additional service. Overall, it is therefore important that the strategies for providing professional support need always to remain sufficiently flexible as there are the complexities inherent in the support needs of Chinese patients as a consequence of the nature of type-2 diabetes as a chronic condition, and of the complexity of Chinese society and culture, and of an across-culture context in which Chinese patients in Wales live, which is clarified further in the next section.

10.4.3 The positive and negative influences of Chinese traditional culture on self-management

As this study's findings have demonstrated, the conflicts between self-management requirements and traditional cultural norms in terms of family roles and social exchange greatly impacted on their self-management. Nevertheless, the comparability of Chinese cultural beliefs in terms of family harmony, mutual support, and nurturance life with the concept of self-management may make it easier for Chinese patients to adopt the practice of self-management. Generally, these positive and negative influences of the cultural norms in the two countries were similar because of similarities of culture. However, compared with Chinese patients in China, Chinese patients in Wales encountered more difficulties in relation to cultural challenges when they conducted self-management. Despite living in Wales, most Chinese patients and their family carers in this study demonstrated low acculturation, such as limited English proficiency and lack of communication with the local community. In addition, their family structure and relationship had changed due to separation of family members after immigrating to Wales. Therefore, cultural challenges including language barriers and lack of family support were main and distinct barriers to self-management among Chinese patients in Wales. It is therefore significant to provide Chinese patients and their family carers in Wales with more support and help, which are tailored to meet their cultural needs during self-management of type-2 diabetes. Moreover, the findings also showed that there was social stigma and discrimination in having type-2 diabetes in Chinese community, which impacted on Chinese patients' self-management through limiting their social activities and reducing social support. Therefore, building a supportive social environment through improving public awareness and knowledge of type-2 diabetes in Chinese community can be used as a strategy to help Chinese patients to overcome cultural challenges in self-management and social stigma and discriminations.

Additionally as the findings have illustrated, the interaction between self-management and Chinese culture was an embodied process which did not lend itself to uniformity or predictability. Furthermore, Chinese culture was one aspect of self-management, which co-exists alongside other complex dimensions, such as socioeconomics, family support, and the level of knowledge of type-2 diabetes, and Chinese culture norms influenced how these factors interplay in multiple ways to inform self-management. Culture is a subjective and dynamic concept; sometimes it is overtly expressed and sometimes is not openly defined, thus the influences of Chinese culture on Chinese patients and their self-management are not homogenous but diverse, and it is impossible to apply specific beliefs and behaviours to all Chinese patients. Therefore, a culturally competent diabetes care and support in self-management is required as a key feature of cultural competent care is meeting the individual needs of patients and their carers. In the following section, the relevance of the findings is discussed.

10.5 Relevance of the findings

Hammersley (1992) suggests that two criteria in relation to the relevance of the findings of ethnographic study should be satisfied in order to confirm their value, namely the importance of the topic and that the findings contribution to existing knowledge. In this section, the relevance and contribution of the findings to the following audiences are considered health care providers and diabetes educators, health policy makers, and the research community.

10.5.1 Relevance and recommendation for health care providers and diabetes educators

Information and support provided by health care providers and diabetes educators, and a collaborative relationship between patients, health care providers and diabetes educators plays an important role in self-management of type-2 diabetes. However, lack of information and guidance from health care providers and diabetes educators has been identified as one of main barriers to self-management of type-2 diabetes in Chinese patients and their family carers in China and Wales as discussed in Chapters six. This study's findings have identified and reported the difficulties and challenges which Chinese patients and their family carers encountered in the course of self-management which contributes knowledge to inform future professional care and support of these patients and carers during health consultations, diabetes education, and professional information delivery. Additionally this study was conducted among Chinese patients and their family carers in China and Wales, thus it will contribute to the development of a distinct understanding of self-management of type-2 diabetes in different social and cultural contexts. A key finding from this study related to how Chinese culture and living in different social and cultural contexts influenced Chinese patients' self-management practices. The identification of cultural influences on self-management can aid development of Chinese patients' self-management by providing culturally competent support and education rather than merely providing expert knowledge and skills. As health care providers and specifically doctors were perceived by Chinese patients as the most trusted source of information and lack professional information and support was a key barrier to self-management, health care providers and diabetes educators are recommended to

- Provide an extended health consultation where patients may have sufficient time to communicate with health care providers and so contribute to obtaining more professional information and guidance and enhance the development of rapport with the health care provider;
- Provide a culturally appropriate, evidence based, and regular or continuing diabetes education programme, which may improve Chinese patients' and their carers' knowledge of type-2 diabetes and skills for self-management. In addition, community-level diabetes education is also needed not only to raise public awareness of type-2 diabetes but also to overcome cultural and social challenges in self-management especially with respect to social stigma of diabetes which is still evident amongst the Chinese community;
- Explore a salutogenic approach as opposed to a pathogenic approach to diabetes care and education so that health promotion is viewed as a core aspect of diabetes care and education and the importance of identifying and building upon

the skills and resources of the patients and their carers to build up patients' sense of coherence.

- Encourage family carer involvement in health consultations and diabetes education, which may facilitate better understanding of type-2 diabetes and self-management, and enhance family support for Chinese patient with type-2 diabetes;

The following recommendations are specific for health care providers and diabetes educators in Wales:

- Health care providers and diabetes educators need to understand Chinese patients' cultural beliefs about health and their condition within a cultural context which may necessitate training to ensure cultural competency;
- A range of outreach programmes or support groups provided by statutory and voluntary organisations are needed for Chinese patients especially for those Chinese patients who live without family carers to help them obtain more support and address their social isolation;
- Health care providers and diabetes educators need to fully understand that language barriers may affect Chinese patients' self-management by limiting the accessibility of diabetes education sessions and information and by creating an ineffective relationship between patient-provider;
- Professional Chinese interpreter service and full implementation of language services including the use of telephone interpreting services such as Language Line in various health care settings and diabetes education programmes are needed.

10.5.2 Relevance and recommendation for health policy makers

The insights into barriers to self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales provides understanding of the value of support networks that enable Chinese patients and their family carers to carry out self-management in their daily lives more confidently and effectively. The findings showed that most of the Chinese patients and their carers interviewed were motivated to practice self-management. The findings from this study are consistent with the proposal of Diabetes UK (2009) in terms of improving supported self-management for people with diabetes through enabling them to access six primary services including personalised care planning, high quality tailored information, structured diabetes education, health care providers and trained specialist advice, emotional and psychological support, and social support. Additionally financial hardship has been identified as a barrier to self-management among Chinese patients and their families in China, especially among those patients with a lower level of income. Although Chinese patients in Wales had less financial burden for self-management as a result of a provision of free health care by the NHS, the costs of maintaining a healthy lifestyle and personal care impeded their self-management. Therefore, financial support that compensates patients' costs of self-management would be a necessary addition to health care system in China and Wales if governments in both countries are committed to enhancing self- management of diabetes

Furthermore, this study identified how Chinese cultural beliefs and living in different social and cultural context impacted Chinese patients' self-management of type-2 diabetes. An area that was identified was the importance of culturally competent care and support provided by health care providers and diabetes education in Chinese patients' self-management. In order to improve support in self-management for Chinese patients and their family carers in China and Wales and health care providers' cultural competence, recommendations for health care policy makers both in China and Wales are that:

- Shifting the focus of diabetes care from the hospital setting to primary care to provide more services locally to reduce the costs for patients in travelling to hospitals and to shift the focus from medical treatment to health promotion and education to support self- management;
- Develop integrated social support networks that enable Chinese people with type-2 diabetes especially those who live without family carers to have access to multiple sources of social support including other patients with type-2 diabetes, social workers, and voluntary and community organisations;
- Strict surveillance of health and diabetes information and medication advertisements especially disseminated through the media is required in order to protect Chinese patients from false and misleading information on type-2 diabetes and self-management;
- Improving financial support through increasing compensation of costs of self-management by social medical insurance system and NHS in order to enable

each Chinese people with type-2 diabetes irrespective of their income level to afford self-management including maintaining healthy lifestyles and personal care;

- Improving health care providers' and diabetes educators' awareness of the influence of Chinese culture on self-management through culture-specific training sessions

10.5.3 Relevance and recommendation for the research community

This study explored and explained perspectives and practices of self-management from Chinese patients and their family carers in China and Wales, However, the findings demonstrated that health care providers and wider social networks also played important role in Chinese patients' self-management. Therefore, further research is needed to explore the perspectives of health care providers, diabetes educators, social workers, and health care policy makers regarding supporting self-management of diabetes with Chinese patients and their family carers. Another important claim of this study related to the influences of Chinese culture on self-management asserted the cultural sensitivity of self-management. This has relevance for research into the influences of culture on health promotion, behaviour modification, and disease management. Nevertheless, evidence from further research is still needed to verify the claims of this study and to support their applicability to other cultural contexts. Therefore, recommendations for the research community are that:

- Further research into the support for self-management of Chinese patients with type-2 diabetes in China and Wales from the perspectives of health care providers, diabetes educators, social workers, and health care policy makers is conducted;
- Further research into factors influencing self-management in other minority ethnic communities especially those with increased risk of type-2 diabetes such as South Asians in Wales is conducted;
- Further research into salutogenesis and evaluation of its application and relevance to other minority ethnic groups and cultural contexts is required.

10.6 Summary

There is increasing prevalence of type-2 diabetes is in both China and Wales and indeed globally. As currently type-2 diabetes remains a controllable but incurable condition understanding how patients can be aided to conduct self-management of their condition is of relevance not only to individuals with type-2 diabetes in terms of improved patient outcomes but also has benefits for their family and the health care system. Nevertheless, there are few studies regarding Chinese patients' self-management in China and Wales. The findings from this study have contributed to the limited body of knowledge related to Chinese patients' self-management of type-2 diabetes in China and Wales. The insights of Chinese patients' self-management of type-2 diabetes was constructed on the basis of the contributions from the participants who provided their perspectives and experiences of self-management of type-2 diabetes, and through observation of diabetes education sessions and reviewing the participants' records of self-management. The use of ethnography provided an appropriate research method to achieve the aim of this study, namely exploring the perspectives and practices of self-management of type-2 diabetes among Chinese patients and their family carers in China and Wales.

Limited awareness and knowledge of type-2 diabetes and self-management and lack of professional guidance were identified as main barriers to self-management among Chinese patients in both countries. In particularly, the findings have highlighted the prominent influence of Chinese cultural beliefs on self-management of type-2 diabetes among Chinese patients in China and Wales. Salutogenesis (Antonovsky, 1979) applied to aid understanding these findings. In addition, the findings demonstrated that support from family, social networks, and health care providers played an important role for Chinese patients from their medical care seeking after perceiving symptoms and diagnosis of type-2 diabetes to the practice of self-management in daily lives. These supports improved their understanding of type-2 diabetes and self-management and helped them perceived that self-management was meaningful and coping resources were existent, which is consistent with the concepts of comprehensibility, manageability, and meaningfulness in salutogenesis (Antonovsky, 1979) and then contributes to improving their sense of coherence and self-management. In addition, when Chinese cultural norms in terms of family harmony, mutual support and nurturance life were consistent with requirements of self-management, patients obtained more support and help from social and cultural setting in which they lived, which contributed improving their sense of coherence. In contrast, when Chinese cultural beliefs regarding traditional family role and interpersonal relationships were inconsistent with requirements of self-management, patients encountered cultural challenges for self-management. Therefore, health promotion based on salutogenic approach (Antonovsky, 1979) need to be as a core aspect to promote self-management among Chinese patients and their carers in order to help them to cope with more challenges.

Overall, this study has described and explained Chinese patients' self-management of type-2 diabetes in China and Wales. The study's aim was achieved and main findings addressed all the research questions. Yet, this study is a good starting point to understanding Chinese patients' self-management of type-2 diabetes as Chinese patients are living in a social and cultural context which is dynamic and their needs also are changeable.

Appendix 1 Ethical approval granted by the Committee in the College of Human and Health Sciences in Swansea University

Swansea University
Prifysgol Abertawe

September 28, 2012

Mr Peng Zhao
C-2-702 Tai Yang Xing Cheng,
No.231 Longquan Road,
Kunming,
Yunnan Province,
China (P.R.) 650021

中国云南省昆明市・泉路231号泰阳欣城C-2-702・瓦（收）650021

Dear Mr. Zhao,

We would like to confirm that your research application entitled : **"An investigation of type-2 diabetes self-management amongst Chinese type-2 diabetics in Wales and China"** was heard at the Research Ethics Committee meeting on September 3, 2012 and was given approval on September 11 , 2012.

Regards,

Dr. Jeanette Hewitt,
<u>CHHS REC</u>

Pennaeth y Coleg • Coleg y Gwyddorau Dynol ac Iechyd • Professor Melanie Jasper • Head of College • College of Human and Health Sciences
Parc Singleton, Abertawe, SA2 8PP, Cymru, DU • Singleton Park, Swansea, SA2 8PP, Wales, UK
Tel/Ffôn: +44 (0)1792 295789 Fax/Ffacs: +44 (0)1792 295487 Web/Gwefan: www.swansea.ac.uk/humanandhealthsciences

Appendix 2 Participant Invitation Letter

(English)

Dear: Sir or Madam

Research study an investigation of type-2 diabetes and self-management amongst Chinese patients and their family carers in Wales and China.

I am a currently a PhD student from China studying at XXX University and am conducting a PhD study which aims to investigate the views of Chinese patients with type-2 diabetes and their family members living in South Wales and China regarding how they manage their condition on their own (self-management) or assist their relative to manage their diabetes. As there has been very little research into this topic of self-management within Wales and China, this study seeks to fill that gap and will use face-to-face individual interviews to gather information.

You are being invited to participate because you are either a Chinese person living in urban and rural areas within a 30 mile radius of a large city in South Wales, or Kunming city in Yunnan province in China who has type-2 diabetes for at least six months and is aged over 40 years or a family member aged over 18 years of a Chinese patient with type-2 diabetes and live within a 30 mile radius of a large city in South Wales, or Kunming city in Yunnan province in China. The study aims to explore understanding, experiences, and practices of Chinese patients diabetes regarding type-2 diabetes and self-management. In addition, to gather the views of family members regarding their role in their relatives' diabetes management. Further information on the study is provided in the Participant Information Sheet enclosed, which is yours to keep. Please use the Reply Slip to indicate whether or not you are interested in participating by ticking and initialing the relevant box and signing and dating the section at the bottom of the form. I would appreciate it if you would return your completed Reply Slip to me by post using the stamped addressed envelope provided.

If you would like to discuss this invitation further please do not hesitate to contact me XXX in Wales, or XXX in China. You are also welcome to email me at XXX.

Kind Regards

Peng Zhao

REPLY SLIP

Title of research study:

An investigation of type-2 diabetes and self-management amongst Chinese patients and their family carers in Wales and China.

Name of researcher: Peng Zhao

Please read each statement, and if you agree with the statement, please tick and initial the box. If you agree to participate in the study, at the bottom of the form please also write your name in block capitals, the date and sign the form. Please also provide your address and telephone number for further contact and indicate which times would be best for me to contact you.

Please tick and initial each box that applies:

1. I confirm that I have been provided with a **Participant Information Sheet**, dated ___________. I have had the opportunity to read the sheet and consider the information. and ask questions. ☐
2. I have been informed by health professionals from the diabetes outpatient department that failure to participate in this study will **NOT** affect my treatment in future at this department. ☐
3. I agree to be contacted with regards to participating in this study ☐
4. I do not wish to take part in this study. ☐
5. I am a patient with type-2 diabetes ☐
6. I am a family carer of a patient with type-2 diabetes ☐

Name of participant: Date: Signature:

Contact address: Tel.:

Best time to contact:

Morning (9-12noon)
Afternoons (12-6pm)
Evening (6-8pm)
Other time: ____________________

(简体中文版 Simplified Chinese）

参与者邀请函

尊敬的先生或女士：

您好！

我是英国斯旺西大学健康和人类科学学院的一名在读博士研究生，我目前正在开展一项博士研究。我研究的题目是中国大陆和英国威尔士地区中国裔二型糖尿病患者自我管理情况的调查。此项研究的主要目的是为了探索中国2型糖尿病患者对自身疾病的理解和认识以及他们如何管理自身的疾病，他们正在管理自身疾病时遇到的困难和障碍，他们又是如何解决这些困难和障碍的。此外，研究中国裔2型糖尿病患者和他们的家属之间的关系，以及这种关系对他们疾病管理的影响也是我研究的主要方向。目前在英国威尔士和中国这个研究课题是一个比较新颖的课题，这个研究也是具有开创性的。在这个研究中，面对面的半结构式访谈将作为研究数据采集的主要方式。考虑到您作为一名2型糖尿病患者或糖尿病患者家属和该项研究的目的，我真诚地邀请您参加到这项研究中来。

关于这项研究的进一步信息将在参与者告知书中提供。请在下列回复栏中相应的表格处打钩以表示您是否愿意参加这项研究，并签署您的姓名和日期。 如果您能将填写好的回复条邮寄给我，我将万分感谢。邮寄地址已经写在信封上并且已经贴妥邮票，直接寄送即可。 如果您还有什么疑问或是想和我进一步讨论这个研究， 请和我联系。威尔士地区请拨打XXX，中国地区请拨打XXX。电子邮件：XXX

此致

赵芃

2012年xx月xx日

附：回复页：

研究题目：中国大陆和英国威尔士地区中国 2 型糖尿病患者自我管理情况的调查

研究者姓名：赵芃

请阅读以下每一个选项，并在你同意的选项后的方框内打钩。如果您同意参加这个研究，请在回复页的下方签署您的姓名和日期。此外为了方便联系，请您提供您的电话号码和通讯地址。并且告知我联系您的最佳时间。

1. 我确定我已于<u> 日期 </u>收到了参与者告知书，并且认真阅读了该告知书中的信息，我的疑问也已获得了满意的解释。 □

2.我已经被 XXX 医院糖尿病中心的医务人员告知拒绝参加这项研究对我今后在该中心的治疗**不会**产生任何不良影响。 □

3. 我**同意**参加这项研究。 □

4. 我**不同意**参加这项研究。 □

5. 我是一名 2 型糖尿病患者。 □

6. 我是一名 2 型糖尿病患者家属。 □

参与者姓名：　　日期：　　签字：

联系地址：　　电话:

方便联系时间:
早上: (9:00-12:00)
下午: (12:00-18:00)
傍晚: (18:00-20:00)
其他时间: ____________________

(繁體中文版 Traditional Chinese）

參與者邀請函

尊敬的先生或女士:

你好！

我是英國斯旺西大學健康和人類科學學院的一名在讀博士研究生，我目前正在開展一項博士研究。我研究的題目是中國大陸和英國威爾士地區中國裔 2 型糖尿病患者自我管理情況的調查。此項研究的主要目的是為了探索中國裔二型糖尿病患者對自身疾病的理解和認識以及他們如何管理自身的疾病，他們正在管理自身疾病時遇到的困難和障礙，他們又是如何解決這些困難和障礙的。此外，研究中國裔二型糖尿病患者和他們的家屬之間的關係，以及這種關係對他們疾病管理的影響也是我研究的主要方向。目前在英國威爾士和中國這個研究課題是一個比較新穎的課題，這個研究也是具有開創性的。在這個研究中，面對面的半結構式訪談將作為研究數據採集的主要方式。考慮到你做為一名 2 型糖尿病患者或糖尿病患者家屬和該項研究的目的，我真誠地邀請你參加到這項研究中來。

關於這項研究的進一步資訊將在參與者告知書中提供。 請在下列回復欄中相應的表格中打鉤以表示你是否願意參加這項研究，並簽署你的姓名和日期。如果你能將填寫好的回復條郵寄給我，我將萬分感謝。郵寄地址已經寫在信封上並且已經貼妥郵票，直接寄送即可。如果你還有什麼疑問或是想和我進一步討論這個研究，請和我聯繫。威爾士地區請撥打 XXX, 中國地區請撥打 XXX. 電子郵件：XXX。

此致

趙芃

2012年xx月xx日

附：回復頁:

研究題目：中国大陆和英国威尔士地区中国2型糖尿病患者自我管理情况调查

研究者姓名：趙芃

請閱讀以下每一個選項，並在你同意的選項後的方框內打鉤。如果你同意參加這個研究，請在回復頁的下方簽署你的姓名和日期。此外為了方便聯繫，請你提供你的電話號碼和通訊地址。並且告知我聯繫您的最佳時間。

1. 我確定我已於 日期 收到了參與者告知書，
並且認真閱讀了該告知書中的資訊， □
我的疑問也獲得了滿意的解釋。

2.我已經被 XXX 醫院糖尿病中心的醫務人員告知。 □
拒絕參加這項研究對我今後在該中心的治療不
會產生任何不良影響。

3. 我**同意**參加這項研究。 □

4. 我**不同意**參加這項研究。 □

5. 我是一名二型糖尿病患者。 □

6. 我是一名二型糖尿病患者家屬。 □

參與者姓名: 日期: 簽字:

聯繫位址: 電 話:

最佳聯繫時間: 早上: (9:00-12:00)

下午: (12:00-18:00)

傍晚: (18:00-20:00)

其他時間: ____________________

Appendix 3 Participant Information Sheet

(English)

Study title:

An investigation of type-2 diabetes and self-management amongst Chinese patients and their family carers in Wales and China.

Invitation:

You are being invited to take part in a research study that I am conducting as part of my PhD studies at XXX University. Before you decide whether you wish to take part, it is important that you understand why the research is being undertaken and what it would involve for you. Please take time to read the following information carefully and contact me if anything is not clear or you require clarification. This information sheet is yours to keep for future reference.

What is the purpose of the study?

In 2011, approximately 346 million people have diabetes all over the world (WHO, 2011). The number of people with type-2 diabetes is also rising at a dramatic rate in the UK, as well as in China. There is no doubt that type-2 diabetes has been a pressing health challenge in the two countries. Despite the recognition of the significant role of managing diabetes by patients themselves in their daily life at home (self-management) in improving control of blood sugar levels and in preventing complications, few studies were identified which have explored the views of Chinese patients living in Wales and mainland China regarding how they manage their condition by themselves in daily life at home. This study seeks to gain a greater understanding regarding type-2 diabetes and self-management in Chinese patients living in South Wales and Yunnan province of China. It is hoped that the findings will inform the development of policies and guidance for type-2 diabetes prevention and management, improve the knowledge and understanding of diabetes self-management practice and may influence future diabetes education and research.

Why is the study good for you?

You are being invited as you are either someone who has type-2 diabetes or you are a relative of someone with diabetes. The study aims to investigate type-2 diabetes and self-management by listening to the views of Chinese patients and their family members.

It is a good opportunity for you to share your views and experiences of managing the condition by yourself or assisting a relative to manage their diabetes.

Do I have to take part?

No, it is up to you to decide whether or not to participate. If you feel that you do not wish to take part or even if having started you do not wish to continue, you do not have to give a reason. I would be grateful if, after due consideration, you would let me know whether or not you wish to participate by completing the enclosed Reply Slip and returning it to me in the stamped addressed envelope provided by post. If you decide not to take part, you will not be contacted further in this respect.

What will happen if I decide to take part?

If you agree to take part in this study, you will be invited to talk about your views in an individual interview which will last approximately 45 minutes to an hour. During the interview you will be asked about your views and experiences of self-management. The interview will be conducted in your preferred language (English, Cantonese, or Mandarin). You will be interviewed at the a local venue which is mutually convenient. A Cantonese-Mandarin interpreter will join our interview if you are a Cantonese speaker. With your consent the interviews will be audio recorded and notes will be taken. Your views and opinions are valued and will be treated with respect.

Confidentiality

Participants' confidentiality is paramount, and will be safeguarded during and after the study:

- A commitment to ensure confidentiality of participants and data will be signed by the Cantonese interpreter before the performance of interview.
- The Cantonese interpreter will not be allowed to keep participants' information, interview record, and notes taken by the interpreter during the interviews will be given to the researcher after the interviews.
- Everything discussed in the interviews will be treated in the strictest confidence, and will not be repeated outside the setting
- All data collected will be stored in a locked filing cabinet, and on the researcher's password protected computer
- All data will be anonymised, and will only be accessible to the researcher and his academic supervisors.

What will happen to the results of the research study?

The study will be completed in September 2013 and will be submitted in the form of a thesis to XXX University. It is also possible that the research findings will be submitted for publication and/or conference presentation. Participants are invited to request a copy of the findings.

Expenses and payment

Unfortunately, I am unable to reimburse participants for their time and expenses incurred from taking part in this study. Although the study may not directly benefit you, it is hoped that the findings will contribute to improving the knowledge and understanding of type-2 diabetes self-management, which will inform the future planning of services and the education of health practitioners.

Has anyone reviewed the study?

This study was reviewed by the College of Human and Health Sciences research and Ethics Committee and the administration department of XXX hospital.

Who can I contact if I have further questions?

You can contact me on my mobile telephone number XXX in Wales, and XXX in China, or email: XXX. If you would like to discuss this study or your participation in it with an independent person you may contact my academic supervisors: XXX

Thank you for taking the time to consider participating in this study.

(简体中文版 Simplified Chinese)

参与者告知书

研究题目：中国大陆和英国威尔士地区中国 2 型糖尿病患者自我管理情况调查

邀请：我是英国斯旺西大学的一名在读博士研究生我衷心地邀请你参加我正在开展的一个关于中国人二型糖尿病的自我管理调查的研究。在你决定是否参与这个研究之前，充分地了解这个研究的目的以及你为什么要参与到这个研究中会对你做出最后决定很有帮助。请你仔细阅读以下的信息，如有任何疑问你可以及时和我联系。

这个研究的目的是什么？2011 年全世界的糖尿病人数已经达到了 3 亿 4 千万。每年英国和中国的糖尿病人数也在以一个惊人地速度在增长。毫无疑问，糖尿病已经成为这两个国家必须正视的健康挑战。尽管糖尿病自我管理在血糖控制和并发症预防方面的重要作用已被证实，但是关于中国大陆和英国威尔士地区中国裔二型糖尿病患者自我管理情况的研究仍旧寥寥无几。此项研究的主要目的是为了探索中国裔二型糖尿病患者对自身疾病的理解和认识以及他们如何管理自身的疾病，当他们正在管理自身疾病时遇到困难和障碍时，他们又是如何解决这些困难和障碍的。这项研究的结果将有助于糖尿病管理相关政策和指导意见的制定以及提高病人和其家属对糖尿病自我管理的认识和理解，对未来糖尿病教育和研究也具有一定的帮助作用。

为什么说这个研究对你很有帮助？作为一名糖尿病患者或是糖尿病患者的家属，你已经被选为研究的参与者。这个研究主要侧重于研究中国大陆和英国威尔士地区中国裔二型糖尿病患者自我管理的情况。对于你来说参加这个研究是一个非常的好机会，你可以充分地表达你对糖尿病自我管理的观点和认识，你也可以将自己在糖尿病自我管理方面的有益经验和别人一起分享。

我必须要参加这个研究吗？是否参与这项研究完全由你自己决定。如果你不想参加这项研究或是想中途退出都是完全允许的并且你可以不用为此做出任何解释。如果你能完成回复页并将你的想法通过邮寄的方式告诉我，我将非常感谢。如果你决定不参加这项研究，你将不再会被打扰。

如果我决定参加下一步是什么？面对面的半结构式采访是这个研究主要的数据采集方式。如果你同意参加这项研究，你将被邀请参加一个个人采访，这个采访将持续 45 分钟到一个小时。 采访将按照一个事先准备好的采访指导进行。您可以选择使用您喜欢的语言完成采访（英语、粤语或者汉语普通话）。访谈将安排

在你觉的合适的时间和地方进行，而且如果你是一位说粤语者，一位粤语翻译者将参加我们的采访。 在你的允许下，采访将被全程录音并且在采访过程中可能会做一些笔记。在整个采访过程中你的意见和观点将被充分地尊重。

机密性： 保护受访者的机密性无论在采访前还是采访中都是一个极为重要的问题。我将采取以下措施来确保整个采访过程和研究数据的机密性：

1. 参加采访的粤语翻译者将与研究者签署一份保密协定，确保参与者信息和采访数据不被外泄；

2. 粤语翻译者不允许保留任何参与者信息和与采访相关的材料。采访结束后，翻译笔记也将交予研究者；

3. 在采访过程中讨论的任何问题都将严格保密，并且在采访以外的环境中不得再次谈论；

4. 所有采集到的数据都将被储存在一个带锁的文件柜内，并且在研究者受密码保护的电脑中备份；

5. 所有研究数据都是匿名的，只有研究者和其导师们有权参阅。

研究结果将作何用处？这项研究将于 2013 年 9 月份完成，研究结果以博士论文的形式提交英国斯旺西大学审阅。该项研究的数据也有可能被用来撰写学术论文发表在学术刊物上。如果参与者需要，研究结果也可以被提供。

研究花费和补偿：我无法用金钱的形式来弥补你由于参加这项研究而造成的时间和金钱上的损失。虽然这项研究不会为你带来任何直接的利益， 但是这项研究的研究结果有可能帮助很多像你一样的糖尿病患者。从这个意义上讲，你的参与是非常有意义的。

其他人会审阅这个研究吗？这个研究将被英国斯旺西大学健康和人类科学学院伦理委员会和昆明医学院第一附属医院医院管理部审阅。

如果我有问题需要联系谁？你可以随时和我联系，威尔士地区参与者请拨打电话 XXX，中国地区参与者请拨打 XXX，邮箱地址：XXX 你也可以和我的导师联系， 联系方式如下：XXX.

谢谢你的参与和阅读！

(繁體中文版 Traditional Chinese)

參與者告知書

研究題目：中国大陆和英国威尔士地区中国 2 型糖尿病患者自我管理情况调查

邀請：我是英國斯旺西大學的一名在讀博士研究生我衷心地邀請你參加我正在開展的一個關於中國人二型糖尿病的自我管理調查的研究。在你決定是否參與這個研究之前，充分地瞭解這個研究的目的以及你為什麼要參與到這個研究中會對你做出最後決定很有幫助。請你仔細閱讀以下的資訊，如有任何疑問你可以及時和我聯繫。

這個研究的目的是什麼？2011 年全世界的糖尿病人數已經達到了 3 億 4 千萬。每年英國和中國的糖尿病人數也在以一個驚人地速度在增長。毫無疑問，糖尿病已經成為這兩個國家必須正視的健康挑戰。儘管糖尿病自我管理在血糖控制和併發症預防方面的重要作用已被證實，但是關於中国大陆和英国威尔士地区中国裔二型糖尿病患者自我管理情况的研究仍舊寥寥無幾。此项研究的主要目的是为了探索中国裔二型糖尿病患者对自身疾病的理解和认识以及他们如何管理自身的疾病，當他们正在管理自身疾病时遇到困难和障碍時，他们又是如何解决这些困难和障碍的。這項研究的結果將有助於糖尿病管理相關政策和指導意見的制定以及提高病人和其家屬對糖尿病自我管理的認識和理解，對未來糖尿病教育也具有一定的幫助作用。

為什麼說這個研究對你很有幫助？作為一名糖尿病患者或是糖尿病患者的家屬，你已近被選為研究的參與者。這個研究主要側重於研究中国大陆和英国威尔士地区中国裔二型糖尿病患者自我管理的情况。對於你來說參加這個研究是一個非常的好機會，你可以充分地表達你對糖尿病自我管理的觀點和認識，你也可以將自己在糖尿病自我管理方面的有益經驗和別人一起分享。

我必須要參加這個研究嗎？是否參與這項研究完全由你自己決定。如果你不想參加這項研究或是想中途退出都是完全允許的並且你可以不用為此作出任何解釋。如果你能完成回復頁並將你的想法通過郵寄的方式告訴我，我將非常感謝。如果你決定不參加這項研究，你將不再會被打擾。

如果我決定參加下一步是什麼？面對面的半結構式採訪是這個研究主要的數據採集方式。如果你同意參加這項研究，你將被邀請參加一個個人採訪，這個採訪將持續 45 分鐘到一個小時。 採訪將按照一個事先準備好的採訪指導進行。你可以選擇使用您喜歡的語言完成採訪（英語、粵語或者漢語普通話）。訪談將安排在你覺的合適的時間和地方進行，而且如果你是一位說粵語者，一位粵語翻譯者將參加我們的採訪。 在你的允許下，採訪將被全程錄音並且在採訪過程中可能會做一些筆記。在整個採訪過程中你的意見和觀點將被充分地尊重。

機密性： 保護受訪者的機密性無論在採訪前還是採訪中都是一個極為重要的問題。我將採取以下措施來確保整個採訪過程和研究數據的機密性：

1. 參加採訪的粵語翻譯者將與研究者簽署一份保密協定，確保參與者資訊和採訪數據不被外泄；

2. 粵語翻譯者不允許保留任何參與者資訊和與採訪相關的材料。採訪結束後，翻譯筆記也將交予研究者；

3. 在採訪過程中討論的任何問題都將嚴格保密，並且在採訪以外的環境中不得再次談論；

4. 所有採集到的數據都將被儲存在一個帶鎖的檔櫃內，並且在研究者受密碼保護的電腦中備份；

5. 所有研究數據都是匿名的，只有研究者和其導師們有權參閱。

研究結果將作何用處？這項研究將於 2013 年 9 月份完成，研究結果以博士論文的形式提交英國斯旺西大學審閱。該項研究的數據也有可能被用來撰寫學術論文發表在學術刊物上。如果參與者需要，研究結果也可以被提供。

研究花費和補償：我無法用金錢的形式來彌補你由於參加這項研究而造成的時間和金錢上的損失。雖然這項研究不會為你帶來任何直接的利益， 但是這項研究的研究結果有可能幫助很多像你一樣的糖尿病患者。從這個意義上講，你的參與式非常有意義的。

其他人會審閱這個研究嗎？這個研究將被英國斯旺西大學健康和人類科學學院倫理委員會和昆明醫學院第一附屬醫院醫院管理部審閱。

如果我有問題需要聯繫誰？你可以隨時和我聯繫，威爾士地區參與者請撥打電話XXX，中國地區參與者請撥打: XXX. 郵箱地址：XXX 你也可以和我的導師聯繫, 聯繫方式如下：XXX.

謝謝你的參與和閱讀！

Appendix 4 Consent Form

(English)

Title of research study:

An investigation of type-2 diabetes and self-management amongst Chinese patients and their family carers in Wales and China.

Name of researcher: Peng Zhao

Please read each statement, and if you agree with the statement, please tick and initial the box. If you agree to participate in the study, at the bottom of the form please also write your name in block capitals, the date and sign the form. Please also provide your address and telephone number for further contact. Note: If you are unable to finish the written consent due to literacy ability, I shall take a recorded verbal consent from you.

Please tick and initial each box that applies

1. I confirm that I have been provided with a **Participant Information Sheet**, dated ____. I have had the opportunity to read the sheet, consider the information and ask questions. Relevant questions have been answered satisfactorily. ☐
2. I understand that my participation in this research is **voluntary** and that I am **free to withdraw** at any time without giving a reason and with no further consequence. ☐
3. I agree to take part in the above study. ☐
4. I agree to the interviews being audio recorded and notes taken on the understanding that the information will be kept anonymous and the content kept confidential. ☐
5. I would like to conduct the interview in **English, Cantonese OR Mandarin**? (Please circle the language you prefer)

Name of participant: Date: Signature:

Name of researcher: Date: Signature:

(简体中文版 Simplified Chinese)

参与同意书

研究题目：中国大陆和英国威尔士地区中国 2 型糖尿病患者自我管理情况的调查

研究者姓名：赵芃

请阅读以下每一个选项，并在你同意的选项后的方框内打钩。如果您同意参加这个研究，请在此同意书的下方签署您的姓名和日期。此外为了方便联系，请您提供您的电话号码和通讯地址。注意：如果您由于识字问题无法完成这份书面同意书，我将获取您的口头同意并将其录音保存。

1. 我确定我已于 日期 收到了**参与者告知书**，并且认真阅读了该告知书中的信息，我的疑问也获得了满意的解释。 □
2. 我完全清楚我完全是出于**自愿**来参加这项研究的，我可以在任何时候选择退出研究，并且**不需要**为此提供任何理由和承担任何责任。 □
3. 我**同意**参加这项研究。 □
4. 我**同意**我的采访过程将被录音，并且已经清楚采访记录将被匿名处理和严格保密。 □

我想用英语、粤语 或者 汉语普通话完成采访。（请选择适合您的语言）

参与者姓名: 日期: 签字:

研究者姓名: 日期: 签字:

(繁體中文版 Traditional Chinese)

參與同意書

研究題目：中国大陆和英国威尔士地区中国 2 型糖尿病患者自我管理情况的调查

研究者姓名：趙芃

請閱讀以下每一個選項，並在你同意的選項後的方框內打鉤。如果您同意參加這個研究，請在此同意書的下方簽署您的姓名和日期。此外為了方便聯繫，請您提供您的電話號碼和通訊地址。注意：如果您由於識字問題無法完成這份書面同意書，我將獲取您的口頭同意並將其錄音保存。

1. 我確定我已於 日期 收到了參與者告知書，並且認真閱讀了該告知書中的資訊，我的疑問也獲得了滿意的解釋。 □
2. 我完全清楚我完全是出於自願來參加這項研究的，我可以在任何時候選擇退出研究，並且不需要為此提供任何理由和承擔任何責任。 □
3. 我同意參加這項研究。 □
4. 我同意我的採訪過程將被錄音，並且已經清楚採訪記錄將被匿名處理和嚴格保密。 □
5. 我想用**英語、粵語 或者 漢語普通話**完成採訪。（請選擇適合您的語言）

參與者姓名:　　日期:　　簽字:

研究者姓名:　　日期:　　簽字:

Appendix 5 Topic Guides (Patients)

(English)

Part 1 Demographic information

1. How old are you?
2. Are you single, married, divorced, or widowed (for how long)?
3. Are you employed in paid work? (If so, What kind of job? and How many hours do you work per week?)
4. What is your education background?
5. How long have you been living here?
6. Are you living with your family members? (If so, who are they?)
7. Does anyone else in your family have diabetes?

Part 2 Perceptions regarding type-2 diabetes and self-management

1. How did you find out you had diabetes?
2. How long you have been diagnosed with diabetes?
3. How did you feel after being diagnosed?
4. What do you understand about diabetes?
5. Where do you get this information from about diabetes?
6. Have you noticed any differences in your life before and after being diagnosed? If yes please tell me about these differences?
7. How has having diabetes impacted on your everyday life?
8. Do you think you can manage your condition well by yourself?
9. What are you doing to manage your condition at home?
10. Could you provide some examples about how you manage your condition on your own?

11. Do you use any traditional medicines or particular foods to help manage your diabetes? If yes, please tell me more.

Part 3 Barriers and facilitators that affect self-management

1. Have you experienced any difficulties managing your diabetes?
2. If so, what difficulties have you encountered when you manage your condition by yourself?
3. How do these difficulties hinder you managing your condition?
4. How do you deal with these difficulties?
5. What kind of support and help have you obtained to deal with these difficulties and was it helpful?
6. What is the source of this support and help?
7. How does this support help you perform good management of your diabetes by yourself?
8. What other types of support or help do you think would be helpful to you?
9. Is there anything else you would like to tell me about how you manage your diabetes?

Part 4 the influence of migration on self-management of Chinese patients. (Only for patients living in Wales)

1.When did you come to live in Wales and how has this influenced your lifestyle? Such as diet, access to health information, access to health care etc.

2.Did you have diabetes before you migrated to Wales? If not, how long after being here did you develop diabetes?

3.Do you think that migrating to Wales has influenced your management of diabetes by yourself? If yes, please tell me in what way?

4.Do you think your diabetes would be better managed in China or not? If yes, please tell me why?

(简体中文版 Simplified Chinese)

采访指导

（适用于 2 型糖尿病病人）

第一部分问题：参与者人员信息：

1.请问您的年龄？

2. 请问您的婚姻状况（单身、已婚、离异 或者丧偶）

3. 您有工作吗？（如果是，什么样的工作，您每周工作几小时？）

4. 您的文化程度？

5. 您住在这里多久啦？

6. 您和您的家人生活在一起吗？（如果是，他们是谁？）

7. 您亲属里还有谁患有糖尿病？

第二部分问题：关于糖尿病和糖尿病自我管理的认识

1. 您是如何知道您有糖尿病的？

2. 您被诊断患有糖尿病有多久啦？

3. 当您被诊断患有糖尿病时您的感觉是什么？

4. 请谈谈您对糖尿病的认识？

5. 您是从哪里获得这些关于糖尿病的信息的？

6. 诊断前后您的生活有什么不同？

7. 糖尿病对您的生活带来了什么影响？

8. 您对通过您自己可以管理好这个疾病有什么看法？

9. 您现在在家都做些什么来管理这个疾病？

10. 您能进一步谈谈您是如何自己管理这个疾病的？

11.您尝试过使用中药或是特殊的食物来帮助您管理糖尿病吗？如果有，您能具体谈谈吗？

第三部分问题：关于影响糖尿病自我管理的障碍和有利因素

1.您在管理您的疾病时遇到过困难吗？

2. 这些困难是什么？

3. 这些困难又是如何妨碍您自己管理疾病的？

4. 您是如何解决这些困难的？

5. 您获得过什么样的支持和帮助当您遇到困难时？

6. 这些支持帮助来源于哪里？

7. 这些支持和帮助是如何帮助你有效管理自己疾病的？

8. 您认为还有什么帮助和支持对您自己管理疾病是有益的吗？

9. 关于糖尿病的自我管理您还有什么想告诉我的吗？

第四部分问题：移居国外对您开展糖尿病自我管理有什么影响？（此部分问题仅适用于居住于威尔士的参与者）

1.您是从什么时候移居威尔士的？移居后您的生活方式是否发生了变化？例如，2. 饮食习惯、获取健康信息、获取健康服务等等？

2.在移居威尔士之前您就有糖尿病了吗？如果不是，您移居威尔士之后多久患上糖尿病的？

3.您是否认为移居威尔士对您管理自己疾病有影响？如果是，请具体谈谈这个影响是什么？

4.您认为如果您依旧生活在中国您的疾病可以得到更好的管理吗？如果是，请具体谈谈您的看法。

(繁體中文版 Traditional Chinese)

採訪指導

（適用於 2 型糖尿病病人）

第一部分問題：參與者人員資訊：

1. 請問您的年齡？
2. 請問您的婚姻狀況（單身、已婚、離異 或者喪偶）
3. 您有工作嗎？（如果是，什麼樣的工作，您每週工作幾小時？）
4. 您的文化程度？
5. 您住在這裡多久啦？
6. 您和您的家人生活在一起嗎？（如果是，他們是誰？）
7. 您親屬裡還有誰患有糖尿病？

第二部分問題：關於糖尿病和糖尿病自我管理的認識

1.您是如何知道您有糖尿病的？

2.您被診斷患有糖尿病有多久啦？

3.當您被診斷患有糖尿病時您的感覺是什麼？

4.請談談您對糖尿病的認識?

5.您是從哪裡獲得這些關於糖尿病的資訊的？

6.診斷前後您的生活有什麼不同？

7.糖尿病對您的生活帶來了什麼影響？

8.您對通過您自己可以管理好這個疾病有什麼看法？

9.您現在在家都做些什麼來管理這個疾病？

10.您能進一步談談您是如何自己管理這個疾病的？

11.您嘗試過使用中藥或是特殊的食物來幫助您管理糖尿病嗎？如果有，您能具體談談嗎？

第三部分問題：關於影響糖尿病自我管理的障礙和有利因素

1.您在管理您的疾病時遇到過困難嗎？

2. 這些困難是什麼？

3. 這些困難又是如何妨礙您自己管理疾病的？

4. 您是如何解決這些困難的？

5. 您獲得過什麼樣的支持和幫助當您遇到困難時？

6. 這些支持幫助來源於哪裡？

7. 這些支持和幫助是如何幫助你有效管理自己疾病的？

8. 您認為還有什麼幫助和支持對您自己管理疾病是有益的嗎？

9. 關於糖尿病的自我管理您還有什麼想告訴我的嗎？

第四部分問題：移居國外對您開展糖尿病自我管理有什麼影響？（此部分問題僅適用于居住於威爾士的參與者）

1. 您是從什麼時候移居威爾士的？移居後您的生活方式是否發生了變化？例如，飲食習慣、獲取健康資訊、獲取健康服務等等？
2. 在移居威爾士之前您就有糖尿病了嗎？如果不是，您移居威爾士之後多久患上糖尿病的？
3. 您是否認為移居威爾士對您管理自己疾病有影響？如果是，請具體談談這個影響是什麼？
4. 您認為如果您依舊生活在中國您的疾病可以得到更好的管理嗎？如果是，請具體談談您的看法。

Appendix 6 Topic Guides (Family carers)

(English)

Part 1 Demographic information

1. How old are you?

2. Are you employed for paid work? (If so, What kind of job? and How many hours do you work per week?)

3. What is your education background?

4. How long have you been living here?

5. Are you living with a family member who has type-2 diabetes?

6. How long have you been living with this family member who has type-2 diabetes?

7. What is your relationship to the person who has type-2 diabetes?

Part 2 Perceptions regarding type-2 diabetes and self-management

1. How do you know your__has been diagnosed with type-2 diabetes?

2. What were your feelings when you knew your____had been diagnosed with type-2 diabetes?

3. What do you understand about diabetes?

4. What differences have you noticed in your life before and after your_______ was diagnosed with type-2 diabetes?

5. Do you think that the diagnosis of diabetes has impacted on your everyday life?

6. Has the diagnosis of diabetes affected the relationship between you and your______? If yes, in what way?

7. Do you think your____can manage his/her condition well by himself/herself?

Part 3 Barriers and facilitators that affect self-management

1. What difficulties does your___encounter when he/she manages his/her condition by himself/herself?

2. How do you help and support your____manage his/her condition well by himself/herself?

3. What difficulties, if any, do you encounter in helping and supporting your___manage his/her condition?

4. How do you solve the difficulties?

5. Do you obtain support and help when you have difficulties?

6. What kind of support and help do you obtain?

7. Where does this support come from?

8. How would you describe your role in managing your___‘s condition at home?

9. Is there anything else you would like to tell me about how you help your___manage his/her diabetes?

(简体中文版 Simplified Chinese)

采访指导

（适用于 2 型糖尿病病人家属）

第一部分问题：参与者人员信息

1. 请问您的年龄？

2. 您有工作吗？（如果是，什么样的工作，您每周工作几小时？）

3. 您的文化程度？

4. 您居住在这里有多久啦？

5. 您是和糖尿病病人居住在一起吗？

6. 您和糖尿病病人居住在一起有多久啦？

7. 您和这位糖尿病病人的关系是什么？

第二部分问题：关于糖尿病和糖尿病自我管理的认识

1. 您是怎么知道您的___患有糖尿病的？

2. 当您得知您的___患有糖尿病时您的感受是什么？

3. 您是怎么理解糖尿病的？

4. 在您的__诊断糖尿病前后你们的生活有什么不同？

5. 请您谈谈糖尿病对你们的日常生活的影响？

6. 糖尿病影响了您和您的___关系吗？如果是，能具体谈谈吗？

7. 您对您的__可以自己管理好自己的疾病如何来看？

第三部分问题：关于影响糖尿病自我管理的障碍和有利因素

1. 您的___在管理自身疾病时遇到的困难是什么？

2. 您是怎样支持和帮助您的 __来管理他/她的疾病的？

3. 您在支持和帮助您的___管理其疾病时遇到哪些困难？

4. 您是如何解决这些困难的？

5. 您是否获得过帮助来解决这些困难？

6. 请您谈谈这些帮助具体是什么？

7. 这些帮助来自于哪里？

8. 您如何看待您在您的___管理自身疾病中所发挥的作用？

9. 关于您是如何帮助您的___管理糖尿病您还有什么想告诉我的吗？

(繁體中文版 Traditional Chinese)

採訪指導

（適用於 2 型糖尿病病人家屬）

第一部分問題：參與者人員資訊：

1. 請問您的年齡？

2. 您有工作嗎？（如果是，什麼樣的工作，您每週工作幾小時？）

3. 您的文化程度？

4. 您居住在這裡有多久啦？

5. 您是和糖尿病病人居住在一起嗎？

6. 您和糖尿病病人居住在一起有多久啦？

7. 您和這位糖尿病病人的關係是什麼？

第二部分問題：關於糖尿病和糖尿病自我管理的認識

1. 您是怎麼知道您的___患有糖尿病的？

2. 當您得知您的___患有糖尿病時您的感受是什麼？

3. 您是怎麼理解糖尿病的？

4. 在您的___診斷糖尿病前後你們的生活有什麼不同？

5. 請您談談糖尿病對你們的生活和家庭關係的影響？

6. 糖尿病影響了您和您的___關係嗎？如果是，能具體談談嗎？

7. 您對您的___可以自己管理好自己的疾病如何來看？

第三部分問題：關於影響糖尿病自我管理的障礙和有利因素

1. 您的___在管理自身疾病時遇到的困難是什麼？

2. 您是怎樣支持和幫助您的___來管理他/她的疾病的？

3.您在支持和幫助您的___管理其疾病時遇到哪些困難？

4.您是如何解決這些困難的？

5.您是否獲得過幫助來解決這些困難？

6.請您談談這些幫助具體是什麼？

7.這些幫助來自於哪裡？

8.您如何看待您在您的___管理自身疾病中所發揮的作用？

9.關於您是如何幫助您的___管理糖尿病您還有什麼想告訴我的嗎？

Appendix 7 Confidentiality Agreement

(English)

This study, an investigation of type-2 diabetes and self-management amongst Chinese patients and their family carers in Wales and China, is being undertaken by Peng Zhao. This study aims to investigate a greater understanding and perspectives in Chinese patients and their family carers regarding type-2 diabetes and self-management in Wales and China.

Whereas the study will involve some Cantonese-speaking participants, I ________shall be invited to participate the study as a Cantonese interpreter.

I __________agree to:

- Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. disks, tapes, transcripts) with anyone other than the principal researcher;
- Keep all research information in any form or format secure while it is in my possession;
- Return all research information in any form or format to the principal researcher when I have completed the tasks;
- After consulting with the principal researcher, erase or destroy all research information in any form or format regarding this research that is not returnable to the principal researcher.

Cantonese interpreter/translator:

Name of Cantonese interpreter: Date: Signature:

Researcher:

Name of researcher: Date: Signature:

(简体中文版 Simplified Chinese)

保密协定

这项研究是一个关于中国大陆和英国威尔士地区中国 2 型糖尿病患者自我管理情况调查的研究。研究将由英国斯旺西大学博士研究生赵芃在英国威尔士地区和昆明医学院第一附属医院展开。此项研究的主要目的是为了探索中国裔二型糖尿病患者对自身疾病的理解和认识以及他们如何管理自身的疾病，当他们正在管理自身疾病时遇到困难和障碍时，他们又是如何解决这些困难和障碍的。

由于在这项研究中，一些参与者是粤语使用者，因此我，____被邀请加入到这项研究中为这些粤语参与者提供粤语和普通话的翻译服务。

在我翻译过程中，我，_____同意遵照以下协定严格保密此项研究的相关信息：

第一，除主要研究者外，不与任何第三方讨论和共享以光盘、录音磁带或手稿等为保 存形式的研究信息。

第二，当我保管研究信息时，我将确保它们的安全。

第三，当研究完成时，将所有研究信息返还主要研究者。

第四，对于一些不可返还的研究资料，与主要研究者商议后将其永久销毁。

翻译者:

翻译者姓名：　　日期：　　翻译者签名：

研究者:

研究者姓名：　　日期：　　研究者签名：

如果您还有何疑问请按以下方式与研究者联系：

Mr. Peng Zhao/ 赵芃

Tel/电话: XXX

Email/电子邮件： XXX

(繁體中文版 Traditional Chinese)

保密協定

這項研究是一個關於中國大陸和英國威爾士地區中國 2 型糖尿病患者自我管理情況調查的研究。研究將由英國斯旺西大學博士研究生趙芃在英國威爾士地區和昆明醫學院第一附屬醫院展開。此項研究的主要目的是為了探索中國 2 型糖尿病患者對自身疾病的理解和認識以及他們如何管理自身的疾病，當他們正在管理自身疾病時遇到困難和障礙時，他們又是如何解決這些困難和障礙的。

由於在這項研究中，一些參與者是粵語使用者，因此我，______被邀請加入到這項研究中為這些粵語參與者提供粵語和普通話的翻譯服務。

在我從事翻譯工作中，我，______同意遵照以下協定嚴格保密此項研究的相關資訊：

第一，除主要研究者外，不與任何第三方討論和共用以光碟、錄音磁帶或手稿等為保存形式的研究資訊。

第二，當我保管研究資訊時， 我將確保它們的安全。

第三，當研究完成時，將所有研究資訊返還主要研究者。

第四，對於一些不可返還的研究資料，與主要研究者商議後將其銷毀。

翻譯者:

翻譯者姓名： 日期： 翻譯者簽名：

研究者:

研究者姓名： 日期： 研究者簽名：

如果你還有何疑問請按以下方式與研究者聯繫：

Mr. Peng Zhao/ 趙芃

Tel/電話: XXX

Email/電子郵件： XXX

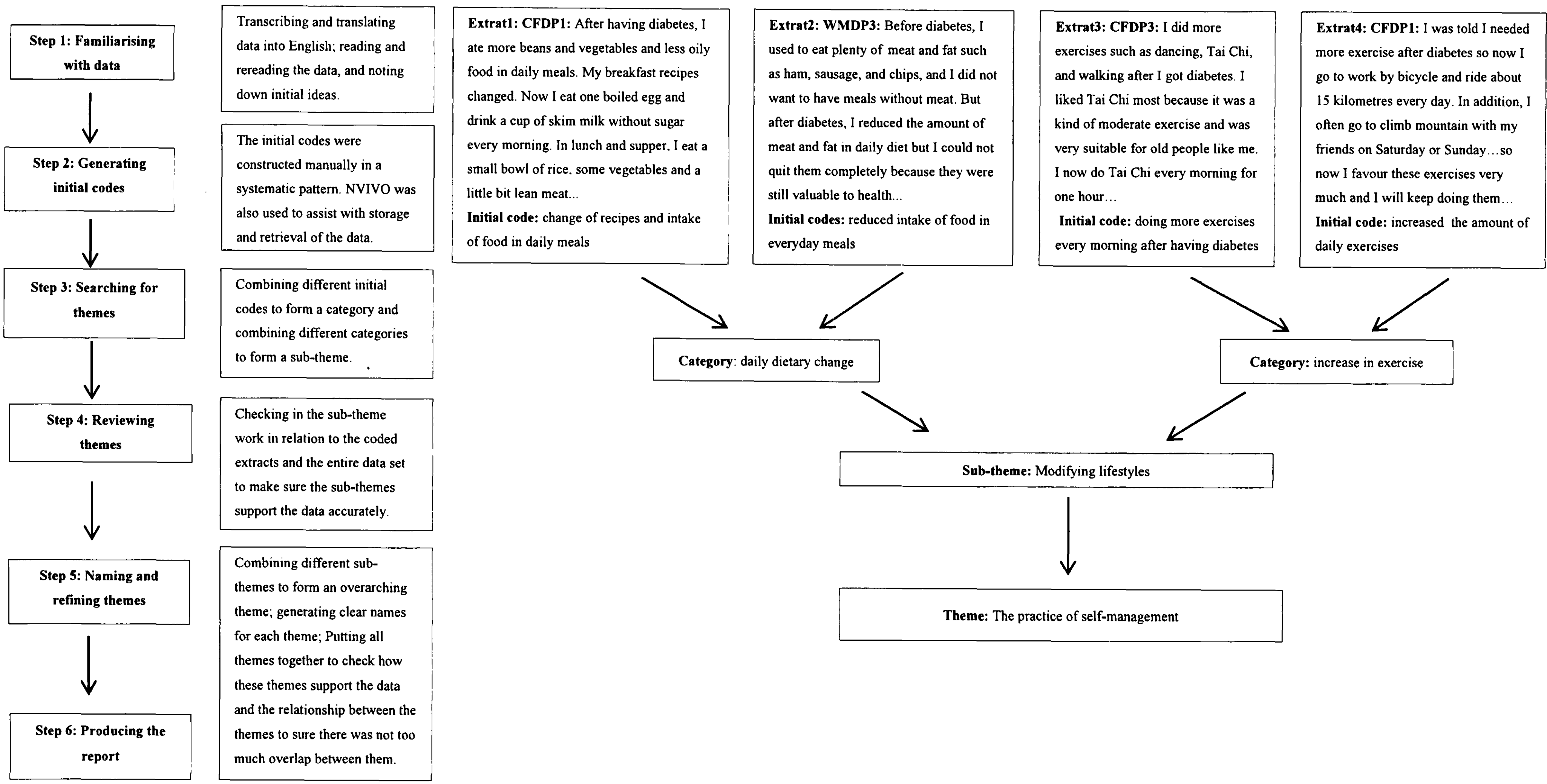
Appendix 8 An example of fieldnotes taken in the observation

Date	12 November 2013
Venue	Diabetes department in xx hospital in Swansea
Participants	13 diagnosed patients with type-2 diabetes (Male 8 and Female 5) 2 diabetes educators
Topic	Weight management
Content	Two educators provided participants with a lecture regarding how to manage daily diet and weight and how to read and understand nutrition table on the package of common food with assistance of flashing cards, pictures, and real food packages. After the lecture, participants were given 30 minutes to ask questions. At the end of the session, educators and participants played question-and-answer game to check if participants understand the content of the lecture and to help participants to remember key information provided in this session.
Interaction with participants	**When I talked to a male participant, he thought this session was very helpful:** "…you know I had little knowledge about diabetes before attending the programme although I have been living with it for nearly three years. But I have got a lot and I can understand the nutrition label on the food packages after the sessions…it's quite helpful for me…" **Another female participant also provided similar comments:** "I was happy with it as I have got a lot of useful information about my condition. Before I participated in the sessions, I was always confused how much food I can eat a day, how much exercise I need to do a day. All these questions have been sorted out in the sessions. They were really nice and helpful courses."
Comments	I have noticed that the participants were allocated 30 minutes to ask questions and to have one-to-one conversations with educators as this programme was conducted on the basis of a small group. Participants also had more chance and time to communicate one another. Moreover, this session provided participants not only with primary pathogenic knowledge about type-2 diabetes but also with information and skills regarding how to conduct diet and weight management and exercise, which could be very helpful. Nobody withdrew from the session and most participants provided positive comments about this session.

Appendix 9 Two examples of reflexive diary for interviews

Interview date and time:	25/10/2012 13:00
Duration:	48 minutes
Interview location:	Meeting room in the diabetes department
Interviewee:	A Chinese male patient with type-2 diabetes aged 62 years (MDP1)
	Pleasant relaxed atmosphere, I and MDP1 were seated face to face in a quiet, bright and warm meeting room. Drinking water was offered. I and MDP1 had a short conversation and I introduced the study briefly and explained consent form to him. He signed the form before commencing interview. MDP1 was optimistic and extroverted and he would like to talk to me about his condition so this interview was completed well. However, I found that MDP1 was reluctant to answer the questions about his personal information such as age, marriage, occupation, and income at the beginning of the interview so I thought I needed to make a change in the order of asking questions and collected participant's demographic information at the end of the interview in the following interviews in order to avoid private and sensitive questions disturbing the interview and relationship between myself and participant.
Interview date and time:	08/02/2013 13:00
Duration:	67 minutes
Interview location:	Meeting room in the diabetes department
Interviewee:	A Chinese woman with type-2 diabetes aged 77 years living (FDP2)
	FDP2 was a retired obstetrician so she was very knowledgeable about type-2 diabetes and its management. Sometimes she did not provide me with detailed responses to my questions. She said " you should know that more than me as your subject is type-2 diabetes." or " I think you have got it from other patients already." when I tried to ask for more detailed information so I felt it difficult to obtain her real feelings and thoughts sometimes and to avoid completely collecting at face value what she described. Moreover, this interview could be affected by my pre-existing knowledge about type-2 diabetes as sometimes I had to assume what she tried to say. Therefore, I really needed to rethink if I should expose my medical background to participants. Furthermore, I found it difficult to recruit participants for this study in January and February as the amount of visit of patients in hospital reduced and most patients and their family carers would not like to talk about their and their relative's disease, which usually was regarded as representation of bad luck in Chinese custom at the beginning of Chinese new year and they thought that talking to disease at the beginning of new year too much could bring about more bad luck in the new year. Therefore, there was a risk of concealing their real feelings and views about their condition when interviewing patients in the January and February. In order to avoid this situation, I decided to suspended recruiting and interviewing participants in February and restarted data collection at the beginning of March (after Chinese new year).

Appendix 10 An example of the development of a theme using thematic analysis



Phases of thematic analysis

Step 1: Familiarising with data

Transcribing and translating data into English; reading and rereading the data, and noting down initial ideas.

Step 2: Generating initial codes

The initial codes were constructed manually in a systematic pattern. NVIVO was also used to assist with storage and retrieval of the data.

Step 3: Searching for themes

Combining different initial codes to form a category and combining different categories to form a sub-theme.

Step 4: Reviewing themes

Checking in the sub-theme work in relation to the coded extracts and the entire data set to make sure the sub-themes support the data accurately.

Step 5: Naming and refining themes

Combining different sub-themes to form an overarching theme; generating clear names for each theme; Putting all themes together to check how these themes support the data and the relationship between the themes to sure there was not too much overlap between them.

Step 6: Producing the report

An example of the development of a theme

Extrat1: CFDP1: After having diabetes, I ate more beans and vegetables and less oily food in daily meals. My breakfast recipes changed. Now I eat one boiled egg and drink a cup of skim milk without sugar every morning. In lunch and supper. I eat a small bowl of rice. some vegetables and a little bit lean meat...
Initial code: change of recipes and intake of food in daily meals

Extrat2: WMDP3: Before diabetes, I used to eat plenty of meat and fat such as ham, sausage, and chips, and I did not want to have meals without meat. But after diabetes, I reduced the amount of meat and fat in daily diet but I could not quit them completely because they were still valuable to health...
Initial codes: reduced intake of food in everyday meals

Extrat3: CFDP3: I did more exercises such as dancing, Tai Chi, and walking after I got diabetes. I liked Tai Chi most because it was a kind of moderate exercise and was very suitable for old people like me. I now do Tai Chi every morning for one hour…
Initial code: doing more exercises every morning after having diabetes

Extrat4: CFDP1: I was told I needed more exercise after diabetes so now I go to work by bicycle and ride about 15 kilometres every day. In addition, I often go to climb mountain with my friends on Saturday or Sunday…so now I favour these exercises very much and I will keep doing them…
Initial code: increased the amount of daily exercises

Category: daily dietary change

Category: increase in exercise

Sub-theme: Modifying lifestyles

Theme: The practice of self-management

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