

**The illness with no 'tail': how foreign-born UK Chinese understand and manage Type 2 diabetes**

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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## Abstract

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Given the global rise of diabetes, the low uptake of GP services and prescribed medicine among UK Chinese is worrying. Little is known about their management of symptoms, compliance with treatment and implementation of lifestyle changes inherent in living with diabetes. Even less is known about whether they use Chinese folk medicine as part of their treatment regime. This qualitative study reduces this information gap based on data collected through focus group discussions and individual interviews. Eight focus group discussions were held in Leeds, Bristol, Birmingham and London with 37 foreign-born UK Chinese participants, including patients, friends and family members. On completion of the eight focus groups, 22 semi-structured individual interviews were conducted with both foreign and British-born Chinese with diabetes. Findings from the focus groups include (i) a reluctance to accept diabetes as a chronic illness, (ii) persistence in the use of folk remedies and (iii) an absence of use of professional Chinese medicine for diabetes, with the exception of one participant. Findings from the individual interviews on ideas about diabetes were similar to those from the focus groups, with further developments in the images of diabetes. With regards to self-management regimes, different coping styles indicated high levels of anxiety and uncertainty surrounding the nature of diabetes. Use of medicine, Chinese or otherwise, was found to be linked to levels of trust and integration with the host community. Themes consistent in both phases of the study include firstly, the description of diabetes as an illness with ‘no tail’ (*mouhmei/meiwei* 没尾) – the tail representing an end of an illness. Secondly, the cultural practice of food abstinence (*gaihauh/jikou* 戒口) was perceived to be an effective method of control and prevention of the deterioration of diabetes. Finally, the relentless search for a cure expressed as ‘cutting the tail’ (*tueihmei/duanwei* 段尾) was evident in all the interviews. This study highlights the difficulties experienced by ethnic groups whose folk models of illness differ from those of biomedicine. It also addresses two important issues in the management of chronic illness: coping with uncertainty and the importance of trust. These results can help

inform the future planning and delivery of healthcare services for ethnic minority groups.

## Contents

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ACKNOWLEDGEMENTS .....	I
ABSTRACT .....	II
CONTENTS.....	IV
LIST OF TABLES AND FIGURES .....	IX
CHAPTER 1: INTRODUCTION .....	1
1.1 Aim of the study.....	2
1.2 The research design.....	3
1.3 Analytical considerations, scope and contribution of the study.....	4
1.4 Recruitment .....	8
1.5 Focus group discussions .....	10
1.6 Individual Interviews .....	12
1.7 Plan of the Thesis.....	15
CHAPTER 2: DIABETES AND THE UK CHINESE POPULATION.....	18
2.1 Diabetes: then and now.....	18
2.2 Management strategies .....	21
2.3 The UK Chinese Population .....	23
2.3.1. The Health Survey of England Data .....	28
2.4 Chronicity .....	31
2.5 Impact of culture on illness management .....	32
2.5.1 Ethnicity and race.....	33
2.5.2 The physical environment .....	34
2.6 Summary .....	36
CHAPTER 3: RECRUITMENT, FOCUS GROUPS AND INTERVIEWS.....	37
3.0 Introduction.....	37
3.1 Guanxi (关系): magnetic threads, human web.....	40
3.2 Practicalities: conducting focus group discussions.....	43
3.3 Individual interviews .....	45
3.3.1 British-born Chinese.....	46
3.4 Summary .....	47
CHAPTER 4: METHODOLOGICAL CONSIDERATIONS.....	48
4.0 Introduction.....	48
4.1 Sampling .....	49

4.1.1 Unsuitable and misinformed participants .....	51
4.2 Cultural and linguistic issues .....	54
4.2.1 Nuances in Chinese speech patterns .....	56
4.2.2 Code-switching.....	58
4.2.3 The indeterminate linguistic space .....	60
4.2.4 Indirect speech styles.....	62
4.2.5 Yes-No ambiguity .....	63
4.2.6 Translation issues .....	65
4.3 Positionality and the insider status .....	67
4.3.1 Ways in which I was not entirely an ‘insider’ .....	69
4.3.2 The seduction of sameness.....	70
4.3.3 Personal status and identity .....	71
4.4 Data analysis .....	73
4.5 Summary .....	77
CHAPTER 5: FOOD, MEDICINE AND HEALTH IN CHINESE CULTURE .....	78
5.0 Introduction.....	78
5.1 Food .....	79
5.2 Chinese medicine .....	83
5.2.0 Key concepts in Chinese medicine.....	86
5.2.1 Yin-yang ( 阴阳) .....	86
5.2.2 The five elements (wu xing 五行) .....	87
5.2.3 The meridians jing luo (经 络).....	88
5.2.4 Qi (气) .....	88
5.3 Health .....	89
5.4 Summary .....	91
CHAPTER 6: DIABETES IN CHINESE MEDICINE .....	93
6.0 Introduction.....	93
6.1 Theories of diabetes in Chinese medicine .....	94
6.2 Treatment of diabetes in Chinese medicine .....	97
CHAPTER 7: DIABETES THROUGH THE EYES OF UK CHINESE .....	101
7.0 Introduction.....	101
7.1 Findings from focus group discussions.....	102
7.1.1 Discovery .....	102
7.1.2 Perception of diabetes.....	103
7.1.2.1 Causation: imbalance, excessive intake of certain foods, hereditary and organ malfunction .....	103

7.1.2.2 <i>Ideas about diabetes: a rare disease, an illness with no ‘tail’, an illness that leads to other illnesses</i> .....	111
7.2 Findings from individual interviews .....	117
7.2.1 Cause(s) of diabetes .....	117
7.2.2 Trajectory of diabetes: neither acute nor terminal, just ‘in-between’ .....	121
7.3 Discussion .....	124
7.4 Summary .....	127
CHAPTER 8: MANAGING DIABETES .....	128
8.0 Introduction.....	128
8.1 Findings from focus group discussions.....	129
8.1.1 Food abstinence (gaihauh/jikou 戒口) versus ‘Sneak and eat’ (Tauh sihk/touchi 偷吃).....	129
8.1.2 Exercise .....	136
8.1.3 Medication (sikhyeuk/chiyao 吃药 = eating medicine).....	139
8.1.4 Maintaining control (keep ju 着) .....	144
8.1.4.1 <i>Finger prick testing, urine testing, and attending follow-up appointments</i> .....	144
8.1.4.2 <i>Transfer ownership of managing diabetes to the NHS</i> .....	145
8.2. Findings from individual interviews .....	148
8.2.1 Coping styles .....	148
8.2.1.1 <i>Accommodate-denial</i> .....	150
8.2.1.2 <i>Accommodate-resign</i> .....	152
8.2.1.3. <i>Accommodate/secondary gain/resign</i> .....	152
8.2.1.4 <i>Accommodate</i> .....	153
8.2.1.5 <i>The resigners</i> .....	154
8.2.1.6 <i>The active deniers</i> .....	154
8.2.2 The social network structure.....	156
8.2.2.1 <i>In-groupers’ contribution</i> .....	156
8.2.2.2 <i>NHS: Out-group support network</i> .....	163
8.3 Discussion .....	169
8.4 Summary .....	174
CHAPTER 9: CHINESE MEDICINE AND FOLK MEDICINE .....	175
9.0 Introduction.....	175
9.1 Findings from focus group discussions.....	177
9.1.1 ‘Money [...] That’s the bottom line’ .....	177
9.1.2 Past experience .....	180
9.1.2.1 <i>Comparison between Chinese and Western medicine</i> .....	180

9.1.2.2 <i>Negative experiences and views of using Chinese medicine</i> .....	184
9.1.3 Chinese medicine: food or drug?.....	190
9.1.4 Ethnocentricity: 'because Chinese medicine is part of our tradition' .....	196
9.2 Findings from individual interviews .....	197
9.2.1 Evidence of uptake of Chinese medicine/health practice.....	197
9.2.2 Benefits of Chinese medicine .....	200
9.2.3 Cultural and linguistic similarities between patients and healers.....	204
9.2.4 Hope in Chinese medicine .....	205
9.2.5 Views on Chinese medical practitioners: good versus bad .....	206
9.3. Discussion .....	211
9.4 Summary .....	213
CHAPTER 10: THE BRITISH-BORN CHINESE .....	215
10.0 Introduction.....	215
10.1 Background .....	215
10.2 Perceptions of diabetes: Concordance and dissonance.....	218
10.3 Management of diabetes: 'I know what I'm supposed to do but...' .....	220
10.3.1 'It depends on how much you eat' .....	220
10.3.2 Medical regime: No other option for the time being .....	221
10.3.3 Illness-management responsibilities.....	222
10.4 Chinese medicine: 'don't trust it', 'resist it' .....	224
10.5 Discussion .....	226
CHAPTER 11: CONCLUSION.....	229
11.1 Revisiting the research questions.....	229
11.3 Strengths of study.....	236
11.4 Possible limitations of study .....	237
11.4.1 The representativeness of the sample.....	238
11.4.2 The use of translation.....	240
11.5 Recommendations for future studies .....	240
11.6 Closing comments .....	241
REFERENCES .....	243
Appendix No. 1A Project information leaflet in Chinese .....	264
Appendix No. 1B Project information leaflet in English.....	265
Appendix No. 2A Consent form in Chinese language .....	266
Appendix No. 2B Consent form in English.....	267
Appendix No. 3 Receipt of voucher .....	268
Appendix No. 4 Copy of topic guide for focus group discussions .....	269



Appendix No. 5A Poster in Chinese .....	272
Appendix No. 5B Poster in English.....	273
Appendix No. 6 Copy of NHS Research Ethics Committee .....	274
Appendix No. 7 Approval letter from Leeds and Bradford Ethics Committee.....	275
Appendix No. 8 Letter to diabetologist.....	277
Appendix No. 9 Letter to participants from diabetologist .....	278
Appendix No. 10 Letter of participant from researcher .....	279
Appendix No. 11 Advertisement posted on Britishbornchinese website .....	280
Appendix No. 12 Advertisement posted on BritishChinese website .....	281
Appendix No. 13 Advertisement posted on Diabetes Forum .....	282
Appendix No. 14 Responses to advertisement.....	283
Appendix No. 15 Copy of summary sheet for focus group interviews .....	287
Appendix No. 16 Copy of summary sheet for individual interviews .....	288
Appendix No. 17 Socio- demographics of individual interviews.....	289
Appendix No. 18 Response from individual interviews .....	291
Appendix No. 19 Response from individual interviews .....	294
Appendix No. 20 Response from individual interviews .....	295
Appendix No. 21 Transcript of individual interviews .....	296
GLOSSARY.....	297

## ***List of Tables and Figures***

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Table 1: Time frame for focus group discussions.....	11
Table 2: Time frame for interviews with British born Chinese .....	14
Table 3: Location of individual Interviews for first generation Chinese.....	15
Table 4: Location of individual interviews of British-born Chinese .....	15
Table 5: UK population 2001.....	28
Figure 1: Focus group discussion setting.....	44

## ***Chapter 1: Introduction***

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The incidence of Type 2 diabetes is rising globally (Fall, 2001, Zimmet et al., 2001) and in the UK (Department of Health, 1999). Biomedical research has established that sufferers can delay the destructive and progressive nature of diabetes through tight blood sugar control, achievable by making changes in diet and lifestyle, and use of medication (UKPDS, 1998, DCCT, 1993). Poor control of blood sugar levels leads to damage to vital organs such as the heart, kidneys and the circulatory system. Thus the question of the effectiveness of self-management for diabetes is of considerable importance. This is particularly so since a substantial rise in NHS expenditure in the care for patients with diabetes is expected (Bagust et al., 2002).

Foreign-born members of ethnic minority populations in the UK may have limited command of English and may also have culturally-based understandings of illness that conflict with biomedical treatment regimens. Research on self-management among these populations is of practical importance, as well as raising significant intellectual issues. There is evidence of an increasing incidence among Chinese populations (Cockram et al., 1993, Chan et al., 2001, Wong and Wang, 2006), including that in the UK (Department of Health, 2001, Department of Health, 1999). Therefore, an understanding of how foreign-born UK Chinese with diabetes manage their illness is clearly desirable. The research on which this thesis is based aims to provide such an understanding.

The thesis examines how foreign-born UK Chinese with Type 2 diabetes experience and treat their illness. Some comparative data is also presented from British-born Chinese. Central issues include how foreign-born UK Chinese with diabetes manage their symptoms, the degree to which they comply with biomedical treatment regimes, engage in lifestyle changes and their use of Chinese folk medicine.

This opening chapter presents the background to the thesis, its specific aims and research questions. Data was gathered using a combination of focus group discussions and individual interviews. Within this chapter I offer justification for

using these research tools, present an overview of the recruitment and outline the plan of the thesis.

### **1.1 Aim of the study**

Studies of Chinese people in the UK indicate low levels of engagement with healthcare services and prescribed medicines (Smaje and Le Grand, 1997, Sproston et al., 2001). Little is known about how UK Chinese manage their diabetic conditions (Chan, 1991, Anderson et al., 1995), or why their levels of uptake of medical facilities are so low. This thesis is directed towards meeting these gaps in our knowledge. Its subject is the self-management of Type 2 diabetes by UK Chinese, with particular reference to the use of Chinese medicine.

The major research questions posed were:

1. How do foreign-born UK Chinese people manage diabetes?
2. How do family members and social networks influence the use of Chinese medicine in the management of diabetes?
3. How do mainstream healthcare structures influence the management regimes of UK Chinese people with diabetes?

In addition, I was interested in two further questions relating to British-born Chinese:

4. whether there were differences in health-seeking behaviour between foreign-born Chinese and British-born Chinese people, and
5. whether being British-born impacts on the decision to use Chinese medicine?

As will be seen, for practical reasons it proved difficult to recruit significant numbers of British-born Chinese with diabetes for this study, since this is a young population, and Type 2 diabetes is typically associated with older people i.e. 40 years old and above. However, I carried out face-to-face interviews with

two British-born Chinese with diabetes which yielded some valuable information. This is presented in Chapter Ten.

## **1.2 The research design**

This is a qualitative study conducted in two phases using two research tools:

- Phase 1 consisted of a series of eight focus group discussions with 37 foreign-born UK Chinese people comprising individuals who have diabetes, and friends or family members of patients.
- Phase 2 entailed 22 semi-structured individual interviews involving only persons with diabetes.

This combination of using focus groups and individual interviews is common practice as both are qualitative research techniques (Morgan, 1996). My reason for using focus group discussions in the first instance was to recruit foreign-born UK Chinese, famously known as a 'hard to reach' (Li, 1992, Parker, 1995), geographically dispersed (Parker, 1995, McKeown, 1999) and an 'invisible' (Shang, 1984) ethnic group.<sup>1</sup>

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<sup>1</sup> McKeown (1999) stated that the geographically dispersed nature of overseas Chinese people was closely linked to economic and cultural factors. In his account of the history of Chinese migration he pointed out that the driving force behind overseas migration was the pursuit of wealth and education opportunities for the second generation. According to Parker (1995), in order to maximise profit margins, Chinese families had been prepared to set up business as far away as possible from another Chinese business.

Importantly, these focus group sessions provided access to persons with diabetes. At the end of each focus group discussion, participants who fulfilled the criteria for individual interviews (see below) were identified by me and recruited by the relevant middlemen for face-to-face individual interviews. A total of eight focus group discussions were conducted as the principal route to recruit 22 participants for subsequent individual interviews. This combination of methods had been shown to be particularly effective in facilitating access to UK Chinese participants (Gervais and Jovchelovitch, 1998, Prior et al., 2000, Kwan and Holmes, 1999).

In my original proposal, individual interviews were to be my primary source of information for the following reasons:

- to discover issues that are pertinent to sufferers of diabetes,
- to explore meanings which they attribute to health and illness and,
- to investigate issues relating to management of diabetes.

In the actual study, I gathered a substantial amount of information relating to the above three areas during the focus group discussions in Phase 1 of the study. Nonetheless, I proceeded with conducting individual interviews in Phase 2 as originally planned, on the assumption that they would provide different and more detailed information on the same and other issues. This proved to be the case, with the individual interviews providing detailed information on the participants' worries about living with diabetes; their expenditure on Chinese medicine, and other significant issues.

### **1.3 Analytical considerations, scope and contribution of the study**

There were two different data sets for this study, one from focus group discussions and the other from individual interviews. In order to find answers to my research questions, I needed to access linguistic, sociological and medical information contained in this data. To do this, I adopted a pluralistic approach to analysis, augmenting a basic content analysis with elements from conversation analysis (CA) and discourse analysis (DA).

From CA, I took the focus on turn-taking and on a more basic level, the transcription conventions. However, in the latter, the documentation of pauses (.), timing (number of parenthesis e.g. 0.4), speech repairs and cut-offs during the group talk were not included. This is because Chinese orthography uses Chinese characters, each character largely corresponding to a single unit of meaning. For example, the words for diabetes in Cantonese and Chinese are made up of three separate Chinese characters 唐尿病, *tong liu beng* or *tang niao bing*, literally meaning sugar urine illness. It is not possible to 'cut' the word 唐 whereas in the English language, the word diabetes can be cut-off at the syllable dia..., leaving the rest of the word unsaid but broadly understood in the context of the conversation. This is one aspect of the techniques of conversation analysis which could not be applied to a Chinese transcript. Significantly, the data presented in this thesis is not verbatim but a translation, i.e. not in its source language, Cantonese, but in the target language, English.

Conversation analysis provided a framework within which I could understand the use of language in group settings. In Chapter 4.2.1, I gave an example of how CA was used to capture data demonstrating consensual views regarding what was considered an ideal solution to diabetes management as expressed within a group setting. Transcription symbols such as forward slash (/) and equal signs (=) were used to highlight overlaps of speech and lack of intervals between turns. These symbols draw attention to a typical Chinese conversation pattern, i.e. talking over each other and completing each other's sentence is a norm rather than an exception. This was important since norms of group interaction strongly affected what was said and how ideas were expressed about diabetes in the focus groups. As shown, the responses I obtained in the individual interviews at times differed quite significantly from those in the focus groups. Conversation analysis gave me both the methods and the analytic framework to make sense of these differences.

All transcripts were analysed for content followed by a more detailed analysis based on the principles of discourse analysis and conversation analysis to add nuances and richness to the findings. Firstly, transcripts from focus groups and individual interviews were read with the view to identify broad themes related to

diabetes, management and medicine. Content was analysed and grouped under the broad headings diabetes, causation, symptoms, illness trajectory, treatment and social significance. This yielded the following information about diabetes: unpredictability of illness trajectory, an illness caused by high sugar content in the blood and or organ malfunction, and an illness with no 'tail', to name but a few categories. Content analysis resulted in four main themes including (i) images of diabetes, (ii) cultural practice of food abstinence, (iii) perceptions of medicine and medicine- taking and (iv) a preoccupation with 'tail cutting'.

Discourse analysis was particularly useful for explaining seemingly incoherent information to non-native speakers (Nunan 1993). I noted, for example, that words and phrases related to moral imperatives such as 'I should' and words denoting control, and the lack of it, such as food abstinence and 'sneak and eat' frequently occurred in all the transcripts. Also, many participants said they ought to abstain from food items that were seen to be bad for diabetes such as roast duck. In Chapter 4.2.3, I highlighted the importance of being culturally attuned to the issue of indeterminate space in order to understand the speaker's motives. For example, Mrs Li was checking out where I worked and lived as this could determine the amount of information she would be willing to divulge at the focus group discussion.

Discourse analysis also served to highlight issues surrounding disease management strategies. For example, information related to time sequence, i.e. first... then... informs us about actions participants took when told they had diabetes. In both data sets, many revealed that their first course of action in managing diabetes was to cut down on sugar and subsequently food in general, albeit intermittently. With regards to views and use of medicine, expressions related to causality (because) and adversity (however, on the other hand) were used by the participants to explain why they chose Western medicine as the main choice of treatment. For example, Mr Lee felt that in the case of diabetes, medicine can only offer symptomatic relief, in his words " it treats the superficial and not the root of the illness".



Thus far, I have presented justification for selecting elements from different analytic approaches. CA was used primarily to illustrate how participants expressed their ideas about diabetes within a group interaction setting, highlighting areas of overlaps to indicate consensual views. Content analysis was used to extract the main themes found in both data sets. Discourse analysis facilitated the explanation and interpretation of linguistic and culturally embedded information.

An important contribution of the study is that it established that the concept of chronicity along the illness continuum was unfamiliar and illogical for the participants. The struggle with coming to terms with chronicity emerged repeatedly from examination of their description of diabetes in both focus groups and interviews. It was clear from this study that this group of UK Chinese were unable to conceptualise diabetes as an illness that could not be cured, and that it had to be managed over a long term, during which it might progress and worsen in unpredictable ways. Their failure to understand Western medical approaches to the management of diabetes was in a large part a result of this mismatch to Chinese ways of understanding illness. The idea of an illness with no 'tail' was not logically acceptable. They reported their dismay that medication could not give them the desired result, i.e. it could not bring the illness to an end or halt the illness progression. While they were generally willing to comply with what they were told to do by their Western doctors, they could not really understand why they were expected to continue taking medicine when this was clearly unable to provide a cure for the illness. Their lack of conviction in the usefulness of self-management may be a major reason for the development of diabetes-related complications.

The results of this study can help a wide range of healthcare providers, particularly clinicians, nurse specialists and dieticians to understand self-management strategies for UK Chinese with diabetes. Other professionals who may find the results useful are policy makers as they will increase awareness of effective ways of formulating meaningful and useful health-related information. Last but not least, researchers in general may find the results of this study helpful in their design of studies on migrant Chinese populations.

While the immediate scope of the study was limited to a relatively small sample of first-generation Chinese people who took part in the focus groups and interviews, plus the two British-born Chinese discussed in Chapter Ten, the results are of wider significance, since the issues that came up in this study are likely to be of relevance both for Chinese populations more generally, and for other ethnic groups in the UK and elsewhere. Above all, results from the study point to the importance for medical professionals of not just providing information, but listening actively and carefully to how people understand what is being said to them, and gaining access to the explanatory models within which they operate. This involves standing by the patient, rather than opposite them. Notably, the patient is not an empty vessel to be filled with knowledge by the healthcare professional. As Helman (1996) highlighted, patients are always partners in the healing process, and they bring their own body of knowledge to the clinical encounter, which may or may not be congruent with that of the healthcare professionals. The thesis provides numerous examples to support these statements.

#### **1.4 Recruitment**

Recruitment of participants for the focus group discussions was mainly carried out by the health workers in voluntary organisations or Chinese community centres. These health workers acted as middlemen or *zhong jian ren* (中间人), conveying the nature of the research project to potential participants on my behalf. For the individual interviews, participants were selected from the focus groups by me but approached for participation by the middleman. The use of middlemen for the recruitment of research subjects is a common practice within ethnic minority groups. In addition to recruitment, they also organised the times and dates, and provided the venue for the focus group discussions.

Prior contacts and familiarity with Chinese community workers facilitated recruitment of participants. Being Chinese, 'connected' and 'an insider' (De Andrade, 2000) proved advantageous in gaining the trust of potential participants. The importance of family and friends was one reason for including spouses, friends and carers of participants with diabetes in the focus group

discussions. Previous studies show that when family members and friends were included in focus group discussions, their presence engendered an atmosphere for a candid, normal conversation (Jovchelovitch and Gervais, 1999). In my study, spontaneity in discussion was encouraged when statement(s) from one participant initiated a chain of responses from other participants. The result was a free flow of information between participants which yielded rich data, not easily accessible in individual interviews. Key issues relating to the management of diabetes and their views on Chinese medicine and the practitioners were gathered at the focus group discussions.

Recruitment of participants for individual interviews was carried out mainly by middlemen and partly by me. Only 11 participants from the focus group discussions satisfied the criteria to be selected for individual interviews (see Section 1.6 for inclusion criteria). Conrad (1990) suggested that researchers should aim to interview between 15 to 20 participants for data to be meaningful and useful. For this reason, I proceeded to recruit a new cohort of participants via the NHS diabetes database in Leeds. This route of recruitment required permission from the Leeds and Bradford Ethics Committee. I submitted the research plan to the committee and this was subsequently approved. With the help of a consultant diabetologist at the Leeds General Infirmary, three participants were recruited. All were foreign-born Chinese. I intended to recruit British-born Chinese for comparative purposes but found none via this route.

Other methods used to recruit British-born Chinese participants included using Internet websites, joining activities organised by British-born Chinese groups around the UK and following up on referrals to other participants by participants themselves. (Details on focus group discussions, individual interviews and recruitment are presented in Chapter Three). It was particularly difficult to recruit British-born Chinese with diabetes since Type 2 diabetes is a late onset disease, and the majority of British-born Chinese are relatively young (Office for National Statistics, 2002). Following a long and protracted effort, only two British-born Chinese were recruited. My interviews with them were nevertheless of considerable interest, and data from these interviews is presented in Chapter Ten.

In the following sections I provide some general information regarding the focus group discussions and individual interviews.

### **1.5 Focus group discussions**

These were held from June to August 2005. Details of focus group discussions such as the interview schedule are presented in Chapter Three. Table 1.1 below shows the dates and locations of the eight focus group discussions. Two group discussions i.e. No. 7 and No. 8 were held on the same day, with a 30 minute interval. This was due to spatial and financial considerations, including train fares, and the availability of my assistant, Joanna (see Chapter Three). Her role was to:

- Take notes of the discussion.
- Help participants to settle down by casual chit-chat.
- Read out the contents of the project information sheet (See Appendix No. 1A and No. 1B) in colloquial Cantonese so that participants who have a low reading ability would be fully informed of the nature of the gathering and to reinforce to the participants the purpose of the forum.
- Explain to participants the need to sign a consent form (Appendix No. 2A and No. 2B).
- Help distribute supermarket vouchers (£5) to participants and assist them with completion of the form 'receipt of voucher' (Appendix No. 3).
- Help serve refreshments at the beginning and end of each group discussion.
- Give verbal and written feedback on my performance and the group behaviour.

**Table 1: Time frame for focus group discussions**

Month	Location	Focus Group	Number of participants
June	Leeds	FG No. 1	5
	Leeds	FG No. 2	4
July	Bristol	FG No. 3	4
	Birmingham	FG No. 4	6
Aug	Birmingham	FG No. 5	5
	Birmingham	FG No. 6	3
	London	FG No. 7	5
	London	FG No. 8	5
Total number of participants			37

All participants in the focus group discussions shared the following characteristics:

- Age: at least 18 years.
- Ethnicity: Chinese (foreign-born Chinese i.e. not UK born).
- Language: Cantonese and/ or Mandarin speakers only.
- Domicile: UK residents only.
- Persons with diabetes, carers and/or family members of patients diagnosed with diabetes mellitus (Note: participants other than patients could only attend in the presence of the patient(s) concerned).

37 participants were recruited, of which 30 had diabetes and seven were family members or friends. The reasons for inviting family and friends to participate in the focus group discussion are presented later.

## 1.6 Individual Interviews

Participants for individual interviews were recruited from the focus group discussions and other sources. From the focus group discussions, 11 participants were found to be eligible as they fulfilled the following criteria:

(a) They could articulate their experiences and opinions either in Cantonese or English. Speakers of other Chinese dialects with which I did not have sufficient familiarity were excluded;

(b) They could narrate their experiences on the management of diabetes and the use of Chinese medicine.

Specifically, I wanted to interview at least one Chinese person with diabetes in each of the following groups:

- People who had been diagnosed with diabetes for 20 years but had not developed any diabetes related complications.
- People newly diagnosed with diabetes with or without diabetes related complications.
- People with a positive experience of using Chinese medicine for diabetes.
- People with a negative experience of using Chinese medicine for diabetes.
- People with past usage of Chinese medicine.
- People with no past usage of Chinese medicine.
- People who claimed to be concurrently using Western and Chinese medicine for diabetes.

The rationale underpinning these selection criteria was to examine whether or not the use of Chinese medicine and its philosophy impacts on self-management regimes.

All the 11 participants whom I selected from the various focus groups agreed to be interviewed after being approached by the members of staff. These individuals acted as intermediaries between the participants and me.

The remaining 11 participants for the individual interviews were recruited through a variety of channels including snowball sampling, the Internet and via the Leeds NHS diabetes register. The selection criteria for participants for the individual interviews were broader, since I did not have prior contact with them, as I did with participants from the focus group discussions. In addition, I was also seeking to include British-born Chinese in the sample. My criteria for inclusion at this stage were therefore:

(a) Participants, as before, must have been diagnosed by their general practitioners to be suffering from diabetes, and must be able to articulate their experience and opinions in Cantonese or, in the case of the British-born Chinese, English.

(b) I looked for participants who met at least one of the following criteria:

- a long history of diabetes which has got increasingly worse i.e. increase or change in medication, developed diabetes-related complications such as renal problems;
- a long history of diabetes which is well controlled i.e. does not require an increase or change in medication, has not developed diabetes-related complications;
- a previous or current experience of using Chinese medicine (elite or folk) for diabetes;
- British-born Chinese.

The principal exclusion criteria were:

- Asylum seekers, overseas students and visitors to the UK were excluded as they are temporary dwellers and possibly have no fixed abode in the UK.

- All other ethnic oriental groups e.g. those from Vietnam, Japan, Korea and Thailand because this study focuses on foreign-born and British-born Chinese only.
- Those diagnosed with terminal illness because inclusion might cause them unnecessary stress.

Individual interviews with foreign-born Chinese were conducted between March and September 2006. Data collection officially ended on 01/10/06 as per ethics application. Within this time frame two participants agreed to meet me for a follow-up interview. At the initial interview, I suggested they visit their GP because I was concerned about their persistently high capillary blood sugar levels. The follow-up interviews were to find out the outcome of their visit to the GP. Individual interviews with BBCs were conducted between March-June 2006. Table 1.2 below shows the locations and dates of interviews with two British-born Chinese.

**Table 2: Time frame for interviews with British born Chinese**

Date	Location	Participant
27 <sup>th</sup> March	London	1
23 <sup>rd</sup> May	Teesside	1

All face-to-face individual interviews lasted approximately one hour except for one that lasted 90 minutes. Individual interviews with 20 foreign-born Chinese were conducted in the locations where the participant lived. These included: Leeds, York, Bristol, Birmingham, London and Belfast. The premises used included community centres, participants' homes, a restaurant and a public library. This is summarised in Table 1.3 below.



**Table 3: Location of individual Interviews for first generation Chinese**

	Public Library	Takeaway/ Restaurant	Community Centre	Participants' homes	University of Leeds
Leeds	1	1	-	4	1
York	-	-	-	1	-
Birmingham	-	-	4	-	-
Bristol	-	-	2	-	-
London	1	1	2	-	-
Belfast	-	-	1	1	-

Individual interviews with the two British-born Chinese were conducted in a boardroom and a student's accommodation. See Table 1.4 below.

**Table 4: Location of individual interviews of British-born Chinese**

	Boardroom	Student Accommodation
London	1	-
Teesside	-	1

### **1.7 Plan of the Thesis**

In the remaining ten chapters of this thesis, I present the following:

Chapter Two gives an overview of diabetes and highlights the global rise of diabetes. Within this chapter, I provide an account of the current state of health of the UK Chinese population with reference to the use of prescribed medicines and healthcare services provided by the NHS. There is a brief discussion of the concept of chronicity and how this could be problematic for individuals coming from a non-biomedical community. The chapter closes with a discussion on the impact of culture on illness management.

Chapter Three discusses the use of focus group discussions and individual interviews in more detail. I draw attention to the influence of Confucian social values on contemporary Chinese societies, and demonstrate the importance of understanding *guanxi* (关系) and the use of intermediaries known as middlemen or *zhong jian ren* (中间人) for recruiting participants for both phases of the study. Various sources of recruitment of participants for the individual interviews were used including the local hospital, snowball sampling and the Internet.

Chapter Four considers methodological challenges involved in the research including the ethical dilemma involved in using middlemen to recruit participants. I also highlight the ongoing debate on the advantages and disadvantages of being an 'insider-outsider'. I will show that researchers who lack proficiency in Chinese social norms may grapple with making sense of and gaining access to 'high context' information. Ethical issues such as anonymity, confidentiality and reciprocity surrounding entry into the UK Chinese people's social network via middlemen will also be presented. Also included in this chapter is a discussion on the analytic approaches used in this study.

Chapter Five introduces three topics that are relevant to the thesis. These are food, medicine and health in Chinese culture. Food categorisation and the importance of balance in a meal are discussed. It will be evident that the boundaries between food and medicine are blur as Chinese medicine, in particular folk medicine, is predominantly food based. An overview of Chinese medicine and its key concepts which are relevant to the thesis are presented in this chapter. I will demonstrate that there is a blurring of boundaries between food and medicine.

Chapter Six presents the literature on the treatment of diabetes with Chinese medicine. I provide an overview of understanding diabetes from the viewpoint of Chinese medicine and show that diabetes is believed to be a condition brought about by *yin* (阴) deficiency. The contemporary Chinese medical approach to the treatment of diabetes is to use both biomedicine and Chinese medicine.

Chapter Seven presents findings on the views of diabetes from the eight focus group discussions and 22 face-to-face individual interviews with foreign-born

UK Chinese. The idiomatic phrase 'an illness with no tail' was echoed at the individual interviews signifying the lack of acceptance of diabetes as a chronic illness. This may be a major factor for poor self-management.

Chapter Eight presents the management strategies used by the patients and carers in the study, with the main emphasis on dietary abstinence (*gaihauh/jikou* 戒口) followed by medication, attending follow-up appointments, finger prick testing and problems of engaging in physical exercises. Significantly, underpinning their illness management behaviour is the pursuit and desire to 'cut the tail of the illness'. In the individual interviews, different coping strategies reflected their attitudes towards managing a chronic condition. An emergent finding was the way uncertainties surrounding the illness trajectory were managed. An unexpected finding was the divulgence of family dynamics, including broken marriages and a confession of attempted suicide.

Chapter Nine presents findings on the use and views of Chinese medicine for diabetes. Reasons for not using Chinese medicine included a lack of trust in UK Chinese medical practitioners, cost, and lack of desired outcome. An interesting finding on this topic was information regarding the training of Chinese medical practitioners and the confidence in word of mouth when making a decision to consult Chinese medical practitioners both in the UK and abroad.

Chapter Ten presents findings from individual interviews with two British-born Chinese with diabetes including their ideas about diabetes, management strategies and views and use of Chinese medicine.

Chapter Eleven brings the thesis to a close discussing the strengths and limitations of the study and recommendations for future studies.

## ***Chapter 2: Diabetes and the UK Chinese population***

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### **2.1 Diabetes: then and now**

Chapter Two begins with a brief discussion of diabetes and current management strategies, and then presents a general survey of the UK Chinese population, before looking at issues relating to health and culture in general, including the impact of culture on illness management.

In 2009, it was reported that 2.6 million people in the UK had been diagnosed with diabetes, 90% of which were Type 2 diabetes (Diabetes UK, 2009). It is estimated that by 2025, 333 million people worldwide will be affected by diabetes (Fall, 2001, Zimmet et al., 2001). Without appropriate treatment, persistent hyperglycaemia leads to systemic organ failure such as renal insufficiency, cardio-vascular complications, gangrene, poor healing of cuts and wounds, recurrent infections, neurological complications and, finally, diabetic retinopathy that could lead to blindness.

Within biomedicine, diabetes was first considered a nutritional and metabolic disease. After insulin treatment was introduced in the 1920s, it became understood as an endocrine disease. From 1960, diabetes was generally regarded as an autoimmune or a genetic disease. The sequential change of definition is linked to on-going clinical observations and patients' response to treatment. According to our present understanding there are two distinct types of diabetes – insulin dependent diabetes (IDDM), commonly known as Type 1 diabetes, and non-insulin dependent diabetes (NIDDM), also known as Type 2 diabetes. Type 1 is characterised by absolute absence of insulin. Type 2 diabetes is the most common form of diabetes affecting large numbers of people from a wide range of ethnic groups and at all social and economic levels. Factors contributing to the development of Type 2 diabetes include age, gender, ethnicity, weight and lifestyle. This thesis deals with UK Chinese with Type 2 diabetes.

In Type 2 diabetes, the body becomes resistant or insensitive to insulin resulting in hyperglycaemia. Consequently, carbohydrates, fat and protein metabolisms are affected. It is reported that beta-cell dysfunction in the pancreas starts some 10-12 years prior to clinical confirmation of diabetes; indicating a long 'incubation period' before the illness is clinically established (UKPDS, 1998). Individuals can suffer from diabetes for a long period of time before a clinical diagnosis is made. Thus, Type 2 diabetes is an insidious illness and can be asymptomatic. By the time of diagnosis, the progress of the condition is generally believed to be irreversible.<sup>2</sup> Recently, this view has been challenged by a group of researchers in the UK (Lim et al., 2011). Currently, it is advocated that the management of diabetes be focused on delaying its onset through screening programmes, change of lifestyle and diet (Zimmet et al., 1997, WHO., 1998).

The classical signs of diabetes are complaints of thirst (polydipsia), hunger (polyphagia), excessive passing of urine (polyuria) and weight loss. The diagnosis of diabetes is clinically confirmed by a biochemical test that shows high levels of sugar in urine (glycosuria) and blood (glycaemia). Prior to the discovery of insulin in 1922, people with diabetes had to adhere to a very strict low-calorie diet to keep blood sugar levels low. Tight surveillance was the

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<sup>2</sup> However, a recent small scale study consisting of 11 Type 2 diabetics in Newcastle-Upon-Tyne, UK found that Type 2 diabetes can be reversed by reducing dietary intake (Lim, Hollingsworth et al. 2011). After an 8-week observation period, the team found that beta cell function and insulin sensitivity improved as food intake decreased. It is beyond the scope of this study to discuss the pros and cons of this single study. Suffice to say that further studies are required to build upon this initial finding.

mainstay of early diabetology, and patients' glycosuria and glycaemia were monitored regularly (Sinding, 2004).

The discovery of insulin in 1922 significantly extended the lifespan and quality of life for people with diabetes. Since its discovery, pancreatic dysfunction was considered to be the primary cause of diabetes and injection insulin its specific treatment. However, this linear model of understanding diabetes overlooks the complex and multi-dimensional causes of diabetes. Indeed, Type 2 diabetes affects large numbers of people from a wide range of ethnic groups and at all social and economic levels. It is associated with a range of factors including age, gender, ethnicity, obesity and a stressful lifestyle.

Another major breakthrough in the treatment of diabetes was the invention of reagents by Leland and Lyons in 1962. This enabled patients to monitor their own capillary blood sugar levels whenever they needed (Tattersall, 1979, Sonksen et al., 1978). This innovation enabled patients to regulate their insulin injections in relation to their daily activities, thereby avoiding the risk of insulin-induced hypoglycaemia. Subsequently, persons with diabetes were expected to monitor their capillary blood sugar levels regularly (Peel et al., 2004). Arguably, this led to medical staff implying a moral obligation to be healthy which was then internalised by patients (Blaxter, 1997).

As a consequence, the task of successful diabetes management now falls heavily on the patients and their families. Taking responsibility to control diabetes is reported to be more common among the white population compared with ethnic minority groups (Lawton et al., 2007). Indicators of accepting responsibilities for having diabetes include admissions of 'lack of exercise n' eating the wrong stuff' (ibid :895). In comparison, many UK Pakistani and Indian respondents blamed migration and its related stress for diabetes. In addition, they believed that health status was the will of God 'whatever diseases comes about will come from Allah, so what can you do?' (ibid :899).

In my study, some participants blamed themselves for having diabetes, while others attributed the disease to change of lifestyle as a result of migration (See Chapter 7). Evidence of hopelessness expressed as 'no other option' (*mouh*

*ban fatt/meih ban fa* 没办法) in regard to diabetes management and limited uptake of moral obligation emerged during the focus group discussions and the individual interviews (See Chapter 8). This information will be reported later in the thesis.

## **2.2 Management strategies**

As noted above, the current biomedical approach to the management of diabetes in the UK and worldwide emphasises self-management. This approach is based on the assumption that a combination of tight control of blood sugar levels, change of dietary and lifestyle habits and compliance with medication can significantly alter the illness trajectory and delay the onset of diabetes-related complications (UKPDS, 1998, DCCT, 1993).

Support for this approach comes from two seminal studies, the United Kingdom Prospective Diabetes Study (UKPDS) and the Diabetes Control and Complications Trial (DCCT). The first study took place in the UK from 1977 to 1997 and the main results were published in 1998. It involved 5102 patients with newly diagnosed Type 2 diabetes. The study showed that micro vascular complications were decreased by 25% when blood glucose was maintained at 7.0 mmols. By lowering blood pressure to a mean of 144/82 mmHg and improving blood glucose control, these significantly reduced susceptibility to strokes, diabetes-related deaths, heart failure, micro vascular complications, and visual loss.

The second study was conducted from 1983-1993 by the United States National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). It involved 1441 volunteers aged 13 to 39, with Type 1 diabetes and 29 medical centres in the US and Canada. The aim was to examine the link between blood sugar levels and the onset and progression of diabetes-related complications. The trial consisted of two groups of patients; one group was treated with conventional therapy and the other with intensive therapy. Conventional therapy was based on the administration of insulin once or twice a day whilst intensive therapy consisted of smaller but more frequent administered doses of insulin especially

before and after meals, combined with strict control of food intake and engaging in regular physical exercises. The intensive therapy group showed a significant drop in glycosylated haemoglobin (HbA1c) compared to the group on conventional therapy. More importantly, the trial showed that any sustained lowering of blood sugar delayed the onset of diabetes-related complications by several years.

The combined results of the DCCT and UKPDS studies significantly altered the management of diabetes. The studies implied that diabetes was never to be considered 'mild'. The British Diabetic Association (BDA) currently recommends that the treatment of diabetes must aim for the following:

- Blood pressure levels of 140/80 mmHg or below,
- HbA1c levels of 7 mmols or below,
- fasting blood sugar levels of 4-7 mmols, and
- self-monitoring of capillary blood sugar levels to be between 4-7 mmols.

Healthcare professionals assist in diabetes management by way of monitoring the patients' glycosylated haemoglobin (HbA1c) at a three to six monthly intervals. Glycosylated haemoglobin is formed when glucose molecules in the blood bond with haemoglobin in red blood cells. The HbA1c test is used to reflect the amount of blood sugar levels over a period of 8 to 12 weeks, the length of time that red blood cells usually live. Thus, the amount of glucose present on the outer wall of red blood cell indicates the glucose levels over this period (Department of Health, 2010).

Despite extensive information on the benefits of intensive therapy, it has generally been found that commitment to effective diabetes management decreases as the duration of illness increases (Lawrence and Cheely, 1980). Griffin and colleagues inform us that less than 7% of diabetes sufferers achieve optimal management (Griffin et al., 1998) while Sullivan and Joseph tell us that many patients fail to adhere to the advice given by healthcare professionals (Sullivan and Joseph, 1998). It has been suggested that failure to achieve optimal management may be due to a patient's refusal to adhere to the



constraints of living with diabetes (Sinding, 2002), and the lack of understanding on the part of healthcare professionals' about a patient's illness beliefs (Snoek, 2002).

Poor illness management results in an economic burden. In the UK context, much of this burden is absorbed by the government. A recent estimate states that about £1 million per hour is spent in the UK on diabetes-related complications (Diabetes UK, 2009). Furthermore, one in 20 people with diabetes receives care from social services because of diabetes-related disabilities (Department of Health, 2004). The next sections presents the background of UK Chinese, the study population for this thesis. This is followed by an overview of their health status.

### **2.3 The UK Chinese Population**

This section describes the early arrival of Chinese people in the UK, and also presents the current image of UK Chinese. The first recorded visit to the UK by a Chinese person was probably in 1687. Shen Fuzong (沈福宗) accompanied a Jesuit missionary, Philippe Couplet, on a tour of Europe to demonstrate the Chinese interest in Christianity. Whilst in England, he met with Thomas Hyde, an Orientalist and librarian, and instructed Hyde on the nature of Chinese language and cataloguing of the Chinese collection in the Bodleian Library at Oxford University (Benton and Gomez, 2008:23).

However, subsequent Chinese visitors to the UK were from different backgrounds. The growth of Chinese population in the UK began about a century later. This was a result of the use of Chinese seafaring labour by the East India Company. The East India Company was a British trading company based in India which dealt with the purchase of spices and other goods from China. Political unrest due to the Opium Wars (1839-1842) coupled with economic crisis led many Chinese men to emigration and seafaring. Many early migrants to the UK were from Guangzhou, the Southern province of China (Parker, 1998:68, Watson, 1977).

Unlike seamen from other racial groups, the Chinese were known to be comparatively easy to manage as they were hard working, did not get drunk as frequently, and were less likely to behave in an unruly manner. More importantly, they accepted less pay. Many Chinese seamen deserted before their contracts expired whilst others were abandoned by their unscrupulous ship owners. Around the 1880s, a growing number of Chinese seafarers were found in the docklands of London, Liverpool and Cardiff. Having limited English, these seamen adapted to the new situation and found jobs in the laundry business which required little use of English (Loh-Lynn, 1982). By 1931, 500 Chinese laundries were recorded nationwide. However, with the advent of washing machines, the laundry trade came to an end. This marked the beginning of a rise of a new profession – catering (Parker, 1995). From then on, Chinese restaurants and takeaway shops appeared in major towns and cities throughout the UK.

Similar to the laundry trade, the catering industry is labour intensive and again, workers required little English. Early Chinese workers in the catering industry were almost exclusively male, and invariably from the same village or lineage (Watson, 1977). Global events including WWII and the Chinese communist victory in China in 1949 led to an influx of Hong Kong Chinese immigrants (Shang, 1984). To control the influx of Chinese migrants, immigration legislation such as the 1962 Commonwealth Act stated that migrants were allowed into the UK only through an employment-voucher system. As Chinese in the UK were mainly in the catering trade, this invariably determined the occupation of future migrants. To date, many remain largely in the catering trade (McKeown, 1999, Parker, 1995, Shang, 1984). According to the Office of National Statistics, there were 247,403 ethnic Chinese people in Britain in 2001, accounting for 0.4% of the total UK population and 5.3% of the ethnic minority population.

The UK Chinese people are noted to be the least assimilated of all major British migrant populations (Home Affairs Committee, 1985, Pharaoh, 2009, Watson, 1977). This may be due to the nature of their occupation where there is little need to speak English or interact with the wider British community. For example, cooks and kitchen helpers required little or no English, and waiters had a wider vocabulary due to their frequent face-to-face interactions with their

British customers. Watson (1977) found that many migrants had no wish to make friends with their European counterparts because of the lack of cultural commonality.

One advantage of chain migration was that initial housing and transport were arranged by their employers, so there was little need for the migrants to venture beyond the security of their workplace. Consequently, they grew to rely on resources internal to their community rather than those available in the UK. Early Chinese settlers were members of mutual-aid societies, established to protect members against possible abuse (Loh-Lynn, 1982, Shang, 1984, Parker, 1995). These organisations also offered legal and financial support. They acted as adjudicators, settling quarrels between members and offering financial aid to send members home for medical treatment. This network of support is still evident today in the form of organisations such as the Overseas Chinese Association and the Chinese Women's Group in cities like Leeds. To date, some UK Chinese, if they can afford it, continue to return to their home country for medical help. Evidence for this is presented later in the thesis.

Another contributing factor for the lack of integration with the host community was their distinctive dispersed pattern of settlements. It has been suggested that this was the result of an unspoken agreement between Chinese restaurant and takeaway shop owners to set up business as far away as possible from each other in order to maximise profits (Parker, 1995, McKeown, 1999). Weak engagement with the host community was further linked to the fact that Chinese people viewed themselves as sojourners rather than settlers (McKeown, 1999). As sojourners, they aimed to maximise income, send remittances home and eventually return to their homeland to enjoy the benefits of their hard work.

However, current literature informs us that present day Chinese migrants are less likely than their predecessors to want to return to their country of origin (Benton and Gomez, 2008). Unlike migrants of the 1950s and 60s who left their families behind in Hong Kong, later migrants brought their wives and children to the UK. This was because they realised that children who were brought up by their grandparents in Hong Kong or China, when brought over to the UK to join their parents, had problems integrating with people from the host community. To

overcome this problem, current migrants brought their children with them. These young Chinese people who joined their parents in the UK attended local schools, were exposed to the British way of life and, significantly, became conversant in English language. As a result of their early exposure to the UK environment, many young British Chinese, unlike their parents, are employed in jobs outside the catering industry, are fluent in English and able to interact with members of the host community.

Some of the migrants' reasons for remaining in the UK included familiarisation with the British way of life and establishment of relationships with Chinese co-workers who eventually became friends. More importantly, children of these migrants were less familiar with Chinese language and culture and were fluent in English and the British way of life (Song, 1997, Parker, 1994). Subsequently, both parents and children generally decided to stay on in the UK and would return to their country of origin for holidays only. Many participants in my study said they would go to Hong Kong for holidays but not to live there permanently for various reasons including on-going medical care and treatments for their diabetes.

The decision to keep their family members with them in the UK brings problems their predecessors did not encounter. For example, they have to arrange for their own housing, transport, getting medical treatment and putting their children in schools by themselves. When confronted with the onset of illness, their lack of ability to communicate effectively with healthcare providers magnified their fear of the illness. Early UK Chinese migrants who could afford to seek help from Chinese medical practitioners relied on Cantonese-speaking Indian physicians who had lived in Hong Kong and were now practising in London (Watson, 1977). But in the case of diabetes, the need for life-long medicines and follow-up care makes the use of Chinese medicine financially and spatially unsustainable, as well as other reasons, as demonstrated in my study.

Until recently, the UK Chinese population has generally been seen as a hard-working group involved mainly in the catering industry. However, a disturbing development is slowly emerging. A new group of sojourners, mainly from the province of Fujian, is drawing attention to the Chinese people including the

already established Cantonese-speaking UK population – the ‘Old-timers’ (Beck, 2007:141). Unlike their predecessors, recent Fujianese migrants are largely illegal immigrants, involved in work such as collecting cockles, street vending and other types of seasonal jobs. They gained media attention in June 2000 following the deaths of 58 illegal Fujianese migrants found suffocated in the back of a lorry at Dover. A second tragedy struck in 2004 when a group of 20 Fujianese cockle-pickers were drowned at Morecambe Bay. These events have serious repercussions on the new sojourners in terms of employment. Any kind of catering work that was previously possible has gradually become denied to them due to their illegal status. The two incidents resulted in intervention from the immigration service. Cantonese speaking owners of Chinese restaurants and retail shops stopped hiring illegal Chinese migrants. Divisions between the ‘Old-Timers’ and the ‘Newcomers’ are emerging, changing the image of UK Chinese.

Thus far, I have presented a brief overview of the UK Chinese population. Unlike the current profile of foreign-born UK Chinese people who are mainly known for their culinary skills, the first Chinese visitor to the UK made contributions to the academic sector. The evolving development and perception of UK Chinese is currently that which is highlighted in the media as illegal immigrants and involved in various types of work as mentioned previously. For the purpose of this study, only the ‘Old-timers’ were included, predominantly because of language compatibility and domicile status, and also for other reasons as detailed in later chapters. The next section presents an overview of the health status of UK Chinese.

**Table 5: UK population 2001**

	Total population		Minority ethnic population
	Count	%	%
<b>White</b>	54153898	92.1	n/a
<b>Mixed</b>	677117	1.2	14.6
<b>Asian or Asian British</b>			
Indian	1053411	1.8	22.7
Pakistani	747285	1.3	16.1
Bangladeshi	283063	0.5	6.1
Other Asian	247664	0.4	5.3
<b>Black or Black British</b>			
Black Caribbean	565876	1.0	12.2
Black African	485277	0.8	10.5
Black Other	97585	0.2	2.1
<b>Chinese</b>	247403	0.4	5.3
<b>Other</b>	230615	0.4	5.0
<i>All minority ethnic population</i>	<i>4635296</i>	<i>7.9</i>	<i>100</i>
<b>All population</b>	58789194	100	n/a

The UK population: by ethnic group, April 2001(source: ONS)

### 2.3.1. The Health Survey of England Data

According to a UK survey, the overall health status of UK Chinese is arguably the best among all British black and minority ethnic groups (BMEGs), and is even comparable to that of the general population (Department of Health, 1999). In Britain, minority ethnic groups are identified on a combination of race, skin colour, country of origin and language. This categorisation of ethnic groups is constantly modified and contested due to its political, theoretical and practical implications (Sheldon and Parker, 1992, Donovan, 1984, Bhopal et al., 1991). Despite its criticisms, continuous usage in health and social research demonstrate its usefulness, albeit limited, in epidemiological studies such as obesity (Saxena et al., 2004) and incidences of cardiovascular diseases (Brindle et al., 2006) in ethnic groups. Similarly, the Health Survey of England (1999) used this categorisation criteria to determine the health status of ethnic groups.

It is however, worth looking more closely at this survey and how it was conducted. The determinants of health status were based on three supposedly objective markers:

- low prevalence of long-term illness,
- low use of prescribed medication, and
- low uptake of healthcare facilities such as services provided at general practitioners' surgeries.

The survey used self-assessment reports on the prevalence of long-term illness<sup>3</sup> as one of the markers of good health. Informants were asked to state whether they have long-term illnesses.

A problem with this method of assessment is that long-term illness is interpreted differently between ethnic groups (Howlett et al., 1992). For example, UK Chinese would affirm the presence of a long-term illness if their abilities to work, eat, exercise and maintain interpersonal relationships were compromised (Sproston et al., 1999). Therefore, self-reporting of long-term illnesses is not a reliable marker for general health status because it does not take into account variations in the interpretation of health and illness (Kelaheer et al., 2003).

Calderwood and Tait (1999) advanced the argument by proposing that reporting of long-term illnesses among black and ethnic minority groups is influenced by:

- differences in perceptions of health and illness,
- 

<sup>3</sup> Within this survey, long-term illnesses are those that affect the individual indefinitely, with or without disabilities.

- cultural and linguistic elements which affect the interpretation of questionnaires,
- lack of willingness to disclose information on health, and
- lack of knowledge about their own health conditions.

Consequently, the low rates of long-term illnesses reported among black and ethnic minority groups might in actuality be a case of under-reporting, while among other ethnic groups, including the general population, it is the direct opposite i.e. over-reporting (Calderwood and Tait, 1999). In interpreting such data, it is important to be aware that lay perceptions of health and illness do not always correspond with those of healthcare professionals, and can also vary in relation to culture (Kleinman, 1988).

The second and third markers utilised to assess the health status of the UK population included the uptake of healthcare facilities and the use of prescribed medicines. Among UK Chinese, these were noted to be remarkably low across all services including GP, mental, dental and screening facilities (Department of Health, 1999, Smaje and Le Grand, 1997, Sproston et al., 1999). It is unclear whether these low figures indicate good health, or a tendency to avoid Western medical treatment. If it is because of the second option (i.e. a low rate of uptake for Western medical treatment), this would be a significant cause for concern. This is because diabetes is generally diagnosed at primary care level, i.e. at general practitioners' surgeries, and the medicine used in the management of diabetes are only available on prescription.

In fact, the rate of diabetes among the UK Chinese population, according to Department of Health, appears to be comparable to or somewhat higher than its prevalence among the general population. In the 1999 and 2004 health surveys, the figures were slightly higher in both cases, but the difference was not statistically significant. This suggests that there is a genuine problem in relation to the low rate of uptake of Western medical treatment for diabetes.

The low rate of uptake, if it is true, raises two questions:

- What health measures are UK Chinese using for their diabetes?



- How do they manage and control their illness?

Little research has been done so far to provide answers to these questions. As stated above, the present study is directed towards meeting this gap in our knowledge. As diabetes is a chronic condition, it is appropriate to present an introduction to the concept of chronicity.

## **2.4 Chronicity**

As with other chronic illnesses, diabetes is a health condition that can be controlled but not cured. A significant issue in this study is the question of how UK Chinese understand the chronic nature of diabetes. As we will see, there is resistance among UK Chinese to accepting that there is no cure for the disease, and it seems likely that the concept of chronic illness does not fit well into the explanatory models through which Chinese patients make sense of their illness. I therefore provide some introductory discussion here of the question of chronicity.

Over the past two decades, interest in qualitative research on chronic illnesses has grown considerably. Many physicians recognise that management of long-term illnesses is more likely to involve non-medical rather than medical treatment (Conrad, 1990). Studies have opened up new lines of inquiry regarding basic conceptualisations about chronic illnesses such as rheumatoid arthritis (Bury, 1982, Williams, 1984), multiple sclerosis (Robinson, 1990), asthma (Chavez, 2008) and its treatments. In particular, some have asked how illnesses that cannot be 'cured' are viewed by those from non-biomedical culture (Hurd and McIntyre, 1996, Anderson et al., 1991). This raises the question of whether all people have a concept of illness as potentially chronic.

Practitioners of biomedicine use the category of chronic illness to refer to ongoing states of disease that have continuity over time and may or may not involve progressive degeneration. It has been suggested that chronicity is a concept constructed and learned by persons in societies dominated by biomedicine (Lefley, 1990, Kleinman, 1988). Such a view implies that individuals in such societies are acquainted with the notion of chronicity even

before they approach a medical practitioner. However, what biomedicine regards as chronic illness may be viewed differently by persons who have grown up in other societies. In any case, curing is central to all healing systems, and the current incurability of diabetes presents a dilemma for both patients and healers.

## **2.5 Impact of culture on illness management**

It is widely documented that understanding cultural norms is essential for the planning and delivery of diabetes care. Cultural norms are enacted in activities such as food, lifestyle and social practices. The term culture encompasses a broad range of ideas including belief systems, norms of behaviour, language, religion, worldviews and ethnicity. Belief systems are based on a body of knowledge that is accepted to be 'true' by individuals within a cultural group, learned through social interactions and transmitted by a common language.

The study of the impact of culture on illness management was pioneered by Kleinman (1980). Kleinman's research was mainly with Chinese people in Taiwan, so cultural differences relating to Chinese populations were part of this discussion from early on. Much subsequent work has examined Chinese populations both in East Asia and in the diaspora in Europe and North America (Leong et al., 2003, Jayne and Rankin, 2001, Gervais and Jovchelovitch, 1998).

Kleinman devised the concept of the 'explanatory model' which provides a framework to gain insight into cultural patterns of behaviours, meanings which individuals assign to health and illness and ways in which they evaluate treatments. These items contribute to the clinical realities which patients and healers bring to medical encounters. An understanding of these clinical realities facilitates illness management because it 'tells us something about how practitioners understand and treat sickness [...] how patient and family [...] make sense of [...] illness and how they choose and evaluate particular treatments' (Kleinman 1980:105).

The clinical realities of lay people and their subsequent approaches to illness management are often dissimilar to the biomedical model (Robinson, 1990,

Kleinman, 1988, Helman, 1996). For example, among a group of African-American women ( $n=60$ ) in New Orleans, Heurtin-Roberts found that there are two interpretations of hypertension: 'high-pertension' and 'high blood'. Management of hypertension depended on what they felt contributed to their condition. 'High blood' was considered to be a disease of the blood, not curable but controllable by medicine. On the other hand, 'high-pertension' was a disease of the nerves and medication was not thought to be particularly helpful (Heurtin-Roberts, 1993, Heurtin-Roberts and Reisin, 1992).

According to lay theories of diabetes, individuals identify a range of causative factors for their illness onset. This includes personal blame of excessive eating and lack of exercise (Arcury et al., 2004), *susto* a form of folk illness (Rubel, 1964, Poss and Jezewski, 2002), environmental factors (Garro, 1995, Lang, 1985), or ill fate (Jayne and Rankin, 2001, Shui and Wong, 2002, Donovan, 1986, Lawton et al., 2007). In the case of diabetes, studies inform us that food in general and sugar and fatty food, in particular, were identified by sufferers as the main reason for diabetes (Arcury et al., 2004, Greenhalgh et al., 1998, Lawton et al., 2008).

It is suggested that clinical realities are influenced by race, ethnicity, and ecological issues such as the physical environment. I consider these in turn in the following sections.

### **2.5.1 Ethnicity and race**

The term ethnicity is commonly associated with race. These terms are loosely used to refer to a range of human groupings. Although the terms ethnicity and race are problematic in many ways, both terms continue to be used by health service researchers as variables in studying prevalence of chronic diseases (McKeigue et al., 1991), treatment adherence (Lawton et al., 2006) and self-management of chronic illnesses (Whitford and Al-Sabbagh, 2010). From the point of view of this thesis, it is sufficient to regard the UK Chinese population that I am studying as an ethnic group which is culturally distinct from the general UK population.

Differences between ethnic groups have been demonstrated to be significant in relation to self-management of diabetes. Lawton et al (2006) reported that many UK Pakistanis with diabetes were not engaging in physical exercise as part of their treatment adherence. A comparative study between two ethnic groups with diabetes was conducted in Bahrain and Ireland by Whitford and colleagues (2010). Many Bahrainis believed that developing diabetes was a result of chance, verbalised as 'Insha Allah- if it is God's will'(:180). It was extrapolated that generally Bahrainis were less likely to adopt healthy lifestyles in terms of diet and exercise to halt the onset of diabetes-related complications. In contrast, many Irish participants believed that diabetes could be controlled by their health behaviours and were noted to score highly in taking responsibility for their illness (Whitford and Al-Sabbagh, 2010). Cumulative research linking ethnicity to success or failure in illness management validates the need to consider including issues related to ethnicity when planning health education programs and in facilitating effective self-management regimes. This does raise the question: if ethnicity is related to successful illness management, does it mean that some ethnic groups are more pro-active in illness management than others? The interest in ethnic groups on illness management regimes suggests that some ethnic groups indeed do better than others. Within the context of this thesis, I will demonstrate that ethnicity alongside other variables such as language barriers, illness perceptions and others factors impact on illness management amongst ethnic minority groups.

### **2.5.2 The physical environment**

Within the context of illness management, the physical environment refers to the healthcare structures and the services offered by primary care services, clinics and hospitals, and delivered by doctors, nurses, dieticians and all other auxiliary medical staff. The tasks of the healthcare team include (i) a close monitoring of the patient's efforts to achieve and maintain normal blood sugar levels, (ii) delivering health education programmes and (iii) carrying out periodic health assessments.

One major hurdle faced by many ethnic minority groups in the use of healthcare facilities is language insufficiency (Pharaoh, 1995, Ahmad et al., 1989, Watt et al., 1993, Liao and McIlwaine, 1995). Regardless of years of residency in the UK, many foreign-born UK Chinese attend medical consultations with limited English (Pharaoh, 2009). Consequently, healthcare services were misused, e.g., using accident and emergency services when a phone call to their doctor would have sufficed (Watt et al., 1993). Other studies echoed the repercussions of language barriers, stating that it limits the use of healthcare facilities and reduces meaningful communication between patients and members of staff in the healthcare team (Gerrish et al., 2004, Facione et al., 2000, Ngo-Metzger et al., 2003). Many refrained from using the healthcare services unless they were seriously ill (Gerrish et al., 2004). Frequently, poor communication can lead to late presentations of illnesses among UK Chinese people.

In relation to diabetes, effective communication with healthcare professionals is the cornerstone of successful self-management. For example, two North American studies reported that foreign-born American Chinese patients who were regularly monitored on their health practices fared better than those who were not monitored closely. The group of patients who were closely monitored had their blood pressure and serum glucose kept within acceptable limits (Chesla and Chun, 2005, Wang and Abott, 1998). In a Taiwanese study, Lai et al (2004) demonstrated that when there were regular contacts between patients and healthcare professionals, onset of diabetes-related illnesses were markedly delayed. These results echo those mentioned earlier in the UKPD and DCCT studies. The authors noted that during patient-healer contacts information given by doctors was acknowledged and adhered to by many Chinese patients both in Taiwan and Canadian Chinese migrants (Lai et al., 2004, Jayne and Rankin, 2001).

However, not all Chinese speaking patients with diabetes respond positively to advice on diabetes-related health habits. Patients from Hong Kong and Taiwan expressed frustration that health professionals did not seem to take into account the difficulties of living with diabetes (Lai et al., 2005, Shiu and Wong, 2002). In the North American studies, many Chinese patients express that environmental constraints such as employment and medical insurance make it difficult for them

to live with diabetes (Anderson et al., 1991, Fisher et al., 2004, Chesla and Chun, 2005).

## **2.6 Summary**

In summary, this chapter has provided information on the current medical management and nature of diabetes, guided by the findings from two seminal studies; the UKPDS and DCCT. Effective management can delay and prevent the onset of diabetes-related complications. Pivotal to successful self-management is the willingness and ability of patients to make changes in dietary and lifestyle habits, including, if required, compliance with medicines. This implies that illness progression is closely linked to the patients' adherence to treatment strategies. However, both the willingness and the ability of patients to make changes and adhere to Western medical treatment depend on their appreciating the importance for the progress of their illness of making these changes. The biomedical model of diabetes management fails to take into account the patients' own explanatory models, and the ways in which these may fail to match the models assumed by biomedical specialists. In particular, individuals who do not share the biomedical concept of diabetes as a chronic illness may struggle to accept the onus of illness responsibility and comply with recommended management strategies. Divergence between explanatory models appears to be especially acute when patients come from a community which engages in the practice of traditional medicines. With regards to Chinese people living outside Chinese speaking communities, studies report that foreign-born Chinese have found it difficult to communicate meaningfully with healthcare professionals. This may be due to cultural and linguistic barriers. These difficulties can potentially affect illness management. The need to understand the consequences for illness management of the mismatch of explanatory models and consequent failures of communication between medical staff and patients is a primary theme of this thesis, and will be explored at length in subsequent chapters. First, however, it is necessary to examine how the sample was recruited, and to discuss the methodology of the research. These are the topics of Chapters Three and Four.

## ***Chapter 3: Recruitment, Focus groups and Interviews***

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### **3.0 Introduction**

This chapter discusses the process of recruitment of the participants in the study. As mentioned in the introduction, the study used a combination of focus groups and individual interviews, with the focus groups in the first phase providing the basis for the recruitment of participants in the individual interviews in the second phase. In this chapter, I explain in detail how the participants at each stage were recruited, and how the focus groups and interviews were carried out.

As part of this chapter, I also provide a discussion of the importance of *guanxi* (关系) and the use of intermediaries known as middlemen or *zhong jian ren* (中间人) within Chinese culture. These are part of the enduring legacy of Confucian social values among foreign-born UK Chinese. My awareness of these cultural norms facilitated the successful recruitment of participants for both phases of the study. Participants for the focus group discussions were mainly recruited by the middlemen. Similarly, middlemen were pivotal to the recruitment of participants for the individual interviews. In addition, I used a variety of methods including recruitment from the local hospital, snowball sampling and the Internet.

Focus group discussion is a research technique used to collect data through group interaction on a topic determined by the researcher (Kreuger, 1994). A focus group is 'a carefully planned discussion designed to obtain perception on a defined environment' (Kreuger, 1998). A lively interaction between group members indicates a successful focus group discussion (Kitzinger, 1994, Morgan, 1998, Myers, 1998). It has been noted that some studies used focus groups as a quick method of data collection (Smithson, 2000) rather than for the collection of group worldviews.

It is often said that data collected using focus group discussions tend to be sketchy (Agar and MacDonald, 1995, Morgan, 1996), in part because the

information may be influenced both by the interactions amongst participants and the techniques of the facilitator<sup>4</sup> (Wilkinson, 1998, Kreuger and Casey, 2000, Agar and MacDonald, 1995). In practice, the focus groups for this study were a major source of data, providing substantial information on the research questions. This was in part because the interaction within the group became a positive resource, rather than a problem. The reasons why this was so are explored in more detail in Chapter Four, in relation to cultural and linguistic issues.

In terms of group sizes, a focus group discussion with fewer than six participants is generally regarded as limiting the amount of potential collective information, while a group with more than ten participants is said to make it difficult for everyone to contribute to the discussion (Pope and Mays, 1995, Kreuger and Casey, 2000). Thus, current guidelines on the size of focus group discussions recommends a group size of between six and ten participants (Kreuger and Casey, 2000). The group size in my study ranged between three and six members in each group. This is because Chinese people in general are

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<sup>4</sup> A person conducting a focus group is often referred to as the moderator. In this study, I used the term facilitator because it is consistent with my role in enabling talk and mediating exchanges between participants. In line with Myer's (2007) rationale for the term facilitator, when one of the participants said "it is just empty talk", I interjected and said "it's what he wants [for his diabetes]". This response puts me in the position of the 'second speaker' and projects the previous speaker as having an opinion and encourages contribution from the other group members. In this instance, I acted as a 'second speaker' and carefully channelled the discussion and opened the topic to other group members. In this way participants' input in data generation increases and my input diminishes.



noted to take short turns and interlocutors tend to complete each others' sentences (Gudykunst, 1998, Yum, 1988). Consequently, I found it necessary to restrict the number of participants in each group considerably to enable data to be sufficiently captured when group members talked over each other. However, this relatively small group size also made it possible to capture the interaction in the focus group in considerable detail, providing a rich source of data for the study.

Thus a substantial amount of information was gathered at the focus group discussions. While much of this was confirmed at the individual interviews, the interviews also gave a more complex and detailed picture in important respects. The interviews were also aimed at obtaining a different and complementary kind of data, an in-depth understanding of the participants' perceptions and experiences of living with diabetes. As in other studies (Anderson et al., 1995, Kwan and Holmes, 1999, Kleinman, 1988) I found that at individual interviews participants were more willing to divulge information on issues such as their expenditure on medicine, personal histories and their anxieties of living with diabetes and its complications. Furthermore, consensual views expressed at focus group discussions were at times contradicted at individual interviews. In addition, voices from persons with diabetes were not contaminated with the views of family and friends. Importantly, it was through individual interviews that I gained most insight into the participants' 'explanatory models' (Kleinman, 1977) and the thought processes underpinning their health-seeking processes and illness experience.

At the individual interviews, which were guided by my interview schedule (Appendix No. 16), I found out how participants first noticed that something was wrong, and what this meant for them; what existing knowledge helped them to make sense of this change; what they did about the problem; how they came to seek medical help; what concerns and expectations they had regarding treatment; how the diagnosis impacted on their personal and social life; and how they coped with adhering to a medical regime. The data gathered at individual interviews deepens our understanding of the experience of people who suffer from diabetes, in particular the UK Chinese population.

### 3.1 Guanxi (关系): magnetic threads, human web

In this section, I discuss the concept *guanxi* to demonstrate its centrality in the successful recruitment of participants, and their willingness to contribute information for and to participate in this study. Within the context of Chinese communities, *guanxi* is a complex social phenomenon. Broadly speaking, there are two types of *guanxi* – economic and social *guanxi*, mediated by two elements, one being tangible i.e. the *zhong jian ren* (中间人) or middlemen (King, 1991) and the other being an intangible element called *renqing* (人情), loosely translated as human feelings. *Renqing* (人情) is a sentiment which not only helps establish but sustains *guanxi*. Thus, *guanxi* brings individuals together, denoting a positive aspect.

On the other hand, it can also be viewed as a ‘human web’ *ren qing wang* (人情网) suggesting negativity and being locked or trapped in a community (Jacobs, 1979). Both aspects of *guanxi* were experienced by me in this study. A common Chinese phrase *la guan xi* (拉关系) meaning ‘pulling strings’ was demonstrated by various middlemen working in Chinese community centres and voluntary organisations as managers, health workers or receptionists. These individuals brought potential participants into contact with me for the study. The specific forms that *guanxi* networks take in Chinese society are strongly conditioned by Confucian values and the associated forms of social relationships between individuals.

Jacobs (1979) showed that *guanxi* ties among Chinese people in Taiwan are ‘particularistic[...] depend[ing] upon two or more persons having a commonality of shared identification’ (Jacobs, 1979:243). Examples of particularistic ties are parent-child and sibling-sibling relationships; these are preordained. Thus, preordained ties are kinship based i.e. individuals are related to each other through familial relationships such as parents, siblings, cousins and anyone related to the family via blood relations or marriage. On the other hand, ties between husband and wife and between friends are voluntarily constructed. These ties are established through work or schooling, or shared place of birth,

surnames, dialect grouping and religious affiliation, allowing individuals to become 'related'.

I have no ties with the UK Chinese community. I am a Chinese migrant who came from Singapore in 1990 to work as a nurse. This meant that the chances of meeting and knowing UK Chinese were limited. As mentioned in Chapter One, foreign-born UK Chinese mostly work in the catering trade. For me, entry into their community came about as a result of my desire to speak and write Chinese, *Putonghua*. In 1996, I enrolled on and subsequently graduated with a degree in Modern Chinese Studies at the University of Leeds.

As a result of my university programme, I was able to form a tie with a university classmate who facilitated access to the Chinese community in Leeds and London. This British-born Chinese classmate, after graduation, found work with a local community centre that worked with Chinese people living in Leeds. Through him I was introduced to his Chinese contact, Joanna, who not only volunteered to assist in seven focus group discussions but also introduced me to her church colleague, Perry, a manager of a Chinese community centre in London. Through Perry two focus group sessions were arranged on my behalf. This chain of introductions helped me become a member of the 'in-group' (Nisbett, 2005) community. Thus, within three months, seven focus group discussions were arranged by the middlemen and conducted by me. Without an initial contact with a member of the Chinese community, i.e. the British-born Chinese classmate, it would have been difficult for me to gain access to this 'invisible ethnic group' (Shang, 1984).

However, access does not necessarily lead to recruitment of participants. Notably, willingness to participate in and contribute information to a research project are dependent on whether or not they were approached by someone familiar and trusted by them. For example, in my study, Mr Mun, a participant with diabetes, indicated that unless familiar persons were present in the group discussion, he would not participate.

Mr Mun: If those two didn't arrive, I would have left. (Focus Group No. 6, Birmingham)

His statement indicates an unwillingness to share information with strangers, and suspicion towards strangers (Barata et al., 2006).

Membership of the *guanxi* network is not without a price. As mentioned earlier, feelings (*renqing* 人情) is a sentiment linked to *guanxi*. By default, members of the *guanxi* network are caught in the 'human web' (*renqing wang* 人情网). This means that members are obliged to respond to the social or economic requests of other members. Presumably, participants agreed to attend focus group meetings because the middleman had approached them. Their agreement to participate can be seen to be a gesture of returning a favour to the middlemen who had acted as their interpreters at medical consultations.

So strong is the relationship between participants and the middleman that one of the middlemen felt that she could interrupt the focus group session to check on whether the participants whom she had approached had honoured their promise to attend. The following extract demonstrates a middleman interrupting the group discussion:

Middleman: I'm here to check. We should have 7 or 8 participants. There is Mr and Mrs Wong and Fong and Ling who said that they were coming. I need to go to the doctors with your second brother. And then there was Liu. He said he would come and now he is not here. What can I do?

Mr Mun: That's no good. That's not reliable.

Mr Lee: If I promise to come, I will definitely come.

(Focus Group No. 6, Birmingham)

Upon establishing myself as an in-grouper at the primary research site, Leeds, I found that one way of sustaining *guanxi* was to engage in the 'human web' (*renqing wang* 人情网) by doing voluntary work. This included teaching Chinese as a second language to British-born Chinese who were children of members of the Chinese community centre, helping out with administrative work, and acting as a medical interpreter for clients of the voluntary organisations. These voluntary duties helped me gain access to other members of the *guanxi* network, and subsequently recruit participants for the study.

As for recruitment of participants in Bristol, I made contact with members of staff from a Chinese community centre in Bristol where in the past I had carried out a period of voluntary work. The manageress agreed to recruit participants on my behalf. Studies on Chinese diasporas inform us that being associated with a group member qualifies one to be an 'in-group member' (Nisbett, 2005), and facilitates interactions with other members of the group (McKeown, 1999).

Apart from Leeds and Bristol, recruitment of other participants involved making telephone calls and writing letters to various Chinese community centres. After a few trails went cold, one health worker at a youth centre in Birmingham agreed to help. Together with another colleague, the health workers in Birmingham organised three focus group meetings, with a total of 14 participants (Focus Groups No. 4, 5 and 6). The participants from Focus Groups No. 4 and 5 were clients of the community centre. Those in Focus Group No. 6 were acquaintances of the middleman from the local casino. They agreed to do her a favour by participating in the study. After three months of correspondence with the middlemen from Birmingham, I was able to conduct three focus groups sessions in Birmingham.

In London, two focus groups were organised by a health worker who knew Joanna through attending the same church. After a number of telephone calls and e-mail correspondence, two focus groups were organised by the London health worker. The speed of recruitment in London demonstrates the influence of *guanxi* when seeking help from Chinese individuals who know each other. Thus, when members within the in-group are known or 'related' to each other, the process of communication between parties is expedited. In contrast, in Birmingham, where I was not known to any members of the organisation, either personally or through another in-group member, the recruitment process was comparatively slower.

### **3.2 Practicalities: conducting focus group discussions**

All focus group discussions were held in Cantonese, led by me and assisted by Joanna. Keywords for the research project were written on A3 flipchart paper in

Chinese to guide participants in their discussion. The keywords were 'diabetes', 'Chinese medicine', 'patient experience', 'food and beverages', 'exercise and weight'. In addition, the topic of discussion 'How do UK Chinese manage diabetes and do they use Chinese medicine for it?' was written in large Chinese calligraphy and attached to both sides of the flipchart paper (see Fig.1 below)

Figure 1: Focus group discussion setting



A semi-structured topic guide (see below) was used in all focus groups. The topic guide was verified by two Chinese language experts. Both were lecturers in Chinese studies at Leeds University. The topic guide included three broad categories of questions related to (i) illness knowledge, (ii) management regime and the use of Chinese medicine, and (iii) patient experience. With the participants' permission, all discussions were audio-taped, using a Sony mini-disc recorder with a multi-directional microphone. Verbal followed by written consent was obtained before commencement of each discussion sessions. Contrary to conventional methods of specifying ground rules, turn-taking and confidentiality (see Section 4.2), both Joanna and I used indirect speech patterns to convey these aspects at the focus group discussions. Evidence of and justification for using indirect speech patterns can be found in the findings chapters.

With regards to costing, for the focus group discussion held in Bristol, I had to pay for the use of office space and an administration fee for making contacts

with participants. No such payments were requested by other organisations. However, as a goodwill gesture, I offered a nominal fee of £10 towards the focus group discussions held in Birmingham for the use of office space. As for the focus groups held in London, I paid £20 for refreshments for the participants.

**An English translation of topic guide used in all focus groups (with revisions after the third focus group discussion. Appendix No. 4)**

Illness knowledge	How did you know you had diabetes? How long have you had diabetes?
Management regime	How do you manage diabetes? How long do you have to take the medicines? Since you were diagnosed with diabetes, what changes (if any) have there been? What are your views and experience of using Chinese medicine for diabetes?
Patient experience	Tell us about your visits to the doctor. Who goes to see the doctor with you? What does the doctor tell you about your illness? What advice did they give you about diabetes?

Each focus group discussion lasted approximately one hour. This proved to be sufficient time for key issues to be addressed. An exception was in Focus Group No. 1 where discussions carried on during time set aside for snacks and refreshments.

**3.3 Individual interviews**

Half of the total number of participants in the individual interviews, i.e. 11 of the 22 participants, were recruited from the focus group discussions – two from Leeds, two from Bristol, two from London and five from Birmingham. One participant from Focus Group No. 6 (Birmingham) was eligible and approached but declined to participate due to holiday arrangements. However, a new participant was recruited by the middleman in replacement. The remaining half of the total number of participants was recruited through other means. They formed a new cohort of participants consisting of non community centre users

and British-born Chinese. To recruit this new cohort, I placed poster advertisements written in Chinese in Chinese community centres, voluntary organisations and Chinese supermarkets (Appendix No. 5). A friend in Leeds agreed to approach Chinese people from her church.

The following describes the process of recruitment for new participants. As per research protocol, I spoke to a member of staff in the Central Allocation Service (CAS) and Research and Development (R&D) to seek advice as to whether the study needed approval from the ethics committee. As I was recruiting from the National Health Service (NHS), I had to apply for ethics approval (Appendix No. 6). This was submitted and subsequently approved by the ethics committee of Leeds and Bradford, Reference: 05/Q1202/108 (Appendix No. 7) and the Research Governance Department at Leeds General Infirmary

I was also advised to speak to a member of staff at Leeds Primary Care Trust (PCT) who suggested that I contact the local diabetologist (Appendix No. 8). He identified a list of 24 Chinese sounding surnames from approximately 12 000 names in the Diabetes Database at Leeds General Infirmary. He then signed a cover letter that introduced the aims of the PhD study to potential participants (Appendix No. 9 and No. 10). In this way, the diabetologist acted as a 'buffer' between the patients and myself, thereby adhering to the Data Protection Act. The recruitment of participants for individual interviews via the hospital yielded only three participants and all were foreign-born Chinese.

The personal and social networks of various middlemen yielded four participants. The first participant was introduced by Joanna's co-worker, the second was a participant's younger sister. The third and fourth participants were introduced by a British-born Chinese. These two participants live in Belfast, Northern Ireland.

### **3.3.1 British-born Chinese**

The recruitment process for British-born Chinese was primarily achieved through the Internet websites including *Britishbornchinese.org.uk* (Appendix No. 11), *BritishChinese.org.uk* (Appendix No. 12) and *Diabetes Insight Support*



*Forum* (Appendix No. 13). The advertisements were entitled 'PhD Research Project'. On the *Britishbornchinese* website, initial viewing rates of my request for participants were high, and a number of questions were posed by the members (Appendix No. 14). I recruited two participants from the *Britishbornchinese* network and two from *Diabetes Insight Support Forum*. Of the four participants recruited, only two were British-born, the others were foreign-born Chinese who were fluent in the English language.

In addition, I also made efforts to engage socially with British-born Chinese. This included participating in their organised social gatherings called 'meets' and other group events such as the annual British-born Chinese country walks held over the August Bank Holiday weekend. During these gatherings, young British Chinese from all over the UK gather to socialise. I took part in the annual gathering held in August 2006 which entailed climbing the Three Peaks (I only climbed one). Through this outing, I recruited one British-born Chinese.

### **3.4 Summary**

This chapter has described and provided justification for the research methods used in this study. The focus group discussions were both an important source of data in their own right and also served as a vital route to recruiting persons with diabetes for individual interviews. For successful recruitment of Chinese participants at both stages, I highlighted the importance of *guanxi* and *zhong jian ren*. These two factors contributed to swift access to foreign-born UK Chinese but did not apply for British-born Chinese. Despite using various recruitment techniques, only two British-born Chinese were recruited. Within this chapter, I also presented details about the practicalities of conducting focus group discussions including keeping the size of the groups small due to the nature of Chinese conversation patterns whereby members speak over each other, and the use of key words written on a flip chart to keep the discussions focused. In the next chapter, I look in detail at further methodological issues involved in the study.

## ***Chapter 4: Methodological considerations***

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### **4.0 Introduction**

In this chapter I discuss a number of methodological issues associated with the project. These challenges include dealing with middlemen to gain access to participants, managing cultural and linguistic issues, ensuring accuracy in translation, analysing audio-recorded data, and juggling anonymity, confidentiality and reciprocity. In addition, I consider the methodological challenges involved in researching my own cultural group, and demonstrate the ways in which I sought to ensure the reliability and validity of the findings. This information is delivered in four broad sections.

In Section 4.1, I present the sampling frame, and the use of middlemen to recruit participants for this study. The sites of recruitment included Chinese community centres, voluntary organisations and a local hospital. As recruitment relied largely on the middlemen, a handful of unsuitable and misinformed participants were present in two focus group discussions.

In Section 4.2, I present the cultural and linguistic challenges involved in researching Chinese people living in the UK. This includes (i) ensuring reciprocity with the middlemen, and maintaining anonymity and confidentiality for the participants; (ii) managing Chinese terms of engagement such as the use of code-switch, (iii) socio-linguistic issues such as the indeterminate linguistic space, indirect speech styles and the yes-no speech ambiguity, and; (iv) translation issues. In Section 4.3 I discuss the issue of positionality, i.e. (i) ways in which I was not an 'insider', (ii) the seduction of sameness and (iii) personal status and identity.

In Section 4.4, I give a detailed account of the way the data was analysed. Finally, Section 4.5 provides a summary to this chapter.

## 4.1 Sampling

A sample refers to a group of individuals who represent or have knowledge of the research topic. Participants in this study were Chinese people with the right of abode in the UK, and had been diagnosed with diabetes by their doctors. There are two general approaches to sampling: probability and non-probability sampling. Probability sampling involves the recruitment of participants through random selection. This means selecting every *n*th person from an information source such as the telephone book or the electoral register. This sampling method was employed by a team of researchers involved in the Health Survey of England (1999) and a sole researcher, Chan (2004).

On the other hand, non-probability sampling, sometimes known as convenience sampling, is a process whereby individuals are selected<sup>5</sup> on the basis of their availability and willingness to participate. This sampling approach was used in this study because sufficient individuals were readily available in Chinese community centres and voluntary organisations. This approach was also used by previous researchers in the UK on illness management (Kwan and Williams, 1998, Pieroni et al., 2008) and the use of healthcare facilities (Wang, 2000, Liao and McIlwaine, 1995).

To reiterate, in order to ensure that suitable individuals (see Chapter One) were recruited who would be able to provide answers to the research topic, the following individuals were excluded from my study:

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<sup>5</sup> In this PhD project, participants were recruited via health workers who acted as middlemen in the various Chinese communities (3) and voluntary organisations (1).

- Students, asylum seekers and refugees were excluded because of their limited length of stay and the lack of fixed abode in the UK.
- Speakers of non-Chinese language were excluded because my study is focused on Chinese people and I cannot communicate fluently in other non-Chinese languages (For discussion of dialect issues with Chinese, see Section 4.26).
- Those with cognitive impairment were excluded because of potential inability to articulate thoughts and feelings effectively.

It must be noted that one consequence of convenience sampling is that an unknown portion of the population was excluded i.e. those who did not volunteer and those who did not know about the project. Nonetheless, non-probability sampling was suitable for this study as it enabled me to identify the core sample i.e. people with diabetes and who have had experience of using Chinese medicine (see Chapter 1.6).

Using the non-sampling approach had enabled me to identify and recruit 11 participants with diabetes from the focus groups for Phase 2 of the study i.e. in-depth individual interviews. I am unable to comment on the response rate, as many of the participants were approached by the various middlemen. I did not ask the middlemen how many declined to participate as they were doing me a favour, and additional enquires might add to their workload.

At the primary research site, I approached three Chinese people with diabetes who were identified by the manager of the Chinese community centre. Two refused outright whilst one offered an impromptu interview at the end of a weekly luncheon. This participant declined to take part either in focus group sessions or individual interviews due to lack of time and family commitments. Another participant outside the primary research site declined due to prior holiday arrangements. In total, 37 participants (30 being diagnosed with diabetes, and 7 being family members or friends) were recruited for eight focus group discussions.

As for the sample for Phase 2 of the study, 36% (i.e. 11 from 30 participants) of participants who satisfied the criteria listed in Chapter 1.6 were approached to

take part. Two out of eleven individuals were identified as anomalous cases whose perspectives on self-management of diabetes were significantly different from the sample as a whole. These are discussed in more detail in the findings chapters of the thesis.

#### **4.1.1 Unsuitable and misinformed participants**

Recruitment of convenience samples via middlemen was not without problems. For example, any queries which they might have had were not made known to me. Importantly, participants did not have the opportunity to ask me questions before agreeing to take part in the focus group discussion. The absence of actual contacts between me and the participants prior to the focus group meetings had a deleterious effect. One drawback of relying on middlemen to recruit is that unsuitable participants were selected.

For example, in Focus Group No. 5, three out of five participants were unsuitable. One participant had a hearing impairment, another spoke limited Cantonese and one was cognitively impaired. The following data demonstrates Mr Wong who has a hearing impairment, giving an inappropriate response when asked about the effects of diabetes on his diet. His response led other participants to laugh at him:

Researcher: How has your diet been affected since you were diagnosed with diabetes?

Mr Wong: What?

Researcher: (Repeated the above).

Mrs Yee: In other words, how has diabetes affected your diet and daily living?

Mr Wong: Western medicine is good and tasty.

Ms Lee: He doesn't know what he is talking about.

Mrs Yee: He says his stomach is blocked with shit!

The problem with absence of prior contacts with the participants emerged at the discussion sessions. Participants raised the following queries to me and the group members at the discussion sessions:

- Why were friends and relatives invited?
- Who will have access to the information?
- Will they be given information on diabetes and the use of Chinese medicine?

Some of these queries were raised in all the focus group discussions. For example, Mrs Ho and Lily admitted that they did not know why they were approached by their health worker to attend the group discussion:

Mrs Ho and Lily: We don't have it [diabetes].

Mrs Ho: I don't know why they've asked me to come.

(Focus Group No. 3, Bristol)

The lack of clarity about inviting friends and family members to the discussion was also echoed in Focus Group No. 5. Participant Ms Lee said that she agreed to take part because she wanted to listen to what others have to say, rather than to give support to her mother and sister who suffer from diabetes. She said, 'I don't have diabetes. I'm here to listen to what others have to say.'

The reason for including family members and friends was to encourage those with diabetes to attend the discussion sessions. However, I soon realised that the issue of lending support at public forums appeared to be a foreign concept. For example, Ms Lee turned to Mrs Yee and said:

Ms Lee: Why doesn't she get people who really have diabetes to be here?

Researcher: Well, you are here because you are a family member.

Ms Lee: It's convenient for me to come and listen.

(Focus Group No. 5, Birmingham)

On many occasions, participants assumed that they would be given information on diabetes rather than actively engaging in discussion with fellow sufferers. Consider this comment made by Mrs Lee and why she decided to participate in the discussion:

Miss X [the middleman] said that this person comes from a long way away, just go and have a listen, that's what she said.

(Focus Group No. 6, Birmingham)

Another piece of information which was not conveyed to the participants was who wanted the information. Mrs Yee needed reassurance from the researchers that the research was not linked to governmental organisations but for educational purposes:

Mrs Yee: This is not a government organisation?

Researcher: No, I'm from the University of Leeds.

Mrs Yee: So it's a private organisation.

Researcher: Yes.

(Focus Group No. 5, Birmingham)

In one of the focus groups, participants expressed anger at being misled. In Focus Group No. 7, a group of female participants unanimously demanded that I gave them information on diabetes and how they should manage it.

Mrs Lee: Waah, you're not giving us any information? That's not very fair. We are not coping.

Mrs Lin: That's right!

Mrs Lee: How much longer are we going to chat?

Mrs Woo: You should give us some information.

Mrs Lee: This is just a waste of time.

Mrs Woo: That's right, tell us.

Mrs Lin: She'll tell us now.

Mrs Lee: Time's up.

(Focus Group No. 7, London)

Evidently the queries raised, the disappointment and anger displayed by the participants reflect a gross misunderstanding of the intended nature of the forum. Comments from participants from two focus group sessions suggest that the middlemen might have misled participants about the nature of the gathering. For example, one participant invited a female visitor who strayed into the interview room, that she could come in to 'listen to stories about diabetes' (Focus Group No. 6). On a separate occasion, two female participants said that they were there 'to listen' (Focus Group No. 5 and Focus Group No. 7).

## **4.2 Cultural and linguistic issues**

When researching Chinese people, it is important to take into account specific nuances involved in speech exchanges (Li and Milroy, 1995, Ma, 1994, Chang, 1999) and to be aware of the need to use a variety of different terms to convey meanings effectively (Tang et al., 2000). Researchers have highlighted problems related to linguistic and cultural issues when conducting research with non-English speaking communities in general (Bradby, 2002, Hoffman, 1991) and Chinese people in particular (Gervais and Jovchelovitch, 1998, Sproston et al., 1999). However, linguistic discrepancies (Temple, 1997, Bradby, 2002) and misunderstandings in inter-cultural communication (Prior et al., 2000, Jovchelovitch and Gervais, 1999, Sproston et al., 1999, Bradby, 2002) are considerably reduced when the researcher is from a similar ethnic group. For example, forms of address are important, and when used correctly, denote a sign of respect for the other person (Bond and Hwang, 1986, Chen and Chung, 1994, Yum, 1988). These strategies were used by Joanna and me when we addressed our participants at the focus group discussions. Arguably, people from similar cultural backgrounds are not only well placed to interact and understand linguistic utterances, but are also more sensitive to facial expressions and other body language (Ting-Toomey, 1988, Xiao, 1992, Xi, 1994, Scotton, 1988, Li and Milroy, 1995). Please see Section 4.2.1 for examples and advantages of this in practice.

One cultural concept encountered in the course of the study was related to reciprocity. In social interactions, Chinese individuals keep a mental log of exchanges that take place (Hucker, 1994, Fairbank, 1992, Baker, 1979). This is to ensure that any social exchange, especially those involved in the giving and receiving of favours should be kept in balance. Over time, favours and 'debts' accumulate and are repaid when an appropriate situation arises. Many of the participants in my study were indebted to the middlemen 'by default'. For example, the middlemen often act as interpreters for the participants or their family members at the GP surgeries. In order for the participants to repay at least some of the debt to the middleman, they had to do something in return.



In this study, the middleman approached the participants to ask if they would take part in the study. Reciprocity was deemed to have taken place when participant Mrs Li agreed to take part. In the following excerpt, the middleman entered the room and interrupted the group discussion to check on how things were going on:

Mrs Li: Look at him, he was feeling faint and yet we forced ourselves to drive over here for this.

And her husband, Mr Li, chimed in 'I've tried my best', a verbal response which indicates that he had responded to the middleman's request to participate in the study. Mrs Li then turned to the middleman and asked if her sister-in-law had also agreed to take part. She was told that her relative had already attended a previous focus group meeting with me.

Mrs Li: We saw second sister-in-law yesterday and she said she was not coming.

Middleman: Sister-in-law has already been!

Mr Li: That's my second brother's wife.

(Focus Group No. 6, Birmingham)

The above example of Mrs Li expressing how difficult it was for them to attend and Mr Li's statement, 'I've tried my best' implied that they were repaying a debt owed to the middleman. Thus, the interpreting needs of the participants were fulfilled by the middlemen, whilst the middlemen's requests were fulfilled by the participants' agreement to take part in the study. When mutually beneficial behaviours are maintained, existing relationships are strengthened and assistance in the future will be provided with greater reliability.

Reliance on middlemen to recruit participants can result in coerced participation. From a cultural perspective, the relationship between the middlemen and the participants can be said to be one that is symbiotic. An approach from the middlemen creates an opportunity for participants to repay any debts. Significantly, my participants were not likely to agree to attend forums of this kind unless approached by familiar person(s) as demonstrated by the data above.

Other cultural issues which challenged the research process included confidentiality and anonymity. For instance, one middleman at the end of one of the sessions asked me to disclose what was said in the group and also what one particular client said. I avoided giving an answer, saying that it was a lively group and I had collected valuable material for the research. Then I quickly moved on to other topics. Consequently, she did not have a chance to ask me about the content of the focus group discussions.

#### **4.2.1 Nuances in Chinese speech patterns**

Chinese conversational discourse is characterised by well-defined rules which govern the way people speak to each other (Bond and Hwang, 1986, Chen and Chung, 1994, Yum, 1988). Typically, people senior in age initiate a conversation (Lu, 1998, Fairbank, 1992). Below, Lily took it upon herself to coordinate the group discussion, posing questions to another group member, Mr Yap. Notice that although the questions posed were closed, they provoked input from other group members:

Lily: Tell her your surname first.

Mr Yap: My surname is Yap. I've had it for more than 20 years.

Mr Lee: His condition is more serious; needs injection.

Mr Yap: Need to inject day and night.

Lily: Well, you go ahead and talk.

(Focus Group No. 3, Bristol)

The ordering of talk is known as turn-taking or 'speech exchange system' (Sacks et al., 1974). In the next example, I show that talking over each other and completing each other's sentences appears to be the norm rather than the exception, and is more pronounced in Chinese group discussions. While textbook guidelines advise facilitators to set ground rules, including turn taking, in practice this cannot be done with a Chinese group without drastically inhibiting the free flow of discussion. Consequently, in order to gather 'naturally occurring data' (Kitzinger, 1995:300) I yielded to the rules of engagement as deemed natural among many Chinese people. The extract below demonstrates

the lack of turn taking amongst members as they complete each other's sentences and talk over one another.

In the extract below participants expressed what they felt was the ideal solution to diabetes management – a gadget in the form of a wrist watch which would remove excess sugar from their blood:

(Key: beginning of overlap (/); no interval between turns (=) code-switch (c/s)

Mr Lau: What's ideal is one which you can wear on your wrist like a watch/

Mrs Ong: /But not like a box!

Mr Lau: Of course /that won't do.

Mrs Ong: /Like a 'boxee' (code-switched from Cantonese to Pidgin English)

Mrs Lin: /Just like the size of a watch

Mr Lau: /You just have to press it

Mrs Ong: /Not like a 'boxee' (c/s) that you carry around=

Mr Lau: =No like a wrist watch

Mrs Mah /The machine will extract all your sugar=

Mr Lau: =And you will know the sugar levels in it

Mrs Wong: =Yes

Mr Lau: And if it's too /much,

Mrs Mah: / Extract all the sugar

Mr Lau: /You don't have to worry too much about it when you are wearing it. You wear it all the time. That is the best. That's most convenient

(Focus Group No. 4, Birmingham)

One distinctive feature of the above is the relatively short turns taken, and the acceptance of other group members finishing each other's sentences. Short turns have many functions. One is to affirm what the other group member has said. Another is to express individual and subsequently, group consensus. These short turns can also serve to clarify and strengthen the original point made by the first speaker, referring to the example described above, the wrist watch is the ideal solution for diabetes management. Short turns indicate that speech exchanges are primarily listener oriented. Hence, as each speech utterance contributes to the theme, 'one story' is spun by a group of individuals. Long monologues are relatively rare in Chinese group interactions. Turn sizes are short and turn taking is fast. Hence, the conventional Western rule for

conducting focus groups of one person speaking at a time presents a real challenge in group interaction among Chinese people.

#### **4.2.2 Code-switching**

Code-switching is defined as ‘the juxtaposition of passages of speech belonging to two different grammatical system or subsystems, within the same exchange’ (Gumperz, 1977:1). Others have described it as ‘going in and out of languages’ (Grosjean and Miller, 1994:201), within the same conversation or sentence. Code-switching is a common speech strategy in any community where more than one language and culture co-exist. At the phonetic level, Grosjean and Miller (1994) found that bilinguals insert a word or a phrase from the guest language into the base language. Instances of code-switching are found in my study. For example, the English words ‘insurance’ and ‘check’ are adapted to Cantonese morphology and pronounced as Cantonese words in my study:- ‘Ngor heu mai **insaur** gam **checuk** dou yauh tongliu beng’ (I went to buy insurance and they checked (discovered) that I had sugar urine illness). Another way of mixing language is to shift completely to the guest language either for a word, a phrase or a sentence. For example, one participant expressed how she managed diabetes: ‘Ngor sheik yeuk leih **keep** ju’ (I take medicines to keep [it under control]). Here, the word ‘keep’ is retained in English.

Code-switching is motivated by social and pragmatic factors (Lee, 2003). The choice of language is a verbal strategy used to convey metaphorically, a social identity, a social cultural attitude and/or a social psychological status. For example, the switch between English and Hindi amongst bilinguals is suggested to reflect the division between urbanites and rural dwellers (Gumperz and Naim, 1960). Others reported that code-switch is used to convey a concept (foreign) that is not easily translated, e.g. Cantonese or Japanese (Li and Milroy, 1995, Nishimura, 1995). Significantly, code-switching is the unmarked choice of communication for in-group conversations (Scotton, 1983).

Code-switching is of particular relevance to my study as I believe that successful interaction between me and the participants relies on my ability to

code-switch. In addition, the extent of code-switching<sup>6</sup> reflects group membership<sup>7</sup> (Yoon, 1996). I viewed it as a manifestation of solidarity between myself and the participants. More importantly, the choice of language reveals what participants think are foreign concepts such as keeping blood sugar under control. For example, participants code-switched between Cantonese and English, encouraging each other to 'keep *ju*', meaning, to keep blood sugar under control (see Chapter Seven).

My ability to engage in code-switching, despite my being in certain senses an out-group member in terms of not being from Hong Kong, and not from the catering industry, enabled interviews to be carried out. Also, it facilitated the gathering of information which might otherwise be difficult and even inaccessible to an out-group researcher. In the next section, I provide a discussion on the insider-outsider dichotomy and the advantages and disadvantages of similarities between researchers and their participants.

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<sup>6</sup> There are two levels of code-switch: a one-word or multiword phrase is considered a small size switch, whilst intersentential code-switch in clauses is considered large size switches. Yoon (1996) found that small size switches are found amongst participants with distant relationships.

<sup>7</sup> Group membership refers to whether an individual belongs to the same cultural group or a different cultural group. In this case, my ability to speak Cantonese qualified me as an in-group member, though the fact that I did not share similar occupations or the same country of origin influenced this to some degree (see below)

### **4.2.3 The indeterminate linguistic space**

The 'indeterminate linguistic space' is defined as a abstract space that is 'created by the exchange of indirect messages, which allows speakers considerable flexibility [...] within the confines of a relational system' (Chang, 1999:537). The purpose of this 'space' is to allow speakers to make decisions on how much information they will be prepared to exchange with each other. When the 'space' between speakers is small, information exchange is free-flowing. The wealth of data gathered at the focus group discussions indicates that the 'space' between myself and across the participants was small. This may be due to the fact that many participants were familiar with each other, and importantly, it indicates a level of trust in me as a researcher. A wide 'space' is denoted by a lack of sharing of information, a situation which I did not encounter in my focus group discussions.

Importantly, the indeterminate linguistic space is controlled by the participants. I had to be invited into the participant's space. Fluency in language and cultural norms can facilitate an invitation into this space. An awareness of the importance of the indeterminate linguistic space and my skills as an interviewer to be invited into the space is arguably easier to achieve because I share their culture. As mentioned earlier, the Chinese social configuration remains heavily influenced by Confucian values. One distinctive feature of Chinese culture is the architectonic structure in which people are clearly located at different social roles and levels. Within this structure, role relations ensure that social relationships are well defined. Hence, there is little need to be verbally explicit since utterances can be interpreted against definitions of the relationship.

Geographical distance can also impact on the indeterminate linguistic space, and the subsequent amount and quality of information exchanged. In the following example, the relationship between me and the participants is considered distant both from a geographical and relational standpoint. I live and work in Leeds and have no kin or clanship ties whilst the participants live in Birmingham. Both elements proved to be an advantage. The physical distance between me and my participants offered a sense of security to the participants with regards to the disclosure of information. Group members would not feel

that I would easily share information to other members of the Birmingham Chinese community. As was stated earlier, ethnic minorities in general are renowned for being suspicious of strangers and research projects, despite assurance of anonymity and confidentiality. This suspicion is further compounded by the apparent disregard for research ethics amongst some of the middlemen. Secondly, the lack of kinship and clanship ties with the participants places my position as being outside the Chinese group. All these factors give reassurance to the participants that it will be unlikely that other members of the community will have access to what I know about them.

Consider the following dialogue between me and participant Mrs Li at the beginning of a focus group discussion in Birmingham.

Mrs Li: Miss Eng, you don't live here, do you?

Researcher: No, I live in Leeds.

Mrs Li: Waaah, you've come a long way.

Researcher: Yes, that's right. Yes, [I] came by train.

Mrs Li: Waah, if we don't come, it'll make you very, very,

Researcher: Yes.

Mrs Li: Very,

Researcher: nobody at home (meaning: I would have made a wasted journey).

Mrs Li: Yes, really. And you will be embarrassed as well.

Researcher: That's all right.

Mrs Li: Now, I feel embarrassed knowing you come from such a long way.

Miss XXX said that this person is coming from a long way away.

(Focus Group No. 6, Birmingham)

To a researcher who is not culturally attuned, this verbal exchange might appear puzzling. From a cultural standpoint, I interpreted this chunk of dialogue as Mrs Li trying to establish my place of residence i.e. does she live and work in Birmingham or does she live in Birmingham and work in Leeds? Note that Mrs Li asked a closed question – 'You don't live here, do you?' I could have replied, 'No' but I sensed she wanted reassurance that I do not live in Birmingham. So I volunteered precise information that it took two hours by train to get to

Birmingham from Leeds. In this way I made it clear that because I live far away from Birmingham, the risk of my meeting of people that they know would be low. Hence, it would not be easy for information to be passed around in the local Chinese community. A final check was made by Mrs Li to assess if unspoken messages will be responded to in a culturally appropriate fashion. This was achieved by switching into the vernacular *mor munn teng/muo men ding* 摸门钉 (literally: touching door nails) meaning 'nobody is home'.

This example of indirect speech used in establishing and inviting another party into the other person's indeterminate linguistic space is often observed between individuals from collectivist cultures. Essentially, where responses between interlocutors are listener-oriented, it is not what is said that is important; equally salient is what is not said and/or that which is conveyed indirectly. The term listener-oriented means that the responses of the interlocutors are based on what the speaker says.

#### **4.2.4 Indirect speech styles**

Following on from the indeterminate linguistic space another signature feature in Chinese speech patterns is verbal inexplicitness (Yum, 1988, Chen and Chung, 1994). Bond and Hwang (1986) reported that many Chinese people resort to 'group-effacing attributions' or avoiding 'group bias' contributions (ibid:233) to prevent conflicts from erupting in group discussions. Yum (1988) stated that to Westerners, Chinese conversation style appears vague, indirect and not getting to the heart of the issue. Indirect speech styles may prove challenging for a researcher who is not from a similar cultural background.

Gudykunst and Ting-Toomey (1988) defined the indirect verbal style as a camouflage which conceals the speaker's true intentions in terms of their wants, needs, and goals in the discourse situation. Chang (1999) stated that Chinese people do not engage in direct communication. When faced with a situation where pre-existing relational definitions are challenged, indirect speech strategies are used. Her study in Taiwan demonstrated that some cultural rules such as filial piety are challenged in modern Chinese families. The example of



'Taking a bus to the department store' (Chang, 1999) shows that in order to avoid embarrassment and rejection, the mother-in-law, rather than asking directly for a car lift to the department store resorts to a 'hinting' strategy to get her daughter-in-law to take her and her husband there:

Mother-in-law: We are going to the department store. We'd better take a bus and take our time getting there.

Daughter-in-law: Mom, why do you need to take a bus? We'll take you there.

The simple response – 'we'll take you there' reaffirms Chinese parental authority and the cultural value of filial piety. This 'hinting' strategy was also used in the focus group discussions with my opening gambit, 'Let's talk about your favourite food'. The reason for this is that I know that food is a favourite topic among Chinese people which both sexes are happy to discuss. More importantly, the topic of food generates a discussion. Prior to conducting the focus group discussions, I discussed using the topic of food as an opening gambit with two Chinese linguists who work with the Chinese community in Leeds. They agreed that a discussion of food would invariably lead the participants to talk about their management of diabetes. Based on my linguistic and cultural knowledge of Chinese people, recourse to a 'hinting' strategy proved suitable to capture useful data. This approach used in the group encounters resembled the 'funnel approach' (Spradley, 1979) i.e. starting from a broad topic and subsequently narrowing it down to the core topic.

Kreuger (1998) stressed the importance of the wording of focus group interview questions. These should appear spontaneous and arranged in a natural and logical sequence. In addition, the focus group facilitator should also carefully and subtly guide the conversation back on target. However, guiding the discussion was challenging in my study.

#### **4.2.5 Yes-No ambiguity**

The lack of commitment to giving a clear Yes or No answer meant that it was difficult to establish whether or not they used Chinese medicine for diabetes.

One aspect of the Chinese speech repertoire is the ambiguous use of Yes-No to queries and requests. Ma (1996) states that Anglo-Saxon counterparts are frustrated that Chinese people often say 'no' when they mean 'yes' and vice-versa. Underpinning this speech strategy is the aspect of self-serving (Ting-Toomey, 1988, Yum, 1988) and other-serving (Bond and Hwang, 1986). This means that saying 'yes' for 'no' is an example of an other-serving response. A Chinese person will say 'yes' to avoid hurting the feelings of the other person, to promote harmony and to prevent confrontation.

When participants were asked if they would use Chinese medicine for diabetes, the response was non-committal. The following extract demonstrates the difficulty in obtaining a clear Yes-No response:

Researcher: The doctor tells you that you have diabetes; will you consult a Chinese medical practitioner?

Mrs Lui: It depends on what other people have to say.

Mr Lui: Of course you rely on what other people say.

Mrs Lui: If people say it is good, then we'll go and try it out. But here going to a Chinese medical practitioner is not an option.

Mr Chang: If I were in China, I would also go to a Western doctor.

Mr Lui: It's convenient.

Mr Chang: There is a system.

(Focus Group No. 1, Leeds)

Although an explicit 'yes' or 'no' was not uttered, the response 'It depends' was indicative of their ambivalence. Apart from the difficulty in obtaining a 'Yes-No' response, it has been demonstrated that the Chinese terms of engagement make it particularly challenging to extract information using quantitative methods such as postal surveys and questionnaires. It must be noted that gaining a 'yes' or 'no' to the question was not the focus of the study. More importantly, the aim of the question was to provoke a discussion of what they felt about using Chinese medicine as part of their medical regime.

#### 4.2.6 Translation issues

In the field of linguistics, translation refers to the transfer of written material from one language (source) to another language (target). Interpretation, on the other hand, refers to oral communication situations whereby one person speaks in a source language, an interpreter processes this input and produces output in a second language (target) so that a third person understands what was said in the source language (Brislin, 1976).

The source material for this study is Cantonese and the target language is English. There is a vast variety of Chinese languages and the commonly spoken ones include *Putonghua* (普通话) Hokkien/*Fujianhua* (福建话), Hakka/*Kejiahua* (客家话), *Shanghaihua* (上海话) and Teochew/*Chaozhouhua* (潮州话) and Cantonese/*Guangdonghua* (广东话). Among them, Cantonese is widely spoken not only in Guangdong and Hong Kong Island but also in South East Asia and by Chinese people living in Western Europe and the United States.

Chinese citizens who live in Hong Kong use Cantonese as the lingua franca. It is the medium of communication for news broadcasting, entertainment (e.g. *Cantopop*) and even literary writings such as poetry. The script used to write Cantonese is a mixture of standard traditional Chinese characters and hundreds of extra characters adapted from Standard Chinese specifically to represent the spoken language. This adapted script, also known as 'dialect writing' is frowned upon and not encouraged by the central government in Beijing (Tong and James, 1994). Nonetheless, Cantonese as a variety of Chinese enjoys both regional and international usage, similar to that of Standard Chinese, *Putonghua* (普通话) among overseas Chinese.

In mainland China, *Putonghua* (普通话), literally means common speech. It is the standard written and spoken Chinese language, based on the Beijing dialect. The rationale for promoting *Putonghua* (普通话) as standard Chinese is to ensure mutual comprehensibility in both spoken and written forms amongst Chinese people. In addition, the standardisation of Chinese language has made

Chinese language and culture more accessible to foreigners, and facilitated communication between Chinese people from different regions within and outside mainland China.

Data for my study was collected in Cantonese as this was an accessible language for both me and the participants. Speakers of other Chinese dialects such as Hakka were excluded as I am not from that dialect group. However, some Hakka speakers confident in Cantonese did take part in the study. It transpired that many Hakka speakers in the UK are also fluent speakers of Cantonese due to frequent interactions with Cantonese speakers in the workplace (Benton and Gomez, 2008).

Efforts have been made by me to ensure that translation techniques are explicit. There are four broad approaches to translations (Casagrande, 1954)<sup>8</sup> The

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<sup>8</sup> Pragmatic translation refers to the translation of a message with an interest in accuracy of the information from source to target language. An example of pragmatic translation is in the treatment of technical documents in which information regarding repair of a machine is translated into another language. Using accurately translated materials, mechanics would be able to perform the necessary repairs. This approach contrasts sharply with aesthetic-poetic translation, in which the translator takes into account the affect, emotion and feelings of the source language. The third type is ethnographic translation, and its purpose is to explicate the cultural context of the source and the second language versions. With this as their goal, ethnographic translators are sensitive to the ways words are used (e.g. yeah versus yes) and are fluent in how the words from the source language fit into the cultures of the target language, in this case from Cantonese to English, in the vernacular. The last type is linguistic translation. This is concerned with equivalent meanings of the constituent morphemes of the second language and with its grammatical form.

choice of translation approach which I used for this PhD project was a blend of ethnographic and linguistic translation because I wanted to convey a natural-sounding version in the target language, English. Brislin (1976) outlined three broad techniques for assessing the quality of translation. The translation technique which I used in this study was back-translation.

The back-translation technique was used in the writing of the project information leaflet. An English version was sent to one of the recruitment site, Belfast. This was because a bilingual member of staff was working in the Chinese community centre, and he offered to translate the English version into Chinese. With regards to the data, a sample of transcripts together with the audio recording was given to a bi-linguist and lecturer of Chinese and Cantonese to assess the accuracy of translation. Another bi-linguist, a native speaker of Cantonese and medical interpreter, certified in public service interpreting (PSI), was also given copies of translated scripts. These were checked against the audio recordings. By way of sight translation, these two bilinguals listened to the material from the source language, Cantonese, and then compared it with translation done by me, into the target language, English. A transcript of the audio recordings in Cantonese was not provided to the bi-linguists. This was because I am not fluent in written colloquial Cantonese which, as explained above, is a combination of standard traditional Chinese script and made-up Chinese script, only understood by speakers of Cantonese.

#### **4.3 Positionality and the insider status**

The question of how the identity and positionality of the researcher in relation to the group studied affects the results of the research is by now the subject of a very extensive literature in anthropology and the other social sciences (Kusow, 2003, Merton, 1972, Narayan, 1993). Much of this has been carried out in the context of what has been called the 'insider-outsider' debate. In the case of the present research, I would suggest that as an ethnically Chinese investigator, fluent in Cantonese dialect, and so in many respects an 'insider', I was able to carry out the research more effectively in most respects than would have been possible for a non-Chinese 'outsider'.

Thus, my familiarity with the norms of social interaction among Chinese people gave me the expertise necessary to recruit subjects for the study through community gatekeepers and other channels. My knowledge of Cantonese dialect was essential to the research, enabling me to understand the responses of my subjects in a much more sophisticated and fine-grained way that would have been possible if I had been working through interpreters or relying on the limited English–language ability of my subjects. My awareness of the norms of conversation among Chinese people made it possible for me to carry out effective focus group discussions despite the impossibility of doing this in the standard manner recommended by the textbooks. My sensitivity to the often indirect and incomplete nature of Chinese communication meant that I could understand the intended meaning, even when this was not stated explicitly. My status as, in some respects at least, an ‘insider’ who shared Chinese cultural understandings meant that subjects were often willing to share information with me that they might have been less willing to divulge to a non-Chinese investigator. As mentioned previously, being geographically distant gave me the advantage of being an ‘outsider’. Therefore, I was both an ‘insider’ and ‘outsider’, depending on the issues discussed with the participants. I have given a number of examples of such factors above. There are others below and many more could have been given.

There are other respects, however, in which an ‘insider’ position is not always necessarily advantageous, and can cause problems of its own (Chavez, 2008). In addition, the investigator is rarely entirely an ‘insider’, and certainly there were ways in which my status was more complicated. Here I consider a number of these issues, and comment on how I attempted to compensate for any possible problems.

I look at the following issues in turn:

- Ways in which I was not entirely an ‘insider’
- The ‘seduction of sameness’
- Ways in which my personal status and identity may have affected the study

#### **4.3.1 Ways in which I was not entirely an ‘insider’**

Those who belong to the same cultural group usually share the same ethnic background and language and can be referred to as in-group members or insiders. Those from dissimilar backgrounds are known as out-groupers or outsiders. However, who counts as in and out is arbitrary and open to change, and different researchers have taken different approaches. For example, Yoon (1996) stated that for the purpose of his study, in-groupers refer to close friends or members who have an intimate relationship (e.g. family members or close relatives). Out-group members refer to people who are socially distant from each other due to their differences in status, age, rank and frequency of encounters (e.g., acquaintances). In some Chinese societies, language choices can determine group membership (Bond and Chueng, 1984). For example, Hong Kong Chinese view Mainland Chinese as out-groupers on the basis of their use of *Putonghua* rather than Cantonese.

However in-grouper and out-grouper are defined, some researchers have felt the need for further intermediate positions. In any given situation, researchers may be insiders in some respects and outsiders in others. Thus, James Banks suggested a four-term typology of indigenous-insiders, indigenous-outsiders, external-insiders, and external-outsiders (Banks, 1998:7). Other authors have also pointed out that the boundary between insider and outsider is not necessarily clearly delineated and that we need to consider the researcher’s positionality alongside a number of dimensions, such as race or ethnicity, class, gender and culture (Green et al., 2006, Merriam et al., 2001, Chavez, 2008). Chavez notes how insider researchers may find themselves close to informants at some times, but less so at others, when social differences such as gender, class, age or region may become significant (Chavez, 2008:478). De Andrade suggests that the researcher’s status as an insider is subject to continual evaluation and revision in the course of encounters with the subjects of research, and that research subjects are continually ‘crafting interpretations in reaction to and through interaction with researchers’ (De Andrade, 2000:286)

### 4.3.2 The seduction of sameness

This is a term used by Tracey Hurd and Alice McIntyre to refer to the way in which in-group membership can lead to being drawn in and to collude with in-group understandings and avoid critical reflexivity (Hurd and McIntyre, 1996). As a relative insider, it is easy to become part of the conversation, and to find oneself taking on the assumption and perspectives of one's informants in an uncritical manner.

I cannot be sure that this never happened in my case, but I believe that it is unlikely to have affected my results seriously. For one thing, while I have been socialised into a Chinese cultural background similar to that of my informants, I have also been socialised into the Western culture of biomedical research, and that created a distance between me and the assumptions of my informants which helped to avoid taking their perspectives on uncritically. In addition, I systematically worked to cross-check my understanding of their perspectives, for example by deliberately asking naïve questions to check that I had things right. In the the following example, I deliberately asked a naïve question about whether the practice of drinking herbal soups in everyday cooking could be seen as tantamount to using Chinese medicine:

All: That is not medicine.

Researcher: But it is herbal medicine.

Mrs Ong: No, no. It's not medicine. That which you buy yourself is not considered medicine. It's ingredients for making soup.

Mrs Mah: Ingredients for making soup.

Mr Lau: If you are short of one or two ingredients,

Mrs Ong: If the doctor writes it down as a prescription, then that is medicine.

Mrs Mah: Yes, that's right.

Mrs Ong: Herbs which you choose yourself are ingredients for making soup, not medicine. It's herbal medicine but it's ingredients for making soups.

Mrs Mah: That is not medicine.

Researcher: So are herbal soups Chinese medicines?



Mrs Ong: She doesn't understand how, she doesn't understand.

(Focus Group No. 4, Birmingham)

According to the above discussion, in Chinese cuisine, making soups with Chinese medicinal herbs does not equate to using Chinese medicine. Participants perceived that actual use of Chinese medicine entailed seeing a Chinese medical practitioner and having a written prescription of amount, type and duration of herbal ingredients. So, when asked if taking medicinal soups is the same as taking Chinese medicine, the participants were upset that I did not know the difference between actual medicinal use and everyday cooking usage of Chinese herbal ingredients. The question succeeded in uncovering taken-for-granted knowledge within the insider community. Without asking the naïve question, I would not be able to provoke them to articulate the insiders' view of what Chinese medicine means. By doing this, I demonstrate that I have reduced the 'seduction of sameness', thereby offering out-group members an insider's view of what Chinese medicine means to my participants.

#### **4.3.3 Personal status and identity**

Other problems arise from the researcher's specific positioning in relation to the subjects of research. This follows on from the points made by Merriam, Chavez and others.

For example, my status as a younger woman had consequences for my relationship to my research subjects, who, whether male or female, were considerably older than me. In Section 4.1, I recounted that in one of the focus group sessions, some participants expressed anger that they were not given information about diabetes. Adhering to the Chinese rules of engagement, as a younger member of the group, I had to keep quiet so that they could vent their anger and disappointment. Any further explanation from me might potentially have resulted in a mass exit. Explanation and defence of my position had to come from one of the participants themselves.

Thankfully, one participant, Lana spoke in my defence. As an in-grouper, she succeeded in getting the group members to listen and agree to stay on for the

rest of the meeting. The following is a truncated version of what she said to the group:

Lana: [she] is a researcher collecting information on Chinese people [with diabetes] so that she can write a report for the *gwailo* (鬼佬), meaning the Western doctors, to help Chinese diabetic sufferers. There's no guarantee that the second generation will not suffer from this. It might not help those who are here, but it could help the next generation.

(Focus Group No. 7, London)

Lana pacified the group members by calling upon their duty of care to contribute information for the sake of the future generation. She reminded the group that the information will become useful in their future consultations. Significantly, Lana is an in-grouper and her position within the group is that of a medical interpreter for the members of the Chinese community centre. As she supported my research, the other group members felt obliged to support her. It can also be suggested that some felt that in the future, they might have to rely on her to interpret at future medical consultations (See Section 4.2 Cultural and linguistic issues for the dialogue between Mr and Mrs Li).

My status as a person with a biomedical background may also have been relevant to how people interacted with me in both the focus group discussions and the individual interviews. While subjects were not necessarily aware of my nursing background, they generally perceived me as having expertise in biomedicine and may have 'crafted' their response (to adopt De Andrade's term) in order not to look ignorant or naïve in front of me. Here again, I was aware of the possible difficulties, and found ways to cross-check information so as to reach a reliable estimation of what my subjects actually thought. While no social research can be a perfect and transparent window into the participants' minds, I believe that the data presented in this thesis gives a generally reliable and valid account of their views on the research questions.

#### 4.4 Data analysis

Broadly speaking, qualitative research methods have in common a general approach to data analysis. This involves an iterative, inductive and deductive process of decontextualisation and recontextualisation of the data. Decontextualising entails 'fracturing' of data (Wolcott, 1994), separating it from the original context and assigning codes to it. In recontextualisation, the codes are reintegrated around the central themes. The aim is to distill textual data to a set of categories or concepts so as to report on the final product (Dey 1993, Miles and Huberman 1994).

As I was dealing with two different sets of data, one collected via focus group discussions and the other from individual interviews, a combined approach to data analysis was required. In both cases, the focus groups and the individual interviews, the aim of the interview questions had been to encourage a wide and free-ranging discussion over relevant topics. Thus the coding approach aimed as far as possible at generating categories from the words and phrases used by the participants, rather than imposing pre-existing categories on the data.

All audio recordings were translated by me and the transcripts were exported to a software programme NVivo2 (also known as QSR NU\*DIST – Non-numerical Unstructured Data: Indexing, Searching and Theorizing) to facilitate the storage, organisation and retrieval of information. Guided by the three analytic approaches discussed in Chapter 1.3, I approached the data in the following way. (a) I took a 'grand tour overview' (Saldana, 2009) of each interview transcript; (b) the raw data was condensed into a brief summary format, (c) broad categories were generated from the raw data and (d) links were established between the summary findings and the research questions. Immediately after each interview I completed a contact summary sheet (Miles and Huberman, 1994). The contact summary sheet was useful because it :

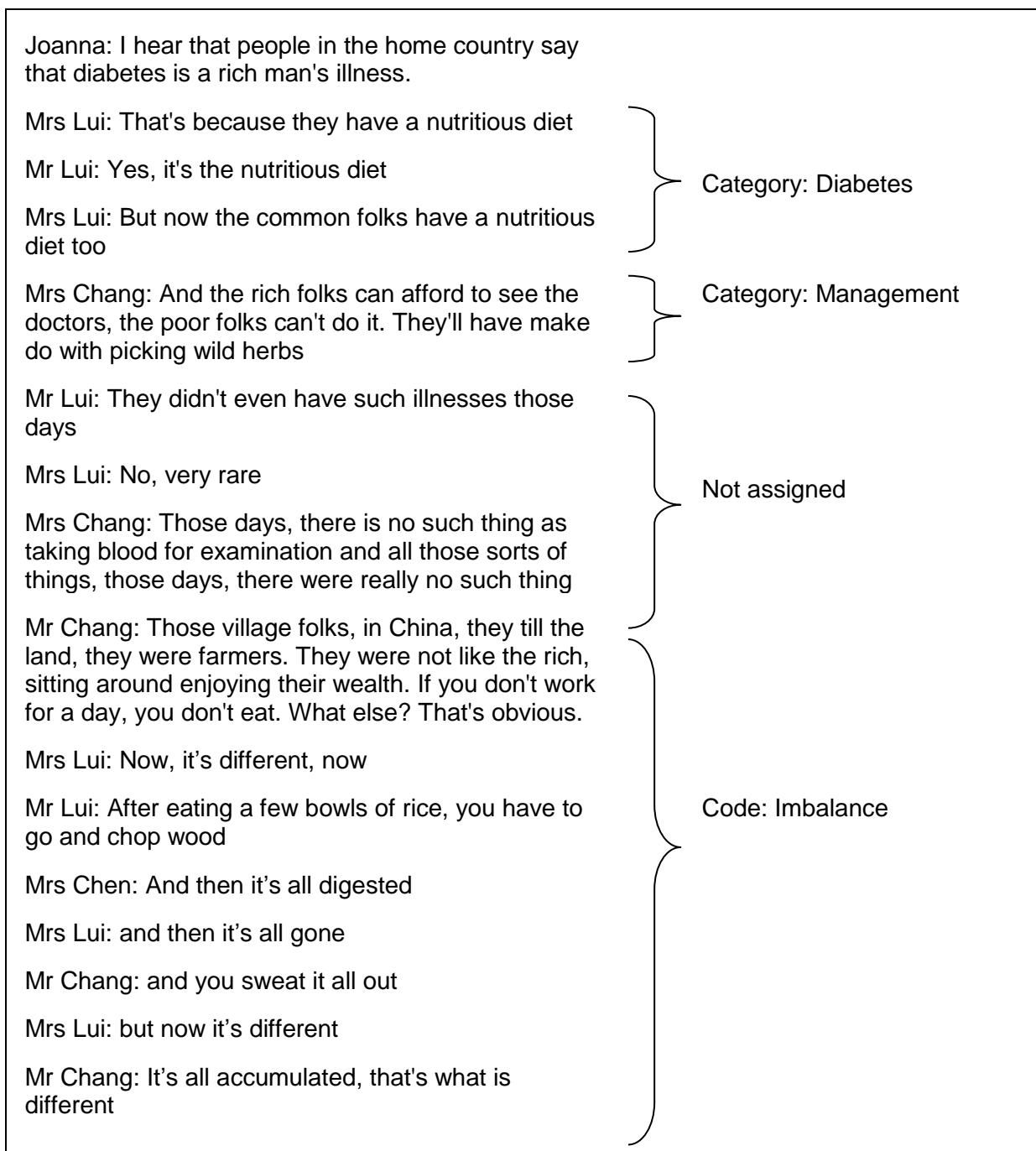
- helped me to refine questions for subsequent group discussions,
- was a rapid and practical way to produce a first run of data reduction,

- helped me to capture thoughts, initial impressions and reflections on the group discussions, and
- helped me to focus on primary concepts, questions and issues raised in the group discussions.

The type of information which I recorded in the summary sheet included responses to topics raised at the group discussions (Appendix No. 15) and individual interviews (Appendix No. 16).

Multiple readings of the transcripts enabled me to become familiar with their contents and to uncover themes and events present in the text. While the initial broad-brush or first-level coding (Bazeley, 2007) involved assigning material to one of three broad categories or 'bins' (diabetes, management and Chinese medicine), the codes and categories used in the detailed second-level coding were based on actual phrases or words from the interview data. For example, the material in the self-management category was coded with phrases such as 'checking blood sugar levels' and words such as '*gaihauh*' (Miles and Huberman, 1994). In practice, some of the themes in the data were easily identified and marked at the first-level coding.

Illustrated below is an example of how the first stage (the broad-brush coding) was undertaken for a section of the interview transcript. It is an extract from one of the focus group discussions. The identification of the three broad categories (diabetes, management, Chinese medicine) was based on the participants' response to the topic, which included material on diabetes and on management. The extract then informs us that the participants felt that both the rich and the poor get diabetes through eating nutritious food and lack of physical activities. This is an example of a specific theme that emerged, which I labelled as 'imbalance' and felt that it was appropriate to introduce as a code at this first stage.



This initial level of coding provides a superficial picture of the transcript. The data was revisited during detailed coding. This involved a line by line examination of data, making annotations, and writing memos. These included my thoughts and insights into remarks made by individual participants.

The following is an excerpt of a transcript which illustrates how a chunk of data from the broad category of diabetes was scrutinised line by line, labelled,

annotated and a memo written at the end of the chunk of selected text, as presented below: While this is more formal and explicit than some of the notes I made while undertaking the analysis, the processes and annotations are the same. In practice, the coding was adjusted through an iterative process until I felt that I had reached a satisfactory set of codes and categories at both levels, broad-brush and detailed.

The data	Broad category	Subcategory	Annotations
People in the home country say that diabetes is a rich man's illness	Diabetes	Information source	Affects rich people
That's because they have a nutritious diet		Diet	
Common folks have a nutritious diet too		Diet	Affects common people too
Now it's different			Indicating change
After eating [...] you have to go and chop wood		Exercise	Previous lifestyle
but now it's different			Emphasis on change
It's all accumulated, that's what is different		Accumulation	intake-output imbalance

Memo written for this chunk of text:

*Group members contributed and interjected each other's sentence or phrase to indicate that they acknowledged what the other was saying. This segment of speech interaction demonstrated consensual views on food. Participants viewed food as a main source of fuel for physical activity. The notion of equilibrium emerged when they described the various ways food was used up i.e. through work and digestion; or it leaves the body in the form of sweat. In this way balance is restored. Given their change in lifestyle in the UK, they said they no longer engaged in physical work, and food that was eaten was not used up but accumulated in the body. The accumulation of food coupled with the absence of physical activity was acknowledged as 'that's what is different'. This difference is seen to be a contributing factor to illness onset. Thus, imbalance between food intake and physical activity was seen to be related to diabetes.*

As presented in Section 1.3, three analytic approaches were used to examine the content and language of the group discussion. The above is an example of how meaning and ideas were expressed at the focus group settings where individuals offered short clauses, presenting a group view to the onset of diabetes.

#### **4.5 Summary**

Throughout this chapter, I have presented a detailed account of the methodological challenges and analytic approaches involved in this study. One unique feature in the recruitment process was the importance for the researcher of establishing working relationships with middlemen. Gaining a foothold into the in-group network is pivotal to accessing Chinese people. However, only foreign-born UK Chinese participants were recruited via the middlemen of the community centres. British-born Chinese turned out to be more elusive and 'invisible' than foreign-born Chinese. The recruitment of British-born Chinese via the electronic social network sites and putting up posters yielded only two participants. Cultural fluency in the intricate Chinese system of social networking, *guanxi* (关系); understanding the nuances in Chinese interaction patterns, and knowledge of the architectonic structure of Chinese inter-personal relationships were all pivotal to successful data collection. Researchers who lack proficiency in Chinese social norms may encounter difficulty in making sense of and gaining access to high context information i.e. contents of dialogue which are understood by those who share the same culture. Ethical issues have been presented such as anonymity, confidentiality and reciprocity surrounding entry into the UK Chinese people's social network via the middlemen. As two forms of data were collected, i.e. focus group discussions and individual interviews, I approached the data analysis using a combination of conversation analysis, content analysis and discourse analysis. In the following two chapters, further background information is presented relating to food and medicine in Chinese culture (Chapter Five), and the understanding and treatment of diabetes in Chinese medicine (Chapter Six). This provides an essential background to the presentation of research findings in Chapters Seven to Nine.

## ***Chapter 5: Food, Medicine and Health in Chinese Culture***

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### **5.0 Introduction**

This chapter presents background information on food, medicine and health in Chinese cultures which is relevant to the thesis. 'Food folklore' (Bennett, 1943:562) is a term used to refer to the various perceptions of food including ideas of food being 'good' and 'bad', illness causing or illness curing and other binary divisions. Food folklore is especially pertinent in the study of UK Chinese with diabetes because of the inextricable link between food, health and medicine. Notably the boundaries between food and medicine are blurred (Anderson and Anderson, 1974, Topley, 1970).

For the purpose of this thesis, we can consider Chinese medicine as comprising two main strands. These can be labelled, following Unschuld, as the 'Great' and 'Little' traditions<sup>9</sup>. The former consists of the learned tradition practised by scholar-physicians and can be traced back to texts such as the *Neijing* (内经) by the legendary emperor, *Huangdi* (黄帝). The latter is informal and is practised by ordinary lay people and non-elite practitioners. It comprises the use of food cures, spiritual healing and medical practices. Except for one participant who is using Chinese medicine from the Great Tradition in conjunction with

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<sup>9</sup> The terms 'Great' and 'Little' traditions were coined by Redfield and Singer (1954) and applied to Chinese medicine by Unschuld (1987).



biomedicine, all the remaining participants who use Chinese medicine are using it in the form of the Little Tradition. The practices based on the Little Tradition are not carried out according to medical texts but are transmitted informally. Nevertheless, concepts from the Great Tradition of Chinese medicine appeared regularly in the ways in which participants in the study talked about health issues in general and diabetes in particular. In this section, I introduce key concepts of Chinese medicine including the *yin-yang* (阴阳) division, the five elements known as *wuxing* (五行), the concept of *qi* (气) and the meridian network. These terms were used by various participants in the study, some talking at length about them, others making brief references to them as they narrated their experiences of living with diabetes.

In Chinese culture, health is believed to be linked to harmony between man, society and nature, and the effects of emotions on health status. Treatment in the event of ill health includes the use of herbs, various food items, acupuncture and exercises such as *qigong* (气功). Significantly, treatment is directed at restoring health to its previous state, achieved through enhanced nourishment and adjustments in diet, lifestyle and medication. In a well-known image from the *Huangdi Neijing* the body and its organs are interpreted as a 'country' and its organs as analogous to twelve 'officials'. This suggests a perspective in which different parts of the body need to collaborate in bringing about a cure. Thus many participants talked about food items and medicines as 'help[ing]' to cure diabetes even though they have acknowledged that the main treatment was biomedical.

## 5.1 Food

Food in Chinese is referred to as *yinshi* (饮食) literally meaning drink and food. Food (食) is divided into two groups namely *fan* (饭) which comprises mainly grain, e.g., rice, and *cai* (菜) which comprises meat, other protein foods and vegetables. Each food type represents an element in the universe. For example, *yin* (饮) drinks represent the water element, *fan* (饭) grain corresponds with the earth element and *cai* (菜) meat and vegetables

corresponds with fire. This classification of food and drink has not changed since the Zhou dynasty 1122 – 256 BC (Chang, 1977).

For many Chinese people, *fan* (饭) is the staple food and is central to a meal. *Cai* (菜) on the other hand, is to *pei* (配) meaning to accompany, supplement or complement so that it is more enjoyable for the individual to eat the main dish *fan* (饭). *Cai* (菜) is only for festive or celebratory meals and *fan* (饭) or rice is more or less ignored and *cai* (菜) dishes take over as the main dish. Significantly, eating rice<sup>10</sup> represents that a ‘real’ meal has been taken for the day.

Traditionally, a Chinese diet was almost vegetarian, comprising mostly rice and vegetables with fish as a common meat at family meals (Needham and Lu, 2000). Poultry, cattle and other types of meat were considered festive foods and eaten on special occasions (Mcnamara and Song, 1995). In contrast, modern day Chinese diet is profoundly influenced by ease of access to a variety of affordable food items, including foods formerly exclusive to festive occasions.

Apart from grouping food into staple and accompaniment, food items are also grouped according to their nutritional and medicinal properties. A particularly important distinction is between ‘hot’ and ‘cold’ foods. This does not primarily refer to the actual temperature of the food, but to their heating or cooling

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10 Historically, during times of scarcity, among poor Chinese, the first and most important item on their shopping list was rice or other grains because this was a cheap source of energy. Extra money was used to buy *cai* 菜 (food to complement rice) such as meat and vegetables. Thus, a real meal would not have been considered eaten for the day unless it was taken with rice.

properties. The hot-cold opposition is fundamental within Chinese medicine as a whole, with particular illnesses being seen as resulting from an excess of heat or cold in particular organs of the body as a whole. Consequently, the binary categorisation of food is elaborate in Chinese cultures with foods being systematically classified as hot,<sup>11</sup> cold<sup>12</sup> or neutral in terms of their humoral effects (Anderson and Anderson, 1974). Rice, when steamed or boiled, is considered a perfectly balanced and 'neutral' food. This is because rice balances out the hot and cold properties in the other food categories. Balance is an important consideration when making food choices (Mcnamara and Song, 1995).

Importantly, the way food is categorised is largely dependent on the way it is cooked. For example, rice which is boiled and then fried is considered a 'hot' food due to being exposed to high heat and frying. However, when cooked in large volumes of water to make rice congee or rice porridge, it is classified as

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<sup>11</sup> Examples of 'hot' food include strong alcoholic beverage (wine), fatty food (chicken skin), spicy food (chilli pepper) and protein food (meat). 'Hot' foods are usually associated with happy or festive events such as Chinese New Year or the Moon Cake festive occasion. Meat, in particular roast pork followed by chicken and duck, mark the celebration of festive occasions. In addition, these foods are status symbols. Traditionally, poor Chinese people only indulge in these food items on special occasions such as weddings or funerals.

<sup>12</sup> 'Cold' foods, on the other hand, include food items such as herbal teas, bland foods, beer, rice congee and any other foods (e.g., soups) involving boiling with lots of water. 'Cooling' foods are used to counteract the effects of the consumption of 'hot' foods, and to help cure 'hot' conditions such as constipation.

'cold' due to long exposure to water. Thus, methods of cooking determine food categorisation (Mcnamara and Song, 1995).

Excessive intake of one of the above categories of food is believed to be the cause of illnesses. For example, eating too much meat or food rich in spices and oil or foods that are fried is believed to make a person 'heaty' (*yithei /reqi* 热气). Anderson (1974) surmises that although some food items do not all share traits of fire or coal, the common denominator is its high caloric value and subsequently, metabolic heat. Physical symptoms which indicate an individual has had too much 'hot' food include sore throats, pimples and carbuncles. These symptoms are treated with 'cooling' herbal teas (*leungcha/ liangcha* 凉茶), soups or teas made of mung beans and various mixtures of tea leaves, flower buds and barks of trees, and food abstinence for a period of time from these 'causative agents'. Thus, symptoms originating from over consumption of 'hot' foods are treated with its antithesis: 'cold' or 'cooling' foods (Koo, 1984, Koo, 1987).

In the case of diabetes, many participants believed that they could have eaten some food items in excess, thus causing an imbalance, sugar in particular. Omitting sugar did not seem problematic until they were told from a biomedical viewpoint, that sugar was present in rice and other carbohydrates such as noodles and bread. A further challenge was posed when they were advised to eat less rice and more vegetables. As presented earlier, rice is central to a meal whilst vegetables and meat dishes are viewed as mere accompaniments. Moreover, vegetables are considered 'cooling' foods whilst rice as mentioned earlier is the neutral or 'balanced' food. Therefore, cutting down on the 'balanced' or neutral item could potentially compound the presumed imbalance present in the sufferer of diabetes. Evidence for their reluctance to make dietary changes is presented later in the thesis.

Given the belief that food choice and ill health are causally related, it is unsurprising that recourse to food items remains the first line of action in many Chinese families (Kleinman and Sung, 1979, Koo, 1984). Kleinman (1977) reported his observation of the treatment of patients with mental illness in

Taiwan. Unlike in America, a Chinese medical practitioner advised the patient's husband to ensure that the patient had adequate rest and good food to promote recovery. He was surprised that the patient responded well to the 'treatment' prescribed. Similarly, Kaptchuk (1985) reported the differences in treatment of mental health problems. A female patient consulted a Western medical practitioner for a complaint of nightmares, dizziness and constant state of anger. The physician noted a slight elevation of body temperature and no other abnormalities and advised the patient to see a psychiatrist. The patient decided to consult a Chinese medical practitioner who treated her with acupuncture and a course of herbal prescription. The patient showed a marked improvement in her condition (Kaptchuk, 1987:130).

## 5.2 Chinese medicine

As noted above, there are two main strands of Chinese medicine consisting of the Great Tradition and Little Tradition, also variously known as Rational versus Magic Medicine, Official versus Popular medicine or Chinese medicine (*zhongyi* 中医) versus folk medicine (*minjian* 民间) (Unschuld, 1987). In Chinese medicine, the Great Tradition refers to a strand of medicine practiced by Chinese medical practitioners educated in the ancient Chinese medical textbooks. The key medical texts for this tradition include the Yellow Emperor's Inner Canon of Medicine (*Huangdi Neijing* 黄帝内经) the Divine Husbandman's Materia Medica (*Shen nong ben cao* 神农本草) the Canon of Problems and the Treatise on Hot-Cold Disorders (*Shang han lun*. 伤寒论) All four texts are of unknown authorship (Porter, 1999).

On the other hand, the Little tradition in Chinese medicine is that which is practised by those who make use of recipes and treatments passed on by family members. Treatments based on the Little Tradition are not based on evidence or periods of education and are mostly based on food cures (Unschuld, 1975). These are prescribed by (1) family members or healers who have not received formal Chinese medical training, or by (2) spiritual healers known as *tangki's* (in Hokkein/Fujianese) in Singapore and Malaysia (Kleinman and Kunstadter, 1974). They also include (3) commercially produced Chinese

remedies such as *Melon cream* which can be bought in Chinese supermarkets or Chinese medicinal halls (Quah and Bishop, 1996, Kwan and Holmes, 1999). Topley's ethnographic work in Hong Kong (1974) reported that socio-economic status determines the types of Chinese medicine being used. Chinese peasants, for example, would seek help from folk or spiritual healers in the event of sickness. On the other hand, individuals from the middle to upper class would seek help from a medical practitioner trained in the Great Tradition (Topley, 1970).

The various methods of practice in Chinese medicine might have contributed to the widespread belief among both contemporary Chinese people and biomedical professionals, that Chinese medicine is 'hocus-pocus – the product of primitive or magical thinking.' (Kaptchuk, 1987:1). This perception is further compounded by medical terminologies such as *qi* (气) and meridians which have no equivalence in Western medicine (Porkert, 1974). Sivin (1971) observed that there is also a tendency for those not well versed in the Chinese medical theoretical systems, to view Chinese medicine as a 'crude and eccentric precursor of modern medicine' (Sivin, 1971: xii).

In reality, the classical tradition of Chinese medicine is a systematic and scholarly body of knowledge which was developed over many hundreds of years. It works, however, on different premises to those of biomedicine. Porkert (1974) states that the Chinese medical 'understanding of the interior body is not a counterpart of the Western anatomy but its antithesis'. Whilst biomedicine deals with organs and their material structure, Chinese medicine deals with functions to which organs are attached. Furthermore, 'the Chinese system is not less logical than the western system, it is just less analytical' i.e. it is more holistic (Porkert, 1974). Other scholars including Needham and Lu (1969) and Crozier (1968) said that Chinese medicine is not scientific in the way Western medicine views science. Its practice is based on naturalistic and rationalistic principles carried out by individuals who have undergone prolonged training.

According to Kaptchuk (1985) Chinese medicine is holistic, directed at treating the patient's entire constitution of physiological and psychological status. He states that Chinese practitioners are not trained to look for causal relationships:

they do not ask the question, 'What X is causing Y'. Instead they strive to understand the relationship between X and Y. Thus, in Chinese medicine, the practitioner aims to 'organise symptoms and signs into understandable configurations' with the aim to restore harmony (Kaptchuk 1985:4).

In contrast, biomedicine, as pointed out by Unschuld, is disease oriented, concerned mainly with treating isolable disease categories (Unschuld, 1987). Its training is based on technical knowledge which allows for standard transmission of knowledge. For example, medical practitioners trained in biomedicine make use of biochemical markers to establish a diagnosis of diabetes, prescribe treatment and other relevant diagnostic tests to ensure uniformity in treatment. Thus, the theory and practice of biomedicine is, in principle at least, based on uniformity in technical knowledge and thought (Atkinson, 1984).

In fact, much of the Chinese medicine practised today, particularly outside China itself, is derived from modern versions of Chinese medicine developed in China during the Mao era (Crozier, 1976, Scheid, 2002, Unschuld, 1975, Farquhar, 1994). This 'Traditional Chinese Medicine' or TCM has already undergone substantial rethinking in dialogue with biomedical ideas and biomedical disease categories. Thus, for example, menopause, which does not appear as a medical issue in pre-modern Chinese medical texts, is recognised by TCM and a series of appropriate remedies prescribed (Scheid, 2007).

As we will see in the following chapters, the level of usage of the classical or 'Great Tradition' version of Chinese medicine among foreign-born UK Chinese is very limited, although ideas and concepts from this tradition undoubtedly have some influence on how Chinese people in the UK think about diabetes. Some discussion of these will be presented below. By contrast, the folk or 'Little Tradition' version of Chinese medicine is quite extensively used by UK Chinese. Within this strand of medicine, diet manipulation is frequently used by both practitioners and patients as the most important way to disease management (Kleinman, 1977, Koo, 1984, Anderson, 1987). Its usage is widespread in the UK particularly for acute symptoms such as coughs, colds, fevers and diarrhoeas (Gervais and Jovchelovitch, 1998, Koo, 1984, Prior et al., 2000).

As will be seen below, UK Chinese do not necessarily recognise the use of these 'Little Tradition' remedies as being 'Chinese medicine' (*zhongyi/zhongyuek* 中医 / 中药) . This 'Little Tradition' of folk medicine nevertheless uses many of the same herbal and other ingredients as the 'Great Tradition,' and also incorporates many of the concepts and ideas of the 'Great Tradition'. It is therefore worthwhile looking at some of these concepts in more detail.

## 5.2.0 Key concepts in Chinese medicine

### 5.2.1 *Yin-yang* (阴阳)

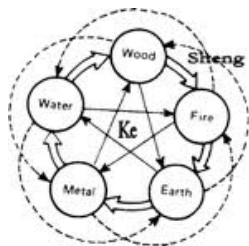
The basic principles of *yin* (阴) and *yang* (阳), the five elements (*wuxing* 五行) and *qi* (气) are concepts fundamental to the understanding of Chinese medicine. *Yin* (阴) and *yang* (阳) is a concept of opposites, developed by ancient scholars from observing the physical world. One example of opposites is that the concept of night is meaningless without the concept of day. Thus, in matters of nature, all have opposite aspects. *Yin* (阴) is literally translated as 'the dark side of the mountain' (Williams, 1996) and represents qualities such as cold, stillness, passiveness, darkness, within and femininity. On the other hand, *yang* (阳) is associated with 'the bright side of the mountain' and represents qualities such as warmth, activity, light, outside and masculinity. In every situation, *yin* and *yang* co-exist and the quality of each is relative to the other. For example, hot tea is essentially *yang* but left to cool, it turns into a *yin* substance. The traditional *yin-yang* symbol represents a simultaneous duality and oneness. The dot in each section denotes that there is always a bit of *yin* within *yang* and vice-versa. This indicates an absence of absolutes.





### 5.2.2 The five elements (*wu xing* 五行)

The five elements (*wuxing* 五行) are wood, fire, earth, metal and water. A clockwise movement known as the *sheng* (生) cycle exists between the elements to maintain balance so that the wood acts on the fire element and so forth. Onset of diseases is believed to be associated with disruption of this movement. A parallel cycle known as the *ke* (克) cycle controls the order which each element affects the others.



Each element represents an organ e.g. wood represents the liver, fire represents the heart, water represents the kidneys, metal represents the lungs and earth represents the spleen, pancreas and stomach. These organs are organised into hollow and solid organs known as the *zang-fu* (脏腑) division. *Zang* (脏) organs are solid organs and are *yin* based. Organs under the *zang* group include the lungs, heart, spleen, liver and kidneys. These are classed as inner organs i.e. deeper in the body whose functions are to manufacture, store and regulate. In contrast, the *fu* (腑) organs are hollow and are *yang* based. These include the small and large intestines, the gall bladder, urinary bladder, stomach, triple burner *sanjiao* (三焦), brain, uterus, marrow, bone and blood vessels. These are classed as outer organs, i.e. closer to the surface of the body.

The labelling of the body organs is different from those in Western anatomy and physiology of the human body. The origins of bloodletting and acupuncture in Hippocratic-Galenic medicine and Chinese medicine highlight the different anatomical theory of each medical tradition (Kuriyama, 1995). For example, the concept of blood vessels was viewed in Greek medicine as a network of hollow tubes for blood flow but in Chinese medicine the network concept is also applied to an invisible network known as conduits for acupuncture purposes.

Similarly, the distinction of hollow and solid organs, and the idea of ‘triple burner’ *sanjiao* (三焦), are unknown in Greek medical tradition.

### **5.2.3 The meridians *jing luo* (经络)**

The term originated from a French translation of the Chinese word *jingluo* (经络) literally meaning ‘to go through’ and ‘a net’ (Kaptchuk, 1987). This is often referred to as a network of paths along which *qi* travels in the body. Unlike blood vessels or the nervous system, there is no anatomical evidence for its existence (Mah, 2000). Its existence is based on the belief that the distribution of *qi* and the major organs are connected via the network of meridians. Another function of meridians is to provide a link between the interior and the exterior of the body, as in acupuncture, when needles are inserted in the skin at various points of the meridian to effect changes to the interior parts of the body. A similar concept exists in biomedicine in the treatment of pain. Based on the gate control theory of pain (Melzack and Wall, 1965), needles are inserted at various acupuncture points to treat complaints of chronic pain, in particular.

### **5.2.4 *Qi* (气)**

Reference to the concept *qi* was made by a number of participants in my study. It is therefore worthwhile to present a brief introduction of *qi* in Chinese medicine. *Qi* is a term which is difficult to capture in one English word or phrase. It has been variously translated as ‘vital energy’, ‘life force’ or simply ‘energy’. There are three sources of *qi*; original or congenital *qi* (*yuanqi* 原气), that which an individual inherited from their parents. This is stored in the kidneys. The second source of *qi* is ‘acquired *qi*’ (*guqi* 鼓气), that which is derived from food and air. Finally, there is ‘air *qi*’ (*kongqi* 空气), that which is extracted by the lungs during inspiration. It is believed that when *qi* gathers, the body is formed and when *qi* disperses, the body dies. Thus, *qi* when derived from food and air is processed by the spleen and the lungs and acted upon by *yuanqi* (原气) to nourish the body and provide its defensive system. Disruption to *qi* can be

caused by insufficiency leading to weakening and stagnation of *qi* and ultimately diseases and aches and pains.

### 5.3 Health

In this section I examine Chinese concepts of health, which again differ in significant respects from the biomedical understanding of health. The biomedical concept of health is based on physical, social and mental wellbeing. Treatment of ill health is guided by diagnostic tests, and the aim is to halt illness progression or to offer a cure. By contrast, health in Chinese is known as *shenti* (身体) literally body constitution. Being healthy is known as *jiankang* (健康) and this entails vitality, vigour and of sound mind and body. Ill health is a result of *yin-yang* imbalance and treatment is focused on redressing the imbalance known as *tiaozheng* (辨证) which involves 'regulation and nourishment' (Lew-Ting et al., 1998). Another Chinese view of health is the idea of the body as a kingdom governed by 12 'officials' which correspond to the *zang-fu* (脏腑) organs mentioned earlier. The heart is the chief official and the other organs are 'messengers' dealing with the transportation and storage of nutrients, elimination of excess and waste, decision to activate body and so on. This idea about the human body is fundamental to responses about health and illness, especially when it is believed that disease is a result of blockages and failures of the circulatory system (Sivin, 1995).

Leung et al (2005) states that, broadly speaking, health is a state of harmony between the physical form and the spirit (*xing shen tong yi* 形神统一), man and society (*ren yu she hui tong yi* 人与社会统一) and man and nature (*ren yu zi ran tong yi* 人与自然统一). The non-physical aspects of health are linked to the seven emotions, including joy, (*xi* 喜) anger, (*nu* 怒) worry, (*fan* 繁) pensiveness, (*si* 思) grief, (*bei* 悲) and anxiety (*jing* 警). These emotions are linked to various organs of the body. For example, joy affects the heart, anger acts on the liver, worry leads to lung problems, pensiveness affects the heart and spleen, grief causes problems to the heart and lungs and fear leads to diseases of the heart, kidneys and liver. Some participants in my study mentioned that worrying and

feeling sad about their diabetes can only do more harm than good to their health.

Studies investigating concepts of health amongst Chinese people were aimed at formulating Chinese quality of life health questionnaires in Hong Kong (Leung et al., 2005, Chan et al., 2006), Taiwan (Hwu et al., 2002, Lew-Ting et al., 1998) and Los Angeles (Lew-Ting et al., 1998). These studies revealed layman's views of health within the Chinese culture. Importantly, the participants' descriptions of health were noted to be linked to the basic concepts of Chinese medicine.

In a study which involved 203 participants, Lew-Ting and colleagues (1998) inform us that Chinese people living in Taipei, Taiwan and Los Angeles state that good health is indicated by absence of physical disorder, is hereditary and depends on birth order and their parent's health. Poor health on the other hand is attributed to one or all of the four forces: (i) advancing age, (ii) the environment including work and living space, (iii) serious illness and (iv) personal behaviour including state of mind. Other factors which cause poor health include life experiences, good food with lack of physical activities. Participants said that healthy food, tonic supplements and regularity in daily life can modify and strengthen one's health.

A recent study in Taiwan using survey and interviews by Hwu et al (2002) explored health concepts involving 80 participants living with chronic illness. Once again, health was viewed as ability to function physically. In addition, participants listed non-physical aspects of health including experiencing contentment, serenity and meaning, having a zest for life and familial relationships.

From Hong Kong, Chan et al (2006) reported that five participants shared their views on what they considered as health. Their views reflected the influence of Confucian and Daoist teachings. For these five participants, health was both a resource which they had to maintain, and a goal in their lives. Health is a resource because it enables them to engage in economic work, and fulfil their social responsibilities. Thus, health is closely linked to social roles, work and

family commitments. Markers of health include vitality, absence of injuries and a safe environment. In the event of bad health, a fatalistic view was adopted echoing the Daoist philosophy of *wuwei* (无为), literally meaning 'do nothing'.

One common aspect of lay concepts of health among Chinese people is an emphasis on physical functioning, emotional and social health. Underpinning these views are the Confucian and Daoist values which in turn guide the practice of Chinese medicine. One striking item is that the ability to carry out activities of daily living is the nub of what constitutes health. From this cultural viewpoint, Chan et al (2006) suggested that professionals involved in health promotion and health education programmes need to be aware of the health concepts of the people they are serving. UK Chinese people are unlikely to say that they are unhealthy if their ability to undertake the activities of daily living is unaffected by their health status. This may mean, for example, that patients who have diabetes which is being controlled by medication may regard themselves as not seriously ill, and not be overly concerned about the disease or its possible future complications.

#### **5.4 Summary**

In summary this chapter presented the inextricable link between food, medicine and health in Chinese culture. Food forms the basis of medicine and health among lay people and the Little Tradition. It is believed that excessive intake of hot or cold foods leads to the onset of illnesses and consumption of its antithesis is the choice of treatment. Underpinning this approach are the key concepts in Chinese medicine including notions of *yinyang*, *wuxing* and *qi*. Disruption in one or all of these leads to poor health. Health within Chinese culture differs from the biomedical understanding in terms of illness causation, focusing on redressing imbalance through 'regulation and nourishment'. Significantly, being healthy is indicated by the ability to engage in economic work and fulfil social and family commitments. This perspective of health and illness can impact on illness management since being diagnosed with diabetes does not necessarily interfere with abilities to work or family responsibilities. Consequently, persons with diabetes may not recognise the importance of

keeping the illness under control. In the following chapter, the theory and treatment of diabetes in Chinese medicine are discussed.

## Chapter 6: Diabetes in Chinese Medicine

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### 6.0 Introduction

In Chapter Six, the theory and treatment of diabetes in Chinese medicine are discussed. The discussion is primarily based on presentations by Chinese medical practitioners. At present, biomedical research on the use of Chinese medicine for diabetes is at a relatively early stage. Some experimental work has been done, mainly on mice, while the limited range of Western-style trials with humans is so far inconclusive. The material in this chapter therefore presents practice in Chinese medicine (particularly the modernised school of 'TCM') without much reference to the efficacy of these treatments. It is nevertheless significant for this study, in particular in relation to the ways in which diabetes is understood from the viewpoint of Chinese medicine. These ideas and concepts underlie the folk-medicine food treatments for diabetes. It also seems likely that they have had a significant effect on ideas about diabetes among the UK Chinese population in this study.

In Chapter Two, I presented the aetiology and management strategies of diabetes according to contemporary biomedicine. Diabetes in biomedicine is defined as an endocrine disorder confirmed through diagnostic tests, e.g., HbA1c tests. Diabetes is said to be prevalent amongst obese individuals, ethnic minority groups and those with lifestyles that are consistent with living in industrialised countries. Treatment of diabetes is aimed at keeping blood glucose levels within acceptable ranges with an emphasis on the individual to be responsible for lifestyle and dietary changes and, if needed, to accept medication. Adherence to medical advice and treatment generally leads to a symptom-free disease.

In contrast to biomedicine, the naming and treatment of diabetes in Chinese medicine suggest different perspectives on diabetes. The medical term for diabetes in Chinese medicine is *xiao ke zheng* (消渴症). *Xiao* (消) refers to a loss of body weight, *ke* (渴) means thirst and *zheng* (症) means syndrome.

Therefore, *xiao ke zheng* literally means a thirsting and wasting syndrome. It is believed to be associated with excessive intake of sweet and fatty foods, emotional distress, work exhaustion and excessive sexual activities (Ho and Lisowski, 1997). Excessive consumption of fatty food leads to accumulated heat in the interior, while sweet food often produces accumulation in the middle *jiao* (焦). If the accumulated heat and stagnancy go upward, this results in *xiao ke zheng* (Chen and Lu, 1994). Treatment of this syndrome in Chinese medicine is focused on symptom relief and correcting the imbalance.

On the other hand, people like my participants refer to diabetes as *tong lui beng/tang niao bing* (糖尿病), literally meaning sugar-urine illness. My participants' beliefs about the cause(s) of diabetes echoed those of the Chinese medical practitioners. However, none mentioned excessive sexual activities as a causative factor. I felt that it was inappropriate to broach this topic with the participants, partly because they did not volunteer this information, and, more importantly, out of respect for their seniority. As mentioned previously, subordinates are not expected to initiate a topic. In addition, being comparatively young and female made it even more inappropriate for me to pose such a question to either the male or female participants.

## 6.1 Theories of diabetes in Chinese medicine

Amongst the several theories surrounding diabetes, the 'three wasting theory' is said to be the foundation of understanding diabetes in Chinese medicine (Zhang et al., 2010a). Diabetes is viewed as a condition brought about by one or all of the following causes including *yin* (阴) deficiency, the weakening of *qi* (气) and destruction of *yang* (阳) (Zhu, 1982, Liu and Tang, 2000). Unlike the biomedical understanding of diabetes, in Chinese medicine, the 'wasting syndrome' is divided into three types: upper, middle and lower diabetes, each corresponding to its symptoms. For example, excessive thirst is categorised as upper diabetes, hunger is associated with middle diabetes and frequency in urination is classed as lower diabetes (Covington, 2001). Each symptom denotes the severity and progression of diabetes. In contrast, within biomedicine, all these symptoms help the medical practitioner to confirm a



diagnosis of diabetes, not classify its severity. As stated earlier, according to the British Diabetes Association (BDA) there is no such thing as 'mild' diabetes.

Zhang et al (2010) summarised the theory of diabetes according to Chinese medicine, explaining the pathogenesis of the symptoms. Excessive thirst and frequent and copious urination are caused by lung impairment via rising heat and downward movement of fluids in the body. Involvement of the spleen and stomach is manifested by complaints of thirst and hunger. Food metabolism and glucose uptake is affected leading to the presence of sugar in the urine and gradual loss of weight. In the final analysis, kidney *qi* is affected.

Other pathogenesis is proposed by different clinicians. For example, Li and colleagues (2004) described the progression of diabetes in stages, stating that in Stage 1 there is consumption of *yin*; in Stage 2 there is a loss of *qi* and in Stage 3, *yang* is under destruction (Li et al., 2004). Simultaneously, the triple burners *sanjiao* (三焦) are also affected indicated by excess in thirst, hunger and urination. These symptoms can be experienced by the sufferer at any time. These ideas about the different stages of diabetes were presented by the participants in the way they spoke about diabetes. For instance, talk of diabetes 'getting deeper', and 'it's affected my kidneys and [...] my heart [...] now I'm blind in one eye' presumably refers to Stage 3 diabetes where multi-organ dysfunction is occurring in the form of visual, renal and cardiac involvement.

Flaws and colleagues (2002) stated that the onset of diabetes occurs with advancing age. According to the *Neijing* as one gets older, various organs in the body gradually deteriorate. For example, when individuals reach their mid 30s, the spleen becomes weak and vacuous, resulting in liver depression and impediments to other organs affecting the free flow of *qi*. By 40 years of age, *yin* is automatically halved. The development of diabetes is believed to be associated not only with age but lifestyle and diet, and hence referred to as a 'knotty disease' (Flaws et al., 2002). This is because diabetes affects a number of other organs such as the liver, stomach, spleen, lung and kidneys. In my study, many of the elderly foreign-born UK Chinese accepted, albeit reluctantly, diabetes as part of their advancing age. However, those below the age of 40 found it difficult to accept that they have developed diabetes. For example,

Tessa wanted to believe that a pre-existing condition, polycystic ovaries, was the cause of diabetes. She hoped that once her polycystic condition is treated, her diabetic condition would resolve.

Significantly, the different ways of explaining the pathogenesis of diabetes raise the question of whether it is the same disease as diabetes as understood by biomedicine. Some of the criteria applied to the diagnosis of diabetes suggest that *xiao ke zheng* and diabetes could be similar but not identical illnesses. Similarities between biomedicine and Chinese medicine in the identification of diabetes include (i) symptomatic complaints i.e. thirst, hunger, increased urination and loss of weight, (ii) pathogenic causes i.e. obesity, diet and lifestyle, and (iii) the need for therapeutic intervention such as advice on changes in lifestyle and diet, and if required, medication. In Chinese medicine, diabetes is seen to be caused by *yinyang* imbalance and the involvement of the five elements. Its management includes the use of herbal preparations, *qigong* and acupuncture.

Evidence of doubts about a definitive diagnosis of diabetes can be found in my study. One participant told me that her Chinese medical practitioner advised her to seek confirmation from a Western medical practitioner for a diagnosis of diabetes. Others sought confirmation from Chinese medical practitioners when told by their general practitioners in the UK that they have diabetes. There were no reports of participants being diagnosed by Chinese biomedically-trained medical practitioners and having the diagnosis doubted by their general practitioners in the UK.

However, one participant, Jeanie, was told by a Chinese medical practitioner that since she was *just* diagnosed, there was a possibility that her diabetes could be reversed. She used Chinese medicine prescribed by a UK Chinese medical practitioner for a brief period and stopped when she developed a rash. Except for one participant, doubts about the Chinese medical practitioners' abilities to treat diabetes resonated throughout the focus group discussions and the individual interviews (See Chapter Nine).

## 6.2 Treatment of diabetes in Chinese medicine

It can be said that the Chinese medical approach to diabetes is somewhat different to that of a biomedical approach to diabetes, reflecting also in some respects more general differences between these medical traditions. This is already evident in the context of the clinical encounter. Farquhar (1994) highlighted that one striking difference in the Chinese clinical encounter is that both the doctor and patient meet with the purpose to *kanbing* (看病) literally meaning 'looking at the illness' (Farquhar, 1994:482). The gaze of both the patient and doctor is directed on the illness process. Before treatment is prescribed, the doctor performs the four examinations (*sijian* 四簡) which include looking, listening and smelling, asking and touching (Kaptchuk, 1987:142). Emphasis is placed on pulse taking which could take between two to three minutes, an important skill amongst experienced Chinese medical physicians (Farquhar, 1994).

Another difference is that in contemporary Chinese medical discourse, illnesses are categorised as either *zheng* (症) i.e. syndrome, or *jibing* (疾病) i.e. disease. A disease (*jibing*) by definition is one which has a 'material basis' (Farquhar, 1987) i.e. viruses or bacteria. For example, an illness such as tuberculosis is categorised as *jibing* i.e. disease. Its categorisation in Chinese medicine determines treatment strategies. Thus, treatment for diseases is delivered using antibiotics or anti-viral agents. On the other hand, a syndrome *zheng* has no 'material basis'. Due to the absence of microbial evidence, treatment is focused on functional status of the organs, believed to have caused the onset of the syndrome. More importantly, a syndrome is 'akin to an illness moment [...] a specific concatenation of symptoms and a phase in a temporal process' (ibid:1018). As presented earlier, diabetes is known as *xiao ke zheng* or wasting and thirsting syndrome.

Whilst biomedical practitioners prescribe synthetic chemical compounds such as Metformin to control diabetes, many contemporary Chinese medical practitioners use plant based medication; a 'polypill' i.e. multiple herbs in one preparation (Li et al., 2004). This preparation is used not only to lower the blood sugar level to its normal range (i.e. 4-7 mmols). In addition, the treatment is

used to promote blood circulation, remove blood stasis, activate energy circulation, clear 'heat' in the body, invigorate the liver and kidney to activate *yang* and invigorate the spleen and the stomach to strengthen the body (Dai, 2000, Xu and Lu, 2000). Whereas the approach in biomedicine is focused solely on diabetes, Chinese medical practitioners aim to simultaneously treat other organs in the body.

In a review article, Yin et al (2008) presented the bioactivities of three ingredients used in the treatment of diabetes including bitter melon, ginseng and berberine. Ginseng is used to replenish *yin* and restore *qi*, whilst berberine and bitter melon are to get rid of 'heat' (Yin et al., 2008). The rationale underpinning the use of multiple ingredients in one prescription is explained by Cheng. The ingredients are selected according to their pharmacological activities, one acting as the 'chief' or main ingredient, followed by 'ministers', 'assistants' and 'guiders' (Cheng, 2000). In practice, a practitioner is expected to modify the combination of these properties and the dosages are prescribed according to the patient's constitution and severity of symptoms.

Chen and Lu (1994) tell us that Chinese medical practitioners prescribe treatment according to the manifestations of the condition i.e. upper, middle and lower diabetes as presented earlier. For example, patients with frequent and copious urination should be given Kidney Qi Pill (*shen qi wan* 肾气丸) to tonify the kidneys, Powder of Gecko (*ge jie san* 蛤蚧散) for thirst and White Tiger Decoction with Ginseng (*bai hu jia ren shen* 白虎加人参) for dry mouth. Another food cure, *Cordyceps sinensis* or (*dong chong xia cao* 冬虫夏草), literally meaning winter worm and summer grass is used (Hsu et al., 2002).

*Cordyceps sinensis* has a long history of usage in Chinese medicine (Bok et al., 1999). It is often referred to as a 'mushroom' because of its appearance. In reality, it came about as a result of *C.sinensis* infecting the larvae of a sphinx moth, *Hepialus armoricanus*, found on the slopes of the Himalayan highlands. The fungus feeds on the host throughout the winter and in the summer sprouts a rod-like stroma from the body of the dead host. Not only has it been reported to have hypoglycaemic effects, this 'mushroom' is merited for other therapeutic

effects e.g. treating heart failure (Kitakaze and Hori, 2000). Two participants in my study told me that they use *dong cong cou* (冬虫草) in Cantonese, *dong chong xia cao* (东虫夏草) in *Putonghua*, in their daily meals for health purpose.

In the article 'Eating Chinese medicine' Farquhar (1994) gave a detailed account of using prescribed Chinese medicine in China. Generally speaking, the prescription consists of a number of different medicinal herbs which have to be cooked with some spice, e.g., ginger, for more than an hour. Someone, usually the grandmother, has to ensure that there are two to three refills to extract maximum use of the medicine. The sufferer has to drink it first thing in the morning. Special earthenware is used specifically for cooking medicinal herbs. The decoction is usually pungent, bitter and unpleasant. It is unsurprising that Chinese urbanites are reluctant to use Chinese medicine as it is troublesome, unpleasant and time consuming. Nonetheless for 'stubborn illnesses' such as diabetes, many Chinese will consult Chinese medical practitioners despite the drawbacks. Many participants in my study echoed these sentiments. They were unwilling to spend the time required to prepare Chinese medicine and deterred by its bitter taste.

In Chinese medicine, there is no one single agreed treatment of diabetes with Chinese medicine. This is because practitioners treat patients according to their presenting symptoms and stages of their illness. Given the different medical orientations in illness causation and treatments between biomedicine and Chinese medicine, arguably, a decision to adopt a single treatment as used by biomedicine can suggest that biomedical practitioners have a firm grip on the treatment and knowledge of diabetes. In contrast, current updates on the use of Chinese medicine continue to offer a variety of prescriptions based on the symptoms presented (Zhang et al., 2010b). This is unsurprising as a basic tenet in the practice of Chinese medicine is to prescribe treatment as the illness unfolds over time (Farquhar, 1994). This is particularly the case with diabetes as we will see later in the thesis that many participants in my study expressed they would like their doctors to manage their medication according to its progression.

In Chapters Seven to Nine, I present the findings from the focus groups and interviews carried out for the study. The first of these chapters, Chapter Seven, discusses how foreign-born UK Chinese perceive diabetes.

## ***Chapter 7: Diabetes through the eyes of UK Chinese***

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### **7.0 Introduction**

This chapter presents the ways in which the participants in the study, patients with diabetes and their friends and family, view diabetes. It was not till recent times that the voice of the patient gained prominence in the history of medicine. Medical anthropologists have argued for the importance of knowing patients' ideas about their illnesses (Helman, 1996, Kleinman, 1988). Kleinman (1974) demonstrated that patients and healers differ in their ideas about illnesses and its treatment. These ideas may be conscious and explicit, but they can also involve implicit, taken-for-granted assumptions deriving from the cultural background of the patient and the healer. He proposed examining the 'explanatory model', i.e. the ideas about health and illness, of both patients and healers. In order to understand the patients' explanatory model, I asked my participants what they thought about diabetes, its causes, symptoms, illness trajectory and treatment and its social significance. Knowledge about a patient's explanatory model can assist healthcare professionals to deliver effective care and treatment. (Anderson et al., 1995, Mercado-Martinez and Ramos-Herrera, 2002, Garro, 1995, Naemiratch and Manderson, 2006). Studies on ethnic minorities in the UK and abroad demonstrate the significance of cultural factors in forming the explanatory model and in shaping both the perception of diabetes and subsequent self-management regimes (Chan, 1991, Anderson et al., 1995, Chacko, 2003, Cohen et al., 1993, Egede and Bonadonna, 2002, Greenhalgh et al., 1998, Jezewski and Poss, 2002).

In this chapter I present findings from discussions with eight groups ( $n = 37$ ) of foreign-born UK Chinese living with Type 2 diabetes. In order to establish their explanatory model for diabetes, participants were asked to share their thoughts about diabetes; to explain what they thought were the causative factors; to describe the symptoms of diabetes, and to present their thoughts surrounding the illness trajectory (Appendix No. 4). This chapter has four sections. Section 7.1 presents data from the eight focus group discussions. This section is divided

into two sub-sections. Section 7.1.1 presents information on how they found out they had diabetes. Section 7.1.2 presents what they thought of diabetes.

Section 7.2 presents material from the individual interviews that were carried out on completion of the eight focus group discussions. This section is divided into two sub-sections. Section 7.2.1 provides information on what they believe causes diabetes. Section 7.2.2 deals with what they know about the trajectory of diabetes. Section 7.3 provides a discussion of the findings from the focus groups and the individual interviews. Section 7.4 draws the chapter to a close.

## **7.1 Findings from focus group discussions**

### **7.1.1 Discovery**

The discussion revealed that some were asymptomatic when diagnosed with diabetes, whilst others experienced classic symptoms such as blurred vision, ('I couldn't get the eye prescription right'); fatigue, ('I was tired all the time'); thirst ('I was constantly thirsty and drinking lots of water'); insatiable appetite ('despite eating three meals a day, I felt I had not eaten!'); and pruritis ('my lower body (genitalia) was itchy').

Those who were asymptomatic did not expect to be given a diagnosis of diabetes from their doctors. Emotional content is not apparent from the transcripts. However, at the focus groups, I could see from their facial expressions and their tone of voice that they were shocked and surprised. The following is a continuous stretch of talk from one of the focus group sessions. Participants recalled how they found out that they had diabetes:

Mrs Lin: I went to see the doctor and he told me that I have diabetes.

Mrs Leong: There was a lump on my neck, my doctor took a blood test and found that I have sugar urine illness.

Mrs Mah: I did not feel comfortable, but when I went to see the doctor he told me that I have sugar urine illness.

(Focus Group No. 4, Birmingham)



In the beginning, I felt very thirsty [and] tired all the time [...] Then I went to buy insurance and they checked me and discovered that that I sugar urine. That is how it was discovered

(Focus group No.7, London)

The reported symptoms, or absence of symptoms is consistent with the biomedical view of diabetes; it is characteristically invisible, there are no external manifestations and it is not palpable. Discovery is often accidental or through a routine medical check-up.

### **7.1.2 Perception of diabetes**

Various perceptions of diabetes and its possible causes were expressed at the different focus group discussions. Possible causes include imbalance between food intake and work, excessive sugar, fatty foods, crustaceans and salt, possibly hereditary and organ malfunction. Perceptions of diabetes ranged from it being a rare disease, an illness with no 'tail', to an illness which leads to other illnesses.

#### ***7.1.2.1 Causation: imbalance, excessive intake of certain foods, hereditary and organ malfunction***

In one of the focus group discussions, all participants said that imbalance was the cause of diabetes. Each group member either supported or completed the other's view on what they believed caused diabetes:

Mr Lui: After eating a few bowls of rice, you have to go and chop wood and then,

Mrs Chang: and then it's all digested,

Mrs Lui: and then it's all gone,

Mr Chang: and you sweat it all out.

Mrs Lui: But now it's different.

Mrs Chang: It's all accumulated, that's what's different.

(Focus Group No. 1, Leeds)

The above group members shared a number of commonalities including occupation, years of domicile in the UK and current social situation. They previously worked in the catering industry as restaurant and or takeaway shop owners, waitresses or kitchen workers. All were born in China and came to live in the UK when they were in their twenties. At the time of interview, all had retired and met regularly at the weekly luncheon served at the local Chinese community centre. Their nature of work could explain why they chose food and work as examples of imbalance leading to diabetes.

Ideas about illness onset as a result of imbalance between intake and output are found in the literature on Chinese medicine (Sivin, 1995, Unschuld, 1987, Kleinman et al., 1974). As explained in Chapter Six, the Chinese lay person's term for diabetes is *tang niao bing* (糖泥病), which literally means sugar urine illness. This description of diabetes arguably influences patients' ideas about and responses to diabetes. Indeed, people diagnosed with diabetes, Chinese or otherwise, often associate it with sugar consumption, and would immediately remove or reduce sugar in their diet. For example, in a UK study on Pakistanis living in Edinburgh, Scotland, Lawton and colleagues' (2008) participants described avoiding sugar or reducing intake of food items that contain sugar because they believed it was 'dangerous' and 'damaging' to the health of those diagnosed with diabetes. One participant said when cooking *kheer* (sweet rice pudding) for guests, she would separate out a bowlful for herself before adding sugar to the dish. Another participant recounted that when offered *metai* (traditional sweets) at weddings he would just have half a piece because he had diabetes. This response to diabetes of 'cutting out or cutting down' sugar in their diet indicates that lay understanding impacts on health behaviour (Lawton et al., 2008:312-313).

Many of my participants felt that diabetes was the result of poor diet and excessive intake of sugar. In the following example, focus group members shared their views about diabetes. Both Lily and Mrs Ho are non-diabetics but are friends of Mr Lee and Mr Yap who were work colleagues in a Chinese restaurant. They were born in China and came to live in the UK when they were in their twenties. Mr Lee and Mr Yap have been diagnosed with diabetes for 20

years. At the time of interview, both had retired and were regular visitors to the local Chinese community centre. The view that sugar causes diabetes was unanimously expressed.

Lily: Did you like to eat sweet things?

Mr Yap: When I was young we were in the business of making candy floss.

Lily: So you ate it every day?

Mrs Ho: When he was a kid, he was all right. It's only in adulthood that it became a problem.

Lily: Are you saying that 20 years ago, you already had sugar urine illness?

Mrs Ho: I say it's because you had too much sugar and that is what caused it.

Researcher: What about you?

Mrs Ho: His is due to excessive eating and drinking.

Mr Lee: It was due to excessive eating and drinking. I used to take three teaspoons of sugar in my tea.

Mr Yap: I don't dare to have sugar anymore.

(Focus Group No. 3, Bristol)

Whilst participants from Focus Group No. 1 attributed diabetes to food accumulation and the lack of physical exercise, participants from Focus Group No. 3 singled out sugar as the main cause of diabetes. Fear of taking sugar had resulted in hypoglycaemia for one of the participants. In order to increase her blood sugar levels, she kept a stock of ice lollies in her refrigerator:

Mrs Yee: Sugar and such like, I don't dare to eat. And now my blood sugar is low every night. I need to get up in the night to eat ice cream and ice lollies.

(Focus Group No. 5, Birmingham)

The emphasis on omitting sugar was also seen in other focus group discussions:

Mrs Lee: Every morning I have two glasses of milk tea, no sugar.

Lana: I have cut down on rice [because it] becomes sugar.

Mrs Wu: The doctor tells me to eat less sugary stuff, for example *lychees*, *logans* (龙眼).

Mrs Chow: I've been told not to eat too much sugary stuff.

Mrs Wu: They tell me I have sugar urine illness so I have abstained from sugar.

(Focus Group No. 7, London)

Lana is a voluntary worker for the Chinese community centre acting as an interpreter for visitors of the centre. The rest of the group members are housewives. They believe that sugar causes diabetes and so they either avoid taking sugar or 'eat less'. Some similarities to Lawton and colleagues' study (2008) are noted, namely, the mention of Western food items for breakfast by some participants in focus group No. 6, i.e. porridge oats and milk. Another similarity is that Lawton's participants also expressed surprise that carbohydrate based food should be reduced because it turns to sugar: 'roti (bread) is dangerous you know, it turns into sugar[...] they also say that rice has sugar' (Lawton et al., 2008:310).

In my study, fear of sugar as a 'forbidden food' was dismissed by one female participant. From her facial expression, Mrs Ngan appeared rather pleased that she would eat sweet foods when her sugar levels fell to within the normal limits. Her statement prompted Mr Lo's curiosity. Equally, Mr Lo's facial expression showed he was surprised that someone with diabetes could achieve normal blood sugar levels. The extract below reveals the participants perception of diabetes. They viewed diabetes as a condition of too much sugar in the blood but once blood sugar levels fall within normal limits, one participant's response 'isn't that normal' followed by the counter response 'it's strange' reveals that both Mrs Ngan and Mr Lo were puzzled that a person with diabetes could have 'normal' blood sugar levels. According to the biomedical model for diabetes, maintaining blood sugar levels within normal limits is not 'strange'; it is the aim of diabetes management. This extract shows that the participants are unfamiliar with the aims of diabetes management. Crucially, Mrs Ngan's decision to 'eat sweet stuff' can only result in a sudden rise in blood sugar levels. Healthcare professionals advise patients to avoid the rise and fall of blood sugar levels to reduce the onset of diabetes-related complications.

Mr Lo: You need to practice food abstinence.

Mrs Chan: Need to watch what you eat.

Mrs Xi: You cannot eat too much.

Mr Lo: And with sweet stuff.

Mrs Ngan: For me, when my sugar levels goes down to 4 points [4 mmols], I'll eat sweet stuff.

Mrs Xi: Well, we don't dare to eat sweet stuff.

Mr Lo: If it was 4 points [mmols], isn't that normal?

Mrs Ngan: It's strange.

(Focus Group No. 8, London).

Participants' view of sugar and other food items as causes for diabetes is potentially detrimental. When participants blame themselves and their dietary habits as primary causal factors for the development of diabetes, they voluntarily abstain from sugar, as illustrated above. However, these participants are at risk of potentially dismissing the importance of support and guidance from health care professionals. Studies have highlighted that patients may ignore medical advice due to their own ideas about the illness. For example, in two separate Hong Kong studies it was reported that many Chinese people with diabetes did not have dextrose tablets on hand to deal with low blood sugar levels (Chan and Molassiotis, 1999, Shui and Wong, 2002). This was because many of the patients believed that taking sugar was harmful. In a study in Taiwan, Lai et al (2004) reported that many sufferers refrained from taking sugar even when blood sugar levels were low. This form of health behaviour in response to hypoglycaemic attacks is contrary to advice from healthcare professionals who advise an immediate intake of a sugary drink to bring blood sugar levels up. Chan and Molassiotis (1999) said that it was difficult to change patients' choice of dealing with diabetes.

Sugar omission in diabetes is not unique to Chinese people. For example, many Pakistani and Caucasian diabetics in the UK also perceived that sugar was bad for diabetes and its intake should be reduced if not omitted (Lawton et al., 2005, Lawton et al., 2008). Attempts were made to omit or reduce sugar intake with the aim of achieving normal blood sugar readings. What is striking about the Chinese response to diabetes is that many of the Chinese sufferers expect diabetes to be resolved through sugar omission. Although this expected

outcome is not verbalised by the participants, bearing in mind that the Chinese language is renowned for hinting rather than explicit verbal affirmation (Ting-Toomey, 1988, Triandis, 1989). I would argue that the Chinese sufferers do expect their diabetes to be resolved through sugar omission. My certainty that participants expect an end to diabetes is based on their repeated questions such as 'What should people with diabetes eat?' and 'I want to know if salt intake is related to diabetes' which are examples of indirect questions aimed at getting an answer to deal with diabetes. In addition, they were frustrated and puzzled that despite all their efforts to omit sugar, eat less, take medicines and achieve, albeit temporary, normal blood sugar levels, they remain labelled as a person with diabetes by their doctors.

In the subsequent focus group discussions, participants revealed a variety of food items such as rice, the skin of poultry and crustaceans which they understood to be causative agents of diabetes:

Mr Lee: The doctor told him (referring to Mr Long) not to eat too much salty food.

Mrs Long: Not to eat fatty foods.

Mr Lee: Yes, not too much fatty foods.

Mrs Long: Not to eat too much rice.

Mr Long: Not to drink coca cola.

Mr Chui: When you eat chicken, you have to remove the skin.

(Focus Group No. 2, Leeds)

Although many participants professed that they avoided the aforementioned food items, such claims must be considered with caution. As is the nature of qualitative interviews, in particular focus group interviews, participants are keen to portray themselves in a socially favourable light. Therefore, they are more likely to say what they perceive to be acceptable dietary changes e.g. reduction of sugar, meat and fats.

The question, 'What should diabetics eat?' was posed in various guises at every focus group discussion. Participants asked me to give them advice on the types of food they should eat. This suggests that some participants are aware of a deficit in their knowledge about diabetes. More importantly, it could be

suggested that they thought I would provide health-related information that would be meaningful and culturally congruent. The 'mutiny' which unfolded in Focus Group No. 7 in London described in Chapter 4.1.1 substantiates this proposition.

Interestingly, many participants answered their own questions by identifying what they found to be 'bad' for diabetes. In the following exchange, Mr Li in Focus Group No 6 from Birmingham started by asking a rhetorical question on food:

Mr. Li: What should people with diabetes eat? Less rice or less meat?

Mr Mun: If your intake of meat is too much, it (blood sugar) will

Mr Li: be high.

Mr Mun: My friend treated me to a meal of lobsters; readings were right up after the meal of lobster!

Mr Li: That's right, it's 'lethal'!

Mrs Li: Prawns and crabs,

Mr Li: Lobsters are lethal.

Mrs Li: Now when we eat chicken, he won't eat the skin.

(Focus Group No. 6, Birmingham)

Within the lay Chinese perception of illness causation, seafood, especially crustaceans, are seen as 'poisonous' food which can compound any illness condition (Mcnamara and Song, 1995). In the above example, Mr Mun tested this belief, only to receive confirmation from a fellow sufferer that eating lobsters was indeed 'lethal' as it resulted in raised capillary blood sugar levels. Lawton and colleagues (2008) reported that UK Pakistanis with diabetes identified some Pakistani ingredients and dishes as 'dangerous' and detrimental for diabetes. These included ghee, which is used for cooking, and dishes rich in carbohydrates such as chapattis and rice.

In addition to fatty foods and crustaceans as possible causative agents of diabetes, members from one focus group discussed salt as a possible cause. Mr Yap who had diabetes said that he used less salt when steaming vegetables. This prompted Lily to raise the question of salt intake in relation to diabetes:

Mr Yap: When I steam vegetables, I don't add any oil, just a bit of soy sauce, I don't even add salt.

Mrs Ho: Is that so?

Mr Lee: When there is no salt, there is no taste.

Lily: I want to know if salt intake is related to diabetes.

(Focus Group No. 3, Bristol)

The discussion of possible causative agents led to whether or not diabetes could be hereditary. One participant who has diabetes said that diabetes can be hereditary: 'there is also an element of hereditary. My mother had diabetes. Now my little sister has it.' (Mrs Yee, 75, Focus Group No. 5, Birmingham). At another focus group, one female participant said that her husband was lucky she spotted it. The word 'luckily' prompted Mr Lee to correct Mrs Ho by saying 'It's not a case of luck'. Mr Lee said that diabetes can have a long incubation period, and that it was only a matter of time before it was clinically confirmed, a view concordant with biomedical understanding. Thus, Mr Lee was aware that a person can have inherited diabetes but be unaware of it :

Mrs Ho: I discovered his at an early stage.

Lily: So you were the first to discover his illness.

Mrs Ho: Luckily Cheng Yi took him to the doctors.

Mr Lee: It's not a case of luck, once you have diabetes, you've already had it when you were young.

(Focus Group No. 3, Bristol)

Nonetheless, not everybody held the view that diabetes can be hereditary. One group member was convinced that she acquired diabetes from eating, presumably the wrong type of food. Another remained unsure if diabetes was hereditary:

Mrs Chan: Some people said that it is hereditary.

Mrs Yau: Is there such a thing?

Mrs Ngan: Some are hereditary and some have it through eating [lit: ingested the disease]. For me, I got it through eating.

(Focus Group No. 8, London)



In another group discussion, participants discussed the possibility of an organ malfunction to be the cause of diabetes. Mr Lau got the attention of all the group members by asking why there was no surgical operation to deal with diabetes. Group members offered stock answers, i.e. it's all about insulin. Some thought that insulin was found in the intestines:

Mr Lau: You can change every bit of your body except the machine that regulates sugar levels in your body!

Mrs Ong: It's the insulin.

Mrs Wong: You might as well remove your intestines.

Mr Lau: But there are operations on the intestines!

Mrs Ong: It's not about the intestines; it's about the insulin.

Mrs Wong: Where does the insulin come from?

Mrs Ong: It's an internal organ.

Mrs Wong: Those bits like the liver, the kidney; all those can be changed except this one.

(Focus Group No. 4, Birmingham)

In the next section, I present broad views from the focus groups on how diabetes was perceived.

### ***7.1.2.2 Ideas about diabetes: a rare disease, an illness with no 'tail', an illness that leads to other illnesses***

Talk of diabetes as being rare was noted in three focus group discussions:

Mr Lui: They didn't even have such illnesses those days.

Mrs Lui: No, very rare.

Mrs Chang: My daughter didn't understand what sugar urine illness meant. [She] was the interpreter, told us that the doctor says that he is not to take sugar. She says that it is '*diabetes*' (code-switch).

(Focus Group No. 1, Leeds)

Note the code-switch from Cantonese to English when Mrs Chang told the other group members what happened at the visit to the doctor's. This indicates that she was not familiar with the illness. However, later in the discussion, Mr Lui

said that he knew lots of people with diabetes in his home country, Hong Kong. Thus, his comment about diabetes being a rare illness was within the context of reflective talk, i.e. that diabetes was rare amongst farmers or those who lived in rural areas. Nonetheless, talk of diabetes as a rare illness emerged again in another focus group discussion.

In Focus Group No. 2, Mr Chui was surprised when the doctors asked if he had a family history of diabetes. In response to his surprise, other group members said that diabetes was rare in their country of origin and that it only happened in England:

Mr Chui: They asked me about my family history and if I have recollection of who had diabetes in the family. I asked them how my diabetes can be related to my family and my siblings.

Researcher: Is there a history of diabetes in your family Mr Long?

Mr Long: No, No.

Mrs Long: It only happens in England.

Mr Lee: It's rare back home.

(Focus Group No. 2, Leeds)

The view that diabetes 'only happens in England' was expressed again in a later focus group discussion at another centre. Group members were sharing their experience of different types of food that they had to avoid to keep diabetes under control. This provoked a remark from Mr Ong, a non-diabetic who attended the meeting with his wife, a diabetic for 30 years:

Mr Ong: Diabetes is a recent illness.

Mrs Ong: We didn't know that it can be so serious

Mr Ong: It was uncommon, few people talked about it.

Mr Ong: And we didn't know that diabetes was a serious illness.

Mrs Mah: It's only since we came to England that we know about this type of illness.

(Focus Group No. 4, Birmingham)

The above group interactions indicate that some participants felt they had become susceptible to developing diabetes after living in England. However,

this view was not unanimously shared by all participants. Many revealed that they had friends and relatives in Hong Kong who were living with diabetes.

One recurring theme was the expression of uncertainty surrounding the illness trajectory. Participants seemed puzzled by the unpredictable illness trajectory. They could not understand why the onset of illness complications was not linked to the duration of illness. They were also disappointed despite medication they did not get better, instead some got worse. Puzzlement was demonstrated by the following participants from Focus Group No. 3:

Mr Yap: I've been diabetic for 20 years, need to inject day and night. I have complications.

Lily: But this gentleman here [pointing to Mr Lee] had it for over 10 years and he doesn't need injections.

Mr Lee: No, no. Mine is over 20 years (Corrected Lily's mistake)

Lily: And he doesn't need injections.

(Focus Group No. 3, Bristol)

Lily expected similar illness trajectories for Mr Yap and Mr Lee, who both have suffered from diabetes for approximately 20 years. From her point of view, severity of illness was closely linked to its duration. However, they discovered that was not the case. When I asked them how long the illness would last, all participants, diabetics or otherwise unanimously said that there was no end to the illness - expressed as 'cannot cut the tail of the illness'.

Further references to tail cutting were provoked by questions from non-diabetics who asked if there was a cure for diabetes. In Focus Group No. 5, a non-diabetic asked if there was a cure for diabetes and Mrs Yee confidently said diabetes was incurable:

Ms Lee: Is there a cure?

Mrs Yee: There's no cure for it.

Mr Wong: It's been over 10 years, the medicine didn't work.

Mrs Yee: My son got me some medicine from Hong Kong, said it'll break the tail.

Mr Wong: There's no recovery.

(Focus Group No. 5, Birmingham)

In another focus group, a non-diabetic stated that there was no cure for diabetes and this prompted one diabetic to say 'you cannot break the tail of this illness':

Mr Ong: There is no cure.

Mrs Ong: The kind of medication for diabetes,

Mrs Lee: It just won't break.

Mrs Ong: You have to control it.

Mrs Lee: You can't break it [the tail].

(Focus Group No. 4, Birmingham)

When talking about illness and medicine, two male diabetics from Focus Group No. 3 said that there was no cure for diabetes and that medicine could only help to keep diabetes in control:

Mr Lee: It's not possible.

Mr Yap: It's a fact. There is no cure.

Mr Lee: They tell you not to let the blood glucose get too high.

Mr Yap: You can't cut the tail!

Mr Yap: It's like high blood pressure; you have to keep it low.

Mr Lee: No matter how much medication you take, it does not get better.

Mrs Lee: That's right.

Mr Lee: If you inject, it presses it down.

Mr Yap: Don't let it rise.

Mr Lee: It drags on.

(Focus Group No. 3, Bristol)

The image of diabetes as an illness that had to be battled with is strongly expressed in this group. Phrases such as 'pressing it down' indicates their perception of control, whilst phrases that imply the possibility of an accelerated death without medicine or injections gives the image that diabetes is a powerful force to deal with. Finally, participants perceived diabetes as having the tenacity to hang on to its host, expressed as 'drag'.

With each focus group discussion, an image of diabetes as an unwanted pet that required control unfolded. This image of diabetes resonated throughout all

the group discussions. The choice of analogy, 'pet' is deduced by participants who said that when they visited their doctor they did not expect to be told they have diabetes. This can be interpreted as being given an illness label. Then they were advised to keep the illness under control. Participants referred to keeping blood sugar in control as 'keep *ju*'. Thus, the idea of being 'given' an illness diagnosis and then advised to 'keep' it under control conjures the image of participants being given an 'unwanted pet' to look after whether they want to or not. Recall, their reference to 'tail cutting' presented earlier. The use of the word 'tail' contributes further to an animal association. Consequently, the owner, i.e. the patient, is given the responsibility to look after the 'pet, i.e. the illness. Failure to keep the 'pet' under control would result in havoc to the owner's health, i.e. developing diabetes-related complications. Thus, a visit to the doctor resulted in an unexpected outcome – to be responsible for an unwanted illness label which they have to 'control' expressed as '*keep ju*' (着)<sup>13</sup>

In Example 1, participants share with each other what they know about the destructive and progressive nature of diabetes. They described diabetes as running amok in their body and cautioned each other to look out for its progression:

Mr Lau: '*keep ju*' (code-switch), don't let it go to the eyes.

Mrs Ong: It'll go to the eyes.

Mr Lau: Make sure your legs don't get it.

Mrs Mah: It follows you.

(Focus Group No. 4, Birmingham)

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<sup>13</sup> *Ju/zhe* is a resultative verb.

Mr Li: If you don't have injections and it goes up to your eyes, you will have blur vision

Mrs Li: Second sister-in-law said that the diabetes has gone up to her eyes

Mr Li: [...] the doctor said that when the diabetes goes to the heart, a lot of complications arise from there

Mrs Li: [...] meaning that diabetes has a lot of complications

(Focus Group No. 6, Birmingham)

Some participants had already developed diabetes-related complications such as blindness, renal failure and cardiac diseases. Talk of complications arose when they mentioned the need for medication to control diabetes. Two participants had undergone cardiac bypasses. Loss of eyesight and multi-organ dysfunction occurred in two female participants, both of whom had had diabetes for over 20 years:

Mrs Ong: It's now gone to the eyes.

Mrs Mah: Mine has gone to the eyes [too].

(Focus Group No. 4, Birmingham)

Mrs Yee: I'm now blind in one eye. Diabetes will affect the heart, liver, skin, lungs and kidneys.

Mr Wong: This eye is no good. This eye, been 'freeze' (code-switch) twice.

Mrs Lee: I had an operation for it as well.

(Focus Group No. 5, Birmingham)

Whilst the focus groups offered collective voice i.e. consensual views, in contrast, the individual interviews (Appendix No. 16 for list of questions posed) offered a personal account, uncontaminated by the need to accommodate the views of others. Similar questions were posed to the interviewees (Appendix No. 17 for socio-demographic data) as in the focus groups, and repetitions were found. For example, causes of diabetes were listed as excessive intake of sugar and fatty foods, malfunctioning of insulin and heredity. Also repeated in the interviews was the reference to diabetes as the illness with no 'tail'.

The next section presents findings from the individual interviews including the causes of diabetes, i.e. identification of body organs, age and food and lifestyle. With regards to ideas of diabetes, these include classification of diabetes, making comparisons with other diseases such as cancer and mental illness, and using metaphors of parts of cars that reflect their ideas of diabetes.

## **7.2 Findings from individual interviews**

### **7.2.1 Cause(s) of diabetes**

Whereas there was no specific mention of the organ involved in diabetes in the focus group discussions, in the individual interviews, renal dysfunction, pancreatic failure and insulin malfunction were singled out as causes of diabetes. It has been said that patients tend to draw on their past knowledge of health and illness in order to make sense of their current illness. For example, in the case of Liam, his baby daughter died from renal failure and he attributed his diabetes to renal dysfunction, which he did not have.

Both kidneys *'failed'* (code-switch) they could not save her. My understanding of diabetes is the *'kidneys cannot handle the workload'* (code-switch) cannot get rid of the sugar and therefore it's all stuck.

Many of the participants attributed diabetes to the pancreas 'giving up' or 'going on strike'. Except for the English speaking participants ( $n=5$ ), all the Cantonese speakers referred to their pancreas as 'the pig's pancreas' being faulty. At the individual interviews, many also expressed they used pig's pancreas as part of their management regime. The 'like help like'(Koo, 1984) approach adopted amongst some Chinese people in illness management episodes may explain how they come to identify the pancreas as an organ responsible for diabetes. Mr Lui's description of the pancreas demonstrates his perception of the cause of diabetes:

That bit, it's not releasing the hormone, it's not releasing the juice, and same as going on strike that means it doesn't work. We call it the pig's pancreas, and if it recovers then your diabetes will be resolved.

Another participant used the analogy of a car to describe what she thinks caused diabetes:

Just like a car where one of the parts is out of order. The part that turns round but now it's stopped and won't go round anymore, so, it cannot get rid of the sugar. It's stuck. This machine part where the insulin is has stopped. Like normally, it will go round and round like an oil drum. (Ong, 50, Female, Birmingham)

Drawing similarities with a car was also expressed by another participant who said that with diabetes, the windscreen is cracked and one has to live with it until it gets worse:

The windscreen is cracked! The problem is you can't change the windscreen. It's not serious enough to warrant a change but at the same time you cannot mend it. For the time being, you are stuck with it. (Liam, 39, Male, London)

The metaphors used by the interviewees demonstrate their ideas about diabetes. Their choice of metaphor reflects the industrialised society in which they are living

Despite being told by their doctors that diabetes was a result of shortage of insulin, Mrs Chueng could not make sense of the information:

He said I'm short of insulin. He talked about it but I don't always understand every word that was said. Till now I understand very little about it.

Many accepted diabetes as part of the aging process. They referred to diabetes as 'an old folk's illness', and 'let[ting] nature take its course'. These participants had already retired from work and felt it was a consequence of old age. Acceptability of less than perfect health after retirement seems to them to be a norm rather than an exception. The following excerpts show their acceptance of a less than perfect state of health once they reached 'a certain age':

When you reach a certain age, you will have this kind of illness urine sugar illness. Old folk's illness, 50-60 years old, all of them will have sugar urine illness. (Yap, 70, Male, Bristol)



Our age, we're getting on, that's what caused it. (Chueng, 60, Female, York)

Their views are consistent with those found for other populations. Consider, for example a web-based survey of 226 Dutch people. The researchers wanted to find out if acceptability of less than perfect health really existed. The team explored five health domains i.e. mobility, self-care, usual activities, pain/discomfort and anxiety and depression; and three health levels for each health domain corresponding to 'no problems', 'mild problems' and 'severe problems' (Brouwer et al., 2005:240). They found that overall, poor health was accepted with increasing age.

Bury highlighted the difficulty of accepting less than perfect health amongst young adults diagnosed with chronic illnesses such as rheumatoid arthritis (Bury, 1982). This struggle to accept chronic illness is also seen in my study. Having to live with a perceived 'chronologically older' (Singer, 1967:143) form of disease such as diabetes was interpreted by some participants to have made them artificially or prematurely aged. A group of young diabetics were shocked with the diagnosis as they perceived diabetes to be linked to old age. Consider the following reactions from the following participants and their family members

I got hit SOONER THAN I THOUGHT! (*her emphasis*), the doctor predicted we'll be in our mid-50s. My dad was 60 when he got it. My dad said 'it can't be!' (Lana, 52, Female, London)

They said, 'You've got diabetes. You're insulin dependent and you've got to take injections probably for the rest of your life.' It was a big shock. (Jeanie, 21, Female, Teesside)

The doctor said, 'Sorry to tell you you've got diabetes.' I was shocked! I didn't expect it. Early thirties, I am still young. Oh no, what about the rest of my life? What am I going to do? I haven't got any children. My mum got it when she was 65. If I tell her I've got diabetes she'll send something over. That's what I don't want. (Tessa, 33, Female, Belfast)

Thus, participants who could not accept the diagnosis experienced an upset of 'internal and external reality' (Bury, 1982:171).

Although diet and lifestyle was mentioned during the focus group discussions, sensitive and personal information related to diet and lifestyle were revealed at the individual interviews. They felt that previous hard work in their youth, and food and sleep deprivation might have contributed to their current health problems. Such personal and emotional issues are not readily shared at focus group settings. In the following paragraphs, I present examples of personal and emotional issues that were shared at the individual interviews. In Example 1, Mr Chang spoke about having to feed the family with offal meat from the restaurant where he worked:

#### Example 1

I was 18 when I came to England. During the day I worked as a labourer and in the evening. I got to work in the restaurants, no time to sleep. I used to bring the scraps from the restaurant, those which the restaurant were going to sling as food for the family such as duck wings and duck offal. (Chang, 66+, Male, Leeds)

In Example 2, Mr Yap told me that he had to eat whatever was available in the kitchen and that he did not have time to engage in physical exercises:

#### Example 2

When you are working you'll eat anything that is in the kitchen, whatever damned fat. That's how I damaged my own health. And you suffer the night shifts and do very little exercise. It was real hard work. (Yap, 70, Male, Bristol)

Others spoke about being so busy with work that they did not have the time to eat properly:

No exercise, eating all those junk food. You know, with Chinese people, they'll eat and work at the same time. I would be wolfing my food down because a customer had just come through the door. You want to make money! The customer comes first! And so you are constantly stressed. So the day ends and you pack up to go home. If you don't go to sleep, you go

to the casino. Lost my business through gambling. (Chueng, 60, Male, Leeds)

Some participants felt that their nature of work contributed to the onset of diabetes:

Back then we had a takeaway and four small children. Where can you find the time to exercise? By the time we finished work, it would be 3 or 4 o'clock in the morning before we can get to sleep, and I have to be up at 6 o'clock [to get ready to fetch the children to school]. (Ong, 57, Female, Leeds)

The disclosure of personal and family hardships at the individual interviews contrasted sharply with the information shared at the focus group settings. Understandably, participants might have felt ashamed and embarrassed about revealing information such as eating scraps and losing hard earned fortunes at casinos, at public forums such as the focus group settings. Also, participants were unlikely to share such tangential information as they were aware that the focus group discussion was about diabetes and its management, rather than personal histories. Bearing in mind that the majority of my participants were economic migrants, disclosure of previous hardships might be potentially upsetting to other participants. However, at the individual interviews, some participants felt free to share personal information as they did not have to contend with responses or reactions from other group members.

### **7.2.2 Trajectory of diabetes: neither acute nor terminal, just 'in-between'**

In the focus groups, participants said that there were two types of diabetes: mild and severe diabetes. In many of the individual interviews, the trajectory of diabetes was compared with other illnesses such as acute, terminal and long-term illnesses. Examples of acute conditions include coughs and colds and other common illnesses. Acute illnesses have 'tails' that can be removed or cured by taking a course of medicine. Importantly, there is no need for long term medication to keep the illness under control or prevent further deterioration.

Terminal illnesses on the other hand, generally cannot be cured. However, some types of terminal illnesses are curable. In the case of cancers and AIDS, although interviewees in general considered these as terminal illnesses, which therefore had no cure, many had known of sufferers who were cured of them, or had heard that a cure was imminent. In the case of diabetes, all believed that there was no cure, only control. Principally, both diabetes and cancer share one similarity; they spread, causing destruction to vital organs. However, unlike cancer, diabetes cannot be excised, a fact acknowledged at the individual interviews.

In terms of illness trajectory, diabetes was viewed as neither acute nor terminal. Mrs Yee said that diabetes is a 'long-term' illness:

Long-term illnesses are those where there is no cure such as diabetes and high blood pressure. (Yee, 75, Female, Birmingham)

And Liam described diabetes as '*karla*', meaning an 'in-between' illness. The term '*karla*' refers to the vagueness of the illness as it is neither a major illness which requires operation or a definite course of treatment, nor is it an illness so minor that there are no long-term complications:

The minor illness [i.e. coughs and colds], the tails can be removed. This type of illness is neither big nor small, it's *karla*- an '*in-between*' (code-switch) illness. (Liam, 39, Male, London)

All the interviewees ( $n=22$ ) described diabetes as a long-term illness that persists despite medication and diet manipulation. Some added that their illness had become 'deeper' and 'heavier':

It's been there for too long. It's just got heavier in the last 8-10 years. Don't know if it's due to aging, it's got worse, progressively deep. (Ong, 50, Female, Birmingham)

However, recognition of its severity did not translate into any constructive activity such as engaging in health-promoting behaviours to delay the onset of diabetes related complications, or finding out more about the illness. Instead, they told me that few changes have been made with regards to their diet and lifestyles except for the obvious 'eat less':

I just know it's one of the serious ones. My uncle got the serious one. The darn thing is I can't remember what they said. I just carry on eating as I've been. (Leong, 47, Female, Birmingham)

People say that you can easily die from diabetes. Like cancer where there is no cure. I don't feel any different. I just carry on eating as normal, just eat less of it. (Yau, 69, Male, Belfast)

Their lack of motivation to make dietary or lifestyle changes might be due to the fact that having diabetes did not impact on their mobility, their ability to engage in gainful employment or otherwise interfere with their lives.

I feel it's not a serious illness. That's what the Chinese books say as well. Don't treat it as an illness, keep to your normal routine and, eat well. (Leung, 54, Female, Leeds).

There's not much to understand. There should be no problem. I've not specifically controlled anything. (Wong, 53, Female, Leeds)

All the above participants are self-employed, working in the catering industry. Their ability to carry on working as they did prior to the diagnosis may explain why they do not actively engage in keeping diabetes under control. The silent nature of diabetes misleads many diabetics into thinking of it as a mild illness and consequently one that can be easily ignored.

Given that the interpretation and experience of illnesses contributes to how it is subsequently managed by the sufferers themselves, Kleinman argues that it is crucial that practitioners understand and take heed of lay persons' perspectives of their illness. Helman echoed this view and urged healthcare professionals to be aware that patients bring with them their '*deformation professionnelle*' (2004:76), i.e. patients' ideas of health and illness are shaped and influenced by their professions. Helman urged health professionals' to frame their medical advice on an awareness of their patients' system of metaphors, and its impact on health practices.

### 7.3 Discussion

In both the focus groups and individual data, there was evidence of concordance with the biomedical explanations about the cause of diabetes. Yet, it was the personal and cultural constructs which formed the core of their understanding of diabetes. Whilst there was acknowledgement that diabetes could be hereditary, I found their responses to diabetes as 'rare', 'didn't have such illnesses those days' and 'only happened in England' contradictory to their acceptance of diabetes as a hereditary illness. This suggests that participants felt that they had developed diabetes because they have migrated to a Western community. Hagey's migrant Ojibways felt that diabetes was linked to 'white man's food and environment' (Hagey, 1984:268). Ten years later, Garro revisited the Ojibways' explanation of diabetes in southern Manitoba, Canada and found that much of the discourse on diabetes remained linked to environmental and societal changes. In her study, respondents said the diabetes is a 'new' illness that was not present 'in the old days' (Garro, 1995:38) – a sentiment echoed in my study.

Despite acknowledgement that hereditary and dietary factors were causes of diabetes, the main thrust of much of the discussion was 'what should diabetics eat?' Indeed, concerns about food are frequently cited in studies on Chinese people with diabetes. In a US West Coast Chinatown, Jayne and Rankin (2001) reported that 23 of 30 subjects (74%) said that eating behaviours including eating too much sugar, foods high in salt and fats and eating too much meat were the cause of diabetes. In Canada, Anderson et al. (1995) reported that Canadian Chinese female diabetics said that eating the 'wrong types of food' gave them diabetes. In Hong Kong, two separate studies reported that those diagnosed with diabetes refrained from taking sugar even in the event of hypoglycaemic attacks (Shui and Wong, 2002, Chan and Molassiotis, 1999).

However, some diabetics will not restrict their diet because of diabetes. Lai et al. (2004) reported that one of her Taiwanese participants who survived a car accident decided not to restrict her diet because she knew that diabetes does not kill. Since the near death experience, she decided to enjoy the here and

now: 'I may not necessarily die of diabetes from an accident so I might as well eat and enjoy the food here and now.' (Lai et al., 2004:288).

Preoccupation with food as a causative agent is not exclusive to Chinese people with diabetes. Hunt and colleagues (1998) reported that 46 of 49 (93%) Mexican Americans in South Texas cited genetic links and food as causes of diabetes. 'Provoking factors' of diabetes included 'not eating your proper meals [...] and drinking too much' (Hunt et al., 1998:960). Similarly, Cohen and colleagues interviewed 54 individuals including patients and healthcare professionals from a diabetes clinic in Iowa, USA, about their explanatory model of diabetes. They reported that one of the most cited reason for the cause of diabetes was excessive sugar and its effects on the pancreas: 'I remember eating a lot of candy. Now I'm not saying that this candy did it, but maybe the excessive amount of sugar in my body, that maybe it just made my pancreas totally overwork itself' (Cohen et al., 1993:62). In a survey of 161 respondents of Latino adults from four diverse communities (Hartford, Connecticut; Edinburg, Texas; Guadalajara, Mexico and rural Guatemala), using a 130-item questionnaire about diabetes, Weller and colleagues reported that respondents believed that diabetes can be caused by eating sugar, sweets or drinking soda pop (Weller et al., 1999). Amongst the Ojibways in Canada, people believed that 'eating too many sweets' (Garro, 1995:41) caused diabetes.

A different picture in the literature on perception of diabetes is found among white Europeans. For example, in a study on diabetes 'disease experience', Searle and colleagues set out to investigate if beliefs about diabetes impact on the prevalence of diabetes related complications, specifically diabetic foot ulceration and retinopathy (Searle et al., 2008). With regards to beliefs on causes of diabetes, participants identified excess weight and lack of exercise. In an earlier study, Searle et al. (2007) looked at perception of diabetes by patients and by their partners and how this impacts on self-management. They found that patients and their partners' understanding of diabetes were similar to the one held by healthcare professionals whereby diabetes was understood to be a chronic illness with serious consequences, and that it could be controlled effectively with treatment.

Given that the participants in my study had little education, I did not expect that their perception of diabetes echoed that of the knowledge found in Chinese medical texts. One possible explanation for the echoes of ideas in classical texts may be attributed to the prevalence of oral transmission. China has a long tradition of oral transmission of knowledge, as proficiency in written Chinese language requires a long period of formal education. This is especially true of the classical Chinese script which is used in ancient textbooks e.g. *Huangdi Neijing*. Since the Chinese Communist Party took over in 1949, Chinese language was simplified to increase literacy levels among the rural population. Despite the simplification of the Chinese script, current levels of literacy remain low in the rural areas. Against this historical background, it can be deduced that participants came to know about diabetes and Chinese medicine through oral transmission.

Whilst accounts of the perception of diabetes may differ from the biomedical model, reports of symptoms were consistent with biomedical constructs of diabetes. These included complaints of thirst, pruritis, blurring of vision and others listed previously. Although some suspected that the symptoms they experienced might be related to diabetes, many participants had to be told by their doctors that they had diabetes. Another finding was that it was not always the symptoms that led them to consult the doctors but other factors such as a routine check-up for insurance purposes, or getting a prescription for glasses, and being referred by other healthcare professionals for other ailments. Given their lack of awareness about diabetes, it was not surprising that they interpreted being diagnosed with diabetes as an illness unexpectedly 'given' to them by their general practitioners. Subsequently, they adopted a picture of diabetes as an unwanted pet that required elimination and or control. The word 'pet' has a positive connotation but in this study, I have chosen this word based on the participants' use of the words related to keeping a pet including, 'keep' and verbs such as 'go', 'get' and 'press'. Hence, the word pet is prefixed by the word 'unwanted' to denote a reluctance of the owner to look after it.



## 7.4 Summary

To conclude, my discussion of the explanatory model framework used by my interviewees has demonstrated that lay ideas about diabetes are influenced by biomedical and lay explanations. Participants stated that diabetes developed because of dietary and/or lifestyle habits; some believed that it was inherited. In particular, talk of eating too much sugar resonated in both focus groups and individual interviews. The causes of diabetes are perceived differently between sufferers. Some attributed it to food intake, either an excess of intake of sugary foods or the lack of adherence to food prohibition. Others claim that it is a hereditary illness. Some even viewed it as an illness contracted simply by living in the West and adopting a 'Western' lifestyle. By exploring the participants' views on diabetes, I have demonstrated that there is a degree of concordance between the biomedical and lay perceptions of diabetes. Contrary to popular belief that Chinese people in general have a holistic view of the human body, the audio recordings from the eight focus group discussions and the individual interviews, have provided evidence that some UK Chinese people have embraced the biomedical view alongside their personal views of diabetes. The description of diabetes, namely illness causation and the trajectory of diabetes have revealed an interesting interpretation of diabetes i.e. an illness with no 'tail' – the tail representing an end of the illness. This idiomatic phrase reverberated across all focus groups and at the individual interviews. Many participants invested money and time to break the 'tail'. This preoccupation with 'tail cutting' indicates their struggle to come to terms with living with diabetes, and its chronic nature. The next chapter looks in detail at the ways in which participants managed diabetes.

### 8.0 Introduction

Like many chronic illnesses, diabetes has to be managed largely by the patients themselves (WHO., 1998, Van den Arend et al., 2000). Effective self-management hinges on a good understanding of the illness (Deakin et al., 2003, Trento et al., 2002), along with the ability to sustain lifestyle changes, make appropriate use of medical therapies and technologies (Lawton et al., 2004, Peel et al., 2004), adjust medicines, and to use health services appropriately. Indeed, self-management is a demanding and difficult task and, unsurprisingly, few diabetics achieve or sustain normal blood sugar levels (Sullivan and Joseph, 1998).

This chapter presents findings on the self-management of Type 2 diabetes. It is delivered in three parts. Section 8.1 presents findings from the focus group discussions. Four actions sum up their management strategies: (i) food abstinence (*gaihauh/jikou* 戒口), (ii) exercise, (iii) medication (*shikyeuk/chiyao* 吃药) and (iv) control, expressed as 'keep *ju*' (着). The first of these, *gaihauh* (戒口) was deemed by many participants to be the primary form of illness management followed by compliance with medication, and finally, 'keep *ju*' (着) i.e. maintaining blood glucose levels less than or equal to 7 mmols. All except one participant acknowledged the need for medication (*shikyeuk/chiyao* 吃药) including the use of Western medicine but were disappointed that they had to take it for life. Taking medicine as a form of control rather than to cure appeared incongruent to the participants. Furthermore, being entrusted with the responsibility to maintain glycaemic control i.e. 'keep *ju*' (着) was also a new concept for them. As presented earlier, when encountering a foreign concept, individuals who do not speak English as a first language resort to code-switching (Wee, 2006, Li and Milroy, 1995, Finlayson et al., 1998). Thus, when participants narrated their monitoring of capillary blood sugar levels, their use of

code-switch 'keep *ju*' (着) demonstrates that the concept of self-monitoring has no equivalence in the Chinese concept of illness management.

Section 8.2 presents material from the individual interviews. As in the focus groups the pursuit of 'tail cutting' remained a central theme despite acknowledgment that diabetes is an illness with no 'tail'. New information gathered in the interviews demonstrated different styles of coping, including acceptance, denial and resignation. Data from the individual interviews is delivered in two broad sections. Section 8.2.1 describes the various coping styles: those who accepted the diagnosis adopted new ways of living; those in denial continued with their previous lifestyles, whilst those who were simply resigned to the illness were not pro-active in management and said there was little they could do to stop deterioration. In addition, participants shared intimate information such as suicide attempts and regrets of loss of wealth from gambling. Section 8.2.2 presents the support network that participants used. This support network includes a combination of in-groupers and out-groupers (Nisbett, 2005).

Section 8.3 of the chapter offers a discussion of the findings, highlighting the impact of uncertainty on the management of diabetes. The idiomatic phrase 'cutting the tail' used by the participants denotes a sense of incompatibility with their understanding of illness management and compounds their feelings of uncertainty.

## **8.1 Findings from focus group discussions**

### **8.1.1 Food abstinence (*gaihauh/jikou* 戒口) versus 'Sneak and eat' (*Tauh sihk/touchi* 偷吃)**

Food abstinence (*gaihauh* 戒口) is the practice of voluntary avoidance and or restriction of selected food items. It is based on the belief that some food items compound ill health or delay recovery from an illness. The voluntary act of abstinence from perceived causative agents is beneficial to the individual from the viewpoint of healthcare professionals as it indicates that the individual is

claiming control of and taking responsibility for their illness. However, this approach can also be detrimental for the patient's health as there is a tendency for patients and carers to minimise the importance of other health information, and of the expertise and skills which the healthcare team can offer to augment existing self-management strategies (Chan, 1991, Chan et al., 2005, Chan and Molassiotis, 1999).

The importance of *gaihauh* (戒口) in recovery from illness episodes is highlighted by Mr Yap's experience in a hospital whilst recovering from a cardiac operation:

Mr Yap: When I was in Oxford for an operation, the old man next to me who had the same operation had deep fried crispy chicken. Chinese people and Westerners are completely different.

Researcher: How are they different?

Mr Yap: They dare to eat ANYTHING! (*his emphasis*)

Mrs Ho: But they are OK.

Mr Yap: They carry on eating as though nothing had happened.

(Focus Group No. 3, Bristol)

The above extract demonstrates that patients and carers regard *gaihauh* as being particularly important after an acute illness episode, in this case the early post-operative phase. For Mr Yap and the other group members, illness episodes restrict the types of food that can be eaten. He was surprised that Western individuals, in particular, did not adhere to food abstinence but this did not affect their recovery of health. He concluded that Chinese people's view of managing post operative recovery is different from other ethnic groups. Significantly, this cultural eating habit reflects an assertion of the collective identity of Chinese people, and the retention of cultural distinctiveness, despite a long period of separation from the parent culture (Wood, 1995).

In the case of diabetes, many participants believed that the main food item which needed to be *gaih*, i.e. to reduce or omit is rice. Yet, a reduction in rice intake appeared to have a significant psychological impact. Participants in the focus groups expressed that only the consumption of rice or other carbohydrate staples can give them a sense of completeness to their meals. Besides rice,

many also found it difficult to restrict the intake of other food items which were deemed 'bad' for diabetes.

For example, roast duck was singled out as a 'bad' and at the same time, a favourite dish which they found difficult to give up. Rather than not eating it at all, they chose to eat it occasionally. But how would they know when to stop? And how do they measure the appropriate amount? The dialogue below indicates that they would knowingly eat what they feel is prohibited and 'bad':

Mr Lui: The biggest impact is that one has to restrict one's food intake.

Mr Chang: Can't eat fatty food.

Mr Lui: I love roast duck.

Mrs Lui: When you eat roast duck, you must not eat the skin. That's a joke. How can one enjoy roast duck without eating the skin? You might as well not bother [but] after you've eaten it your blood glucose will shoot sky high.

(Focus Group No. 1, Leeds)

The lack of practice of *gaihauh* was also noted in Focus Group No. 5 where Mrs Yee said that she did not *gaihauh* because there was no need for this practice as she now lives in the UK. Ms Lee was surprised to know that diabetics in the UK did not have to *gaihauh*. In the following extract, Mrs Yee tried to impress on Mrs Lee that *gaihauh* was not advocated by Western medical practitioners:

Mrs Lee: Huh? Dried shrimps!

Mr Wong: Yes.

Mrs Lee: You eat dried shrimps! *Aiyah*, my God! Prawns, crabs, must not eat those.

Mrs Yee: Westerners don't do that, foods like duck, it's OK to eat.

Ms Lee: They don't abstain (*gaihauh* 戒口)?

Mrs Yee: I'm different, I believe in Western medicine.

(Focus Group No. 5, Birmingham)

This suggests that at least some of those who use Western medicine feel they do not have to adhere to Chinese norms of illness management which demand self-imposed restrictions on food intake and compliance with prescribed

treatment. Furthermore, those who embraced Western medical treatment appeared to be blasé about their illness management.

Attitudes towards food make it difficult to *gaihauh*. In the next example, Mr Chang's past experience of poverty made it difficult for him to refuse food. For him, to refuse food was an act of waste. Although his wife agreed that it was bad to waste food, she felt that she had a duty to ensure that her husband observed food restrictions as advised by the medical professionals. She was upset when he ignored the medical advice to cut down on food intake as this would potentially put his health at risk:

Mrs Chang: Eat when food is available; don't waste it, that's what he (referring to her husband) says [...] you cannot argue with that, can you? (...) but now that your health is such, you CANNOT (her emphasis) carry on eating with that mindset [...] the doctor said [...] control it (referring to food intake), otherwise he will need injections  
(Focus Group No. 1, Leeds)

Similar attitudes towards food were expressed by other group members. Whilst they expressed empathy with Mrs Chang's dilemma on the one hand, they also expected her to be sensitive to her husband's view on food. Yet, she felt she was expected to follow the doctor's orders to ensure that her husband observed dietary restrictions. Two of the group members, Mr and Mrs Lui demonstrated empathy for her by saying that they were familiar with Mr Chang's attitude towards food, adding that his attitude towards eating was essentially rooted in the past. However, the support for Mrs Chang's view did not last long. Mr Lui advised Mrs Chang to restrict her own intake so as to help her husband adhere to a diet appropriate for a person with diabetes: 'If he cannot eat, it's reasonable to expect that you shouldn't eat it either.'

This attitude can be traced back to the Confucian philosophy of familial roles where family members are expected to fulfil their allotted responsibilities. In accordance with Confucian ethics, wives are expected to be subservient to their husbands, and children have a duty to look after their parents, i.e. filial piety. This was evident in some of the focus group discussions. For example, Mr Chui expected his wife to look after him:

Mr Chui: In the morning at about ten, my wife makes me a cup of tea, English tea, with artificial sugar (sweeteners). Chicken, I tell my wife to remove the skin.

(Focus Group No. 2, Leeds)

Reciprocal roles and shared practices were not commonplace. In Focus Group No. 6 in Birmingham, Mrs Li said she made no attempt to prepare special meals for her husband who suffers from diabetes. She said, 'He'll eat whatever I cook.' While some family members engaged in caring for the sick, others appeared to deviate from traditional caring practices. Some of the spouses of diabetes sufferers did not want their own lifestyle affected. In particular, there were weak attempts to reduce food temptations. For example, Mrs Chang in Focus Group No. 1 was not willing to sacrifice her own enjoyment of food just because her husband was not allowed certain foods. She said, 'Well, mate, it's YOU who's not supposed to eat. It's not reasonable to expect me not to eat it just because you are not allowed!'

*Gaihhauh* is especially difficult to maintain when eating out. However, eating out provides an opportunity for getting together with fellow migrants. After the communal meal, one participant said she would go walking with her friends. Another participant used eating as an opportunity to consolidate relationships with family members, 'my daughter comes over from Europe and we have a meal together.' However, he was willing to forego his social life for his health and would go to dinner parties just to 'give face' to his friends. He claimed that he ate very little of the food on offer, 'when it comes to social dinners, I rarely go. Why? It's because there's lots of mono sodium glutamate (MSG) and sugar in the food. I attend such functions to 'give face' to my friends, sit around and socialise.' (Mr Chui, Focus Group No. 2, Leeds).

For one participant, strict adherence to food abstinence had led to a strain in familial relationship. Mr Li had less contact with his daughter-in-law because of his diabetes. His wife said, 'When our son and his wife invite us round for tea, the first thing is to order vegetarian steamed dough for him, that's it. And when there are beef noodles, he can only pick a few strands out, that's all. So now my daughter-in-law does not invite us to tea as much as she used to. After all,

when we are at the restaurant, there is not much choice for him.’ (Focus Group No. 6, Birmingham).

Thus far, I have shown that participants found it difficult to adhere to *gaihauh*. This difficulty is also reported in previous research on ethnic minorities with diabetes e.g. UK Bangladeshis (Kelleher and Islam, 1996) and Afro-Caribbeans (Pierce and Armstrong, 1966). Participants in these studies also expressed their distress about dietary restrictions. In particular, For instance, many UK Bangladeshi Muslims regard rice as a food that feeds their soul. Eating ‘soul food’, i.e. rice, was important for them as it reminded them of home (Kelleher and Islam, 1996:227). For many Afro-Caribbeans, rice is the main source of energy. To be told that they needed to reduce their intake of rice was interpreted by many diabetics as weakening their energy source (Pierce and Armstrong, 1966).

Similarly, Lawton et al. reported that many South Asians with diabetes found it difficult to reduce the intake of their staple carbohydrate, roti. They described roti as ‘foundation food’ without which they would ‘not be able to sleep’ (Lawton et al., 2008:310). The need to consume high caloric food items was found in Naeem’s study on diabetic Kashmiri men in Leeds. When asked about their dietary changes, a common reply was ‘We have to have some enjoyment in life - we cannot eat grass’ (Naeem, 2003:114). Accounts of food consumption patterns are consistent with anthropological work (Delphy, 1979, Goody, 1982) which observed that ‘the identity and differentiation of the group is brought out in the practice of eating [...] as well as the content of what is eaten’ (Goody, 1982). Thus, food is never just food but it has cultural and social implications. In the context of the UK Chinese, the practice of food abstinence during an illness event separates them from other ethnic groups, and reinforces their identity within a multi-cultural environment.

Whilst *gaihauh* involves a voluntary act of food abstinence, *tauh sikh*, literally meaning ‘sneak and eat’ is when some participants knowingly indulged in what they felt they were not supposed to, e.g., duck skin and chocolates. Some *tauh sikh* when their blood sugar levels were within the acceptable range of less than or equal to 7 mmols: ‘For me, when my sugar levels are ‘good’, I will eat what is



forbidden. Once it comes down to about 4 points [mmols], I'll eat sweet stuff.' (Mrs Ngan Focus Group No. 8, London). The action of *tau h sikh* indicates that some of the participants felt that it is permissible to allow a lapse in their *gaih hau h* regime. This indicates that participants had not internalised the logic behind the biomedical treatment regimen.

*Tau h sikh* can be said to be similar to taking a 'drug holiday' (Erlen and Mellors, 1999, Barton et al., 2000, Stone et al., 1998) a phenomenon where patients make decisions about their medications without consulting a medical professional. This includes adjusting, skipping or taking tablets separately rather than all at once. Both Mrs Ngan's and Mr Lui's lapses in *gaih hau h* can be interpreted to be taking an 'illness holiday', presumably to temporarily forget about diabetes. This action also suggests that both participants were managing diabetes according to their capillary blood sugar readings..

Other researchers (Robertson, 1992, Johnson et al., 1999) also found that patients would check their blood pressure and decide on dosage accordingly. Arguably, *tau h sikh* is tantamount to taking an 'illness holiday', potentially compounding the illness trajectory through bouts of 'glucose excursion' whereby blood sugar concentrations swings between peaks and troughs.

The moral language of illness in general, has been extensively reported in many studies. Sontag (1978) observed that illnesses are experienced according to individuals' perceptions. Any individual diagnosed with an illness can claim the sick role (Parsons, 1951). In the case of diabetes, the sick person's health cannot return to its original state. However, a sick person's worthiness to the family and society can be upheld if the individual adheres to cultural norms of behaviour (Posner, 1977, Estroff, 1993, Kassenbaum and Bauman, 1965), in the case of UK Chinese, through actions such as *gaih hau h*. Thus, the moral language in diabetes, inculcates an unwritten social contract, whereby persons diagnosed with an illness have to adopt health behaviour that is medically correct in order to be accepted by the society (Rogers et al., 1998). As mentioned in the previous chapter, some participants blamed themselves for the onset of diabetes through overindulgence or a lack of self control in eating. This view is reinforced by healthcare professionals in the form of advising them

on food restriction and to increase their physical activities. Yet, should this kind of health advice continue? The following paragraphs show that patients are more likely to comply with health advice if healthcare professionals monitor patients' disease status closely rather than leaving the patients to manage it by themselves.

### **8.1.2 Exercise**

A second strategy used by some participants to manage diabetes was exercise. Studies inform us that those who receive support from friends and family members are shown to have better self-management outcomes compared to those who have to manage diabetes by themselves (Glasgow and Toobert, 1988, Toljamo and Hentinen, 2001, Williams and Bond, 2002). One couple acknowledged the importance of exercise as a way of keeping diabetes under control:

Mr Ong: We usually go

Mrs Ong: swimming and jogging after dinner. We go out for half an hour for a stroll.

Mr Ong: Go to the park for a stroll.

(Focus Group No. 4, Birmingham)

However, in the case of Mrs Ong, she had already developed diabetes related complications – both her eyes had received laser treatment for diabetic retinopathy. Her current exercise routine, revealed at the individual interviews, only began after both she and her husband retired from full-time employment.

Not all participants received spousal support in physical exercise. For example, Mrs Chang did not support her husband in his exercise regime, stating that her legs hurt from walking slowly:

Researcher: Do you go walking with him?

Mrs Chang: No, I don't.

Mr Chang: No, she does not come with me, she walks too quickly.

Mrs Chang: He's a slow walker and if I walk slowly, my legs go numb.

(Focus Group No. 1, Leeds)

Nonetheless, Mr Chang persevered with his exercise and claimed he walked as much as he could tolerate. On the other hand, Mrs Lui, also a diabetic, confessed that she was too lazy to exercise, even if someone carried her in a sedan chair! However, the group seemed more interested in exercise when one member said that the local gym was free to use. It transpired that one of the members of the Chinese community had free entry to the gym because she was accompanied by my assistant moderator, Joanna, who was a member of the gym. All said they were interested in doing exercises in the forms of *taiqi* if someone was available to teach them. Also, they would consider going to the gym if it was free of charge.

Compared with the practice of *gaihauh*, engaging in physical exercises requires a pro-active role and the willingness to engage in a particular activity such as walking or *taiqi*. One observation of the above dialogue is the 'moral language' (Broom and Whittaker, 2004) which the other participants used, e.g. 'good' 'willing' and 'lazy' in response to Mr Chang's claim that he exercised daily. His health behaviour was applauded by his fellow participants. Mr Chang appeared to be the only diabetic in the group who upheld two of the three pillars prescribed for the biomedical management of diabetes i.e. diet and exercise.

Participants identified barriers to exercise including self blame, cost and the lack of time. Despite acknowledging the need for exercise, they failed to carry out the required activity as part of their diabetes care. Studies with other populations show that failure to participate or maintain physical activity are often associated with personal and environmental barriers (Clark, 1998, Dishman et al., 1985). For example, a qualitative study on UK Pakistanis with diabetes uncovered some of the personal and cultural barriers to exercise, such as fulfilling obligations to help family members in running a business or to provide childcare. They were worried that community members would view their taking time out to exercise as part of their illness management as selfish and or culturally inappropriate (Lawton et al., 2006). Furthermore, many of the participants felt that healthcare professionals' recommendations to go swimming or exercise in the gym were culturally inappropriate because of taboos about exposing their bodies to the opposite sex, given the lack of availability of single-sex facilities and same-sex instructors. In my study, some

participants listed general feelings of weakness and lethargy as personal barriers. Others felt unsure about exercising post coronary bypass operations.

For example, in Focus Group No. 3, Mr Yap acknowledged that walking as a form of exercise was good but said that his legs hurt from walking as the blood vessels in his legs were blocked. Also, he could not do any upper body exercise because of a scar on his chest following cardiac bypass surgery. His experience of blocked blood vessels had provided him with a legitimate excuse not to exercise as much as was recommended. He also said that transport was an issue in relation to getting any exercise done. Mrs Ho commented that depending on public transport to get to places was problematic. Presumably, Mr Yap thought that exercise meant going to a gym.

In a questionnaire study on patients with diabetes ( $n= 406$ ) in Dundee, Scotland, only 33% of the patients had engaged in some form of physical activities in the previous two weeks, of which only 9% exercised effectively to challenge their cardiovascular status. Reasons for the lack of exercise included tiredness, lack of time and facilities and distraction (Thomas et al., 2004). They reported that patients who were physically active tended to be younger diabetics. Amongst older diabetics, walking and gardening were popular activities. However, the levels at which these activities were performed did not increase heart rate and breathing sufficiently to provide cardiovascular benefits. In the US, a lack of exercise was also reported by Nelson et al. based on data collected from a large scale survey of 1 480 adults diagnosed with diabetes (Nelson et al., 2002).

When I asked the participants if exercise was part of their diabetes management, members from Focus Group No. 4 said that exercise was important in keeping blood glucose under control. An effective level of exercise was indicated by copious amounts of perspiration rather than an increased heart rate and breathing. Mr Lau said that perspiration was a good sign as it meant that energy was expended resulting in a lowering of blood sugar levels. Mrs Ong added that exercise was one important way of controlling blood sugar levels. Talk of benefits of perspiration was also mentioned in a study in Taiwan on Chinese people with diabetes. Lai et al. (2004) reported that many of her

participants visited the sauna to induce perspiration as a way of reducing blood sugar levels.

Acknowledgement of exercise as part of a management regime for diabetes is a positive sign and consistent with healthcare providers' views of effective illness management. It has been amply demonstrated that physical activity must be integrated into diabetes management (Zinman et al., 2004). An active lifestyle enhances cardiovascular fitness and well-being, increases insulin sensitivity, reduces blood pressure and favours a healthy lipoprotein profile in people with or without diabetes (Paffenbarger et al., 1993, Pate et al., 1995).

In contrast, the lack of exercise and a general reluctance to engage in physical activities among my participants and other ethnic groups such as UK Bangladeshis (Greenhalgh et al., 1998) was based on the belief that exercise weakens one's constitution and potentially exacerbates their diabetes. These ideas have arguably decreased their likelihood to engage in preventive health practices since it is believed to outweigh the perceived benefits.

### **8.1.3 Medication (sikhyeuk/chiyao 吃药 = eating medicine)**

The third management strategy employed by almost all participants was the use of prescribed medicine for diabetes. All except one participant viewed the use of prescribed medicine as unwelcome but necessary. Their attitude to medicine taking is consistent with results from a synthesis of qualitative studies of medicine taking where there is a general reluctance to use medicine and a preference for using as little as possible (Pound et al., 2005). Likewise, not all patients would accept orthodox medical treatments for their illness, preferring to use complementary and alternative therapies such as Reiki (Adams et al., 2002). The following ideas about medicine were also found in my study:

- you only take medicine when you are ill,
- the body needs a rest from drugs from time to time, and
- taking medicine involves a risk of becoming dependent like a drug addict (Shui et al., 2003).

One participant, Lana, showed a considerably stronger aversion than the other focus group participants towards taking medicine, insisting 'I will not let medicine control my diabetes'. Her opposition may be juxtaposed to the attitude of another participant, Mrs Lui from Focus Group No. 1 who repeatedly lamented the lack of medicine for her diabetes: 'I've had diabetes for three years. I've been to the doctors for so many years, each time I go and see him, he does not prescribe any medicine.'

Helman talks about the 'prescription ticket' which patients expect to get when they consult a doctor, and especially when told of a diagnosis. Within the Western literature on Chinese medicine, once a person is diagnosed with an illness, the person and their family expects the doctor to prescribe some kind of treatment, medical or otherwise. Farquhar (1994) observed that visits to Chinese medical doctors are legitimised and acknowledged through a medical prescription, whether the patient requires it or not. Bearing this in mind, it may explain why Mrs Lui was baffled that her GP did not prescribe medication for her diabetes. The absence of a 'prescription ticket' could have led her to doubt if she has diabetes. It might also help to explain her lack of interest in engaging in preventative health behaviours. Her expectations for medicine as part of her illness legitimisation indicates that she was not aware that according to practitioners of western medicine, diabetes can be kept in control with proper diet and exercise.

In contrast, Lana believed that medicine for diabetes can cause more harm than good. Below is a truncated version of her long monologue as she explained to the group members that not everybody can tolerate the use of medicines:

I conceded to injection therapy. Aiyah! I *had an inscrutable spell* (code-switch) of diarrhoea! [...] So, instead of saving my life, they made things worse for me; I fell into a coma. [...] It is bound to be that [...] there will be one [person] who is not suitable to the treatment.

The general consensus from the focus group discussions was that many participants agreed they should comply with prescribed medication. For example, one participant Mr Li, appeared to order his life around diabetes as his wife described his life as very disciplined and 'busy':

Mrs Li: He's at the doctor's as often as he is at home. He's always at the doctor's, and the medicines, it's like children eating chocolates.

Mr Li: The doctor,

Mrs Li: The minute he gets out of bed, his 'job' is very busy, checks his blood pressure and checks this (blood glucose), injection,

Mr Li: finger prick testing.

Mrs Li: The entire morning is centred on medication and injection.

Mr Li: It's (the medicine) all on my body.

Mrs Li: He's even more diligent than going to school.

(Focus Group No. 6, Birmingham)

It is obvious that Mr Li's life has been radically altered to accommodate diabetes. A parallel can be drawn with Stone et al.'s study of HIV AIDS patients where he described his participants' adherence to medication as 'the central organising principle' which is so overwhelming that they no longer had control of their lives (Stone et al., 1998). Mr Li's apparent acceptance of his medical regimen is an exception rather than a norm amongst my participants. McDonald et al. (2000) found that men appear to fit their daily routines around their medical regime whilst women tend to fit their medical regime around family needs. This might explain why Mr Li was able to adhere to his 'busy' medical routine.

The need for medication to deal with diabetes was acknowledged in all 8 focus groups, with the exception of one participant, Lana, from Focus Group No. 7. Some participants and family members invested in what has been called the 'medical merry-go-round' (Bury, 1991:458), pursuing alternative medical treatments, before reconciling themselves to biomedical treatment provided by the NHS. Thus in Focus Group No. 1, Mrs Chang initially turned to her family in Hong Kong for Chinese medicine. She telephoned her family and asked them to send medication over to the UK and accepted 'what was good for diabetes' as recommended by people in Hong Kong:

When it was first discovered, lots of medication was sent from Hong Kong. We telephoned home and asked mum to send it to us. And when other people tell us what's good [for diabetes], we'll call home and ask Mum to send it to us.

Other members in the group lamented that the use of imported Chinese medicine sent by family members in Hong Kong was unsustainable, as diabetes required long-term medication. All the participants said that the best option was to take Western prescribed medicine and accept the follow-up treatments offered in the UK. This was because medical consultations, medicines and other health services were free to old age pensioners in the UK:

Like us old folks, when we see the doctors we don't have to pay. They will ask you to come back and see them in 1-2 months and might give you medicine.

Furthermore, it was deemed acceptable to use Western-style prescribed medicine and to be taken care of by Western doctors since family and friends in Hong Kong also turned to Western-trained Chinese medical doctors for help:

I have lots of friends and family members in Hong Kong who have sugar urine illness, and they all see Western [trained Chinese medical] doctors.

For Mr Chang, the medical merry-go round trip was short-lived. Although Mrs Chang originally turned to Chinese medicine for a solution to her husband's illness, this was quickly aborted and she encouraged her husband to use Western medicine.

As for Mrs Ong in Focus Group No. 4, she was more persistent in her pursuit of a cure from Hong Kong although financial constraints eventually put a stop to taking Chinese medicine prescribed by a Chinese medical practitioner sent from Hong Kong:

Mr Ong: Our daughter sent us Chinese medicine [from Hong Kong].

Mrs Ong: I boiled the medicine every day. After taking the medicine, it (blood sugar) went down [to] around 3-5 points. But the minute I stopped taking it, it went up again. It's expensive.

Mr Ong: The medicine which she was on was very effective.

Mrs Ong: Could 'keep *ju*' (code-switch) all the time which is 5 points or 4 points.

(Focus Group No. 4, Birmingham)



A recent exploratory study on the use of Chinese medicine for diabetes reported similar results where blood sugar levels fall to within normal limits whilst taking Chinese medicine but when treatment was stopped, blood sugar levels rose again (Collins and McFarlane, 2006). These researchers recruited a total of 10 type 2 diabetes patients who were not taking orthodox medicine and gave them Chinese medicine. The patients were given a commercial preparation of *Trichosanthes kirilowii*, *Polygonatum sibiricum*, *Dioscorea opposita*, *Panax ginseng* and *Stevia rebaudiana* and chromium nicotinamide (Glucostat: Health World Limited, Eagle Farm, Australia) of 3.2g dose, three times a day over a 90-day period. During the period of administration, blood glucose dropped, but when treatment stopped, fasting blood sugars rose over 15-20 days to pre-treatment levels. However, when treatment was resumed, blood sugar levels reduced again over the following 6 weeks. This study echoes what Mrs Ong said at the focus group discussion, i.e. that blood sugar levels fall to within normal limits when on treatment and rose once treatment stops.

Mrs Ong continued to pursue the elusive cure as later on in the discussion, she said that a certain type of grass in Hong Kong could help with diabetes. She said she would be asking her elder sister in Hong Kong to send it to her:

Some people said to eat a certain type of grass [for diabetes]. They used to boil it with lean meat. I've asked my elder sister to sun dry it and send it to me.

The use of Chinese medicine, prescribed or otherwise, for diabetes among my participants will be discussed further in Chapter Nine. In brief, only one diabetic (Mrs Ngan) was taking prescribed Chinese medicine, from a Chinese medical practitioner in Hong Kong. She returns to Hong Kong at least twice a year to visit her family. During these visits, she seeks medical treatment from a trained Chinese medical practitioner. At the same time, she continues taking Western medication prescribed by her doctor in the UK. There was however considerable use of domestic 'Little Tradition' forms of Chinese medicine in the form of medicinal soups by Mrs Ngan and other participants.

#### **8.1.4 Maintaining control (keep ju 着)**

A fourth aspect of self management entails glycaemic control articulated by the participants as *keep ju* (着). Use of code-switching suggests that the task of glycaemic control is a new concept within their understanding of diabetes management. More importantly, code-switching demonstrates that the concept of *keep ju* (着) i.e. control, has no equivalence in the Chinese concept of illness management. Their understanding of glycaemic control was expressed in phrases such as ‘press[ing] it down’ and ‘don’t let it get your eyes’. The following paragraphs reports on what the participants do to keep blood sugars under control.

##### ***8.1.4.1 Finger prick testing, urine testing, and attending follow-up appointments***

Two diabetic activities which participants described involved finger prick testing, also known as self-monitoring of blood glucose and urine testing. These issues were only discussed in some groups, as these terms were not among the key words listed on the flip chart used for all the focus group discussions; talk about finger prick testing and urine testing arose from sharing recipes about *gaihauh*. Participants used capillary blood results from finger prick testing as markers to assess if their *gaihauh* was effective in bringing blood glucose levels down. In one of the discussions, two male participants said that a finger prick test confirmed that after eating crustaceans and duck skin, their blood sugar was raised. In another group, one participant used urine dipsticks to test urine to assess blood sugar levels.

Current literature shows that there are conflicting views as to whether SMBG levels are important to diabetes care (Gallichan, 1994, Coster et al., 2000, Worth et al., 1982, Leese et al., 1994). It is argued that providing patients with the equipment to test capillary blood sugar levels has not yielded the desired outcome of producing effective blood glucose monitoring. Nonetheless, this debate has not affected current practice as healthcare professionals continue to provide diabetics with glucose monitoring machines as part of their self-

management regime. Given that only one participant in this study is using urine dipsticks for his diabetes care; this suggests that urine testing is not as widespread as finger prick testing.

When asked for their experiences of seeing doctors in the UK, all participants mentioned attending follow-up appointments. This topic generated tangential issues such as views regarding services provided by the NHS, which were mainly positive. For instance, many were grateful for the free medical support including medical consultations, medical and surgical treatments, and free prescribed medication. This group discussion revealed gravitation toward, and subsequent reliance on healthcare professionals for management of diabetes. This is a positive sign as it indicates that these groups of UK Chinese with diabetes are currently accessing the health services in a similar manner to the general population. In addition, their regular attendance of follow-up appointments can enable healthcare professionals to monitor their illness progression. However, increasing reliance on healthcare professionals contradicts the tenets of self-management where individuals are expected and encouraged to 'manage the symptoms, treatment [...] inherent in living with a chronic conditions.' (Barlow et al., 2002:178).

#### ***8.1.4.2 Transfer ownership of managing diabetes to the NHS***

When I asked participants about how they manage diabetes (See Appendix No. 4, core question No. 3), various responses indicated that they were comparatively unconcerned about living with diabetes as the 'government carries the burden'. They gave concrete examples of free medical treatment including surgical procedures, medicines and medical follow-up appointments. For example, Mr Yap required cardiac bypass surgery for which he was grateful as it had prolonged his life:

4 years ago [I] had a bypass. You can say that I am reborn. If not for England, I would have left this world. Now, every living moment is a bonus.  
(Focus Group No. 3, Bristol)

The fact that he needed surgical intervention suggests a poor control of diabetes. It appears that participants had come to be heavily reliant on the health service to help them manage diabetes. In all the focus group discussions participants remarked on their relief that medicine was free for those diagnosed with diabetes. In the first example, Mr Ong expressed his relief that his wife's illness was taken care of by the UK government. Other group members chipped in to confirm that they too received free medicines because they had diabetes, regardless of their age. It appears that they think that all they can do to manage diabetes is to 'avoid certain foods', coupled with taking medicine to control it.

Mrs Ong: The doctor gives you medicine and injections to help control it and you avoid eating certain foods.

Mr Ong: If you have diabetes in Hong Kong, you have to pay for it. In England, the government pays for everything and in this aspect, it's a great help.

Mr Lau: Don't need to pay.

Mr Ong: That makes all the difference.

Mrs Mah: Going to the doctor is free.

Mrs Ong: When you have diabetes, the government will carry the burden.

(Focus Group No. 4, Birmingham)

In the next example, Mrs Li compared the differences in the healthcare systems of Hong Kong and the UK, highlighting that in the UK 'there is a doctor looking after your illness'. This is evidence of a transfer of ownership of illness from the individual to the healthcare professionals. It is disconcerting that both patients and family members felt 'it's no use worrying about your illness':

Mrs Li: I feel that Chinese in England are quite blasé about their illness.

Mr Li: Tell them to go to the casino, and they won't feel the pain.

Mrs Li: Look at him. His attitude is, 'I'll eat first and think about it later.' He'll eat whatever I cook. In Hong Kong, people with diabetes are so preoccupied with their diabetes. They are either skinny as a pole or fat like a pig. I'm not anxious about it. There's a doctor looking after his illness. It's no use worrying.

Mr Li: I don't even have to book for an appointment, it's all arranged by them.

(Focus Group No. 6, Birmingham)

Thus far, I have presented findings from the focus group discussions on diabetes management strategies including *gaihauh*, exercise, medication and maintaining blood sugar levels within acceptable limits. The problem with *gaihauh* was the difficulty in sustaining it as some participants admitted to *tauhshik* whilst others gave up after a period of abstinence. Equally, they found it difficult to engage in physical activities and keep blood sugar under control. The use of code-switching when they discussed sugar control indicates a lack of understanding of self-monitoring in illness management. Finally, all except one participant said they were taking medicines regularly as part of their management regime, however they found it puzzling that medicine could not offer a cure, just illness control.

In the next section, I present findings from the individual interviews, delivered in two broad sections. In Section 8.2, I provide details of the coping styles adopted by those with diabetes. In Section 8.2.2, I demonstrate the influence of social network structures on management strategies. Notably, data collected at the focus groups was echoed at the individual interviews, however new material obtained included personal accounts of attempted suicide, health conditions and expenditure on Chinese medicine. Also new in this section are expressions of dissatisfaction with on-going care and dietary advice offered by the NHS.

At the individual interviews, participants described how they were coping with diabetes. Those who accepted the diagnosis adopted new ways of living, those in denial continued with their previous lifestyles and diet, and then there were those who simply felt there was nothing they could do to stop the illness progression. Again, use of certain food items was mentioned as the most effective way of dealing with diabetes. During the individual interviews, a much wider selection of foods was mentioned, used with the view to strengthen the body and reduce further harm caused by diabetes. Differences in management regimes were found to be linked to the strength of their ties to the social network structure within and outside the UK Chinese community. Experiences and views of engagement with healthcare professionals are shown to have had an impact on their management efforts.

## 8.2. Findings from individual interviews

### 8.2.1 Coping styles

This section presents the various ways which diabetes is managed by 22 UK Chinese diabetics. Radley and Green (1985) proposed four broad modes of managing chronic illness:

- Accommodation - characterised by an acceptance of illness such that it is integrated into their lives;
- Secondary gain - in which the constraints of the illness have themselves become the context of the person's life, followed by a withdrawal from social activity in order to pursue other rewarding activities, e.g., voluntary work;
- Active denial - characterised by an attempt to fight against illness by retaining social activities and minimising symptoms and or implications of the underlying condition; and
- Resignation - in which the loss of social activity is accompanied by a sense of being overwhelmed by the illness.

The authors suggest that all four modalities are potentially available to a person at anytime (Radley and Green, 1985). Consequently, the sufferer is confronted with changes that will require adjustments. The range of behaviours when coping with changes includes bargaining, denying, and others as presented later. These behaviours can provide an insight into the social processes of people living with and managing uncertainties surrounding diabetes

Brashers (2001) posited three behaviours of managing uncertainty including 1) seeking and avoiding information; 2) adapting to chronic uncertainty and 3) accepting social support. Access to information can confirm or refute existing beliefs. Two participants made use of the Internet to obtain information about diabetes: 'I wanted to know what this illness is [...] I started collecting information on it [...] the Internet in Hong Kong is quite comprehensive ' (Liam, Male, 39) and 'I was losing weight and I was really thirsty [...] so I knew that

there was something wrong and so I looked online and it all led to diabetes [...] and they confirmed it at the doctors.’ (Jeanie, Female, 21). When healthcare professionals explain to patients why they are experiencing the illness symptoms, this information will allow patients to make sense of what is happening to them (Brashers, 2001).

Whilst Liam sought information regarding diabetes, he did not seek information about his diabetes medication because he felt it was pointless:

My feeling is that the tail cannot be broken, so you don’t really need to ask - if the *end is in sight* (code-switch), the doctor will say [...] you don’t have to take it anymore [...] but if they don’t say anything, then there is no real need to ask [and] I don’t need to know why!

Liam looked at the Internet for information about his illness, but stopped seeking information about his medicines, when he realised there was no end to the illness. I interpret this as information avoidance and as a form of escape or shield which Liam used to protect himself from information that is overwhelming or distressing.

Many participants initially rejected the diagnosis of diabetes but with time eventually accepted it. Their methods of coping were not confined to one modality. There was evidence of an overlap of all four modes of coping in some interviews alongside an active denial of the illness in other interviews. There was only one active denier, Lana, who refused medication for diabetes, and in addition refuted the diagnosis of diabetes. Her narrative was chaotic as she simultaneously acknowledged and denied she had diabetes. The following excerpt is verbatim, not a translation:

I kinda know that [...] I have diabetes. I would be type 2 [...] accepted it because there’s no way around it. I can’t get rid of it [...] you’ve got it for the rest of your life! [...] if I ever have that illness, I’m not going to let any illness control my lifestyle, my well-being [...] when I got it, it was by accident [...] whenever I am ill, my blood sugar level and urine will be really high [...] however, I was getting better [...] I told them (the doctors) that my dad is diabetic [...] but I don’t know what the symptoms were, I hadn’t a clue [...] because I’m diet control [...] I’m not on the conventional medication [...] I

often tell people that I ate red grapefruit morning, noon and night (and my blood sugar levels drop) from 9.9 to 4 point something [...] they tried to persuade me to take medication [...] they are not hearing my own self control [...] diet control

In the above excerpt, Lana said she had diabetes but almost immediately said 'If I ever have that illness' which suggests that she is saying that she does not have diabetes. This self contradiction could indicate that Lana struggles to come to terms with having diabetes. As for the other participants, the sense of chaos, futility and helplessness were comparatively less pronounced, albeit evident. The following paragraphs present the various ways diabetes is managed by the participants in my study.

#### **8.2.1.1 Accommodate-denial**

Participants who were not pro-active in keeping their diabetes under control accepted the illness as part of their lives but did not allow it to control their lives. These individuals gravitated towards normalisation, integrating the illness into their lives. In the following example, Mrs Ngan's way of accommodating the illness was to carry on as normal as much as possible; for her the worst thing she could do was to focus on the illness:

Mrs Ngan: Life goes on as normal. There's nothing to be vexed about. There's no pain. I feel the same as before. I don't feel I have an illness. If you focus on it, it will 'deepen' and the stress will worsen it. Be happy. Do whatever you like, eat whatever you like. If you are not supposed to eat certain things then don't eat them.

Researcher: So with diabetes, you are on long-term medication?

Mrs Ngan: Just take it as though it is nourishing (*bou/bu* 补) take it as you would eat rice. It's out of your control.

(Ngan, 70, Female, London)

When I talked to Mrs Ngan about the need for medication, she said that it was not an option for a diabetic person to refuse medication. Rather than acknowledging that taking medicines means that she is ill, she turned medicine taking into a norm; as one of the food items she eats on a daily basis, just like



eating rice. In this way, Mrs Ngan does not associate medicine taking for diabetes as being a part of her illness but as one of the dishes which she eats with her meals. She even convinced herself to view medicine as ‘*bou*’ 补<sup>14</sup> i.e. nourishing her body. This was how she overcame her attitude towards lifelong medication and accommodated diabetes in her daily routine. From the perspective of a healthcare professional, this could be seen as a positive sign as it indicates that she is not fighting diabetes but has incorporated it into her daily life.

I was alarmed when Mrs Ngan talked about not focusing on the illness and carrying on as normal. Although she does not concentrate on seeking a cure, she is also not making efforts to control diabetes. It seems that Mrs Ngan thinks that taking medicine for diabetes is all there is to managing diabetes. Similar

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<sup>14</sup> Tan and Wheeler (1983) reported that the Chinese participants in their study on illness management spoke about “*bou*”. Foods were assigned three properties – beneficial, i.e. good for the body, patching or repairing (*bou/bu*), and basic or essential. The term beneficial has nothing to do with food components such as carbohydrates or vitamins. Participants said that medicinal soups and other slow boiled or double boiled herbs are for patching or repairing purposes. *Bou/bu* denotes something between nourishment and medicine. This is a class of edible substance which are literally said to repair the body. Again this bears no relationship to the western idea that proteins are used to build and repair the body. Use of *bou/bu* relates to the need to restore the body to equilibrium from a state of imbalance, and to help it recover in convalescence. *Bou/ bu* is not to treat the symptoms of the illness but to correct the imbalance. It helps build up resistance so that a person does not become ill, and it strengthens body convalescence. *Bou/bu* ingredients can be obtained in Chinese grocery shops. *Bou/Bu* foods are generally high in protein and calories and are used commonly as supplements for pregnant and lactating women.

responses in dealing with diabetes such as 'did not feel anything', 'take life as if you were not ill' or 'I do not feel diabetes is a problem' are noted in a study in Mexico (Garcia et al., 2007:2227).

### **8.2.1.2 Accommodate-resign**

In the next example, Mr Chui accommodates and resigns himself to diabetes. He said that he does what the doctor tells him regarding managing diabetes:

I've always had rice in the past. I don't want to make my diabetes worse. I've done what the doctor said. You have no choice. When there is a banquet or whatever, I will try my best not to go. Your illness will very easily become worse.

Researcher: How do you know if your blood sugar is high or low?

Mr Chui: You have a machine. In the morning you should check it [your blood]. Another time in the afternoon [keep it] within 6-8 points [mmols]. If it goes beyond 10 points [mmols] see the doctor.

(Chui, 76, Male, Leeds)

Mr Chui's management of diabetes involves taking prescribed medicine, and also restricting and changing the type of food that he eats. One important change he has made is to reduce his social outings as the food served at such occasions is seen to be bad for diabetes. Contrary to the way Mrs Ngan accommodates diabetes, Mr Chui includes diabetes management as part of his daily routine, following two of the three pillars of the current biomedical prescription for the management of diabetes i.e. dietary restriction and taking prescribed medicine. At this point of the interview, he made no mention of engaging in physical exercise as part of his self-management regime.

### **8.2.1.3. Accommodate/secondary gain/resign**

Mrs Ong was initially shocked upon learning she had diabetes but has now accepted it and made the recommended lifestyle changes. In particular, she has taken up swimming in the last three years and appears positive about her future:

When I was first diagnosed, I cried for a few months, didn't want to go anywhere, and didn't want to see anybody. There's a time for birth and a time to die. I am already of a certain age. Other people had their hands and legs chopped off and still they carry on. So why shouldn't I be happy? Now I'm a lot more chilled out. I went to Spain for a holiday and stayed at my friend who had a swimming pool. I was just left there watching. I said to myself 'I must learn to swim!' [Now] I go swimming every day for an hour, *no stop* (code-switch).

#### **8.2.1.4 Accommodate**

Unlike many participants in my study who have low levels of literacy, Robert is a 50 year old post-doctoral researcher. His profile is not common to the study population as he faced the diagnosis head-on. For example, he began gathering information about diabetes from his local library and the Internet after he was diagnosed with diabetes by his doctor. He started to experiment with food items, identifying what causes his blood sugars to rise by using a *glucometer* to check his 'BG levels'. He views diabetes as an illness that can be controlled by making changes to his lifestyle, diet and using prescribed medicine. This approach to diabetes management is consistent with those of the biomedical healthcare professionals. Below is an extract of his view of diabetes and the way he deals with it:

I was diagnosed as diabetic in May. I got the BG meter and started recording my BG (blood glucose) level in the morning and then two hours after the evening meal. I correlated the BG level with the amount of carbohydrates that I ate and the amount of exercise. I did a step-wise regression. Within 7 days of data, the step-wise regression shows that food and peanuts cause the BG level to go up!

Researcher: What foods?

Robert: Any fruits! I heard that peanuts were low GI, but NO! I stopped eating fruit and peanuts immediately, and the BG level went down, and so did the HbA1c I monitored it every day.

### **8.2.1.5 The resigners**

This group of participants were overwhelmed by the illness, to the point where they gave in to 'let nature take its course'. Mr Yap felt that he was not coping and had run out of options (*mouhbanfatt/meibanfa* 没办法). He felt there was no way of controlling diabetes. The following excerpt demonstrates his feeling of hopelessness and his attempts at suicide:

I thought of hanging myself. There is no other way! The suffering was too much. My son found out and he dismantled it. I thought of another plan. I would use coal to resolve [the problem i.e. commit suicide]. That's the easiest solution. Let nature take its course. There is nothing you can do about it (*mouh fatt ji/mei fa zi* 没法子). How do you control it? Unless you don't eat rice, it's not possible. It's very miserable. It's very difficult for me to control it. I can't cope, really, really there's no other way (*mouh ban fatt/mei ban fa* 没办法). (Yap, 70, Male, Bristol)

Another participant, Mr Yau also felt there was nothing he could do but to wait for nature to take its course. Thus, Mr Yap and Mr Yau expected their health to deteriorate, and they did not take active measures to control the illness progression:

I just accept it. Let nature take its course. People say no medicine can treat it. It's a terminal illness, like cancer. (Yau, 70, Male, Belfast)

### **8.2.1.6 The active deniers**

There was only one participant in this category. Lana appeared knowledgeable about diabetes and its destructive consequences. Despite expressing knowledge about diabetes as a progressive and degenerative disease, this did not translate into delaying or preventing the onset of diabetes related complications. Lana refuses to take medication but notes that her blood sugar levels can be erratic and that she feels unwell and has suffered 'mini-strokes' and a 'heart attack'. The incongruence between knowledge and action is indicated by her refusal to accept prescribed medicines:

I'm not under any medication. My body can't accept it. Red grapefruit, after 10 days, it was remarkable. If I ever have that illness, I'm not going to let any illness control my lifestyle. When I'm slack, my sugar levels go up, close to ten points.

Researcher: How long after you were diagnosed did you start this?

Lana: 3 years ago!

Researcher: What was it like before?

Lana: I didn't care! Now I feel unwell a lot more. I have high blood pressure, several mini strokes, and a heart attack 18 months ago.

Researcher: Are you on medication for that?

Lana: No conventional medication, NOTHING! [just] my very strict diet!

It can be argued that by using food as the main form of diabetes management, Lana's approach concurs with that of the 'Little Tradition' mentioned in earlier chapters. What is of concern to me is that although she was aware that her deterioration in health was related to diabetes, she remained adamant that she would not take medicine for diabetes. Later in the interview, she expressed that medicine for diabetes was like a 'fix'. She believed that medication would make her body crave for it and that she would need it to keep diabetes in control. There is no data in the interview to suggest where she got the idea that medicine is addictive. However, a study in Hong Kong on Chinese people with diabetes reported that participants were not keen to use injection insulin because the public mistook them as 'intravenous drug addicts' (Shui et al., 2003).

Thus far, we have seen that many of my participants were initially motivated to keep diabetes under control. However, with the passage of time, many found it difficult to keep diabetes under control. Adherence to a strict dietary regime and sustaining changes to lifestyles was a burden. Nonetheless, three participants said they engaged actively in their diabetes management following the onset of illness complications such as heart attacks, loss of eyesight and renal dysfunction.

## **8.2.2 The social network structure**

As we have seen, participants revealed that they accessed a variety of resources to help them manage diabetes. They turned to family members, friends and Chinese people from the local community and from back home for help. Depending on affordability, some sought help from Chinese medical practitioners in the UK and Hong Kong. Others would use the healthcare services provided by the NHS. Participants also sought help and information from Chinese language media sources such as cable television programs and magazines. The aforementioned sources of help are grouped under the broad term social networks. Members of social networks can be divided into 'in-groupers' and 'out-groupers' (Nisbett, 2005). In-group members include family, friends and other Chinese people living in the community. Family members, especially spouses and adult children, were found to be most frequently consulted, whilst friends and acquaintances provided health-related information. In contrast, out-group members consist of healthcare professionals including doctors, nurses, dieticians and all other allied healthcare personnel. In the following sections, I discuss the contributions of 'in-groupers' and 'out-groupers' in more detail.

### ***8.2.2.1 In-groupers' contribution***

In-group members were involved in the participants' management regimes in various ways including food surveillance and by way of encouraging the use of food cures. Food surveillance as a form of illness management was undertaken both by the diabetic person and their family members. Familial involvement in illness management was evident in many of the individual interviews. Some participants appreciated being watched like a hawk by family members, others resisted familial involvement. Generally, sustained self-management behaviours were linked to support and encouragement from friends and family members

Self-surveillance was carried out by some participants, believing that it is the individual's responsibility:

Roast duck, I yearn for it too. I don't dare to sneak and eat. Nobody can help you. You have to help yourself. (Chui, 76, Male, Leeds)

Others, however, seemed rather pleased that someone cares for their wellbeing. Accounts of being monitored were discussed and this was mainly done by female members of the family:

If my daughter knew about it, she would scold me, won't let me eat sweet stuff. [now] she feels that I can control myself, she has loosened her grip on me. She's very anxious about what I eat. (Ngan, 70, Female London)

My wife is always nagging me. She watches me like a hawk. I haven't had any fatty foods, not even pork. I only take the soup together with the ingredients. She throws them into the bin, won't allow me to eat it. I just kept quiet. She's in charge. My daughter is always saying 'FATHER! The doctor said that you're not to eat so much rice!' (Chang, 66+, Male, Leeds)

However, not all participants appreciated familial involvement in the management of diabetes. Some resisted surveillance from family members and remained defiant, carrying on with their past eating habits:

They are always telling me off when I eat chocolates. 'Waah, you mustn't eat that stuff!' But the mouth is on me. I am the mother and if I want to eat, they have no power over me. My daughter says, 'You're naughty.' (Chueng, 49, Female, Leeds)

One extreme case of not exercising any restriction on dietary intake was Mrs Yee from Birmingham who felt strongly that life was meaningless without the joy of eating tasty food:

I still eat loads. I'd rather die than to eat food that has no salt, oil or taste. There's no meaning to life if I have to eat like that. People with diabetes who give up salt, grease and oily foods and fried foods have lost out a lot in life. (Yee, 75, Female, Birmingham)

Of note is that husbands with diabetes expected their wives to provide meals appropriate to their health needs. On the other hand, wives with diabetes felt obliged to cook meals that catered for the needs of their husbands and children. Thus, a diabetic wife would cook meals to suit the tastes of her husband and

children and not put her dietary needs before theirs. For example, Mrs Wong, a diabetic said she was initially pro-active in *gaihhouh* but her efforts waned. One reason for this was that she felt it was not fair for her to impose her dietary restrictions on other family members.

I was much disciplined. I almost reverted to vegetarianism but I had two small children. This can't go on. It's you who can't have it. Why should they have to accompany you, right? How can you carry on year in year out not to use this or that? (Leong, 47, Female, Birmingham)

For many participants, family and friends have indeed had positive influences on self-management regimes. On the other hand, some studies, including this study, have shown that family and friends can have a negative impact on self-management behaviours. For example, studies have shown that misconception and a lack of understanding of illness aetiology resulted in well-meaning advice being given that conflicted with medical recommendations (Prior et al., 2000, Ahmed, 2003).

Following on from food surveillance by the individual or via familial involvement, members from the in-group network were also involved in encouraging the use of food cures in the management of diabetes. The concept of food in Chinese culture is different from that in the west. Many foreign-born UK Chinese do not see food as simply being made up of nutrients. To them, food not only has the function of satisfying the appetite and providing energy for work but is also closely bound up with the causes of illness. During the individual interviews, participants said they use similar types of food cures mentioned at the focus group discussions including various types of fruit and vegetables, animal parts and herbs with medicinal values. The most frequently used were pig's pancreas, followed by vegetables and fruit and lastly herbs.

Additional information that was obtained at the individual interviews regarding the use of food cures was (i) the source of information, (ii) the types of food cures and (iii) how they obtained it. Information regarding food cures was obtained from Chinese satellite television programmes and family members living in Hong Kong or Malaysia. Food cures were mainly sent from Hong Kong by family members or brought back by individuals to the UK after a holiday trip.



New information was also obtained regarding herbal medicines. These included expensive herbs such as 'Winter worm and summer grass' (*dong chong xia cao* 冬虫夏草), not mentioned at the focus group discussions. When participants were asked how they knew what food cures to use, many said its usage was based on recommendations from friends. Others referred to a satellite televised programme in Cantonese called 'Doorway to China' (*Da hoi zhong mun/da kai zhong men* 打开中门).

An influential source of information in the use of food cures was hearsay from people within and outside the Chinese community:

Guava leaves and bags of dried star fruit. I get it when I go back to Hong Kong annually. Just like what people said, I took it for a long time. That was 10 years ago. (Ong, 57, Female, Birmingham)

From Hong Kong, sent by my sister. Boiled guava skin, drink it like tea. Recommended by Malaysian friends. (Leung, 54, Female, Leeds)

My elder sister in Hong Kong was told by other people that *yauh gam zi* (余甘子) is good for people with diabetes. Ground *yauh gam zi*, just add water and a pinch of salt [drink it as tea]. I've got boxes of teabags to help get rid of sugar. (Chuang, 49, Female, Leeds)

Other participants used an array of fruit and vegetables including pumpkin, winter melon, bitter melon, guava leaves (*Fructus phyllanthi*) and dried star fruit. These were taken as tea or juices. Participants said that it made them 'feel better' and that 'it really worked'.

A new finding arising from the interviews was that some participants said the herb-based products could be classed as medicine even when not prescribed by a Chinese medical practitioner. At the focus group discussion, use of herbs was only classed as medicine if it was prescribed by a Chinese medical practitioner. Except for *dong cong cou*, the list of medicinal ingredients used by the participants from the individual interviews is not routinely used by Chinese medical practitioners:

*Dong cong cou* (冬虫草) (*Cordyceps sinensis*) is Chinese medicine but it is food as well. (Yee, 75, Female, Birmingham)

My sister sent a few jars of 'celestial grass' (*shen xian cao* 伸仙草) from Hong Kong. I now use it to make soup for the family. *Go lai sum* (高丽蔘) (Korean Ginseng) is the best. It can control diabetes. (Mrs Ong, 60, Birmingham)

My mum makes soup with meat and *cishi* (茨实 fox nut) for my father [who has diabetes]. (Lana, 50, London)

'four celestial soup' (*si xian tang* 四神汤) is for curing diabetes, and if it doesn't cure it, it helps reduce blood sugar. (Mr Lui, 70, Leeds)

I add a little of it in the soup; *waisang* (淮山) *geizi* (枸杞子) with *dong cong cou* (冬虫草). You can't get it here. It's very expensive. My son-in-law got it for me from Hong Kong. I gather it (information) from hearsay, from cable television. (Mrs Ngan, 70, London)

From the above quotes, it can be extrapolated that the use of food cures is dependent on the participants' social network. Access to food items with medicinal values was easy for those who:

- had family members living in their country of origin,
- could afford to buy it independently, or
- had children who were willing to pool funds to get hold of the food items.

Of note is that Mrs Yee was dismissive about Chinese medicine at the focus group session, claiming that she 'threw the bloody lot' of Chinese medicine which her son brought from Hong Kong for her. However, at the individual interview, she said that some of the Chinese herbs which she was using in conjunction with Western prescribed medicine were good for diabetes. Despite the expenses incurred, she was willing to spend her savings on it:

Can't get it [the medicinal stuff] here. It's expensive stuff and there aren't many people in the UK who can afford it. The running cost is high. My children pooled funds to get it from Hong Kong and I had money saved up.

Not all food cures used were Chinese specific. Robert was aware of the impact of cinnamon on glucose absorption but the actual test described below was not done due to the lack of time:

On cinnamon for 30 days and off for 30 days and then do T-test and compare the difference but I haven't got the time to do it.

With a few exceptions, many participants stopped using food cures due to a lack of desired outcome. It became apparent that there was a sense of disappointment, reflected in comments like 'It was no bloody use', '[the blood sugar] did not come down'. The adverse effects experienced included 'it was too cooling for me. I had to use a stick to walk, it didn't do anything, and after taking it you can't go to the toilet.' (Ong, 60, Female, Birmingham) and that it was 'too weakening' (Leong, 47, Female, Birmingham).

Others stopped using them because they felt that they were troublesome to make just for one person. The overarching reason for discontinuation was the belief that only Western medicine can control diabetes:

No matter what food items you eat, you'll still have to take the tablets. You might feel better, but it is only temporary because it treats the superficial and not the root of the illness. (Lee, 70, Male, Bristol)

Mr Lee's view of food cures is unexpected. His statement contradicts the oft cited dictum that Asian medical practices deal with the cause of the illness unlike Western medicine which is widely believed to only provide symptomatic relief.

Those who said they used food cures at the focus group discussions had stopped by the time of the individual interviews:

I don't dare to take the food cures that I mentioned at the focus group. I took it for 3-4 months till my stomach hurts. Now I don't dare take that anymore. (Yap, 70, Male, Bristol)

Made no difference, my blood sugar did not come down. After drinking apples, carrots, celery juices, my blood sugar was even higher, over 20 points [mmols] (Chang, 66+, Male, Leeds)

However, rather than a complete discontinuation, usage of food cures remained intermittent. Mr Lui continued to use food cures because he believed that bitter gourd soup could activate the release of insulin and subsequently lower his blood sugar, particularly after a meal of roast duck. He also believed that pig's pancreas soups 'helps' with diabetes:

I eat roast duck and my blood sugar goes up but when I drink bitter gourd soup, the blood sugar drops. Bitter gourd helps to produce insulin; pig's pancreas helps with diabetes. (Lui, 70, Male, Leeds)

Intermittent usage was due to various reasons. The most frequently cited ones included:

- difficulties of access to the type of food cures,
- some of the food products were 'different' from the ones they get from their home country,
- cost, and
- lack of time.

In the case of pig's pancreas, many found it difficult to obtain but once available, complained of it being 'different':

English pig's pancreas are as big as pots. And they stink. (Lui, 70, Male Leeds)

Only one participant, Lana, continued to use food cures to keep her blood sugar down:

Pink grapefruit suits me, religiously ate three a day for one month and the blood sugar fell from 9 to 7 points. (Lana, 52, London)

Presumably, Lana perceived her type of diabetes to be an episodic kind. Existing literature informs us that episodic diabetes does exist but only amongst

Jamaicans. This type of diabetes is known as J-type diabetes which is exclusive to individuals of Afro-Caribbean descent (Morrison and Ragoobirsingh, 1991).

Thus, the use of food cures is strongly related to availability and access to individuals who can get hold of them, as well as affordability and trust in those who advocate them. However, their usage is intermittent due to the lack of desired outcome and the overarching belief that only Western medicine can keep diabetes under control. Additional materials from the individual interviews include divulgence of sources of information, the types of herbs used and the social and financial support for its usage.

### **8.2.2.2 NHS: Out-group support network**

During the individual interviews, details of interactions with healthcare professionals were expressed. These included what was done at the clinics and the conversations that took place. Interactions with doctors and nurses were predominantly focused on participants' biomarkers such as HbA1c and cholesterol levels, and physiological status, i.e. routine checks on eyes, blood pressure, vascular status of limb extremities and heart function.

Apart from the initial consultation where they were told they had diabetes, subsequent visits to their general practitioners were not accompanied by interpreters or family members, despite their limited proficiency in English. Many said there was no need for interpreters, be they family members or professional interpreters because they felt that no new information could be obtained at the consultation, and that there will be no change in their illness:

In the beginning we chatted, but now, there is no need for chats. It's almost 10 years now. [you] know it all. Firstly, they speak in English and I don't understand. Secondly, no matter what they say, it's still about exercise, take medicine, that kind of talk. Nobody interprets for me. They know that I can only understand a little of what they say. And so they ask you a few [questions] Ah! Why bother? You know that it's like this. There's nothing much to ask. (Lui, 70, Male, Leeds)

Dialogue regarding self-management strategies between doctors and patients were constrained by language barriers. It could be assumed that dialogue between doctor and patient was broadly unidirectional – doctors talking at patients. From the excerpt, it appears that the doctors told patients what they were supposed to do to manage diabetes i.e. exercise and medicine, but did not seem to encourage patients to say what they were actually doing with regards to self-management. Therefore, it was not surprising that participants felt there was little to gain from the follow-up visits. One participant felt that it was all a 'bluff':

I'll be seen in August. So at the beginning of June or July, I'll just eat less it's all a bluff! When it's time for a blood test, I'll just eat less! (Chueng, 49, Female, Leeds)

On the other hand, her response can be an indication that she finds follow-up surveillance an unwelcome intervention.

When participants were asked what advice NHS staff offered on self-management with regards to diet, many said that the advice given was not suitable to Chinese people. This was because the kinds of food they were told to reduce or avoid were those eaten by the 'devil heads' (*gwai tauh*) - referring to non-Chinese people. The dislike of bread, dairy products and Western foods resonated throughout all interviews:

I don't like bread. I don't eat dairy products like cheese and 'yogit' (code-switch) those foods are eaten by devil heads. (Wong, 53, Female, Leeds)

I find Western food repugnant. (Yee, 75, Female, Birmingham)

Those Western foods will not fill you up. (Chueng, 60, Male, Leeds)

They would give me a booklet. But all of the food items are what Westerners eat. There wasn't anything like fermented tofu. (Liam, 39, Male, London)

The lack of feelings of satiation and the fear of hunger if rice was not eaten every day was clearly expressed by many participants. For them, rice was the only meaningful food:

That bowl of rice is important, if I don't have that bowl of rice, I will be hungry all the time. Chinese people are born to eat rice. Day and night we are holding on to that bowl of rice. Without that bowl of rice, we can't make it. (Cheung, 60, Female, York)

I carry on eating as before. I eat according to what my stomach says. If I don't have rice I cannot cope. (Cheung, 49, Female, Leeds)

Similar reactions to the reduction in rice intake advocated by health professionals are reported in studies on Chinese Americans, Taiwanese and Thais (Sowattnagoon et al., 2009, Lai et al., 2004, Chun and Chelsa, 2004).

Mrs Chueng said that Chinese people with diabetes were better looked after in Canada than in the UK as they were given advice that was culturally congruent:

The nutritionist showed me a picture of Western food. Waste of time! My sister's mother-in-law lives in Toronto Chinese doctor. Nurses tell them what to eat, 'You shouldn't eat *cheungfun* (肠粉) (steamed rice dough) or *bao* (包) but eat beef and *suimai* (烧卖) (minced pork with chopped mushrooms, carrots and prawns) [but in the UK] the food and drink [which the British talk to you about] is not Chinese [stuff]. [they] show you pictures and tell you not to eat those *gwailo* (鬼佬) (devil man) stuff. But I don't eat such stuff! What's the use in telling me all of that?

Mrs Yee said that reduction of rice can only be harmful. She recounted what became of a neighbour who ate little rice, 'she just eats half a bowl of rice per meal, and her body hangs like a clothes hanger, so skinny that her complexion is well scary.'

This view was echoed by another participant who said that he witnessed the deterioration of health in a fellow diabetic who reduced his rice intake and adopted a diet as advised by the dietician. Here he reiterated what many Chinese participants had to say about rice:

She said not to eat too much rice to eat more potatoes. But if we don't have rice, it won't do! *Bakgwai/baigui* (白鬼) (White devil) said, 'One bowl of rice will do', but I am used to 2 bowls of rice per meal. One bowl just won't do. [the food] Gets to the mouth but not the stomach. I've seen some friends who eat just one small bowl. I see them getting weaker and weaker and gradually; they can't even climb stairs! You are going to die anyway. I decided to just carry on eating. The dietician was telling you according to the Western ways of doing things. But for Chinese people, this advice is wrong. She told me not to eat cheese and that I should eat cottage cheese. [the advice] doesn't suit me. (Lui, 70, Male, Leeds)

It's just Chinese culture you know. I can't live on bread or potatoes. At least one meal per day with rice. I'm a rice person. (Tessa, 33, Female, Belfast)

It appears that many participants were not convinced that carbohydrate reduction was beneficial to the management of diabetes.

The Western doctor tells me to eat 2 spoonfuls of rice. I'm such a big person and to eat 2 spoonfuls of rice, it'll just get to the mouth and not to the stomach! We Chinese people, genetically, we are 'rice bins' (*fantong* 饭桶). You can eat more vegetables but vegetables are 'cooling' (*liang* 凉). (Chang, 66+, Male, Leeds)

The above extract demonstrates that many participants felt that out-groupers such as dieticians offer advice that is culturally incongruent with their needs. Dieticians' advice was ignored because participants' felt that it did not assist them in making changes to their diet. One participant felt that not much was gained from the dietician as the information given was mainly 'common sense' and forgot a lot of the other information given:

I've forgotten most of it now. Anyway, the information is common sense, avoid sugar, increase the level of exercise and be more active (Liam, 39, Male, London)

The most damning report about dieticians was from Robert, a male postdoctoral researcher. He was very dissatisfied with his referral to a dietician:



I wasn't happy with the dietician. All she did was to tell me, I can eat so many pieces of bread and a bowl and half of rice. I'm a researcher! I'm not happy with 4 pieces of bread. Can you quantify that? Tell me exactly what you mean by 4 pieces of bread. If I go to the supermarket, you get thick, medium [slices], obviously different amount of carbohydrates in there. I asked her about [the] difference between sodium and salt. All she did was to give me some printouts from a website.

Other advice which dieticians offered to participants included having frequent, small meals. Once again, this advice could not be implemented due to the nature of many of the participants' occupations. Many were involved in the catering industry where working hours were long and irregular. They found it difficult to eat three meals a day and even harder to 'eat little and often':

I get up too late in the morning to have breakfast and the last meal is taken in the early hours of the morning. I don't eat regularly. (Wong, 53, Female, Leeds)

You can't expect to eat every 2 hours! You are on the till collecting money or doing other jobs in the shop. You can't go foraging for food! (Chueng, 49, Female, Leeds)

Liam, who works and owns a takeaway found it particularly difficult to eat regularly:

I have my meal here [i.e. in the takeaway]. A customer might come in, so it's best that you have your meal as quickly as possible. The dietician said, 'You have to eat on time.' But you can't do that. You eat when there aren't any customers!

A lack of appreciation of the participants' lifestyle may account for poor advice from dieticians. Mrs Leung said that she would have to wait till she retired from work in order to manage her diabetes. This was because of her current lifestyle:

Our lifestyle is different. You tell me to 'Eat little and often'. I can't do it unless I retire. We stop work at about 12 midnight. I have to be up at 11.30a.m to go to work in the restaurant. A lot of Chinese people have different timings for people like us who work in the catering industry, our sleeping and waking times are not like normal people.

Although healthcare services are provided by out-groupers, some aspects had little impact on the way UK Chinese managed their diabetes. Nonetheless, all the participants expressed gratitude for the free medical services, especially medicines, provided by the NHS. Simultaneously, all felt that follow-up medical care and referrals to dieticians were not helpful.

Many participants were issued self-monitoring blood glucose devices to monitor their capillary blood glucose levels. All participants were aware of the need to assess their capillary blood sugar levels through finger prick testing. However, not all participants checked it regularly, and would only do so in the event of a hypoglycaemic attack, or when they felt something was not right:

I do a finger prick test to check how low it is and especially when my vision is blurred. I do a finger prick test when I feel something is not right. I don't do it every day. (Yee, 75, Female, Birmingham)

It appears that irregular finger prick testing could be attributed to common sense. For example, many felt that sugar levels were expected to be elevated after a meal. Hence, they did not bother testing capillary blood sugar levels after a meal:

I know it will be high after dinner so why bother? (Cheung, 60, Female, York)

Generally, participants did a finger prick test first thing in the morning and last thing at night. Timings for the finger prick test were dependent on the time they got out of bed:

I don't do it regularly and it depends on what time I get up. I rarely do a finger prick test at lunchtime because I don't have the book with me and I don't eat a lot of at lunch. I do my finger prick test before meals, twice a day, when I get up in the morning and just before I go to sleep. (Leung, 54, Female, Leeds)

Alternatively, they would do SMBGs when it was convenient for them to do it, or if they could remember:

I've not been doing finger pricks for a long time. I only do it when I feel like it. Can't remember where I've put my blood monitoring machine. If I don't do finger prick tests, I can plead ignorance. (Chueng, 49, Female, Leeds)

Finger prick test in the morning but sometimes I 'cheat' although I am supposed to do it twice a day. Tend not to do it in the night as I can't see in the dark, so I don't bother. (Chueng, 60, Female, York)

Advice on finger prick testing was not standardised. One participant was told not to test it every day:

Don't do finger prick test every day. Told to do one in the morning, next in the afternoon, the next day and then in the night the day after. Spread out the finger prick test. (Yau, 70, Male, Belfast)

Only one participant, Robert, believed that regular monitoring of capillary blood sugar levels was imperative to good management of diabetes:

You don't need statistics, you don't need SPSS. You need a *glucometer*. (Robert, 50, Male, London)

In addition to concentrating on capillary blood sugar results, Robert also adjusted his food intake and level of exercise accordingly. He even embarked on T-testing and step-wise regression methods to keep his sugar levels within normal range, as mentioned earlier in this chapter. His course of action is starkly different from some of the participants who seemed quite ready to transfer the responsibility of monitoring the illness to healthcare professionals. For example, Mrs Yee who is on renal dialysis said that she did not have to check her sugar levels because the nursing staff would do it:

For us who have our kidneys washed (i.e. dialysis) the nursing staff do it.

### **8.3 Discussion**

In the management of diabetes, individuals are expected to be responsible for the control of diabetes, particularly control of blood sugar levels and food consumption. The language used to describe the participants' experience of managing diabetes indicates an ongoing struggle to keep diabetes in control. A

common theme in their accounts is the struggle to comply with a regime that has strong moral overtones. In Chinese language, these explicit moral overtones are embedded in words such as food abstinence (*gaihhauh* 戒口) and 'sneak and eat' (*tauhshik* 偷吃) - parodies of adults scolding children.

Wood (1995) highlighted the symbolic dimension of food. He stated that some food items carry powerful meanings which go beyond the actual gustatory satisfaction, and are charged with overtones of luxury and self-indulgence. In the case of Mr Lui and Mrs Ngan, foods such as roast duck and sweet foods are charged with pleasure but also anxiety concerning diabetes. Thus, *gaihhauh* evokes a strong moral obligation to deny oneself of the pleasures of some food items for the sake of health.

Many participants felt that there was no need for them to worry about their health as the 'government will carry the burden of diabetes', providing them with free medicines, follow-up checks and surgical treatments if required. This transfer of ownership of diabetes care from patients to healthcare professionals and the NHS organisation is a disturbing finding. It indicates that many of my participants have failed to understand the importance of self-management. Nevertheless, there is evidence of compliance with medical treatment. Some participants practised lifestyle changes engaging in physical exercises such as walking, going to the gym and swimming. Other evidence of adherence to medical regimes includes monitoring capillary blood sugar levels and attending clinic appointments.

The degree to which people incorporate biomedical perspectives into their daily management of chronic illness depends both on their awareness of biomedical explanations, and if so, whether they find them meaningful. This study suggests that biomedical explanations do not concur with the majority of the participants' ideas and therefore are rejected or ignored. Whilst many participants regurgitate the physicians' explanation of the illness sequelae, their narratives reflect they believed that their diabetes trajectory can be forestalled by perseverance with *gaihhauh*. Arguably, their actions suggest they dismiss the possibility of developing diabetes-related complications as a reality that they have to live with.

Hunt and Arar (2001) highlighted the contrasting views between patients and providers on the management of chronic illness. They reported that despite semantic similarities in the discourse of healthcare professionals and patients regarding the management of diabetes, in particular the need to keep diabetes under control. It appears that participants' ideas of control differ from that of the healthcare professionals. The use of the term 'control' among healthcare professionals refers to:

- Control over acceptable blood glucose levels, emphasising the pathophysiology of the disease and the prevention of long-term complications and,
- Inducing patients to 'control' their health behaviour.

Healthcare professionals base their assessment of goal achievement on objective clinical indicators such as HbA1c levels. These numerical levels are taken as unequivocal indications of success or failure in controlling diabetes. My participants, on the other hand, based their assessment of goal achievement on subjective and personal indicators such as their ability to *gaihhauh*, reduce their food intake of 'prohibited' foods such as sugary foods, salt and crustaceans, with little emphasis on finger prick testing, engaging in regular physical exercise, eating small, regular meals or losing weight. Hence, there is a mismatch between what counts as effective illness management between the participants and their healthcare providers.

Although participants in my study were equally concerned with their numerical 'success' related to blood sugar levels, the prevalence of diabetes-related complications indicates a poor control of diabetes. An overwhelming feeling of hopelessness and powerlessness was echoed by many participants in the phrase 'Mouh ban fatt'(没办法), meaning no options available. Repeated failures to achieve and sustain euglycaemia expected by the medical professionals had led many participants to 'surrender' to diabetes indicated by the phrase 'let nature take its course'.

Similar findings of powerlessness experienced by patients with chronic illness were reported by Aujoulat and colleagues (2007). They found that their

participants faced a multitude of distressing losses and that their lives had become unpredictable, leading them to feel insecure and out of control (Aujoulat et al., 2007). This study, as in previous studies on the experience of chronic illness shows a distinct sense of loss in general and loss of health in particular (Bury, 1982, Charmaz, 1990).

The idiomatic phrases used to describe diabetes indicate incompatibility with their understanding of the use of medicine for illnesses. Ambiguity alongside the incurability of diabetes means the disease trajectory is long and variable. As is the nature of chronic illnesses, their sequelae are complex, inconsistent and probabilistic. Consequently, sufferers become their own lay clinicians, engaging in self-treatment and experimenting with a wide range of medically unorthodox therapies (Adamson, 1997, Robinson, 1990).

In conjunction with the use of medicine, many participants favoured using traditional Chinese popular medical recipes for diabetes. Usage ranged from continuous to intermittent efforts and notably, they continued with prescribed Western medicine. Views regarding efficacy of folk recipes differed; some said they could be dangerous enough to cause death, others were adamant about persevering with folk medical remedies. Many of the participants would add herbal ingredients to soup recipes at family meals and held the view that it helped with diabetes and offered general health enhancing properties. On-going usage of folk medicine can be attributed to the influence of oral transmission and anecdotal views as presented at the group discussions. In studies among non-white populations, use of folk recipes appears to be a norm rather than the exception. For example, bitter melon is used by Indian, Pakistani and Bangladeshi communities in the UK for the management of diabetes. Persons with diabetes in these ethnic groups claimed that bitterness reduces blood sugar levels, a sentiment also expressed by Vincentians with diabetes (Moss and McDowell, 2004).

Some authors reported that bitter melon contains a substance that interferes with the uptake of glucose in the small intestines (Lankani-Fard and Li, 2008, Krishnapura, 2008). These studies were conducted on mice. Amongst other ethnic groups including Vincentians with diabetes, they were found to be using

a variety of mainly herbal and folk medicine (Moss and McDowell, 2004). Factors which influenced their usage included lay beliefs about diabetes, faith in folk medicine and strong religious beliefs about the remedies. In this study, participants in all focus groups with diabetes used prescribed Western medicine which was taken in conjunction with folk medicine, or took no Western medicine at all.

Thus far, I have demonstrated that participants have exhausted all their resources to overcome diabetes and have become resigned to be reliant on the NHS for their diabetes management. This could explain the apparent transfer of ownership of the illness onto the healthcare system. Parry and colleagues (2006) found that when respondents believed diabetes was beyond their control they would transfer the management of diabetes to healthcare professionals whom they regarded as 'the experts'.

Perhaps, rather than encouraging self management of chronic illness, given that compliance is not problematic in the case of the UK Chinese, healthcare professionals might perhaps foster joint management of illness over self-management of chronic illnesses. A study of Chinese migrants with diabetes in Canada demonstrated that patients who receive regular support from the Chinese-speaking healthcare professionals in various guises such as tele-care, home visits or regular meetings with doctors showed better control of their illness than those who were left to their own devices (Chan et al., 2005). Similarly, the UKPDS (1998) reported that subjects who received regular contact with healthcare professionals were less likely to develop diabetes related complications such as myocardial infarction. In a study in Hong Kong, the authors reported that patients were more likely to keep better control of their sugar levels as their condition was closely monitored by healthcare professionals and experienced lower rates of glucose excursions as they feared being chided by doctors or nurses (Shui and Wong, 2000)

## 8.4 Summary

Broadly speaking, the self-management strategies used for diabetes by UK Chinese are similar to those of the general UK population. This is because they acknowledged and often claimed that they engaged in diet control, physical exercise and took prescribed medicines. Findings from both the focus group discussions and individual interviews revealed the importance of the socio-cultural impact of self-management of diabetes. Diet control takes the form of the Chinese cultural practice of *gaihauh* and was believed by many to be the most effective form of illness management. They believed that using food items, medicinal or otherwise can help minimise the effects of the illness. Along with *gaihauh* was the resounding advice of 'eat less', with no clear parameters of what counts as 'less'. Both *gaihauh* and 'eat less' are not advice given by dietitians but one which is culturally bound and meaningful for them. Advice given by the dietitians was considered culturally incongruent. With regards to engaging in physical exercise, many felt that what they needed was rest to recover from their manual work, previous surgeries, and to strengthen their constitution against diabetes. Viewed from this perspective, it becomes clear why the participants stressed the importance of diet control as the primary form of management. Finally, for those who complied with medication, it was not difficult since medicine and follow-up treatments were free of charge. Yet, incidence of diabetes-related complications indicates a lack of effective self-management. As stated in the introduction of this chapter, self-management is a demanding and difficult task and few diabetics, Chinese or otherwise, achieve or sustain normal blood sugar levels. My study population also found it difficult to keep diabetes in control. Their difficulties are compounded by cultural differences and language barriers which impact on their engagement with healthcare professionals. I would urge healthcare providers to reconsider approaches to the management of chronic illness and help patients within the patient's explanatory framework, rather than placing the onus of illness management onto the patients themselves. The following chapter discusses the use of, and attitudes to the use of, Chinese medicine by participants within the study.



## **Chapter 9: Chinese medicine and folk medicine**

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### **9.0 Introduction**

This chapter discusses the use of, and attitudes to, Chinese medicine by participants within the study. Broadly speaking, in the UK any form of medicine outside of biomedicine is considered to fall within the category of complementary and alternative medicine (Tindle et al., 2005, Factor-Litak et al., 2001, Keith et al., 2005). The term complementary and alternative medicine (CAM) covers both pharmacologic treatment, and non medicine based treatments such as acupuncture and *qigong*. The use of CAM therapies is reported to be on the rise in the UK (Thomas et al., 2001), Europe, Australia and North America (Harris and Rees, 2000).

It has been said that for Chinese people there are only two types of medicine: Chinese medicine and Western medicine (Crozier, 1974). So, it seems likely that the concept of CAM is unfamiliar to them. According to the World Health Organisation (WHO), traditional medicine such as Chinese medicine is defined as a collection of therapies used by indigenous communities to maintain health and to treat, diagnose or prevent the onset of illnesses. In the UK, many Chinese people use Chinese medicine as an integral part of their culture, and because they are familiar with its medical connotations (Gervais and Jovchelovitch, 1998). Research suggests that many Chinese people use Chinese medicine, predominantly in the form of food cures, as the first line of therapy when they feel unwell (Prior et al., 2000, Kwan and Holmes, 1999, Koo, 1984, Koo, 1987). This practice is prevalent among foreign-born Chinese as well as newly arrived immigrants (Kwan and Holmes, 1999, Prior et al., 2000). In my study, many foreign-born migrants said they used over the counter Chinese medicines which they brought from their home country when they felt unwell. Others would wait till they have enough funds and then return to their country of origin for treatment and to stock up on medicines (Botha et al., 2002).

One of the aims of this study is to investigate if Chinese medicine is used by UK Chinese people with diabetes. The answer depends in part on what is meant by Chinese medicine, since a distinction is necessary (see Chapter Five) between recourse to trained practitioners of Chinese medicine (the so-called 'Great Tradition' of Chinese medicine), and the informal use of popular versions of Chinese medicine in the form of food cures, medicinal teas and soups (the so-called 'Little Tradition'). My study found that only one participant was using Chinese medicine in the first and narrower sense. As we have seen, she was using Chinese medicine prescribed by a practitioner in Hong Kong, intermittently and in conjunction with Western prescribed medicine. However, as might be expected, the informal use of Chinese medicine in the form of food cures, teas and soups was relatively common.

Recourse to traditional medicine alongside the use of biomedicine is increasingly associated with the concept of 'risk society' (Beck, 1992, Giddens, 1990). There is rising anxiety about what evidence to believe in and who to trust. Within the risk society, individuals become progressively responsible for managing risk. A harm reduction strategy is predicated by one's sense of susceptibility and vulnerability to illness. A hallmark of this form of 'self government' (Rose and Miller, 1992) is that people are encouraged to manage their own illness through choice and responsibility for their future.

In this chapter, I discuss some of the study's findings in relation to the use of Chinese medicine for diabetes among the study population. I gathered a broad range of interesting findings on the use of Chinese medicine including reasons such as 'we are Chinese', faith in Chinese medicine, laypersons' perceptions of Chinese medicine and the negative image of UK Chinese medical practitioners. This information is delivered in four parts.

In Chapter 8.1.3, when participants spoke about using medicine as part of their management regimen, they also touched upon Chinese medicine briefly. This chapter focuses solely on participants' responses to questions specifically asked about their use and views of Chinese medicine. In Section 9.1, I present findings from the focus group discussions. Four broad themes emerged from their discussions including (i) cost; (ii) experience of using both Chinese and Western

medicine; (iii) food as medicine and medicine as food and (iv) 'because Chinese medicine is part of our tradition'. Section 9.2 deals with findings from the individual interviews. Five themes emerged from the individual interviews including (i) evidence of usage; (ii) benefits of Chinese medicine; (iii) cultural and linguistic congruence; (iv) hope in Chinese medicine and (v) views on Chinese medical practitioners. With regards to the use of Chinese medicine, contrary to what was said at the focus group discussions, some participants revealed at the individual interviews that they used Chinese medicine in the form of food cures because they believed that it can do no harm, and that cultural and language barriers are reduced when practitioners and patients share the same culture. Views about Chinese medical practitioners remained polarised with a belief that a 'good' practitioner is yet to be found and were suspicious about those who practice in the UK. Section 9.3 offers a discussion of the findings. Section 9.4 summarises the chapter.

## **9.1 Findings from focus group discussions**

### **9.1.1 'Money [...] That's the bottom line'**

Participants said that not only was the consultation with a Chinese practitioner expensive, but also the prescribed Chinese medicine. Therefore, cost was a strong deterrent to using Chinese medicine in the UK. In Focus Group No. 3 Lily, a non-diabetic, wanted to know if Mr Lee and Mr Yap, would consider using Chinese medicine in the UK if it was free:

Mr Yap: Money is the problem. That's the bottom line.

Lily: Seeing a Chinese doctor here is very expensive.

Mrs Ho: There aren't many around.

Researcher: If Chinese medicine was free

Lily: We'll go and try it out.

Mr Yap: Definitely!

Lily: (turning to Mr Yap and Mr Lee) Which doctor will you go to first, if Chinese medicine was available?

Mrs Ho: Of course you will go to the Chinese doctor first, isn't that right?

(Focus Group No. 3, Bristol)

In Focus Group No. 7, Mrs Lee highlighted the financial burden of using Chinese medicine in the UK. She reminded everyone that when one has diabetes in the UK, the choice of treatment is pre-determined, given that medical consultation, healthcare services and prescribed medicine are provided free to all diagnosed with diabetes. She cautioned them that UK Chinese practitioners will 'stretch the treatment', meaning the practitioner will knowingly under-prescribe so that the medicine will work even slower, and subsequently prolong the treatment. This meant that patients would have to make repeated visits to benefit (if at all) from the full course of the treatment.

Lana told the group that she had used Chinese medicine for diabetes. However, after extended periods of usage, with huge sums of money spent, she did not achieve the desired results. Her verdict on Chinese medicine for diabetes was that it did not make a difference in her diabetes:

Mrs Lee: From the economics point of view that is where the difference lies. Western medicine is free, Chinese medicine is exorbitant and some of them will stretch the treatment. A friend of mine went to see one for a minor problem. The whole experience cost her £5000 and still she was no better.

Mrs Chow: That's tragic!

Lana: I've been to the Chinese doctors. The practitioner said that this was a long-term illness. Each consultation was about £40-50. I saw a practitioner for a few months. Funds dried up. I had no choice. There is entirely no...not a bit.

(Focus Group No. 7, London)

In a recent national survey of Chinese in the UK<sup>15</sup>, a team of researchers reported that 71% of UK Chinese had 'never visited' a traditional Chinese practitioner (Sproston et al. 1999:99). This is arguably an incomplete reflection of the actual use of Chinese medicine, but due to the lack of subsequent research it has become the official statistical resource. The study asked the following broad question: 'Would you see a Chinese doctor if you were ill?' This question was not formulated in a sufficiently culturally sophisticated way to access tangential but highly significant issues of actual use. In terms of Chinese conversational conventions, the format of these questions is likely to elicit incomplete, or even inaccurate answers (Chang, 1999, Ma, 1994).

The Chinese are renowned for giving simple and direct answers which nevertheless may conceal their true feelings about the matter in question (Li and Milroy, 1995, Ma, 1994). Thus, when asked if they would see a Chinese doctor for treatment, if the simple answer 'No' was given, the answer, although truthful, may not accurately reflect the level of actual everyday use of Chinese medicine in the form of food cures. As mentioned in the previous chapter, UK Chinese people make use of Chinese medicine without consulting a practitioner. Hence, there is a clear mismatch between the aim of the questions and the information they are likely to obtain. In fact, the responses to these superficial questions are unlikely to be insightful. This flaw is not specific to Sproston's study as other researchers, e.g., Prior et al. (2000) asked similar

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<sup>15</sup> Commissioned by the Department of Health, this study was conducted with the aim of providing information for future planning and development of services for Chinese people living in the UK. 1022 Chinese people took part in this survey.

questions in an attempt to establish the use of Chinese medicine in UK Chinese people.

My study shows that Chinese people with diabetes have tried using Chinese medicine in the early stages of diagnosis but at the time of fieldwork, they had ceased using Chinese medicine. Reasons given included (i) the inability to keep up with the high cost of using Chinese medicine in the UK, (ii) the high postage fees incurred by relatives who sent it from Hong Kong to the UK and, (iii) more importantly, the lack of the desired outcome i.e. lowering blood sugar levels, cure etc, summarised by the phrase 'cutting the tail'.

Studies report that individuals from affluent and well educated Chinese societies such as Taiwan (Kleinman, 1977) and Singapore (Quah, 1985, Quah, 1989) use Chinese medicine regularly, and its practice continues to be influential and 'successful' (Unschuld, 1987:1024). In the UK, foreign-born UK Chinese people are comparatively low income earners (Office for National Statistics, 2002) and are relatively unskilled workers (Shang, 1984, Parker, 1995). It can be argued that if Chinese medicine was free of charge like Western medicine, its uptake might be higher. Many of my participants expressed a willingness to try Chinese medicine for diabetes if it was provided free of charge. The next section presents their experiences of using Chinese medicine, discussed in relation to their experiences and use of Western medicine.

### **9.1.2 Past experience**

Past experience emerged as another determining factor, with trust underpinning their choice of therapy. Participants had positive views and experiences of using Western medicine. On the other hand, except for one participant, Chinese medicine and its practitioners were portrayed negatively.

#### ***9.1.2.1 Comparison between Chinese and Western medicine***

Many perceived the practice of Chinese medicine to be 'unscientific'. In contrast, they felt that practitioners of Western medicine had a systematic

approach to diabetes management. Many believed that Western medical practitioners have a good understanding and management of diabetes. In the following excerpts, Examples 1 and 2 show two male participants speaking disparagingly about Chinese medicine and those who practise it. They were convinced that Chinese medicine lacked evidence. In contrast, Western medicine had a systematic framework to deal with diabetes:

#### Example 1

Researcher: So, Mr Li, have you used Chinese medicine before?

Mr Li: No, never used it before. Some people advised to eat certain parts of a plant. What exactly are these plant parts? Yes? Should have evidence, that's the way it should be. Isn't that right? The injections that the doctors gave us for diabetes, there is a drug literature for you to read. That medicine which comes in the form of lumps and sorts and you boil them, like the leaves and barks of trees, is there any literature to inform you as to what it is? If that is available for me to read, it will give me confidence. You need scientific evidence!

(Focus Group No. 6, Birmingham)

#### Example 2

Mr Lui: If I were in China, I would also go to a Western doctor because in Western medicine, there is a system.

(Focus Group No. 1, Leeds)

Trust in Western medicine was linked to length of stay in the UK. For Lily, long periods away from her country of birth led her to become dependent on Western medicine and deterred her from using Chinese medicine in the UK. Thus, by 'default', Western medicine became her choice of treatment:

Mr Yap: Whether you like it or not, you are dependent on the system. They give you medicines.

Lily: If we were in China, then we will not have confidence in the medicine of other countries. We've been here for over 40 years, had our babies here and have depended on Western medicines. So we have grown to trust Western medicine.

(Focus Group No. 3, Bristol)

A common theme from the above examples is that many participants perceived Western medicine to be superior to Chinese medicine in dealing with diabetes. The widespread use of Western medicine for diabetes in the UK, compared with almost no use of prescribed Chinese medicine indicates participants believed that Western medicine has a good understanding of diabetes and can offer effective treatments, in terms of keeping diabetes in control.

Importantly, the lack of evidence of sustained normal blood sugar levels using Chinese medicine had led many participants, diabetics or otherwise, to conclude that Chinese medicine cannot be used to treat diabetes. Effective treatment for many of my participants implies bringing the illness to an end or to halt its progress. Lam reported that within the lay understanding of Chinese medicine, users expect Chinese medicine to 'clear the root of the disease' (Lam, 2001:763), similar to the phrase 'cutting the tail' meaning, to remove the causative agent of the illness, and to bring the illness to an end.

Efficacy of Western medicine for the treatment of diabetes was reported in all eight focus groups. By far, the most convincing reason for the use of Western medicine over Chinese medicine for diabetes was treatment outcomes i.e. reducing blood sugar levels. Diabetics and their family members bear witness to the speed and efficacy of Western pharmaceuticals for diabetes. For example, Mr Chang recounted how his sugar levels were high prior to treatment but as soon as he started insulin injections, his sugar levels fell to within the normal range of 4 to 7 mmols:

Mrs Chang: His sugar level was really high, up to about 20 points.

Mr Lui: Waah, that is serious.

Mrs Chang: After the injection, it controlled it slightly.

Mrs Lui: 6 to 7 points is considered good.

(Focus Group No. 1, Leeds)

The above extract is a personal testimony of the impact of the efficacy of Western medicine in reducing blood sugar levels. Western-style medical treatment for diabetes was also widely used by Chinese people in their country of origin. In Focus Group No. 4 Mrs Mah said that she was prescribed Western-style medicine for diabetes, prior to coming to the UK:



Mrs Mah: People [in Hong Kong] mostly go to the Western-style doctors. I continued with the same treatment when I came to UK.

Mrs Ong: You are only taking one tablet a day but once it deepens then you cannot do that.

Mr Lau: Nothing else will help. Western medicine can keep it stable.

(Focus Group No. 4, Birmingham)

A similar view was expressed by Mrs Yee in Focus Group No. 5:

Mrs Yee: You depend on [Western] medicine to control it.

All participants concluded that both Chinese and Western medicine can only control the progress of diabetes but not halt or cure it. Consequently, all except one participant chose to take Western medicine:

Mr Chang: Chinese medicine is troublesome; you need to boil the medicine for a few hours.

Mrs Lui: It can be effective.

Mr Chang: You don't need to do that with Western medicine. You just need to pick up the tablets and take it all at once. Convenient!

Mr Lui: I have lots of friends and family in Hong Kong who have diabetes and they all see Western-style doctors.

Mr Chang: You can't carry around your Chinese medicine. Don't tell me you boil your medicine and put it in a jar and carry it around with you?

(Focus Group No. 1, Leeds)

In addition to the ease of taking medicine, Western medicine also offered a faster result and a perceived greater efficacy, compared to Chinese medicines which they believed were slow in action and possibly lacking in efficacy:

Researcher: If all of you are now in China and you were diagnosed with diabetes, will you see a Chinese or a Western-style medical practitioner?

Mrs Wu: Of course you will see a Western-style practitioner, it's more effective and you can see the results faster.

Mrs Ngan: We will mostly go to the Western-style practitioner.

Mrs Xi: The results are faster.

Mrs Ngan: Yes, that's right.

(Focus Group No. 8, London)

Although Mrs Ngan uses both streams of medicine, she complains of the inconvenience of using Chinese medicine. However, she did not stop taking Western medicine when she was taking Chinese medicine.

Fear of incompatibility, expressed as 'clash' of concurrent usage of Chinese and Western medicine prevented them from encouraging those with diabetes to use Chinese medicine. In Focus Group No. 5, Ms Lee said that her mother did not consider Chinese medicine because 'she is taking a lot of Western medicine and it might clash'. In addition, an element of faith is attached to the use of medicine, Western or otherwise suggesting a pseudo-religious deference in the use of medicine (Hare, 1993):

Mrs Ho: *Aiyah* (唉呀) Chinese medicine cannot be used for this kind of illness. There's Western medicine for it.

Mr Lee: Cannot let the medication clash.

Mrs Ho: Yes, that is true, must not let it clash.

Mr Yap: Yes, it'll clash. If you believe in the medicine from England, you should not take medicines that will clash with it.

(Focus Group No. 3, Bristol)

The above example shows that Mr Yap felt he had no choice but to use Western medicine as he depended on the NHS to provide medicine to control his diabetes. The next section presents their negative experiences of using Chinese medicine in the UK.

### **9.1.2.2 Negative experiences and views of using Chinese medicine**

Nowhere else in this cohort of focus group discussions is the belief in the superiority of Western medicine more pronounced than in Focus Group No. 5. Mrs Yee was dismissive of Chinese medicine. She believed that Chinese medicine is used by those whose 'thinking is not developed', and were stuck in the 'conservative period':

Mrs Yee: I've always used Western medicine. Have not really gone to a Chinese medical practitioner. I don't trust them. Firstly, I'm afraid they will

cheat me of my money. Secondly, I don't have much confidence in Chinese medicine. Don't trust them. Don't know if they are genuine or fake.

Ms Lee: There are lots of them here.

Mrs Yee: If everybody was like me, Chinese medical practitioners will go out of business. People from the conservative period, they would mostly believe in Chinese medicine. Their thinking is not developed.

Mrs Lee: (Spoke in Hakka which I could not understand)

Researcher: Are you speaking Hakka?

Mrs Yee: She said that she knows of someone who saw the Chinese medical practitioner first, and then consulted a Western doctor and eventually, it was the Western doctor who was good.

Ms Lee: If you consult the Chinese doctor and want to be cured, it will require a long period of treatment and lots of money! Better to go to the Western doctor. The sugar urine could get better.

Mrs Yee: Western medicine has no other solution [to diabetes]. Are you telling me that Chinese medicine have the answer?

(Focus Group No. 5, Birmingham)

It transpired that Mrs Yee had used Chinese medicine in the past and was very disappointed because the effects were not permanent. As stated earlier, only one diabetic, Mrs Ngan, trusted Chinese medicine because she had found the 'right' practitioner to care for her, and had benefitted from the treatment:

Mrs Ngan: I've met the right practitioner. The minute I get off the plane, I'll go and see him.

Researcher: Are you still seeing this person?

Mrs Ngan: Yes, the minute I go back to HK I'll look him up.

Researcher: You're taking both Chinese and Western medicine?

Mrs Ngan: Yes, that's OK as long as there is a 2 hour interval.

Researcher: Who told you that you need a 2 hour interval?

Mrs Ngan: The Chinese practitioner.

Researcher: Does your Western doctor know?

Mrs Ngan: He doesn't know. Once my blood sugars dropped, my [Western] doctor asked me, 'why is it [sugar] down?' That was when I told him that I've been seeing a Chinese practitioner in HK.

(Focus Group No. 8, London)

A variety of reasons accounted for why many participants did not trust Chinese medical practitioners in the UK. An apparent absence of Chinese medical practitioners known to have specialist knowledge of diabetes contributed to lack of confidence to use Chinese medical practitioners in the UK for the treatment of diabetes. In Focus Group No. 3, Lily checked with me if I knew of any Chinese practitioners for diabetes. When I said, “Not that I know of.” my response reinforced her belief that only Western practitioners knew how to manage diabetes:

Mr Lee: Chinese doctors in England are not very famous.

Lily: And you don't know their history, isn't that so?

Mr Yap: You don't know if they are famous.

Mrs Ho: And you don't know if they have the skills to cure you.

Mr Lee: There aren't any Chinese doctors for this kind of illness.

Lily: Are there any Chinese doctors who specialise in the treatment of sugar urine illness in England?

Researcher: Not that I know of.

Lily: Now don't you agree that you have to put your trust in Western medicine because they have specialists in this area?

(Focus Group No. 3, Bristol)

As well as a lack of confidence, it was unanimously agreed that Chinese medicine in the UK was broadly 'no good'. In relation to the practice of acupuncture, the use of hyperboles such as 'jab' and 'blows' indicates the participants' traumatic encounters with Chinese medical practitioners in the UK. The following demonstrates their regret in turning to UK Chinese practitioners for treatment:

Mrs Ong: They will go to China for 2 or 3 months, master it [the art of acupuncture] and come back [i.e. to the UK] to jab you,

Mrs Leong: That's right.

Mrs Ong: It's a good job that you don't die from their jabbing.

Mrs Mah: [at least] thousands of pounds!

Mrs Ong: Have you been jabbed before?

Mrs Lin: [they'll] jab you till you're in a worse state.

Mrs Ong: What did you have acupuncture for?

Mrs Lin: My hands and feet were numb. So I went for acupuncture!  
(Focus Group No. 4, Birmingham)

The above indicates the participants' disappointment after receiving acupuncture from UK Chinese medical practitioners. The phrase 'it's a good job that you don't die from their jabbing' shows their willingness to risk their health despite doubts about the skills of UK Chinese medical practitioners. Other phrases such as 'master it [skill of acupuncture]' denotes sarcasm because they know that the art of needling takes years of practice, not merely two or three months.

In Focus Group No. 6, Mrs Li recounted her experience of using Chinese medical therapy in the UK for headaches. As a result of repeated treatments with acupuncture, she was left with bruises on her back. Mrs Li was puzzled that for a complaint of headache, the treatment was delivered on her back rather than her scalp. Nonetheless, she consented to the treatment three times a week, each treatment costing £25. Although Mrs Li did not say if the headache was resolved, the entire experience made her 'very frightened' of going to UK Chinese practitioners for any form of treatment:

Mrs Li: I went to London [for] acupuncture. Well, I cannot understand, you tell them you've got a headache, so you expect them to plant the needles on my scalp but they inserted the needles on my back. Now there are three patches of bruise marks on my back. It looked like I was given a few blows in a boxing ring. I'm still very frightened.

A lack of trust in Chinese medical practitioners in the UK was further compounded by the experience of suspicious treatments and a purchase of mouldy medical ingredients. In Focus Group No. 4, Mrs Leong was prescribed a 'whole jute bagful of medicine' for gynaecological problems. The outcome of the consultation and subsequent treatment was indeed absurd, but unsurprising to all present:

Mrs Leong: People told me to go and see a Chinese practitioner for women's problems, so off I went. They prescribed a range of medicine.

Mrs Ong: A whole jute bagful.

Mrs Leong: After taking the medicine, I felt worse. By the third dose I didn't dare carry on. I say, how is it that my medicine which is for women's problems is similar to that *Ah Ca* 阿差 (Indian person)? Don't know what the person [presumably a man] saw the practitioner for. But where is the logic?

(Focus Group No. 4, Birmingham)

In Focus Group 3, Lily told group members that she visited a Chinese practitioner for an arthritic complaint. She was given acupuncture, a bottle of ointment that was out of date, and a bag of herbal medicine that was mouldy. She threw both the bottle of ointment and the herbal medicine away because she doubted the safety of the products. Her experience confirmed her perception of Chinese practitioners in the UK whom she felt were charlatans:

Lily: I went to a Chinese medical practitioner in the UK because of arthritis. They suggested acupuncture and to rub with an ointment. When I arrived home, I noticed that the ointment was out of date, couldn't trust them. I would rather throw away the medicine than use it. If it was in Hong Kong, that would be different. Lots of people consult Chinese practitioners, so the medicine is comparatively fresh. [However] by the time it [the herbal medicine] arrives in England, it will be all mouldy.

Researcher: How do you know that the [herbal] medicines are not fresh?

Lily: When you open the packet, you can see it [that it's mouldy].

Mr Yap: Yes, you can see it [the mould].

Lily: It's like when you buy a piece of fruit or vegetables, you can tell if it's fresh, isn't that so? It's not possible that you don't know. There's a smell to it if it's not fresh.

Stories were recounted about how they were advised by friends to consult their local Chinese medical practitioners for complaints such as eczema, gynaecological problems and common coughs and colds. In Focus Group No. 1, Mrs Lui described her experience of consulting her local Chinese practitioner as a 'write off'. She visited a Chinese practitioner for skin complaints but was disappointed that the practitioner would only prescribe herbs for immersion, and that the treatment only worked temporarily. She also told the practitioner that she suffered from diabetes but he did not suggest taking any oral medicine for

it. The lack of prescription for oral medicine was interpreted by Mrs Chang as an indication of poor medical skills:

Mrs Lui: My hands itched like mad. I went to see a Chinese medical doctor. Was given some cream to apply and told to boil some herbs and immerse my hand in it. I told him that I had diabetes. He didn't give me any tablets. He didn't dare prescribe any medication.

Mrs Chang: He knows he's not authentic.

Mrs Lui: Spent about £100. Just soaking my hands in the water mixed with herbs! I still had to go to the Western doctor for treatment.

Mr Lui: Well, it worked but after a few weeks,

Mrs Chen: it came back again.

Mrs Lui: £100 written off.

(Focus Group No. 1, Leeds)

Perceptions about UK Chinese practitioners lacking in medical skill and professional integrity were expressed in Focus Group No. 7. Note that Mrs Yeoh was trying to present a more positive picture of Chinese practitioners but failed. Hostility and lack of trust and respect between northern and southern Chinese were revealed in this discussion group:

Mrs Lee: They say we sell Western [she corrects herself], Northern medicine, and not Southern medicine. I said, 'What do you mean Northern, Southern medicine?' I was fuming mad. Is there such a thing as Northern medicine and Southern medicine?

Mrs Yeoh: Perhaps, they were not too sure. There are two places of production.

Mrs Lee: No, they said that they only sold Northern medicines, not medicines from the South. That was so annoying, saying things like that. They should go back to Beijing to open a shop, don't come here and do business with the southerners. They have bad medical ethics.

(Focus Group No. 7, London)

Territorial allegiance is exhibited by these participants. This could be partly due to cultural and linguistic differences as northern Chinese speak Mandarin and southern Chinese speak Cantonese. Although both northern and southern Chinese share the same linguistic script, the spoken language is mutually

incomprehensible. In addition, historical animosity between northerners and southerners is still present. These factors reduced UK Chinese practitioners' (predominantly from northern China) credibility as they were viewed by their mainly southern Chinese patients as lacking in skills and medical integrity.

Suspicious about Chinese medicine and its practitioners were substantiated by personal encounters.

#### Example 3

Mr Ong: That's the one thing bad about Chinese people. They are afraid that people will know.

Mr Lau: Afraid that other people will know.

Mrs Ong: Yes, afraid that other people will know.

Mrs Leong: It's a shame that such practices exist. It's as if it's a secret.

Mr Ong: The Western doctors, once they specialise in this area, they will make the knowledge known to everybody. But in Chinese medicine, it is not the case. The prescription that one Chinese doctor writes differ from the prescription from another Chinese doctor! People will begin to sense that Chinese medicine is not systematic. And it all seems to be so secretive

(Focus Group No. 4, Birmingham)

However, as will be seen later in the thesis, participants often expressed contradictory views about Chinese medicine. In the next section, participants shared their experiences of experimenting with food based cures with one participant, Lana, still using it for diabetes.

### **9.1.3 Chinese medicine: food or drug?**

Recourse to food items perceived as having hypoglycaemic effects was a common practice amongst participants in all focus group discussions. These food items include various types of fruit and vegetables, animal parts and herbal soup ingredients. In this aspect, my sample resembled other cultural groups with a history of traditional medicine, who use non-prescribed medicines, and perceive certain food products as medicinal. An example of using non-prescription medicine was documented in a study on rural Vincentians with diabetes (Moss and McDowell, 2004).



In my study, Mr Yap from Focus Group No. 3 in Bristol said that he had previously tried a catalogue of food therapies ranging from soup recipes to a vinegar and egg concoction in an attempt to get rid of diabetes. Some of the folk recipes he recounted sounded bizarre even to his peers. This suggests that he was very desperate to find a solution to diabetes. He admitted that he would try anything, including 'eat[ing] soil' to get rid of diabetes:

One bag of cuttlefish, 8 slices of ginger, took it for a few months, doctors in Hong Kong says that it's harmless. About 10 years ago, I used chicken eggs, soaked it in vinegar overnight. Mix the eggs with honey; take it over 2 days day and nights. I used to take it for diabetes. I've tried a whole catalogue of stuff. If they tell me to eat soil, I'll do it.

Other food recipes were more acceptable to the other participants on the basis that they were tried and tested. These included eating bitter melon or drinking mixed bean soups and guava leaves tea. Contrary to existing perceptions that food based therapies were harmless, one of the group members said that food remedies can be harmful. Ms Lee said that after taking mixed beans soup, recommended by friends for lowering blood sugar levels, she experienced low blood pressure:

Mrs Lin: Some people say eating bitter melon [is good for diabetes].

Mrs Ong: Mixed bean soups [as well], I've tried that before.

Mrs Leong: *Wahhhhhh* I became low blood [hypotensive].

Mrs Mah: No, that won't do. It's too 'cooling'.

Researcher: Why did you take that?

Mrs Lin: It's to reduce the blood sugar, it helps with blood sugar.

Mrs Leong: I got it from Hong Kong. Dried star fruit, ground it, add water to it and drank it. I couldn't tolerate it. Now it's all left in the house.

Mr Ong: That's too 'cooling'.

Mrs Leong: That's right, too 'cooling'.

(Focus Group No. 4, Birmingham)

These personal experiences of adverse effects of food cures reinforced their existing beliefs that diabetes is linked to food intake. One emergent finding is

that patients test their own perceptions at the risk of compounding the illness trajectory.

Despite using tried and tested recipes, some who used food cures experienced unfavourable results. Mr Chang offered information about the use of guava leaves to control diabetes. Mrs Lui agreed that it was possible but quickly added that he had heard that some people became worse after taking it. Discussion tailed off with Mr Lui saying it was difficult to know what types of food cures to use for diabetes:

Mr Chang: Those guava leaves, boil them and drink it as tea.

Mrs Lui: Yes, that is possible, but

Mr Lui: some people became worse after the drink, had three of those drinks.

Mrs Lui: The drink killed them.

Mr Lui: So, it's very difficult to say [what works].

(Focus Group No. 1, Leeds)

Using non-pharmacologic treatment as medicine is not exclusive to Chinese people. Several authors reported that many patients used a catalogue of food and or home remedies for various types of chronic conditions such as arthritis, diabetes and asthma (Robertson, 1992), pain (Ersek et al., 1999) and hypertension. For example, Morgan (1996) found that 17 of the 30 Afro-Caribbean people in her study took food cures to reduce blood pressure. They would boil grapefruit skins with garlic and drink it to reduce blood pressure. She observed that they regarded these concoctions as potentially less harmful than

conventional medicines, and a more 'natural' way of dealing with hypertension (Morgan, 1996).

A common culinary practice noted throughout all the 8 focus groups was the tradition of making soups (*bouhtong/butang* 补汤). Both male and female participants believed that soups were both nutritious and medicinal. Some oft quoted soup recipes which had hypoglycaemic recipes included pig's pancreas and corn silk soup. These were widely used and seemingly successful recipes.<sup>16</sup>

Mrs Yee: We would mostly make soups (*bouhtong* 补汤) daily like sweet corn silk, pig's pancreas. Soups are beneficial; drink it like tea, helps with your health.

(Focus Group No. 5, Birmingham)

Lana claimed that drinking pig's pancreas soup on a daily basis had prolonged her father's life and kept his blood sugar levels under control:

Somebody from church taught my mum [to make] pigs pancreas soup with [pork] and a Chinese herb called 'cishi' (茨实 fox nut). My mother made it religiously. The doctor gave him 5 months to live when it was first discovered. It's been 30 years now. He's in his 90s and he's OK.

(Focus Group No. 7, London)

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<sup>16</sup> The use of pig's pancreas and corn silk soup in the management of diabetes dates as far back as 752 (Lu,1986:139).

Note the influence of social networks on health behaviours. In this case, Lana's mother was encouraged by a church member to make pig's pancreas soup with a herb known to them for treating diabetes.

Drinking soups is part of the Chinese 'tradition' for maintaining health and strengthening one's constitution. Many believe that medicinal soups cleanses the body of 'heat' which is a common bodily imbalance in the event of illness. The drinking of soups to remove 'heat' suggests that participants think diabetes is a 'heaty' illness or that it had upset the body's equilibrium. The vagueness regarding their health and illness beliefs can be noted by expressions such as 'don't know if' and 'I think':

Mr Mun: Chinese people feel that making soups will cleanse your body of heat. Some of the herbal soups will help to strengthen and nourish your body. You just need to nourish and replenish all parts of your body. Sometimes when you are 'heaty' (*yeathei/reqi* 热气) you need to cleanse your body of the 'heat' by taking 'cooling soups' you may make chicken soup and add herbal medicine.

Mrs Li: Don't know if it's because it is tradition, passed down from previous generations that we have to have soup. I think it is more or less the case that we have to have soups, just like other people have water.

(Focus Group No. 6, Birmingham)

Many participants could identify the types of herbs which were prescribed by Chinese medical practitioners for diabetes. In the excerpt below, they demonstrated recognition of the types of ingredients in the prescription. An important finding is what they believe to be medicine. Many participants believed that identical ingredients are simultaneously both medicine and non-medicine. This is dependent on whether or not the ingredient is part of a medical prescription or merely ingredients for soups:

Mrs Ong: There is *pagkkei* 北芪 (ginseng derivative) what else, many kinds!

Mrs Mah: 7 types of ingredients, is that it?

Mrs Ong: Yes, it's about 6 or 7 types of ingredients.

Mrs Leong: 7 types? Once, I had a concoction that was for the eye. Well, he picked a few ingredients and I made soup out of it.

Mrs Ong: The herbal medicines in this country (i.e. UK) wouldn't do.

Mrs Mah: I use herbal medicine in soups.

Mrs Ong: The Chinese doctor did not prescribe it for you. You got it yourself. It is only when the Chinese doctor writes a prescription, only then is the ingredients considered Chinese medicine.

(Focus Group No. 4, Birmingham)

In London, Chan (1991) found that the use of Chinese medicine is common among UK Chinese suffering from diabetes. She reported that 17 out of 20 patients adhered to a dietary regime based on the principles of Chinese medicine. Chan (1991) interpreted the use of dietary principles or the ingredients of Chinese medicine as taking Chinese medicine. However, participants in my study stated that unless the ingredients were prescribed by a medical practitioner, they did not feel they were taking Chinese medicine.

Faith and hope, a theme which emerged from the individual interviews, turned out to be a contributing factor underpinning the motivation to use Chinese medicine among some participants. Despite the negative perceptions and traumatic personal experiences of using Chinese medicine in the UK, hope that Chinese medicine would provide a cure became evident. Degrees of affinity to Chinese culture, socio-economic status and the nature of the illness were listed as factors influencing continued usage of Chinese medicine. Faith in Chinese medicine is best reflected by Mrs Lee who described it as 'waiting for the bus, and you hope that the next dose will be a better one.' This statement was in response to the question on why UK Chinese continue to seek help from Chinese practitioners despite their bad reputation.

The willingness and the patience to wait for a 'better' dose of medicine and for something good to come along suggest faith in Chinese medicine. When asked if they would use Chinese medicine if it was offered freely to them, many said they would try it because 'it is harmless', and because Chinese medicine is part of their culture. The antiquity of Chinese medicine clearly makes them believe that years of empirical usage is potentially equivalent to proof of safety and efficacy. In the following section, some participants said they would use Chinese medicine because it is part of their identity.

#### 9.1.4 Ethnocentricity: 'because Chinese medicine is part of our tradition

Ethnocentricity towards the use of Chinese medicine was noted in the following focus groups. In Focus Group No. 1, Mr Chang was clearly in favour of using Chinese medicine and his reason was that it was because he is Chinese:

Mrs Chang: [In Hakka] If you were in Hong Kong, and you discovered that you have diabetes, would you prefer to see the Chinese medical practitioner or the Western-style doctor?

Mr Chang: **Of course** (*his emphasis*), I would go and see the Chinese medical practitioner!

Researcher: Why would you go to a Chinese medical practitioner?

Mr Chang: Because Chinese medicine is part of our tradition. Therefore, you will consider it.

(Focus Group No. 1, Leeds)

This view was also echoed by both Lily and Mrs Ho in Focus Group No. 3 who advanced the reason by comparing it with English people using English medicine, i.e. that it was natural for individuals to turn towards the medical system they were accustomed to:

Researcher: Let's just say that all four of you are now in China, and the doctor tells you that you've got diabetes. Would you go and see a Chinese practitioner or a Western-style doctor?

Everybody: Oh, if we were now in China, of course we will go to a Chinese practitioner.

Lily: Of course we will go and see the Chinese practitioner first.

Mr Yap: If you were in China, of course you will go to the Chinese practitioner first

Researcher: Why is that?

Mrs Ho: If, (interrupted)

Lily: That's because we are Chinese.

Mr Lee: We're Chinese.

Lily: Let's say in England we don't need to pay to see a Chinese practitioner,

Mrs Ho: I'll,

Lily: I'll go and see the Chinese practitioner first.

Mr Lee: See the Chinese doctor.

Lily: And if it doesn't work, then we'll go to the Western-style doctor. As Chinese people, we're bound to.

Mrs Ho: We should believe in Chinese medicine because we are Chinese so we trust our own Chinese folks. Like the English, they would naturally go to their own English doctors.

(Focus Group No. 3, Bristol)

The information gathered on the use of Chinese medicine for diabetes is consistent with the literature on motivation for the use of medicines from their own cultural group (Leong et al., 2003, Pieroni et al., 2008, Wu et al., 2007). Members from these two focus groups felt strongly about Chinese medicine. Note their argument about Chinese using Chinese medicine and English people using English medicine. This indicates their affinity towards Chinese culture and perhaps a need for the reinforcement of their Chinese identity whilst living amongst non-Chinese. Also reiterated in these discussions is the view that Chinese people who use Chinese medicine are of older age groups, female and have lower levels of literacy.

However, participants from the focus group discussions expressed contradictory views on the use of Chinese medicine. Despite previous negative encounters with Chinese medical practitioners. These negative experiences did not deter them from wanting to use Chinese medicine if it was offered free of charge. On the contrary, many participants felt it was 'natural' to use medicine from their country of origin. I elucidate on the possible reasons for these contradictory views in the discussion section of this chapter. In the next section, I present findings from the individual interviews.

## **9.2 Findings from individual interviews**

### **9.2.1 Evidence of uptake of Chinese medicine/health practice**

Besides Mrs Ngan, the only participant from the focus group discussions who said she was using Chinese medicine concurrently with Western medicine, at

least five participants revealed that they used Chinese medicine or engage in Chinese health practice. The following two participants were pleased that they used it, but not for diabetes. Mrs Ong described symptoms that resembled stroke:

My face, suddenly it went lop-sided. Then a friend recommended that I go and consult a Chinese practitioner, GOT TO HAVE ACUPUNCTURE!! (*her emphasis*). I was jabbed six times and then everything was back to normal. That is why I went to a Chinese practitioner.

Another success story was from Liam who suffered from hay fever which was resolved after using a type of Chinese food cure::

[my mother-in-law] sent some *lingchee/lingzhi* (灵芝) (a mushroom) over.

All you have to do is add hot water. She said that it would help.

Researcher: Any results?

Liam: My pollen allergy disappeared

In the case of Mrs Yee, she used a range of expensive Chinese herbal products from Hong Kong for various health reasons including 'nourishing the kidneys'. Mrs Yee had developed renal failure due to poor control of diabetes and now required renal dialysis three times a week. At the individual interview, she said that her efforts were focused on reducing damage to other organs rather than controlling diabetes. She said that diabetes was no longer a problem and her main concern was to prevent further damage to her kidneys. Her reason for taking *dong cong cou* was to 'nourish the kidneys':

Mrs Yee: I now have all the complications. The eye, the kidneys and I'm starting to have problems with my heart. But if you have good food, that's good too [for your health].

Researcher: Like what?

Mrs Yee: *Dong cong cou* (东虫草) that is food but it's medicine as well. It's good for diabetes [and] bird's nest as well.

Researcher: Is that to reduce the blood sugar?

Mrs Yee: Yes, *Dong cong cou* nourishes the kidneys.

However, at the focus group session, Mrs Yee said that she did not take the medicine her son bought from Hong Kong. She said:



I don't dare to take it. It's Chinese medicine I threw the bloody lot away

In the next example, Tessa, a 30 year old nurse and community health worker, sought help from Chinese medical practitioners when she was living in Hong Kong. Since settling in the UK, she had stopped using Chinese medicine for 'weak kidneys' (*shenxu* 肾虚) as she did not know of a reputable Chinese medical practitioner. Then a work colleague introduced her to one. She consulted the Chinese practitioner for a different ailment – irregular periods. Below is an account of her experience of using Chinese medicine:

Tessa: [in] Hong Kong, I consulted a Chinese practitioner. I took Chinese herbal tea for nearly 6 months. I have a very weak kidney, *shenhui/shenxu* (code-switch). He was one of my friend's uncle. So it's like reliable, you know.

Researcher: When you came over, did you carry on with the Chinese medicine?

Tessa: No! Because we know nobody in Glasgow [later] I moved to Belfast.

Researcher: OK. So when you came to Belfast, did you look for a Chinese practitioner?

Tessa: Knew nobody at that time in Belfast. No, that's not true. I went to see one lady doctor on and off about 3 months.

Researcher: And what was this for?

Tessa: Period [problems]. I didn't go and seek a Chinese practitioner for diabetes. I find that sometimes it's quite confusing. If I have to take Metformin and take herbal tea for diabetes, I'm not sure if they would contradict each other.

Researcher: How did you know about this practitioner?

Tessa: Lin introduced. There are loads of different Chinese practitioners around Northern Ireland. But if no one introduce to me, I will not go. I don't want to go to someone I don't know.

Recommendations from familiar persons are central to using Chinese medicine outside China. Users perceived these recommendations as a sign of credibility and trustworthiness.

Only one participant, Mr Lui mentioned doing *qigong* (气功) as a form of Chinese health practice to enhance and maintain his health:

I do *heigong/qigong*. I've been doing it for about 7 or 8 years. No problems with my heart because I've been doing *heigong/qigong*.

Thus, a different and positive image of Chinese medicine was presented at the individual interviews. This positive image was framed against the background of Western medicine. In the next section, I present the possible reasons for the extensive use of Chinese medicine by my participants.

### **9.2.2 Benefits of Chinese medicine**

Medicine, mainly in the form of food cures is a common practice amongst the Hausa of Northern Nigeria, (Etkin and Ross, 1982), Chinese people in Hong Kong (Koo, 1984), the UK (Jovchelovitch and Gervais, 1999) and in Singapore (Leong et al., 2003). Among my study population, they used it for a variety of reasons, predominantly because it does no harm and that it can counter the harmful side effects of Western medicine. They believed that Chinese medicine:

- enhanced their health,
- 'cleansed' their bodies of harmful residues of Western medicine,
- boosted their immune systems,
- is 'natural' in comparison with toxic pharmaceuticals, and
- is safe based on its long history.

The perception that herbal medicine is safe and has fewer side effects than conventional medicine is a contested topic (Ernst, 2003, Saks, 2003, Kelner, 2000, Siahpush, 1999). Besides the aforementioned reasons, the following contributed to its widespread usage among UK Chinese:

- a prescription is not required,
- can be bought over the counter,
- contains familiar herbal ingredients, and

- have positive effects such as feeling ‘alert’ and facilitating sleep.

An oft cited reason for the use of food-based Chinese medicine was the belief that it has multiple health benefits including getting rid of ‘heatiness’ in the body, and as a ‘helping’ agent to western medicine (c.f Chapter 5.3). In this context, it can be argued that Chinese food cures were used as complementary to mainstream Western medicine:

There is *waisang* (淮山), *geiji* (苟子), *foksann* (伏神) and *dongsum* (党参) that is for curing diabetes. And if it doesn’t cure diabetes, it can also help (Lui, 70, Male, Leeds)

Other participants used Chinese herbs for ‘cleansing’ (*chengyun/qingrun* 清润) purposes including counteracting the effects of eating fried foods and central heating:

On my days off, I will make ‘cleansing’ soups because the central heating is very ‘drying’. I use watercress, dried cabbage and white fungus (Leung, 54, Female, Leeds)

*Cheng yun* (cleansing), three strips of *pagkkei* (北芪), 3 strips of *dongsum* (党参) and a few *geizi* (枸杞子). When I eat fried stuff, the next day I’ll be straining my stool [so] I make *Cheng Po Leung* (清保凉) soups. (Ong, 57, Female, Birmingham).

A male participant, Mr Cheung, believed that Chinese medicine would not deplete the body of essential vitamins from the body, which he perceived Western medicine would. So he took Chinese medicine when he had a cold or when he was suffering from *yit hei* (‘heatiness’):

The medicine, the vitamin gets eliminated by the medicine. With Chinese medicine, that would not happen and you won’t suffer from ‘heatiness’. It will ‘cleanse’ the heat.

Another participant, Mrs Ngan also used Chinese medicine for health enhancement and harm reduction, ‘just to replenish my blood [...] for balance.’ Importantly, these recipes are not directed at controlling blood sugar levels, but to protect other organs such as the kidneys from diabetes-related

complications, and to eliminate the harmful residues of Western pharmaceutical products.

According to Kaptchuk (1987) in Chinese medicine, the endocrine system does not exist although practitioners treat diabetes. Many of the foreign-born participants in my study had difficulty identifying the organ related to diabetes. This might explain why they seem to focus on organs that are familiar to them like the eyes and kidneys.

The use of Chinese food cures indicates that patients are making efforts to take control of their illness, reduce the harm caused by diabetes and to maintain other bodily functions. It also signifies that they are reframing their illness to one that is more in keeping with a preferred interpretation of their illness. An American study reported that several of their participants used herbal medicines instead of conventional medicine out of fear of pharmaceutical toxicities (Nichter and Thompson, 2006). In my study, only Lana refused conventional medicines:

Once you're on insulin, your body gets adapted to it very quickly like a drug. In the long run, my body is clean, is clear from chemicals. All conventional medications contain chemicals. I won't accept it, and the body is breaking down all the time.

This is an unusual lay interpretation of medicine and the body. The phrase 'breaking down' alludes to a mechanistic view of the body. Referral to the body as a machine is contrary to existing literature which posits that Chinese people view the body as an interwoven garden as opposed to the pipes and drains as portrayed in Western medicine (Kelner and Wellman, 1997). This could be a result of migration. Furthermore, displaced members of the Chinese communities had, to an extent, taken on the Western view of the body. By adopting ideas from the host community, this could help them align their understanding of diabetes with the host community and the Western medical practitioner. As mentioned in Chapter 8.2.1.6 there is no evidence from the interview data as to where Lana derived the idea that insulin is addictive.

As mentioned previously, motivations to use non-prescribed Chinese medicine are underpinned by the desire to reduce the harmful effects of conventional

medicines. In contrast, herbal products offer a 'natural alternative. The word 'natural' carries with it the connotations that it is genuine, pure or unadulterated, especially when juxtaposed against commonly held notions of Western pharmaceuticals as being chemically synthesised and potentially harmful:

Chinese medicine is *wo/he* 和 (wholesome); there is not so much adverse effects. It's not *san* 散 (weakening). It can 'adjust' your health. (Chueng, 60, Male, Leeds)

Apart from the lack of undesirable effects of feeling weak, participants also felt that taking Chinese medicine helped them to feel 'alert':

I feel more alert when I take those Chinese medicines. (Yee, 75, Female, Birmingham)

And to sleep better:

After taking [Chinese] medicine, when night comes and I go to sleep, I sleep for five to six hours. *Waah!* That was so comfortable, [compared to when I take Western medicine] I can [only] sleep for two to three hours, (Ong, 57, Female, Birmingham)

Nichter and Thompson (2006) highlighted the influence of advertisement and the longevity of use as factors for gravitation towards, and subsequent use of Chinese medicine. Secondly, its practice is not based on 'new discovery' which requires human subjects to assess efficacy. The use of human subjects to assess drug efficacy was viewed by Mrs Ngan as 'dangerous':

They said they were afraid that it [the drug] would affect my kidneys! *Waah!* I've been taking that for many years! And now you tell me you are afraid that it would affect my kidneys! These people are really not conscientious, they are dangerous! But science these days are like that. They're just using people to experiment [with the drug].

Researcher: What about Chinese medicine?

Mrs Ngan: Seems it does not happen with Chinese medicine. They have thousands of years of [history]. There is no fault with it. Does not cause any harm. Western doctors these days would say, 'Oh there is this new discovery', and they look for people to try it. Well, if I have a cold, I would go to a Chinese practitioner. I have confidence in Chinese practitioners

because when I see a Western practitioner, after taking the medicine, I feel *san*.

Researcher: What does *san* mean?

Mrs Ngan: It means a feeling of fainting. It could be that the speed [of action], it's fast. But with Chinese medicine, it would repair a tear, stitch by stitch.

Negative ideas about the side effects of Western medicine were echoed by another participant, Mrs Chueng from Leeds. She was told by her friends that when large amounts of Western medicine were taken over a long period of time, it can get 'stuck' in the body and result in tumours. She thinks that when medicine is taken and not dissolved, it turns into tumours. Also, she thinks that repeated injections will give her 'holes' in her body:

If the blood sugar continues to be bad, I'll need to inject insulin directly! Hey! I don't want injections! Makes holes here and there. I'll rather eat medicine. But some people tell me that if you eat too much medicine, you will have growths in your body, that's what long term medication does to the body.

Researcher: What growths?

Cheung: If the medicine does not dissolve, it'll get stuck in your body like a lump of something, a tumour.

Many participants felt compelled to use Western medicine despite their reservations about its effects. However, not all participants in the study have a high regard for Chinese medicine. Some participants from the focus group discussions and from the individual interviews expressed doubts about the science and practice of Chinese medicine. Their views are presented later in this chapter.

### **9.2.3 Cultural and linguistic similarities between patients and healers**

One reason cited for the use of Chinese medical practitioners in Hong Kong was the ease of communication. Two female participants, Mrs Leung and Ms Wong said that they sought a second opinion from a Chinese medical practitioner whilst on holiday in Hong Kong. They felt it was easier to

communicate with a doctor who spoke Cantonese, and that they would be able to know if they had other problems besides diabetes:

Go back for a full body check to see if anything else is a problem. It's convenient. You can speak to them in Chinese. (Wong, 53, Female, Leeds)

When we went back to Hong Kong, we went for a body check. You can communicate and all but [in England] you don't understand what the *gwailo* (lit: devil man, referring to the Western doctor) is saying. (Leung, 54, Female, Leeds)

Previous research found that health-related terms and concepts required little explanation between healers and patients who come from similar cultural backgrounds (Kleinman, 1977, Helman, 1996). Thus, Chinese patients had no problems with concepts such as hot-cold and dry-damp conditions, but could not make sense of biomedical explanations presented by Western doctors. For example, Mr Lui shared candidly about his interaction with Western and Chinese medical doctors:

I asked him what illness is that, and he said, 'If I tell you, you won't understand.' Waste of time! That is why when I see the doctor; it's just three to five minutes! When you have diabetes, you go back to Hong Kong [and] ask the Chinese medical doctor [and he] will tell you what he knows about it. (Lui, 70, Male, Leeds)

Although many could not understand what was said at their follow-up appointments, their lack of ability to converse in English did not stop them from using the services provided by the NHS. Those who could afford it would travel to their country of origin to consult a doctor who would explain the illness and how it should be managed in a way that they could understand.

#### **9.2.4 Hope in Chinese medicine**

Only three participants expressed hope in Chinese medicine that it could offer a cure for diabetes. Mr Cheung said that he had faith in Chinese medicine. He believed that amongst the huge array of Chinese medicine, there must be a cure, and in time, someone will discover it:

Chinese medicine, there is a cure from Chinese medicine! (very excited)  
There should be, it's just that nobody has tried it, that's all. Nobody has found the Chinese medicine. (Cheung, 60, Male, Leeds)

One participant hoped that Chinese medicine might be able to activate the pancreas to produce insulin.

After you take the Chinese medicine, will the pancreas work properly? I'm not 100% sure whether it works or not on diabetes. I haven't tried that before. (Tessa, 30, Female, Belfast)

Although Tessa did not use Chinese medicine for diabetes, she did not dismiss the possibility of future usage. Liam, who arrived in the UK at age 8, said he had contemplated the idea of seeing a Chinese practitioner for diabetes at a later time. This was because his parents were diagnosed with diabetes in the UK but had gone home to Hong Kong for treatment. They used Chinese medicine and claimed to be cured of diabetes:

Both my mum and dad have diabetes, but my mum is no longer taking Western medicine. She said that she has become normal again. I don't know if the old lady is just lying to me. My dad said the same thing, and I feel that I have nothing to worry about.

However, these positive views about Chinese medicine did not deter some to express doubts about the abilities of Chinese medical practitioners. The next section presents data on what some of the participants think about Chinese medical practitioners and the influence of friends and family members in seeking help from Chinese medical practitioners.

#### **9.2.5 Views on Chinese medical practitioners: good versus bad**

According to the participants, no Chinese person in the UK or Hong Kong had been successfully treated for diabetes using only Chinese medicine. The criteria for successful treatment is indicated by the elimination of diabetes, not mere control of symptoms. Although many participants said that they would not use Chinese medicine in the UK, it did not influence their views about Chinese medicine and its practitioners:



- Chinese medicine in Hong Kong is comparatively affordable,
- Chinese medicine as practised in Hong Kong is perceived to be authentic,
- UK Chinese are suspicious that practitioners in the UK have false certification,
- practitioners in the UK are mainly from north China (i.e. Putonghua speakers); this was seen as a cultural barrier.

Significantly, the use of Chinese medicine is inextricably linked to what patients think about their practitioners and their skills, and treatment outcomes. Word of mouth and hearsay are equally powerful forces in determining whether Chinese medicine is used. Mr Cheung believed that Chinese medicine might be able to provide a cure as 'lots of people said so':

Lots of people said that Chinese medicine might be able to affect a cure [but] I don't know if that is the case! I've not tried Chinese medicine.

Although Mr Cheung had not used Chinese medicine for diabetes, he seemed convinced, based on hearsay, that Chinese medicine can offer a cure. But not everybody felt that way about Chinese medicine. For example, Mr Lee was convinced that Chinese medicine could not offer a cure:

You cannot use Chinese medicine to affect a cure for diabetes, that's definite

Disparaging remarks about Chinese medical practitioners in the UK emerged again at the individual interviews:

Can't even treat a cold, no use going to them for other ailments. (Yee, 75, Female, Birmingham)

If they were so good, they would have stayed in Hong Kong, not run to a place like this country. (Chuang, 60, Female, York)

The good ones don't need to come and practise here. (Lui, 70, Male, Leeds)

Many felt that 'good' Chinese medical practitioners would not leave China for the UK if they had an established clientele. They felt that the ones who come to the UK lack skill and are therefore unable to carry on practising in China. These comments about UK Chinese practitioners were not shared at the focus group discussions. One possible reason why this was not shared at the focus group setting might be that such remarks could also be directed at them. Since many of the foreign-born Chinese were in the catering industry, either working for or self-employed in the food industry, it could be conjured that if they were good at what they do, i.e. cooking, they would not have to come to the UK to make a living. In any case, such remarks could potentially insult group members who were self-employed in the catering trade.

Continuing with the theme on 'good versus bad' Chinese medical practitioners, Mr Lui offered a detailed account of what makes a good practitioner and used this information to decide whether or not he would see one in and or outside of Hong Kong:

They will write a medical prescription for you so that you can go and get the medicine. If the medication does not suit the person and the person does not get better then they will give them another prescription. And by the third time, you should be all right. And if you're not better, then they'll have to change the medical prescription, mm. and if by the fifth prescription, if you're still not better, then you have to consult another doctor. Three visits and if he is not better he'll do a runner and go look for another practitioner. I've always encountered good Chinese practitioners, when I was ill.

Another participant, Mr Chui offers an account of why he would consult a Chinese medical practitioner and states that the 'clever ones', also meaning 'good', are few and far between:

In Chinese medicine there are Chinese doctors who [are] genuinely smart doctors. I know of a Chinese doctor who treated a friend so that he could play football again. An authentic doctor is one who is well versed in all illnesses. It's based on long-term achievements, on how many patients he has treated and made well. This is the testimony of a good doctor.

On the other hand, 'bad' practitioners were those who claimed they could offer a cure-all. This view was expressed by three participants who were newly diagnosed with diabetes. Robert, 50 years old, a post-doctoral researcher:

Researcher: Have you ever used traditional Chinese medicines?

Robert: What are they? I don't know what they are? I have no idea. You've got three Chinese medicine doctors' shops in my local area. They put me off because they say they can cure diabetes. Should have won a Nobel prize.

Another participant questioned the authenticity of the practitioners who sell their wares and expertise on television. For example, Mrs Chueng felt it was ludicrous that some practitioners would advertise their services on the Internet and claimed to offer a cure for diabetes:

Chay! (Get away!) I surfed the net and they said the medicines are from Beijing. Problem is, each person is different, brother. It's me who takes the medicine, into my stomach!

Hesitation to use Chinese medicine was raised by Liam. This was due to negative publicity about Chinese medicines and their levels of toxicity:

Well it is publicised in the *BBC report (code-switch)* that Chinese medicine contains toxins and that it's not up to standard. I was so disappointed.

Many participants felt that the skill of the Chinese medical practitioner is crucial to the treatment and prescription of medicine. This belief can be traced back to lay knowledge about Chinese medical practitioners. One participant shared his experiential knowledge on Chinese medicine. He said that the calibre of Chinese practitioners post 1949, was much improved since the modern Chinese medical practitioners receive formal education. However, he gave an account of Chinese medicine as practised in Hong Kong, detailing the different types of practitioners and the impact of the 'master-disciple' relationship. It appears that the skills of the Chinese practitioner are not standardised as the training is based on apprenticeship rather than formal learning.

Chinese medical practitioners used to be COOKS! (*his emphasis*) Pantry hands, they help out with picking the ingredients according to the prescription chit. Ground the ingredients to a fine powder, roast it. Then

familiarise themselves with the medicine. He would do that job for about one or two years and once he becomes *samgwai* (number three) the Chinese medical practitioner of the medical shop will assess the young man. And if he feels that the young man is intelligent, he will ask the assistant if he wants to be an apprentice. He will offer to teach him the skills of the trade. If the master's skills are good, he [the helper] will be by the side of the doctor observing. That is how he gathers his experience.

Besides having the necessary skills to practice Chinese medicine, Chinese practitioners were also expected to have the relevant equipment for biomedical checks. These biomedical checks include electro-cardiograms (ECG) to assess heart function, capillary blood monitoring machines and a urine dipstick for monitoring sugar in the urine.

However, none of this monitoring equipment is available at Chinese medical practitioners' clinics. One participant who had diabetes for 20 years said that only doctors trained in Western medicine could monitor and confirm if anything was wrong with her heart, as they had the necessary machines and knowledge:

The doctor checked my heart; it's only the Western doctor who can confirm it. I need to [have my heart] checked, once every 6 weeks, and if it get worse then it's checked every 2 weeks. (Yee, 75, Female, Birmingham)

Another participant revealed that when she went back to Hong Kong on holiday, she consulted a Chinese doctor trained in Western medicine rather than a Chinese-trained doctor as the former had the equipment to provide a comprehensive medical report of her health status:

We did the check and [paid] HK\$6000 for it. Western trained doctors have the equipment. Nothing wrong with my heart, blood pressure not a problem, triglycerides is slightly high. (Wong, 53, Female, Leeds)

Thus far, I have demonstrated that poor opinions about UK Chinese practitioners were based on a combination of personal experiences and hearsay. Many felt that UK Chinese practitioners lacked the appropriate skills, knowledge of, and equipment to deal with diabetes. Participants believed that skills, knowledge and equipment required to manage diabetes were exclusive to medical practitioners trained in Western medicine. Healthcare professionals in

the NHS use various monitoring devices and biomarkers to assess the progress of the participants' illness. This method of illness management was viewed by many participants as using objective markers of health and illness, compared with the traditional method of pulse diagnosis used by Chinese medical practitioners. Perhaps long periods away from their country of origin have contributed to their confidence in Western medicine. This might explain why many UK Chinese diabetics felt that Western practitioners were better suited to manage and advise them, rather than Chinese practitioners.

### **9.3. Discussion**

According to a national survey in the USA, there is a general perception that Western medicine is effective in controlling blood sugar levels and so there was no need for other therapies (Yeh et al., 2003). However, in a review article Lee reported that most Chinese people in Hong Kong have confidence in Chinese medicine. He reported that attitudes of Chinese people in Hong Kong towards Chinese medicine included a general perception that it:

- is better than or as good as Western medicine,
- has fewer side effects,
- cures the cause and not the symptoms of disease, and
- is good for treating certain diseases.

Broadly speaking, many Chinese people are of the opinion that Chinese and Western medicine are both of use, and that for certain diseases Chinese medicine is superior to Western medicine. Consequently, it was common for Chinese people in Hong Kong to seek medical help from both Western and Chinese medicine either simultaneously or consecutively, finally settling on the stream of medicine which offered the desired outcome (Lee, 1980). Similar views on the use of Chinese medicine by Chinese people are reported from Canada and the UK (Sproston et al., 2001, Anderson et al., 1995, Gervais and Jovchelovitch, 1998).

Studies on the use of medicine amongst migrant populations show that choice of treatment is based on cost of therapy and the type of illness (Wu et al., 2007) and lay understanding of illness (Gervais and Jovchelovitch, 1998). Central to these factors was trust in the medicines and those delivering the treatment. Rao (2006) reported that many of his participants were not only sceptical about the effectiveness of Ayurvedic medicines in the USA but also the credibility of the practitioners. Participants in Rao's study echoed the same concerns as in my study:

There are so many practitioners here claiming to be [...] experts. But you don't know [...] if they are genuine. In India you always knew someone who had gone to a practitioner. So you got your information from them. But here it is difficult. (Rao, 2006:161).

In my study, the use of Chinese medicine by UK Chinese with diabetes is seen to be linked to trust in Chinese medicine and those practising it. As is evident from other studies, trust in a physician is based on the expectation that the physician will act in the patient's best interest i.e. 'to put their medical needs above all other considerations when treating their medical problems' (Kao et al., 1998:683). Recent health surveys in the USA ( $n= 961$ ) and Sweden ( $n= 27\ 963$ ) found that low trust in the healthcare system is associated with poor self-rated care (Lindstrom and Mohseni, 2007, Armstrong et al., 2006). Likewise, research has reported that trust in one's physician is positively related with self-reported health status and symptom improvement (Thorne et al., 2004). Since trust is the core component of therapeutic partnerships, it would follow that patients with high levels of trust have better outcomes than those with lower levels of trust. My participants said that they trust Western medical practitioners more than they trust Chinese medical practitioners for the treatment of diabetes. However, the prevalence of diabetes-related complications shows that trust did not yield the desired results of better illness management.

Beyond treatment choices and trust is the element of length of stay in the adopted country of choice. It was clear from the comments in the focus groups and at the interviews that years of domicile in the UK and experience of using the NHS had made it easier for the participants to accept Western medicine in the treatment of diabetes. This does not mean that they would not use Chinese

medicine. On the contrary, it was articulated during both the focus group discussions and individual interviews, that given the choice they would try both traditions of medicine. The decision to use both streams of medicine is consistent with existing literature on motivations for use of mixed therapies which include beliefs about harms in medicines (Anderson et al., 1995, Chan, 1991, Chesla and Chun, 2005). Hence, users feel that the use of western medicine can be supplemented with non-biomedicine for a superior therapy.

Embedded in the element of trust is the notion of hope – wishful thinking that a new drug will be discovered to eradicate diabetes or a ‘good’ doctor will provide the cure to diabetes. Some participants had great faith in and respect for ‘good’ doctors characterised as those giving the ‘right treatment’. Some hoped for a cure or an effective treatment in the future. Both lay and medical literature attest to the importance of hope as part of the responsibility of illness management (Good et al., 1990). In oncology, relatively successful treatments had generated hope for cure in previously incurable diseases. Participants in my study also hope that a cure will be eventually available for people with diabetes.

The tacit knowledge that there is a great variety of Chinese medicine and the willingness to try it till a ‘good dose’ is prescribed indicates the strength of faith in Chinese medicine. Hare (1993) describes this attitude to medicine as ‘subscribing to a medical system as a quasi-religious system – something to believe in’ (Hare, 1993:40). This approach to medicine as a belief system can be attributed to patients no longer finding biomedical therapy useful and so they turn to Chinese medicine for hope of a cure. Although many participants said they did not use Chinese medicine for diabetes, they used it for minor complaints such as coughs and colds, skin problems and to seek a second opinion. This is a strong testimony of their faith in Chinese medicine.

#### **9.4 Summary**

This chapter has demonstrated that hope, trust and treatment outcomes and a general pragmatic approach to illness management are the driving forces behind the use and non-use of Chinese medicine in the UK. The general

consensus amongst my study participants is that the practice of Chinese medicine in the UK is disappointing and that there is a lack of confidence in the practitioners and the products they use. In contrast, significant trust and respect is given to Western practitioners, the basis of which is years of experience using the NHS, and the opinion that Western practitioners are competent and accountable for their actions. Although many expressed that they would like to be given the choice to access both Chinese and Western medical practitioners, the use of Chinese medicine in the case of diabetes was not an option as they believed that Chinese medicine could not offer a cure. Participants believed that just like Western medicine, Chinese medicine can only treat the symptoms (superficial) but not the cause (root) of the illness. This chapter has concluded the presentation of the main findings of the study. Data from the two British-born Chinese participants in the individual interviews is presented separately in Chapter Ten.



## ***Chapter 10: The British-born Chinese***

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### **10.0 Introduction**

As mentioned in Chapter One, only two British-born Chinese with diabetes were recruited for the study. In this chapter, I present the views of these two participants. Both were interviewed face-to-face on an individual basis. The same interview schedule was used as with the foreign-born Chinese participants. The interviews were held in English as both spoke very little Cantonese. Extracts of their views are therefore presented verbatim rather than in translation as with the foreign-born UK Chinese.

The information is delivered in five broad sections. Section 10.1 provides a background to British-born Chinese people in the UK. Section 10.2 presents their perceptions of diabetes. Their understanding of diabetes is a blend of biomedical concepts and their own ideas about diabetes. Section 10.3 describes their management regimes including the use of prescribed medicines, monitoring of blood sugar levels, engaging in exercise and exercising self restraint in their food intake. Section 10.4 presents their views and experience of using Chinese medicine for diabetes. They believe Western medicine is the treatment of choice although Jeanie used Chinese medicine briefly when encouraged by her Chinese boyfriend. Their views about Chinese medicine and its practitioners were not positive, concurring with those of the foreign-born UK Chinese in this study. Section 10.5 offers a discussion of the findings.

### **10.1 Background**

In comparison with the number of British-born Indians and Africans, the population of British-born Chinese is smaller. Of the 247 000 UK Chinese, those who were British-born accounts for just 38%, with the majority aged between 16-34 years old (Office of National Statistics 2004). With regards to the onset of diabetes, a typical age for diagnosis is 40 years of age and upwards. This accounts for the lack of British-born Chinese with diabetes. The largest number

of British-born Chinese is said to be found in Liverpool and were born between the 1950s and 1970s. Those born in the 1950s are mainly children of mixed marriages, whilst those born in the 1970s and after had two Chinese parents (Benton and Gomez, 2008:331). This information concurs with the background of my two participants, Tony and Jeanie who are both offspring of Chinese parents and were born in the 1970s and after. British-born Chinese are generally highly educated, socially mobile and represented in various professions (Benton and Gomez, 2008:1). For example, in my study one is an accountant and the other an undergraduate student.

A typical experience might follow the following pattern: a male migrant worker leaves his wife and family behind while he works in the UK. Later, due to increasing demand for Chinese labour, his wife joins him, leaving their children to be looked after by their grandparents. When the parents become financially established, they send for their children to join them in the UK. Soon, they realise that their children have problems adjusting to living in the UK (Watson, 1975). Subsequent migrants decided to abandon the 'grandparent socialisation' (Watson, 1977:201) to minimise their children's future problems of integrating in the UK. They opted for their children to be raised in an environment that is alien to them but beneficial for their children's future in respects such as language proficiency and job opportunities. These British-raised Chinese children would subsequently have siblings born in the UK, making them British-born Chinese.

Having their family with them was an advantage as spouses and children provide ready labour and keep the costs of running a business low. Recent studies report that young Chinese children felt frequently obliged to 'help out' (Song, 1997:345) in the daily running of the family business. Duties included food preparation, counter service, dealing with English speaking clients and legal and financial matters. In addition, they also act as interpreters for their parents at the doctors.

Significantly, the 'hierarchical order' of Chinese family dynamics gradually changed as their children were given social roles that conventionally belonged to their parents. These included dealing with figures of authority such as doctors

and legal personnel. One Chinese participant in a study conducted by Gervais said:

Traditional family, father on top, mother below, then the children [...] my father [...] he's the ultimate decision-maker (Gervais and Jovchelovitch, 1998).

Song (1997) found that many British-born Chinese whose family own a restaurant or take-away shop spoke about being categorised as a 'good' or 'bad' child by family members. A good child helps out in the shop whilst a bad child does not. The degree of involvement in the family business was seen to be implicitly linked to affinity to or rejection of Chinese heritage. Song's findings echoed those found in Parker's study (1995) where young British-born Chinese narrated their negative experiences of working in their parents' take-away shops and their encounters with English-speaking customers. Both authors reported that the 'take-away experience' had led them to distance themselves from their past negative experiences and its associated culture including future recourse to use Chinese medicine.

Other indicators of the British-born Chinese desire to distance themselves from their Chinese environment can be deduced from their lack of ability to converse in Chinese (Li and Milroy, 1995). In a study on a Chinese community in Tyneside, UK, Li and Milroy presented data on their speech interaction. Whilst parents used Chinese to speak to their children, the children's replies were invariably mainly English, interspersed with a Chinese word or a clause in Chinese. The following is an example of an interaction between mother and child about dinner (A=mother; B= daughter):

A: *Oy-m-oy faan a?* Ah Ying a? (Want some rice?)

B: (no response)

A: *Chaaufaan a. Oy-m-oy?* (Fried rice. Want or not?)

B: I'll have some shrimps.

A: *Mut-ye? Chaaufaan a.* (What? Fried rice)

B: *Hai a* (OK)

(Li and Milroy 1995:288)

A sign of disengagement with Chinese roots may be reflected in a mistrust of Chinese remedies. In an exploratory study on oral health beliefs in Leeds, Kwan and Williams (1998) reported that first generation Chinese said their children refused to use Melon Cream for toothache, and that they expressed disdain and mistrust of Chinese remedies. Similarly, a study of Chinese health beliefs in London by Jovchelovitch and Gervais (1998) inform us that first generation Chinese lamented the strained relationships with their offspring and their lack of knowledge about Chinese culture and a reluctance to learn the language.

Against this background, I present the views of my two British-born Chinese participants, Jeanie and Tony who are diagnosed with diabetes. Both requested a copy of the interview questions. Copies of their written responses are found in Appendix 17 and 18 respectively. In addition, Lana, a foreign-born UK Chinese was offered and agreed to give a written response to the interview questions. This is found in Appendix No. 19.

## **10.2 Perceptions of diabetes: Concordance and dissonance**

Both participants' knowledge of diabetes was similar to the medical view. They knew that diabetes was linked to failure of the pancreas to produce insulin. They suspected that excessive thirst, frequent urination and loss of weight were signs and symptoms of diabetes. The absence of a cure and the need for prescribed medicine were acknowledged as the nature of diabetes. These are key differences in their perceptions of diabetes compared to their foreign born diabetic counterparts.

Deviations from the medical understanding of diabetes include drinking water to dilute the sugar content in the body and that lack of insulin causes a rash on the body:

Excessive thirst because you are trying to wash the sugar out of your system, so you are drinking lots of liquids. And also pins and needles in the night which is due to blood circulation problems. (Tony, 50, Male, London)

The main reason I went to the doctor was I ended up with a rash. They say the lack of insulin in your body produce some sort of rash in your body. I had a friend who had it. It had something to do with sugar. She's always on sweets or sugary drinks. So I was actually drinking more sugary drinks during that period. (Jeanie, 21, Female, Teesside)

Similarities in their accounts of diabetes include their description of the symptoms of diabetes, its chronicity and the lack of knowledge about diabetes. Both recalled insatiable thirst, frequent urination and loss of weight before a diagnosis of diabetes was confirmed by their general practitioners. They felt that the healthcare professionals did not explain adequately the nature of the illness. As a result they had to find out about diabetes themselves. After diagnosis, they believed that eating without delivering an injection of insulin or injecting a dose of insulin without having food was an irresponsible act, because of the effect of food and medicines on blood sugar levels. Whilst they did not express the desire of a cure, they hoped for a new form of treatment for diabetes - one which is less troublesome than the current regime. Thus, both participants recognised and accepted the use of prescribed medicine to control blood sugar level.

Differences in their descriptions of diabetes include symptom recognition, reasons for the symptoms, and their understandings of the effects of low and high blood sugar levels. Jeanie suspected her symptoms were linked to diabetes and this was confirmed when she searched for information via the Internet. However, her subsequent behaviour of taking more sugar because a friend who has diabetes takes sugar demonstrates that her alleged understanding of diabetes did not translate into rational behaviour. Tony, on the other hand felt that taking too much sugar in the form of drinking many bottles of coca-cola contributed to his onset of diabetes. Unlike Jeanie, Tony admitted that he did not recognise the symptoms of diabetes until it was 'spotted' by his doctor.

In terms of understanding the effects of uncontrolled blood sugar levels, Jeanie is aware that persistent high blood sugars lead to blindness. On the other hand, Tony did not talk about the repercussions of sustained high blood sugar.

Instead he focused on the immediate effects such as feeling ill, needing lots of fluids and frequent urination. In addition, he said that low blood sugar levels lead to feelings of dizziness, sweating, feeling hot and flustered and the need to eat something sweet.

### **10.3 Management of diabetes: 'I know what I'm supposed to do but...'**

#### **10.3.1 'It depends on how much you eat'**

Controlling fluctuations in blood sugar levels was their main concern and challenge. Being diabetic meant that their blood sugar levels were affected by types and timings of food intake. Insulin had to be injected on time to control blood sugar levels post intake of food. Initially, both endeavoured to maintain a strict dietary regime by eating on time regardless of whether or not they felt hungry:

Having to eat three meals a day when I'm not actually hungry. I get quite frustrated especially when I know people do not eat at like half past six every day! (Jeanie)

I would often have to eat when I wasn't really hungry. You're just eating for the sake of it. (Tony)

Like many diabetics, with the passage of time, they learnt what they 'can get away with and what they can't'. In addition, they allowed themselves a degree of slack by indulging in eating sweet foods and making adjustments in their meal times:

You get used to it; understand about it a bit more, what you can get away with and what you can't. Oh *tauh shik!* Yeah, yeah, when you sneak [and eat] a bit of chocolate cake, you think, 'One bite is not going to hurt and you end up taking the whole thing!' (Jeanie)

Particularly [at] work, people tend to buy cakes [to] celebrate. I know I shouldn't. You have to be very discipline, that's not easy. (Tony)

Strict adherence to maintaining blood sugar levels between the ranges of 4-8 mmols gradually relaxed as both 'got used to it (diabetes)'. In particular, both admitted to not keeping diabetes under control as indicated by fluctuations in blood sugar levels. To avoid experiencing symptoms of hypoglycaemia, both kept sugar levels high:

I don't think I'm that well controlled because my blood sugar levels do go up and down. I don't often have a problem with it being low. I tend to be more conservative. I tend to eat more than I should. I run high; neither is a good thing. (Tony)

Because of exams and all I haven't been managing it too well and so they've been going quite high, over the 10s and 12s. It's getting tedious to do it all the time. I kept quite good records [initially] but not anymore. (Jeanie)

Thus, both the British-born Chinese I interviewed claimed that they generally made efforts to control their diabetes, with the occasional slips due to work or exams. Meals were sometimes delayed and sugar levels fluctuated. They were aware of what to do in the event of hypoglycaemic attacks, carrying glucose tablets or chocolate bars when required.

### **10.3.2 Medical regime: No other option for the time being**

When asked how long they will need their medications both said that medication was for life as there is no cure for diabetes. However they expressed hope for new treatments:

I'm just hoping something new comes up and then I won't have to do that for long. The next 2 years or something like that. They said they've got these beta cells that you can inject. (Jeanie)

I have read things like pancreas transplant and insulin pump. I suppose you can't bring in new treatments without it going through risk assessments. (Tony)

Their daily routine was centred on their medical regime:

Get up at half eight, I'll eat breakfast and do my injections and probably go back to sleep. Wake up at about half eleven, have lunch, go to lectures. About half past six I'll have dinner and do my other injection before meals. I monitor my blood once in the morning, at lunch, dinner and before I go to bed. (Jeanie)

Tony described his medical regime as a difficult way of life:

It's a burden, really. The regime is 24 hours; injecting 4 times a day, blood testing twice a day. It gets in the way. If you go for a meal, you have to go to the bathroom to inject. It's not easy to adapt. You have to adjust. You can't just go out; you have to take these paraphernalia with you.

Both chose a change in their medical regime by the time of the interview i.e. from four injections a day to two a day. Jeanie chose the two injections a day regime because of fear of pain from injections whilst Tony felt that twice a day injections gave him freedom to eat when he wanted. This reduced dosage is contrary to the recommendations of the UKPDs and the DCCT studies mentioned earlier which demonstrated that superior blood sugar control can be achieved through having injections four times a day over twice-daily insulin injection regimes.

### **10.3.3 Illness-management responsibilities**

These include performing self monitoring of blood glucose levels (SMBG), attending follow-up appointments, and being pro-active in seeking information on illness. In contrast to the foreign-born UK Chinese with diabetes, Jeanie and Tony demonstrated pro-active management styles, in particular to their information seeking behaviours. They searched for information on diabetes from a variety of sources such as the Internet, pamphlets in clinics, specialist magazines such as 'New Balance' for people with diabetes and friends. Tony felt that he understood the illness better after he obtained additional information himself. He stressed that access to information is only possible for those who are literate:

The diabetic clinics give you a lot of material particularly when you are first diagnosed. But what's really absent is that there is not much information



after. You have to search it yourself, pick up the various pamphlets that are in the clinics. You'll have to access that kind of information. The Diabetic Magazine '*The New Balance*', I used to subscribe to it. It gives you an insight into what the problem is.

By the time of the interview, Tony had stopped subscribing to the magazine as, in his opinion, there was no new information to be had. Similarly, Jeanie was actively searching for information about diabetes pre and post diagnosis. She used the Internet to find out more about diabetes and blood testing advice:

I knew something was wrong so I looked online and it all led to diabetes. When I was first diagnosed, I wanted to find out more about it and just went on the forum [online] to ask a few questions. I read online that if you wanted an accurate blood test, do it about two hours after you eat. I don't really do that.

Not all information obtained was acted upon as shown above. Jeanie said that she would check her capillary blood sugar level before meals so that she can adjust the amount of insulin required. Given that the blood sugar level rises after eating, she did not see the point in checking it after meals.

With regards to engagement with follow-up services, they provided a full account of what happens at the clinics. They recounted having their eyes and feet checked, the consultation being a very 'quick clinic' and an expectation that the patient would inform the healthcare professionals of any abnormalities. Significantly, they shared a similar medical vocabulary and understanding of the services. For example, they are aware of eye testing for detection of retinal damage and examination of feet to detect diabetic neuropathy.

Tony's account of diabetes and its treatment demonstrates compatibility of interaction between patient and healer:

I understand it from the Western perspective. It's the failure to produce insulin. I go to a diabetic clinic twice a year. They give you a long-term blood test; check your feet for circulation, just in case you lose your limbs and stuff. They do an eyesight test for retinal damage. It's a very quick clinic; they do basically a check list on various things

Similarly, Jeanie's account is packed with medical jargon as well:

Ketones [in the urine sample] and blood was high [with sugar] they did a finger prick test.

As presented in previous chapters, when healer and patients share the same language, treatment outcomes tend to be successful and meaningful.

#### **10.4 Chinese medicine: 'don't trust it', 'resist it'**

Neither considered using Chinese medicine for diabetes unless a Chinese person suggested it. They felt that its usage had to be linked to degrees of affinity to and proficiency in Chinese language and culture. Tony said he was unwilling to try even if suggested by his mother because he believed that using Chinese medicine was linked to faith and a good understanding of Chinese medicine, culture and language. He believed that this lack of knowledge of Chinese language and culture contributed to his resistance to try Chinese medicine.

Tony felt he understood what Western medicine did, but not Chinese medicine. He believed that this was because he could not speak Chinese or Cantonese and that the lack of fluency in the language contributed to not using Chinese medicine:

I'm not a fluent Chinese speaker, apart from a few basic Cantonese sentences. I think that would impact on my use of traditional Chinese medicine. I've been born and brought up in the UK, [Chinese medicine] it's a bit more unknown to me really although I've taken various things like, Tiger Balm. I haven't come across people who advised me to use TCM for that particular complaint. It's easier for me to understand Western medicine rather than Chinese medicine. If I come across Chinese medicine and someone explained to me how it can alleviate the diabetic condition, then maybe I would have tried it. I think the Chinese medicine, traditional medicine is not [well] defined and a lot of it is done through faith. If you have an understanding of it, you can believe in it and accept them. My mother has never really said to me, 'Let's go and see a Chinese doctor.' I

would have resisted it really because I don't have an understanding of traditional Chinese medicine.

On the other hand, actual usage of Chinese medicine for diabetes was experienced by Jeanie. Close contact with parents and individuals with Chinese ancestry may account for her brief experience of using Chinese medicine. At the time of interview, Jeanie was in a relationship with a foreign-born Chinese boyfriend from the university. He encouraged her to seek help from Chinese medical practitioners saying that they might be able to 'fix it'. Jeanie turned to her parents for financial support to use Chinese medicine. Although Jeanie did not think that Chinese medicine could cure diabetes, she succumbed to her boyfriend's wishes as he said that she should not just accept the opinion of one group of practitioners:

My boyfriend said that bitter melon would help lower it. I actually had a bit of that. It's not nice at all. I went to *Herbal Inn* to see what they can do. He (the Chinese medical practitioner) spoke Mandarin and I went with my parents. My mum spoke a bit of Mandarin but she's not that good. I don't think they communicated that well and that doctor didn't really speak English. He prescribed some tablets and also this black liquid thing, quite bitter. It was the first 3 weeks after I was diagnosed. My boyfriend was like saying that you should maybe try some Chinese medicine. How could you be like just ACCEPT it! [and that I should] figure out ways to fix it.

Jeanie's experience of using Chinese medicine also revealed what some Chinese people think of UK Chinese practitioners. This was revealed through an altercation between her boyfriend and the Chinese practitioner. The content of the exchange is similar to the content revealed at the focus group discussions i.e. that Chinese medical practitioners in the UK are dubious practitioners:

He immediately said, 'Ah, that person is probably lying to you.' He went to *Herbal Inn* and asked questions. The doctor got quite offended saying he helps mainly English people and he's helping me because he thought I was a sad case, as my parents aren't around and that his stuff is for British people. The doctor said, 'If you don't trust me, then don't take my medicine.'

The uptake of Chinese medicine is often linked to informal usage in the forms of food cures or home remedies. This appears to be the case with Jeanie as her parents visit Hong Kong, their country of origin and presumably remain in contact with their social network. This may explain why Jeanie's mother took her to a Chinese medical practitioner to seek help. A significant other, like her boyfriend contributed to her consulting a Chinese medical practitioner. In contrast, Tony told me that he only visits his family occasionally, hardly speaks any Chinese and feels that he understands very little about the culture.

## **10.5 Discussion**

The main findings in the interviews with the two British-born Chinese include the similarity with the biomedical model in the understanding of diabetes and ways of self-management, and mistrust of Chinese medicine and its practitioners. Concordance with the biomedical model of diabetes and its management is indicated by their recognition of the need to adhere to guidelines on dietary management, engaging in physical exercise and compliance with medication. On the questions of the impact of being British-born Chinese and the use of Chinese medicine, and the difference in health-seeking behaviour, this study suggests that cultural affinity impacts on illness behaviour and uptake of Chinese medicine.

As mentioned in previous chapters, foreign-born UK Chinese differ in many areas with their healthcare professionals. They do not share a similar culture or language, and these discrepancies are barriers to communication. In contrast, British-born Chinese have a strong sense of being European while at the same time acknowledging their Chinese ancestry (Parker, 1995, Song, 1997). Split between two cultures, they describe themselves as 'a banana. Because I am yellow on the outside and white on the inside [...] that's a perfect description of what I am basically. That's what they saw' (Gervais and Jovchelovitch, 1998:28). Physically marked out as Chinese persons, they are expected to be familiar with Chinese culture and be able to speak and understand the Chinese language.

This study confirms findings from previous studies that British-born Chinese struggle with both Chinese language and culture. Living in an English speaking country and having English friends contributes to the inability to engage in Chinese language and culture. It is therefore unsurprising that when confronted with an illness, recourse to Western medicine is the first choice of therapy. Chinese medicine, in contrast to their parents, appears an alien form of medicine. Its usage is perceived as requiring one to be fluent in Chinese language and culture.

Being predominantly English speakers, many British born Chinese resort to code-switching to communicate with their parents (Li and Milroy, 1995). They show disdain for Chinese health beliefs (Jovchelovitch and Gervais, 1999) and grapple with issues around self-identity (Parker, 1994). These are arguably indices of disengagement with *Chineseness*. A strong sense of *Britishness* among British-born Chinese may explain their ease of understanding of diabetes and its management requirements. More importantly, close affinity with the values of the healthcare service approach to illness management enabled them to accept help and advice from healthcare providers.

Prior to the study, I presumed that any Chinese person growing up and living with Chinese parents would be familiar with its language and culture. Parker (1994) reported that UK Chinese family dynamics were governed by economic activities with their energies focused on food preparation, customer demands and the overall management of the business. Interactions between family members were brief and business related. Much of what young Chinese knew of their world around them was influenced by their peers or older siblings. Transmission of values from parent to child is very much limited by the nature of the parents' occupation and the impact of their family business on family relationships. It follows that transmission of Chinese concepts of health, illness and medicine is equally limited. The interlocking relationship between illness, medicine and culture is evident in their understanding of illness and the use of medicine.

Gervais and Jovchelovitch (1999) reported that when a group of foreign born UK Chinese were interviewed about their health beliefs, they found that many

struggle to maintain their cultural identity. For example, a Chinese migrant recalled how her English mother-in-law insisted on taking the mother and child to the park for some sun and fresh air after she gave birth in the UK. This contravened the Chinese post-partum practice known as 'sitting the month'. This entails being confined indoors for one month and during this time the child and mother should not be exposed to the outside elements. The Chinese migrant mother in this case followed her English mother-in-law's wishes but subsequently complained that she suffered from rheumatism after contravening the Chinese practice of confinement. An illness episode potentially seriously challenges basic cultural values and the allegiance to one's own conventional practices. Nonetheless, foreign born Chinese may choose to use both streams of medicine separately or at the same time as a pragmatic choice, and still fiercely retain their cultural identity.

However, amongst British-born Chinese, such events do not produce this sort of conflict. British-born Chinese have been reported to be more integrated with the values and culture of the host community compared with other ethnic minority groups. The recent information from the ONS (2004) informs us that many UK Chinese describe themselves as British Chinese. This is significant to this study as it helps explain the data i.e. that they speak the same language as the healers and those working in the healthcare structure. It also explains why they think that Chinese medicine is alien and that its practitioners are dubious. Chapter Eleven, which follows, presents the conclusion to the study.

## **Chapter 11: Conclusion**

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In this final chapter, I provide a summary and evaluation of the research. This information is delivered in five sections. In Section 11.1, I revisit the research questions presented in Chapter 1.1 and provide answers based on the findings presented in this thesis. In Section 11.2, I discuss the strengths of the study. Section 11.3 presents some limitations of the study. In Section 11.4, I present recommendations for future studies and Section 11.5 gives a brief closing comment on the study.

### **11.1 Revisiting the research questions**

The three main research questions posed in Chapter One were:

1. How do foreign-born UK Chinese people manage diabetes?
2. How do family members and social networks influence the use of Chinese medicine in the management of diabetes?
3. How do mainstream healthcare structures influence the management regimes of UK Chinese people with diabetes?

I also posed two further questions relating to British-born Chinese:

4. whether there were differences in health-seeking behaviour between foreign-born Chinese and British-born Chinese people, and
5. whether being British-born impacts on the decision to use Chinese medicine?

In relation to Question One, the central question of the research, I found that UK Chinese with Type 2 diabetes were aware of the three pillars of diabetes management as prescribed by Western healthcare professionals; diet, medicine (if required) and exercise. In practice, however, many participants said that they struggled to make the lifestyle changes required to keep diabetes under control.

There were practical issues in the working lives of many of the participants which made it difficult for them to implement the changes recommended by healthcare professionals. However, it became evident in analysing the research findings that the difficulties they experienced were not simply a result of their practical situations. In particular, a central finding of the research was the extent to which my participants' perception of diabetes was heavily influenced by the concepts of health and illness derived from traditional Chinese medicine, and the implications this had for their understanding and management of diabetes. These implications can be seen in relation to each of the three pillars of diabetes management recommended by healthcare professionals, diet, medication and exercise.

This was particularly significant in relation to dietary control. When diagnosed with an illness, making dietary changes was expected by participants. However, these did not necessarily correspond to the changes recommended by healthcare professionals. Amongst foreign-born UK Chinese, dietary changes entail a cultural practice called *gaihauh*, a strict regime which many failed to sustain. *Gaihauh* was believed to be the most effective way of dealing with diabetes, everything else was considered 'a bluff'. The cultural practice of *gaihauh* is not well understood by dieticians, and this was reflected in their dietary advice to the participants. For example, telling them to reduce their intake of confectionery items such as cream cakes and chocolate made little sense to the participants, who typically preferred Chinese sweet savoury items such as steamed pork buns. Since participants do not normally eat the food items the dieticians mentioned, they continued with their previous diet. A mismatch took place between what information patients expected and what healthcare professionals provided.

Another issue regarding dietary advice was that healthcare professionals typically recommend the eating of small meals at regular intervals. This fits poorly with the cultural logic of *gaihauh*, which implies that one should eat less and avoid specific food items that were believed to cause diabetes, rather than eat small and frequent meals. The advice was also difficult to follow given the practical working circumstances of participants, who are typically working long



hours at a stretch with little opportunity to break for carefully structured meals at regular intervals.

Participants also found it difficult to understand that diet and exercise alone could be seen as an appropriate treatment, without also taking medicine. In the Western medical tradition, not everyone diagnosed with diabetes is seen as requiring drug therapy. This is because for many people it is expected that diabetes can be kept under control through dietary and lifestyle changes such as engaging in physical exercise. Medicine is prescribed when blood sugar levels are poorly controlled or persistently high despite dietary and lifestyle changes. However, the use of medicine as part of, and not the entire management of, diabetes was poorly understood by the foreign-born UK Chinese participants in my study. They expected that a medical diagnosis would necessarily involve being given medicine.

From the participants' perspective, they believed that medicine and the practice of *gaihauh* in combination can bring diabetes to an end, which was expressed as 'cutting the tail' of the illness. The close relationship between food, medicine and 'tail cutting' may explain why many participants were more interested in experimenting with food cures than in concentrating on keeping blood sugar under control, or maintaining a lifestyle that would delay the onset of diabetes-related complications. Dietary changes were enacted by the patients in ways that were culturally meaningful to them, but not always as healthcare providers expected.

Moving on to medication, the second of the three pillars, this was in some ways less problematic. All except one of the participants expected and accepted medication, either in the form of food items or pharmacological products, as part of being diagnosed with an illness. Given that taking prescribed medicine indicated legitimacy of the illness, compliance with medication was not a problem. In addition, one reason for taking prescribed medicine was that medicine and medical consultations were provided free of charge by the NHS.

Thus the use of medication for diabetes was not an issue. What was problematic for foreign-born UK Chinese was that medicine taking did not

provide the desired result of halting or eliminating the illness. This expectation of the use of medicine emerged when participants shared their views on Chinese medicine. Underlying their expectations about the efficacy of medicine is that within the Chinese medical framework, the use of Chinese medicine is to bring the illness to an end, or to redress imbalances caused by illnesses. This is still generally believed despite there being no evidence that Chinese medicine can effect a cure for diabetes. Many participants nevertheless believed that with time the use of Chinese medicine would gradually remove the root of the disease, i.e. the causative agent, in other words that it would 'cut the tail' of the disease.

Western medicine also cannot provide a cure for diabetes; it can only ameliorate progression of the illness. Since Western medicine will not give participants their desired results, i.e. curing the illness, it is understandable that some UK Chinese experiment with non-biomedical approaches and adopt an empirical orientation towards treatment regimens. In this respect and others, the results of my study illustrate the influence of cultural concepts on illness perceptions, its management and the subsequent use of various types of medicine, Western or Chinese.

Another significant point regarding medication was discussed in Chapter Eight. As we have seen in the thesis, many participants relied on medicine to keep diabetes under control, rather than engaging in dietary and lifestyle changes. This resulted in a transfer of responsibility for illness management to healthcare professionals, which is discussed further under Question Three.

In relation to the third pillar, exercise, we have seen in the thesis that my participants found the advice to engage in physical exercise puzzling. The majority of the participants were manual workers. They were often on their feet all day and could not understand why they were being told to exercise. They felt that they needed to rest since they had this illness called diabetes. More exertion could only compound their illness and further weaken their constitution. Here again, there is a disjuncture between what constitutes a meaningful and therapeutic regime from the point of view of healthcare professionals and what makes sense to the participants within their own lifestyle and cultural practices.

The above has shown the significance of the patients' understanding of the disease for the self-management of diabetes. Being diagnosed with a long-term illness meant that the patients were faced with the need to negotiate with the UK healthcare system on a regular basis. However, there was a lack of effective communication between patients and healthcare professionals. We have seen how the information provided by healthcare professionals was frequently culturally incongruent and so poorly understood. In practice, many participants combined elements of Chinese folk knowledge with biomedical knowledge in order to make sense of diabetes. This blending of information was probably unavoidable, but it led to confusion, at any rate from the point of view of biomedical treatment. Thus, although participants said that information about diabetes was provided, many could not remember much of what was said, suggesting that not all of what was said about diabetes was understandable or memorable. Often, too, information was given at inappropriate times e.g. at the time of diagnosis when participants were overwhelmed by the disclosure of an illness they did not expect. It also appeared that the advice and explanations provided by biomedical practitioners were at times inconsistent. At other times the advice and explanations given were not assimilated, because they contradicted the participants' lay knowledge of illness causation and illness management.

Effective and meaningful health-related information can be conveyed when healthcare professionals spend time listening to patients. As mentioned in my thesis, Helman (1996) highlighted that at a clinical encounter, both patients and healthcare professionals bring their own ideas about how an illness should be managed. This indicates that if healthcare professionals want to help patients in their self-management regimes, they need to start with listening and understanding what their patients' ideas are and organise their health education from the patients' worldview. I believe that working in partnership with the patients can be an effective way of helping patients in their self-management regimes.

The issue here is not so much that dieticians need information, or to be educated on the various dietary habits of different cultural groups, or that there is a need for a list of more relevant food items and other advice information to

be given to Chinese people with diabetes. Clearly language difficulties are real and need to be addressed, and the provision of culturally inappropriate information should be avoided. However, the best way to ensure that culturally congruent information is delivered is to listen to what the patients themselves have to say. The analytical approaches underpinning this study demonstrated the importance of listening, observing non-verbal communication behaviour and, finding out what patients think of and how diabetes should be managed.

Question Two was a subsidiary question regarding the role of family members and social networks on the use of Chinese medicine in the management of diabetes. Both focus groups and individual interviews provided considerable information in relation to this. There was extensive use of Chinese food cures, but a pervasive distrust of Chinese medical practitioners in the UK. Family members of participants with diabetes contacted friends and family members living outside the UK for advice on food cures and to seek medical opinion, both Chinese and biomedical, from medical practitioners from their country of origin. Some participants who could afford the cost, or who had family members who were willing to help, had Chinese medical products sent to them from outside the UK. In my study, while there was occasional use of Chinese medicine for other complaints, such as eczema, its use in relation to diabetes was limited to two people in the sample, one of whom subsequently stopped because of the expense associated with long-term use. One foreign-born UK Chinese also used Chinese medicine (as distinct from Chinese food therapies) in conjunction with Western medicine.

As the data presented in the study demonstrates, there was a variety of opinions expressed about the value of Chinese medicine, both in the focus groups and the interviews. However, it is likely that more participants might have used Chinese medicine if it were provided free of charge. The question of cost appeared to be a significant factor, since unlike Western medicine, there are significant costs involved in obtaining Chinese medicine.

Question Three was about the effect of mainstream healthcare structures. On the positive side, the availability of free healthcare led to a high level of engagement with the services available in the NHS. The provision of free

medicine and healthcare services contributed to the participants' engagement with the healthcare providers despite the cultural and linguistic barriers mentioned in the thesis. This also enabled the NHS to monitor the condition and intervene when further complications arose. However, as noted above under Question One, the availability of free medical care also gave rise to a transfer of 'ownership' of the illness from the patient to the healthcare professionals, and a false sense of security on the part of patients as to the ability of healthcare professionals to monitor and treat their condition effectively. Put otherwise, the availability of free healthcare, along with the limited surveillance which they are able to provide, can lead to the responsibility for the management of the illness being transferred to the healthcare professionals.

From the point of view of the Western healthcare providers, it is worrying that some participants relied on healthcare providers to manage their diabetes-related complications, such as offering cardiac bypass surgery and renal dialysis to those with poorly controlled diabetes. The shift of illness responsibilities to healthcare professionals runs contrary to the principles of self-management. Whilst healthcare professionals expect patients to internalise the Western medical understanding of diabetes, and consequently to take on the responsibility of keeping diabetes under control, in reality patients transferred the onus of illness management to healthcare professionals.

Questions Four and Five refer to British-born Chinese, and as noted the data here is restricted to two interviews. While these interviews provided much interesting information, they do not really provide the data for meaningful answers to the two questions posed. As far as health-seeking behaviour was concerned (Question Four), what was striking for me was that the two British-born Chinese were both aware of diabetes before they were given a clinical diagnosis. 'Diabetes' was already a meaningful disease label for them, and they approached their general practitioners to confirm their suspicions that they might have it. This was not the case for any of the foreign-born Chinese, who were generally diagnosed after family or friends suggested they consult a doctor for their symptoms, or when consulting the doctor for a completely different reason. In most cases they did not expect a diagnosis of diabetes and were taken by surprise when told that they had the disease. In relation to the use of

Chinese medicine (Question Five), it was clear that both of the British-born participants felt distant from Chinese medicine because of their lack of fluency in Chinese language and culture. One of them used Chinese medicine because she had been encouraged to do so by her foreign-born Chinese boyfriend.

### **11.3 Strengths of study**

The preceding sections give an overall view of the findings of the study, with particular reference to implications for biomedical approaches to diabetes among this population. In the next two sections, I evaluate some of the strengths and possible weaknesses of the study.

An undoubted strength of the study is the combination of using focus group and individual interviews to collect information for this research topic. Another strength was my success in recruiting what are, for a qualitative study of this kind, substantial numbers of participants: eight focus group sessions in Phase 1 and twenty-two individual interviewees in Phase 2. As the account in Chapter Three shows, while my position as a relative 'insider' was central to the success of the project in many respects, it also involved overcoming considerable challenges (see also below). Crucial to my success was my personal effort and persistence in engaging with the Chinese community in the primary research site enabling me to network throughout the UK.

The eight focus group discussions allowed me to gather the opinions, knowledge and problems facing UK Chinese with diabetes. These broad views enabled me to design meaningful questions for use in the twenty-two face-to-face individual interviews. More importantly, the focus group sessions facilitated access to individuals who have diabetes, and provided the basis for recruiting willing participants who would provide useful data for the research topic for the individual interviews. The invitation of friends and family members to participate in the focus group discussions encouraged a more open and lively discussion of experiences, eliciting both consensual and conflicting views on the use of Chinese medicine.

The face-to-face interviews with individual participants in Phase 2 of the study allowed me to pursue topics raised in the group setting. I was able to explore salient topics raised in the group setting with individual participants in their own homes or at a venue of their choice. At these private settings, participants spoke freely and shared their views without being challenged by their counterparts as reported in earlier chapters of this thesis. Significantly, at the individual interviews, participants felt free to verbalise their doubts and concerns regarding management and the use of Chinese medicine. For example, lay knowledge regarding inherited illness was verbalised without fear of ridicule, a personal family history of illness could be shared without fear of other members of the Chinese community knowing about it, and personal concerns about finances and other matters related to ill health could also be talked about.

Ethnic and cultural similarities between myself and the participants were pivotal in successful recruitment and collection of data. Knowledge of the cultural milieu and linguistic skills were two important elements required to undertake this study. Fluency in cultural and linguistic nuances facilitated ease of communication with participants. Significantly, being an 'insider' (De Andrade, 2000) facilitated access into the Chinese social network and recruitment of participants. In sharing the same cultural background, I was able to encourage participants to express their views of diabetes and Chinese medicine. In addition, my background in nursing and knowledge of Chinese language and culture strengthened my position to understand the illness experience, and carry out the subsequent translation and interpretation of the audio recordings. Consequently, intra-cultural communication difficulties were markedly reduced, data collection was greatly facilitated, and recruitment of foreign-born participants for individual in-depth interviews was achieved.

#### **11.4 Possible limitations of study**

In the following, I consider a number of possible weaknesses and limitations of the study. These are dealt with under the following headings: (i) the representativeness of the sample, (ii) the effects of the researcher's positioning in relation to the participants of the research, and (iii) the use of translation .

#### **11.4.1 The representativeness of the sample**

This is a qualitative study, not a quantitative one, and while the sample aims at representativeness of the subject population in a general sense, it does not attempt or claim to be fully representative of foreign-born UK Chinese diagnosed with diabetes in statistical terms. While considerable care was taken in relation to the recruitment of an appropriate sample (cf. Section 4.1), a couple of issues remain in relation to the recruitment that should be considered.

Firstly, in the sites other than the primary research site, recruitment was successful because of support from the middlemen. The use of snowball sampling for recruitment could contribute to bias as participants could have been coerced to take part as a sign of good will towards their friends or those who helped them in one way or another. For example, some participants might have felt obliged to take part out of gratitude for getting assistance with interpreting at medical consultations carried out by middlemen.

However, it is unlikely that this would have significantly affected the representative nature of the population, except in that the sample might have been biased to some degree towards people with an active and ongoing link to middlemen, rather than those who did not have such links. Given the range of issues that emerged in the focus group discussions, I do not believe that any



bias of this kind led to the exclusion of significant perspectives among the subject population.<sup>17</sup>

A second issue here is that the focus groups included both persons diagnosed with diabetes and accompanying family members. It might be suggested that the data is 'contaminated' by the presence of family members. In practice, though, there seems little reason to assume that there are significant differences in the understanding of diabetes, and its management between sufferers and family members, particularly their spouses. In fact, the presence of non-sufferers occasionally led to the introduction of additional viewpoints, e.g., in relation to the use of Chinese medicine. As is the nature of qualitative research, the data collected using focus groups is 'sketchy' (Agar and MacDonald, 1995) and can only provide broad themes, so that a systematic differentiation between the views of diabetes sufferers and family members is unrealistic.

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<sup>17</sup> A related issue, though not strictly a weakness in relation to the sample, was the process of obtaining information. The nature of informed consent has received increased attention recently (Barata et al 2006), and the practice of consent-taking, as it is currently recommended, may not be applicable to all populations. Indeed, taking consent in accordance with good research practice proved problematic in my study. This was because many participants had low levels of education. Low levels of literacy became evident at some of the focus group discussions when I handed out the Patient Information Leaflet written in Chinese. Many of the participants struggled to read the written Chinese script. To resolve this problem, Joanna, the assistant, offered to read the Chinese script in Cantonese, followed by an interpretation in *colloquial* Cantonese for participants to understand both the content of the Project Information Leaflet and the consent form. This meant that 'understood consent' (Bhutta (2004) rather than informed consent was obtained at the focus group discussions.

#### **11.4.2 The use of translation**

As the interviews were conducted in Cantonese, the data presented in this thesis are for the most part translations, not verbatim transcripts (cf. 4.2.6). This clearly introduces the possibility of loss of meaning and inaccurate translation. These were guarded against in a variety of ways in the research. A sample of translation was verified and checked for accuracy by a linguist. Another linguist was approached to do a sample of audio-sight translation. Both procedures indicated that the translations were generally reliable and accurate.

In addition, significant Cantonese terms have been given in the original wherever it was felt that the use of the translation alone would lead to significant loss of meaning. Here, my 'insider' status and knowledge of Cantonese dialect meant that I was aware of many of the nuances of language use that might otherwise have been lost. I believe that the use of translation provides a good balance between accuracy and accessibility, and that my degree of cultural sensitivity has meant that I have in practice been able to compensate for possible loss of meaning through translation.

#### **11.5 Recommendations for future studies**

This study highlights the impact of the patients' explanatory model of illness on the way they manage diabetes and their decision to use Chinese medicine as part of their management strategies. The explanatory model encompasses illness causation, duration, consequences and management strategies. These are common to anyone diagnosed with diabetes regardless of geography, race and culture. A meta qualitative analysis informs us that people with diabetes share similar experiences (Vermeire et al., 2007). The authors recommended that future research should be conducted on how to overcome obstacles pertaining to explanatory models of illness and management strategies.

Given the opportunity to continue with this study, I would like to conduct a longitudinal study over a one year period to detect any changes related to health behaviours, attitudes and explanatory models of illness and medicine. The main inclusion criteria would be UK Chinese newly diagnosed with Type 2

diabetes, i.e. within the last four years. This desire to carry out a longitudinal study is based on my observation that selected participants from the focus group discussions who were interviewed face-to-face at a later stage, offered different views between each interview session. In addition, a longitudinal study would provide a deeper understanding of the effect of daily events on management behaviours. In the primary research site, in the local Chinese supermarket, I happened to see various participants who took part in the study. They were happy to see me and volunteered information about their health. Since the interviews, one had had a toe amputation and another had become depressed, stopped working but had since recovered.

Within this time frame, I would endeavour to audio-record consultations between doctors and patients to uncover issues that emerge during the clinical encounters. In particular, I would like to obtain information on issues related to self-management. I would aim to obtain three audio recordings - baseline, first and second consultations, over a one year period. At the baseline consultation, I envisage that the physician will be revealing the diagnosis to the patient. At this initial consultation, I would audio record the content of interaction between the doctor and the patient, look out for how the information is delivered to the patient, what questions or concerns the patient had and how the doctor responded to the patient.

In the subsequent first and second consultation, I would be looking for information regarding discussions on self-management strategies. For example, I would be interested in information pertaining to diet, lifestyle and exercise. As part of the longitudinal study, I would invite patients to be involved in the design of a culturally congruent diabetes self-management regime. Data from this longitudinal study would be used for educational purposes, aimed at three groups of healthcare professionals, i.e. nurses, doctors and dieticians.

## **11.6 Closing comments**

I believe that my study provides both significant and practical insights into how diabetes is understood and managed by my main study population of foreign-

born UK Chinese, and that it is a valuable addition to the general literature on the cross-cultural understanding of illnesses such as diabetes. Key issues in this study, such as the lack of appreciation by my participants of the concept of chronicity (i.e. that there was no 'cure' for diabetes), and their consequent failure to live up to the expectations of biomedical staff in relation to self-management of their illness, are both important for the management of diabetes among this specific population, and are also likely to prove significant in relation to the explanatory models of many other culturally-specific populations.

For me, the most enjoyable part of my study was the focus-group discussions, in particular witnessing the candid information generated within these settings. As mentioned previously, data obtained from the focus groups provided broad answers to the research questions. In addition, it enabled me to design a set of questions to pose at the face-to-face individual interviews. At these encounters, I gathered information which was of a personal and sensitive nature touching on hardships, familial relationships and attempted suicide. The data from the individual interviews provided a fuller picture of what it is like to be Chinese and to live with diabetes and negotiate with a healthcare system that is culturally and linguistically different from that of one's country of origin.

Together, the two sets of data enabled me to achieve a rich and detailed understanding of how my participants made sense of and attempted to manage one of the most widespread and challenging of modern health issues. I hope that the results of my study will be found useful and illuminating both to social and medical scientists, and that they will assist healthcare professionals to deal with situations such as the growing prevalence of diabetes among UK ethnic populations more effectively, through greater sensitivity to and awareness of their patients' own understanding of their illness.

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-

## Appendix No. 1A Project information leaflet in Chinese



### 研究內容

題目：英籍華人如何使用中醫處理糖尿病？

#### 參與邀請：

本人誠懇地邀請您參與此項研究，該項研究由利茲大學提供贊助。參與者可以隨時退出並不必提任何原因。

#### 研究的目的：

從以往的研究中我們得知在英華人很少去看大夫或西藥。目前患糖尿病的華人數目日益增加。他們是如何對待疾病的呢？我們知道第一代英國華人往往採用中醫治療的方法，但對第二代來說，我們一無所知。這個課題將涉及英國華人中糖尿病患者的調查治療與管理方法的研究。

這項調查將採用小組面談和個人談的面談的方式。研究調查包括：

- A) 華人如何對待糖尿病
- B) 在英出生的華人后代在利用傳統治療糖尿病上受到什麼影響？
- C) 英國健康服務機構如何影響糖尿病患者的處理方法？

本人將會對您個人的情況保密。當研究項目結束時，所有的錄音帶將會被銷毀。在調查之前我將提供一份項目信息合同書。

感謝您的大力支持與合作！

英淑好

健康服務系

利茲大學

電話：0113 343 7186

## Appendix No. 1B Project information leaflet in English

School of Healthcare

Baines Wing  
The University of Leeds  
PO Box 214  
Leeds LS2 9UT

### Project Information Sheet



#### **A PhD study on the use of Traditional Chinese Medicine (TCM) in the management of diabetes mellitus by UK Chinese.**

##### **Invitation to participate**

I would like to invite you to take part in the above study. Please take some time to read the following information. You are free to change your mind anytime and no questions will be asked. This is a PhD study funded by the School of Healthcare, University of Leeds for which ethical approval from the relevant bodies has been obtained.

##### **The purpose of the study**

The study aims to investigate the treatments used by UK Chinese with diabetes. Studies have demonstrated a low usage of GP services and prescribed medication by the UK Chinese. This is worrying as diabetes is on the rise among Chinese people in the UK. It is also reported that among the first generation Chinese, Traditional Chinese Medicine is often used. However, little is known about its usage among British born Chinese. This study will investigate the role of Traditional Chinese Medicine in the management of diabetes by UK Chinese people.

##### **The research method**

A series of face to face interviews will be conducted. The first stage of the study will make use of focus groups interviews which will be held with carers, relatives and individuals with diabetes. The aim is to gather group views regarding the illness and to identify individuals for in-depth interview. The second stage of the study involves a face-to-face interview with individuals selected from the focus group interviews. Both types of interviews will last up to an hour and will take place in at your convenience. If you wish to take part in this study travel expenses will be reimbursed and you will be given a £5 gift voucher as a token of thanks.

If you decide to take part in the study, whatever you say in the interviews will be confidential. Your identity will remain anonymous in all published documents. With your permission, interviews will be tape recorded. Your permission will be sought to use your words and phrases in all publications (your identity will not be disclosed). The interview tapes will be transcribed by me and destroyed within one year. In accordance with regulations from the Department of Health, copies of the transcripts will be retained for 15 years after the study has finished. You will be provided with a copy of this information sheet and a consent form for your records.

If you have any queries, please do not hesitate to contact me on 0113 343 7186. Email: [chi6se@leeds.ac.uk](mailto:chi6se@leeds.ac.uk). Thank you very much for your help.

Version 4  
07/10/05

Professor Peter N McWilliam  
Dean of the School of Healthcare



## Appendix No. 2A Consent form in Chinese language



### 同意書

地點:

參加人員密碼:

研究題目: 傳統中醫治療糖尿病及其管理

研究者: 英淑好

本人已閱讀了有關的研究內容。

本人有機會與親戚朋友共同討論本課題研究內容。

本人了解有關的研究目的與參與目的。

本人了解有關這項研究的一切信息都會嚴格保守秘密。如果研究成果被發表,有關個人的詳情將被銷毀。

本人自願參與這項研究並了解可以隨時退出,不必給予任何原因,而且參與者的治療服務與法律不會受到任何不利影響。

面識錄音一定要征得您的同意並且會引用您的原話。

本人願意參與以上研究。

參與者簽名:

日期:

研究者簽名:

日期:

\*個持一份該同意書復印件。

## Appendix No. 2B Consent form in English

### CONSENT FORM

Location:

Participant Identification Number:

Title of research: **The use of traditional Chinese medicine in the management of diabetes mellitus by UK Chinese**

Name of Researcher: Sookhoe Eng

**Please tick  
to confirm**

- I have read the project information sheet for the above research study.
- I have had the opportunity to ask questions about the research study, and to discuss it with family and friends.
- I understand the purpose of the research study, and how I will be involved.
- I understand that all information collected in the research study will be held in confidence and that, if it is presented or published, all my personal details will be removed.
- I confirm that I will be taking part in this research study of my own free will, and I understand that I may withdraw from it, at any time and for any reason, without my medical care or my legal rights being affected.

I agree to take part in the above research study.

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Researcher's signature \_\_\_\_\_ Date \_\_\_\_\_

\*1 copy for participant, 1 copy for researcher

Version 1  
4/4/05

## Appendix No. 3 Receipt of voucher



### 参与调研人员的赠券收据凭单

此表为赠券收据凭单

请认真填写以下表格,以便您能领到为「使用传统中医治疗糖尿病」研究的五英镑赠券报酬。

以下“表格一”需要研究人员填写,请勿在上面书写任何字样。

“表格二”需您填写本人的姓名及职业等项目,并在最后签名。如果没有您本人的签字,系财务部门将不予办理,您将不能拿到该项酬金。

#### 表格一 (需研究人员填写)

姓名: 英淑好 (SOOKHOE ENG)
地址: RM. 317. BAINES WING. SCHOOL OF HEALTHCARE. UNIVERSITY OF LEEDS
职务: 博士生 (PHD STUDENT)
资金目的: 参加研究的酬劳费 (GIFT VOUCHER)

#### 表格二 (请您认真填写)

参加人员密码:
参加人员职务:
我确认已收到了 英镑赠券,我可以在 使用。
参加人员签名:

## **Appendix No. 4 Copy of topic guide for focus group discussions**

### **Focus group topic guide in Cantonese**

Introductory questions

1. Gaisui zigei 自我介绍 (*zi wo jieshao*)

Self- introduction

2. Pengsih ge yamshikh jaapguan haih matyeh? 谈谈你平时的饮食习惯。 (*tan tan ni pingshi de yinshi guan xi*)

What are your usual food and drink habits?

3. Gordak sikhmatt dui tongluibeng yauh matyeh bongjo? 你觉得饮食对糖尿病有什么帮助? (*ni jue de yin shi dui tangniaobing you shenme bangzhu?*)

How does food and drink help with your sugar urine illness?

4. Sikhmatt ho m hoyi dong yeuk yong? 你觉得饮食可以当药用吗? (*ni jue de yinshi keyi dang yao yong ma?*)

Can food and drink be used as medicine?

Transition questions

1. Lumfan chuentau, zicong yauhjo tongluibeng, neihge samwoud tongmaih yamsikh sauho matyeh yenghueng? 自从你患了糖尿病，你的生活和饮食受到了什么影响? (*zicong ni huan le tangniaobing, ni de shenghuo he yinshi shou dao le shenme yingxiang?*)

Think back, since you have sugar urine illness, how have your life and diet been affected?

2. Neih haih dimyeung hongzaih tongluibeng? 你是真么管理你的糖你的糖尿病? (*ni shi shenme guanli ni de tangniaobing?*)

How do you control your sugar urine illness?

3. Dong yisang gong neih yauh tongluibeng, neih yauh mouh hauhleuih taih zhongyisih denghaih heuih jaapyeuk? 当大夫告诉你你有糖尿病，你有没有考虑

看中医师或者用草药？ (*ni youmeiyou kaolui kan zhongyishi huozhe yong caoyao?*)

Since the doctor said you have sugar urine illness, have you considered seeing a Chinese medical doctor or going to the pharmacy for medicine?

4. Zhongyi haih bin fongmin hoyi bongjo gamdaih wan tongluibeng ge geiwuih? 你觉得中减低患糖尿病的机会吗？ (*ni jue de zhongyao keyi jiandi huan tangniaobing de jihui ma?*)

Can Chinese medicine help with reducing the chance of getting sugar urine illness?

Core questions

1. Yiqing toulooh dui gong Yinggwok ge zhongyi mouh lui danhaih wuih gaaihzhok taih zhongyi tongmaih yong zhongyeuk – dimgaih? 以前参加讨论的讨论者说英国的中医师没料担还继续看中医师还有用中药，这是为什么？ (*yiqian canjia taulunzhe shuo yingguo de zhongyishi mei liao dan hai jixu kan zhongyishi hai you yong zhongyao, zhe shi wei shemme?*)

Previous focus groups have said that Chinese doctors in England lack skill but that they would continue seeing Chinese medical doctors and using Chinese medicine, why would that be?

2. Peihyu neihdeih yigah haih zhonggwok fattgwok yauh tongluibeng, neih wuih taih zhongyisih denghaih saiyisih? 比如你们现在在中国发现你有糖尿病，你会看中医师后者西医师？ (*biru nimen xianzai zai zhongguo faxian ni you tangniaobing, ni hui kan zhongyishi huozhe xiyishi?*)

If you were in China and discovered you had sugar urine illness, would you see a Chinese medical doctor or a Western-style medical doctor?

3. Zicong yauhjo tongluibeng, neih minduih ge mantaih haih matyeh? 自从有了糖尿病你面对什么问题？ (*zicong you le tangniaobing ni miandui shenme wenti?*)

Since you have had sugar urine illness, what problems have you faced?

Closing questions



1. Peihyu Yinggwok jingfu gong zhongyi minfai waiyahn taih beng, neih wuih m wuih gaaizok taih sai yi? 假设英国政府说糖尿病者可以免费用中药，你会继续用西药吗？ (*jiashē yīngguó zhèngfǔ shuō tángniǎobīngzhě keyì miǎn fēi yòng zhōngyào, nǐ huì jìxù yòng xīyào ma?*)

If the government in England said that seeing a Chinese doctor is free, would you continue seeing a Western medical doctor?

2. Gaihsigan Yinggwok jingfu beih muih gor yahn yaat baat chihn leih quleih tongluibeng, neih wuih dim yong? 假设英国政府给你一笔钱管理你的糖尿病，你会真么用？ (*jiashē yīngguó zhèngfǔ gěi nǐ yī bǐ qián guǎn lǐ nǐ de tángniǎobīng, nǐ huì zhēnme yòng?*)

Hypothetically, if the government in England were to give you a sum of money to manage your sugar urine illness, how would you use the money?

3. Bin fongmin yilui fookmohk hoyi bongjo neih quleih tongluibeng? 目前英国的医疗服务哪方面帮助你管理糖尿病？ (*mùqián yīngguó de yīliáo fúwù nǎ fāngmiàn bāngzhù nǐ guǎn lǐ tángniǎobīng?*)

How can the healthcare system help you to manage your sugar urine illness?

## Appendix No. 5A Poster in Chinese

  
university of leeds  
school of healthcare

！！需要人員！！

使用傳統中醫治療方法治療糖尿病。

你是中國人嗎？

你是糖尿病患者嗎？

你是不是英籍華人？

你有没有親人或朋友患有糖尿病？

如果你有以上一種或多種情況，請與我聯系。

我是利茲大學健康服務系的博士生，目前在研究英華人患糖尿病的患者如何使用傳統中醫治療方法處理病情。這項研究將針對疾病以及護理人員共同處理病歷的方法。這項研究的結果將會設計到對在英華人糖尿病患者健康服務的計劃。

為感謝您的幫助，每位參與者可收到五英鎊的酬勞費。如果您有意參加，請儘快與以下地址聯系。

英淑好  
健康服務系  
利茲大學  
電話：0113 343 7186

## Participants wanted!!

PhD study- University of Leeds  
Using Traditional Chinese Medicine (TCM) in the management of  
diabetes

- Are you Chinese?
- Are you diabetic?
- Are you a British Born Chinese?
- Do you care for someone who is diabetic?

If YES to one or all of the above, I'd like to hear from you.

I'm a Phd student at the School of Healthcare (University of Leeds) currently investigating the role of TCM in the management of diabetes by UK Chinese. This research will provide a forum for people with diabetes and their carers to share their experience of managing diabetes. This study aims to provide information which will help in the future planning and delivery of healthcare services to the UK Chinese community. ( A £5 gift voucher will be given to all participants as a token of thanks).

If you are interested to take part in this study, please contact:

Sookhoe Eng  
School of Healthcare, Room 3.17, Baines Wing  
University of Leeds  
LS2 9JT  
Tel: 0113 343 7186  
Email: [chi6se@leeds.ac.uk](mailto:chi6se@leeds.ac.uk)

## Appendix No. 6 Copy of NHS Research Ethics Committee

Date: 31/08/2005

Reference: 05/Q1202/108

Online Form

### NHS Research Ethics Committee APPLICATION FORM

This form should be completed by the Chief Investigator, after reading the Guidance Notes.  
See Glossary for clarification of different terms in the application form.

**Short Title and version number:** (maximum 70 characters – this will be inserted as header on all forms)  
The role of TCM in the management of diabetes mellitus by UK Chinese

**Name of NHS Research Ethics Committee to which application for ethical review is being made:**  
Bradford REC

**Project Reference number from above REC:** 05/Q1202/108

**Submission Date:** 31/08/2005

#### PART A: Introduction

##### A1. Title of Research

Full title: The role of Traditional Chinese Medicine in the management of diabetes mellitus by the UK chinese.

Key words: chinese people, traditional medicine, diabetes mellitus, health belief, chronic illness, focus groups, individual interviews

##### A2. Chief Investigator

Title: Ms  
Forename/Initials: Sookhoe  
Surname: Eng  
Post: PhD Research Student  
Qualifications: RGN; ENB100; MSc.Nursing;BA(Hons)Modern Chinese Studies  
Organisation: School of Healthcare  
Address: University of Leeds  
Baines Wing  
Post Code: LS2 9JT  
E-mail: chi6se@leeds.ac.uk  
Telephone: 0113 343 7186  
Fax: 0113 343 7560

*A copy of a current CV, (maximum 2 pages of A4) for the Chief Investigator must be submitted with application*

##### A3. Proposed Study Dates and Duration

Start Date: 01/10/2005  
End Date: 01/05/2006  
Duration: Months: 07 ; Years: 00

## Appendix No. 7 Approval letter from Leeds and Bradford Ethics Committee



Top Floor  
Extension Block  
St Lukes Hospital  
Little Horton Lane  
Bradford  
BD5 0NA

Chairman: Professor Alan C Roberts  
OBE TD DL MPhil PhD DSc LLD FLS CBiol FIBiol  
Administrator: Sue Bell

Tel: 01274 365508  
Fax: 01274 365509

Email: sue.bell@bradfordhospitals.nhs.uk  
Email: alan.roberts@bradfordhospitals.nhs.uk

20 October 2005

Ms Sookhoe Eng  
PhD Research Student  
School of Healthcare  
University of Leeds  
Baines Wing  
LS2 9JT

Dear Ms Eng

**Full title of study:** The role of Traditional Chinese Medicine in the management of diabetes mellitus by the UK Chinese.  
**REC reference number:** 05/Q1202/108

Thank you for your letter of 07 October 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised].

### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

An advisory committee to West Yorkshire Strategic Health Authority

# Appendix No. 11 Advertisement posted on Britishbornchinese website



Select an area

British Born Chinese Discussion Board > The  
Community Centre > Support Your Community  
**Post New Thread**

**Welcome, HaoRui.**  
You last visited: 29th March 2005 at 04:23 PM  
Private Messages: 0 Unread, Total 0.

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## Post New Thread

Forum:

Title:  
PhD research project

Logged in as

Message:

[Font] [Size] [Color]  
**B** *I* U     
 Guided Mode    Enhanced Mode

Hi there,  
I am a second year PhD student at the university of Leeds and my research  
is on the management regimes of UK chinese diagnosed with diabetes  
mellitus (ie Type 2 diabetes). In particular, I am interested in how, and if,  
BBCs use traditional chinese medicine in their management regimes. I will  
be glad to hear from you.  
Many thanks,  
Haorui :)



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## Additional Options

# Appendix No. 12 Advertisement posted on BritishChinese website

www.britishchinese.org.uk :: View Forum - Notice Board

Page 1 of 2



**www.britishchinese.org.uk**  
The British Chinese Society

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## Notice Board

Moderators: None

Users browsing this forum: None

[www.britishchinese.org.uk Forum Index -> Notice Board](#)
[Mark all topics read](#)

Topics	Replies	Author	Views	Last Post
<b>Announcement: How to use the Notice Board</b>	0	<a href="#">Admin</a>	292	Mon Mar 08, 2004 10:17 pm <a href="#">Admin</a>
<b>Volunteers required for A PhD study of Chinese Medicine</b>	0	<a href="#">Admin</a>	4	Fri Sep 09, 2005 8:47 pm <a href="#">Admin</a>
<b>JOB POSTING FOR CHINESE Refugee Communities History Project</b>	0	<a href="#">Admin</a>	181	Fri Jun 24, 2005 5:56 pm <a href="#">Admin</a>
<b>Mandarin lessons offered in London area</b>	0	<a href="#">Admin</a>	304	Wed Jun 08, 2005 8:36 am <a href="#">Admin</a>
<b>Mandarin TV serials DVDs and VCDs for sale!</b>	0	<a href="#">Admin</a>	418	Fri Apr 08, 2005 9:03 pm <a href="#">Admin</a>
<b>Chinese Music Summer School</b>	0	<a href="#">Admin</a>	791	Mon Jul 05, 2004 10:08 pm <a href="#">Admin</a>
<b>Double Room available in Docklands (Isle of Dogs) House E14</b>	0	<a href="#">Admin</a>	285	Fri Jun 11, 2004 11:36 am <a href="#">Admin</a>
<b>Job Vacancy - Graduate Building Surveyor</b>	0	<a href="#">Admin</a>	345	Thu May 13, 2004 10:19 pm <a href="#">Admin</a>
<b>Job Vacancy - Business Support Supervisor</b>	0	<a href="#">Admin</a>	275	Mon Apr 19, 2004 9:40 pm <a href="#">Admin</a>
<b>'Show-Offers' theatre vouchers available through the BCS!</b>	0	<a href="#">Admin</a>	240	Thu Apr 08, 2004 9:40 pm <a href="#">Admin</a>
<b>"UIP ScreenChina" - free tickets - Tue 6 Wed 7 Apr</b>	0	<a href="#">Admin</a>	300	Wed Mar 31, 2004 12:09 am <a href="#">Admin</a>
<b>The Last Emperor - director's cut - Sat 13th March 2004</b>	0	<a href="#">Admin</a>	245	Wed Mar 10, 2004 11:47 pm <a href="#">Admin</a>
<b>Please help!</b>	0	<a href="#">Admin</a>	309	Mon Mar 08, 2004 10:10 pm <a href="#">Admin</a>
<b>Learning Cantonese</b>	0	<a href="#">Admin</a>	314	Mon Mar 08, 2004 10:02 pm <a href="#">Admin</a>
<b>I can be a chinese tutor</b>	0	<a href="#">Admin</a>	307	Mon Mar 08, 2004 9:59 pm <a href="#">Admin</a>
<b>Mandarin tutor needed in East London -- Isle of Dogs area</b>	0	<a href="#">Admin</a>	247	Mon Mar 08, 2004 9:54 pm <a href="#">Admin</a>

Display topics from previous: All Topics

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All times are GMT

Page 1 of 1

http://www.britishchinese.org.uk/phpbb/viewforum.php?f=6

10/09/2005

281

# Appendix No. 13 Advertisement posted on Diabetes Forum

Page 1 of 2



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Click here for help.

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Thursday, June 22, 2006

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- [Diabetes & Dentistry](#)
- [Diabetes Glossary](#)

## Diabetes Newsletter

- [Newsletter Editions](#)

## Diabetes Diet

- [Diabetes Recipes](#)

Topic: **Looking for British Born Chinese with diabetes:**  
Posted by: **Queenie**  
Date/Time: **22/06/2006 16:46:54**

Hi there!  
I'm a doctoral student at the University of Leeds and looking for British Born Chinese diagnosed with diabetes. I am conducting individual interviews to find out how you manage the illness. If you are interested in taking part, please email me.  
I look forward to hearing from you.  
Many thanks,  
Queenie





[Forum Home](#)


<http://www.diabetes.co.uk/forum/ShowMessagenew2.asp?ID=1522>

22/06/2006



## Appendix No. 14 Responses to advertisement

7th May 2005, 05:14 PM	#2
<b>Vien</b> "Hello moto..!!" 29/12/04	<b>Re: Do you have diabetes ?</b>
	i may have.... for some reason i always tend to feel tired, and i hardly eat anything sweet which has sugar in it.... hmm... and everytime i wake up i wake up feeling tired, thats after 10hours of sleep btw... ☹
Join Date: Sep 2001 Location: London Posts: 1,234	<i>The most painful feeling in the world is to watch someone you love, love someone else...</i>
● ▲	<a href="http://www.xanga.com/vienly">http://www.xanga.com/vienly</a>
 Quote	
7th May 2005, 08:59 PM	#3
<b>blue_starlight</b> Member	<b>Re: Do you have diabetes ?</b>
	What is the difference between Type 2 Diabetes and 'normal' Diabetes? ☹
Join Date: Apr 2005 Location: London Posts: 1,048	
● ▲	
 Quote	
9th May 2005, 03:56 PM	#4
<b>HaoRui</b> Member	<b>Re: Do you have diabetes ?</b>
Join Date: Mar 2005 Location: Leeds Posts: 9	Well, there are two types of diabetes. Type 1 is congenital, ie you're born with it. Basically, your body does not produce insulin which is essential for the uptake of glucose into the cells. So, Type 1 diabetics require insulin injection for the rest of their lives. Rather drastic, eh? Type 2 diabetics are usually associated with severe trauma, illness and bad diet and lifestyle. Oral medication, change of diet and lifestly usually help to control the illness. Type 2 diabetes is mostly discovered during routine checkups, is relatively common in individuals with a family history of diabetes.
●	
 Quote	
9th May 2005, 04:20 PM	#5
<b>SiuMeiMei</b> Member	<b>Re: Do you have diabetes ?</b>
	I don't think we have a family history of diabetes, but my mum had a little "scare" a while ago of type 2, but it




Join Date: Feb 2003  
Location: France/UK  
Posts: 593

turned out to be just floaters (in her vision) caused by ageing...and high blood pressure :\

If anyone is worried about suffering from diabetes, [Lloyd's Pharmacy](#) do a free testing service. 😊

Pourquoi pas moi?



9th May 2005, 07:43 PM
#6

**MattCheung**  
Member


Join Date: Feb 2003  
Location: southampton  
Posts: 51

**Re: Do you have diabetes ?**

Quote:


Originally Posted by **Vien**  
*i may have.... for some reason i always tend to feel tired, and i hardly eat anything sweet which has sugar in it.... hmm... and everytime i wake up i wake up feeling tired, thats after 10hours of sleep btw... 🙄*

Do you get any other symptoms?  
people who have diabetes tend to be thirsty alot of the time and have increased volumes of urine. If your urine smells of something for example sweets or honey then you might have diabetes.



9th May 2005, 11:59 PM
#7


**Vien**  
"Hello moto..!!" 29/12/04



Join Date: Sep 2001  
Location: London  
Posts: 1,234

**Re: Do you have diabetes ?**

well i do tend to drink a lot and pee a lot at work lol... i dunno, my pee smells normal enough



10th May 2005, 01:12 AM
#8

**Sherry**  
Member

**Re: Do you have diabetes ?**



Join Date: Aug 2004  
Location: UK  
Posts: 447

Quote:

Originally Posted by **HaoRui**  
Hi there, 😊

*I am a 2nd year Phd student at the University of Leeds and my research is on the management regimes of UK chinese diagnosed with Diabetes Mellitus( i.e. Type 2 Diabetes). In particular, I am interested in how, and if BBC's use traditional chinese medicine in their management regimes. I aim to conduct focus group interviews and individual interviews to gather data for this study. I will be glad to hear from you.  
Many thanks,  
Haorui 😊*

Hello ... HaoRui

My grandfather has had diabetes for more than 20 years. Will I get diabetes ?? ( Later years in my life, late 30s, 40s, 50s ..etc ..) .. 🤔 ... How high or low will my percent be in getting diabetes ???

I'am very scared in getting diabetes later years in my life, I can't help it, just by thinking about it ... It gives me the creeps and bumps ...!!

Oh I better mention this as well, I like eating chocolates, sweets, cakes etc ... I know, I shouldn't be eating to many/much chocolates, sweets, cakes .. etc ... but I just can't seem to help it, I just can't seem to control myself . I'am still trying to cut down on chocolates, sweets, cakes .. etc ..

1314 ... 1314 ... 1314 ... 1314 ... 1314 ...  
1314 ... ( Cantonese ) ... 🤔 🤔



10th May 2005, 09:44 AM

#9

**HaoRui**  
Member

Join Date: Mar 2005  
Location: Leeds  
Posts: 9


**Re: Do you have diabetes ?**

Hi Sherry,  
Are you registered with a GP? A routine urine check and a chat with the practice nurse will confirm whether or not you have diabetes. Don't forget to tell them that your grandad (paternal?/maternal?) is diabetic. BTW, I'm looking for participants for my study, will he be interested in talking to me?  
Thanks,  
Haorui

Quote

10th May 2005, 10:59 AM #10

**Em**  
Member



Join Date: Jul 2002  
Location: On a banana boat  
Posts: 657

**Re: Do you have diabetes ?**

All my grandparents have type 1 and my sister has type 2 so basically im screwed ☹️  
And im addicted to regular cocacola so im screwed twice over! 😊  
My sister got it by living on a diet of chocolate, cocacola and McDs for approx 2yrs 😊  
Y didnt supersize me come out sooner!


We'll get along fine as soon as u realize I'M GOD

Quote

Quote

10th May 2005, 05:00 PM #11

**Sherry**  
Member



Join Date: Aug 2004  
Location: UK  
Posts: 447

**Re: Do you have diabetes ?**

Quote:

Originally Posted by **HaoRui**  
*Hi Sherry,  
Are you registered with a GP? A routine urine check and a chat with the practice nurse will confirm whether or not you have diabetes. Don't forget to tell them that your grandad (paternal?/maternal?) is diabetic. BTW, I'm looking for participants for my study, will he be interested in talking to me?  
Thanks,  
Haorui*

Registered - ummm .... mmmm .... I think so, I don't know, I'am not sure, I will need to check up on that to see I'am registered ... ☺️ ☺️ .....

As for my grandfather, he won't be able to chat to you sorry. Because he lives in HK and plus he only speaks and understands cantonese.

Sorry I can't help you. But anyway good luck with your studying ... ☹️ ..

Quote

10th May 2005, 05:08 PM #12

**HaoRui**  
Member

Join Date: Mar 2005

**Re: Do you have diabetes ?**

Thanks, and good luck at the GP.

**Appendix No. 15 Copy of summary sheet for focus group interviews**

Contact type: Focus Group Discussion

Site:

Date:

Main issues in this contact:

Information obtained (or failed to get)

Question	Information obtained, or not
----------	------------------------------

What's salient or deviant about this contact?

What questions for the next FGD/for individual interviews?

## **Appendix No. 16 Copy of summary sheet for individual interviews**

Contact type:

Site/ time/ date:

Main issues in this contact:

What's salient or deviant about this contact?

Information obtained (or failed to get)

Question	Information obtained or not
----------	-----------------------------

Tell me what does diabetes mean to you?

How did you learn about diabetes?

Is there a cure for diabetes?

What was your diet like before diabetes?

What advise would you give to someone who is newly diagnosed?

Some people would 'cheat and eat', what is your view on this?

What do you do to 'keep it'?

What are your views on using food items to control blood sugar levels?

Views on taking medication

Types of food that is good/bad for diabetes

Impact of diabetes on family

What do you think of traditional Chinese medicine as practised in the UK?

What are your views on using TCM to treat diabetes?

How can you prevent the onset of diabetes?

Tell me about your experience of the care you have received from your doctor/nurse for your diabetes?

What types of illness will you use TCM for?

### Appendix No. 17 Socio- demographics of individual interviews

Name	Sex	Age (Approx)	Place	Occupation	Duration of illness (Approx)	Diabetes related complications	Taking prescribed medicine	Education
Chang	Male	66+	Leeds	Retired (catering)	21 years	CABG	Yes/ Oral and injection	2 years (Primary)
Chueng	Female	49	Leeds	Shop assistant (Chinese supermarket)	>10 year	Renal hypertension	Yes/ Oral	Middle school
Chueng	Male	60	Leeds	Retired (catering)	~ 10 years	CABG	Yes/ Oral and injections	Did not say
Chueng	Female	60	York	Retired ( shop owner)	3 years	Hypertension	Yes/ Oral	Secondary School
Chui	Male	76	Leeds	Retired (shop owner)	15 years	Renal dysfunction	Yes/ Oral	Secondary School
Jeanie	Female	21	Teeside	Student	< 1 year	None reported	Yes/ Injection	University undergraduate
Lana	Female	52	London	Volunteer Chinese community worker	10 years	Hypertension, Ischaemic heart disease, Horner's syndrome	No (refuse medication)	Did not say
Lee	Female	62	Birmingham	Housewife	16 years	None reported	Yes/ Oral and injection	1 year (Primary School)
Liam	Male	39	London	Shop owner ( Chinese takeaway shop)	<10 years	None reported	Yes/ Oral	Secondary school
Lui	Male	70	Leeds	Retired (catering)	12 years	None reported	Yes/Oral	3 years

								(Primary)
Lee	Male	70	Bristol	Retired (catering)	>20 years	None reported	Yes/ Oral	Did not say
Robert	Male	50	London	Post doctoral researcher	>1 year	None reported	Yes/Oral	Postgraduate
Leung	Female	54	Leeds	Restaurant owner	3 years	None reported	Yes/Oral	Secondary school
Leong	Female	47	Birmingham	Housewife	3 years	None reported	Yes/ Oral	6 years (Primary)
Ngan	Female	70	London	Housewife	10 years	None reported	Yes/Oral	Did not say
Ong	Female	57	Birmingham	Retired ( restaurant owner)	30 years	Diabetic retinopathy	Yes/ Oral and injection	2 years (Primary)
Tony	Male	50	London	Accountant	>10years	None reported	Yes/injections	Did not say
Tessa	Female	33	Belfast	Chinese community worker (qualified nurse)	2 years	None reported	Yes/ Oral	Did not say
Wong	Female	53	Leeds	Restaurant owner	<1 year	None reported	No (not prescribed)	Secondary school
Yau	Male	69	Belfast	Retired (catering)	16 years	Cardiac arrhythmias	Yes/ Oral	Did not say
Yap	Male	70	Bristol	Retired (catering)	>20 years	CABG	Yes/ Oral and injections	5-6 years (Primary)
Yee	Female	75	Birmingham	Housewife	30 years	Blind in one eye, renal failure and on dialysis three times a wee	Yes/ Injections	Secondary school



## Appendix No. 18 Response from individual interviews

- What does diabetes mean to you?

Being diabetic means that I have to constantly monitor my blood glucose levels and having to watch what I eat all the time. My body does not produce the insulin required to control my blood glucose so I need to take injections of insulin to replace this.

- How did you learn about diabetes?

Before being diagnosed I was experiencing all the symptoms related to insulin deficiency; excessive thirst, weight loss, frequent urinating and body rash. I searched online regarding these symptoms and they pointed to diabetes. This is how I first learnt about diabetes. In addition to the diabetes nurse and doctors explaining to me about this disease, I searched online about it as well.

- Think back about your diet and lifestyle before you were diagnosed with diabetes, what was your diet like?

I think my diet is pretty much the same as before, with the exception of eating a lot less of the sugary foods and beverages and having regular meals. I try hard not to cut out meals and to eat on time each day, but at times this is difficult and I get lazy of doing so. But in general, I try to keep a routine of waking up for breakfast and my injection at 8:30 am and having lunch at 12:30 and then dinner around 6:30 and taking my injection again. So basically, the biggest change is trying to keep the routine and not skipping meals.

- What if any changes have you made since your diagnosis

Like I said earlier, trying to keep to a routine, not skipping meals and controlling the amount of sugary foods included in my diet. I tend to eat a lot more fish as well.

- What advise would you give to someone who is newly diagnosed with diabetes?

People with diabetes can lead a perfectly normal life but will need to make some minor adjustments in your eating habits and daily routine. These minor adjustments are just those that will help you lead a healthier lifestyle.

- How do you keep your blood sugar levels stable?

I eat less of the sugary foods and lots of carbohydrates. I try to eat a variety of carbohydrates, protein and vegetables in every meal and I try to only eat sweet stuff like chocolate and that after meals, but it's quite hard and I do snack in between meals with chocolate and crisps and that.

- What are your views on using food items to control blood sugar levels?

I think the food you do eat could significantly affect your blood sugar levels so it is important to control what you eat. It could be beneficial for your diet as well as your

diabetes if you control properly your intake of food and the types of food you eat. Hence, I think it is better to adjust the food you eat rather than adjusting your insulin intake to control your blood sugar levels.

- Are you on any medication for diabetes?

I am insulin dependent so I take the novo mix 30 twice a day, each time I take between 8-10 units. I also have to do the finger prick test about 4 times a day to check my blood sugar levels.

- If yes, what are your views on medicine taking?

It is really annoying to have to take the injections twice a day, especially when I go out for dinner and have to go to the bathroom every time before dinner to do so. But I hope I would not have to this for long as I am hopeful there will be some new medication/fix for diabetes soon.

- What type of food do you consider bad/good for diabetes?

Obviously anything with high sugar content is bad for diabetes and should be avoided or taken in minimum amounts- chocolates, fizzy drinks etc. It is best to eat lots of complex carbohydrates to help maintain stable blood sugar levels as they release sugar slowly rather than sugary foods that tend to make your sugar levels rise and drop down again quickly.

- What impact if any, has diabetes on your family?

My mom is really worried about me not being to control my diabetes and is constantly checking up on me to see whether I have eaten on time and not eating too many sweets. She tries to use sweeteners rather than sugar in her cooking when I am home.

- How do you think you can prevent the onset of diabetes?

I don't think type 1 diabetes can be prevented but then it would probably be helpful if one didn't eat too many sugary foods in the first place and try to eat healthily and do lots of exercise.

- Tell me about your experience of the care you have received from your doctor for your diabetes?

All the doctors and nurses have been very helpful in answering my questions and supportive since I was diagnosed. I am able to text the diabetes nurse whenever I have questions I want to ask her so it is quite convenient.

- What do you think of traditional Chinese medicine as practiced in the UK?

I haven't had a good experience with the Chinese practitioners at the Herbal Inn when I went there after the first few weeks when I was diagnosed. My pulse was measured in the Chinese way, where they like use their fingers to listen to the pulse. Then I was told that from that they could hear that I was weak and had a weak liver or some sort. The doctor didn't speak English but mandarin and my mom knew some mandarin so they tried to communicate in mandarin in the end. After speaking, he gave my parents the impression that he could cure me because I was only just recently diagnosed. He prescribed a course of tablets and a concoction of herbal medication that I was supposed to take for at least the next 6 months which also cost a bomb! I took it for less than a week but during that period I ended up with a body full of rashes-hives. I couldn't pin down what had caused it so I stopped taking the herbal medicine and after taking a course of anti-histamines the rashes cleared. Hence I don't particularly have a good impression of herbal medicine practitioners because I know that diabetes is not reversible and the doctor there was just giving me false hopes of which we believed.

- What are your views on using traditional Chinese medicine to treat diabetes?

I think Chinese medicine needs to be taken for long periods and it can aid promoting your health and immune system. The process is however very slow. Chinese medicine cannot be a replacement for the insulin but it can be used in addition to the insulin to help to promote your health.

- Would there be circumstances when you would use traditional Chinese medicine instead of western medicine for diabetes?

Chinese medicine can not replace the insulin I take, hence I wouldn't think of substituting. I do still drink the herbal soups and drinks my mom makes for me as they are good for your general health.

## Appendix No. 19 Response from individual interviews

*Diabetes insight*

Traditional Chinese medicine and diabetes: How do UK Chinese manage diabetes?

*Good exercise insulin*

- What does diabetes mean to you? *— have an illness which requires me to follow a particular medical regime for life.*
- How did you learn about diabetes? *— symptoms = weight loss, excessive thirst, toilet + pins + needles re circulation*
- Think back about your diet and lifestyle before you were diagnosed with diabetes, what was your diet like? *— eat irregularly, fast food + sweet things*
- What, if any, changes have you made since your diagnosis? *— eat low GI foods, Match insulin to food intake*
- What advice would you give to someone who is newly diagnosed with diabetes? *— Read up on everything as a.p. / Try + follow diet recommendations + exercise*
- What/ how do you keep your blood sugar levels stable? *— Blood testing + insulin*
- What are your views on using food items to control blood sugar levels? *— Accept advice as much as I can. Generally recommended plan.*
- Are you on any medication for diabetes? *— Insulin. Human Mix 30/70. New Novorapid / Glucagon*
- If yes, what are your views on medicine taking?
- What types of food do you consider is good/ bad for diabetes? *— low GI carbohydrates*
- What impact if any, has diabetes on your family? *— cook more healthily*
- How do you think you can prevent the onset of diabetes? *— ?*
- Tell me about your experience of the care you have received from your doctor/ nurse for your diabetes? *— initially v good, Diabetic Nurse clinic visits. NO UPDATES. Must find own info*
- What do you think of traditional Chinese medicine as practised in the UK? *little knowledge, only used via Mother, not aware of conflicts with western medicine, language + cultural problems*
- What are your views on using traditional Chinese medicine to treat diabetes? *— limited + little advice on subject.*
- Would there be circumstances when you would use traditional Chinese medicine instead of western medicine for diabetes?

*Accept but Lot of trouble difficult, come and see*

*Prone to diabetes*

*Can how*

- 1 - if understand basis of treatment*
  - 2 - interaction effect of western medicines*
  - 3 - cultural conflict*
- ibc red form*

M drive:Thesis parts/ individual interview schedule bbc version.doc

HbA1c

## Appendix No. 20 Response from individual interviews

10/05/2006 03:19

01133437560

SCHL OF HEALTHCARE

PAGE 01

F.A.O. MANNA.  
GO PERRY FUNG.

Traditional Chinese medicine and diabetes: How do UK Chinese manage diabetes?

- What does diabetes mean to you? *blood sugar / urino*
- How did you learn about diabetes? *when I was very ill & did not get better.*
- Think back about your diet and lifestyle before you were diagnosed with diabetes, what was your diet like? *fat free, alcohol free, never smoke, heat they*
- What, if any, changes have you made since your diagnosis? *stricter diet control*
- What advice would you give to someone who is newly diagnosed with diabetes? *check, change diet & life style, take closer look of various ways to improve the illness, prevent deterioration*
- What/ how do you keep your blood sugar levels stable? *control diet & having at least a red grape fruit 1st thing in the morning*
- What are your views on using food items to control blood sugar levels? *Personally very effective, especially having red grape fruit in the morning.*
- Are you on any medication for diabetes? *- No*
- If yes, what are your views on medicine taking? *-*
- What types of food do you consider is good/ bad for diabetes? *lots of fresh fruit & vegetables are good, MSG is bad*
- What impact if any, has diabetes on your family? *great concern in general*
- How do you think you can prevent the onset of diabetes? *By reducing of intake sugary food & drink as from young age*
- Tell me about your experience of the care you have received from your doctor/ nurse for your diabetes? *- none, but persistently pressing to take medicine that caused me to be ill.*
- What do you think of traditional Chinese medicine as practised in the UK? *- As of any medicine, some suit certain individual, but not others.*
- What are your views on using traditional Chinese medicine to treat diabetes? *- Personally, I did not try any, I have started to reduce my sugar intake, nearly 30yrs now.*
- Would there be circumstances when you would use traditional Chinese medicine instead of western medicine for diabetes? *- definitely yes as there are no chemicals consistence and personal view that my body would not be bombarded with all the chemicals & could cause or have caused severe side effects with unnecessary pain & suffering.*

M drive:Thesis para individual interview schedule bbc version.doc

MANY THANKS.

Queenie

## Appendix No. 21 Transcript of individual interviews



Jeanie\_for\_thesis\_2  
011.doc

## Glossary

Cantonese/Pinyin	Chinese Characters	English Translation
Ah Ca/ Ah cha	阿差	Referring to an Indian person
Bai hu jia ren shen	白虎加人參	Tiger Decoction with Ginseng
Bakgwai/baigui	白鬼	Literally: white devil, referring to white, non-Chinese people
bao	包	Soft dough bun
bei	悲	Grief
bou/bu	补	Nourish, repair
Bouhtong/butang	补汤	Boil soup
Choi/ cai	菜	Vegetables or dishes to accompany rice or other carbohydrates
Chengyun/ Qingrun		cleansing
cheungfun/ Changfun	肠粉	steamed rice dough
Da hoi zhong mun/da kai zhong men	打开中门	'Doorway to China'
Dong cong cou/dong chong xia cao	冬虫草/冬虫夏草	<i>Cordyceps sinensis</i> ; literally meaning winter worm and summer grass
Dongsum/dangshen	党参	Codonopsis pilosula. Poor man's ginseng

Fan/fan	饭	Rice or staple food
Fan/fan	繫	Vexation, worry
Fantong/ fantong	饭铜	Rice bins: referring to individuals who like to eat lots of rice
Foksann/ fushen	伏神	Chinese herb
fu	腑	Hollow organs in body
gaihauh/Jikou	戒口	Food restriction
Geizi/gouqizi	枸杞子	<i>Fructus Lycii</i> , commonly known as gogi or wolf berries
Ge jie san	蛤蚧散	Powder of Gecko
Go lai sum/ gao li shen	高丽蔘	Korean ginseng
guqi	鼓气	Energy from food
Guantai/ guanxi	关系	Social network; connections
Gwailo/gwai tauh/yanggui	鬼佬/鬼头/羊鬼	Literally: devil head , referring to white, non-Chinese people
Kinhong/ jiankang	健康	Healthy
jibing	疾病	disease
jing	警	Anxiety
jingluo	经络	Meridians
Taibeng/ kanbing	看病	Look at illness
ke	克	Control
Hott/ ke	渴	thirst



keep ju/ zhe	着	A resultative verb
kongqi	空气	Energy from air
la guanxi	拉关系	Making connections
leungcha/ liangcha	凉茶	“cooling teas”
Leung/ liang	凉	‘cooling’
Lingchee/lingzhi	灵芝	Ganoderma lucidum (bracket fungus)
Tong lui beng/tang niao bing	唐尿病	Sugar urine illness
minjian	民间	Folk
Mor munn teng/muo men ding	摸门钉	Wasted journey
Mouh ban fatt/mei ban fa	没办法	No other option
mouhfattji/meifazi	没法子	No options
nu	怒	Anger
Pagkkei/ beiqi	北芪	Ginseng derivative
Pui/ pei	配	To accompany
Hei/ qi	气	Energy force
Heigong/ qigong	气功	A form of chinese martial arts
Qisat/cishi	茨实	Fox nut
ren yu she hui tong yi	人与自然统一	Oneness between man and nature
Yanching/ renqing	人情	Human emotions
Ren qing wang	人情网	Human emotion web
samgwai	三鬼	Number three (person)

san	散	'weakening'
sanjiao	三焦	Triple burner
San xin cou/shen xian cao	伸仙草	'celestial grass'
shenhui/shenxu	肾虚	'Weak kidneys'
Suntai/ shenti	身体	Bodily constitution
sheng	生	Alive
Shen qi wan	肾气丸	Kidney Qi Pill
shikyauk/chiyao	吃药	Eat medicine
si	思	Pensiveness
si xian tang	四神汤	'four celestial soup'
sijian	四简	Four examinations
Suimai/shaomai	烧卖	minced pork with chopped mushrooms, carrots and prawns
Tauhsihk/touchi	偷吃	Sneak and eat
Tuilei/ tiaozheng	挑证	To regulate
tueihmeih/Duanwei	断尾	Break the tail
Waisang/ huaishan	淮山	Wild yam
wo/he	和	wholesome
wu wei	无为	Do nothing
wuxing	五行	Five elements
xi	喜	Joy
Xiao	消	Wasting

Xiao ke zheng	消渴症	Wasting and thirsting syndrome
xing shen tong yi	形神统一	Harmony between body and spirit
yang	阳	Hot
Yauhgamzi/ yuganzi	余甘子	Indian gooseberry
yeathei/reqi	热气	'Heaty'
yin	阴	Cold
yin shi	饮食	Food and beverages
yithei /reqi	热气	"Heaty"
yuanqi	原气	Congenital energy
Zang	脏	Solid organs in body
zheng	症	syndrome
zhong jian ren	中间人	Middleman
Zhongyeuk/zhongyao	中药	Chinese medicine
zhongyi	中医	Chinese medicine/doctor