

The current status of self-management of type 2 Diabetic people in Beijing, China

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Abstract

Introduction:

In the Chinese community, rapid urbanization, sedentary life style, stress, smoking and changes in dietary may increase the risk of type 2 diabetes. Studies conducted in China showed an increasing prevalence rate from 1.1% in 1980 to 4.56% in 1996. However, no studies carried on self-management implementation is available in China now.

Objectives:

To describe the status of self-management implementation among diabetic people in Beijing and to identify possible factors influencing self-caring activities in Chinese context. The purpose was to provide the necessary information for future studies.

Methods:

This was a cross-section study. It had a descriptive approach. The study combined both qualitative and quantitative research techniques. The quantitative method included a questionnaire. The qualitative method included an unstructured interview at respondent's home and two focus group discussions.

Results:

The age span of all participants, including both male and female, was 35-70yrs. 17% respondents had poor self-management of their diabetes. Dietary regimen, physical exercise, adherence to both prescription and self-monitoring were the most difficult activities related to self-management. People in the younger age group had the tendency of poor self-management.

Knowledge about diabetes and self-management, good public health insurance and good family care played a positive effect on the self-management implementation, carelessness about diabetes, stress and poor quality of health service offered played a negative effect on self-management.

Conclusion:

The self-management among type 2 diabetic people in Beijing was poor. Attitude towards diabetes, stress, socio-family care services had effects on self-management. There is a need to focus on advocating healthy life style, keeping on traditional Chinese diet. A professional team, including physician, dietician, diabetic nurse and educator needs to be built. Systematic education is one important measure to encourage life style changes and consequently diabetic self-management.

Abbreviation and Definition

TCM: Traditional Chinese Medicine

Dietician: is an expert in nutrition who helps people with special health needs plan the kinds and amounts of foods to eat.

Meal plan: a guide for controlling the amount of calories, carbohydrate, proteins and fats a person eats.

TaiJiQuan: a traditional Chinese physical exercise.

YaoShan: to put some Chinese herbs while making food so ordinary food has the supporting function of keeping healthy or treating diseases.

BaoJianCha: to put some Chinese herbs into tea so ordinary drinking has the supporting function of keeping healthy or treating diseases.

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Chapter One

Introduction

Diabetes

Diabetes is a chronic disease in which the body does not produce or properly use insulin (insulin resistance). Its main symptoms include polyuria, polydipsia, blurry vision and rapid weight loss (17).

There are two major types of diabetes mellitus:

Type1 diabetes is caused by a destruction of pancreatic B-cells. Approximately 75% of the patients are less than 30 years at onset. Some studies showed that short duration or absence of breastfeeding and early introduction of cow's milk increase the risk of Type1 diabetes (17).

Type2 diabetes is caused by a combination of decreased insulin-action (insulin resistance) and insufficient insulin production (11). There are two phases in the natural course of type 2 diabetes. Impaired glucose tolerance (IGT), a lesser degree of hyperglycaemia, represents an intermediate stage in the development of type2 diabetes (11), one-to –three-quarters of those with IGT develop diabetes within a decade of discovery of IGT (4). Type2 diabetes is a heterogeneous disorder (8). Risks of developing type2 diabetes increases with age, over-weight, food intake, genetic factors and sedentary life style. Visceral obesity rather than subcutaneous or total obesity are independently correlated with insulin resistance (8).

Global prevalence of type2 diabetes

The world is now experiencing a change in the epidemic pattern, from infectious diseases to chronic diseases. Diabetes is a disease of great concern and the fifth greatest cause of death around the world. It was an estimated 135 million people with diabetes in 1995 and by the year 2025, this rate is expected to reach 300 million. About two- thirds to three - fourths of the new cases will be in developing countries. This is the new challenge in 21 century.

The Asian region contains some of the most populous countries in the world and is at the forefront of the current epidemic of diabetes. Type2 diabetes prevalence showed marked difference throughout this region. It remains low in traditional societies but are rising rapidly in association with life-style changes, which is usually due to urbanization and modernization (2).

India, due to its immense population size and high diabetes prevalence, will contribute 57 million type2 diabetes patients by the year 2025 (1,2).

In Vietnam, the prevalence of type 2 diabetes in HO Chi Min City is 2.5%, compared to the 1.4% in Hanoi (less-economic developed city) (1,2).

In Singapore, the prevalence rate in the majority ethnic Chinese population had reached 8.1% in 1992 (1,3). Sequential studies from Singapore since the mid-1970s have indicated approximate doubling in prevalence rate during each decade (3).

In Indonesia, studies performed in 1982 and 1992 in different districts of Jakarta showed crude prevalence rates of 1.7% and 5.7% respectively, indicating a three-fold rise within a decade (1).

In Japan, recent surveys report prevalence rate approaching 10% for type 2 diabetes and more than 20% for IGT. Earlier prevalence studies in 1960 showed 2% to 5% (1).

In Hong Kong, studies conducted in 1990 and 1995 showed age-adjusted prevalence rates of 7.7% and 8.9% respectively (5,10). Results from Taiwan in 1995 also showed age-adjusted prevalence rates of 11.0%. (6)

The prevalence of type 2 diabetes in China

With the increasing intake of westernized food in China, the decreasing of physical activity and the increasing number of elder people, the number of diabetic people is increasing rapidly. Studies conducted in China between 1980 and 1990 consistently show low type 2 diabetes prevalence rates of 1.5% or less, even in urban population such as Shanghai in 1980 (7). Recent data from Shanghai suggest a prevalence rate of 6% in that city. Data obtained from Da Qing area showed a prevalence rate of 3.5%, which is 3.4 times greater than the rate of 1.04% found in a survey in the same area in 1986—only 8 years earlier. Studies conducted in Beijing showed an increasing of prevalence rate from 1.1% in 1980 to 4.56% in 1996.

The cost of diabetes

Studies in USA show that comparing with the non-diabetic people, the occurrence of ischemic cerebral and heart disease among diabetic people is three times more than the occurrence among normal people. The occurrence of lower extremity ulceration is five times more, the occurrence of renal failure is 17 times more and the occurrence of blindness is 25 times more. (20)

Studies in China also show occurrence of hypertension, ketoacidosis, coronary heart disease, peripheral neuropathy and renal diseases caused by diabetes is 36.56%, 29.94%, 21.48%, 18.75% and 18.61% respectively. (27)

In many countries, diabetes and its complications are now becoming the main reason of morbidity, mortality and the increasing medical cost. For example, in USA, from 1987 to 1992, the cost caused directly or indirectly by diabetes is increasing from 210 billion US\$ to 920 billion US\$ annually. (20)

In China the cost of diabetes and its complications is increasing astonishingly. It is estimated that about 60% the diagnosed diabetic people have poor control of blood glucose level, which finally leads to severe complications. If no proper and effective

methods to be implemented, the medical costs related to diabetes will increase even more rapidly. (27)

The prevention and control of diabetes

Until now, no effective way to cure diabetes has been found. Diabetic people need life-long treatment. However the occurrence of Type2 diabetes and its complications are preventable. According to experience around world, three levels of prevention method are effective ways to control diabetes. The primary prevention aims to prevent high-risk population from contracting diabetes. It focuses on keeping a healthy diet, increasing physical activity and controlling body weight. This is the most cost-effective way and also the most difficult way to be implemented. The secondary prevention aims to control blood glucose level as normal as possible in diabetic people, in order to prevent the occurrence or early occurrence of diabetic complications. Self-management of diabetic people is the cornerstone of this stage. The tertiary prevention is to diagnose and treat diabetic complication as early as possible and to improve the life quality as better as possible. (27) Investment in primary care, education and simple drugs and monitoring technology is very cost-effective. In most countries, developing and developed, too many resources are spent on complication treatment compared to what is spent on “secondary” prevention - good management to prevent the complications. (26)

Importance of this research

As mentioned above, there is an increasing burden of type 2 diabetes in China and the self-management is the corner stone in controlling diabetes and in preventing possible diabetic complications. However, by now, there is no specific research carried out on the status of self-management of diabetic patients in China. Systematic diabetic services are not available, possibly because diabetic nurses and dieticians are of great shortage in China. Diabetic education and self-management are only new concepts introduced two to three years ago.

This research aims to describe the current status of self-management of diabetes in the urban area of China and also try to identify the possible factors that may influence the implementation of self-management in the context of Chinese traditional culture and current economic and health service conditions. The outcome of this study may be useful for the Chinese health facilities to set up realistic diabetic education programs in China in the future and to improve the life quality of diabetic patients.

Conceptual framework

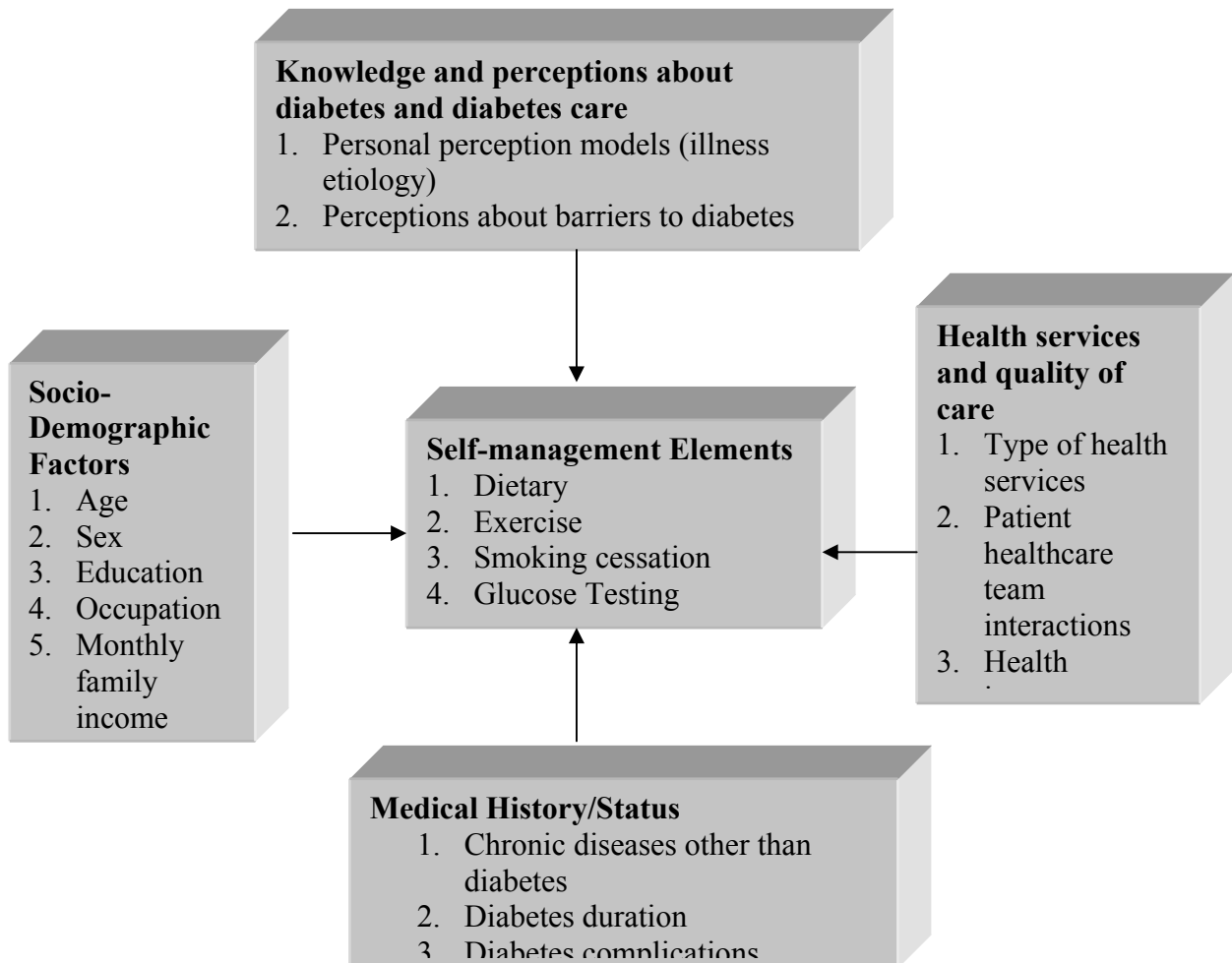
Self-management

Diabetes self-management is defined as a set of skilled behaviors engaged in managing one’s own illness (23). Diabetes is foremost a self-managed disease.

Figure1.1 (appendix 1) presents a modified model of various factors influencing diabetes self-management (24). Diet, exercise, smoking cessation, blood glucose monitoring and medications are integral elements of diabetes self-management.

Socio-demographic factors, patient's knowledge and perceptions about diabetes, health services and quality of care, patient's medical history and health status are the main factors which influence the implementing of self-management (24).

Figure 1.1 Variables Influencing Diabetes Self-Management



Study Objectives

Overall objective:

This study tries to describe the general status of self-management implementation among type 2 diabetic patients in the urban area of Beijing, China. It also tries to locate possible variables that may facilitate (or hinder) the implementation of self-management in the social context of Beijing, China.

Specific objectives:

Objective 1

To describe the general picture of the implementation of self-management among people with type 2 diabetes in the urban area of Beijing, with special respects to:

- *Glucose monitoring at home.*
- *Following of diet regimen.*
- *Following of exercise regimen.*
- *Self-inspecting of feet.*
- *Following of medicine treatment.*
- *Cessation of cigarette smoking.*

This part aims to describe the content of central box in Figure 1.1.

Objective 2

To assess factors concerning socio-demography, medical history (status), health services and quality of care, health knowledge and attitude that facilitate or hinder the implementation of self-management among type 2 diabetic patients in the urban area of Beijing, China.

Sub-objective 2.1

To assess the relationship between socio-demographic factors and the implementation of self-management.

- *What are the demographic factors concerning education, economic, marital status that may affect the implementation of self-management?*
- *To what degree are patient's satisfied with their daily life and how does patient's stressful life affect the implementation of self-management?*

This part aims to describe the contents in left box and its relationship with the central box in Figure 1.1.

Sub-objective 2.2

Try to describe patient's knowledge and attitude towards disease and health and to assess its relationship with the implementation of self-management.

- How do the type 2 diabetic patients describe their sickness and how do their attitude towards diseases and health affect the implementation of self-management?

- How does patient describe their disease according to the traditional Chinese medicine concept and how does their attitude towards traditional Chinese medicine affect the self-management implementation?

This part aims to describe the contents in upper box and its relationship with central box in Figure 1.1.

Sub-objective 2.3

Try to describe patient's report about health services and the quality of care and to assess its relationship with the implementation of self-management.

- To what degree are type 2 diabetic patients satisfied with the social health care system?

- How does patient's report about health services affect the implementation of self-management?

This part aims to describe the contents in right box and its relationship with central box in Figure 1.1.

Sub-objective 2.4

Try to describe patient's medical history (status) and to assess its relationship with the self-management implementation.

- How does patient's medical history (such as disease duration and complication) affect the implementation of self-management?

This part aims to describe the contents in lower box and its relationship with central box in Figure 1.1.

Chapter two Literature Review

Self-management

Diabetes self-management is defined as a set of skilled behaviors engaged in managing one's own illness (23). Diabetes is foremost a self-managed disease. Treatment and prevention of acute and long-term complications are largely a function of the patient's decision on a daily basis (13). Self-management of patient is a complex regime, especially it requires life-long practice and life-style adjustments. Patient's compliance, is a decisive role in an effective diabetic management, which may be influenced by both individual and outside factors (13)

Figure 1.1 presents a modified model of various factors influencing diabetes self-management (24). Diet, exercise, smoking cessation, blood glucose monitoring and medications are integral elements of diabetes self-management. Socio-demographic factors, patient's knowledge and perceptions about diabetes, health services and quality of care, patient's medical history and health status are the main factors which influence the implementing of self-management (24).

Guidelines of Self-management

The American Association of Clinical Endocrinologists (AACE) System of Intensive Diabetes Self-management is divided into three phases. (12)

1. Provide the opportunity for the initial patient assessment (12)

According to the patient's disease status, risk factors for complications and laboratory test, physicians will develop initial recommendations for the patient (12) The following aspects must be included:

1.1 Nutrition

The goals of medical nutritional therapy in diabetes management are to maintain optimal glucose and lipid levels, attain or maintain a reasonable body weight, prevent, delay or treat nutrition-related risk factors and complication and improve overall health (12). Obesity has long been accepted as a risk factor for type 2 diabetes (8) It is usually reported that about 80% of patients with this disease are obese (18) Abdominal obesity, more than other localization of adipose is associated with insulin resistance (18).

High fat diet may deteriorate glucose tolerance in normoglycemic individuals by worsening insulin resistance (18), moreover, high fat diets are particularly liable to induce overweight (18).

Sucrose consumption has also been suggested to play a role in the etiology of type 2 diabetes (18). It has long been recognized that dietary fiber improved glucose

tolerance, reduced insulin resistance and lowered plasma insulin levels (18).

Diet rich in vegetables, fibers and low saturated fat can prevent the progression rate of IGT to diabetes (11). Diet and exercise intervention was the most effective in decreasing the development toward the insulin resistance syndrom (19).

For diabetes, eating is a complicated activity. It involves monitoring daily caloric intake, minimizing the ingestion of simple sugars and fats and maximizing the intake of vegetables, fruits and vegetables. It also involves eating smaller, more frequent meals with the largest meal at the midday. The recommendations are quite difficult to follow (24).

1.2 Exercise and increased physical activity

Exercise is an important component in prevention and treatment of diabetes. Physical activity is found to be inversely related to BMI (21). Exercise increases insulin-mediated glucose disposal in muscles (11) and reduce insulin resistance.

Studies have emphasized the preventative effect of increasing physical activity in reducing the progression rate of IGT to diabetes (11,18). On the other hand, physical activity consistently decreases plasma TG levels and VLDL in type2 diabetes (12).

The increased sensitivity to insulin occurs not only during physical activity but for up to 48 hours after exercises (12). Therefore, exercise should be repeated at least every 48 hours to maintain this effect (12).

Every exercise prescription should be tailored to the individual patient's capacity and coexistent conditions, such as hypertension, or prior myocardial infarction. The duration of exercise should be a minimum of 20 minutes every 48 hours (12). At the start of exercise program, patient should not push to achieve ideal duration but should stop as soon as fatigue is experienced.

The timing of the onset of an exercise program might be important because post-prandial physical activity seems to lower postprandial blood glucose level (12).

1.3 Stress and psychosocial adjustment

Because of the impact of chronic illness of lifestyle, the need for increased therapy functioning through stress reduction and coping skills is nearly universal among patient (12). Stress is a major contributor to hyperglycemia and may even precipitate the onset of diabetes. Behavior modification and psychological support are important if weight management is to be effective (22) and good self-management is obtained (13).

1.4 Medications

Oral hypoglycemic agents and insulin are widely used in diabetes management and are important aspects of self-management. As with all medications, people who take these glucose-lowering agents need to understand their use, correct administration action and potential side effects (12).

1.5 Glucose testing

Monitoring of glucose daily is important to prevent attack of hypoglycemia (15).

Capillary blood glucose monitoring (CBGM) is an essential tool for diabetes self-management. It has been shown that people with diabetes can learn how to use CBGM data to adjust their diabetes regimens and improve metabolic control (15).

1.6 Foot, skin and dental care

Foot, skin and dental care are important aspects of self-management. At least 50% of all Lower Extremity Amputations (LEAs) can be prevented by proper self-care (12). A case controlled study of diabetes-related LEAs showed that negligent self-care practices were the initiating events in 72% of the LEAs. Routine foot care reduces the incidence of lower extremity morbidity (12). To reduce LEAs by 40%, at least 80% of all people with diabetes at high risk for LEAs must receive effective foot care, including self-care instruction (12).

Use of lotion on dry neuropathic feet reduced the risk of ulceration by 50%. The supporting tissue of teeth is prone to the systematic effects of diabetes. Severe periodontal disease or infections can negatively impact glycaemic control. Thus the value of skin care and routine dental care is high (12).

2. Follow –up assessment

A goal of each follow-up assessment is to evaluate the patient's physical condition, level of blood glucose control and degree of adherence to guideline. On the basis of the results, the physician and patient may elect to revise any or all aspects of the patient's treatment plan (12).

Because a patient with diabetes has a considerably increased risk of coronary artery and peripheral arterial disease, dyslipidemia and hypertension, lipid levels and blood pressure must be rigidly monitored and controlled (12).

Follow-up assessment should be scheduled at intervals of no longer than 3 months (12).

3. Assessment of complication

The goal is to assess the presence and severity of complications associated with diabetes mellitus. On the basis of the patient's history and findings on the current examination, the frequency of follow-up, the need for more intensive testing and the need for referral must be determined (12).

Actual status of self-management

From the guidelines of the AACE system of Intensive Diabetes Self-management, we can find that a successful implementation of self-management needs three factors: (A) Active patient participation (B) A committed health-care-team (C) Adherence to the scheduled interactions between patient and health-care team (12).

It has been documented that poor control and non-compliance rates account for problems in one-third to three-quarters of diabetic patients (13). It is reported that diabetic patients complied more with the medication regimen, followed by self-monitoring, exercise and diet recommendation (13,15). Approximately 75% of diabetic patients report deviating significantly from dietary guidelines at least weekly. Between 40% and 80% of patients underreport their blood sugar levels on at least half

their recordings (13,6,5). Half the diabetic population does not follow foot-care recommendation (13). Also non-adherence to exercise programs in diabetic patients is 70% (13).

Unfortunately, due to the limited time, data regarding the availability of health-care team and the quality of communications between the patient and health-care givers is not available during my searching for literature review.

Barriers that influence the implementation of self-management

According to the Figure 1.1 model, the following aspects may be the barriers for the implementation of self-management (24).

1. Socio-demographic factors

Age appears to be related to the compliance and different self-management skills. Some studies found that older people with type 2 diabetes manage their oral hypoglycemic medication more effectively than younger people (13). However the effect of age on other aspects of self-management was not reported. On the other hand, age and compliance relationship may be confounded by variables such as length of time since diagnosis (13,14). Contrary to earlier speculations in the literature, self-management is not associated with other demographic variables, such as household income, gender, ethnic group, years of education (13,14).

2. Knowledge and perceptions about diabetes and diabetes care

2.1 knowledge

Some studies found that patients who were more knowledgeable of their disease were more successful in performing self-management practice. Study by Nagasawa et al also indicated that compliance behavior increased with the amount of knowledge that the patients acquired. (13)

2.2 Health belief

Health beliefs of diabetics have been reported to account for 41% to 50% of variance in patient's reported self-management. Perceived severity of illness and perceived benefits of treatment were associated with more effective self-management reports. However the associations were cross-sectional, which does not establish if health beliefs were the causes or effects of better management (13).

3. Health services and social context

3.1 Public health service

Access to health care is necessary in order to implement diabetic self-management. Diabetic patients must have health care providers who have expertise in this field (12). Good communication between caregiver and patients lead to successful management of diabetes. Insufficient communication will often lead to poor compliance (12). In most developing countries, the affordability of health care services is another factor which influence the self-management.

3.2 Social support

Social support also has been proposed as a determinant of effective self-management in adults with diabetes. It was found that there are differential effects of social support in men and women with type2 diabetes (13). Satisfaction with social support was correlated with better self-management behavior in women, but men may reinforce eating, drinking and exercise behavior that don't lead to good glucose control.

3.3 Diabetic education

Diabetic education is a kind of intervention aiming to improve the self-management compliance (15). Studies in Taiwan show that a formal education program can enhance diabetic self-management compliance and consequently improve metabolic control. It also emphasized in this study providing knowledge per se may not be the major determinant in improving diabetic control. Behavior modification may be of great importance in producing improved outcomes (6). Studies in Hong Kong also showed that most patients did not have the skills of problem - solving, decision-making and action - taking, although they got high scores of diabetic knowledge (5). The result strongly suggested that practical skills should be incorporated into the diabetic education program in order to improve the self-management practice (15).

Future study direction

Evidence suggests that trait variables (e.g. personality, age, sex, education, knowledge, health belief and social support) have little impacts on the compliance of self-management. At the same time, some studies suggest transient factors such as psychological stress and social pressure to eat may play an important role in the compliance. So research on the important determinants of self-management in the future may pay more attention on this direction (13,14).

There is still no effective way of assessing the adequacy of self-management. Our understanding of adequacy of self-management has been inappropriately relied on measures of glycaemic control, which is not solely affected by self-management behavior. Current studies on the relationship between glycaemic control and self-management have been cross-sectional design, which can not demonstrate causality. In the future, longitudinal studies are necessary to better understand the relationship (13).

On the other hand, all aspects of treatment, including preventive behaviors (e.g. foot care), were combined into this single measure of self-management. Many of these aspects would not be expected to directly relate to glycaemic control. How to effectively measure the adequacy of self-management needs to be further studied (13).

Chapter Three

Methodology

The whole study will have a descriptive approach, focusing on basic information about self-management among diabetic patients in the urban area of Beijing. This study will use triangular methodology, combining both quantitative and qualitative research techniques.

1. Sample description

Sample size

In the literature review, similar studies (3,5,6,7) enrolled about 50 to 80 respondents; also considering the practical limited resources, a total of 100 respondents will be collected. On the other hand, during analysis, the total respondents were usually divided into three groups, which means that each group has at least 30 samples and makes the statistic analysis possible.

Sampling methods

This study was conducted in 2001 in three urban districts of Beijing, China. Hai Dian,

Xuan Wu and Chong Wen are the three most populated districts in Beijing. Hai Dian is famous for her hi-tech; Xuan Wu is the former inner city of Beijing; Chong Wen is now the commercial downtown of Beijing. In all these three districts, the researcher has good personal relationship with doctors at district hospitals. This personal relationship gave the researcher an easier way to get access to qualified respondents.

Actually, a total of 98 type 2 diabetic people were enrolled in this study. They all came from the patient registration of three clinics. All these respondents were selected according to the *Selection criteria*, (Appendix 3) which focused on the balance between different age group, different education background, different socio-economic level and different health history / status (such as disease duration, with or without complications, with or without accompanying disease). And also the convenience of connection and transportation for future interviewing was considered while choosing these respondents from round 2000 candidates.

2. Training and preparation for the field work

A total of 7 field work assistants were enrolled, all of them came from general outpatient department of hospitals at district level and they all educated as medical doctor. A meeting was hold and purpose of this study was explained. Also simple interviewing skill training was held. The avoiding of interviewer's hints / professional bias was stressed.

3. Pilot study

A pilot study was carried out in order to identify potential problems and to revise the methods before the actual work. Its aims include:

1. To find out if the informants can be contacted with selected methods.

2. To test the questionnaire in order to find out if questionnaire understood and can be answered.
3. To assess if the sequence of question is logical, the wording clear and translation accurate.

A total of 10 respondents were selected to take part in the pilot study, according to the first version of *selection criteria of respondents* prepared in Oslo. After the pilot study, not only questionnaire but also the respondent-selection criteria was revised. Considering the actual difficulty of finding out type 2 diabetic people with at least 3 years disease duration at the age group of 25 to 30, the age of respondent was changed from 25-65 to 30-70. At the same time, questionnaires were revised according to the pilot study and copies were made.

4. Data collection phases used in this study

Phase one: Outpatient department visit

The aim of this phase is to find out the possible study participants and get moral consent from them. With the help field - work assistant, diabetic people was collected in the outpatient department according to the *selection criteria*. The purpose behind this study was explained to these people and related materials were handed out. All these people were asked to fill a form, including the address, telephone number and disease history.

Phase two: Selection of study participants

Through telephone or home visit (if no phone number available), subjects who agree to participate was located. All these participants were send an invitation letter for further home visit, including the date and time depending on the information he (she) gives about being at home.

Phase three: Interview at the respondent's home

Usually, interviewing took place at respondent's home or in neighborhood garden, or any other places where interviewing was not supposed to be disturbed.

Researcher conducted the interview in Haidian district, at the same time, 3 assistants conducted the interview in both Chongwen and Xuanwu districts. The method used in this phase was the questionnaire (See appendix 1). Questions were asked in a standard manner using Chinese and answers recorded in pencil. Each interview was lasted about one hour.

Questionnaire for this study is divided into the following sections:

Section 1. The demographic background includes data such as sex, marital status, education, socioeconomic status and working condition, etc.

Section 2. The history of diabetes includes duration, complication and treatment of diseases. The availability of Chinese traditional medicine is also included in this part.

Section 3. Self-management implementation includes the diet regime, the exercise regimes, the medicine taking, monitoring of glucose at home and feet-inspection.

Section 4. Test of diabetic knowledge.

Section 5. Possible factors which may influence self-management implementation, which includes family care context, social care context, life satisfaction etc.

About 20 candidates for focus group discussion participants were collected at this stage. Candidates must have the will to share their experience of handling diabetes with others.

Phase four: Focus group discussion

Candidates for the focus group discussion were recruited from all respondents. Letters were sent to 20 diabetic patients. The letter explained the aims and place of meetings. A permission to use a tape recorder was obtained from the participants in advance.

A total of 20 participants were invited, according to the balance of gender, age, education and disease history and actually only 13 people took part in two focus group discussions (5 males and 8 females). Focus group discussion took place in a private restaurant that provided a free lunch special for diabetic people.

The researcher acted as the group facilitator and took notes. The participants were sit round an oval table and were asked to introduce themselves by name, age and diabetic disease duration. Then questions prepared for the meeting were discussed one by one.

5. Field work supervision

Fieldwork of this study was supervised at two different levels.

First level:

The fieldwork was supervised to guarantee the quality of data collection by a local supervisor from Beijing University. She checked the Chinese version of questionnaire. Unfortunately, she went to an international meeting during data collection. But she took part in the final supervision stage of this study.

The study was supervised also by two supervisors from the Oslo University. In Beijing, they supervised the interviewing process, got contact with respondent, discussed the possible findings with researcher and finally gave further instructions.

Second level:

All assistants were instructed by the study researcher in order to control the quality of data collection.

All assistants were asked to provide a list of their respondents (according to the selection criteria) to the researcher. Only after getting the approval, could they continue to interview.

The researcher took part in the interviewing at least once for each assistant. Comments were given later. Researcher checked finished questionnaires randomly in order to make sure that each question was correctly marked.

6. The ethical clearance

Permission to run this study was obtained from both the Norway and Chinese government. An official letter of permission to start this study from the Public Health College, Beijing University was obtained, after a meeting with the officers in the college. Before any interview, the aims and objectives of the study were explained to the participants who had been treated with respect and dignity. They were reassured about the confidentiality of data.

7. Main challenge of this field work

1. All field work assistants are educated as a medical doctor, they are easier to understand the questions related to diabetes and are familiar with the context of social health care system. However, they may bring the interviewer bias while they conducted the interview.
2. All respondents were enrolled in the outpatient department and interviewed by doctors. This patient—doctor relationship must have both negative and positive effect on the quality of data. Esp. on the part of “evaluation of social health care system”.
3. Although these three district hospitals have combined westernized medicine and traditional Chinese medicine, all respondents were captured in the general outpatient department. This study excluded those people who went only to traditional Chinese department for their diabetes. This must have some negative effect of the part of “attitude to traditional Chinese medicine”.
4. Nowadays, in Beijing, especially in the well-organized district hospitals/ neighborhood, patients were usually overwhelmed by different kinds of questionnaire (mostly provided by pharmaceutical company for commercial purpose). Respondents are getting tired and they are becoming more and more careless while being interviewed. This must have negative effect on the data quality, although the character of non-commercial use of this study was explained to all respondents.
5. Due to the shortage of human being and time limitation, the age span was a little bit elder than originally planned. This study did not cover the relatively younger population, such as the age group of 25—34.

8. Data analysis

After checking and coding carefully, we entered the data into computer using SPSS software. As most distributions of variables belong to non-parametric distribution, Non- parametric analyzing method was used here. As in the literature review, similar studies (3,5,6,7) choose significance level of 0.05, and also because the sample size in this study is small, so the significance level of 0.05 was chosen here.

*Important variables**

1. Dietary regimen: 13 foods items intake was given a score according to each change of intake. Changes in favorite direction (2 or 1), No change (0), Changes in non-favorite direction (-2 or -1). Then each food item was grouped into four basic groups, such as the fatty food, protein – rich food, fiber – rich food and sweet food. The score of fatty food intake change = (peanut +oil +white meat)/3. The score of protein – rich food intake change = (milk +fish +soybean products +egg + red meat)/5. The score of fiber – rich food intake change = (vegetables +corns)/2. The score of sweet food intake change =(fruits +sugar +soft

- drinks)/3. Finally the total dietary change score = (the score of protein – rich food) + (the score of fiber – rich food) + (the score of sweet food) + (the score of fatty food).
2. Physical activity: The changes of physical activity before and after the diagnosis of diabetes were given a score. (Increase = 2, no change = 1, decrease = 0).
 3. Adherence to prescription: strict adherence =1, no adherence = 0)
 4. Adherence to self-monitoring: Regular self-monitoring = 2, irregular self-monitoring = 1, no self-monitoring = 0)
 5. Foot inspection: no foot inspection = 0, foot inspection =1
 6. Smoking: no smoking or cessation of smoking = 1, current smoking =0
 7. Self-management score: self-management score are constructed by adding the scores of each activities related to self-management mentioned above. (Dietary therapy 2 points, exercise 2 points, medication 1 point, monitoring glucose level at home 2 points, feet-inspection 1 point). The total score is then categorized into three groups. 0-3 points = poor self-management, 4-6 points = in – between self-management and 7-9 points is good self-management.
 8. Diabetic knowledge: Diabetic knowledge score is constructed with the right answers to all questions.
 9. Stress: Stressful life is indexed by a summary scores given to the occurrence of frequency of three positive feelings and negative feelings. Each frequency is given a score (Positive feeling = 1,2,3; negative feeling = -1, -2, -3). Adding together, score of stress for each respondent is available. The score ranges from –18 to 18. Then the whole respondents will be divided into three stress groups.
- * The scoring of the above variables, esp. the construction of dietary regimen score was not validated.

Chapter Four

Quantitative Findings

This chapter is mainly divided into three parts. First part is about the description of sociodemographic characteristic of the respondents. The second part is about the description of current status of self-management, regarding the dietary regimen, physical activity regimen, following upon medication, glucose- monitoring etc. The final part is the description of possible factors that may affect the self-management implementation, regarding different fields, such as sociodemographic factors, medical history, social and family care system and also the attitude to and knowledge about the type 2 diabetes.

In the data analysis, it was found that usually there was no significant difference between sex, except the smoking behavior, so in this chapter, data were analyzed from the point of age differences.

Part One: The sociodemographic characteristic

As can be seen from Table 1, male respondents were evenly distributed among four different age groups. Most women were however in the age between 45-64yrs. About one fifth of males and one third of females reported that their family income as less than 2000 RMB per month, which indicates a low economic status. When considering the highest education degree the respondents got, this study enrolled a relatively higher educated group, more than half of the male and female were highly educated.

Table 1

The sociodemographic characteristic by sex

Level	Male		Female	
	N	%	N	%
<i>Age group(yr.)</i>				
35 - 44	10	25.6	10	16.9
45 - 54	11	25.6	16	27.1
55 - 64	9	24.4	21	35.6
+ 65	9	24.4	11	20.4
<i>Monthly income of family</i>				
Less than 2000 RMB	8	20.5	17	30.5
2000 RMB -- 5000 RMB	19	48.7	31	52.5
More than 5000 RMB	12	30.8	18	17.0

<i>Education group*</i>				
Highly educated	20	53.8	31	52.5
Moderately educated	16	41.0	22	37.2
Lowly educated	2	5.2	6	10.3

* Education group is divided by the highest education degree one got. Bachelor degree and above = Highly educated; middle school graduated = moderately educated; primary school educated or lower = lowly educated

Part Two: The current status of self-management

1. Dietary regimen

The respondents were asked to report the changes in 13 foods items intake in recent one year. Then each changes of intake was given a score (stop =2, decrease =1, no-change =0, increase =1), Each food item was grouped into four basic groups and the total score of changes in intake of these four groups was calculated.

As shown in Table 2, the change in sweet food intake is the largest. 86.7% respondents decreased the sweet intake and no one increase it. The mean score is 1.2.

The change in fiber intake was very small. The mean score of fiber intake is - 0.3, only 3.1% respondents increased fiber intake while 78.5% actually decreased it.

The protein intake increased somewhat (mean score = 0.2), but the fat intake decreased (mean score = -1.2), In total, 53.1% respondents increased the protein intake and 70.4% of them decreased the fat intake. In fact, the change range of fat intake is the biggest one among four different basic food items.

Table 2

Changes in food intake

Change in food intake	Change in intake *			Mean score	SD	Score range
	+	0	-			
	%	%	%			
Fatty food intake	4.1	25.5	70.4	-1.2	0.5	-1.7 – 0.7
Protein-rich food intake	53.1	35.5	11.2	0.2	0.4	-1.3 – 1.0
Fiber-rich food intake	75.5	21.4	3.1	-0.3	0.3	-1.3 – 0.3
Sweet food intake	86.7	13.3	0.0	1.2	0.7	0.0 – 2.0

*+ = Change in favorite direction; 0 = No change; - = Change in non-favorite direction

Table 3 shows that only 14.3% of respondents reported that they follow the dietary regimen strictly. 69.4% of respondents reported that they usually break the dietary regimen, 16.3% reported that they never follow the dietary regimen.

Table 3

Adherence to dietary regimen

	No dietary regimen	Poor dietary regimen	Good dietary regimen
Frequency	16	68	14
Percentage	16.3%	69.4%	14.3%

As for the reasons for non-compliance of dietary regimen, 56.1% reported the social pressure of relatives and friends forced them, 10.0% reported they broke the dietary regimen because of the anxiety, stress or other bad mood.

2. *Physical activity*

Considering the hours per week spent in different physical activities, it was found that the respondents used most of time sitting during their non-sleeping hours.

When comparing age groups, it was found in Table 4 that number hours spent in vigorous activity, walking and sitting differed significantly. The older age group spent less time sitting and more time walking, while younger group spent more time sitting and less time walking. It means that younger people tends to live a more sedentary life than older one.

When considering the changes of physical activity after diagnosis of diabetes, 29.6% reported that they reduced their physical activity, 48.0% reported no change of physical activities. Only 22.4% reported that they have increased the physical activity because of the diabetes.

Table 4

Physical activity by age group

Physical activity	35 – 44 (yr.) Mean (hrs/week)	45 – 54 (yr.) Mean (hrs/week)	55 – 64 (yr.) Mean (hrs/week)	+65 (yr.) Mean (hrs/week)	P Value
Vigorous	1.7	0.9	0.7	0.4	0.001
Moderate	5.0	4.9	4.2	6.8	0.732
Walking	2.7	4.7	7.4	10.5	0.000
Sitting	68.3	49.1	46.4	32.4	0.000

3. *Smoking*

Table 5 shows a significant difference between male and female considering the smoking habit. 53.1% of female and only 23.5% of male never smoked, that is mainly because the female smoker is not accepted in the Chinese culture. Only 4 out of 23 smokers quit the habit after the diagnosis of diabetes.

Table 5

Smoking by sex

	Male (N)	Female (N)	Total
Never smoking	23	52	75
Current smoking	13	6	19
Stop smoking	3	1	4
Total	39	59	98

Pearson Chi – Square test: P = 0.004

4. Adherence to prescribed medication

Table 6 shows that most respondents take oral hypoglycemics to control blood glucose, only 15.2% inject insulin (with or without oral drugs). There is still another 5.3% report that they never take any medicine although they are asked to by doctors.

Table 6

Current treatment of Diabetes

	Oral drug	Insulin	No medicine	Total
Number	78	15	5	98
Percentage	79.5%	15.2%	5.3%	100%

Among the 93 respondents who take medicine (insulin or oral drugs), 94.5% reported that they took medicine daily, 5.5% reported that they did not take medicine regularly, only with symptoms or only when remembering it.

5. Self-monitoring

Table 7 shows 73 out of 98 respondents self-monitor glucose with different instruments, 25 respondents never self-monitor. For the frequency of self-monitoring, most respondents (53.1%) reported that they did it irregularly, only with symptoms or when they felt it necessary.

For the 73 respondents who self-monitored glucose, 18(24.7%) reported that they changed the medicine or dosage if blood glucose was not normal, 46(63.0%) reported that they changed the physical activity or diet according to the result. The remaining 9(12.3%) reported that they took no action according to the result. No one reported that they would consult with their doctors about the results.

Table 7

The way, frequency and usage of self-monitoring

	N (%)	Total N (%)
<i>Ways of self-monitoring</i>		
No self-monitoring	25 (25.5%)	
By blood	24 (24.5%)	
By urine	31 (31.6%)	
By blood & urine	18 (18.4%)	98 (100%)
<i>Frequency of self-monitoring</i>		
Never	25 (25.5%)	
Irregularly	52 (53.1%)	
Once a week or more	10 (10.0%)	
Once a day or more	11 (11.4%)	98 (100%)
<i>Usage of self-monitoring</i>		
Changing medicine	18 (24.7%)	
Changing diet & exercise	46 (63.0%)	
No use of self-monitoring	9 (12.3%)	73 (100%)

6. Foot Inspection

Foot inspection is the worst among six self-caring behaviors, only 14 out of 98 persons (14.3%) self-inspected the feet at home. 85.7% reported they never knew diabetic people should self-inspect foot.

7. The total self-management status

As mentioned in the methodological chapter, each self-caring behavior was given a score: dietary regimen = 2, following of prescription = 1, exercise = 2, self-monitoring = 2, food inspection = 1 and changes of smoking = 1. The total self-management is the sum mentioned above.

Table 8 shows that between male and female, there is no significant difference among the six self-caring activities and the total self-management score except the smoking change score.

When considering the difference among four age groups, the score of physical activity and foot inspection differed significantly. The score of foot inspection is very high among the two oldest age groups, while in the two youngest groups, the foot inspection score is 0. Elders usually complain numb of lower extremities more often than younger, so they may perform more foot massage than younger.

The significant difference of physical activity score among four age groups is quite similar to the result of Table 4. Elders pay more attention to increasing physical activity than younger.

In Table 8, there is also significant difference considering the adherence to prescription and the final self-management score. Younger groups practice less than the older groups. And also totally, the youngest group practices less self-management activities than older ones.

Table 8

The score of six self-caring behaviors and total self-management by sex and age group

	Male Mean Score (SD)	Female Mean Score (SD)	P Value	35-44 Mean Score (SD)	45 –54 Mean Score (SD)	55 –64 Mean Score (SD)	+ 65 Mean Score (SD)	P Value
Dietary	0.9 (0.6)	1.0 (0.5)	0.648	0.9 (0.7)	1.0 (0.6)	0.9 (0.4)	1.2 (0.6)	0.192
Physical activity	1.0 (0.7)	0.9 (0.7)	0.409	0.9 (0.6)	1.3 (0.6)	0.6 (0.7)	1.0 (0.9)	0.005
Adherence to prescription	0.6 (0.5)	0.8 (0.4)	0.114	0.5 (0.5)	0.8 (0.4)	0.9 (0.3)	0.7 (0.5)	0.009
Adherence to self-monitoring	0.7 (0.7)	0.8 (0.6)	0.794	0.7 (0.7)	1.0 (0.7)	0.7 (0.5)	0.6 (0.7)	0.135
Foot inspection	0.1 (0.4)	0.1 (0.3)	0.801	0.0 (0.0)	0.0 (0.0)	0.1 (0.3)	0.5 (0.5)	>0.000
Smoking change	1.6 (0.5)	1.9 (0.4)	0.005	1.8 (0.4)	1.8 (0.4)	1.8 (0.6)	1.9 (0.2)	0.293
Self-management	5.1 (2.3)	5.4 (1.6)	0.123	4.6 (2.1)	5.9 (1.9)	4.9 (1.5)	6.0 (1.7)	0.018

As mentioned above, the total self-management score is from 0 to 9. The score was then divided into three groups according to quality of self-mangement. 0-3 = Poor self-management group; 4-6 = In-between self-management group; 7-9 = Good self-management group. The number and percentage of each group is shown in Table 9.

Table 9

Groups according to self-management score

	Frequency	(Percentage)
Poor self-management group	17	(17.5%)
In-between self-management group	53	(53.6%)
Good self-management group	28	(28.9%)

Part Three: Possible factors that may affect the implementation of self-management.

In this part, it was focused on the description of relationship between self-management and four different aspects. Finally the use of traditional Chinese medicine to treat the type 2 diabetes was discussed.

1. The relationship between self-management and socio-demographic characteristics

Table 10 shows that there is no significant difference of self-management score among different education backgrounds. The self-management score in different family income levels differs significantly. It shows that the middle family income group has the highest self-management score. Families at the lower economic level have other things (which is much more important than the daily prevention of diseases) to concern with limited amount of money. At the same time, the better economic situation makes families in the higher income group careless about the daily prevention of diseases, because they can bear the high medical cost once they are ill. And also as mentioned before, younger groups practice poorer self-management than older ones.

Table 10

Self-management score according to age group, family income and education background

	Self-management score Mean (SD)	P Value
<i>Age group</i> 35 – 44 yr. 45 – 54 yr. 55 – 64 yr. +65 yr.	4.6 (2.1) 5.9 (1.9) 4.9 (1.5) 6.0 (1.7)	0.018
<i>Family income group</i> Low family come	4.9 (2.1)	

Middle family income	5.9 (1.4)	0.002
High family income	4.4 (2.0)	
<i>Educational background</i>		0.114
Poorly educated	5.5 (1.9)	
Moderately educated	5.2 (1.9)	
Highly educated	4.3 (1.4)	

2. The relationship between self-management and medical history

When considering the influence of medical history on the implementation of self-management, there seemed no significant difference of disease duration and disease complications among different self-management group, as shown in Table 11.

Table 11

The table of self – management by disease duration and disease complication

	Poor self-management group		In-between self-management group		Good self-management group		P Value
	Mean	SD	Mean	SD	Mean	SD	
Disease duration (yr.)	8.0	4.0	7.6	3.4	9.3	4.9	0.126
Number of complication	0.8	1.1	0.6	0.9	0.7	1.1	0.883

2. The relationship between self-management and socio- family care service

In China, each work unit pays different percentage of medical cost for its employees. This is the main constitute of public medical insurance. In this study, if people is repaid 70% - 95% of their medical cost, it is grouped into high degree medical insurance; similarly, 50% - 69% = middle degree medical insurance, lower than 50% = low degree medical insurance. Table 12 shows that self-management score differed significantly among different medical insurance groups. The more percentage people enjoy the public medical insurance, the higher they get the self-management score.

It is also found in Table 12 that respondents who goes to diabetic education program gets a higher self-management score than those who does not. Respondents who goes to the education program provided by hospital gets a higher self-management score than those who goes to program provided by private institute. The difference is statistically different.

Table 12 also shows that people living with others tend to have a better self-management than those living alone, the P value is less than 0.05. And also it shows that there is no relationship between the implementation of self-management score and the satisfactory degree to the public health care received.

Table 12

Self-management score according to the availability of public medical insurance, diabetic education, attitude towards public health service and family members

	Self-management score		P value
	Mean	SD	
<i>The degree of public medical insurance available</i>			
High degree	5.7	1.8	0.003
Middle degree	4.5	1.6	
Low degree	2.5	1.9	
<i>The diabetic education available</i>			
No diabetic education	4.6	1.9	>0.000
Diabetic education by hospital	6.5	1.4	
Diabetic education by private institute	5.5	1.9	
<i>Attitude to public health service</i>			
Totally dissatisfied	5.4	1.4	0.973
Satisfied	5.2	2.0	
Totally satisfied	5.3	1.9	
<i>Family members</i>			
Live by self	3.5	1.5	0.041
Live with one other person	5.1	1.8	
Live with at least two persons	5.6	1.8	

4. The relationship between self-management and the knowledge of diabetes

In this study, a knowledge test is included in the questionnaire. This part has a total of ten questions, four are about the knowledge of diabetes itself and other questions are about the daily self-caring behaviors. The total rate of correct answer is 37%, with 35% to diabetes itself and 38.3% to self- management. So the knowledge of respondents is very poor.

Table 13 shows that knowledge score differs significantly among three self-management groups. It seems that respondents who belong to good self-management group have relatively higher knowledge score.

When considering where the good knowledge comes from, Table 14 shows that good knowledge has a strong relation with taking or not taking part in the diabetic education, and also has a relation with who provide this kind of diabetic education program, either by hospitals or by private institutes.

Table 13

The score of knowledge according to different self-management groups

	Score of knowledge*	
	Mean	SD
Poor self-management	3.9	1.5
In-between self-management	5.4	2.0
Good self-management	7.0	1.5

*P = 0.000

Table 14

Knowledge Score according to the availability of diabetic education program

	Score of knowledge*	
	Mean	SD
No diabetic education program	4.8	2.2
Diabetic education program by private institute	5.8	1.6
Diabetic education program by hospitals	7.0	1.4

*P = 0.000

5. The relationship between self-management and stress

As mentioned in the methodological chapter, respondents were asked the occurrence frequency of three positive feelings and negative feelings. Each frequency is given a score (Positive feeling = 1,2,3; negative feeling = -1, -2, -3). Adding together, score of stress for each respondent is available. The score ranges from -18 to 18. Then all respondents were divided into three different groups. Table 15 shows that the mean age differs significantly among the three groups. Younger person seems live a more stressful life.

Table 16 also shows that the difference of the self-management score among three stress groups is significant. It seems that people with less stress tend to perform better self-caring activity.

Table 15

Mean age in different stress groups

	Mean age
More stressful group	50
In-between stressful group	54
Less stressful group	58

P = 0.019

Table 16

Self-management score according to different stress groups

	Self-management score	
	Mean	SD
More stressful group	4.7	1.5
In-between stressful group	5.0	1.7
Less stressful group	6.3	2.0

P = 0.001

6. The Attitude towards Traditional Chinese Medicine (TCM)

When asked about the attitude towards TCM, 51% respondents (57 individuals) reported that they never go to TCM for their diabetes. For the rest 41 persons, no of them has been keep on the TCM treatment. Table17 shows the main reasons for them to give up the TCM.

Table 17

Reasons for giving up TCM

Reasons	Frequency	Percent
1. No effect	20	49%
2 .Out of control of diabetes	2	5%
3 .Time consuming to make medicine	6	15%
4. No specific way to control glucose	13	31%
Total	41	100%

Chapter Five

The Qualitative Findings

This chapter is going to present the main findings from focus group discussion and informal interviews. Two focus group discussions were arranged in Beijing and a total of 13 persons (5 males and 8 females) took part in. All focus group participants were chosen according to the sex, age, social status and medical history. The researcher was the organizer of focus group discussion and she was also responsible of taking notes and records. All questions were prepared ahead of time.

The qualitative findings in this chapter will be divided into two parts, one is about the self-management activities, and the other is about the possible factors that may affect the implementation of self-management.

The analysis of the qualitative findings will be incorporated in the discussion chapter.

Part one: The self- management

This part is going to present the implementation of self-management. It focused mainly on four activities, the following of dietary regimen, exercise, the self-monitoring of glucose and the prescribed medicine.

The following of dietary regimen

It was found that some people had changed their life style after the diagnosis of type 2 diabetes, others did not. The following are answers describing the changes they made and what they think about it.

I stopped eating candy, chocolate, peanut, watermellon and grape, all those are my favorite. My husband usually reminds me if I am eating too much some days. (Female, 46 yr.)

I usually ate a lot before. But now I am trying my best to restrict food intake, especially, rice, oil and animal products. I always feel hungry, so I eat lots of vegetables and Doufu to lessen the hunger. (Male, 58 yr.)

At home, it will be easy to restrict the food intake. But eating outside is more difficult. The atmosphere around the table will make me loose control. And also it will be impolite to refuse the food others serve for you. Usually I will drink wine with friends. (Male, 46y.)

I don't want to restrict the food intake although I am supposed to, because that makes me dizzy all the day and finally I fall on the ground. Having diabetes does not make me uncomfortable, but eating less may lead me to death. (Female, 68yr.)

Everybody knows that fish, meat and milk products are much better than rice and vegetables, but I can't afford to buy that much. Who would give me that money? I have to eat rice in order to make me not hungry.(Female, 68yr.)

It was said that those drugs will help to consume the extra glucose in blood, so must I restrict the food intake? I never follow the dietary regimen. If I eat more, I will take more medicine, it is simple. (Male, 39yr.)

I never restrict food intake, but make some adjustment. If I eat more rice one day, I will decrease the amount of other foods. I try to make my meal balanced. I don't think it will be difficult for us elderly people. Because on one hand, we are losing appetite when getting older; on the other hand, we are used to the plant - oriented food, it is our tradition. Youth need to pay more attention to what they eat. My grandson likes to eat fried chicken, hamburger and all kinds of sweet drinks. I think he is too fat for his age. (Male, 68yr.)

The life is improving greatly. Before, we can only eat lots of rice, grains and vegetables. Before the amount of meat and eggs were restricted by government and they were too expensive to afford. Now we can eat as much as meat and eggs as we want to, grains now become rare food only seen in festival meal. (Female, 55yr.)

Exercise

It was found that some respondents like to increase their physical activities after the diagnosis of diabetes, esp. those who retired: but for most young people, they prefer the sedentary life.

After I retired, I can have my own plan. I usually play Taiji in the morning, with my wife, we climb the Xiang Shan (a famous mountain in Beijing) twice a week. Comparing to the years I was not retired, I am now doing more exercise. I have increased the physical activity not solely for my diabetes. (Male, 57yr.)

After a long tiring working day, I am too tired to do exercise again. The only thing I want to do is watching TV in bed. During the weekend, I must do some cleaning and I like to sleep for the rest of time. (Male, 35yr.)

I like to sit before computer in my free time. Once a while, I go to swim with my friends. I don't know why the physical activity has some relation with glucose control? (Female, 33yr.)

I don't think there is any need for me to increase physical activity. Once waking up, I have lots of things to do, sending and picking up my grandson, going to shops by bicycle, cooking, washing clothes by hand. Every night, when I go to bed, I feel a little bit tired and I usually have a good sleep. Why must I pay money to do exercise? (Female, 59yr.)

Also some respondents have physical limits to do exercises.

I have decrease my physical activity a lot because of the joint pain..

Glucose monitoring

There is quite a difference among the respondents considering self-glucose monitoring. Some monitor glucose regularly and make good use of the results; while others never monitor glucose themselves, the main reason is not the money problem, it is because they do not realize the importance of regular glucose monitoring.

I usually test urine sugar every morning and test the blood glucose once or twice a week. I will modify the food intake or physical activity according to the result. I have kept this habit for 10 years. It makes me feel capable of controlling my diseases. (Female, 59yr.)

No, I don't test blood glucose at home regularly. I have bought that machine. I only use it when I feel discomfort or I feel that I have eaten too much. I don't see the need to test it at home, I don't know how to make adjustment of medicine according to the result. (Female, 55yr.)

When first diagnosed, I tested urine and /or blood glucose everyday. Later I found no fluctuation of daily result and when I went to the doctor, they did not consult me on my own result. They always asked me to have a test in hospital. So finally, I stopped the regular blood testing at home. (Male, 56yr.)

Yes, I test blood glucose by myself. And I usually change the medication according to the result without doctor's permission. You can't depend on doctors, they don't know your disease as well as yourself. Only visiting doctors once a month and usually a different doctor each time, How can they know your situation?

Medication

Adhering to prescribed medication varies substantially among people.

I usually forget taking medicine three times a day, especially at noon. When I am at my working place, it is often the case that when I think of taking drugs, it is three or four hours too late. (Male, 42yr.)

At first, I followed the prescription strictly. The doctor told me that my blood glucose improved a lot. So I stopped the drug by myself. It makes life complicated to take drug everyday, I don't like to. But recently, doctor told me that my blood glucose is worsening again. (Female, 55yr.)

Doctors told me that I should change to insulin, I insist on not using that. It will be terrible to take the syringe everywhere I go and inject insulin before each meal. It was said that once I start with insulin, I would not get rid of it for the rest of my life. (Female, 58yr.)

I usually take more drugs when I want to eat more. (Female, 48yr.)

I prescribe the drug by myself. There is no use to see the doctor. They will say the same thing to different patient. They usually change the prescription, but there is no sign of improvement. So I buy drugs recommend to me by friends according to their own experience with this or that kind of drugs. Sometimes I will try something according to an advertisement. (Female, 56yr.)

Part two: Factors that may affect the self-management implementation

The attitude towards diabetes

Only few respondents have a scientific whole picture of this silent disease. Most seem to be terribly careless about this disease and have some quite wrong opinions about it.

I think it is a disease especially for rich people. Nowadays, people are eating better and better, so lots of us got this disease. But it is not serious, it made me no pain or other discomfort. It is only in the city that people pay attention to it. In the countryside, no one will look it as a disease. (Female, 68yr.)

Diabetes is simple to cure. We can eat less, especially sweet food. And also those drugs will help to bring down the glucose level by consuming extra sugar in blood. (Male, 54yr.)

Doctors warned me that if I don't use insulin, I am going to be blind. It is ridiculous. Blurred vision is natural sign of getting older. Chinese medicine says that when people are getting old, both the spirit and blood supply will decrease, so old people usually have problems of numbness of extremities and blur of eyes. (Male, 68yr.)

Diabetes is the disease for older people. I am too young to get it. Maybe there is something wrong with the lab test. I have not noticed any hunger, urination or losing weight since diagnosis. (Male, 32yr.)

The attitude towards stress

Most elderly people did not pay much attention to stress and they did not realize what is distress. But most of the younger people have lots of opinion about stress and they think that stress has a stronger influence on diabetes even than diet.

I realized that stress is the big enemy of my daily life. When I was in low mood, I had no interest in doing anything. I felt lots of physical discomfort at the same time, such as dizziness, palpitation and loss of appetite. Usually quarreling with my wife or something wrong with my son will cause me stress. (Male, 42yr.)

When I am in a bad mood, the blood glucose will be very high, I don't know the reason. Maybe it is because I don't pay much attention to self-care activities; or maybe that bad mood will increase blood glucose by itself. This is my own experience. (Male, 38yr.)

When in bad mood, I will eat a lot and then go to sleep. I don't mind the diabetes any more. (Female, 54yr.)

Sometimes the failure of controlling blood glucose will also make me feel bad. But that does not last a long time. The main reason making me stressed, is my work and my daughter. (Female, 40yr.)

The attitude towards social care system

I don't want to see doctors. It is crowd in the waiting room. You must wait for four hours for a 5-minute talk with doctors. (Male, 58yr.)

Once in a district hospital, a doctor asked me what kind of drugs I wanted to take. It is ridiculous. So I never went to district hospital any more. (Female, 42yr.)

I have no confidence in the clinical skills of doctor in district hospitals. I usually go to bigger hospitals, but it is truly difficult to see a doctor in that kind hospital. (Female, 38yr.)

Sometimes doctors have recommended to me to have a urine or blood test, but, usually I have refused, because that means I must wait another 1-2 hours to have that test. (Male, 56yr.)

Doctor's attitude towards patient is not good. They have no patience to answer questions or explain the disease condition. Nurses are even worse. They have less knowledge about the diabetes than I have. (Female, 56yr.)

I now enjoy the community health care provided by a district hospital. I have a fixed doctor. She knows all my medical history and usually gives me consultation by phone. I think that is enough for us patients to control diabetes. For this kind of chronic disease, too complicated medical instructions are not needed for a daily life. (Female, 58yr.)

A different kind of education program is a good compensation for hospital services. But it needs careful selection. I usually went to a special program provided by the hospital. Some company want to advocate their drugs or machines, they also provide this kind of program. They focus on the effect of their products. Sometimes even mislead the patients. (Female, 58yr.)

I never went to the education program provided by hospital. It is not far from my home. I don't see any needs to take part in that education. But usually, my wife will go there and bring some news for me. (Male, 56yr.)

The attitude towards TCM

Most respondents did not depend on TCM to control their blood glucose level. Some use it as a supporting way to modulate the whole body function.

I don't like to go to TCM, because it has no specific way to bring down the glucose level. Doctors from TCM even prescribe western medicine along with some herb. They told me that it is the western medicine that controls the glucose level, herbs only have a supporting role. (Male, 56yr.)

Nowadays, people advocating the combination of TCM and westernized medicine. (Male, 44yr.)

I think that TCM may play some role if glucose is not too high. Its main role is to modulate the whole body function. (Male, 58yr.)

When I got the kidney complication, I tried to use the TCM only to maintain a balanced milieu in my body. (Female, 68yr.)

It is difficult to find some true TCM doctors today. All the TCM doctors available now have too little knowledge about TCM. Maybe TCM is too wild and too deep for us modern people to learn. (Male, 44yr.)

Chapter Six Discussion

Part 1: Methodological discussion

This study is mainly cross-sectional, but it is not a typical one. It is a pilot study, which aims to explore the different ways of the self-management implementation and affecting factors in the Chinese context. The results are thought to be useful as a basis for further study.

The strength of this study

The triangular study design

The strength of this study is the triangular design used here, combining both quantitative and qualitative research techniques. The qualitative part (mainly focus group discussion) answered some of the questions that were not included in the questionnaire, for example, “attitudes towards diabetes and health beliefs”. But also the qualitative part could throw light on the data collected with the questionnaire. It is known that the most important limit of a cross-sectional study is that it measures the exposure and effect at the same time, therefore it is difficult to see the direction between two variables. However, the findings of the qualitative part of this study can explain the quantitative findings and sometimes can also sort out the cause and effect direction. Qualitative findings enrich the final discussion and conclusion of this study.

The sampling method

According to the possible factors that may affect the implementation of self-management as described in related literature, strategic sampling method was used. The respondents in this study distributed evenly among different age groups, different socioeconomic status and different medical history. Under this circumstance, the researcher tried to find out how these factors played a different role in affecting self-caring activities. This non-random sampling method makes it much easier and more economical to conduct the field-work.

The limitations of this study

Sample size

This study enrolled 98 respondents in three different districts of Beijing. Comparing with the nearly 20,000 type 2 diabetic people in these districts, it is a small sample size.

The small sample size has lots of limits on the data analysis and the final result. During data analysis, there always exist situations that some weak trend between certain variables exists, but no statistical significance. That kind of result is too ambiguous to be explained. Sometimes small sample size easily hides true relations between variables. To improve this, one way is to improve the accuracy of instrument, another way is to enlarge the sample size. Also, a small sample size limits the possibility of further analysis because the sample size in each further subdivided group is too small to have any statistical analysis.

Bias

As in all cross-sectional studies, there also exists bias in this study. The bias mainly comes from two parts: selection bias and measurement bias. The most obvious selection bias is to select respondents in western medicine-based hospitals to study the attitudes towards Traditional Chinese Medicine (TCM). It excludes those people who only went to TCM – based hospitals for their diabetes. Another selection bias is that some people refused to take part in this study because they were indifferent to it.

The important measurement bias may come from the field work assistants who were medical doctors, who conducted the interview. Their medical background may bring in some measurement bias during interviewing. And also the doctor- patient relationship will also bring measurement bias into this study, esp. in the part of “the attitude towards health care provided”.

Another measurement bias comes from respondents. Nowadays, in Beijing, especially in well-organized district hospitals/ neighborhood, patients were usually overwhelmed with different kinds of questionnaires (mostly provided by pharmaceutical companies for commercial purpose). Respondents are getting tired and they are becoming more and more careless while being interviewed. This must have negative effect on the data quality, although the character of non-commercial use of this study was explained to all respondents.

Part 2: Results discussion

Implementation of self-management

Management of diabetes is aimed at maintaining blood sugar levels within the normal range. Effective management depends on the individual with diabetes performing a series of self-care behaviors that can include insulin injection several times a day, ingestion of oral hypoglycemics, a strict caloric-controlled diet that is low in fat and high in fiber and regular exercise. The regimen is made more complex by the need to modify each of these factors over time according to the level of activities of patients and their self-monitored blood glucose. Preventive behaviors, such as daily foot care also are important for minimizing the effect of possible complications.

In this study, the researcher tried to focus on six self-reported activities related to diabetic self-management. (diet , exercise, adherence to prescribed medication, self-monitoring, no- smoking and foot inspection). Quantitative findings of this study showed that about 17% respondents had poor self-management of their diseases. Qualitative findings also showed that diet, exercise are the most difficult parts of self-management, when participants were asked the question “which is the most difficult thing for you to control your disease?”

Diet and Exercise

In this study it was found that 16% of the respondents never tried to follow the diet regimen because they underestimated the seriousness of diabetes and depended too

much on the effect of medications. For most other respondents, the problem was the long-term compliance to meal plan. Related literature suggests that trait variables (e.g. personality, age, sex, education, knowledge) have little impact on the compliance, at the same time, transient factors such as psychological stress and social pressure to eat may play an important role in the significant deviation from meal plan. (24) This study showed similar results. When under social pressure or stress, the respondents said that they tended to overeat or eat non-proper food although they were clear in mind that this behavior was wrong.

How to select proper food items is another problem. The results showed that only the change in intake of sweet food was according to the prescribed dietary regimen. No one ate more sweet food after being diagnosed with diabetes. This is because most people have the concept in mind that diabetes is the overburden of sweet food in body. As to other food items (fiber, protein and fat), the change score was not according to recommendations. Results from the diabetic knowledge test showed that 2/3 respondents did not know that fiber-rich food is the most unlikely one to increase blood sugar. Almost half of the respondents did know that egg yolk is rich in cholesterol. Results from focus group discussion indicated that a large percent of respondents ingested more fatty food (instead of sweet food) to alleviate hunger. Most respondents did not know the protective role of fiber and protein-rich food and the dangerous effect of fatty foods. The old idea that eating meat instead of vegetable and grain is the symbol of richness still exists, especially in the poor area of cities.

Largely, the traditional Chinese food culture is beneficial to prevent modern chronic diseases. But nowadays, due to the westernization of life style in big cities, more and more people are changing their diet from a plant product-based traditional model to a animal product-based western model. Comparing 1992 to 1982, the daily consumption of meat, egg and milk products increased by 81%, 200% and 323% respectively, at the same time, the consumption of grains and potato decreased by 10.4% and 49.9% respectively. (25) In this study, respondents reported the same change pattern of their intake pattern. How to keep the traditional food culture seems to be the main task of all health promotions.

Although people know the benefits of exercise in keeping healthy, not only for controlling diabetes, only few respondents reported to have increased physical activity after the diagnosis of diabetes. The qualitative findings suggested that people usually had trouble getting enough exercise because they were too busy or too tired. Other related studies also showed that non-compliance to exercise programs in diabetic people is 70%. (?)

As for physical activities, quantitative findings showed that the older age groups seemed to have more active time than younger ones. Here, something about the relationship between tradition and exercise should be discussed. In China, after retirement, without the burden of work, people have more spirit and time to plan their daily life and to pay more attention to physical exercise. Nowadays, as a fashion in big cities, elderly people organize themselves to play *Taijiquan*, *Taijijian*, *Qigong* or to dance in the neighborhood garden in the morning and to climb mountains once or twice a week. These gatherings on one hand provide the chance to communicate with each other to alleviate loneliness, on the other hand, the mild to moderate exercise

helps to keep people healthy physically. Unlike other countries, older people in China are the main participants of mild out-door activities.

Another point is that in China, a large percent of physical activities comes from daily life (house-working, shopping, cooking and washing) and labor-demanding work. With the modernization of life style, physical activities from this part has decreased a lot. The introduction of TV and computer gives people more chances to stay at home. This changing life style has much more influence on younger ones than elder ones, as elders usually inclined to keep more tradition than youth.

Self-monitoring and taking medicine

The quantitative findings of this study show that $\frac{3}{4}$ respondents had the instruments to practice self-monitoring of glucose level, either by urine, blood or both. Similar study in the US showed that 78% diabetes self-monitor blood glucose. (?) However this study also showed that as much as 70% respondents who had instruments did not self-monitor glucose level regularly. Concerning the present study, the researcher believes that the availability and affordability of instruments of self-monitoring of glucose level is not the main problem in Beijing. The main reason for non-compliance of self-monitoring is the people do not know how to make use (or good use) of the test results. Usually, if people can not find a benefit of special behavior, they will not stick to it.

This study also shows that almost half of the respondents try to regulate their food intake or physical activity according to their own test result. They do it without professional consultation, only according to their own experience. At least they are on the right way. But another $\frac{1}{5}$ respondents seemed to have problem in using the test result. They changed the dose or medicine by themselves.

The following of prescriptions was even worse. Although quantitative findings suggest that 95% respondents reported taking medicines daily, they show that the chance of missing a dose is very high, especially during the work hours. In addition, they will change the time and dose in order to compensate for the earlier dose missed. Few respondents even reported that they chose drugs according to the recommendation from friends or public media. It seemed that after a long- time diabetes history, they could not expect any significant help from doctors any more.

Not strictly following prescription given may be very dangerous. It will directly influence the effects of the clinical treatment. It will also quicken the occurrence of drug resistance and cause hypoglycemia.

About the factors that may affect the implementation of self-management

Knowledge

The quantitative study showed that the most of the respondents have poor knowledge both in the field about the diabetes itself and the daily self-management as it concerns. Although in reference it was found that good knowledge does not always lead to good behavior, (5) in this study, we found that there was a strong relationship between knowledge score and levels of self-management. Also the results from the qualitative

study showed that lack of understanding of diabetes directly leads to misuse of medicine and unwillingness to follow the diet regimen. It is true that good knowledge does not necessarily lead to good behavior, but long-time good behavior must result from good knowledge. Quantitative findings of this study also show that there is no relationship between knowledge score and educational background, but a strong relationship between knowledge score and receiving diabetic education program. Those who have attended diabetes education program sponsored by hospital or commercial company have higher knowledge score and higher self-management score than those who have not participated in any of the diabetic education program. It is interesting to note that there are significant differences concerning the self-management and knowledge score between those who received hospital-sponsored program and those who received commercial company-sponsored program. This must be related to the contents of education they provided. How does the content of diabetic education program affect the self-management needs further study. Related literature shows that knowledge should be practical rather than theoretical. Perhaps the term know-how is more appropriate than knowledge. (26)

Careless

The availability of diabetes education program is not the main topic here, because all respondents who were enrolled in this study were from the same hospitals or the same neighborhood committee. They were provided with the same public health care, especially the free diabetic education program. The main qualitative finding of this study is that the respondent's willingness to go to the program is the point that makes things different. The respondent's attitude towards health and disease is the decisive point. Type2 diabetes is a silent disease, it may be symptom-free which makes patient ignore it easily. A young person may refuse to accept it because it is a disease only for older people. Older persons usually suffered from other painful chronic diseases as well and thus they paid little attention to diabetes. Carelessness in diabetes is the main obstacle for respondents to receive diabetic education and to self-manage disease. Also in our society, diabetes is rather a new disease, people usually are more concerned about hepatitis B, AIDS and influenza. The whole society has not paid enough attention to chronic diseases, such as hypertension, diabetes, although this situation is improving now.

Stress

Stress has a direct effect on the glucose metabolism in diabetic people. This association may reflect the direct physiological process such as stress hormone altering glucose metabolism. Alternatively, indirect effects may result from alteration in self-management behaviors when the diabetic person is under stress. Psychological stress may lead to omission of medicine, diet and exercise. (15)

The quantitative findings show that there is an inverse relationship between self-management score and stress score. Qualitative findings also reveal that the more people have a stressful life, the less they implement self-caring activities. This is especially true for younger people. This study finds that younger respondents are more inclined to feel stress than older ones. In the Chinese context, stress usually comes from the work situation, family economic condition and health status. Older people, especially after retirement, are free of any possible burdens. They need not go to work, their children can support themselves and they have enough savings for the rest of life. They do not have too many expectations, except keeping healthy and

having a happy big family. On the contrary, younger people have high expectations both for themselves and for family members. They put too many burdens on themselves, they became more easily stressed.

The availability of health insurance

Both qualitative and quantitative findings of this study show the more participants enjoy the public insurance, the better they perform self-caring activities. This is particularly true in China, especially for older people. Since liberation in 1949, people have been getting used to obtaining medicine free of charge. Only ten years ago, government began to abolish the free health care gradually. The commercial insurance is quite a new thing for most Chinese. People do not have the conception of having to invest in their health. This great change has a big effect on diabetic people's self-management. Those who have no or little public medical insurance are reluctant to go to hospital for drugs because of the high registration fee, so they buy cheap drugs in drug stores. Many don't want to use insulin, because in their opinion, paying for insulin during the rest of their life is not so valuable.

The quality of health care service

Although quantitative findings shows that most respondents go to hospital regularly and seemed to have little dissatisfaction with doctors, the focus group discussion revealed that only the public insurance system forced people to go to hospital regularly and they were not satisfied with doctors. Most respondents complained that there was no communication between doctor and patient. It was too difficult and tiresome to see doctors. Usually they have to wait the whole morning just for a 5-minute talk with doctor.

From the researcher's point of view, the main reason for this dissatisfaction towards the health care service is the under-use of current health care system. In Beijing, each district has three levels of hospitals, the lowest level is district hospital. For some reasons, patients seldom have confidence in the district hospital. They all go to bigger hospital even only for obtaining medication. This makes it difficult to see doctors in big hospitals. At the same time, district hospitals have few patient visits. District hospitals now have the same task as the bigger hospitals, but both the human resource and the equipment make them less competent.

The construction of community health care system is now underway. The main task of district hospitals will be changed greatly. These hospitals will focus more on community health. They will play a leading role in performing community health care. For those who want only to consult with doctors about their meal plan, exercise or other daily activities, district hospitals will be the place to visit. This will solve the difficulties of seeing a doctor and will also lessen the burden of bigger hospitals. The researcher's opinion is that the current problem in Beijing is not the construction of different health care levels, it is how to make good use of current health care infrastructure.

About the self-management in youth

The quantitative findings of this study showed some significant difference that among the four aspects of self-management behavior, the youngest group usually has the poorest performance. The qualitative findings also suggest that youth have the

tendency to practice poor self-management. That may be because they are more careless towards diabetes, they are more likely to accept the westernized life style and they are living a more stressful life. All these factors result in the poor self-management among youth. Since youth is the main force of a society and their life style and health attitude will influence the next generation, further study is needed on how to make changes among youth.

TCM and self-management

Both quantitative and qualitative findings of this study show that almost all respondents did not consider TCM as an effective way of controlling blood glucose. However they all believe in the modifying function of TCM, especially among those with complications of diabetes. Usually the modifying function is incorporated into people's daily life, not only for a couple of Chinese herbs.

In our tradition, for centuries, people did not think that others should be responsible for their health. They never depended solely on doctors providing the treatment. An old Chinese saying "To cure a disease, three tenths for treatment, seven tenths for self-caring" is very popular. People invent different kinds of *YaoShan* and *BaoJianCha* to make daily eating and drinking with the function of preventing and treating diseases. Also for centuries, people keep the habit of exercising different kind of *Taiji* and *Qigong* which on one hand are good physical exercises and on the other hand, different *Taiji* and *Qigong* have a supporting role in curing different chronic diseases.

Diabetes is for life and self-management is not easy to maintain, the circumstances of diabetic people always change, diabetic people easily feel isolated and perplexed, the best way is not to teach people how to manage their disease, it is to empower people to deal their disease by themselves. For a people with good self-caring tradition, it is not so difficult to introduce the concept of "empowerment". Here, something about the "empowerment" must be introduced. In a chronic disease like diabetes, the aim of the learning process is to empower persons with diabetes to make their own decisions, and to make them independent of the health care system, using it for advice rather than for care and instruction. The "golden moment" of education is when the person with diabetes has a problem, contacts the adviser, discusses the problem, and together they find a solution that then is found to work. (26)

Of course, empowering people must have strong professional support of medical and educational team. The availability is therefore an essential part of diabetes healthcare delivery. An effective feed back system at different levels, between health workers and diabetic people must be built. All these are both lacking now in China. But, this does not mean we are lacking proper human resources and proper infrastructure. What we desperately need now is a management system that will help to make best use of current available human resources and infrastructure.

The more difficult part of "empowering people" maybe not the construction of professional team and it is the construction of the self-caring idea in ordinary people. When considering this point, Chinese culture of self-caring has advantage.

The researcher does not want to argue that diabetic care is a easy task for Chines health workers, she only wants to emphasize that at least, the TCM and its related self-caring culture is a strong base on which we can build.

Chapter Seven

Conclusion and Recommendation

Conclusion:

Findings from this study revealed poor self-management among the type2 diabetic people living in Beijing, China. The most difficult parts of self-management are following of dietary regimen, physical activity, adhere to prescription and adherence to self-monitoring. People in the younger age group have the tendency to practice self-caring poorly.

Attitude towards the disease and perception about the etiology may influence the performance of self-care activities and the reluctance to take part in any diabetic education program.

Knowledge about diabetes and diabetic self-management activities also influences the performance of diabetic self-care activities. The more the knowledge people get, the better they perform self-management.

The lack of communication between diabetic people and health care givers and the lower quality of health care service offered in Beijing also influence the performance of diabetic self-management. The abandon of public health insurance plays a significant role in hindering the self-management performance among type 2 diabetic people. People who enjoy better family care have the tendency to practice self-caring well.

Educational and medical background seemed have no relationship with the performance of self-management in this study.

Recommendation:

There is a need to focus on traditional lifestyle and systematic education to increase the individual awareness of diabetes and health issues. This will encourage responsibility for one's own health and reduce diabetes complications.

Increased appreciation of the role of diet and physical activity in type 2 diabetes is essential. Advocating of traditional Chinese food pattern and traditional Chinese physical exercises should be emphasized. The combination of western medicine and TCM in treating type 2 diabetes needs more investigation.

Training of the health care teams on the management of diabetes and how to education people with diabetes is one major strategy in improving diabetes care. Dieticians and diabetic nurses are of great shortage in China. Access to dieticians' services is needed to promote knowledge and awareness about nutrition.

To build a well-organized community health care system on the available resources is a practical way to improve the self-management of type 2 diabetic people in Beijing. Access to dieticians, diabetic nurses, physicians and TCM doctors in each community district will greatly improve the self-caring activities among diabetic people. And also systematic diabetic education should be provided in each community districts.

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Appendix 1

Questionnaire of the Status of self-management of diabetic patient in Beijing

Demographic information

1. Sex

1. Male
2. Female

2. Age

3. Marital status

1. Single
2. Married
3. Widowed
4. Divorced

4. With whom, have you been living with for the last two years?

1. By myself
2. With wife
3. With wife and children
4. With home maid
5. Others, specify

5. Education background

1. University degree and above
2. High school graduate
3. Middle school graduate
4. Primary school graduate
5. Lower than primary school graduate

6. Monthly family income

1. Less than 1000 RMB
2. 1000-2000 RMB
3. 2000-5000 RMB
4. More than 5000 RMB

7. Have any of your first degree relatives ever had diabetes mellitus

1. Yes (please specify members)
2. No
3. I don't know

8. What is your medical insurance?

1. Public insurance (more than 70%)
 2. Public insurance (less than 70%)
 3. Commercial insurance
 4. No
-
9. What kind of work do you usually do?
 1. Professional
 2. Business
 3. Skilled worker
 4. Non-skilled worker

Health Status

1.1 When were you diagnosed with Diabetes?

Month: Year:

1.2 Have you been diagnosed with diabetes by a doctor in hospital?

1. Yes (skip to 2.3)
2. No

2.2.1 If no, who made the diagnosis?

2.3 Under what condition, were you diagnosed with diabetes?

1. Routine check
2. With symptom
3. Prepare for surgery
4. Others, specify

2.4 Did you have any of the following symptoms at the time of diagnosis?

1. Sharply losing weight
2. Thirst
3. Urination
4. Hungry
5. Blurry vision
6. Skin infection
7. Others, specify

2.5 Have you ever been diagnosed with retinopathy or other eye disease by a doctor?

1. Yes
2. No (skip to 2.6)

2.5.1 When were you diagnosed with retinopathy?

Month: Year:

2.5.2 What did the doctor tell you about the cause of the eye disease?

1. Aging
2. Accident

3. Infection
4. Diabetes
5. Others, specify

2.6 Have you ever had a skin infection in your feet?

1. Yes
2. No (skip to 2.7)

2.6.1 If yes, when did you have the feet problem?

1. Before the diagnosis of diabetes
2. After the diagnosis of diabetes

2.6.2 What did the doctor tell you about the cause of feel problem?

1. Accident
2. Diabetes
3. Others, specify

2.7 Have you ever been diagnosed with kidney disease by doctor?

1. Yes
2. No (skip to 2.8)

2.7.1 When were you diagnosed with kidney disease?

Month: Year

2.7.2 What did the doctor tell you about the cause of the kidney disease?

1. Primary
2. Infection
3. Diabetes
4. Others, specify

2.8 Have a doctor ever told you that you have high blood pressure?

1. Yes
2. No (skip to 2.9)

2.8.1 If yes, are you currently, regularly taking medication?

1. Yes (please specify type)
2. No

2.9 Do you have any other chronic disease?

1. Yes (please specify)
2. No

3.0 The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

Activity	Yes, limited a lot	Yes, Limited a little	No, Not limited at all
a. Vigorous activities, such as running, lifting	1	2	3

heavy objects, participating in serious sports			
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, playing Taiji	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking half a mile	1	2	3
i. Walking one hundred yards	1	2	3
j. Bathing or dressing yourself	1	2	3

Diabetes recommendation and recommendation

3.1 Have you ever gotten recommendation for diabetes?

1. Yes
2. No (skip to 3.2)

3.1.1 From whom, did you get the recommendation?

1. Doctors
2. Nurses
3. Family member or friends
4. Others

2.1.2 Which of the following aspects have you gotten?

- a. Dietary recommendation
 - b. Increase physical activity
 - c. Decrease body weight
1. None of them
 2. Two of them
 3. All of them

3.1.3 What is the specific recommendation for dietary?

- a. Reduce intake of energy
- b. Increase intake of high fiber food
- c. Reduce intake of fat, esp. saturated fat
 1. None of them
 2. Two of them
 3. All of them

3.2 What is your medicine treatment now for your diabetes?

1. Oral drugs
2. Insulin
3. Oral drugs plus insulin
4. Traditional Chinese medicine

3.2.1 How often do you take medicine?

1. Every day
2. Only when I have symptoms

3.3 Have you ever been treated with traditional Chinese medicine?

1. Yes
2. No (skip to 4.1)

3.3.1 If yes, who advice you to take the traditional Chinese medicine?

1. Myself
2. Doctor/nurse
3. Family member/Relatives/Friends
4. Others, specify

3.3.2 What is the reason for taking the advice of traditional Chinese treatment?

1. Effective
2. No side effects
3. Disease condition is not serious
4. Others, specify

3.3.3 Have you been keeping on the traditional Chinese treatment?

1. Yes (skip to 3.3.5)
2. No

3.3.4 If no, why did you make changes to the traditional Chinese treatment?

1. No effect
2. Increased seriousness of disease
3. Others, specify

3.3.5 Which kind of traditional medicine you think is most effective in treating diabetes. (According to your own experience)

1. Herb
2. Acupuncture
3. Ba guan
4. Others, specify

Diabetes self-management

4.1 To what degree has the following aspects changed after the diagnosis of diabetes?

Aspects	0	1	2	3	4
Diet					
Physical activity					
Smoking					
Taking medicine					

Diet

4.2 Have you changed your food since you were diagnosed with diabetes?

1. Yes
2. No (skip to 4.3)

4.2.1 If yes, what changes have you made for the following food items?

Food items	More	Less	Same	Stopped
Rice				
Chinese bread				
Soybean products				
Egg				
White meat				
Chicken				
Fish				
Vegetables				
Fruits				
Corns				
Red meat				
Sunflower seeds & peanut				
Sugar				
Vegetable oil				
Milk				
Soft drink				
Snakers				
Foods commercially special for diabetes				
Energy Intake				
Others, specify				

4.3 Have you changed your habit of taking meal after the diagnosis of diabetes?

1. Yes
2. No (skip to 4.4)

4.3.1 If yes, what is the specific changes concerning meal taking?

1. Taking meal regularly (3-4 meal per day)
2. Reduce the intake of snaker between meal
3. Others, specify

4.3.2 Under what conditions, do you most likely not adhere to your diet plan?

1. Social affairs
2. Feel stress in the family
3. Feel stress in the work
4. Others, specify

Exercise

In answering the questions, think about only those physical activities that you did for at least 10 minutes at a time.

4.4.1 During a typical 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics or fast bicycling? Vigorous

1. -----days per week
2. None (skip to 4.4.2)

4.4.1.1 How much time in total did you usually spend on one of those days doing vigorous physical activities?

1. ----hours

4.4.2 During a typical 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace or play tennis? Do not include walking.

1. ----- days per week
2. None (skip to 4.4.3)

4.4.2.1 How much time in total did you usually spend on one of those days doing moderate physical activities?

1. -----hours

4.4.3 During a typical 7 days, on how many days did you walk for at least 10 minutes at a time? This include walking at work and at home, walking to travel from place to place, and any other walking that might do solely for recreation, sport, exercise or leisure. Was there any change in the daily activity after you got the type 2 diabetes?

1. ----days per week
2. None (skip to 4.4.4)

4.4.3.1 How much time in total did you usually spend walking on one of those days?

-----hours

4.4.3.2 At which pace did you usually walk? Did you walk at:

1. A vigorous pace, that make you breathe much harder than normal
2. A moderate pace, that make you breathe somewhat harder than normal
3. A slower pace, that there is no change in your breathing

4.4.4 The last questions a about the time you spend sitting each day while at work, at home, while doing course work and during leisure time. This includes time spend sitting at a desk, visiting friends, reading or sitting or lying down to watch TV.

During a typical 7 days, how much time in total did you spend sitting on a week day?

-----hours

4.4.5 What is your general opinion about the changes in your physical activities, when comparing before and after the diagnosis of diabetes?

More sedentary ----- More activity
1 2 3 4 5

4.4.6 What kind of benefit in controlling diabetes have you had from changing exercise habit?

- 1 Loosing weight
- 2 Feeling better, less symptom
- 3 No benefit
- 4 Other, specify

Blood monitoring

4.5 Do you practice home monitoring for glucose level?

1. Yes
2. No (skip to 4.6)

4.5.1 How do you monitor your glucose level?

1. Blood
2. Urine test
3. Others, specify

4.5.2 How often do you home monitor the glucose level?

1. More than once per day
2. Once per day
3. Once per week
4. Irregularly, when I have symptoms

4.5.3 Do you adjust your dose of medication (insulin or drug) according to the result of your own glucose measurement?

1. Yes
2. No

Foot inspection

4.6 Do you practice foot inspection?

1. Yes
2. No (skip to 4.7)

Smoking

4.7 Do you smoke?

1. Never (skip to 5.1)
2. In the past
3. Currently

4.7.1 Did you make any changes in your smoking habits since the diagnosis of diabetes?

1. No
2. Increase
3. Decrease
4. Stop

4.7.2 Did you make this change only for diabetes?

1. Yes
2. No

Stress

4.8 During a typical one month, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities		
b. Accomplished less than you would like		
c. Did not do work or other activities as carefully as usual		

4.8.1 During a typical one month, to what extent has your physical health or emotional problems interfere with your normal social activities with family, friends, neighbours or groups

- Not at all -----1
 Slightly -----2
 Moderately ---- 3

Quite a bit -----4
 Extremely -----5

4.8.2 These questions are about how you feel and how things have been with you during a typical month. For each question, please give the one answer that comes closest to the way you have been feeling .How much of the time during typical month.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt clam and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

4.8.3 What are the common reasons for being stressed for you?

1. Too much work
2. Economy
3. Living conditions
4. Future thoughts
5. Children matters
6. Health situation

7. Or any other

4.8.4 Have you noticed any relationship between health and stress?

1. Yes
2. No
3. Don't know

4.8.5 In which aspects of the following do you think stress influence most?

1. Diet plan
2. Exercise
3. Monitoring glucose level
4. Taking medicine
5. Others, specify

4.9 Have you had any changes in your body weight during the last year?

1. No
2. Increase
3. Decrease
4. Do not know

Knowledge evaluation

5.1 How do you know that your blood sugar is too low?

1. Feel thirsty
2. Feel faint and sweating
3. Do not know

5.2 What do you do to prevent high blood glucose when you over eat?

1. Drink a lot of water
2. Do some exercise
3. Relax and sleep
4. Omit the next meal or eat less in the next meal
5. Others, specify

5.3 Which of the following will least raise your blood glucose?

1. Chinese bread
2. Vegetable
3. Eggs
4. Fish
5. Do not know

5.4 For diabetic people, fats increase the risk of:

1. Nerve disease
2. Kidney disease
3. Heart disease
4. Eye disease
5. Do not know

5.5 For people with diabetes, the best way to take care of their feet is:

1. Massage them with alcohol

2. Look at and wash them everyday
3. Buy shoe size larger than usual
4. Wear worm soaks
5. Others, specify

5.6 Which of the following is usually not associated with diabetes?

1. Vision problem
2. Kidney problem
3. Obesity
4. Lung problem
5. Do not know

5.7 Which is better for your health?

1. To eat small meals infrequently
2. To eat big meals infrequently
3. To eat one big meal per day
4. To eat one small meal per day
5. Do not know

5.8 Which of the following food is rich cholesterol?

1. Fish
2. Vegetable oil
3. Milk
4. Soybean products
5. Egg yolk
6. Do not know

5.9 The most important in losing weight for diabetes is?

1. Improve blood glucose levels
2. Improve vision
3. Cure skin infection
4. Prevent from lung cancer
5. Do not know

5.10 You should have an eye exam, a lipid profile, kidney tests at least:

1. Every month
2. Every three months
3. Every six months
4. Every year
5. Do not know

5.11 Do you know what amounts of staple food you should take everyday?

1. 3 liang
2. 5 liang
3. 8 liang
4. Others, specify

5.12 Are the diabetes patients prevented from eating rice or wheat?

1. Yes
2. No

3. Do not know

5.13 What kind of knowledge do you need in order to manage your daily self-care?

1. Basic knowledge of insulin
2. Knowledge about how to live diabetes (food, exercise, glucose monitoring and medicine)
3. More education to relatives and friends
4. Others, specify

5.14 From where, do you usually get your knowledge about diabetes?

1. Hospital doctor
2. Nurse
3. Family member and friends
4. Media
5. Others, specify

5.15 Which is the most effective way to spread knowledge to patients?

1. Through hospital
2. Through community
3. Through public media
4. Others, specify

Family and social health care

6.0 How many times do you go to hospital only for diabetes consultation?

1. Once or more per month
2. Once per three months
3. Once per six months
4. Once per year
5. Never

6.1 What doctors do you usually meet?

1. GP
2. Endocrinologist
3. Others, specify

6.2 From where do you get your drugs?

1. Hospital
2. Neighborhood health house
3. Drug store
4. Others, specify

6.3 Do you have any problem in getting your drugs?

1. No problem
2. The cost
3. Others specify

6.4 Have you even been to any diabetic education program?

1. Yes

2. No (skip to 6.5)

6.4.1 Who sponsor this kind of program?

1. Hospital
2. Public health facility
3. Private company

6.5 To what degree are satisfied with the available diabetic service?

Totally unsatisfied ----- very satisfied
1 2 3 4 5

6.6 Who prepare the meal in your family?

1. Myself
2. My spouse
3. My children
4. Others, specify

6.7 Is your meal prepared separately?

1. Yes (skip to 6.10)
2. No

6.8 If no, what is the reason?

1. Too complicated
2. Too time-consuming
3. Too expensive
4. Not necessary, I can control myself
5. Others, specify

6.9 What is your family member's attitude to your diabetes?

1. Very concerned
2. Not concerned
3. Feel as a burden
4. Others, specify

6.10 Which of the following role does your family member play in your self-management of diabetes?

1. Reminder
2. Information collector
3. Advisor
4. No role
5. Others, specify

6.11 Are you satisfied with your family member's action to your diabetes?

1. Yes
2. No

6.12 How does your family member influence your control of diabetes?

1. Help me control diabetes
2. Hinder me control diabetes

3. Has no effects on my control of diabetes

The following questions will be used in the focus group discussion

1. What is your experience of managing diabetes?
2. What is the reason that you have not been successful in managing diabetes?
3. What is your opinion about the Chinese traditional medicine and western-style medicine in the field of treating diabetes?
4. What do you think of health care offered and what is your expectation for the health care provided?

Appendix 2

Declaration of consent for the study of “The current status of self-management of people with type 2 diabetes in Beijing”

Together with this letter of invitation, I have received information on this study. I am therefore informed about the purpose of this study. I know the information I provide during interview will be used in this study.

I am further aware that all information pertaining to myself will be treated strictly confidentially. I know that the study has been approved by related facilities both of Norway and China. I know that I can later withdraw from this study if I intend to in the future. I also know that both myself and the information pertaining to myself can be contacted and used in similar study in the future.

1. I agree that information I will provide can be used in similar study in the future.
2. I agree that I can be contacted and invited to attend a similar study in the future.

Please cross out any item(s) to which you do not give your consent.

Signature:

Date and place:

Selection criteria for study respondents

The main selection criteria

1. People who is older than 35 years.
2. People with type 2 diabetes at least 3 years long.
3. People without severe diseases or complications that may prevent the self-management practice.

The other selection criteria

For candidates each field work assistants provided, they must balanced among different age groups, different socio-demographic background (such as different marital status, different family income level and different family size), different education background, different medical history (such as disease duration, disease complications and accompanying diseases).

