CHAPTER 3

Research Methodology

This chapter presents the methodological approach including the research design, participants, setting, instruments, data collection and analysis procedures, in each phase of this two phase study. The chapter concludes with a description of trustworthiness, rigor techniques, and ethical considerations of the study.

Research Design

This study was carried out in two phases:

Phase I: Current Situation of Glycemic Control Among Adults with T2DM

This phase adopted a descriptive approach to investigate the current situation of glycemic control among adults with T2DM. Findings from this phase were a foundation for further exploring the sociocultural context that influenced glycemic control behavior among adults with T2DM.

Phase II: Sociocultural Context Influence on Glycemic Control Behavior Among Adults with T2DM

As described in the introductory chapter, there is a paucity of available data indicating influences of sociocultural context on glycemic control behavior among

adults with T2DM in Sri Lanka. Hence this phase used an ethnographic approach to explore such influences.

Research Participants

Phase I

This included two groups of participants, adults with T2DM and health care personnel. Inclusion criteria for adults with T2DM were: age ≥ 18 years; diagnosed with T2DM for more than six months; had either controlled (FBS ≤ 126 mg/dl) or uncontrolled fasting blood glucose levels (FBS >126 mg/dl); took their diabetes care from the CSTH/ FPC; and had visited the DM clinic for the first time. Duration of more than six months of diagnosis was required because adults with T2DM need some time to adapt to the disease and also to practice glycemic control behaviors. Adults with T2DM who had severe complications (e.g. stroke, myocardial infarction), and who were unable to speak in Sinhala or English were excluded from the study. There were 230 adults with T2DM who eventually entered into this study.

Health care personnel were nurses and doctors who worked at CSTH/FPC. Inclusion criteria for health care personnel were: provided care for adults with T2DM for more than one year in medical/surgical wards or the DM clinic at CSTH/FPC. Doctors were an endocrinologist, a surgeon, eight physicians and six family practitioners currently working at CSTH/FPC at the time of the study. Nurses were registered nurses and diabetic educator nurses. Work experience of more than one year was required for health care personnel because they needed experience to care

for adults with T2DM in order to understand their behavior. There were 30 nurses and 16 doctors participating in this study.

Phase II

Research participants in this phase included key informants and general informants. Key informants (KIs) were adults with T2DM. Inclusion criteria were: those aged ≥ 18 years; diagnosed with T2DM for more than six months; had either controlled (FBS<126mg/dl) or uncontrolled fasting blood glucose levels (FBS >126mg/dl); and received their diabetes care from the CSTH/ FPC. There were 14 key informants. General informants were family members and Ayurveda practitioners/traditional healers from whom KIs sought care and treatment in the community. There were six family members and nine Ayurveda practitioners/ traditional healers participating in this study.

Research Settings

As mentioned in the introductory chapter there was high prevalence of diabetes in the Colombo district/Western province (Katulanda et al., 2011) hence this district was selected for the study. Phase I was conducted at the CSTH, a tertiary care center, and at the FPC, a primary care center, in Colombo district. The reason for selecting these two sites was that they provided care for a large number of adults with T2DM in the Colombo district. Phase II was undertaken at Boralesgamuwa and Dehiwala communities in the Colombo district/Western province.

Research Instruments & Quality

Phase I

In order to obtain both quantitative data and qualitative data four research instruments were utilized. They were the Diabetes Information Form (DIF) and three guidelines for focus group discussions and in-depth interviews. These instruments were developed by the researcher based on literature review. Details of each instrument are described as follows.

Diabetes Information Form (DIF). To ensure all required information was obtained, this form (see Appendix A) was developed with three sections:

1) Identification of patient: includes clinic identification (date, setting, clinic number) and participant information (address, contact telephone number, gender, age).

2) Demographic and socioeconomic status: to describe ethnicity, religion, marital status, educational levels, occupation, and average monthly household income.

3) Diabetes-related information: to describe duration of diagnosis with T2DM, family history of diabetes, type of medication use, medication taking regularly or not, practice diet control or not, brief summary of dietary intake for three meals in general, practice regular exercise or not, type of exercise undertaken, and latest values of height, weight, BMI, FBS, PPBS, and HbA1c as mentioned in the patient's medical record. Regarding medication adherence, diet control and regular exercise open-ended questions were included to get more information. Examples of questions were:

If not taking medication properly what are the reasons? If not practicing diet control what are the reasons? If not practicing exercise what are the reasons?

Guidelines to explore glycemic control situation. To obtain required information, three types of interview guidelines were developed. The first was developed for conducting focus group discussions among nurses (see Appendix B). The second was for conducting in-depth interviews with doctors (see Appendix C). The third was a guideline for conducting in-depth interviews with adults with T2DM (see Appendix D). All guidelines were originally written in English, then translated in to Sinhala (native language in Sri Lanka) and back translated with the supervision of my Sri Lankan advisor.

Phase II

In this phase I, the researcher worked as a facilitator to obtain information. My background and experience assisted in helping me to assume the role of being a research 'instrument': given that this phase had both qualitative and quantitative methodologies. The following sections described the researcher's background and experiences to illustrate the quality of the researcher as an instrument and to attain the internal validity of the instrument.

In addition, four other types of guidelines were developed such as participant observation guideline to facilitate observation (see Appendix E), in-depth interview guideline for adults with T2DM (see Appendix F), in-depth interview guideline for family members (see Appendix G), and in-depth interview guideline for Ayurveda practitioners/traditional healers (see Appendix H). Again all guidelines

were translated from English to Sinhala, and back with the supervision of my Sri Lankan advisor.

The Researcher as Instrument

I am a Sri Lankan, middle class and Buddhist woman. I have experience in caring for the adults with diabetes in my own culture for about 15 years and also living in the same cultural context for 43 years. During that time I became interested in glycemic control behavior among adults with T2DM. I frequently noticed these patients had issues in adherence to glycemic control behavior in order to control their blood glucose levels. I had many questions in my mind: Why cannot these patients adhere to glycemic control behaviors? What are their real problems related to these behavior? How could their compliance be improved? These experiences in my personal and professional life inspired me to become interested in exploring the glycemic control behavior among adults with T2DM.

During prior learning periods in my doctoral study at Chiang Mai University, I undertook two qualitative research courses namely "Qualitative research as a methodology" and "Qualitative data analyzing methods" in order to gain comprehensive knowledge. In addition I obtained practical skills in qualitative data collection methods, transcribing interviews verbatim, analyzing qualitative data and writing discussions based on the analyzed data under the supervision of experts in ethnographic research. I further studied the culture of Sri Lanka through reading, and talking about cultural aspects with Sri Lankan experts in sociology and anthropology to enhance the reliability of the researcher as an instrument.

Besides the above mentioned instruments, the other devices used for ethnographic data collection methods included artifacts, pens, papers, audio recorders and a digital camera. Notepads held initial impressions; sketches of the physical layout of an area; details of conversations; outlines of informal social situations; preliminary analysis during and after each participant observation, and in-depth interviews. The audio-recorder was used to record the lengthy in-depth interviews without distraction. The camera was used to photograph some of the behaviors and artifacts that were observed during field visits. Permission was obtained for tape recording and photographs during each field visit and in-depth interviews. Field notes and a reflective journal were used throughout the study.

The DIF and all types of interview guidelines were reviewed by the advisory committee many times. In addition the DIF was reviewed by three physicians involved with diabetic care in Sri Lanka. Some questions were revised in accordance with the experts' suggestions. Furthermore, I pilot-tested the DIF with 10 adults with T2DM and some questions were revised as needed. This was done to assure that the questions in the DIF were appropriately linked to the research questions.

Furthermore, clarity of questions of instruments and respective guidelines were reviewed and revised where necessary: after the first focus group discussion: and prior to in-depth interviews conducted with a doctor; with an adult with diabetes; with a family member; and with an Ayurveda practitioner/traditional healer.

Research Procedures

Phase I: Current Situation of Glycemic Control Among Adults with T2DM

During this phase four main activities were carried out: a) assessment of situation of glycemic control among adults with T2DM b) focus group discussions with nurses, c) in-depth interviews with doctors, and d) in-depth interviews with adults with T2DM. Ethical approval for the study was obtained prior to data collection.

Assessment of situation of glycemic control. DIF was used to collect data from adults with T2DM who visit the DM clinic at CSTH/FPC for the first time and who met the inclusion criteria. During the first 6 weeks data were collected from the FPC since approval was obtained from the FPC first. After obtaining ethical approval from the research committee/CSTH and permission from the head of the DM clinic/CSTH, data were collected at the CSTH/ DM clinic for the following 6 weeks. First I introduced myself to the participants and described the purpose of the study. After their written informed consent was obtained, data were collected taking 15-20 minutes for each participant.

Focus group discussions with nurses. These were conducted with 30 nurses working in different settings (e.g. medical wards, surgical wards, DM clinic). Four focus group discussions (FGDs) were arranged to gain their perspectives regarding the reasons for glycemic control, barriers to providing care and suggestions to improve glycemic control among adults with T2DM. All FGDs were conducted in one room at CSTH. Each session consisted of seven to ten nurses and lasted 60 - 90 minutes, and were moderated by the researcher and supported by a note taker trained

by the researcher. Permission was obtained for tape-recording and photographs during each FGD. Upon completion of each FGD, the researcher and the note taker held a debrief discussion the same day.

In-depth interviews with doctors. In-depth interviews with 16 doctors were conducted to obtain their perspectives regarding the reasons for glycemic control, barriers to providing care, and suggestions to improve glycemic control among adults with T2DM. This activity was done at the FPC and CSTH in a quiet room. Permission was obtained for tape-recording and photographs during each interview, which lasted approximately 60 minutes.

In-depth interviews with adults with T2DM. Seventeen in-depth interviews were conducted to gain their opinion concerning glycemic control, barriers to control, and suggestions to improve this. This activity was done at the FPC (seven interviews) and CSTH (ten interviews) in a private room. The voice recorder was explained and written informed consent from each participant was obtained. All participants were encouraged to talk and every effort was made to facilitate the interviews. Permission was obtained for tape-recording and photographs during each interview, which lasted for approximately 90 minutes.

Phase II: Sociocultural Context Influencing Glycemic Control Behaviors

This section explains the ethnographic approach used to explore the sociocultural context on glycemic control behaviors. The following parts describe the procedures undertaken in this phase.

Reasons of selection of the field/setting to conduct the second phase. The areas of Boralesgamuwa and Dehiwala were selected to be the settings to explore

sociocultural context as a result of high attendance of adults with T2DM to the DM clinics of /CSTH and FPC.

Gaining access and gate keepers. There were many gatekeepers. Since the first phase of this study, I already had a good relationship with gatekeepers such as the chief nursing officers, head nurses at CSTH, and head of the FPC to gain access to key informants. Later, I also approached gatekeepers in the community such as the Medical Officer of Health (MOH) in the study area, Public Health Midwife (PHM), Public Health Inspectors (PHI) of the study area, the village headman/"Gramasevaka" and the Head Monk of temples in the study area to access key informants and general informants in the community.

Recruiting informants. In the first phase, I gained basic information about some key informants: their address, ethnicities, religious practices, and socioeconomic status. Then I discussed with the Medical Officer of Health in each study setting and got permission to discuss further with PHMs, and PHIs in each setting. I recruited potential informants who met the inclusion criteria. Eventually, the informants consented and expressed their willingness to participate in the study after I visited their homes several times.

Some of their family members were also invited to engage into the study. After, building relationships with KIs, I approached some Ayurveda practitioners/traditional healers who resided in the Colombo district where KIs sought their treatment. The gate keepers also helped me to meet Ayurveda practitioners/ traditional healers in the study area. I met them, introduced myself, explained the purpose of the study and invited them to participate in the study.

Establishing rapport and trust. I worked as a supportive worker in the DM clinic at CSTH and FPC, before starting data collection to establish rapport and trust with these KIs. I met KIs in the DM clinics and in their residences several times. These multiple contacts helped me to build rapport and trust with them. Once this was established, I explained the purpose of the study and asked permission to observe their glycemic control behaviors during their daily living at their residences. Likewise I built the rapport with general informants too. After that I obtained informed consent to conduct participant observation and in-depth interviews with them. I met the general informants: family members and Ayurveda practitioners/ traditional healers, several times and explained the purpose of the study and asked permission to interview them.

In addition, to fit into the setting I engaged in as many aspects of participants' lives as they allowed me to do. I visited each participant's home many times during the study period and sometimes I participated in their daily living activities such as washing dishes, giving a helping hand to cook meals, cleaning the house, caring for children, and joining in their religious activities. By doing these activities gradually, I became a part of participants' daily life and it was easy to access the "emic" perspectives by observing their dietary, exercise and medication taking practices.

Furthermore, in an attempt to have trustworthy relationships with the KIs I presented myself as a student and not a superior professional. I dressed in casual outfits, went to the settings using public transport, and shared a meal with them. During these activities it became evident that most of the KIs and their family members acknowledged me as an insider of their family.

Data Collection

There were several techniques adopted for collecting data in terms of participant observation, in-depth interviews, and reflective diary. These techniques are described as follows:

Participant Observation

Participant observation was used to describe the context along with the interview. Permission was obtained for taking photographs on some of their day-to-day activities. While participating in their day-to-day activities I observed how they adhere to prescribed diet control, what they do as diet control, type and quantities of food they take as their main meal and what they take as snacks in between. Further I observed how informants do exercise and what they do as exercise. Also I observed how they take medication, time of taking medication and other treatment they use to control their diabetes. Field notes were used to supplement and enhance the data. Field notes were written accounts of the things what I saw, heard, experienced and my thoughts on data collected. These field notes were jot down notes, made during or as soon as possible after my observations, in-depth interviews, informal interviews and were expanded accounts for descriptions and details filled in the same day.

In-depth Interviews with Adults with T2DM

Fourteen in-depth interviews with many subsequent interviews were conducted among adults with T2DM, in order to gain their beliefs, attitudes, and practices related to their glycemic control activities. All in-depth interviews were

conducted at the informants' homes at their convenience. Each interview began with general questions such as "How is your life with diabetes?" followed by questions asking each participant to talk and reflect on their perspectives regarding each glycemic control behaviors. During the interviews important words and informants nonverbal responses were noted. Permission was obtained for tape-recording and photographs during each interview. Each interview lasted approximately 90 minutes.

In-depth Interviews with Family Members of Adults with T2DM

Six in-depth interviews were conducted with family members of adults with T2DM to obtain their perspectives on diet control, exercise, and medication taking activities done by their family member with T2DM. Written informed consent from each participant was obtained to conduct the interview and record it. All in-depth interviews were conducted at their homes during the free time of the family members. Permission was obtained for tape-recording and photographs during each interview. Each interview lasted approximately 90 minutes.

In-depth Interviews with Ayurveda Practitioners/Traditional Healers

Nine in-depth interviews were conducted among Ayurveda practitioners/ traditional healers to obtain their perspectives on diet control, exercise and medication taking activities among adults with T2DM who come for treatment. Written informed consent from each informant was obtained to conduct each interview and record it. All in-depth interviews were conducted at the Ayurveda practitioners /traditional healers' consultation center during their free time. Each interview lasted approximately 90 minutes.

Reflective Diary

I used a reflective diary to write my reflections on what I saw, heard, experienced and thought about the data I collected. During the data collection I was aware of the fact that I was a Sri Lankan woman. However I had to focus on remaining open, being attentive, and non-judgmental in my attempt to the nature of qualitative inquiry. Therefore writing this reflective diary allowed me to be sensitive to the participants' reality and the intensely personal nature of the experiences being shared.

Data Analysis Procedures

Phase I

The quantitative data was analyzed in SPSS 16.0 for descriptive statistics such as frequency distribution, percentages, mean scores and standard deviation. Demographic data, illness related data, glycemic control and glycemic control behavior were described by using descriptive statistics in terms of frequency and percentage. Chi-square test was used to compare the association between the factors related to glycemic control.

Matrix analysis was used to analysis qualitative data. By using a matrix display, one can graph the known intersections between dimensions of phenomena, providing and expansive picture of the researchers' focus area (Morse & Filed, 1995). First, qualitative data was prepared, verified and transcribed verbatim as soon as possible, and then transcripts were coded line by line, underlying key words or

phrases and then put on to matrixes. These descriptive matrices allowed the researcher to display categorized data in individual cells, just observe what appears.

Phase II

Thematic analysis by Miles and Huberman (1994) was used to analyze in-depth interview data. Data were prepared, verified and transcribed verbatim as soon as possible after each in-depth interview. The data collected from, field notes and artifacts were used to support the interview data during the analysis. Initial coding was done to identify the preliminary analysis of the transcripts, then these codes were clustered and used to form preliminary subthemes. The subthemes that integrated several of the originally identified codes encompassed more general topics that were the focus of the transcripts. Further analysis was done until the themes emerged. The following chapter presents the findings from this study.

Trustworthiness

Lincoln and Guba's (1985) naturalistic inquiry was used for assessing the rigor of qualitative research. In order to improve the trustworthiness in this study, I attempted to enhance credibility, confirmability, dependability, transferability and adequacy. Credibility was ensured by I as a researcher developing possible interpretations and conclusions, gain using data gained from various sources. During the in-depth interviews process credibility was ensured by repeating, summarizing and paraphrasing participant's responses, and prolonged engagement to clarify and confirm understanding. Confirmability was gained by interpretations and completeness

of each interview. Moreover, the Dissertation Committee's discussions and critique of the process being engaged was obtained.

Dependability was ensured with field notes and reflective journal. Additionally the Dissertation Committee provided their expertise as external auditors. Transferability was increased by conducting the proposed research in the natural setting, where the participants were, sharing their experiences at times and in places they preferred. No claim was made that the participants' experiences represented the experiences of every adult with T2DM, every family member who cares for them, every Ayurveda practitioner's /traditional healers who treated them and or every health care provider who cared for adults with T2DM in Sri Lanka. Adequacy was attained by establishing honest and mutual relationships between the researcher and each participant. All FGDs and in-depth interviews were scheduled depending on the participants' time. The study process was kept rigorous by having several team meetings and two-way communications with the dissertation committee members.

Ethical Considerations

The research proposal was reviewed and approved by the Institutional Research Ethics Review Committee, Faculty of Nursing of Chiang Mai University, Thailand (see Appendix I), the ethical review committee of the University of Sri Jayewardenepura (see Appendix J) and CSTH research committee in Sri Lanka (see Appendix K). Permission was also obtained from the Director General of Medical Officer of Health (Western province) to conduct the study at Boralesgamuwa and Dehiwala MOH areas (See Appendix L). All participants were informed about the purpose of the research and methods of the study. Their participation was voluntary

and they had the right to refuse, stop or withdraw from the study at any time. A research consent form (see Appendix M) was given to the all participants to assure protection of human rights. A statement was included in the information form to guarantee confidentiality and anonymity of individual responses. In order to protect the confidentiality of participants, code numbers and pseudonyms were used and all transcripts including tapes were kept under lock and key. All materials such as diabetes information forms, audiotapes, transcriptions, photographs and field notes will be destroyed when this study is fully completed. The results of the study will be published in peer reviewed international journals, at conferences and workshops with no identification of participants.