

The experience and the meaning of hypoglycemia to Cambodian diabetes patients

A qualitative study conducted in Phnom Penh, Cambodia

Chun-An Sun

Supervisor: Per Kristian Hilden



Department of Community Medicine

Institute of Health and Society,

Faculty of Medicine

University of Oslo

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Summary

The burden of diabetes is increasing in low-income countries, including Cambodia. Hypoglycemia is an important topic in diabetes care: an episode may bring physiological, psychological, and social impacts to patients and their social networks; influence how patients perform self-care and in addition, affect how they maintain their target glycemic levels. Issues around hypoglycemia are complex and cannot be studied with biomedical perspectives alone.

Little is known about the situation of hypoglycemia in Cambodian diabetes patients. This project aimed to contribute towards better diabetes care through an exploration of the experience and the meaning of hypoglycemia to Cambodian diabetes patients in cooperation with a local NGO—MoPoTsyo, which provided the accessible and affordable care to the patients. The data was obtained in Phnom Penh city from July to November, 2013 through a qualitative approach with repeated interviews, a focus group discussion, observations and textual analysis.

This study highlighted that when exploring participants' experiences of hypoglycemia, the continuous interpretation of glucose levels was the essential theme to understand. Participants tried to interpret their glucose levels through discomforts they experienced and the terminologies used in Khmer when discussing diabetes and hypoglycemia. Furthermore, they used the results from biomedical measurements even though daily glucose measurements were not available for most diabetes patients in this setting. In addition, the self-care activities were thought to shape their understandings of glucose levels. In turn, these understandings would then influence how they self-manage in their daily lives. Several other influencing factors for self-care were also mentioned in this study, such as influences from social networks and cultural aspects of foods.

The findings of this research reflected on how participants and peer educators communicated about the glucose levels, the ways of exchanging information at the checkups and how to address the self-care instructions. As a result, recommendations are given to the organization: emphasize on individual experiences in the checkups; embrace and discuss information from different dimensions; introduce self-care principle instead of standard instructions.

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Chapter 1: Introduction

Diabetes is one of the growing public health challenges globally according to World Health Organization (WHO). It is believed more than 80% of diabetes deaths occur in low- and middle-income countries (WHO, 2012b). Due to several severe complications, global guidelines suggest strict treatment regimens for all, namely maintaining blood glucose levels as normal as possible (ADA, 2013; IDF, 2012)¹. In addition to the usage of medication, healthy lifestyle choices are strongly recommended. Meanwhile, according to its chronic characteristic, diabetes is considered as a life-long disease and patients should be able to self-manage most of the time (IDF, 2012; WHO, 2012b).

Hypoglycemia, literally “low blood glucose,” is usually addressed in the patient education program as an acute complication due to medications (ADA, 2005; IDF, 2012). It is believed to be one of the barriers to achieve optimal blood glucose levels (Cryer, 2008b) because of its unpredictable nature and strong unpleasant, even dangerous reactions. And the occurring of severe hypoglycemia, which is defined as an episode involved others’ assistances, may predict the mortality in diabetes (Cryer, 2012). Patients and their family are seen to gain fear and perform avoidance behaviors in order to prevent and intervene to the episode (Bohme, Bertin, Cosson, Chevalier, & GEODE group, 2013; Richmond, 1996), which make them become “non-compliant” to the treatment. Hypoglycemia also influences patients socially and psychologically, and affects their quality of life. Social and cultural factors, such as life-style (Awah & Phillimore, 2008), economic status (Shiu & Wong, 2002) and cultural understandings of the disease and the body (Awah & Phillimore, 2008), play important roles in diabetes patients’ daily lives. In order to better the glycemic control and minimize the influences of hypoglycemia, it is then essential to explore patients’ experiences and meaning of hypoglycemia. Among the existing literature, there is a strong predominance of studies conducted in resourceful countries.

Cambodia is a limited resource country, where diabetes care is usually unaffordable and inaccessible to most of the patients (van Pelt, 2009). MoPoTsyo, a local NGO² established in 2004, organizes peer-based support and provides

¹ ADA: American Diabetes Association; IDF: International Diabetes Federation

² NGO: non-governmental organization

health care and medications with affordable prices for the diabetes patients in Cambodia. Patients can join the peer educator networks in their communities, where they access the basic diabetes care, such as regular measurements and relevant biomedical information. Patients may go to the contracted hospital once in a while when their conditions are not stable and when they get the permissions from peer educators. As a result, it is interesting and important to gain insight into their experience in hypoglycemia in such setting, which is different from the western countries.

Objectives

This research is aimed to contribute towards better diabetes care in Cambodia through an exploration of the experience and the meaning of hypoglycemia to Cambodian diabetes patients. The study pursues this objective through an investigation of the following fields of inquiry, which therefore form the secondary objectives in this study.

1) To explore *what hypoglycemia is in Cambodian context*. It can be understood in different ways, including how hypoglycemia is told from different persons or professionals, how hypoglycemia is perceived by different persons, especially diabetes patients and their social network and how they feel, experience, interpret and understand what hypoglycemia is. The episode of hypoglycemia is often linked to the risk and the danger from literature review. As a result, what kind of risk and danger participants perceived from hypoglycemia is also explored in this study.

2) *How do people act with regard to hypoglycemia?* Questions under this objective includes what are the general ideas for prevention and intervention that people with diabetes receive and how their social networks and they understand these ideas; what are their opinions for these instructions, what they exactly do to prevent and intervene, and the reasons for these interventions.

3) Hypoglycemia is related to diabetes self-management in daily lives. Therefore, it is important to gain insight into *their everyday lives*; how they integrate technologies, for instance, medications, physical activities, diet and monitoring, with their lives.

4) Last but not least, exploring *relationships to helpers* is also important. The episode of hypoglycemia may involve people in the social networks of the patients and lots of articles discuss doctor-patients relationships. Nevertheless,

the study explores the relationships between patients and health professionals, peer educators and their social networks in order to learn about how they view their relationships and how it can affect participants.

Due to the constraints in the field, the research participants were all from the capital city—Phnom Penh. This might make the findings of this study different from the majority of persons with diabetes in Cambodia.

After exploring through these objectives with the research participants, I found out the thesis has become one about the experience of glycemic fluctuations. It does not mean there is no hypoglycemia among Cambodian diabetes patients but probably because the unavailability of every day blood glucose measurement technologies makes their every-day management become one of reading signs of fluctuations in the correct and functional way. As a result, interpreting the abnormal glycemia becomes one of the main issues discussing in this thesis. The following section will introduce the structure of this thesis.

Structure of the thesis

This thesis contains eight chapters in total, including this introduction chapter.

Chapter 2 provides the background information. It begins with an overall of Cambodia and its health care situation. The general description of MoPoTsyo then follows.

Chapter 3 presents the literature review. It begins with the current global knowledge about hypoglycemia. The presentation of the studies about diabetes and hypoglycemia in Cambodia follows. And two articles with the similar objectives conducted in different settings are discussed in particular. Finally, the research gap is then identified in the end of the chapter.

Chapter 4 provides the description of the research methodologies and the analytical framework. This includes the rationales for each chosen methods, the descriptions of fieldwork practices, analysis, ethical considerations, reflexivity and the weakness and strengths of this project.

Chapter 5 provides the information of the research setting in details. It illustrates the lives of the research participants, including their living conditions, their diet, the accesses to health system and diabetes care. How diabetes and hypoglycemia are perceived in Khmer society and the description of Khmer ideas of healing and illness follow. Activities related to MoPoTsyo and information provided by

MoPoTsyo are described in the end of this chapter.

Chapter 6 and Chapter 7 are the two findings chapters and the discussions are presented along the contents. Chapter 6 describes the interpreting process of the research participants. It demonstrates how participants understood their discomforts before they met the biomedical framework and how the discomforts, the terminologies, the results from measurements and the self-care activities shaped their understandings of the glucose levels in biomedical definition. Chapter 7 describes how participants perceived the instruction of the diabetes self-care and what might influence their practices.

Chapter 8 is the conclusion and the recommendations based on the previous chapters. Each secondary objective is summarized respectively and the recommendations to MoPoTsyo are given.

Chapter 2: Background

Cambodia in general



Figure 1 Map of Cambodia
(Based on OCHA/ReliefWeb)

Cambodia, officially known as Kingdom of Cambodia, is located in the Indochina peninsula in Southeast Asia and bordered by Thailand, Vietnam and Laos.

The history of the Khmers can be traced back between the first and fifth centuries AD. Around ninth centuries AD, the Khmer Empire of Angkor was built, which was fell around 14th centuries. French arrived in 1863 and Cambodia was under their rule until the beginning of 20th centuries. During the WWII, Japanese forces occupied Cambodia and it was

returned to French colonialism in 1945. In 1953, Cambodia was independent from France and had a short period of “golden years” at the beginning of the cold war. The country then suffered from Vietnamese war and underwent a catastrophic revolution, Khmer Rouge, from 1975-1979. Everyone needed to work in the fields and got little foods during that time. It was believed one to three million dead during that period because of hunger, disease or the execution (Ray & Bloom, 2012). Plenty of the survivors are still suffering mentally nowadays (Kemp, 1985). Pol Pot government was toppled by the Vietnamese. However, Cambodia was still unstable in political situation. International organizations and United Nation has involved in Cambodian politically since 1991 and the country developed gradually. In 2013, Hun Sen won the election again and is one of the longest serving prime ministers in the world that he has governed Cambodia since 1985 (Ray & Bloom, 2012).

According to WHO (2014), the population of Cambodia was 14.8 million in 2012. Ethnically, 90% of the population is Khmer; other ethnics groups include Vietnamese, Chinese and other minorities. Buddhism is the dominant religion in Cambodia. 80% of the population resides in rural areas, depending mainly on agriculture (WHO, 2012a). Cambodia was the 138th among 158 countries in Human Development Index published by United Nation in 2013; although economic has grown stably since 1993, the country still has some of the worst

human development index indicator among countries in Southeast Asia (WHO, 2012a).

Health-related issues in Cambodia

According to WHO (2011), the Cambodian Health Coverage Plan divides the country into 73 operational districts, which comprises 10-20 health centers and a referral hospital. Health centers deliver minimal packages which provide basic services and the essential medication listed by the Ministry of Health. However, utilization of health facility, financial situation of the government and lack of expertise, facilities, access to medication and other resources are the main problems in Cambodia; physical access, lack of trusts in public health, social and cultural practice, especially strong usage of traditional herb medicine and costs are viewed as barriers for utilization (WHO, 2012a). With the aids from international donors, the government started exemptions of costs for the poorest in public sectors, and international organizations also play an important role in health service delivery (WHO, 2011).

Life expectancy is 60.5 and 64.3 years for men and women respectively. Communicable disease, including Dengue fever and malaria, is the main cause of morbidities. Recently, the burden of non-communicable disease (NCD), including diabetes, has been soaring (WHO, 2011). The prevalence of diabetes was estimated in 2005 to be 5- 11% (King et al., 2005); most of them are diagnosed with Type 2 diabetes. Type 1 diabetes is rare on account of under-diagnosis which is suggested to give reasons for early deaths (van Pelt, 2009).

Even though the government notices the problems of NCDs, there is limited provision in the public sectors. WHO (2012a) states “diabetes services are limited due to a lack of expertise, facilities, and access to medications in public sectors” (p.3). From 2002, several NGOs have established several diabetic clinics with free medication and patient education (van Pelt, 2009).

MoPoTsyo—the patient information center

In 2004, MoPoTsyo was established by four Cambodians and one Dutch, in order to provide adequate cares and information through peer educator networks to patients with diabetes and hypertension. It receives donations mainly from international organizations, such as AusAID, World Diabetes Foundation and Medecins Sans Frontieres (MoPoTsyo, 2014).

MoPoTsyo provides affordable medication and medical services to patients, including regular blood glucose checkups and doctor consultations; the poorest may receive financial aids from the organization. Glucose-lowering medications provided by MoPoTsyo include oral medication (Metformin and Glibenclamide) and insulin (NPH, Actrapid, Lantus, mix 70/30). They also cooperate with other organizations to follow up patients' long-term complications, such as retinopathy. Until 2012, there are around 6000 members registered with diabetes among 153 peer networks. Among these patients, almost 300 members are self-injecting insulin every day; others use oral medications (MoPoTsyo, 2013).

Peer educator networks are established in a range of communities throughout the country, where patients can access diagnosis testing and discuss problems related to diabetes and self-management with their peers and peer educators. MoPoTsyo identifies the possible candidates for being the peer educators in the prospective communities. Candidates receive training for few weeks. During the training session, candidates learn about basic biological knowledge of the human body, diabetes and hypertension, relevant self-management and the administrative routines; they also practice of blood pressure - and blood glucose-measurements. After passing the examination, the candidates become the peer educator in their own community. The peer educator system is volunteer-based; they do not get salary but they may get the small amount of money as reimbursement based on what they have done for the organization, such as how many invoices from the pharmacy they checked for the patients.

The peer educators then help to detect the possible new patients in their community through survey, but some patients may be introduced to MoPoTsyo through others patients. When patients become the member of the organization, they need to attend the checkups at peer educator center at least once per month in order to maintain their membership and get the affordable and accessible services. The checkup is held once per week in each peer educator center. Patients measure their blood pressure, glucose levels and weight at the checkups. The peer educators serve as counselors, giving advice of self-care to the patients. Self-management is highly promoted. Patients are expected to take care of their daily lives, such as diet, exercise and medication. Due to the limitation of the resource, patients need the permission to go to the doctor consultation and the peer educators are the gate-keepers.

MoPoTsyo conducts many researches with different researchers or organizations all over the world. Meanwhile, lobbying is also one of the main focuses in the

organization that they hope the Cambodian government will take actions in the relevant health policy.

Chapter 3: Literature Reviews and Research Rationale

Literature Search

Literatures search had been done mainly from the end of January, 2013 until the beginning of March, 2013 and an update in May, 2014 in many ways. Electronic databases on the internet were used, including PUBMED, CINAHL, EMBASE, Psycinfo, and internet searching engine, Google scholar. Some articles were obtained from reference lists of the read literatures. Also MoPoTsyo and the supervisor provided some valuable articles.

Searching terms included diabetes, hypoglycemia (or hypoglycaemia), experience, meaning or perception and social or cultural. Titles were examined first. Exclusive criteria of literatures were gestational diabetes, pharmaceutical related, biochemical related, molecular-biological related and non-English articles.

Excluding non-English articles might lead to miss important articles in the study field. However, according to a professor from Cambodian National Institute of Public Health, literature of non-communicable disease in Cambodia was relatively scarce.

Existing knowledge in hypoglycemia

Existing knowledge in hypoglycemia can be divided into different themes, including definition, symptoms and risk factors, interventions and preventions, and consequences of hypoglycemia.

Definition

Hypoglycemia is defined by ADA (2005) as plasma glucose concentrations lower than 3.9mmol/l (70mg/dl). However, it is known the symptoms are nonspecific and differ from people to people even in the same level of glucose (ADA, 2005). A review about hypoglycemia by Amiel, Dixon, Mann, and Jameson (2008) states severe hypoglycemia is the only agreement internationally. The episode of severe hypoglycemia means the individual cannot self-treat their hypoglycemic episode and need help from others. These facts indicate hypoglycemia is beyond the number shown in the blood glucose test. It should be studied within individuals and based on their contexts.

Symptoms and risk factors

The episode of hypoglycemia usually happens with psychological and physiological symptoms. Generally, it is an unpleasant and inconvenience experience (Frier, 2008; Hilden, 2003; Lawton et al., 2013; Merbis, Snoek, Kanc, & Heine, 1996; Richmond, 1996; Ritholz & Jacobson, 1998; Shiu & Wong, 2002; Tan, Chen, Taylor, & Hegney, 2012; Wu, Juang, & Yeh, 2011). Symptoms vary from giddy and weakness (Tan et al., 2012), emotional change (Frier, 2008; Tan et al., 2012; Wu et al., 2011), hunger sensation (Lawton et al., 2013; Tan et al., 2012), disorientation (Lawton et al., 2013) to confusion (Tan et al., 2012), which depend on the severity of the hypoglycemia. Furthermore, hypoglycemia can bring stress to the body and cause myocardial infarction and cognitive neurological dysfunction (Frier, 2008). Patients are encouraged to recognize their own warning signs because unawareness can make the situation of hypoglycemia worsen (Barnett et al., 2010; Richmond, 1996). However, some diabetes patients may develop unawareness due to the disease progress (Cryer, 2008a). Also non-consistency in blood glucose levels and symptoms make participants confused (Shiu & Wong, 2002; Weiss & Hutchinson, 2000). Moreover, one study conducted in India suggests patients may report their symptoms differently because of the different language and cultural background (Bhutani et al., 2013). Therefore, individual and cultural differences should be considered in the study of hypoglycemia.

Diabetic hypoglycemia is usually iatrogenic, meaning it occurs because of using glucose-lowering medication (Amiel et al., 2008). At the same time, gender (Giorda et al., 2014), age, duration of diabetes (Bohme et al., 2013), comorbidity of cancer, the presence of diabetes complications (Giorda et al., 2014), history of hypoglycemia, fluctuated glucose levels (Choudhary & Amiel, 2011; Wild et al., 2007), mood and stress (Balfe, 2009), alcohol (Balfe, 2007), exercise (Mol & Law, 2004) and diet (Tan et al., 2012) may also influence the occurring of hypoglycemia. Some studies state different roles in life may also influence self-care and bring the episodes of hypoglycemia (Berg & Sparud-Lundin, 2009; Mol & Law, 2004; Wu et al., 2011) and the employment status may increase the risk of symptomatic episodes (Giorda et al., 2014). As a result, hypoglycemia is not only linked to biomedical factors but also social elements. Because of its complexity, some participants feel hypoglycemia is unpredictable (Weiss & Hutchinson, 2000).

Interventions and preventions

International guidelines suggest patients should check their blood glucose levels regularly and when they feel ill to intervene and prevent hypoglycemia (ADA, 2005; IDF, 2012). After the measurements, patients should know how to adjust their medications (Wu et al., 2011). Meanwhile, the diabetes patients should monitor the intensity of physical activities, their diet, and live with a routine life (Balfe, 2009; Tan et al., 2012; Wu et al., 2011). When being hypoglycemic, patients should take proper amount of sugar (Clarke, Jones, Rewers, Dunger, & Klingensmith, 2008). Some studies also state revealing their diseases to others in social networks can be helpful for preventing the severe hypoglycemia (Amillategui, Mora, Calle, & Giralt, 2009; Tan et al., 2012; Wu et al., 2011).

However, studies show the expense and the procedures of glucose measurement, which also involves the issue of privacy, bring troubles to some participants (Balfe & Jackson, 2007; Rajaram, 1997; Shiu & Wong, 2002; Tan et al., 2012; Wu et al., 2011). At the same time, living in a routine life can be challenging (Balfe, 2009). Some participants state they do not live with diabetes only; everyone has different characteristic and different tasks in their lives, such as they might be sporty or in the situation of losing weight (Mol & Law, 2004). Moreover, in the status of hypoglycemic, it would be difficult for the British participants to determine how much sugar they should take (Lawton et al., 2013). Also intervention may involve others' decisions where the participants cannot handle (Rajaram, 1997). In order to prevent hypoglycemia, studies also mention some participants developed avoidance behavior by eating more foods or injecting less insulin (Bohme et al., 2013; Richmond, 1996), which lead to the problem of "compliance."

Compliance

Studies show 25% to 40% of the participants maintain high blood glucose after experiencing hypoglycemia (Amiel et al., 2008; Bohme et al., 2013; Diago-Cabezudo, Madec-Hily, & Aslam, 2013). As a result, hypoglycemia is believed to be one of the barriers achieving optimal blood glucose levels (Cryer, 2008b), which indicates diabetes patients become "non-compliant" to the treatment (Bohme et al., 2013; Rajaram, 1997; Richmond, 1996). Compliance means patients follow the treatment recommendations for medication, exercise and diet. Being hypoglycemic is viewed as a failure or out of control event in the medical encounters (Rajaram, 1997) since health care providers believe diabetes is a condition that patients should and can self-manage (Ferzacca, 2000; Montez

& Karner, 2005).

However, studies show “compliance” is not that easy. Not only the condition of diabetes affects their willingness to stick to treatment, but also their understanding of the disease (Awah & Phillimore, 2008), their cultural and social concept of food (Borovoy & Hine, 2008), their roles and status in society and family (Baglar, 2013; Ferzacca, 2004, 2012; Shiu & Wong, 2002) may also influence. Meanwhile, the word “compliance” creates a sense of moral judgment. Participants become bad patients and they would be blamed because they are not able to control their blood glucose (Richmond, 1996; Shiu & Wong, 2002; Tan et al., 2012). They may also feel guilty when maintaining higher glucose levels (Richmond, 1996). Thus, some participants will try to “lie” to their doctors before the monthly checkups (Ferzacca, 2000) and/or not report and discuss episodes of hypoglycemia to them (Barnett et al., 2010). Moreover, some participants say they feel stigmatized by being diabetes because everyone would think they have a bad lifestyle (Ritholz & Jacobson, 1998).

Relationships between health care providers and patients

Many studies discuss the relationships between healthcare providers and patients. From participants’ point of view, doctor cares more about the number from the measurements of blood glucose and not cares about feeling and emotion of them and their family (Bohme et al., 2013; Richmond, 1996; Ritholz & Jacobson, 1998; Shiu & Wong, 2002; Wu et al., 2011). Meanwhile, although information from healthcare providers are the main sources for knowledge of diabetes and hypoglycemia (Tan et al., 2012), some participants in Hong Kong mention the knowledge and information provided by doctors are too optimal that they cannot follow easily and impersonal (Shiu & Wong, 2002).

Consequences of hypoglycemia

In the current literatures, several influences are mentioned, including patients’ quality of life, social and psychological influences.

Quality of life

Hypoglycemia episodes make patients’ lives different from others; participants state they feel limitation in their lives; they do not enjoy what they were fancy to, lose confident and not enjoy eating (Wu et al., 2011), exercising, traveling and driving (Frier, 2008; Richmond, 1996). Some might even give up their employment (Shiu & Wong, 2002; Wu et al., 2011) and educations (Richmond, 1996).

◆ *Social influence*

An Italian study shows the episode of severe hypoglycemia may affect patients' overall work productivities and interferes the social activities (Lopez, Annunziata, Bailey, Rupnow, & Morisky, 2014). Hypoglycemia does not only influence diabetes patients but also their social networks. Some participants state it may bring burden to their family (Amiel et al., 2008; Balfe, 2007). Significant others and caregivers may be more anxious than people with diabetes, which made them feel loss of autonomy and independence (Rajaram, 1997). When others remind participants about their possible hypoglycemia, participants may feel offended, and it may cause tension between them (Hilden, 2003). When the episode occurs in public places, several studies indicate wrong interpretations from others also bring pressure to participants. They may feel stigmatized with disability and drug-addiction (Balfe, 2007; Ritholz & Jacobson, 1998; Wu et al., 2011). Meanwhile, whether disclosure disease status to friends is another issue addressed among participants. Some view it as privacy because it may bring unnecessary worries and cares from others; some say they can gain help from others (Balfe & Jackson, 2007; Ritholz & Jacobson, 1998; Wu et al., 2011).

◆ *Psychological influence*

Participants mention dependence (Rajaram, 1997; Richmond, 1996), embarrassment, unwanted attention, loss of confidence (Ritholz & Jacobson, 1998; Wu et al., 2011) when they were in the episode of hypoglycemia. They also feel lonely because no one can understand their episodes (Richmond, 1996; Ritholz & Jacobson, 1998; Shiu & Wong, 2002; Wu et al., 2011).

Some participants show fear and anxiety after the episode of hypoglycemia (Amillategui et al., 2009; Rajaram, 1997; Shiu & Wong, 2002; Wu et al., 2011) or after witnessing episodes of others (Tan et al., 2012). Several quantitative studies develop fear of hypoglycemia scale. It includes two subscales—worry and behavior (Amiel et al., 2008; Wild et al., 2007). Studies compare different variables which may influence the degree of fear from person to person, such as ages, types of diabetes, history of diabetes and treatment (Bohme et al., 2013; Diago-Cabezudo et al., 2013; Shiu & Wong, 2000). Whether the degree of fear is correlated with maintaining higher glucose levels remain unclear; some show significant and some do not (Bohme et al., 2013; Diago-Cabezudo et al., 2013; Shiu & Wong, 2000; Wild et al., 2007). Qualitative studies show participants understand the consequences of being high and low in glucose levels, but still in a dilemma when talking about glucose controls; some participants state they accept hypoglycemia as part of their lives; some are still struggling (Richmond,

1996; Shiu & Wong, 2002; Wu et al., 2011). Family and friends surround may be anxious and fear of hypoglycemia, too (Balfe, 2007; Frier, 2008; Rajaram, 1997; Richmond, 1996; Wu et al., 2011)

Some studies recommend better educations that should include family members (Shiu & Wong, 2000), cognitive-behavioral therapy (Boyle, Allan, & Millar, 2004) and blood glucose awareness training (Wild et al., 2007), may reduce the degree of fear of hypoglycemia.

Literature in Cambodia

Existing literature in Cambodia were studies of the prevalence of diabetes (King et al., 2005; Otgontuya, Oum, Palam, Rani, & Buckley, 2012; Raguenaud et al., 2009) and the evaluations of the clinic and organization services (Eggermon, 2011; Raguenaud et al., 2009). There is one master thesis discussing the self-management among Cambodian diabetes patients, which pictured how Cambodians used technologies, chose diets and perceived the idea of diabetes (Green, 2011). One recent study shows more than 80% of diabetes patients attending diabetes program in the national hospital in Phnom Penh do not reach the recommended target levels of HbA1c, which can be used as an indication a prolonged period of time for glycemic control (Jung et al., 2014).

Discussion

There are two articles discussing type 2 diabetes patients' experience in hypoglycemia (Tan et al., 2012; Wu et al., 2011). They both used one-time semi-structured interview as the research method. Wu et al. (2011) reviewed the medical records after interview. As other studies shown before, privacy is one of the issues in hypoglycemia. Therefore, individual interview is suitable in the setting when researchers understand the language, the culture and the issues around hypoglycemia well. However, rapport may be difficult to be formed during one-time interview.

Meanwhile, both studies were conducted by nurses. No reflexivity was shown in the paper, probably due to the limitation of the pages. Also both studies recruited participants through the health facilities. As mentioned before, some studies indicate the power of biomedicine may make participants feel judged, which may make them not tell the truths to the health providers. With one-time interview, it is reasonable to doubt the results.

They explained the strategy for data collection and analysis clearly. The study by

Tan et al. (2012) only showed the number of participants and the range of ages. Further information about participants was not provided in the paper. Some important issues might be hidden since hypoglycemia is influenced by social factors as suggested previously.

Both studies quoted words from participants. They were easy to distinguish from authors' voice, but sometimes they were too short to find the relations between themes and quotation.

Research Gap

Most patient-centered research on hypoglycemia focuses on type 1 diabetes patients alone, since hypoglycemia has traditionally been linked to insulin treatment. Moreover, there is a strong predominance of studies conducted in resourceful countries. Finally, studies are often conducted under the auspices of health facilities, where the research participants are recruited. This may be a weakness since hypoglycemia is linked to actions performed by the patients, and the clinic may be associated with the normative biomedical perspective on how patients should ideally manage their self-treatment.

To my best knowledge, however, there is no literature in English on hypoglycemia experience of diabetes patients in Cambodia or comparable contexts in the region. This study will help to gain insight into the experience and the meaning of hypoglycemia of diabetes patients and their family in a resource limited setting, as well as the way this topic is handled in patient education and patient support services. The study will be conducted outside the regular health facilities, in collaboration with an NGO (MoPoTyso) that organizes peer based support and training for persons with diabetes and their families.

Chapter 4: Methodologies and Analytical Framework

As shown in the previous chapter, there is a need for conducting research with regard to the meaning and the experiences of hypoglycemia in Cambodian diabetes patients. This chapter aims to explain the chosen methods for gaining insights into the experiences of hypoglycemia and demonstrate how the research has been designed.

The chapter will begin with the rationales for the chosen methods and address how the data were collected, the possible limitations and influences and the analytical processes. Secondly, ethical consideration regarding the project will be presented. Since the researcher myself is the tool in this research, reflexivity will then be discussed followed by limitations and strengths of the project.

Methods

Rationale for the chosen methods

In order to gain insight into the experience and the meaning of hypoglycemia, it is important to acquire descriptions from diabetes patients within their daily lives. It is possible to gain knowledge from verbal discussions with patients, their social networks and people involved in diabetes health care. There are several quantitative studies discussing issues related to hypoglycemia. They determine different variables in order to understand why degree of fear can be different from person to person (Bohme et al., 2013; Diago-Cabezudo et al., 2013; Shiu & Wong, 2000). However, there is no literature in issues related to hypoglycemia in Cambodia to my best knowledge; as a result, it would be difficult to come up with the variables in advance. Meanwhile, I would like to know not only about their degree of fear of hypoglycemia but also their living experiences; therefore, quantitative approach was not considered as suitable in this study.

Most of the qualitative articles use the interview as the method to explore and understand the experience of hypoglycemia. Some articles use observation as supplement in order to gain a deeper insight into the lives of diabetes patients. There are two similar studies exploring the meaning and experience of hypoglycemia in Type 2 diabetes patients in Singapore and in Taiwan (Tan et al., 2012; Wu et al., 2011). They both use one-time semi-structured interview as the method and are conducted by nurses and they recruit participants through a health facility. As mentioned in “social influences” section in the previous chapter,

hypoglycemia may touch upon the issues of privacy, therefore, individual interview is considered as suitable when researchers understand the language, the culture and the issues around hypoglycemia well.

However, data generated from one time interview may be questioned. Participants might say something that is not represented their true situation. They may not intend to lie, but it takes time for human beings to understand what they have been asked. As a result, people might tend to say what they have heard, what they have learned from others, and even what they may think they have done instead of what they exactly do themselves. As a consequence, repeated interviews were considered in order to strengthen rapport and improve communication.

Meanwhile, recruiting participants from a health care facility may bring the concerns of power. Even though the researchers may not reveal their opinions about what “correct” and “good” diabetes management is, the setting and the roles as nurses may still influence how people tend to answer to these normative questions and they may give socially acceptable answers instead of their own experience. Therefore, it is important to consider how to avoid the power of the biomedicine.

At the same time, triangulation in methods was also considered to present the lives of diabetes patients in this study because the meaning and the experience of hypoglycemia are related to what patients might think mentally, their verbalized reflections and their actual behaviors. By observing participants’ daily lives, I could hope to acquire more insight of “how the actions of participants correspond to their words” (p.49) (Glesne, 2006).

The health issues are not only about the disease and the individual patient; the socio-economic factors and environmental factors should be considered when exploring the health-related issues among people (Helman, 2007). At the same time, social and cultural aspects should be included for the project in relation to hypoglycemia as discussed in the literature review. As an outsider in Cambodian society and moreover, trained as a nurse, it was important to understand the society, the culture and local settings as much as possible. Observation, focus group and textual analysis were considered to benefit the situation.

Glesne (2006) mentions observation can provide the opportunities to understand the research setting, its participants and their behavior. Observation also means learning from people directly. In addition, I planned to conduct

textual analysis in order to understand how Khmer society discussed about health- and diabetes-related issues. Meanwhile, through textual analysis, I could be familiar with the setting, such as what kind of information MoPoTsyo hand out and the health care situation in Cambodia. Moreover, Morgan and Krueger (1993) suggest that “focus groups can be used when there is a gap between researchers and target group due to such factors as language, culture, region and professionals” (p.16). At the same time, focus groups can provide opportunities to explore how Cambodian diabetes patients discussed relevant issues. Since I did not speak Khmer, I needed the help from a translator, which will be discussed in the “fieldwork practices” section.

I will address how each method was conducted, where I deviated from the proposal and the possible influences and limitations in the following sections.

Repeated interview

Interviews can obtain descriptions of the life world of the interviewee in order to interpret the meaning of the described phenomena (Kvale & Brinkmann, 2009). They can be used to understand complex issues (Ritchie & Lewis, 2012). Therefore, in order to gain insights into patients’ experience and meaning of hypoglycemia and because of the reasons discussed previously, repeated interviews were the main sources of the collected data in this study.

During the fieldwork, nine diabetes patients were recruited for repeated interviews. Three were only interviewed once due to being out of the town or sick during the rest of the fieldwork period. I had planned to interview family members but only informal interviews were done because they were usually busy with their work. The process of recruitment will be discussed in the “fieldwork practices” section and the credibility of one-time interview will be addressed in the “limitations.”

A thematic guide for interview, shown in the appendix 1, was prepared before the research started but it remained flexible as suggested by Ritchie and Lewis (2012). Several new and unexpected themes and different knowledge were identified after I entered the field.

Since I did not understand and speak Khmer, a research assistant was recruited and was therefore present during the interviews. He translated what I said to the participants and what the participants said to me.

Audio-recording was used for all interviews after granting permission from the

participants. It can help to capture the words and tones of participants and note the important ideas without interrupting the interview; at the same time, the interviewer can concentrate on the topic and the dynamics of the interview (Kvale & Brinkmann, 2009). However, audio-recording cannot provide information about participants' body language and the context of the interview. At the same time, some parts of a few interviews were not clearly recorded because of the noise of the street and the rain. Therefore, the research assistant and I also took notes. I was aware that audio-recording and note-taking might influence the way how participants spoke, therefore, I placed the recorder discreetly and I took note when the assistant finished translating to me and continued the conversation with the participant; meanwhile, I only noted the key words in order to shorten the writing time. The research assistant and I would discuss the scenario and the reflection note was taken right after our discussions.

The researchers may control how an interview flows; therefore, an interview is not the situation where two people talk equally (Kvale & Brinkmann, 2009). The authority of biomedicine may make people feel being tested as what Martin (1994) illustrated for the problem of expertise. Therefore, they may adjust their self-presentation so that they meet their perceived expectations of the health professionals. This is also the reason why I choose the word "participants" to describe people involved in the study because they joined the study and influenced by the researchers or vice versa.

In order to minimize the potential influences of the power of the biomedicine, I interviewed participants mostly in their home or in the food shops near their home. During the interview, I stressed my role as a student, who wanted to learn from their experiences. I also disclosed myself and shared my feelings to them. For instance, when they mentioned it was easy to follow the dietary recommendations, I told them it sounded difficult for me and I might feel annoyed. Sometimes they would explain more regarding the diet and share about how they exactly did for their diet. Further issues will be discussed later.

The constraint of interviews is the researcher may not obtain the actual behaviors of the participants (Ritchie & Lewis, 2012); therefore, observation was used in order to complement verbal methods.

Focus group discussions

As Ritchie and Lewis (2012) explain, a focus group is a group discussion where participants are involved in the discussion and hear from others in a relatively

social context; it may provide them with a chance to refine what they said and what they experienced through interaction with others. Researchers can learn how participants speak about the issues and their general understanding on certain topics (Ritchie & Lewis, 2012). These issues emerge spontaneously from discussions within the group; as a result, focus group can be used, for instance, to explore the topics in a novel field at the beginning stage of the research (Ritchie & Lewis, 2012). Due to the characteristic of interaction between people, choosing participants is important for focus groups, where diversity and commonality may influence the discussion (Ritchie & Lewis, 2012).

One focus group aimed to explore the general ideas around diabetes and hypoglycemia. It was conducted at the very beginning of the study with seven participants, three men and four women. Participants were recruited from four out of five MoPoTsyo peer networks. Issues around recruitment and its possible limitations will be discussed in details later. It was held on Saturday morning in the meeting room at MoPoTsyo headquarter. Due to time constraints, the second focus group, to reflect on how researchers analyzing and interpreting the collected data and check whether the result is complete (Ritchie & Lewis, 2012), was not conducted as planned. Instead, I had a preliminary result presentation to the staff in MoPoTsyo, which gave rise to discussion and feedback based on the initial analysis.

A thematic guide was used for the focus group discussion, which will be shown in the appendix 2. Because the focus group discussion was conducted in the early stage of the study, some issues appeared in the later stage of the study had not explored in this focus group. For instance, the complex situation of terminologies for hypoglycemia would have been a good topic to explore within a group discussion. However, the issue was discovered at the same time when the focus group had been recruited so the selection had already been made.

Due to the fact that I did not speak and understand Khmer, the research assistant translated what was being discussed and both of us served as observers in the focus group discussion. A moderator, who was the classmate of the research assistant, was then recruited. He had several experiences in holding discussions for different organizations. We had met twice before the focus group and discussed about the procedure and the content. There was no other staff in MoPoTsyo presented during the focus group discussion.

Audio-recordings were used with participants' consent. Meanwhile, privacy was considered as suggested by Morgan and Krueger (1993). Participants were

informed they had the rights to reject and leave the discussion if they did not feel comfortable to do so. We also stressed that personal experiences were not the aim for the discussion unless the participants volunteered to exemplify the discussion with such examples. Confidentiality and other ethical concerns will be discussed in the later section.

Observation

Observation, or participant observation, aims “to understand the research setting, its participants and their behavior” (p.51) (Glesne, 2006). It can help the researcher to gain insight into what happens in a natural way and rebuild perspectives (Ritchie & Lewis, 2012). At the same time, it provides opportunities for researchers to learn about the cultural and social norms among participants, which is particularly essential at the beginning of the study (Glesne, 2006). Meanwhile, in addition to the expected topics, researchers may experience unexpected during the observation (Glesne, 2006); therefore, it is important to be flexible and reflective during the research period. Participant observation is a spectrum, from mainly observation to mainly participation (Glesne, 2006). I was more likely an observer as participant or participant as observer in the study since I did not only observe what had happened purely but also interact with the participants. Meanwhile, I did not serve as a staff in MoPoTsyo or the member of the peer networks, so it was not mainly participation, either.

During the fieldwork, I learned about Khmer history, culture and society through visiting different places, such as museum, schools, parks, markets, restaurants, hospitals and health centers, with research assistants and local friends. And I also joined several festivals and parties with friends to experience Khmer culture.

Meanwhile, I observed the settings concerning diabetes care and services from MoPoTsyo. I attended several peer educators’ checkups to observe and gain insight into how it functioned and the interactions between peer patients and between patients and peer educators. Field notes were taken about the general situation. In order to prevent the possible ethical concerns in confidentiality, I did not note down anything that could identify the observed persons.

During the focus group discussion and interviews, I also observed participants. Unfortunately, I did not have chance to participate in participants’ daily lives as planned. However, I visited their kitchens and the surroundings; and sometimes I had opportunities to taste their dishes, gaining further insights into what kind of foods they ate. I observed and was involved in the hypoglycemia interventions

twice at participants' houses when I interviewed them. This is a limitation of the study since I did not observe their behaviors directly.

As a new-comer, who did not speak and understand Khmer, in Cambodian society, the research assistant played an essential role in observation. He helped me to “comprehend” the setting and translate what was going on to me. We discussed and reflected every day or after the observation section. He would answer my questions and I might challenge his “taken-for-granted” perspectives in his own culture. This will be discussed more in the following section.

Textual analysis

I reviewed governmental reports, news, health magazine and posters and brochures used in MoPoTsyo. Most of the documents were in Khmer. As a result, textual analysis was done with help from the research assistant.

The governmental health plan was accessed through their website. With the observations and visits, I was clearer about the health system in Cambodia. Meanwhile, the research assistant helped me to search health-related reports on the internet. However, it was not easy to find them in newspaper. Some were commercial advertisements for private clinics, while others were the news from the government or WHO, such as the decrease of malaria in Cambodia. We read one article from foreign radio stations about diabetes and one about low blood glucose levels. This helped me to know how Khmer society discusses health issues publicly.

The research assistant and I took a close look at all brochures and posters that were available in MoPoTsyo, including the patients' booklets, food pyramid posters, the materials for peer education and an illustrated book for health promotion. This helped me to become familiar with the settings. With the assistance of observations and interviews, I could understand what people involved in the study mentioned and the framework of what they talked about.

Fieldwork practices

Timeframe

I arrived in Phnom Penh on July 19, 2013 and visited MoPoTsyo on July 22, 2013. The ethical approval was gained on August 09, 2013; the focus group discussion was on August 17, 2013, and 19 interviews were conducted afterwards. A presentation to MoPoTsyo staffs of preliminary result was held on November 06,

2013. The field work was 17 weeks in total. The election of Cambodian Prime Minister, which resulted in several clashes and tensions on the streets, occurred during the fieldwork period. The detailed timeframe will be shown in appendix 3.

Approaching

The general program manager in MoPoTsyo guided me so I became familiar with services and the peer educator networks at the beginning stage. I met all staffs in MoPoTsyo headquarter on the first day and I was introduced to five peer educators in Phnom Penh in a meeting in the first week, where I introduced myself and my research to them. We agreed upon every time before I went to the weekly checkup in each network, I needed to inform them beforehand.

After the ethical approval was obtained, I started visiting checkups in different peer educator networks. The recruitment was in line with the procedures of the ethical approval. For the first few sessions, when the assistant and I arrived, we would greet to the presenting patients and the peer educator first and the peer educator would explain who we were and what we would like to talk to patients. They would then “*assign*” patients to talk to us. Some patients would reject if they were busy but usually they would join the conversation since there was also a queue for checkup. I used the verb “*assign*” because, first, the peer educators would know who was available for a short time to talk with since some patients were in a hurry to work; secondly, they would introduce those they were more likely to know who had experienced hypoglycemia to us.

However, after two observation sessions, I figured out the complexity in using terminologies of hypoglycemia in Khmer. Therefore, the assistant and I decided to conduct a little survey through informal conversation with patients. In order to understand exactly what Cambodians understood about the terminology, we talked with different patients, whether they had experienced hypoglycemia before or not. In this session, I took note of what they said about the terminologies and I did not note down details that could reveal their identity. The aim of the survey was to understand the possible and different understandings of terminologies; therefore, I did not count the number for their answers, such as how many patients among total patients did not think of hypoglycemia when they heard “low sugar.” These terminologies arose in the survey then explored with the research participants in the interview.

After peer educators introduced us to all the potential patients, and we would approach patients by ourselves while they were waiting in queue. We started

informal conversations with small talks, such as how long had you waited here. Some patients would take the initiative to talk to us since it was an open space and everyone could know and hear what we talked about; we had an open attitude towards who we were going to talk to. However, some of them viewed it as an opportunity to get medical advices. We would listen to them but also explain that I was a student conducting a project, and referred them to meet the doctor or the peer educators for further helps.

After greeting, I would introduce myself in Khmer and tell them I could not speak Khmer so the assistant would help me to translate. The research assistant would introduce himself and the project. After introduction, we would obtain the permissions from individuals before we started asking questions. The contact information was obtained after I knew they had experiences in hypoglycemia and they expressed their willingness and interests to join in the project. The possible influences will be discussed later in the “recruitment” section.

◆ *Complex situation in terminology and its influence in recruitment*

While checking the translated informed consent forms, staffs in MoPoTsyo had discussed about the Khmer terminology for hypoglycemia. They had explained there was no unified word for hypoglycemia; most people would use “low sugar” but “extreme low sugar” and “too much low sugar” were also heard. We had thought patients would understand them all as hypoglycemia anyway. Therefore, the assistant and I decided to explain my research with the word “low sugar.”

However, when I approached patients in the checkup, some patients would say “low sugar” was good and they were happy to hear “low sugar.” At the beginning, the research assistant and I thought it was because of our mistranslations, but it kept happening. We then tried to use other words and ask if they had experiences the discomforts with regard to hypoglycemia after medications or before meals. Usually they did not have experiences as such. For these patients, “extremely low sugar” and “too much low sugar” did not mean hypoglycemia, either. They thought it was lowering from extremely high to normal, and they were still happy to hear that. Thereafter, we found out the different understandings of terminologies among patients and its influences for recruitments.

After discussing with my supervisor, I changed the way of inquiry. I asked them “how diabetes influenced your life after you got diagnosed,” and probed more during our subsequent discussion. I would ask their permissions for joining the focus group discussion or further interviews if they had experiences in hypoglycemia. If they did not mention the discomforts, the interventions, or the

timing of happenings in relation to general understandings of hypoglycemia, I would define those patients as “no experience in hypoglycemia.”

Meanwhile, in further discussion with MoPoTsyo personnel, another word—“lack of sugar”—was mentioned, which was usually used within health facilities. Moreover, we also inquired peer educators for their understandings; they had similar understandings as the research participants. Owing to the selection criteria, participants in the research all understood one of the words as hypoglycemia and could describe the situations, how they acted and its possible reasons for its occurring. However, the terminologies were still confused sometimes, which will be discussed in details in the finding chapter.

Recruitment and brief information about participants

Participants		
Core participants	Key informants	Others involved in study

Everyone I talked to and observed during the fieldwork is considered as a participant in this study. I divided people into three different groups. Core participants were these interviewed adult diabetes patients who had experiences in hypoglycemia. They were the participants providing the direct information to the objectives. Key informants were these who might or might not have diabetes themselves, but they could provide some insights because their position in MoPoTsyo or in the society provided a strategically useful vantage point in relation to the topic of the study. Other participants were those attending the focus group discussion and those I spoke to during the checkups.

◆ ***Core participants***

Brief information of core participants was as shown below. The number in brackets after insulin means the dosage they injected each time. Severe hypoglycemia was defined as fainting or near-syncope.

I recruited core participants through five peer networks in Phnom Penh. Initially, I had planned to interview patients from rural Cambodia. However, due to the time constraints, all collected data were from the city. Two participants lived in relatively suburb districts, while other seven participants lived in the city.

I did not set criteria for recruitments when we approached patients in general. The maximum variations were considered during the recruitment process, such as gender, age, occupation, medication and geography. After I had interviewed

five participants, I found out the participants were relatively old when compared to the Cambodian life dependency and most of them stayed at home because of being retired or as housewife. This might influence the data and make the research biased. This might have occurred because it was difficult to approach relatively young and working patients, usually they were in a hurry during the checkup. Therefore, I asked for help from network coordinators and peer educators. They introduced three patients to us. We could not reach one because of a problem with the mobile number. A young female patient was approached and we met at peer educator's place once. However, after the one-hour informal conversation, which was permitted to be hand-noted and used in the study, she kindly refused for the further formal interview. Only one patient was recruited in this method. I did not meet the patient personally before we interviewed him. We contacted him through telephone after the peer educator informed him about our existence. We made sure he was willing to join in the telephone and before the start of the interview.

P	Pseudonym in this thesis	Age	Diabetes diagnosed time	Medication	Occupation	Interview time	Experiences in severe hypoglycemia
1	Srey	F 60+	12y	Oral	house wife	1	X
2	Theavy	F 72	3y	Oral	retired & help in child house	1	V
3	Ratha	F 56	11y	Oral	house wife & help	3	V
4	Sao	M 60	10y	insulin (18), 6months	policeman retired	3	X
5	SreyTouch	F 63	7y	insulin (15, 20, 15), 2-3years	Unemployed	3	V
6	Rithy	M 56	18y	Insulin (12), 2-3years & oral	retired& seller	2	X
7	San	M 33	4y	insulin(30, 15, 20)	worker in primary industry	3	V
8	SreyLeak	F 40+	5-6y (join org. 3y)	Oral	house wife	1	X
9	SokLeang	M 49	7y (med. 5y)	Oral	Craftsman	2	X

◆ *Key informants*

I had several informal conversations with the general peer program manager, peer educators' trainers, urban (Phnom Penh) program manager, and the peer

educators in Phnom Penh. I also met contracted doctors for consultation in MoPoTsyo, other researchers in cooperation with MoPoTsyo and the chief of diabetes care in national hospital (the first diabetes care in Cambodia). All contents were recorded in observation notes. Some conversations were in English; others were in Khmer with the help from the research assistant.

During the beginning stage, they provided plenty of useful information with regard to the research. For instance, I had not considered the relation between alcohol consumption and hypoglycemia; they reminded me and also asked me to deal with this carefully since it might be a taboo issue. Staffs in MoPoTsyo also helped me to pre-test the interview thematic guide, provided suggestions for compensations and checked the translation from English to Khmer. I had lunch almost every day with staffs in MoPoTsyo. They helped me to clarify and understand more about MoPoTsyo and Cambodia in general, things related to diabetes and to verify my perspectives generated from the collected data.

◆ *Other participants*

I did not note down specifically about these I talked with and conducted surveys with in checkups because of the ethical concerns. Brief information of focus group participants was as shown in the table below.

P	Gender	age	DM	medication	Occupation
1	F	55+	3y	insulin +oral	officer and guard in the evening
2	M	55+	1y	Oral	Worker
3	M	68	3y	Insulin	retired officer
4	F	54	4m	Oral	cook in restaurant
5	F	50+	6y	Oral	house wife
6	F	40+	3y	Oral	house wife & seller
7	M	45+	2-3m	Oral	Worker

None of them served a position in MoPoTsyo, so in this way, I wished for the group discussion to be guided by patients' point of view. Meanwhile, because of the selection, all participants understood "low sugar" as hypoglycemia and had experienced it.

Participants were from four out of five peer networks in Phnom Penh. Patients from AK, the suburb network, were not presented in the discussion after initial approach. Distances were the first concern for patients; having kids or others family members to take care of were the other concerns they addressed during the approach although the focus group was held in the morning of Saturday.

Tools (thematic guides)

Based on the tentative thematic guides, interview guidelines were revised several times during this study. The terminology itself became one of the biggest themes in the guides as explained before. With the feedback from staff in MoPoTsyo, several questions were added, such as the alcoholic drinking habits. Meanwhile, the interview guides were evolved while the interviews had been conducted. The example thematic guides for interview and focus group are in appendix 1-2.

Language and interpretation

Conversation and observation, to some extent, is about interpreting as Gadamer stated “all understanding is interpretative, and insofar as all interpretation involves the exchange between the familiar and the alien, so all interpretation is also translatable” (Malpas, 2003, The Linguisticity of Understanding section, para. 1). Language is created by human beings in order to describe something happening. Everyone may have the different feelings or thoughts on language. Through discussion, people may understand each other better. Moreover, Gadamer also stated language is related to others and the world (Malpas, 2003), so taking social and cultural factors, including social-economic status, into account may facilitate the understanding of the language.

As I could not speak Khmer, the official language in Cambodia, and people in Cambodia rarely spoke English or Chinese, two languages I understood and could speak fluently, the assistance of translation was needed. At the same time, I was not familiar with the study field; I needed someone to help with practical issues in research, for instance, contacting participants and arranging meetings. Therefore, I recruited a research assistant.

At the beginning, the staff of MoPoTsyo suggested I could recruit the diabetes patient as the translator. However, due to the practical issues, I ended up recruiting a fourth-year university student, who studied social work and had done practicum of his social work course in MoPoTsyo previously, as my research assistant. He was recommended by MoPoTsyo. I had met him two times before we signed the contract so that I could be sure of a good working relationship and his interests in my project. In addition to social work study, he attended English language classes in the evening as his second major. He did not have a medical background but he was familiar with the system and people in MoPoTsyo. He had worked as translator before with other foreign researcher in cooperation with MoPoTsyo. He did not have experiences in research and was due to learn the

research methodologies in the coming semester but he had previously conducted surveys with diabetes patients.

Using a translator in qualitative research increases the risk of misinterpretation. In order to minimize this risk, a continuous discussion of the topics around study and fieldwork activities and progression was needed with the research assistant. Trust, respect and communication were also important during the process. The assistant and I spent the first three weeks to prepare the research work. We visited different places in order to understand the Khmer culture and society, such as museums and markets, and get familiar with each other; we exchanged what we knew, discussed what we observed and shared our opinions. At that time, we also practiced translation through textual analysis. We comprehended the information in MoPoTsyo together by reading their books and posters. Moreover, we discussed the protocol of this project word by word. He asked questions if he did not understand and I would explain. Later on, he helped me to check the translations of informed consent with the help from staff in MoPoTsyo. Before we approached the patients, we practiced translating the questions from English to Khmer and vice versa in order to make sure the meaning was not changed. This process was repeated throughout the whole research period.

During the interviews, the assistant translated what I said to the participants and also what they said to me. He sometimes probed by himself if he felt the questions were not answered deeply. We both took note and the audio-recorder was used during the interviews. When finishing the section, we would discuss how we felt transparently, the possible misunderstandings or mistranslations, what might influence the participants in particular, what patients had said and what had happened in the sections together. We focused on the language and translation specifically at the beginning since English was not a first language for either of us. At the same time, we would discuss our observations. He would provide the cultural insights while I often asked and challenged him about these things. For instance, I did not notice when one participant sat in certain way, which illustrated a perception of hierarchy for the participant. After his explanation, I understood why I felt a distance with the participant in that interview; we then discussed how to overcome this situation and practiced in the next interview.

After interviews, we transcribed the first three transcriptions in English sentence by sentence together. We listened to the recordings accompanied with my notes; he translated again both his questions and the responses from the participants,

and we discussed and reflected on any differences that could be identified between English and Khmer questions and whether the translation in recordings were similar to what he just translated. We compared different words, consulted key informants and decided on the proper translations for certain words. For the following interviews, he transcribed alone, but we would discuss the contents face to face when I had doubts or could not understand his words. The last six interviews were discussed through the internet because he could not complete them before I left Cambodia.

I had planned to transcribe all interview data into English only in proposal. However, after I was in the field and discussed face to face to staff in MoPoTsyo, transcriptions in Khmer were requested. The ethical issue will be discussed later. The assistant was volunteered accepting this job. And the process of transcribing in Khmer started after the English transcriptions were all finished.

After transcribing, I would conduct primary analysis because repeated interviews were planned. We would discuss what had been missing in the previous interview and if I understood correctly of the previous information. After these discussions, the interview guide was formed and we continued on interviewing. Even though we tried hard to avoid misunderstandings and misinterpretations, it still happened sometimes in the interview and it might also happen in the transcription, and we did our best to shrink the possible mistakes.

Registration and Anonymization

Focus groups and interviews were audio-recorded and note-taken since all interviewees agreed on being recorded and they were transcribed into English after the interview. Before the analysis, names were replaced with codes in transcripts, for instance, P1 for patient 1 for interview and FG1 for focus group patient 1. A field note with observations, reflections and comments was written.

Repeated interview marked as P3-1, P3-2; the second number was indicated the order of the interview. A document was created in my password protected laptop with their personal information and the code. I was the only person to access the laptop and only the research assistant and I knew the exact links between the patient and their code.

All possible information that could identify the participant was replaced in both English and Khmer transcriptions, too. For instance, the date of checkup, the name of the hospital they went and the name of the peer educator were changed.

Primary Analysis in the field

The primary analysis had been done in the field. After each section, the research assistant and I would reflect and discuss together. Field notes were taken right after. I listened to the audio-recordings and read through the field notes in order to get a total impression. Meaning units (Malterud, 2001) were identified along the study. They provided the total impression around the topics and were used to examine if the objectives could be answered. Meanwhile, new themes were discovered through the primary analysis. This process helped to better the tools as mentioned above about how to produce the second interview guideline.

Possible mistranslations and unclear words were discussed with the research assistant when transcribing. At the same time, repeated interviews gave me the chances to clarify the doubts and my understandings directly from the participants. I also discussed with staff in MoPoTsyo during the fieldwork for certain issues. They provided new angles and gave feedback from their point of view, which also helped to renew the tools.

Even though the last six interviews were not completely transcribed in the field, they were the follow-up interviews. I listened to the audio-recordings and took note. This did not influence much for the primary analysis in the field.

The preliminary result presentation was an official meeting to show and discuss the primary findings for the study with staff in MoPoTsyo, including sociologist, doctors and managers; some of them were diabetes patients. The results were presented in response to the objectives simply at that stage. This presentation was aimed to share the findings; their opinions and experiences as professionals or diabetes patients in Cambodia could help to verify the data. Meanwhile, the discussions along with my observations and experiences being in the field provided social, cultural and structural perspectives in further analysis.

The main analysis was conducted after the field work in the spring semester, which will be discussed in details in the following section.

Data analysis

All collected materials together with observation and reflection notes were read through again in order to gain the overview after I came back in Oslo. The systematically coding was done manually and data with codes were categorized in accordance with thematic groupings. Microsoft OneNote was used for drawing the links with all themes. Possible findings were then generated. Partial

anonymous transcriptions were shared with the supervisor and peer classmates, who helped me to be aware of the potential pre-understandings and also provided new perspectives that I had not come across yet.

While writing up the final report, transcriptions were read again and again with closer look but also in the bigger picture of the individual participant in order to interpret statements through contextualization in the lives and situation of the study participants. I also self-reflected during the process in order to prevent the possible biases. At the same time, continuous literature reviewing was conducted in the writing up stage with the help from the supervisor, which provided new theoretical perspectives as a response to the themes.

Theory of Experience and expression

During the analytical process, I read the theory of experience and expression by Bruner (1986) and was inspired by it. It was the analytical framework for writing up this thesis.

Reality is composed by experiences people consciously perceive, which are culturally constructed. Experiences are personal and people can only experience their own life; it is impossible to know completely about others' experiences even though people may have different hints about them. When someone shares their own experiences, they have to decide the beginning and the end of the experiences. The stories are framed and articulated differently to various people. This is called expressions. Expressions are socially and culturally constructed. In order to understand others' experiences, everyone will have to interpret what others have expressed. However, everyone interprets others' experiences based on their own experiences. Therefore, gaining insights into others' experiences is about interpreting others as they interpret themselves through expressions. Meanwhile, expression may also structure own experiences (Bruner, 1986).

In this study, participants experienced several episodes of abnormal glucose levels. In order to understand the reality of abnormal glucose levels, they consciously interpreted what had happened and these interpretations became their experiences, which were influenced by their previous knowledge and their own culture and society. Therefore, the first finding chapter of the thesis was called "interpretation." It will illustrate how participants tried to interpret their "lived lives" with experiences.

Meanwhile, as mentioned before, the whole study was about interpretation. The possible limitations will be discussed later. Indeed, it was impossible to

understand fully with participants' experiences in hypoglycemia. However, through carefully gaining insights into participants' lives and continuously reflecting on, it is possible to get closer to their true experiences.

Other relevant theories

While analyzing participants' experiences in hypoglycemia and how they interpreted the episodes of abnormal glucose levels, I was inspired by the idea of semiosis, which discusses about how people continuously understanding the world through interpretations of the signs (Middelthon & Colopietro, 2012). Meanwhile, idea of power from Ferzacca (2000) based on Foucault's theory is also referred to in this thesis, where it shows the problem when biomedical aspect of disease is dominant and the personal experiences of illness are often missed.

Ethical considerations

Ethical principles should be considered for all research involving human subjects (CIOMS, 2002)³ so it is important to examine some ethical issues in this project.

Ethical permissions

Norwegian Regional Committees for Medical and Health Research Ethics (REK) had examined the project and stated this study was exempt from review in Norway because it was out of the substantive scope of the Health Research Act on June 05, 2013, reference number: IRB 00006244.

Therefore, the project had been reviewed and approved by Norwegian Social Science Data Services (NSD) on June 20, 2013, project number: 34741 for the data protection. They confirmed the personal data stored and used in the research proposal was in line with the ethical procedures. After I entered the field, the plans for data managements had been changed that interviews would be transcribed into Khmer anonymously and shared with MoPoTsyo. The changes were informed to NSD on August 22, 2013 and the replied approval was sent on January 15, 2014 by email.

The Cambodian ethical approval for student project was obtained on August 08, 2013 from Cambodian National Ethics Committee for Health Research in Minister of Health.

³ CIOMS: The Council for International Organizations of Medical Sciences

All documents mentioned above will be attached in the appendix 4-7. I will discuss each ethical concern in the following sections.

Informed consent

◆ *Observation*

I had conducted observations mainly in MoPoTsyo headquarter, peer educators' center and in participants' house. Individual informed consents can be problematic to be obtained in observation, which is conducted with a group of people (Oeye, Bjelland, & Skorpen, 2007). Meanwhile, due to expectation of "unexpected" in the study, informed consent of observation was tricky. First of all, it was difficult to inform participants what I observed for. Secondly, it was hard to define whom I observe. Last but not least, it might make participants aware of what they were doing and behaviors became unnatural.

Tentatively, the sign would have been planned to hang on the wall. However, illiteracy was a problem in Cambodia mentioned in previous study (Green, 2011) and I was also aware of this issue. Therefore, instead of the written notice, oral announcement was used in all observation situations since they were relatively close environment. The observations were aimed to understand the situation; therefore, the individual opinions were not obtained and personal information was not recorded.

◆ *Focus group discussion and interview*

I had prepared the written informed consent in English which was translated to Khmer to make sure "possible participants receive the necessary information, understand adequately and can choose freely if to participate in research" (p.32) (CIOMS, 2002). However, because of the issue of illiteracy, oral consent was also prepared. As CIOMS's guideline suggests "when the research carries no more than minimal risk, it is possible to obtain oral consent only" (p.34) (CIOMS, 2002). In this study, the aim was to gain knowledge through individuals, which would not change the situation of treatment, so the minimal risk could be expected.

One Khmer master student helped me translate them into Khmer and the research assistant and staff in MoPoTsyo double-checked the consent forms. The issue of the terminology for hypoglycemia in Khmer had been discussed as described before. Oral explanation was also discussed before approaching possible participants.

The contents of the consents included the purpose and information of the study; procedures; their right to refuse participating before, during and even ask for

withdraw after the interviews or focus groups; issues of benefit, risks, reimbursements and confidentiality.

Before the focus group discussion began, the moderator and the research assistant explained in details about the informed consent. Participants had been told they were welcomed to share their own experiences only if they felt comfortable to do so.

After the possible interview participants had accepted to join the research, the research assistant and I would make an appointment with them at their home. The assistant would explain the informed consent in details before the interview began. Participants were informed about their rights to question and to ask for withdraw at any stage. Meanwhile, the ongoing observations and notes-taken had been also informed. After they read and understood the consent, we would ask participants to sign for the consent. Several participants were illiteracy as expected but they could recognize the numbers in Khmer and in Romantic. One other witness, such as neighbor or family member, was present, read the form for participants and co-signed on the informed consent. Finger stamps had been recommended at the planning stage. However, finger print was viewed as strongly serious. At the same time, participants had been practiced signing for different activities in MoPoTsyo. Therefore, they all signed the informed consent. The example informed consent form in English is attached in the appendix 8.

Vulnerability

In this study, participants was viewed as vulnerable groups since they were relatively poor in the society, lack of education, illiterate and generally lack of medical resources. Meanwhile, this study was conducted in cooperation with MoPoTsyo, which provided diabetes care and services to them. As a result, participants might concern the power of the organization.

However, this study was necessary to be conducted within these groups. As CIOMS states, “the research is intended to obtain knowledge that will lead to improved situation to the vulnerable class- either the actual subjects or other similarly situated members of the vulnerable class” (p.64) (CIOMS, 2002). This study was aimed to improve the diabetes care for those people. Therefore, several protections were considered and conducted.

Free willingness

As mentioned previously, some participants were *assigned* by the peer educators to talk to us. Even though peer educators were diabetes patients themselves, they

still served a special position in the organization. Therefore, I was aware of the issue of free willingness. When approaching possible participants, the research assistant and I reassured their rights to reject and promised the same services would be provided if they did not attend the study. During the interview, they were informed they could refuse to answer anything they did not want to mention and they could ask for withdraw at any points during the research.

However, I also learned refusing someone was viewed as impolite in Khmer setting. Therefore, some might use other ways to show their rejections, such as busy schedule or hurry to work. Among three participants who I had interviewed only once, two were actually out of the city after I interviewed them. One participant kept postponing our appointment. And the research assistant reminded me the possibility of polite refusal. We continued contact the participant through telephone almost every week, chatted with her and updated her condition and did not push to make a new appointment. Meanwhile, we also made sure if she would like to withdraw from the study and delete the data collected from the first interview. She still responded she was willing to join but she was busy and we could use the data from the first interview.

◆ *Reimbursements*

According to a previous study (Green, 2011) conducted in the same groups, participants asked for compensation. I had planned that participants should get something as compensation for not being at work and attending the study instead. In Cambodia, hourly wage is around 0.3USD to 1USD according to Cambodia Institute of Development Study (2011). As a result, 1USD as compensation was considered in this study. However, one Cambodian professor recommended not paying cash directly to the participants. Instead, after the discussion with staff in MoPoTsyo, approximate 1.5USD of green bean or brown rice was prepared because MoPoTsyo promoted these foods to diabetes patients. At the beginning, I prepared both alternately. However, after several interviews, I found out brown rice was not popular among participants. Therefore, green bean was given most of the time because I was afraid it was not useful for participants.

During the focus groups, participants got 3USD of green beans as the reimbursement for their presents and the travel fees. Water and fruits were also provided.

◆ *Hypoglycemia and my researcher position*

The repeated episodes of hypoglycemia of participants should be discussed under the section of vulnerability. Some participants worked closely with

MoPoTsyo in terms of dealing with hypoglycemia while some dealt with it alone. The latter participants suffered frequently hypoglycemia and sometimes peer educators did not know about this. I had considered if I needed to intervene with the situation. However, after careful consideration, I decided not to. The reasons included, first, the participants knew the organization was the place to obtain help and all participants attended the checkups regularly; secondly, all participants and their family knew how to intervene and prevent their hypoglycemia so there should be no emergent risks; thirdly, my position was the researcher instead of the health worker in the organization; if I had informed the peer educators or staff in MoPoTsyo about their situations, the confidentiality of participants would have been destroyed. Meanwhile, the research was aimed to better the diabetes care in Cambodia through exploring the experience of hypoglycemia. Hopefully, this research will provide valued insights into the situation and the suffering of hypoglycemia can be reduced.

Risks assessments

Guidelines mentioned intervention procedures as the main resources of risks (CIOMS, 2002). For this study, there was no intervention involved. During the fieldwork, psychological influences, which were considered as the risks of the study, among participants were not noticed.

Participants were generally willing to meet us repeatedly. Reflexivity and discussions were taken throughout the process in order to minimize the possible emotional harm and we had informed properly about the termination of the study to each participant. By doing so, I hoped the social or emotional harm could be minimized (Murphy & Dingwall, 2007; Oeye et al., 2007). Several stories with the possibilities of being stigmatized, such as heavy drinking and civil status, were mentioned during the interviews automatically by the participants and the assistant and I had done strict anonymization to guarantee their confidentiality.

Confidentiality

According to CIOMS (2002), "the investigator must establish secure safeguards of the confidentiality of subjects' research data" (p.75).

As mentioned before, the audio-recorded was used and the name of participants was replaced during analysis. The recording files and the document of the reference numbers with personal information were stored in the external hard drive and linked to the personal computer when needed, which was password protected and locked in the safe place with the field notes, and only the assistant

and I could access to those raw data. The shared transcriptions, both in Khmer and English, were all anonymized as described before. The raw material, including audio-recordings and the document of the reference codes and personal information, will be deleted once the thesis is finished.

Reflexivity (assistant and I)

I will discuss about personal and epistemological reflexivity separately.

Personal reflexivity

◆ *Roles in the field*

I am a 25-year-old Taiwanese female, studying in Norway. Even though I looked like the Chinese Cambodian in appearance, when people knew I did not speak Khmer, it was easy to distinguish the difference. I was easily to be viewed as the young professional coming from a relatively rich country, with plenty resources and in cooperation with MoPoTsyo.

Therefore, some patients asked for medical advice from me although I never told any patient I used to be a nurse. In order to minimize the possible influences, I dressed like the student in Cambodia with jeans and T-shirts. The research assistant, who was 21-year-old Khmer male, dressed his college uniform also during the interview. When participants discussed the health condition of either them themselves or the family member, we would listen to them but also stressed our position as the student learning from them. One participant had discussed the condition of the family member with us when we met for the interview. Because I knew it was the main concern of the participant, I listened carefully and responded cautiously. I told them I was a student and came to Cambodia learning from their experience. Therefore, I was not familiar with the health system in Cambodia. If they had any concerns in relation of health, peer educators, staffs and the doctor in MoPoTsyo might know more than me. One participant also inquired if I provided financial helps to them. We also listened to their statements and stressed again our roles as student.

However, some participants might start teaching me with all biomedical facts and the standard diabetes self-management when they heard we were student and wanted to learn from them. During the reflection, the research assistant and I found out this situation and we decided to change our way in asking questions. For instance, we would appreciate their teaching and say, “we understood the diabetes patients should limit their diet and we would like to know more about

you—how do you deal with your diet?”

During the interviews, I had witnessed three episode of hypoglycemia with participants. As the literature shown, it was difficult to notice their occurring if I was not familiar with their own signs and symptoms. Therefore, the participants took actions and called for help before I discovered. We just saw how they intervene and sometimes helped, such as buying the sweet drinks for them. These experiences were precious but I often felt bad afterwards because I thought I should have done more for them. It was the same feeling as I addressed above about whether I should inform MoPoTsyo about their situations. During the reflection, I understood it happened because of my role as a nurse in the hospital before. I then assessed the possible risks and influences to the study and reflected on my position in the field.

◆ *Biomedical background*

I was trained as a nurse in university back in Taiwan and worked in a cardiovascular ward for a year. My previous knowledge about diabetes came from biomedicine. Therefore, during the interview, I might question whether what the participants said was reasonable. However, I knew this might happen before I was in the field, so I consciously observe myself and tried to jump out of my pre-understanding. For instance, when participants mentioned the figure from glucometer 80mg/dl was hypoglycemia, I would consciously think it was a wrong statement. However, I understood if I thought it was wrong and did not believe what participants said, I would not get the whole stories from participants. I needed to consciously reflect and adapt into their stories. By doing so, I could probe more and understand better what they expressed.

As an outsider of Cambodian culture, I observed and relied on the explanation of the research assistant as I described in the observation section. However, some issues I might take for granted. For instance, in Taiwan, “Guasha (coining)” was also widely used. Therefore, when I heard about it, I did not verify whether it was the same idea as in Taiwan. I took it for granted that Asian culture was similar in some ways. The primary analysis and the discussion with research assistant helped me to be aware of my preconception and I started probing on this issue for the following interviews.

As human beings, the research assistant and I also had several good and bad days in the field. First issue was related to health. I had fever of unknown origin days before the focus group discussion was held and the research assistant got a cold in the middle of the fieldwork. We tried to take a day off if we felt really bad;

sometimes because of the schedule, we would still work but in shorter hours.

Second issue was related to the political situation in Cambodia. After the election held in the end of July, there were several demonstrations and clashes on the street. The research assistant was preoccupied with the relevant news and easily got influenced by them at the beginning. After we discussed about it, I could understand he was worried and cared about the news and he would understand we would have breaks every 45-50 minutes. By doing so, we could be more focused on the work and during the break we could discuss the situation together. Meanwhile, because of the tense situation, I was asked to stay at guest house for safety reasons twice so the schedule had been changed for few times.

The research assistant started his new semester in September, and sometimes he might have a busy schedule and with great pressure. In order to cope with this situation, we agreed to finish as many transcriptions as possible and he could leave some after I left Cambodia. We decided to transcribe the interview from who we would conduct follow-up interview first in order to identify the possible misunderstandings and form the follow-up interview guide.

The assistant and I spent lots of time visiting different places, discussing issues around the project and chatting with each other in the first few weeks. This helped us to cooperate better later. We knew better about each other and we agreed to be transparent and gave constructive comments which focus on the work rather than the person. For instance, when we found out the possible mistranslation and misunderstanding in the interview, we would discuss how to change the questions both in English and in Khmer so that he could understand me better and how he could then translate much clear to the participants.

Epistemological reflexivity

Before entering the fieldwork, I had reviewed several literatures and got some ideas of the issues around hypoglycemia. This might influence how I understood my own project. For instance, when participants stated hypoglycemia was usual and normal, I automatically thought of one sentence in literature, stating participants accepted it as part of their lives (Tan et. al, 2012). However, during the analysis process, such as discussion of transcription and second interview guide, I figured out I needed to probe on what the meaning is when they said it was usual and normal. Meanwhile, literatures did not talk about the complexity of terminology in many places. And from my background knowledge in English and Chinese, I was not aware of the issue so I took for granted that in Khmer

there would be one word to describe the situation of hypoglycemia.

Reflexivity of the research designs was about the repeated interview. As mentioned before, three participants were interviewed once. Whether their data was creditable should be discussed carefully. I made the second interview guide for those participants. Therefore, I understood what questions I have not touched upon or what I should probe more. By doing so, I could get the sense of what might be much completed in the first interview. For instance, one participant talked mainly about the experience in repeated hypoglycemia and mentioned little about the diet. When talking about the hypoglycemic experiences, I might refer to this participant's experiences while when discussing dietary habit, I would not consider much about the statements from this participant.

Translation and language barrier were definitely influenced the project. I had been aware of this issue before I entered the field. Therefore, continuous and transparent discussions and reflections between the research assistant and me were planned. However, these procedures took more efforts than I had thought. The situation had got better and I knew we tried to do our best to minimize the misunderstandings but it was still the biggest limitation of the study.

Limitations and strengths

As mentioned above, the biggest limitation of the study would be the issue of translation and interpretation. Due to the financial and time constraint, the translation of data was done by the research assistant and discussed by us. I did not recruit other Cambodians to proofread the translation after the transcriptions were done. Since the whole project was about interpretation—the participant expressed their experiences in Khmer to us; the research assistant translated to me and I interpreted their expressions in the translation—the possibility of misunderstanding was definitely existed. Meanwhile, the data was mainly come from narrative methods and I did not participate in participants' daily lives. These expressions were their interpretations of their own experiences and their behaviors. Through transparent reflections, thorough discussions, repeated interviews and triangulations in methods as described previously, the misunderstandings might be minimized and the true experience might be obtained but not promised.

Moreover, I tried to stress on my role as a student, but participants might still view me as someone with closer relationships with MoPoTsyo. Therefore, whether they responded from their personal point of views or from the

perceived official truth of MoPoTsyo ultimately remains unknown. For instance, they might try to explain their glucose levels through the chemical numbers to me even though they did not access to glucometer all the time. However, this might also be one of the main findings in their experiences and understandings of hypoglycemia as the Cambodian diabetes patients.

Last but not least, the variations of the research participants should be discussed. Participants were relatively older in the society and they all lived in the urban or suburb area. As a result, the finding of the result might be different from the majority of the population in Cambodia and could not represent the whole situation in Cambodia. In the meantime, patients in certain jobs, such as office worker, were not recruited in the study. In addition, due to the time and financial constraint, sample size might be comparatively small even in qualitative research. It might be uncertain whether the study could be representative for Cambodian participants' experiences in hypoglycemia. However, all participants were different in many ways as shown above; several issues were kept occurring in the interviews. Some topics might be missed out in the study, but there was no literature in relevant field, to my best knowledge, in Cambodia. As a result, it was difficult to compare and know in advance whether any topic was not touched upon. This study would provide one of the possible understandings in this group of Cambodian diabetes patients' experience in hypoglycemia, focusing on diabetes patients living in Phnom Penh city.

Chapter 5: Research setting

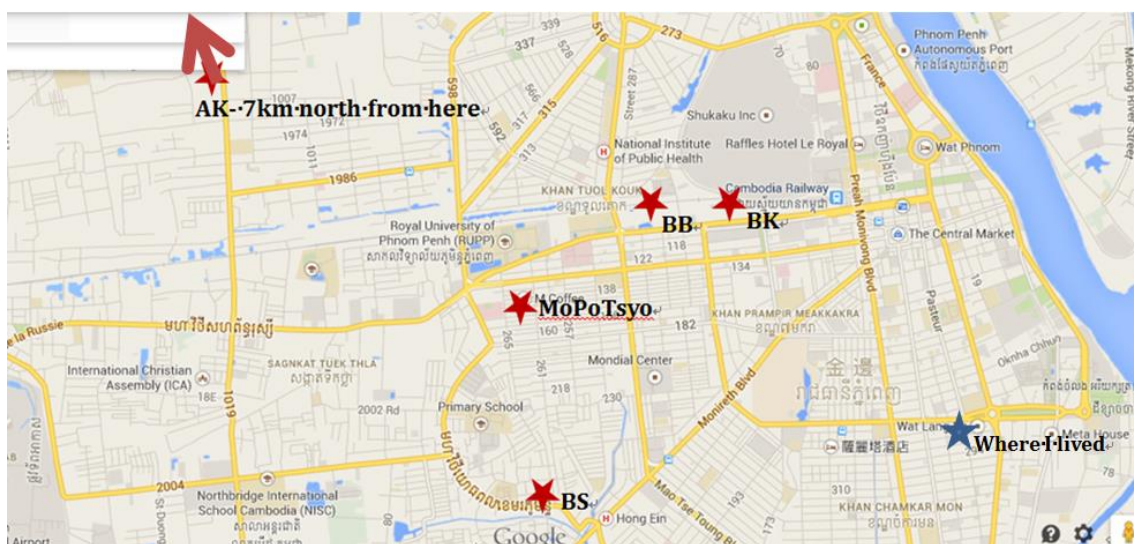
In this chapter, I will present the research participants. I will describe their living conditions, transportations, occupations, dietary habits and access to the health system. I will then describe the general perspective of diabetes in Cambodian society. Traditional Khmer ideas of healing and illness, which were mentioned throughout the fieldwork, will be presented in this chapter. Finally, I will describe activities related to MoPoTsyo and show an example of biomedical information handed out by MoPoTsyo.

Research site

Phnom Penh

The research was conducted in Phnom Penh, the capital and the largest city of Cambodia. It is located in the central-south of Cambodia and on the banks of three rivers—Mekong, Tonle Sap and Bassac—which provide the freshwater to the municipality. It covers an area of 678.5 km² and its population is 1.8 million.

Peer educator Network in Phnom Penh



In Phnom Penh, there are five peer educator networks, where around 2000 diabetes patients go for the weekly checkups. Four of the networks are in the city; one is in the suburb area. For several reasons, one network center is in the MoPoTsyo office, which is slightly different from other four centers; I will describe later their differences. I could cycle to most of the places within 20 minutes from where I lived, and it was usually less than 6km. My assistant and I had to ride motorcycle to the AK peer network and it took around 25 minutes.

Patients were usually assigned to the networks according to the locations where they lived. However, several patients went to networks further away because they moved after they had joined in. Several patients I met did not live in Phnom Penh but because there was no peer network in their community, they joined the one in the city; therefore, it was difficult to know which network center was the closest for them.

As mentioned previously, interview participants were recruited in these five peer educator networks. The following section will describe their living conditions in general.

Lives of research participants

Social-economic status

I did not ask the participants about their monthly wage, however, through observations of the factors I will discuss below, I could roughly distinguish their differences in social-economic status. Two participants were more likely part of the middle class since they lived in comparatively affluent houses and neighborhoods; they owned normal cars; they mentioned their family member or they themselves had experienced for treatments in Vietnam even though they also mentioned these experiences had brought a financial burden to their families. Others were generally part of the lower social-economic class and many of them had experienced being treated in national hospitals but had to stop because of financial issues. One participant received financial aid from MoPoTsyo for medical treatments. MoPoTsyo aims to help the poor in Cambodia so they do not assess the financial status of the patient before admitting members.

Living conditions

Several skyscrapers and modern taller buildings can be found in Phnom Penh but buildings with two to four floors are more common around the city. There are also slum areas in the city. Both the BB and BK centers are situated in the slum areas. The main streets are wide and usually paved. However, when turning into the side-streets, they are usually bumpy and muddy. The riverside and the southeastern part of the city are places many refer to as the “rich area,” where government officers, people from the upper-class and foreigners live.

Participants lived scattered around the city. Some of them lived by the paved main roads in two-floor houses and front yard while some lived by the muddy and bumpy side-streets in relatively crowded houses with a small garage in front.

The surroundings varied from participant to participant. Some areas flooded easily after the heavy rains.

The whole city has access to electricity but is not always stable. Air-conditioners and electronic refrigerators are rare. People buy ice cubes and filled in a plastic box if they need to keep something cold. Most of the participants did not have refrigerators at home so they needed to go to the market almost every day. Houses usually have a water supply, but the water is not drinkable and it needs to be boiled. Buying bottled mineral water is common. Most of the participants bought mineral water but some would boil the water from taps.



Figure 2 & 3: Different street sceneries in Phnom Penh

In Phnom Penh, people usually live with their family as the traditions. Young people may live with their relatives or friends because of financial issues or because it is not easy to find a place suitable for one. Most of the participants lived with their family but one lived alone.

There are not many parks and trees in Phnom Penh and they are mostly situated in the east of the city by the river banks, where most of the tourist attractions and foreign companies are situated. In the western part of the city, there is a stadium. In the mornings or evenings, many people are exercising in these places. The popular sports in Cambodia include volleyball, badminton and football. Some people would join group aerobic dances in the parks while some would go for a walk or run in a group. Participants mentioned they would do exercise, such as walking, in the nearby places, like schools or a community square. Some would do stretching at home.

Transportation

There is no public transport within the city. Some private mini-van or bus companies service between towns. Roads are always crowded with motorcycles, tuk tuks (auto rickshaws) and cars. Cars are the symbol of wealth. When I walked or cycled on the streets, I was always surprised by how many expensive cars there were, such as Lexus and BMW, because it was different from the image I

had of Cambodia as a resource-limited country. Male drivers and riders are more common on the streets. Bicycles are viewed as the transportation for the poor and students. Therefore, if they can afford it, most people will get a motorcycle. In addition to tuk tuks, people can also choose motor taxi as the transportation. Walking on the street is not common and sidewalks were rare. Almost everyone rides motorcycles and they seldom wore a helmet. The air is severely polluted. After biking for 20 minutes, everything will be covered by sands and the hair will be sticky from the pollution.

All families of research participants owned motorcycles except one. Some families owned tuk tuks and some owned cars. Some of them would walk to nearby places, such as the shop on the corner or the school in the next block. Most participants lived near the peer educators' place so they could get there by walking or by riding a motorcycle for 15 minutes. One participant lived further away and it took him around 1hr by motorcycle to get to the center for the checkup because there was no peer networks in his community at the moment when I interviewed him.

Livelihood

I had heard from Cambodian friends that doctors, businessmen in the markets or office workers in international companies might earn 400-800 USD per month. In contrast, factory workers or tuk tuk drivers might earn 80-100 USD per month. Teachers or government officials might earn around 200-300 USD per month but some of them would have a second job or other alternative income.

None of the female participants worked outside the home at the time when I interviewed them. They had retired, quitted work after getting diabetes or were housewives. Sometimes they would help their children or family with small business, such as sellers in the market. One male participant was retired; others worked as workers in primary industry, sellers or craftsmen. Family members had various jobs, such as teachers, doctors, sellers and tuk tuk drivers.

Diet

Most Cambodian women cook for their family. Therefore, female participants could decide what they wanted to eat with considering others' preference while male participants were somewhat depended on other family members, such as wife and mother-in-law. Most of the time, they would eat at home but they would buy drinks, desserts or eat out sometimes.

Several participants mentioned they needed to watch out for the seasoning while eating because they had diabetes (and some also had hypertension). As I experienced, foods were generally oily and salty in Cambodia. If people did not ask beforehand, the cook would add many seasonings, such as monosodium glutamate (MSG, also known as Ajinomoto), sugar, salt, oyster sauce, soy sauce, chili sauce and fish sauce.

Sugar was also widely mentioned among participants since it was an important seasoning; they cooked most of the dishes with sugar. Furthermore, sugar was always placed on the table in every restaurant and local food shop; so often people would add more sugar to their dishes even though the dishes had been seasoned already. Drinks and desserts were also sweet with a high content of liquid sugar (sucrose) and condensed milk. Fresh juices or fruits smoothies always had added sugar and condensed milk; “Cambodian coffee latte” (literally translated as coffee with milk in Khmer) was coffee with sugar and condensed milk.

When participants explained their diet, white rice was always mentioned since it is a staple dish in Cambodia. However, white rice was known as food with higher glycemic index and therefore, not good for diabetes patients. MoPoTsyo promoted beans and brown rice but brown rice were comparatively expensive and not easy to get in all markets. Participants also often mentioned soups because they often cooked it at home and every family had their own recipe. Khmer Soup is mixed with vegetables and different meats or fish and contained different spices, such as turmeric, coconut milk and lemongrass. The seasonings mentioned above are also in soups. Foods are also influenced by Vietnamese, Chinese and Thai food traditions. Noodles and rice noodles (kway teow) are popular in Cambodia.

Tropical fruits, such as durian, jackfruit, pineapple, banana, papaya and watermelon, were often mentioned by participants. These were generally categorized as “sweet fruits,” which contained high levels of sugar.

◆ *Access to food*

Even though participants ate at home most of the time, they also stated they would eat out sometimes. Food vender, food shops or grocery stores could be found in almost every corner and they sold foods long hours daily. They sold many foods mentioned above. The price for a portion was usually 1-2 USD. None of the western foods, such as pasta, pizza and hamburgers were mentioned by the participants. Although western restaurants and fast food stores existed,

prices were higher for general population in Cambodian society.



Figure 4, 5 & 6: soft drink vender; grocery stores and street food vender

Access to the health system and diabetes care

There is no national health insurance in Cambodia as I knew in the field so people need to pay all expenses in the clinical situation. I was told by the research participants one doctor consultation in national hospitals may cost more than 10 USD. A private clinic or hospital might be even more expensive. Usually wealthy people would go abroad to Vietnam or Thailand for medical treatment.

Participants often mentioned the health services, blood tests and medications outside MoPoTsyo were expensive. For instance, one glycemic test from glucometer might cost 2USD outside MoPoTsyo while it cost 0.4USD in MoPoTsyo. Therefore, MoPoTsyo was important in terms of diabetes care to participants.

Glucometers and its strips were rare among participants because there were pricey. Only two participants had their own glucometers bought from MoPoTsyo but when I interviewed them, both of them did not use it; this will be presented in the finding chapter later. Some participants would buy urine strips, which were relatively cheap, from MoPoTsyo for monitoring their glucose levels. Participants usually went to the checkups at peer educator center and doctor consultation for obtaining their glucose levels from glucometers.

Diabetes and hypoglycemia in Khmer society

Before I describe the lives in relation to MoPoTsyo and diabetes care, I would like to address the general idea of diabetes and hypoglycemia in Khmer society.

Diabetes (*tuk nom phaem*) can be translated word for word as “urine sweet disease.” Diabetes is generally linked to sugar because of the name. Some participants referred to themselves as diabetes patients by the expression “my urine is sweet.”

The research assistant mentioned the story when his classmates heard he was going to have an internship in MoPoTsyo, they giggled and teased him. He said when his classmates, young university students, heard the word—diabetes, they thought of old people with bad smell. In the focus group discussion, research participants mentioned villagers (people in the community) might know diabetes could not be cured and diabetes patients got many limitations in their lives, such as limitations in eating. Focus group participants compared their situation to people having HIV/AIDS, stating that diabetes is worsen because having diabetes meant they could not enjoy partying, eating or drinking anymore.

During the focus group discussion and interviews, participants also discussed the reason why they got diabetes. These issues were related to the question—why me, which Becker (1997) suggests is common among chronically ill patients. As stated before, Cambodia is a Buddhist country and the concept of Karma plays an essential role in the society. Participants might link their sufferings of diabetes to Karma, namely doing something wrong in the past or to their ancestors. Meanwhile, focus group discussion and some participants in interviews also mentioned modernized food industries caused modern diseases, such as cancer and diabetes, which were rare in ancient times. After much discussion, there was a consensus in the focus group discussion that more and more people got modern diseases was due to diet; foods were contaminated by chemicals and people got affected after eating. Participants also stated that stress might make the disease worsen. This idea might come from the humoral theory of balance in Khmer tradition that illness occur when body became imbalance (Ong, 1995). It is similar to findings from research by Becker (2003) that Filipinos' health belief that health is viewed holistically and illness is viewed as a state of imbalance; in that case, worry and overwork are viewed as forms of imbalance, which leads to sickness. Therefore, it is also important to understand how Khmer people generally understand about healing and illness.

Hypoglycemia

During the fieldwork, I figured out there was no unified word for hypoglycemia in Khmer language, which caused some problems during the recruitments as mentioned before. This fact was one of the findings for my research but also the background knowledge of the situation in Cambodia.

Four different words were mentioned—"low sugar" (*Chos Cheat Score*), "extremely low sugar" (*Chos Cheat Score Klam*), "sugar low too much" (*Score chos*

dep) and “lack of sugar” (*Qua Cheat Score*). As mentioned in the recruitment section, some patients did not link these words to hypoglycemia at all. All interview and focus group discussion participants understood at least one of these words as hypoglycemia and could share their experiences. Variations understandings will be discussed later in the findings chapter.

Among those who had experienced hypoglycemia, the episode was usually linked to the medication or diet. These participants generally said the experience could be dangerous and uncomfortable. Stories of the death of different patients due to hypoglycemia were mentioned several times in different interviews and in the focus group discussion. The discomforts they mentioned included sweating, dizziness, loss of power (weakness), hunger and shaking (tremor). Usually they said it was difficult for others to notice they were in an episode of hypoglycemia unless they told them. However, when the severity of the episode increased, family members could notice the patient was in a hypoglycemic state by observing excessive sweating and inability to move.

Some participants said “their urine was not sweet anymore” when they mentioned the episode of hypoglycemia. Participants also used salty as the opposite idea of sweet to express their status of being hypoglycemic. This will be discussed in details also in the findings chapter.

Khmer ideas of healing and illness

As mentioned above, participants’ perspectives on health and illness included elements of Khmer medical tradition. Therefore, it is also important to understand the ideas of healing and illness from traditional Khmer perspective.

According to the account given by Frye (1991), Khmer understanding of the human beings views as a combination of the physical body, social self (mind) and the soul (spirit) in Khmer Theravada Buddhism; keeping the complete form of these three is important for health. Able-bodied people undergoing surgery mean the balance is destroyed and it may represent bad fortune for this life and the next. Ong (1995) gives an example of this way of viewing the human being by describing the situation of a woman who is informed she has a breast mass through an x-ray examination but feels nothing, and may therefore not accept having biopsy because it is taking away part of her being.

The Khmer idea of health includes religion and the Buddhist belief that death and suffering are moral conditions of existence (Ong, 1995). Therefore, pain is both

about suffering and healing as the example of coining (Marcucci, 1994) which will be explained later in this section.

Another important element of folk religion in Khmer culture is the belief that magic spirits may cause either mis-fortune or fortune (Marcucci, 1994). Some traditional Khmer healers are believed to have spiritual powers so they “know” everything without inquiry. Ong (1995) explains the reason why patients do not answer many questions in medical encounter in a Cambodian refugee setting is perhaps because patients have experiences with traditional Khmer healers who do not ask questions in order to know their conditions. Therefore, if someone asks plenty of questions, Khmer patients will be skeptical of their abilities and this makes them silence. My research assistant explained to me about the Khmer healer who had the spiritual ability to heal patients, however, I do not know if this would affect how patients in Cambodia experienced medical encounters.

In addition, balance is important when talking about well-being. Wind and blood are the indicators for health and may be linked to Ayurveda medical culture. In Ayurveda concepts, all creation, including human beings, is made up of earth, water, fire, air or wind, and the ether; the wind has the functions of propulsion and movement and in yoga, wind is the flow of energy (Ranade, 2001).

When the body is healthy, wind and blood will flow smoothly without interruption, while poor appetite or irregular sleep, for instance, may destroy the balance (Hinton, Um, & Ba, 2001). The menstrual period is viewed as “stuck blood” in a woman so taking herbal medicines with wine is believed to “melt the clots, and makes the blood flow freely” (P.112) (Kulig, 1990). The idea of “cold and warm” is also mentioned; for instance, delivery is viewed as cold; therefore, a woman needs to eat hot foods after delivery and the temperature of the bed should be considered (Frye, 1991). Meanwhile, after delivery, the body contains “old water,” which is cold and poisonous for the body; some women will keep themselves warm by wrapping the body in a blanket, wearing a long sleeved top and a pair of long pants, or having a steam bath. By doing so, heat makes the body sweat, which is the “old water”. After it is expelled, the body can become warm by absorbing “new water,” and women will regain health (Townsend & Rice, 1996). This action is based on the humoral medical theory and in this way most Cambodians find the reasons for their discomforts and ways to correct the imbalance (Eisenbruch & Handelman, 1989).

When “bad wind”, which is viewed as disequilibrium of health, occurs, people will try to bring the body back into balance. For example, headaches or other

bodily pain can be treated by pinching, cupping, and coining. Those procedures can bring out the toxic and by doing so, the bad wind will escape from the body. In this way, people regain the balance in the body and between the body and the environment (Frye, 1991; Ong, 1995).

Cupping, pinching and coining are the treatments for different discomforts, usually pains, car-sickness or fever. They use hot coin or cup, putting on or rubbing on the treated area, usually the neck and upper chest. This treatment will break the capillaries and leave a red bruise, which is believed to direct the blood flow and to take the bad wind out of the body (Sargent & Marcucci, 1984).

In Cambodia, women are important in the daily care of their families while men are still said to be in charge of decisions related to long-term and chronic problems (Frye, 1991). Women take care of the health and safety of the family through diet, healing practices, such as coining and ancestor-worship. Ancestor-worship is important in every family with both women and men worshipping at least in certain special occasions. Therefore, ideas of well-being and healing in Cambodia encompass the idea of balance between physical health and relations in this world, the past and the future world (Ong, 1995) and gender may have different roles in terms of maintaining well-being at home.

Studies say many Cambodians accept Western medicine since they have experienced the death of their relatives or friends due to lack of proper medication (Frye, 1991; Kemp, 1985). Kemp (1985) states “they view health care primarily as the dispensing of medications” (p.43), and in particular, they have great faith in intravenous injection (Ong, 1995). On numerous occasions, I saw people sitting on the back of their motorcycles, perhaps going home from a clinic or pharmacy and holding up a bottle of injection fluid. A friend in the field, who was a doctor, also said to me doctors still needed to prescribe vitamins or injection to patients even they could not find any diagnosis with patients; otherwise patients would not be satisfied and reluctant to leave.

Activities related to MoPoTsyo

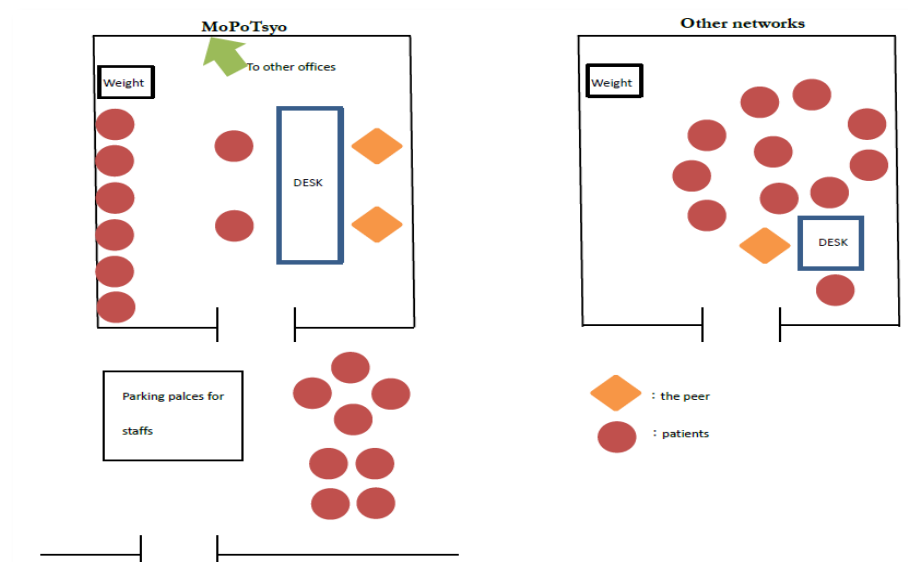
In this section, I will describe the activities related to MoPoTsyo. Patients would meet the peer educators more often than the doctor and the peer educators were the gate keepers for doctor consultations. The checkups were especially important interfaces for patients, where they received diabetes health services, such as measurements for glucose levels and blood pressures. They also gained knowledge and understandings under biomedical framework about their

conditions through peer educators. Peer educators delivered self-management recommendations based on information handed out from MoPoTsyo to patients. This setting was quite different from the Western medical encounter where the patients usually meet up with their doctor alone and the results from the examination are usually private to the patients themselves. Also, in order to comprehend the following chapters and gain insight on experience and meaning of hypoglycemia for participants, it is important to know how patients interacted with the organization.

Weekly peer educator checkout

Participants usually went to the checkups at peer educator centers at least once a month since this was the requirement in order to keep their membership, continue treatment and buy medications with affordable prices from MoPoTsyo. Each peer educator center would hold the checkout weekly in the morning on the same day; therefore, some participants went weekly. Most participants said they would like to go to the checkups every week but it depended on their schedules; they might go there once two weeks. One participant lived further away and could go there only once a month.

As mentioned before, one out of the five peer educator networks in Phnom Penh was held in MoPoTsyo office, where the arrangements of the setting and the atmosphere were quite different from the other four centers.



The checkups were usually held at the peer educators' home, either in the garage or the living room. One desk would serve as the checkout station and the peer educator would sit in front of the desk. There would be several plastic chairs

and patients could sit and wait there. Seats were placed, usually, towards the desk, but patients could move them if they liked. While waiting, most of the time, patients would keep silent and listen to what peer educators said, but patients would sometimes chat with each other. Therefore, it was not like in the classroom setting that only one teacher talked all the time, and it was different from the medical encounter that only one patient and one doctor were in the examination room. Sometimes several different topics were discussed at the same time in the house. They discussed about the news and the elections as the assistant translated to me. Peer educators would join their discussions sometimes. The relationships between patients and the peer educators differed from person to person; some participants viewed their peer educator as friends while some called the peer educator “teacher” because they felt the peer educator knew more than themselves, and they could ask questions to them and get the correct answers from the peer educators.

The setting in MoPoTsyo was different; since it was in the office, seats were placed along the wall in one row inside the office and patients could sit in the garage, where two small tables were placed. Otherwise, they had to wait outside the building, sitting on their motorcycles. Therefore, it was more difficult for patients to talk to others, while, at the same time, it was not as easy to hear what the peer educator said to other patients.

In order to better explain what these checkups were like, in the following, I will describe the situation I observed with the story of patients Thyda and Dom, peer educator SoPheap and other peer patients in one typical checkup.

SoPheap often started the checkup around 6:00-6:30 in the morning because some patients needed to go to work and the checkup would last until around 9:00-9:30. It varied every week; sometimes the place was crowded and SoPheap was busy checking patients one by one; sometimes there were few patients so it was not that busy. Some patients would stay even after the checkup but mostly they would leave right after the checkup was completed.

When Thyda arrived, she gave SoPheap her recording book, where her name, contact number, dates of birth, occupation, date she became a member of MoPoTsyo and disease history had been written down. Books were placed in the order of arrival so SoPheap would examine patients in this order. Thyda went to weigh herself and after weighing, she sat and waited. It was a busy day.

SoPheap measured the blood pressure with electric sphygmomanometer;

sometimes patients would help themselves with the gauge. The glucose level was measured by glucometer, which was always performed by SoPheap.

While waiting, sometimes Thyda chatted with other peer patients about the news; sometimes she was quiet and listened to what SoPheap said; SoPheap often announced new policies or activities from MoPoTsyo, such as the fee for doctor consultation rising because of lack of fund of MoPoTsyo or that patients could sign up for retinopathy checks. SoPheap also talked to the patient who was being examined.

When SoPheap is examining the other patient—Dom, who injecting insulin, his glucose level was 100mg/dl; SoPheap says, “Good, good.” Dom smiled and then said he had experienced hunger, shaking and sweating after injecting insulin over the last few weeks. SoPheap said loudly, “This is low sugar,” and asked him what to do. Dom said he would eat some rice, and it would be better. Other patients around the desk said “Drinking coke is also fast.” SoPheap said, “Yes, yes. Don’t keep it for a long time. You may die.”

When it was time for Thyda, she paid first for the checkup (0.4USD). The fee was for the glucometer strips. Her blood pressure was 120/74mmHg and the glucose levels were 230mg/dl. SoPheap wrote them down in the recording books with romantic numbers, read the previous records and said, “Last few months you were low; but last two weeks it is getting higher and higher! Have you had breakfast yet?” Thyda answered no. Then SoPheap asked Thyda loudly, “What can make the glucose levels increase?” but Thyda kept silent. Other patients around the desk answered SoPheap. They mentioned eating many fruits and rice, drinking alcohol and so on. SoPheap said, “Yes, yes. Also you need to take medications regularly. Do you take it regularly?” Thyda said yes. SoPheap then told Thyda that she should eat less and should start exercising. Meanwhile, SoPheap said if the glucose levels were still high next time, Thyda had to meet the doctor on Wednesday afternoon in the hospital. Thyda nodded her head, recovered her recording books and left.

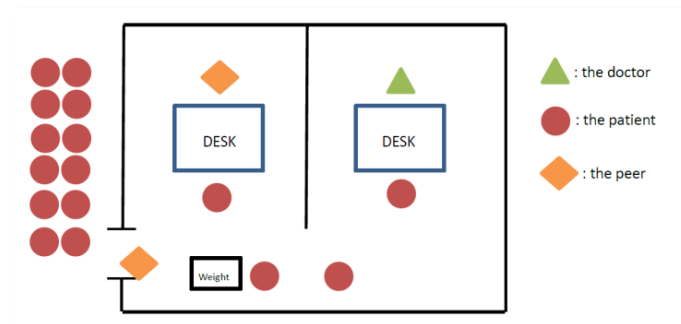
Dom did not leave after his checkup and he asked if he could go to the doctor’s consultation because it had been a long time since he went there. SoPheap said no to him because he had no problem in controlling his glucose levels and the consultation was fully-booked for patients from this network for this week. However, SoPheap also told him, if there was a place in the next few weeks, he might get a ticket.

Doctor's consultation

The doctor's consultation in Phnom Penh was held in the afternoon on Wednesdays. Patients could get an appointment through peer educators. Every week, 10 patients from each peer educator network could sign up for a doctor's consultation, but if it was an emergency, patients could get an extra place. Patients needed to pay 2.5USD for the session of doctor consultation first to the peer educator in order to get the ticket. This is at least one fourth of the price from the national hospital in Cambodia.

In the consultation, in addition to the doctor, two peer educators would be there. They helped to arrange the order; performed the routine measurements, including weight, blood pressure and blood glucose.

Patients would get a number as their sequence when they arrived. And they would wait outside. When they were called by the peer educator, they would enter the room and first have their weight, blood pressure and glucose levels measured. They might wait again inside the room.



When they met the doctor, the doctor would read the measurement data and review the recording book. The doctor might ask if they had any questions and then wrote a prescription. The prescription would be written in the recording book as well. The doctor would write an extra prescription for MoPoTsyo's database.

I had chatted with the doctor for few minutes during my observation and he said the peer educators will know more details about the conditions of the patients in terms of hypoglycemia since they are much closer to the patients and they meet frequently.

Pharmacy

Patients could go to the pharmacy when they got a prescription in their recording book. The prescription would not expire unless patients had another doctor's consultation and got a new prescription. They could buy medications for up to three months at one time. There were several pharmacies that had contracts with MoPoTsyo and they sold medicine from MoPoTsyo with lower prices compared to from other health facility. For instance, they could get 30 tablets of Metformin for 1USD while they might need to pay 3USD from other health facility. In order to prevent the pharmacies from overcharging the patients, MoPoTsyo asked the pharmacy to write an invoice for the patients so they could bring them with them to the next checkup and the peer educator would check for the patient. At that time, MoPoTsyo was trying an online system.

MoPoTsyo information

As described above, patients had their own recording books, which included prescription, recording pages and different information about diabetes.



All patients would receive a food pyramid printed in the back of the recording book, which showed three different categories of foods. The pyramid was also printed as poster and hung on the wall at peer educators' centers. The three different categories were “cannot eat/ sugar increases fast”, “eat a little bit/ sugar increases medium” and “can eat/ sugar increases slow.”⁴ Fruits, such as banana, pineapple, sugar cane, durian, watermelon and ranbutan, and white rice belonged to the first category. Brown rice, oil and fish sauce were classified in the second category.

Vegetables and fish were in the third group. It also reminded patients that if they had other diseases, they should consult doctors for further instructions on diet.

Other diabetes self-care was included in the book, such as the advice to exercise 30 minutes per day, take medications according to prescription, stop smoking, reduce alcohol-assumption and take care of their feet.

⁴ Translated from Khmer to English by the research assistant

Normal ranges of body weight, waist circumference, blood pressure, blood glucose levels and other laboratory data were also printed in the book. They stated the normal range of fasting glucose levels was 70-110 mg/dl; the normal range of after one-hour taking meal was 70-160 mg/dl.

Hypoglycemia was stressed in the instruction. The book said “When your sugar is low, you may experience seizure, sweating, anger, palpitation, coma and death.”⁵ The intervention was also described as follows: “You may face those discomforts before eating dinner, at midnight or in the early morning. When it happens, please drink sugar water and eat sweet fruits. Otherwise, your sugar can be low down abnormally.”⁶

⁵ Translated from Khmer to English by the research assistant

⁶ Translated from Khmer to English by the research assistant

Chapter 6: Interpretation of Blood Glucose Fluctuations

Participants interpreted their experiences in abnormal glucose levels in order to understand the reality of the glucose levels as Bruner (1986) stated. The process of interpreting the glucose levels can be understood as semiosis. Human beings understand the world through interpretations of the signs, such as words, images, actions, events or somatic signs (Middelthon & Colopietro, 2012). We understand them with different perspectives, which may come from different cultural, social and personal experiences. These understandings will influence how people view, act and interpret the objects or phenomenon. The process of interpretation is continuous and may bring different layers of understandings to the objects or phenomenon. In making sense of signs, we are influenced by the different meanings attached to them, by others, as well as by the impression that the signs carry, such as, pain and discomfort.

Discomfort caused by glucose levels fluctuations in this sense also as signs with different interpreting processes and meanings. There are different frameworks for patients to understand their discomforts. Before patients access the biomedical framework, they may review their experiences, give meanings to these discomforts and act based on their experiences differently from after the moment of diagnosis. I will discuss more about how participants expressed this process in the section of “interpretation of the discomforts.”

As patients get in touch with the biomedical understanding of diabetes, they are introduced to a new framework to explain their discomforts. The idea of glucose levels is then introduced to them. At the same time, the whole set of steps in diabetes self-management, aimed at balancing the glucose levels, are also introduced. Patients need to link their symptoms to the abstract scales of glucose levels and act accordingly. Their experiences in symptoms are as what Kleinman (1988b) illustrates about the *illness*; the *illness* is a lived experience for patients and their social networks that they need to explain and cope with the distress. On the other hand, the abstract scales of glucose levels are the *disease* in Kleinman (1988b) definition, created by the practitioner in order to make diagnosis. The process to link these two ideas may not be easy as it sounds.

From a biomedical perspective, biomedical technology defines a scale system and boundaries between normality and abnormality. Glucose levels of 126dl/mg for fasting or 200dl/mg two hours after taking glucose is the upper boundary for normal glucose levels while 70dl/mg is the lower boundary in the definition of

the American Diabetes Association (ADA, 2005). Those numbers are relatively abstract and cannot be read without biomedical instruments. The terminologies, hyperglycemia and hypoglycemia, are created to indicate the situation when the result of measuring blood glucose levels are above or below the normal ranges. Chronic situation of hyperglycemia is defined as diabetes. The treatment is aimed at correcting hyperglycemia to the normal glucose levels with the glucose-lowering medication and other changes in live style, but diabetes patients under treatment may experience variations in glucose levels which the non-diabetic persons do not experience, including the possibility of going dangerously low. As a result, after being diagnosed with diabetes, patients will need to learn what the meanings of terminologies are and how to interpret their blood glucose values. Meanwhile, they need to recognize and define their discomforts in these definitions. Patients may learn abnormal glucose levels can cause discomforts, such as sweating, shaking, dizziness and weakness for hypoglycemia and numbness, frequent nighttime urination, itchy skin, ulcer and blurred vision for hyperglycemia. These experiences are concrete for patients; however, discomforts may differ from person to person and may occur under different conditions, making interpretation complicated. Meanwhile, in Cambodia, it is not easy for patients to access the blood glucose monitoring technology. Patients need to rely on their subjective feelings most of the time, which can make the process of interpreting the glucose levels problematic.

Their interpretations of the glucose levels may influence their self-care but, at the same time, self-care activities can shape the meanings as such. If patients get uncomfortable feelings after these activities, patients' may interpret the activities as one of their understandings of the glucose levels.

Therefore, in order to gain insight into the experience and meaning of hypoglycemia for diabetes patients, it is essential to understand how diabetes patients interpret their glucose levels. Their understandings are not only about biomedical definitions but also subjective symptoms and their activities mentioned above.

I will describe first how participants interpret the signs of discomfort; after, I will describe how they interpret their glucose levels through their discomforts, terminologies, results from biomedical measurements and self-care activities.

Interpretation of the discomforts

Before being introduced to the biomedical understanding of glucose levels, the

discomforts or the “abnormal” experiences would be the first encounter for participants in this study to cope with. Participants needed to make sense of these bodily differences and regain the order of the bodies (Becker, 1997). These discomforts served as signs and participants tried to interpret their meaning. Some of participants reviewed their prior knowledge, trying to ease the discomforts in familiar ways. Before they were exposed to *the professional explanatory model* (Kleinman, 1988a), the discomforts did not have any meanings in relation to glucose levels. Rithy told the story about how he found out he was diabetic with the example of the process before going to the hospital.

“It (the ulcer) happened when I hadn’t known I got diabetes. It was the initial stage of furuncle. In Khmer, we called it ‘come out the initiate,’ similar to the initial stage of furuncle. Then it became bigger and bigger and I let others squeeze it out and then it became swollen. Then, I was worried and went to see the doctor and ...before I went to see the doctor, I just came to the Khmer traditional teacher (healer) and put the Khmer traditional medicine on that furuncle. To tell the entire story, when I took that medicine, it became much severer and the back became rotten. The flies came to my shirt and I could smell it. Then, I went to the hospital. Because we didn’t know it was diabetes, just thought it was a normal furuncle; but actually the sugar had been increased fully.” (Rithy(1), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

He had experienced or had knowledge about the initial stage of furuncle (the ulcer) that it could be cured by squeezing it out or by the Khmer traditional healer. At this moment, the ulcer carried the meaning of something he was familiar with; therefore, he chose to treat himself in familiar ways. Linking his ulcer to increased sugar did not come into his mind since he did not know about it and diabetes was probably not widely known in his local community. However, when the situation got more severe and could not be solved with his existing knowledge, the original meaning he gave to the ulcer became suspect, and he decided to seek helps from a medical doctor. It was at this point that he met the new ideas—increased sugar, also known as diabetes. This experience linked the ulcer with the biomedical understanding and the terminology; the ulcer got a new meaning in relation to being a diabetic.

As shown in this story, when the discomforts were unfamiliar or remained unstable, participants might consult others, such as a Khmer healer and/or a medical doctor. One study in relation to diabetes and HIV/AIDS patients

conducted in Cambodia shows a similar situation: when participants treat their symptoms based on their perception and interpretation, traditional healers are frequently mentioned as the first resource where they seek help; when symptoms persist or worsen, they go to a medical doctor to obtain a diagnosis (Men, Meessen, van Pelt, Van Damme, & Lucas, 2012). However, as shown in the following example, this did not mean participants would always get exposed to the biomedical framework of blood glucose levels when they went to the hospital. When discussing diet with the following participant, she described how she did not like fruits:

“Yes, I don’t like it (fruit). And this (makes me wonder) why I get this (diabetes). I wonder also. I was like this at the beginning [...] My uncle in the province, he is a doctor, and when I always told him that ‘err I always lose power and feel dizzy and so on.’ I was always dizzy, and he always put the infusion for me. And when I injected the infusion like this, next time I said ‘err I am dizzy and when I walk, I am fell down and so on.’ And he didn’t...normally the doctor in the province, they didn’t know...like here (Phnom Penh). He always put the infusion for me [...] when I went to check my sugar, it increased since that time. Diabetes, this can be caused by the western medicine also.” (SreyLeak(1), 40-year-old female, housewife, lived with her family)

The symptom of dizziness and loss of power, which might be a somatic signs for many different diagnoses, was treated by the intravenous infusion. The participant stated later in the interview that she believed that the doctor in the countryside had less knowledge about diabetes compared to the doctor in the city, and did not perform any action in regard to glucose levels. According to the staff in MoPoTsyo, it was quite common to hear stories of patients being “misdiagnosed.” At the same time, the study with diabetes and HIV/AIDS patients mentioned above illustrates the same situation; lack of proper technology and the limitations of biomedical knowledge among health-care providers in Cambodia lead participants to the incorrect diagnosis or treatment regarding patients’ symptoms (Men et al., 2012).

SreyLeak accepted the interpretation made by the doctor in the province as her understanding of weakness and got infusions repeatedly until she met a new definition from the doctor in the city for her weakness; this interpretation was made by the biomedical doctor in the countryside, and Khmer people generally have faiths in intravenous injection since it means “putting good things in the

body” (p.1251) (Ong, 1995). Although participants consulted different people for advice, interpretation made by others were not always accepted by participants, as shown in the following example as a participant told the story of how she got diabetes:

“SreyTouch: I knew I got the illness, I ate rice a lot but I was still hungry immediately (after eating). As I had eaten (food) already, I relaxed and hadn’t cleaned the dishes yet. I kept one or two dishes [without cleaning] then I went to relax. While relaxing, I felt in my stomach, the rice had been gone, and I became hungry, hungry... then I always asked others, and they said probably I had tapeworm [small laughing]...most of them said that I had tapeworm, then I tried to find this kind of medicine. They said, ‘Ooh, eat Bok Cleur (kind of tree that its fruit can kill tapeworm).’ Do you know it?”

RA⁷: Yes I know.

SreyTouch: Bok Cleur, some people told me I needed to find seven fruits and ate with the coconut cream and what? For some people, they said ‘How old are you? You need to eat same amounts of it (Bok Cleur) as your age.’ I said ‘Ooh how can I finish it? I am now 50, how can I eat them all?’ [Laughing] And when I found them, I didn’t dare to eat. (...)” (SreyTouch(1), 63-year-old female, unemployed, lived alone)

SreyTouch consulted her neighbor and lay people in her social environment about her illness, and tapeworm was a new interpretation to explain her situation. She hesitated in taking the suggested treatment—because she also heard from someone that *Bok Cleur* could make people weaker— thus influencing her own interpretation of the discomforts. She was uncertain about the proposed suggestions so the discomforts remained untreated. This story showed the process of interpretation of symptoms could be influenced in various directions and the treatment itself might also influence how participants viewed their illness.

The study about diabetes and HIV/AIDS patients states trust is one of the key factors influencing the treatment. Even though patients get discomforts and go to hospital, lack of trust in providers may make them refuse the diagnosis and the treatment (Men et al., 2012). Even though the lay person SreyTouch consulted was not a medical professional, her doubts in treatment showed the same effect

⁷ RA: research assistant

as the study. Meanwhile, this excerpt showed how the condition and the illness might be explained by different people for the same discomforts; and different people may have their own *explanatory models* for a same illness as Kleinman (1988a) illustrates.

The understanding process was similar for hypoglycemia. Before participants got exposed to the biomedical framework, they would not think of hypoglycemia. Instead, they tried to figure out what the discomforts meant, either by reviewing their own experience or consulting others, and then tried to ease the discomforts with the familiar methods. The following participant described what happened when she became unconscious:

“Ratha: Yes, low sugar, firstly, we feel shaking, shaking and sweating drop drop drop drop. Sweat, so I (wanted to) use the fan. And then I went upstairs to take the fan. When I took the fan, I fell down and unconscious. [...] And they came to ask (express sympathy to) me, full in the house. ‘We burn the fire,’ and I was on this, it burned my back. And he pulled my hair hardly. Some, they pinched my armpit; and bit on my heel in order to wake me up. When I woke up, I felt hurt in my body for one week. And they did Guasha (coining) to me also and it was red also.

RA: So beside your husband, was anyone there?

Ratha: No, my children all went to work in factory. Only I stayed with him. And the young grandchildren they all went for a walk, and he stayed alone. And he didn’t know what to do. ‘(I) Waited and waited for a long time, and didn’t see you. I went up to see.’ And (he) saw me I sleep deeply (unconscious). And I didn’t know; he told me like this. He was so worried and ran out to call others, but no one came. Then he came to shake me in order to wake me up and he ran back and saw other walked... the old man house (who lived) near here came. ‘You should make the fire and put her above the fire.’ ‘And we don’t have coals (to make the fire), we put the small gas stoves.’ I stayed still and straight; and one stove in the leg and one in the head. And he was very worried and he cried.” (Ratha(1), 56-year-old, female, housewife, lived with her family)

The description of how others treated Ratha resembles the description in a study by Hinton et al. (2001) about “cultural syndrome—kyol goeu (wind overload)”. Almost every Khmer person knows about wind overload from their parents or elders; the symptoms include short of breath, dizziness, palpitation (shaking of the chest), cold hands and feet, blurred vision; if it is severe and remains

untreated, patients may experience syncope and even die (Hinton et al., 2001). These symptoms are similar to the symptoms caused by hypoglycemia. The increased wind is cold, causing thickening of the blood and patients may go to a doctor and ask for an injection (Hinton et al., 2001). This is why Ratha was put on the fire. Later on, Ratha also mentioned she had asked for injection from the doctors when she had faced these kinds of discomforts until she knew it was hypoglycemia. Other interventions mentioned in the study aimed to “awaken the body,” “remove wind” and “increase circulation” (p.418) (Hinton et al., 2001). Therefore, Ratha had undergone the treatments of being pulled, coining and put on fire. This explained how some participants and people around them might interpret the signs and treat themselves in ways they were familiar with.

Compared to the process of knowing diabetes, participants were more likely to meet the biomedical framework of hypoglycemia earlier because hypoglycemia was mainly iatrogenic, and a majority of the interview participants knew the terminology from peers, peer educators or doctors. They could usually relate the discomforts to diabetes or the diabetic treatment. Therefore, when they had experienced shaking, hunger and sweating, hypoglycemia would be one of the explanations to the discomforts but it did not mean the interpretation of hypoglycemia would be straightforward, which will be discussed later on.

Understanding the discomforts was a long and continuous process as shown in the quotes above. It not only involved previous experiences and others' knowledge in cultural structures, but also related to the actions attached to these understandings. The aim was to ease the discomforts and reach a new balance of well-being. Participants were eventually introduced to the biomedical ideas of diabetes and blood glucose levels after they gave meaning to the discomforts from their prior knowledge and treated the discomforts but did not ease them. These new ideas explained their conditions in biomedical framework and could bring stability to their health situation. Blood glucose levels became one of the interpretations to their discomforts. Participants began to realize they had diabetes and might try to manage their disease, especially after joining the organization.

Interpretation of the glucose levels

Every participant had different experiences after being diagnosed with diabetes. Some of them were exposed to the information around the disease while some were not. However, after joining in MoPoTsyo, all participants were introduced to

the biomedical framework of diabetes and blood glucose levels. They were expected to control their blood glucose levels through diabetes self-management since it was harmful to the bodies when the glucose levels were either higher or lower than the normal range. The aim was also to regain and maintain their well-being. However, after diagnosis, most of the symptoms they doubted were linked to the biomedical definitions of glucose levels with regard to diabetes treatment. Therefore, it was important for participants to understand the concepts of blood glucose levels.

Understanding the ideas of glucose levels was not easy since everyone experienced differently and since few were in a position to learn by measuring on an ad hoc and every day basis. Meanwhile, glucose levels might be influenced by many different factors and be fluctuant. The concepts of glucose levels consisted of different components, including the terminologies, the results from biomedical measurements and the subjective discomforts participants felt. The self-care activities might alter the glucose levels and then influence the ways participants interpret their glucose levels. As a result, the somatic signs, the terminologies, the results from biomedical measurements and the actions could be viewed as the signs of glucose levels, and participants gave meanings to them in order to understand their glucose levels. In the following section, I will discuss how participants interpreted them separately.

Meanwhile, the glucose levels may also function as signs. The result of the measurement could be understood as normal, higher than normal range or lower than normal range. This interpretation could then transfer as the understanding of the condition of the diabetic self-management. It showed whether the status of glucose levels was in control or out of control and told about how participant took care of their disease. And it might also carry the meaning of good or bad self-care skills of the participants. This issue will be also touched upon throughout the section.

Through somatic signs

After participants encountered the biomedical framework of diabetes and glucose levels, the experienced discomforts or the somatic signs could be one of the signs for them to interpret the abstract ideas of their high or low glucose levels. Some participants mentioned their status of glucose levels by expressing what kind of somatic signs they had experienced.

“He (The doctor) said it was not another disease, it was just low sugar, the

effect that made us shake in the muscle (tremor). If I put (ate) the sugar, it could be better. [...] I experienced those and I know about this. Now mostly, it's low, not high, and balance, so comfortable. If it increases, it is hard (numb and tough) in the hand, heavy in the body, headache. And this is increasing. And (if I) take something to measure, it increases 4+. And when (I feel) comfortable like this, when I check, I don't see. It doesn't increase. I have, I buy it (urine strip)." (Ratha(1), 56-year-old, female, housewife, lived with her family)

Here, Ratha explained the signs representing high sugar or low sugar; hard in the hand, heavy in the body and headache indicated the glucose levels was increased, while shake in the muscles (tremor) would indicate the low sugar. She learned the signs through observations and through teaching from the doctor. Meanwhile, she mentioned the urine strip test as the supplement to prove her interpretation. She introduced the measurement from urine strips to either verify or supplement her interpretation of somatic signs as "high." She also introduced her interpretation of balanced/controlled glucose levels when she did not have the strange feelings. This might cause the concern whether the somatic signs can represent the glucose levels and I will discuss together with the next example.

The similar expressions came up during the interviews while participants described high or low glucose levels by discomforts. These discomforts representing high or low glucose levels had some commonalities. Therefore, patients, peer patients, peer educators and doctors could all communicate by talking about these common discomforts. However, the somatic signs might vary from person to person and everyone could experience differently within the same diagnosis—diabetes. For instance, some participants would use blurred-vision or an ulcer instead of headaches as signs for high glucose levels. Moreover, this specific somatic sign might occur in different situations even for the same person. For example, headaches might be the symptoms due to insomnia rather than high blood glucose levels. The following participant exemplifies this:

"I faced this ...before I drank coffee, I hadn't eaten anything yet. I brought the grandchild to school and so on...then after I had drunk coffee and tea already, it made me dizzy and blur and so on. Then, when I tried to check the sugar in order to know, I saw the blood levels were low. Yes... such as it used to be 100 and it remained 80 or 90 and so on; and because of this, it made me dizzy and not felt comfortable as previously. Based on this, we made an assumption by myself that this, the sugar would be low...I felt like this. After I drank it, and I

came home and I sit for a long time; it made me shake in the leg and so on...then, I rushed to eat rice or porridge and it made me become normal. This happens sometimes, one or two times when I drink it, it makes me blurred and shake in the leg and arm...as I have this (symptom), I rush to go home to find the rice to eat...and (after) this (I) will be normal.” (Sao(3) 63-year-old male, retired officer, lived with his family)

Here, Sao addressed one episode of hypoglycemia after drinking coffee in the morning. He got dizzy, blurred-vision and shaking. However, these symptoms might not only relate to hypoglycemia. For instance, tremor might be caused directly by the effect of caffeine. As a result, hypoglycemia could be one of the possible explanations of the discomforts and the situation could be confused for the listeners.

Sao later explained he conducted blood test when he was home; the figure was 80 or 90. Again, the participant verified his discomforts with the results from the biomedical measurement. However, this numbers made the story more confusing. According to the definition, 80 or 90mg/dl was not “hypoglycemia” (ADA, 2005). The interpretations with regard to numbers and results from biomedical measurements will be addressed in the later section.

In addition, diabetes or abnormal glucose levels might be asymptomatic; for instance, the effects only happen in the extremely high glucose levels for diabetes patients (Weiss & Hutchinson, 2000). Therefore, determining glucose levels based on somatic signs alone could be dangerous. For example, one review suggests that acting in response to the falling of glucose levels, which may not be actual hypoglycemia, may increase the risk for complications. On the other hand, weak signs of falling glucose level could make the person unaware of dangerous low levels that are fast approaching (Amiel et al., 2008).

In conclusion, somatic signs could be one of the interpreting methods patients use to determine their glucose levels and the language to discuss their glucose levels. Most of the participants seemed confident in recognizing the meanings of the signs. However, the different possibilities in explaining the somatic signs and participants’ various experiences made the interpretations remain uncertain. The complexity in glucose levels, where the patient’s subject feelings did not always reflect the actual chemical numbers, might cause the doubts whether participants could act accurately. As shown in the example above, some participants would use the results from measurements as the proof for their interpretation. However, the interpretation of the numbers led to the other

concern, which will be discussed in the section of results from measurements.

◆ *Normalcy*

One interesting topic that arose through the interviews was that when participants did not have somatic signs, they viewed themselves as normal. Normalcy could have several meanings, such as being back to the health state—free from the illness, or feeling like normal people. Before participant understood the idea of chronic disease, once their somatic signs were eased, participant might think they got cured. This is described in the following example by a participant telling the story of how she knew she had diabetes:

“The result was I got diabetes. ‘Your sugar is 285’, the first time; and, and they told like this. And I didn’t know what diabetes was, because I was stupid; and I bought the medicine outside (not in MoPoTsyo) because I checked it outside. And I took diabetes medicine that they gave a lot to me. And when I checked again, and they checked my blood sugar, it was low, only 100+. And it was low like this, and (I felt) I was healed. And then I stopped taking and then I stopped buying. And I didn’t care about it. And then it affected again. And then I doubted, (because I thought) it had been healed already. Because I didn’t understand what diabetes is and it can’t be cured. And then I didn’t take the medicine again. And then I went to meet the doctor again. I hurt like this, it was hurt. And they said ‘Do you take the medicine every day?’ And I said I stopped taking it because I got better. And they said ‘No [tone up], you must take it forever.’ They said diabetes can’t be cured...Oh, I had to buy the medicine to take again.” (Srey(1), female in her early 60, housewife, lived with her family)

Before the discomforts happened repeatedly, Srey wondered if she was healed and back into “normal” again. This showed how understanding diabetes based on somatic signs might fail to catch the idea of being chronic and have an influence on the long term continuation of treatment.

The other example of feeling normal was when participants indicated the glucose levels were well-controlled, as in the following excerpt.

“When I limit foods and sweets, my sugar will low and I must take the medicine and follow the prescription. And then the sugar previously is only 85. 99, 93, 100, 103 (when I) checked in the morning before eating. And when one day, I was brave to eat desserts, such as jackfruits, which is so sweet, when I went to check my sugar, it would increase to 125. It would increase; it was

based on our eating also. But to me, if (I) let myself eat regularly, and no desserts and the fruits that are not too much sweet, such as the skin of the dragon fruits, lime, which are normal to eat, and the power is normal. And they said, 'Ahh, sister, you are so strong and walk fast,' and people walk together said 'you are so energetic.' And they said 'Look at you, you look so comfortable (good in shape) and not hurt (ill).' In fact I told them I got diabetes, and they said 'Ohh, if you don't tell, no one knows you are diabetes (laughter).'" (Srey(1), a female in her early 60, housewife, lived with her family)

From the excerpt, the participant did not use the word "normal" but instead Srey used other words to describe how she was not different from ordinary people, which can be interpreted as being "normal". This was similar to the situation in Naemiratch and Manderson (2008)'s study of Thai diabetes patients, they mention once patients have the ability to work and maintain "normal" social lives, they may refer to them as normal and the diabetes become invisible. "Visible diabetes" is referred as disruptive symptoms; and when they follow treatments and the symptoms are under control, the patients view their diabetes as invisible. It indicates they know they are diabetic and their normalcy is in the condition when they self-manage their disease.

Meanwhile, the meaning of "normal" was not only about this situation. When I asked participants how they felt when they experienced hypoglycemia the next time, and one participant said *"it was normal. When it shakes, I eat sugar and it is stopped."*(Ratha(1)) Many participants stated like this during the interviews. And it illustrated participants understood their lives was different from general people who were free from the illness but they still used the word "normal." The word—"normal" meant it was usual for diabetes patients to experience these symptoms and she knew how to deal with it. It also showed the confidence of the participant. "Normal" in such example showed how participants accepted the condition that they had a chronic disease—diabetes.

Normalization defined by Bury (2001) in chronic illness includes maintenance of the pre-illness lifestyle and incorporation of illness into life, which indicates the new definition of "normal life," meaning embracing illness in life. It meant participants acknowledged the fact of having diabetes and its influences; but when they interpreted their glucose levels correctly, acted accordingly and got things under control, they would experience the normalcy as diabetes patients. Normalcy in this sense represented the degree of control of the disease but, at

the same time, it carried some sense of judgments. It indicated if the life was disturbed by the disease or something unfamiliar happened because of the disease, things were out of control and their self-management might be “wrong”; they were not “normal” anymore.

Meanwhile, Srey also mentioned in the above quotation how other people perceived the normalcy of the participant. In the focus group discussion, participants raised discussion that villagers (people in the community) would think diabetes patients were worse than HIV/AIDS patients because they needed to limit their diet. One participant in an interview also mentioned that when she ate out, people might be curious about why she ate less and she would have to tell them she had diabetes. Meanwhile, when focus group participants discussed about the perception of hypoglycemia from villagers, all participants said at the same time *“they don’t know.”* One participant in the focus group discussion said if they did not explain and describe their symptoms to others, people would not understand. Meanwhile, another participant said even their family did not know sometimes, how they could expect villagers to know. Furthermore, an episode of hypoglycemia might lead to villagers labeling the participants as “lazy.”

“Moderator: [...] you said they don’t believe you.

6: They don’t believe us.

7: Totally don’t believe.

6: ‘Why you eat a lot?’ [mimicking the other person’s speaking]

1: For the job, (when it’s hypoglycemia) we can’t do. For example, in the grocery store, where they sell rice and food, we help each other wash the dishes. When the guest comes to buy the food, and when we fatigue and weak in our hands and legs, and we go to sleep and cross our leg (relax)...

6: [interrupt] Our feeling is we don’t want to work.

1: Feeling we don’t want to work. They say we eat a lot, but why we can’t do....

3: [interrupt] They said we are lazy.

1: So lazy [emphasis]! If we eat and we work, it’s not the problem (for them), but we can’t work, why we eat a lot?”

The excerpt showed it might be not easy for others to notice participants’ disease let alone the status of participants’ glucose levels. And people might have negative impression of participants, because they could not work as “normal people” and ate more compared to “normal people.” When the “abnormal

behavior” occurred, people would start noticing the differences. If they asked, they might be informed about participants’ disease. Meanwhile, several participants mentioned their family would understand they needed to rest when being hypoglycemic because they knew they had diabetes. In this case, participants were not perceived as “normal” as general people but “normal” as diabetes patients, who needed to rest. This also showed others’ interpretations of participants’ actions or discomforts, which made the disease or the abnormal glucose levels become socially.

To sum up, normalcy could mean different things for participants when they did not have any somatic signs. It might influence how participants viewed and acted toward the disease. Meanwhile, it represented their interpretation of their normal glucose levels. The “normal” expressions were also about the degrees of control and the confidence in diabetes management. Normalcy might bring out the issue of moral judgment, which I will return to later in the next chapter

Through terminologies

Diabetes, hyperglycemia and hypoglycemia are three terms created by biomedicine indicating the abnormal glucose levels. They seem quite well-defined and should be understood the same in relation to glucose levels even though the normal range of glucose levels may be debatable. In contrast, the signs and the symptoms vary from person to person. The language might be understood differently by participants depending on their cultural and individual experiences. Therefore, I am going to address how participants interpreted the glucose levels by using these terminologies and relevant ideas.

◆ Diabetes

In Khmer language, diabetes is called sweet urine disease. Participants were likely to be informed their sugar was high and they should limit the sugar consumption for diabetes self-care when they were diagnosed with diabetes. Urine strip was the measurement advocated by MoPoTsyo in order to monitor the status of diabetes control, a positive result of glucose in the urine indicating high blood glucose levels. Therefore, it was quite intuitive for participants to establish the connections between the disease and urine, the disease and sweet and sugar. It was quite common to hear participants referring to their diabetes as “sweet urine” and determined their glucose levels through indicating if their urine contained sugar. One participant described this as follows:

“[...] this organization, they introduced very well to me, and they gave us the

urine strip in order to see, and they let us to check our sugar every week. Is it low or high? And they follow us up every time. Tell you honestly, this organization is so good. I admire them, and they come to follow often, French (the foreigners), they ask 'how is your health?' something like this. And I follow their advices. One day, French they saw my sugar was low, and I said 'first I exercise, second, my diet, third, I take the medicine, follow the doctor.' And they said "good, good." And they said 'have you checked your urine?' And I said 'I have checked my urine and it doesn't have (sugar).' And they said 'good, good.' They said like this to me." (Srey(1), female in her early 60, housewife, lived with her family)

From this story, Srey stated her urine did not contain sugar, which meant her glucose levels were under control. This translation came from the name of sweet urine disease and sometimes some participants would say "it seems like my urine is not sweet anymore" to indicate they felt well and diabetes was under control. On the other hand, for some participants, instead of saying the urine did not have sugar, they would use salty urine to indicate the opposite situation.

"[...] when I taste my urine, it doesn't contain any taste. (The urine) tastes like the water. As I noticed, every time when I tasted, it was so salty. But this few months, these two months as I taste... it tastes like water. The urine doesn't taste anything... this is not good..." (San(2), 33-year-old, worker in primary industry, lived with his family)

San tried to explain the reason why, in his opinion, he needed to inject insulin at noon again, which he had not been doing for the past three months, after he went to the checkup and found out his sugar was high. His glucometer had been broken and he had tasted his urine to monitor his glucose levels. When the urine had been salty, he thought his sugar had been under control; that was the moment when he began to skip his injection at noon. However, after this, he stated that his urine tasted like water, which he interpreted as his glucose levels moving from being balance towards imbalance. In the interview, he also used the other ways, such as somatic signs, to verify his interpretation of glucose levels.

One study set in Cameroon describes a similar situation where tasting urine becomes one of the methods to self-diagnosis and for those who have been treated, it can be used as a measurement for showing their blood glucose levels; meanwhile, seeing the arrival of ants to their urine indicates the status of having diabetes (Awah & Phillimore, 2008). In focus group discussion, one participant also shared the story that he started noticing something wrong with his body

when he saw ants coming to the toilet, where he just urinated.

On the other hand, salty urine might also be used to determine hypoglycemia, as described by one research participant in the following excerpt:

“Low sugar, first, when I didn’t know; I saw something two (double vision, blurred), I saw two people sit at the same place like this; when I was so weak, I couldn’t see (clearly). And now, as I know, I eat sugar or rice, because rice contains sugar also. I eat this, it would be ok. If I eat enough, it’s no problem, like the normal people. It doesn’t break anything, I have power. And when it’s low sugar, this probably is the salty urine.” (Theavy(1), 72-year-old, retired teacher, house wife and helps in children’s shop, lived with her children)

Here, Theavy tried to explain how she managed the episode of hypoglycemia. At the beginning, the research assistant and I could not understand what the meaning of salty urine was. The doctor in MoPoTsyo explained to us that salty urine meant *proteinuria*, the presence of an excess of protein in the urine. However, if proteinuria was what Theavy meant in her words, the whole sentence would not make sense. As a result, the assistant and I interpreted the term—salty urine Theavy mentioned was her expression for being hypoglycemic.

From these stories, participants used the ideas of sweet and salty to represent their glucose levels. Salty could mean the balanced or low glucose levels. The ideas of sweet and salt was generated from the participants’ interpretation of the terminology—diabetes (sweet urine disease). When they expressed their interpretation, they might also mention other things, such as the discomforts, to verify their understandings, to verify what they said.

Moreover, the terminologies of sugar and salt did not only influence how participants explained their glucose levels and evaluated their control, but also how they acted. One participant stated she treated her ulcer, which, she believed, developed because of diabetes, with salt and lemon. The following story also showed how sweet and salt influenced the way participants practiced their diet.

“[...] Then I told my daughter because she bought the salty snack to me. Yes, eating at night or whenever I got hungry because it didn’t contain sugar. It contained only salt and I could eat that biscuit, it is ok! But when I ate it, after this, I got normal and limbs stopped shaking. But when I was fatigue, I could take this medicine and it could prevent me from shaking arms and legs and sweating a lot. For the first time, I was so worried, uhhh whether side effect from medicine or low sugar or high sugar. Then I came here and doctor said

‘when it has effect, I must find something to eat immediately or swallow candy in order not to get too much low sugar.’ I was so afraid of eating sugar. I thought on my mind and I told doctor ‘I don’t eat sugar, I eat only salty food.’”
(Focus Group P6, female in her early 40s, house wife and seller)

These examples showed how the terminology of diabetes (sweet urine) influenced how participants interpreted, represented and acted towards their glucose levels. Sweet and sugar were viewed as high glucose levels, which might carry the meanings of bad and out of control; however, at the same time sugar was essential to ease their episode of hypoglycemia. On the other hand, salt and salty were viewed as good and in control; but participants might refer it as hypoglycemia, which was also one of the out of control events. Here it showed the complexity of being sweet (high) or salty (low) and they were not completely opposite. The experiences in both situations might alter participants’ interpretation of those terminologies. Moreover, the individual feelings might be expressed at the same time and influence how they interpret their glucose levels. It showed participants did not use terminologies to show their disease alone and the interpretation was influenced by many factors.

◆ *Hypoglycemia*

As mentioned above, salty urine might represent the episode of hypoglycemia for some participants but I only heard it once from the interview. The common terminologies for hypoglycemia in Khmer could be “low sugar,” “extreme low sugar,” “too much low sugar” or “lack of sugar” since there was no unified language practice.

Different words could mean different things for different people. Even though all participants in interviews referred to “low” as the discomforts of being hypoglycemic, it was also possible for them to mention low as balanced sugar at some points during the interviews. It depended on the context and it had caused confusion to the interviewer, the research assistant and interviewee. Sometimes the confusion might be due to the question itself, but sometimes it might be because of the terminologies. For instance, after participants described one episode of hypoglycemia, I then asked the participant how they felt about being low sugar; they might answer “I felt normal.” Here, I was not sure if this expression was the true feeling of hypoglycemia since I did not link to what they said and they might understand it as balanced sugar. In order to avoid the misunderstandings, during the interviews, I consciously replaced the word low sugar with the discomforts they just mentioned as low sugar. I would ask them

again, for instance, how they felt when they were shaking, sweating and so on.

“Low sugar,” “extremely low sugar,” “too much low sugar” and “lack of sugar” could have slightly different meanings for some participants, while some thought all words had the same meaning. These words all represented, to some extent, hypoglycemia, but they could differ in severity, or be used by different people and professionals, such as health providers. Some participants expressed each word represented different discomforts; for example, low sugar was slightly shaking while *“extreme low sugar, this would become unconscious.”*(Ratha(1), 56-year-old, female, housewife, lived with her family) “Lack of sugar” was the term most of the participants mentioned that was used in the hospital by the health professionals. The doctor in MoPoTsyo also said he learned the term of “lack of sugar” in medical school. However, one participant thought “lack of sugar” was one disease for people without diabetes.

“RA: So based on your opinion, the lack of sugar and low sugar what is the difference?”

Rithy: It’s the same. but she...she...the lack of sugar is not like us who are low; low, low to all (no sugar levels and dead). For her, just the effect—lose power, fatigue and so on; sweating also, but not like our sweat that drops drops drops, for us (diabetes patient), it (sweat) comes out like we take a bath. This is really low, and it can be dead. For her, just she is so weak and cannot do any work. Yes, when we add the sugar into this (body), She...two or three days later, she will have the power back; it’s like this. And for me (it affects) immediately; the low sugar because I inject the insulin... it is so dangerous. Yes, for her, it is chronic, a kind of chronic. Dizzy, mostly she got dizzy; dizzy and cannot walk, person would lack of sugar cannot walk; when they walk, they would get really dizzy. Yes.” (Rithy(1), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

Consequently, using terminologies applying to the status of being hypoglycemic could be messy given that there was no unified terminology and it could mean different degrees in the spectrum of glucose levels. Within the same participant, the same terminology might mean differently based on the context, which made the interpretation difficult. In order to understand their experiences correctly, other components, such as somatic signs and results from measurements, was used in addition, to clarify the terminologies.

Through results from biomedical measurements

The system of chemical numbers is created biomedically and measured using biomedical technology. The diagnosis of diabetes is based on the results of measuring plasma glucose levels (WHO, 2006). Self-monitoring of blood glucose, used to gain the real-time feedback on diabetes patients' glucose levels, is one of the important self-management tools in the international guideline developed by IDF (2012), especially for those who injecting insulin. Therefore, chemical numbers become one and perhaps the most dominant language in biomedicine-related facilities after patients get diagnosis of diabetes.

As mentioned earlier, however, because of the limited resources in Cambodia, daily measurements with glucometer were usually unaffordable and inaccessible for participants. Some participants bought urine strips for monitoring their glucose levels and no color changed was one of the indications for well-controlled glucose levels. One participant mentioned that after an episode of hypoglycemia which she treated by drinking sugar water, she would check her glucose levels with urine strip since she was afraid of being hyperglycemic.

Biomedical experts doubt the accuracy of urine strips because a negative urine glucose test can represent the conditions from hypoglycemia to moderate hyperglycemia. At the same time, the result indicates the average levels during an interval before the test is taken rather than the actual levels at the point of testing. Moreover, the result may be influenced by fluid intake and urine concentration; and the renal thresholds, the concentration when the kidneys begins to remove sugar from the body to the urine, might vary from person to person. Last but not least, it cannot be transferred directly to the blood glucose levels (Goldstein et al., 2004).

Participants would check the plasma glucose levels at least once a month at peer educators'. Some insulin-injecting participants did have glucometers at home, but they did not perform it often. The reasons for not testing at home included machines being broken or participants believing the measurements at checkups were more accurate. However, as staff in MoPoTsyo told me, both patients' and peer educators' glucometers were not calibrated as what I did regularly when I worked in the hospital after using a period of time. The prices of the test strips might be also the reason but participants also needed to pay for the strips while going to the peer educator's place and they did not mention it as the reason for not using it.

During my observation of the checkups at peer educators', it became clear that numerical numbers from glucometer nevertheless became the main language in relation to glucose levels for peer educators and patients. Patients learned the biomedical definition of euglycemia, glucose levels in normal range, when they got the result from peer educators, usually with the expression of "high, normal and low." Therefore, the numbers became one of the meanings attached to glucose levels. Meanwhile, the expression of "high, normal and low" was the interpretation of the numbers to present the condition of the patients. Some participants might also learn the idea from biomedicine that blood glucose levels were the only way to indicate their glucose levels accurately, as the following example shows:

"Low, it is like...I find the reason, it is low or not...I don't know. I just know I have doubts with the symptoms. Someday when it (symptom) happens, I don't know; first, the sugar lows or increases, I don't know, unless I check my blood with the machine test. I have it in our house. I check to see what sugar levels are. If it is lower than 100 or just less than 80, this means I am low. This, it affects like this. But when it affects like this and I check the blood sugar, it is mostly 80; if I am normal and I check, it is 100 or 120. And I can keep it as normal because it has no problem. And I don't make assumption it is over also because I check also at that time. I know it is low; less than 80 and it affects in the body, I lose power and want to vomit and so on. So when (I feel) normal and I check, it is normal also, such as it increases to only 100 or 120, for example. This, in my body, it is no problem. So I follow it also; I cannot estimate (assume) it is low or high when I lose power; I don't know; I need to check also. Yes, if I (don't) check here, I go to the hospital also, (find out) the reason why it is much severer, such as being dizzy and wanting to vomit. So the reason is like this. Yes." (Sao(2), 63-year-old male, retired officer, lived with his family)

Here, Sao mentioned several numbers to indicate his glucose levels and he also emphasized the importance of measuring. In his opinion, the discomforts could not tell the glucose levels precisely; measurement was the only way to verify the glucose levels. This idea was similar to what American Diabetes Association, one of the leading organizations in diabetology, suggests that blood glucose test is essential in terms of glycemic control (Goldstein et al., 2004).

However, the excerpt above also demonstrated the meanings of the numbers could be different among participants. For Sao, 100 or 120mg/dl was no problem

(normal range), while for another participant (Ratha), glucose levels under 200mg/dl was alright. One possible reason for this was that the numbers were abstract. 80, 100 or 200 were just three numbers and did not seem to make sense to any of the participants unless they felt and experienced something with the numbers. When feelings attached to the numbers, the numbers became concrete. When Sao mentioned the numbers, he also described his feelings. 100 or 120mg/dl was normal because he felt nothing while 80mg/dl or less was low since he got effects.

Meanwhile, the different understandings of the numbers among different participants might be due to the personal experiences. Ratha shared the story that she got the numbers—75mg/dl in the morning checkup at peer educator's after she experienced shaking in the evening one day before. Therefore, she stated *"It low...remaining only 95, 75 and it's just slightly shaking; it doesn't sweat. It's only this."* (Ratha(1), 56-year-old, female, housewife, lived with her family) Sao got the numbers—80 mg/dl after he drank coffee and got the effect of hypoglycemia, 80mg/dl became his understanding of being low. Actually, none of these numbers are viewed as low in the biomedical definition, where hypoglycemia is defined as below 70mg/dl; therefore, participants' interpretation of numbers might cause concerns with regard to actions, where the situation with the understanding of the numbers could give rise to misunderstandings with serious consequences. However, most of the participants stated they acted toward their glucose levels based on their uncomfortable feelings. This raised a very important reflection as to whether numbers really matter to Cambodian diabetes patients.

Moreover, within the biomedical definition, the scale itself was also chaotic. For instance, as shown in the literature review, there is no consensus definition for hypoglycemia (Amiel et al., 2008). At the same time, symptoms are nonspecific and may differ from person to person even in the same levels (ADA, 2005; Weiss & Hutchinson, 2000). In the research of Dow (2006), they illustrate the similar concern in defining diabetes through numbers; some participants were defined as "borderline diabetes" before they start the medication and the medication is viewed as the start point of being diabetes by their participants; participants may get several "normal results" and occasionally "abnormal results" when they have been diagnosed with both terms and they do not feel much different. However, the doctor, at one point, puts them on the medication. The participants wonder how numbers exactly represent the status of diabetes. These statements may indicate the complexity of glucose levels, which are not only about the biomedical

definition but also the subjective feelings from patients.

Montez and Karner (2005) state that when diabetes patients express the disease in terms of the numbers, they also dissociated the self and the body; this happens because patients are expected to control their glucose levels, which is understood purely as the chemical numbers obtained by measurements. However, as discussed above, glucose levels are both about the numbers and the subjective feelings. As a result, it might be difficult to separate the self and the body when talking about the condition of diabetes patients. Members in MoPoTsyo seem to be expected to subject themselves and express their status by using biomedical language appropriately. Together with the concern of whether numbers really matter for participants, it might show the relations of power which superimpose biomedical knowledge on other knowledge.

Participants used numbers as “common language” referring glucose levels even though numbers were not easy to obtain in Cambodia. This happened mainly in activities held by MoPoTsyo. They got used to numbers as expressions in order to communicate with biomedicine, and this was one of the possible reasons why they would mention numbers to me spontaneously during the interview. Meanwhile, regular attendances in checkups for measurements served as the keystone to maintain the membership in MoPoTsyo. These factors made the measurement become essential. It was worth noting the result of the measurement, which could be interpreted as the degree of the control in diabetes, would not influence their membership.

Research participants would use the results from measurement, urine strips or glucometer, to refer to their glucose levels; to make judgment of their glucose levels and the control. However, they could not obtain the numbers easily most of the time and they might understand differently about the scale of the numbers due to their various experiences. They would usually express their conditions with the description of their feelings and the discomforts in addition, which suggested that both the chemical numbers and the subjective feelings were important.

Through results from self-care activities

The diabetes self-care is aimed to improve the immediate and long-term quality of life of people with diabetes through different methods aimed at balancing glucose levels, such as diet, exercise and medication. After diagnosis, patients need to get education of self-management; and in cooperation with health

professionals, patients need to monitor glucose levels, modify lifestyle and continue in taking medication (IDF, 2012). That is to say, activities related to diet, exercise and medication would influence patients' glucose levels directly and the glucose levels might be changed after these activities. After participants experienced the changes in blood glucose levels, for instance, having discomforts like headaches, sweating and shaking, the self-care activities which made their glucose levels change, would become their interpretations for the glucose levels and influence their self-care. As a result, before I address issues around self-care in next chapter, it is important to gain insight into how participants might relate activities to the glucose levels.

◆ *Diet and glucose levels*

As described in the terminology section, after learning the word “sweet urine disease”, participants generally understood urine would be sweet and contain sugar if they consume too much sugar. This information came from education program or their own observations. Therefore, the relationship between the diet and hyperglycemia was formed. One participant described she got hyperglycemia because of careless eating.

“(I fell into a coma due to hyperglycemia) in 2005. I got (diagnosed) in 2003 and in 2004 (the discomforts) happened the first time. I sold vegetable on the trolley. And then I always drank sugar cane juice, four to five bags. And watermelon, I cut it and I ate the whole, and I ate all at one time. When it affected, I felt like what, oh, when the sugar was high, it was headache and like something beating in the brain. So I left the trolley here and went to the doctor, and checked the blood test. When I tested it, it increased until 600+.”
(Ratha(1), 56-year-old, female, housewife, lived with her family)

Ratha shared the story before she joined MoPoTsyo but she had already known she had diabetes. At that time, she ate sweet foods, which she understood later as “cannot eat” foods in the food pyramid, carelessly and this made her feel uncomfortable. She learned a careless diet might cause hyperglycemia and thus became one of her interpretations of hyperglycemia. Other participant shared similar stories.

“If I eat too much (rice), the sugar will be high also. Based on my analysis, it is based on the food. When I eat too much, sugar will have a lot (in the body) also, and my health will become weaker.” (Rithy(1), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

From the excerpts above, participants described how eating sweet foods or eating too much would influence the glucose levels and caused discomforts. As a result, they understood their glucose levels would be increased if they did not control the diet. This experience might influence how participants practiced their diet.

"I want to say the banana others sell, they take banana under the sun (dried); this (banana jam) I can't eat, it is so sweet. When I eat, I get headache immediately. But if I eat the (fresh and green) banana, this is no problem. It never affects to my body; when I eat it, I feel normal. Such as...sugar increases, but it increases less and the body can control it and make it stable. Such as the sugar increases less and it will decrease less, also, so it is stable, and it makes me feel better. But if I eat banana jam which is sweet, as I want to know (taste), it (the body) can't (control); when I eat, it makes me headache and uncomfortable because sugar increases so high" (SokLeang(1), 49-year-old male, craftsman, lived with his family)

SokLeang explained how he would have different experiences after eating banana jam and the fresh banana. He would not feel uncomfortable after eating fresh banana, but he would get discomforts, which were linked to hyperglycemia, after eating banana jam. Therefore, eating banana jam became one of the interpretations of being hyperglycemia. And this interpretation made him avoid eating it. In Becker (2003)'s study with Filipino American diabetes patients, one man also states even though the doctor has told him not to eat certain foods, he still tries the foods; he then stops eating these foods because he gets effects and he feels worried about the further impacts

On the other hand, participants were also concerned that hypoglycemia was caused by diet. Some participants thought eating less might cause hypoglycemia.

Rithy injected insulin once a day at 10am and he mentioned low sugar was *more likely* to happen in insulin-injecting patients. He also explained, if he ate less in the evening, after urination at midnight, he would get the discomforts.

"[...] And if in the evening, I eat less, and it is a long time (to morning) and as I inject the insulin and when I get up to urinate; and when at 1 am or so on, it will start to affect, and the sugar is low and shaking in the leg and arm, and sweat drop drop, drop..." (Rithy(1) 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

Here he showed eating less was one of the factors for having low blood glucose

levels. Meanwhile, low sugar occurred to Rithy only at this moment. Even though he mentioned insulin-injection was the main reason for getting hypoglycemia, within his experiences, eating less was the reason for low sugar as he described. He did not always get low sugar, but when he ate less, it would happen. Patients in the research of Tan et al. (2012) also mention light breakfast may cause hypoglycemic episode. Therefore, the amount of food consumed became one of the understandings of the cause of abnormal glucose levels for some participants.

From Rithy's story, in addition to insulin and diet, another explanation for him was urination. He stressed in the same interview that *"it affected only after I urinated and I came back to sleep."* From his previous words, he thought the urine would carry out sugar in the body, which might come from the name of diabetes in Khmer. Later he also explained the reason why he felt fatigue in the morning after eating too much rice and urinating a lot at night was because *"the sugar was extremely low through urine,"* and this was reflected by other participants in the study. Actually, I was not sure if his fatigue was due to hyperglycemia or hypoglycemia. He explained it as the signs of high sugar but, at the same time, he stated the sugar levels became low after urination. These two statements were contradictory, however, in humoral theory (Ong, 1995), it seemed not important to understand if it was hypoglycemia or hyperglycemia; it was the imbalance that caused the discomforts. Both eating too much and eating too little were imbalance situations in diet. Furthermore, urinating too much could also be viewed as imbalance. Perhaps the participant combines his cultural and social understandings, the balance and imbalance situation, with the understandings in biomedicine. Rithy's example showed the other possible framework than biomedical framework to interpret the glucose levels for participants.

At the same time, some participants observed themselves and found out the time of eating and the certain foods might make their glucose levels low. This is shown in the following example:

"Uhh, I didn't do anything, such as I stay stilled, watching TV. And when I ate overtime, such as I needed to eat at 12, but I delayed until 1, it made me hungry and shaking muscle (tremor). Yeah, only this, it made me weak in leg and arm, and shaking. And when I had rice to eat, after a while, my powers would change and it came back, and it came back to normal. I needed to learn from this experience because I ate overtime and lose power." (Srey(1), female in her early 60, housewife, lived with her family)

It has been claimed by researchers in biomedicine that irregular eating is one of

the reasons for hypoglycemia (Barnett et al., 2010; Clarke et al., 2008) This reflects the observations made here by Srey and the participant described how she came to understand that if she ate irregularly, she might experience low sugar. As a result, irregular eating became one of the understandings of her experiences in hypoglycemia.

Some participants also mentioned certain foods made them low sugar. And those understandings would influence their actions, especially when those foods were promoted as “good for balancing glucose levels” by MoPoTsyo.

“It lows. If I eat much vegetable, this would be low. Less rice but much vegetable like this. One day, organization, where they check the sugar and provide the medicine, they called (everyone) to the party, and they provided vegetable, soup and brown rice, red rice and boiled bean. When I ate these foods a lot, when I came back home, it lowed. If (I ate) white rice, it would not be low. If (I ate) the boiled bean and brown rice and soup, when I came back home and got off the car, I knew I was low and ran to find the sugar (water) to drink. And they called me often, twice a year, sometimes only one time, not regular. They didn’t cook white rice for us. When I went to that place where they had party, (they served) only brown rice. They served brown rice and bean on one plate and two parts (half plate of brown rice and half plate of bean) and I ate brown rice half of the plate and the bean half of the plate, and totally, it was low sugar.” (Ratha(1), 56-year-old, female, housewife, lived with her family)

Brown rice (*Bai Somrob*), the product produced one stage before white rice, was highly advocated by MoPoTsyo since it had relatively low glycemic index and multiple nutrients. Generally, participants understood beans and brown rice as “good foods” that could help to control the glucose levels in normal range. However, in Ratha’s story, brown rice and beans became the reason for her experience of low sugar. There might be other reasons for the episode, such as physical activity or medication, but in Ratha’s mind, diet was the reason for low sugar and this understanding made her decide not to eat brown rice and bean.

In summary, issues of diet, including amount, timing and what sort of foods were consumed, were all used in interpreting increased or decreased glucose levels. These understandings might then influence how participants performed their self-care, which will be discussed in the next chapter.

◆ *Medication and glucose levels*

Medication are essential to most of the diabetes patients in order to lower the glucose levels by increasing the amount of insulin secreted by pancreas, to increase the sensitivity of the target organs to insulin or to decrease the sugar absorption rate (Amiel et al., 2008). To ensure accurate medication use, the IDF guidelines say diabetes patients need to cooperate with health professionals closely, to take right amounts of medication on specific times as instructed and to follow up regularly; meanwhile, the health professionals need to provide the information to patients and make sure they understand the instruction (IDF, 2012). During the interviews, most of the participants understood they needed to take medications regularly. Medication was also mentioned as one of the possible reasons for hypoglycemic episodes.

“And in the beginning when I joined this organization; when I joined for the first time and I took the medicine irregularly, I still not (didn’t feel) better; until I tried to take it (medicine), such as in the morning... at 7am, I took it; and in the evening, what time? Ooh at 5pm. And when I took the medicine regularly, blood sugar did not increase; it didn’t affect to my body; I felt very well.” (Ratha(2), 56-year-old, female, housewife, lived with her family)

As Ratha stated, she experienced negative side-effects when she took medications irregularly. Because she experienced this change in her body, she understood irregular medications might lead to the discomforts, which she linked to hyperglycemia, and it became one of the interpretations of the glucose levels for her. Meanwhile, she indicated medications were helpful to control diabetes. Participants usually mentioned medications could lower the glucose levels. However, when glucose levels decreased extremely, participants might face the episode of hypoglycemia. The dosages of medications were important for participants to interpret the happening of hypoglycemia.

“Talk about reduction level of injection...as the doctor told that...this disease; when we used to inject 18 like this, for example, 18, so when I injected and still got effect, I went to meet the doctor again. And then, when I go to meet the doctor, they told I (needed) to reduce a little (glucose levels). When it (glucose levels) increased, he added the medicine; I understood by myself, when I injected less (level), like he let me to inject 10, when I went to check the sugar, it still increased as before, the sugar...it still increased. So, he wrote (prescribed) more, in the morning 18 and in the evening 10 and so on. So, when it affected, I think... to ask him again to clarify...the doctor... said

'reduce a bit,' and I reduced a little. Following him; when I was reduced, it still affected. Then reduced a little more, from 18 to 17... to 15 and I stopped at this 15, like I started to feel better, I started to practice from this (level), and when I went to meet the doctor he said 'it's no problem.' [...]" (Sao(1), 63-year-old male, retired officer, lived with his family)

Sao experienced adjusting insulin levels in cooperation with his doctor when he started to inject insulin. He described how he reported his discomforts to the doctor and the doctor raised or reduced the dosages of insulin for him. In this way, the dosages of medications became the reason for the participant's discomforts. This participant worked with the doctor and got a relatively balance afterwards; however, for some participants, they still had strong effects after the doctor adjusted the dosages, and they decided to adjust or even stop the medications themselves.

"SreyTouch: Such as what I told you, I reduce the level of medicine when I inject. The doctor allows me to reduce to 25, but I inject only 20...and the sugar is still low, in the morning they let me to inject 25, but to me, I inject only 20; at noon, they let me to inject 15, but I inject only 12; or sometimes when it affects much severer, I inject only 10...reduce 5 levels also but the sugar is still low. [...]"

RA: So you reduce this by yourself?

SreyTouch: Yes, I reduce by myself; sometimes in the evening I don't dare to inject, too. I didn't inject one time, I don't know why it always affects like this [...]" (SreyTouch(3), 63-year-old female, unemployed, lived alone)

She did not dare to adjust the dosage by herself at the beginning, but after peer patient told her *"your sugar is always low like this, you can reduce injection,"* she started reducing her dosages. Sometimes she even decided to skip the injection. She had discussed her medication with the peer educator since she mentioned the peer educator told her if she did not inject insulin regularly and skipped it, her diabetes would not be under controlled. And she said *"How can I not skip? If I stay alone, and it becomes weaker and weaker, and (I) have no power... and cannot do anything, so I need to skip. Yesterday, I skipped injecting at noon also [...]"*

She was not the only one who skipped medication due to episodes of hypoglycemia. Theavy had tried to adjust her oral medication with the advice from the peer educator at the beginning from one tablet, to a half tablet to a quarter tablet gradually, but when the discomforts kept happening, she decided

to stop completely just few days before she was interviewed. However, she stated she would discuss with the peer educator in the following weekly checkup.

These stories showed participants interpreted the dosages of medications as the reasons for decreased glucose levels, and these understandings made them adjust or skip the medication. The communication between participants and peer educators might also influence how they interpreted and acted. Some participants also stated the doctor did not allow them to stop the medication, so they decided to eat more in order to balance the glucose levels.

"I still take one tablet same (as before). But just the food, for eating, I don't limit or stop that much. And now I become braver than before; when I dieted so much, it would decrease so fast. The sugar decrease so fast, and then I diet less than before; previously I dieted a lot, and it decreased so fast; and when...now I diet but I diet as...I put the sugar...but I don't diet and I eat much more than before. Such as previously (I ate) only a small Chinese bowl, but now I eat two bowls. And I will not get effect as dieting before; I am brave to eat." (SokLeang(1), 49-year-old male, craftsman, lived with his family)

This excerpt showed the participant understood that diet was the interpretation of higher glucose levels while the medication was understood as lower the glucose levels. Therefore, he combined two understandings together in order to prevent the effects of low sugar. This also showed the complexity of glucose levels, which might be influenced by many different factors. This complexity would influence how participants interpreted and acted according to their interpretation. As a result, the experiences of abnormal glucose levels were then different from person to person and even from time to time for the same participant.

◆ *Exercise and glucose levels*

Internationally, physical activity is viewed as beneficial for type 2 diabetes patients, improving glycemia control through increasing insulin sensitivity of cells and weight loss (ADA, 2004), which is highly linked to diabetes patients in western world (Gaebel, 2011). In this Cambodian study, most of the participants did not mention exercise as the methods for glucose control. Only one participant stated she did not limit her diet because she exercised.

"I eat fully, I don't stop eating rice but I limit desserts and the sweeter fruits (fruits taste much sweeter), such as jackfruits, durian I limit them, but rambutan and mangosteen I eat them. Sometime, I want to eat, I eat half of

kilo at one time and I don't eat one or two (pieces) like others. Some people they limit like they eat only one. To me, I am different from others, but I exercise. I try to exercise. The exercise is very important.” (Srey(1), female in her early 60, housewife, lived with her family))

Here, it seemed like she viewed physical activity as one of her understanding in lowering the glucose levels. However, when probed further about issues of exercise and hypoglycemia, she answered *“I go to exercise; it's normal. No weak, no fatigue. If you don't have power, how can you exercise?”* Most participants answered like this, stating that it was impossible to be hypoglycemic during exercise. Meanwhile, they did not mention they exercise in order to lose weight as international guideline suggest. Moreover, participants stressed the importance of sweat during exercise; they would feel better after sweating and sweat was the aim for exercise.

“[...] I exercise in order to let the poison come out. (If) I...don't sweat a lot, the sugar will be stuck much (in the body), and I exercise in order to get sweat. If I cannot run, I can walk in order to have sweat. And I do different exercise because I want to make me sweat.” (Rithy(1), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

Most participants stated they could expel poison from the body through sweat. This idea of sweat and poison reflects results from a study into Cambodian traditional birth customs: giving birth is viewed as losing heat in body, which makes the body of women imbalance and cold; and the body contains poisonous “old water.” Therefore, making women sweat after giving birth can help women get the “new water” and regain health. The sweat is the poisonous “old water” (Townsend & Rice, 1996).

Even though Rithy mentioned sugar would be stuck in the body, he did not seem to exercise to relieve the symptoms of hyperglycemia and, in his opinion, exercise would not make him hypoglycemic. It seemed like he related the exercise to the traditional ideas of sweat, instead of to the influence of glucose levels. These understandings would influence how the participants performed physical activities and will be discussed in the next chapter in the physical activity section.

At the same time, when exploring daily activities, which can be viewed as physical activities, some participants would state they experienced fatigue or tiredness while they did the house work. They interpreted the reasons for those signs as sweating too much, being old or because of hypertension. The

discomforts could be eased by stopping working and relaxing. Usually interventions for hypoglycemia were not mentioned. It seemed participants separated exercise from house work, even though some of them agreed house work could be tough and could also make them sweat. Only one participant said she felt hungry and shaking when she did the house work after having breakfast and she needed to drink sugar water.

The interpretations of exercise might be because patients in Cambodia are generally diagnosed with type 2 diabetes, which has less problems of hypoglycemia caused by exercise (ADA, 2004). However, one study in the United Arab Emirates (UAE) with type 2 diabetes patients states when patients mention physical activities, they think of activities both outside and inside the home (Baglar, 2013). The possible explanation for the difference between this study and my study in Cambodia would be the article mentions obesity is one of the problems in UAE and the relationships between physical activity and obesity; obesity and diabetes are widely known (Baglar, 2013). However, obesity seems to be a relatively smaller problem in Cambodia (King et al., 2005); therefore, the links between obesity, diabetes and physical activities were not emphasized by participants in this current study.

In this section, I have discussed how participants interpreted their glucose levels through different activities with regard to diabetes self-care, although the relationship between exercise and glucose levels was unclear. These activities became the reasons for their experienced discomforts, which were attached to either hypoglycemia or hypoglycemia and shaped their understandings of the glucose levels. These interpretations would then influence how they act in their self-care. Issues of non-compliance, which means patients are away from their suggested treatment, from biomedical point of view, were then generated. I will discuss the possible influence factors of “standard self-care” in the next chapter.

Conclusion

This chapter described how participants interpret the experienced discomforts before encountering the biomedical framework and the process of understanding the glucose levels. The cultural perspectives of traditional healing and different uses of language would influence their interpretations. At the same time, the fact that Cambodia is a country with limited resources made the subjective feelings of discomforts become substantial. Individual experiences then played essential roles in their interpretations of their glucose levels. However, because of the

power of the dominant biomedicine presented in MoPoTsyo, participants also expressed their understanding of glucose levels through the results of biomedical measurements.

Through interpreting their glucose levels, they could make decisions and take in action in order to gain control of their glycemic levels. The results of the actions might also influence how they interpreted the glucose levels and then influence their self-care. Therefore, in the next chapter I will discuss further about how participants perceive the diabetes self-care and the possible factors that influence their daily self-care. The power of biomedicine may also influence how participants self-manage their disease, which will be discussed further also in the next chapter.

Chapter 7: Diabetes Self-care

Since diabetes is a chronic disease, the international guideline developed by IDF (2012) state that self-care is an important part of diabetes management for patients. Patients need to have the relevant biomedical knowledge related to diabetes management and understand how to control their glucose levels by self-monitoring and following guidelines related to diet, exercise and medication. Meanwhile, they need to make correct decisions according to their glucose levels for balancing glucose levels in order to maintain their well-being and prevent complications (IDF, 2012).

MoPoTsyo is no exception to the guideline mentioned above. Patients are told that they should take care of their health and know how to control their glycemic levels. Not surprisingly, diabetes management became one of the focuses in my research. When participants described one of their episodes of hypoglycemia, and when I tried to explore their daily lives, they often addressed how they managed to balance glucose levels and the relevant concerns. It was nearly a reflex response for participants to say they needed to firstly, take care of their diet; secondly, take medication and thirdly, exercise. As mentioned in the previous chapter, doing exercise did not seem to be linked to control glucose levels but participants generally knew it was good for diabetes patients. However, participants in this study described how daily self-care routines were not always easy to fulfill and they might be viewed as “non-compliant” from biomedical point of view. Therefore, in this chapter, I will address the issues around diabetes self-care, especially what factors may influence the diabetes self-care.

In this analysis of the findings, I have been inspired by the decision-making model created by Paterson and Thorne (2000). The model describes decision-making for patients in familiar and unfamiliar situations when faced with unanticipated blood glucose levels. Patients will access and analyze the situation first; after they get their own answers, they will choose their actions; the choice of actions is considered with the influencing factors, such as context, personal preference and perception of risk. After the actions, they will then evaluate. This is a continuous process and habits may be formed if actions are seemed to be effective and repeated (Paterson & Thorne, 2000).

These actions may then become the interpretations of the fluctuant glucose levels, as addressed in the previous chapter. These understandings might influence how they performed their diabetes self-care. Firstly, I will discuss the

possible influence of physical activity and diet on diabetes self-care. Since the episodes of hypoglycemia are strongly related to medications, I will address this issue in greater depth at the end of the chapter.

Physical activity

As mentioned previously, physical activity is seen as important to diabetes patients because of its benefits to glycemic control. International guidelines recommend diabetes patients to do moderate to intense physical activities, reaching 50%-70% of maximum heart rate, three to five times per week and 30-45 minutes each time (IDF, 2012).

Generally, participants knew about the importance of exercise. They exercised in various ways, including walking and stretching; however, while they described their exercise, most of the participants would mention sweat instead of the intensity. They viewed sweating as good and the goal for exercise as described in previous chapter. As a result, Rithy, who explained the importance of sweat, mentioned massage as one of the physical activities.

Massage machines, which bettered the blood circulation in body through heat generated by electricity, could make the participant sweat. Therefore, in his opinion, Rithy said that exercise and massage served the same roles for health. Meanwhile, focus group participants also discussed issues around sweat and exercise. One participant stated she did not have to exercise because she always sweated.

“To me! Every day (if I) don’t sit near the fan, I will sweat a lot. Even I walk out only 3 minutes, I will sweat, full of my body. So, my poison comes out through this sweat. I do not need to exercise, I sweat a lot. It sweats automatically. Every day if I go to kitchen for cooking, I must change my clothes 3 times one day.” (FG6)

Therefore, instead of monitoring heart rate as international guideline suggests, participants aimed to get sweaty. The cultural understandings in sweat combined with the biomedical concepts of sugar, also described in previous chapter, might be one of the influencing factors for how and what they did for exercise.

Diet

As described in the chapter of setting, white rice, sugar and sweet foods, fruits, drinks and desserts are important in Khmer cuisine. Meanwhile, diet is heavily

emphasized in patient education as the most central component of treatment and self-management in addition to medication. Therefore, I was not surprised when diet was widely mentioned during the whole fieldwork.

Diabetes self-management in relation to diet advocated by MoPoTsyo emphasized to patients that they should reduce sugar consumption, eat regularly and eat less but often. Participants knew all these instructions from MoPoTsyo and they received food pyramids as a reference of what foods cannot be eaten and what foods can be eaten regularly. However, these instructions were viewed as a limitation for some participants. The following excerpt showed how focus group participants shared their opinions on this dietary advice. The discussion was after the question “how the community thinks of diabetes⁸.”

“2: I just know that the villagers said the diabetes patients are worse than AIDS. (Everyone laughing and the voices is mixed in the following recording)

2: AIDS person, they eat everything they like.

1: AIDS person, they eat whatever they love.

6: To us, stop or limit the foods (go on diet). For delicious foods, we want to eat, we can't eat it.

1: They drink and eat in the shop and Karaoke.

2: They say we are worse than AIDS.

1: I am not brave to eat anything. I don't eat.

2: We have money to eat, but we are afraid to eat like them, because we are afraid of increasing the sugar. They eat whatever they want.

[...]

1: For diabetes patients, we can eat sometimes. At that time, we don't eat fully. For example, it's good to eat three pieces of durian... (F2 at the same time: ...they can eat all durians in the big basket; it's ok.), but we are afraid. Only one is enough.

1: They can eat 1kg each time.

6: People are brave to eat more every day. Their sugars are always low, so they are brave to eat.....

1: They are so happy with singing and going to karaoke. To us, it's so difficult, especially urinate (we urine a lot and frequently).

6: The person whose sugar is 200, if they eat durian even a little bit, it's not good.”

⁸ The limitation of the perception is it was the voice of the participants and the voice of the villagers were not heard in this study.

As shown above, focus group participants showed their perception of the contrast impression from the villagers between HIV/AIDS patients and diabetes patients. The diet was extremely important for diabetes patients; and in this sense, they were limited in comparison with HIV/AIDS patients, who could eat whatever they wanted. This was further compounded by the fact that the specific foods that they needed to limit were usually those delicious foods. One study from the United States also describes how diabetes educators teach patients that they need to control their desire for certain foods since “foods with bad taste or lack of flavor” are generally better for glycemic control (Borovoy & Hine, 2008). Therefore, to some degrees, the instructions become challenging and impractical since it is difficult for human beings to follow, especially in Cambodia, sugar is such central part of cooking.

Breaking these dietary instructions might cause the problem of moral judgment, where participants understood it was bad for their health but at the same time, they followed their desires to eat foods damaging to their health. Participants stated everyone had various practices in diet even though they got the same instructions. One participant described his dietary habits and what he did not eat:

“[...] Less! This because it contained sweet, sugar...But for the rice...and fruit, I can eat one or two (piece). This, they don’t allow us to eat, not don’t eat anything, banana, lime...I eat only one; (I don’t) eat as the normal people who can eat 5 to 6 (pieces)...for something which is sweet, I am not dare to eat much.”(Rithy(2), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

What Rithy meant “they” here could be understood as the food pyramid, where it demonstrated what kinds of food were forbidden (cannot eat as translated directly from the material). His saying was coincided with what staff in MoPoTyso told me when we discussed the food pyramid. They said patients would understand “cannot eat foods” not as completely forbidden. However, the staff said if they had categorized those foods into the “eat a little,” the patients would not have paid as much attention as they did.

Participants explained how they determined whether their behaviors were appropriate and how they paid attention to their diet through the occurrences of their discomforts, where I would call it “monitoring” as described in the previous chapter that the discomforts were one of the methods to interpret their glucose levels. Since measurement from glucometer was not widely available and used

every day by the participants in this study, the somatic signs became one of the ways to monitor their controls in glucose levels. When participants felt everything was in control, the moral judgment of breaking the standard instructions might somewhat ease.

“Ratha: [...] sometimes when I bought sugar cane juice, I could drink it half (of the cup), but it (sugar) didn’t increase.

RA: So even you drink sugar cane juice, you don’t feel headache...

Ratha: [interrupt] no, I didn’t drink it all, the whole glass, but I drank only half; the remaining, I put a new straw, changed it, and gave it to my grandchild. When I see others buy it, I always hunger, but I don’t drink much, just remain half and I give it to my grandchild. And I never get any affect.”
(Ratha(2), 56-year-old, female, housewife, lived with her family)

Ratha knew sugar cane juice was placed in the “cannot eat” category in the food pyramid but she still wanted to drink it. At the same time, she knew she should be cautious. No effect appeared after she drank it so this behavior was defined as alright. This raises the concern in the previous chapter as to whether the condition of “normalcy” with no somatic signs could be interpreted by participants as normal glucose levels. Some participants would use the often late and therefore inadequate figures from glucometer as the proof of their control.

“Ratha: This morning I went to check sugar because yesterday evening I had eaten durian. Test this morning was 100. The sugar was 100+.

RA: 100+, how much was 100+?

Ratha: 110.

RA: Ooh low also.

Ratha: Yes [stressed tone], only this.

RA: (You had) eaten durian already...

Ratha: [Interrupt] this, I said it increased. Every time (it is) only 99, 75, 75. And yesterday evening, (I) ate one piece of durian, it was not small, this amount [point to the gesture] and in the evening I ate a lot of rice also; someday the food was delicious, so I added more. And when added more, the sugar increased to 100. And previously I went to test when I didn’t eat durian, before eating something, when I went to check, it was 99, 95. They note on the book...now they notice I am the one who always low sugar, they don’t allow me to go to hospital. [...] This morning I asked to go next week and they said no place; the sugar is low like this, they allow only (patients) with increasing sugar [laughter].” *(Ratha, 56-year-old, female, housewife, lived with family)*

From this story, Ratha mentioned figures from glucometer as the proof that glucose levels did not increase much after eating durian, the “cannot eat” food. It is also similar to the study by Baglar (2013) in UAE; one patient gets normal figures from glucometer even though she eats everything health professionals tell her not to eat; she then confirms her diet can produce the normal glucose levels.

In addition, it might be questionable if the blood glucose measurement could truly represent the situation for Ratha from a biomedical perspective. This doubt may be the reason that the international guideline promoted HbA1c, which is also known as glycated hemoglobin that can represent the average control of the glycemia through a period of time, as the “true” indicator for glucose control (IDF, 2012). HbA1c test is available in Cambodia and in MoPoTsyo but patients need to pay 7USD for the test. However, in my opinion, the feeling of discomfort still played a major rule since she used no signs to indicate her in control status of glucose levels as shown in the previous excerpt. Even though Ratha did not speak out loud in the excerpt, I infer she did not experience the discomforts after she had eaten durian. The action of obtaining result from glucometer might be just one occasional event to prove she was well controlled since she stated she did not check her blood glucose levels daily; she checked only when she had doubts.

The discomforts were then important in influencing how participants chose to eat. As mentioned in the previous chapter, some participants would avoid certain foods that brought the discomforts of high glucose levels. In Becker (2003)’s study, bodily monitoring or bodily awareness of illness is also mentioned as part of the daily lives of Filipino Americans patients. Bodily awareness is facilitated to maintain balance and, therefore, becomes important to achieve well-being and health by patients (Becker, 2003). This made the discomforts, or the bodily awareness, became their ways of verification of control. Because of variation of the discomforts, the degree of control also varied from person to person.

Montez and Karner (2005) state in their research the definition of control is individualized by different patients and health personnel may have a definition of control different from the patients’. This difference may encourage patients to develop personalized strategies for integrating control. Therefore, some patients may feel they are in control while from biomedical point of view, they may not (Montez & Karner, 2005). Here comes the issue of to whom “non-compliance” is a problem.

The other concern would be how the instructions of food should be addressed. Most of the participants understood the general ideas of the sugar content in

different foods through the food pyramid but they did not always “follow” what it said. They still ate foods in the category of “cannot eat” and they decided if they would eat the particular food based on their feelings after eating. If the purpose was to remind participants and not truly forbid as staff in MoPoTsyo told me, it is worth considering how to demonstrate the knowledge without creating the feeling of doing something wrong and cause the feeling of being morally judged. Ferzacca (2000) describes similar situation in his research; when patients’ behaviors are out of the “gold standard” and results of measurements in the medical encounter are “bad,” the reasons for individual differences in self-care might not be considered and patients could be labelled as “non-compliant.”

Family also played important roles in diet since most of the participants lived with family and ate together. The following paragraph will illustrate how they influenced participants’ diet with regard to brown rice.

As mentioned before, brown rice was advocated by MoPoTsyo as a better food for diabetes patients and encouraged patients replace white rice with brown rice. However, although all participants said they knew how good brown rice was, none of them adapted to this; only Sao ate brown rice three times a week. Brown rice was considered as difficult to cook and store. Some participants did not like the taste and felt they became hungry quickly after eating brown rice. It was also more expensive than white rice and it was not easy to buy compared to white rice, even though for some participants price was not the main concern. These explanations were similar to those mentioned by Cartwright et al. (2006) who state that “healthy cooking, is associated with food that is overly expensive and lacks flavor and sufficient quantity to render one feeling full” (P.103). Meanwhile, usually food shops and restaurants did not serve brown rice if participants dined out. In addition to the possibilities to cause the episode of low sugar as Ratha believed, family members who lived and had meals together would influence in this practice, too.

“[...] And because it was difficult for the family to cook also. Cook this (brown rice), cook that (white rice)...and she was busy with her work also...and because of this...I limit and stop only soup. For the rice, we eat the same.”
(SokLeang(2), 49-year-old male, craftsman, lived with his family)

In general, people eat white rice in Cambodia. Therefore, it was problematic when the participant was the only one in the family who needed or wanted to have brown rice. In the study of Russian *émigré* in the United States, Borovoy and Hine (2008) describes how the culture of the foods influences these Russian

participants' diet practice; the suggestions in diabetic regimes are very different from these patients' dietary culture and, therefore, may become impractical to them. It might suggest why participants in this Cambodian study did not adapt to brown rice. In contrast, for Sao, it was easier because his wife was also a diabetes patient. Even though Sao said the taste was not good and they did not adapt and replace white rice completely, after Sao got stroke, they started viewing "brown rice" as medication and regularly ate it three times a week.

The other example of how family influenced diet was about using sugar as seasoning. As described earlier, sugar is one of the common seasonings in Khmer kitchen, therefore, it was difficult for some participants to reduce or stop using it. However, for San, it was not difficult since his wife did not like the sweet taste at all.

"San: To my family, we cook the soup without putting the sugar...ooh they put also, but just a little bit. And my family, we cannot eat sweet (taste) also; such as my wife, she doesn't eat sweet. And when she cooks, she also knows I have this disease, she cooks without putting the sugar.

RA: So to your family, you don't have the habit of putting the sugar in the soup and so on?

San: We put also, but just we put a little bit. Sometimes, we don't put it also because my wife doesn't eat sweet, if the soup tastes a little bit sweet, she cannot eat...because her habit is like that; she cannot eat sweet." (San(2), 33-year-old, worker in primary industry, lived with his family)

Those stories showed how dietary decisions were different from person to person and from family to family. It depended on not only the diabetic person but also their social network, especially their family.

In addition to advice from MoPoTsyo and family members, participants might receive information about the diet from social media, such as TV commercials. When discussing sugar for cooking, some participants mentioned sweeteners.

"Rithy: We eat together, but...if we cook, she likes to put err... [Go to take it] the diabetes sugar; we can put one package of it, and we rarely put the normal sugar. We replace normal sugar with this sugar. We can put this one package in order to substitute for the normal sugar.

RA: So your wife eats this sugar, too?

Rithy: Yes, she eats this sugar as well [laughing]. [Point to the sugar] This has the power, but it doesn't have sugar. It tastes sweet also, but it doesn't taste much sweeter and (make the sugar) increased as the normal sugar." (Rithy(2), 56-year-old male, retired auto mechanic, now work as seller, lived with wife)

Rithy saw the advertisement on TV, which was promoted to people who wanted to go on a diet including girls who wanted to be slimmer and diabetes patients. The claim that sweeteners were totally free of sugar and did not increase glucose levels remained doubtable to me, but it showed participants might learn things outside the organization and put these new ideas into practice.

The last issue I would like to address regarding diet was about the schedule. As mentioned earlier, participants would refer to eating late as one of the possible reasons for having hypoglycemia episodes. Regular eating was the recommended by MoPoTsyo. However, everyday life could be different for people. It is a similar situation as a study conducted with university students in the United Kingdom states; it is challenging to follow the same routine every day (Balfe, 2009).

SokLeang explained how he always got low sugar while he went to work. He was a metal craftsman working with machines. Every time he went to the work place, he said would experience low sugar around 11am. *"But if I don't do the work there, I don't...it never low"* (SokLeang(1), 49-year-old male, craftsman, lived with family). In the interview he described his analysis of the situation and thought being concentrated on work and forgetting to eat around 10am as he always did at home could be the reasons for low sugar. However, he had to work anyway, so in his opinion, what he could do was to intervene while the low sugar happened.

To sum up, participants showed their understanding of standard instructions of dietary self-management; however, they might perceive those instructions as limitations in their lives. Sometimes they would practice differently from the regime but, at the same times, they would pay attention to their glucose levels through bodily signs. Therefore, somatic signs remained one of the factors influencing their diet and feeling good or not became an important criterion for food consumption. Meanwhile, social network, especially family members, might also affect their choices in diet. Last but not least, difficulty in keeping a strict daily routine might influence their diabetes self-care. Hypoglycemia could also influence how participants acted in diet, which will be discussed further in the next section. The examples given in this section showed how individual differences and other influential factors, such as family, should be considered in self-management education, in addition to biomedical facts of diet.

Medication and hypoglycemia

As described earlier, since medication functions as to lower glucose levels, participants would link the medication to hypoglycemia as indeed they were told in patient education. Some participants were informed by doctors or peer educators that they might get side effects—hypoglycemia—after taking medication.

“Yes, because this I...previously I didn’t have it (discomforts); I never (face this)...the (oral) medicine that I needed to take it had no problem. When I started to inject insulin; the doctor advised like ‘when you inject...sometimes it has problems such as it (will make you) lose power or feel dizzy and so on; this, don’t be worry; this is the form of the medicine, we eat something sweet and the sugar increases, it will be normally.’ Yes, the doctor advised like this; that’s why I am not worried ...and when I inject, sometimes it is true, and I am not worried...ooh this is the side effect of the medicine.” (Sao(2), 63-year-old male, retired officer, lived with his family)

Even though biomedicine stresses hypoglycemia is mainly the reaction of the medicine (Amiel et al., 2008; Barnett et al., 2010), participants might express different interpretations of the reasons for hypoglycemia as described in the previous chapter and some of them did not think of medication at all, especially for those who took oral medicine.

Insulin-injecting participants were more likely to get the information about hypoglycemia before experiencing a hypoglycemic episode because of the biomedical characteristic of insulin, but all participants stated they got information and knew about hypoglycemia eventually and received instruction of interventions. Most insulin-injecting participants had experienced the transition from oral medicine to insulin. Therefore, insulin became a symbol of severity in the status of the disease. Some insulin-injecting participants feel negative about insulin. This is different from the perception of intravascular injection that Cambodians prefer as mentioned in the setting chapter (Ong, 1995). The reasons might be diabetes participants would experience the uncomfortable side-effects of insulin while after intravascular injections, the Cambodians in the study usually feel better. However, some participants might have other perspectives in insulin-injection.

“Insulin...in doctor’s opinion, when I had taken oral medicine for long time, it could have affected to my stomach, kidney...that was why they let me to inject

insulin. It can affect to the inside body. That was why the doctor let me to use insulin. At the first time, I worried also, but now using insulin is easier than oral medicine...it affected to my stomach and I could not accept it...and I have problem in stomach also. Then, they let me to (inject) insulin, it is so easy.” (Rithy(2), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

For Rithy, insulin might help the situation of his problem in the stomach so it was not completely negative. However, most of the participants still got the impression that insulin would cause higher chances for hypoglycemia. Some of the participants would feel negatively because they might experience an unpleasant hypoglycemic episode repeatedly and frequently and they wished they could have continued taking oral medicine. Participants, either taking oral medicine or injecting insulin, stated they felt that dealing with hypoglycemia was more difficult than hyperglycemia.

“To me, low sugar is difficult than increasing sugar. Yes low, it is so difficult in the body such as it is difficult (for me) to breath, it is difficult [stressed tone]. To sum up, it is so difficult. And when it increases, it is difficult also, but not much as low (it is not difficult much as when it is low).” (Ratha(1), 56-year-old, female, housewife, lived with her family)

Several studies show the similar situation that patients expressed greater anxiety or fear over hypoglycemia than hyperglycemia (Shiu & Wong, 2002; Wu et al., 2011), because the effects of hypoglycemia happen immediately compared to hyperglycemia (Rasmussen, O'Connell, Dunning, & Cox, 2007). Meanwhile, the episodes of hypoglycemia are unpleasant and attached to the risk of unconsciousness and death (Shiu & Wong, 2002); patients may feel “loss of control” (Rajaram, 1997). Many participants had experienced it themselves or heard about others shared their experiences.

“Err... I went to MoPoTsyo and they told me like that. She went to visit her mother who was sick in Batombong. Yes, to her, in the morning she had to inject insulin and she didn't eat anything. She didn't eat anything...then when on the bus, from Phnom Penh to Batombang, it took long time. And on the half way, insulin started to affect so much...this because the sugar was low...then when they arrived at hospital and brought her (to go there); everything was ended; she died. That's why I said being low sugar, the sugar lows and makes us die quickly. But if we are over sugar, it would be no problem; it just affects some part in our body such as it is easy to get ulcer. Yes. It is like this.”

(Rithy(2), 56-year-old male, retired auto mechanic, now work as seller, lived with his wife)

In Tan et al. (2012)'s study, patients also become fearful and cautious after witnessing others' episodes of hypoglycemia. These stories seemed to successfully deliver the messages of how dangerous hypoglycemia could be if they were not aware and did not deal with it in suggested ways to participants.

When a hypoglycemic episode happened, participants in this study described how they would eat something sweet as instructed by the peer educators or the doctor. Participants also showed variations in choosing foods for the intervention. According to their experiences, preferences, economic status or their health condition, participants acted towards low sugar in different way. SreyTouch was recommended by her doctor to prepare some juices because the insulin was strong. However, she did not have money for buying juices, so she was asked to buy candy, which was relatively cheap compared to juice. Another possible influencing factor was health condition.

"He (the doctor) said it was not (because of) another disease, it was only low sugar; it was the effect that made us shaking. If I put (eat) the sugar, it could be better. Coke also (can be better), but I was afraid of drinking coke, because at that time I got stomachache. 'Drinking coke can (make sugar) increase faster than eating sugar and eating candy is slower than sugar mixed with water.' And the doctor said to me I could prepare candy on the bed near me because mostly it happened at night." (Ratha(1), 56-year-old, female, housewife, lived with her family)

Studies show some patients state health-care providers are professional and friendly but the advice in relation to diabetes self-care is usually too general or impersonal and does not consider the individual condition (Shiu & Wong, 2002; Tan et al., 2012). This excerpt showed how Ratha received personal advice about intervention to hypoglycemia from her doctor. However, not all participants received personal advice in diabetes self-care, which will be discussed later.

The intervention to treat a hypoglycemic episode was the opposite of the long-term diabetes self-care regimes—limiting sugar consumption. Therefore, some participants showed their hesitation when getting instructions. Even though they would perform in this way after they experienced it, the concerns and worries of hyperglycemia were always in their minds. Therefore, they often stated "[...] when we eat so much, the sugar increases so high, so it is difficult to

control; (when) we eat less, it lows too much, it is difficult to control also.” (Sao(1), 63-year-old male, retired officer, lived with his family)

Meanwhile, the action of consuming sugar would make some participants wonder if they became “normal,” especially when it happened repeatedly.

“I knew (it’s low) because I had something to check. I bought one. When I checked, it lowed. When it affected much, it lowed until 35, 30+ like this. And when I have drunk coca or sugar cane juice already, it becomes 110, 120 also; it is good like this. So I always eat sugar. It seems (I am) not diabetes anymore. (Laughing)Because I have eaten sugar already, it can gain enough.”(Theavy(1), 72-year-old, retired teacher, house wife and helps in children’s shop, lived with her children)

This, once again, showed how action of consuming sugar would influence how participants interpreted their glucose levels. Because of the repeated hypoglycemia and the action of keeping eating sugar, Theavy wondered whether she was diabetic, the chronic condition of being hyperglycemic. Her interpretation would then influence her self-management actions, for example in relation to taking medications. She described how she tried to prevent the discomforts of hypoglycemia by stopping her medication.

As mentioned above, hypoglycemia was perceived as an unpleasant and dangerous event, so participants would try to prevent its occurring. The ways they managed their low sugar were based on their interpretations of the reasons that made it happen, including avoiding foods that they suspected could cause to low sugar as described earlier with the example of brown rice; eating more or eating sweet foods regularly; adjusting or stopping medication.

“This month, yes, such as...because it is often low sugar, and I need to eat some sweet...so to me I eat old banana. And when I eat it, it makes me feel comfortable. That’s why, I continue eating it always.” (Ratha(3), 56-year-old, female, housewife, lived with her family)

Studies show fear of hypoglycemia will make patients regularly eat snacks (Bohme et al., 2013) or keep their glucose levels higher by adjusting insulin levels (Wu et al., 2011) or modifying other life-style recommendations (Rajaram, 1997; Richmond, 1996). In these studies, patients would state by themselves they try to keep the glucose levels higher than the target levels, which are expressed as a number in the scale of glucose levels (Bohme et al., 2013; Rajaram, 1997; Richmond, 1996; Wu et al., 2011). However, in my research in Cambodia,

participants did not mention maintaining higher glucose levels when talking about intervention. Difficulty to access the chemical figures might be one of the reasons for this difference. For the participants in this study, eating more or adjusting insulin levels may be one of the methods they use to ease the discomforts so they would feel better. By doing so, they might aim to feel better instead of keep higher glucose levels. The participants stated that glucose levels were still under control because they did not feel anything. Once again, this might suggest the importance of bodily signs of blood glucose imbalance in the Cambodian setting.

Together with the stories of adjusting insulin dosages from previous chapters, these points bring up an interesting issue, namely how participants negotiated the contradictory advice given to manage both chronic hyperglycemia and acute hypoglycemic episode. Both advice concerning “following the self-care instructions” for chronic diabetes and “intervening and preventing hypoglycemia” came from MoPoTsyo; usually both advice were contradicted to each other, and it showed the self-care management was flexible. However, when participants performed the actions, they viewed them as the prevention and intervention of hypoglycemia, such as eating more, they might be told their actions were inappropriate by peer educators. If the regime could be flexible, then it would be worth reflecting, in this setting, on whether the “standard self-care regime” exists and, to what extent, participants would be viewed as following the standard regime.

The following story shows how medication, hypoglycemia and the relationship between the peer educator and the participant influenced his diabetes self-care. The example could also be viewed as a short summary of the whole study, with many parallels to other participants in the study.

San, a 34-year-old male lived with his family in suburb area, was a bit shy and did not talk much at the beginning of the interview. He went to checkup at the peer educator’s place only once a month because it was far from where he lived. He injected insulin three times a day. When I first met him, he adjusted insulin dosage by himself and had skipped the noon injection for the past three months without discussing with the peer educator. This was because he also got effects, such as sweating, after injections, and the discomforts stopped after he skipped injecting at noon. No one in the organization knew about this since he kept buying medications from the pharmacy and the monthly checkup seemed alright. He said *“the doctor would not allow me to stop injecting; they let me to inject*

forever... but to me, when I stopped it, I felt so comfortable [...] I stopped it by myself.” (San(2))

He had been taught to monitor his glucose levels every week by himself with his own personal glucometer, and based on the numbers he could and should adjust the dosage of insulin by himself. However, the glucometer had been broken for quite a period of time. He decided the dosage mainly based on his discomforts. He also tasted the urine to check if everything was under control.

“Stop injecting at noon...at the first time, I seemed like...it made us shake, shaking...and I couldn’t do any work. It was so weak on the leg and arm...and when I stopped injecting, I felt so comfortable and no problem [...]” (San(2))

He also mentioned he noticed he became a bit slimmer after he stopped injecting, but he stated he felt quite alright. The weight-loss was something he considered, and planned to consult the peer educator about when he went to checkup next time. When I interviewed him second time few weeks later, he just went to the weekly checkup. Because MoPoTsyo asked to get the fasting glucose levels, he did not eat anything and waited for a long time since there were many people. He got discomforts—shaking (tremor) and hungry. When it was his turn, his glucose levels were 210. He was surprised since he used to be around 100. In our conversation, he recalled that *“the peer said loudly from her mouth ‘wow, why you (your sugar) increase so high.’”* The peer educator then asked him if he drank alcohol or if he smoked. He answered no. Then the peer said to him, *“Now you need to stop the cigarette and wine and so on, and you need to exercise every day.”* He did not get a chance to raise his concern about skipping injections and becoming slimmer because he thought the peer educator was busy. After this checkup, he decided to start injecting at noon again.

I asked him about the discomforts he had that day since these two somatic signs had been referred as low sugar by him previously. He said his sugar was high (by figures) and probably the discomforts happened because he had not have eaten anything. This statement shows the complexity of glucose levels and the possible concerns in power of the biomedical numbers. When the numbers from measurements told him he was hyperglycemic, even though he was shaking and sweating, what he had told me as the sign of being low, he would then change his interpretation of the subjective discomforts. Meanwhile, the figures made him question if his decision of skipping had been correct.

The participant then explained about his observation of being slimmer. He gave

meaning to the sign of being slimmer as glucose levels increasing and it meant something had gone wrong (glucose levels out of control). This interpretation might come from his experience and the fact that losing weight is one potential symptom before people get diagnosed with diabetes (IDF, 2014). Meanwhile, he stated after injecting two days at noon, he felt he was gaining weight a bit, and the glucose levels were under control. Here, it showed again how participants combined different information and gave meanings to the signs in a continuous process (Middelthron & Colopietro, 2012).

A week later, we met again for the third interview. He still injected three times daily as he had decided last week but he adjusted the dosages, such as from 30 to 20. He had faced two episodes of low sugar within that week, but they did not happen after injecting at noon. Few days before the interview, after he ate a normal amount of breakfast and injected insulin in the morning, he started sweating, became weak and lay down in a hammock. His mother saw this and bought the coke for him. After a while, he felt better. The other experience happened the day before we met; he became mild low sugar as he defined it. He got hungry, shaking and sweating around 3pm when he was busy at work and could not leave the place, which was far away from any food or liquids besides water. He thought this was only mild low sugar so he decided to finish working. After half an hour, he rushed home and ate something. In his opinion, the injection at noon was not a problem anymore. Because he did not skip the injection, he would probably not discuss this issue with the peer educator next time. He considered buying a new glucometer soon.

This story shows how hypoglycemia could affect a participant's actions, both intervention and prevention. He estimated the severity of his hypoglycemia based on sensations and decided to wait or to drink coke. Sometimes other people might decide for him, too. The discomforts of hypoglycemia influenced the way he determined how he should inject insulin. He did not think of eating more as prevention. He knew the general rules of diet, such as limiting himself for eating desserts or eating less rice, but he ate based on his sensations. If he still felt hungry, he would add more rice to his plate.

At the same time, the story showed how participant perceived and defined the status of being in control and out of control. Bodily signs were the main clues; he also tasted urine and observed the weight. However, when he went to the checkup, none of these were mentioned. The peer educator perceived his status of being in control or out of control through the numbers from glucometer.

Meanwhile, he was not asked by the peer educator about how he felt or what had been going on with him, instead instructions was given directly. Therefore, his concern in relation to medication was not raised by the peer educator. Moreover, probably because of his characteristic and the environment, he might not actively ask about this.

Ferzacca (2000) describes the clinical encounter, how it shapes patients' lives with records and documents of results; how through laboratory results, the life of the patient is formed, including *"patterns of behavior, social forms and practices occurring outside the clinical encounter both in the present and the past"* (p.33). As seen in this Cambodian study, the chemical numbers direct the narrative flow during the meeting and also determine whether the patient self-managed his or her diabetes correctly and whether the patient put enough effort into their self-management from the peer educators' perspective. This measurement of blood glucose levels creates an atmosphere of "judgment." The feeling of being morally judged is not only or even necessarily created by the particular health personnel in front of them. In other words, patients may have internalized this moral understanding from biomedical framework and will often feel guilty even if the doctor does not do anything, or do much, to invoke such feelings of guilt (Ferzacca, 2000; Hilden, 2003). Some patients then try to lower their glucose levels for this reading while some make no attempts in this (Ferzacca, 2000).

The situation was quite similar as described in San's story even though it was not a clinical encounter and the peer educator was diabetes patient and often perceived as friends from patients' point of view. According to the participant, when San attended the checkup, the results from examinations were the only focus of their conversations and the later conversations were around the results. According to the participant, there was little care or attention given to him in this peer educator environment. For him the checkup became a place for obtaining objective figures and maintaining membership in organization. Sometimes, perhaps it was also a place for delivering standard and impersonal self-care advices for the participant. After the result was given, self-care advice was provided in a general fashion without consideration for the individual's situation. The benefit of having a peer educator, who might also have similar experiences, was not seen in this story or the majority of my observations of peer educator sessions. Therefore, it becomes worthwhile to reflect upon, when the goal for both patients and the organization is to regain and maintain the status of well-being, whether there is any other way to create a better environment for the patients and communication between patients and peer educators.

Conclusion

There were several influencing factors when participants practiced diabetes self-managements daily. Their interpretations of the glucose levels in terms of self-care activities would influence how they behaved. Meanwhile, subjective feelings of discomforts, such as hypoglycemic episodes, were also important in influencing how participants acted in daily life. Moreover, the social influences, such as family, cultural aspects of foods and relationships with biomedicine also played roles in determining their behaviors. Therefore, when considering all individual differences among participants, perhaps “non-compliance” would not be suitable to describe the situation of participants and it was then not the problems for the participants in their self-care. This addresses the question if there is a gold standard self-care for diabetes patients.

Chapter 8: Conclusions and recommendations

Diabetes is fast becoming one of the major global health issues. Anti-diabetic medications together with life-style management often result in the problem of hypoglycemia, which is viewed as one of the barriers for patients to maintain the optimal glucose levels and follow treatment regimes (Cryer, 2008b). In addition, hypoglycemia may influence the quality of life of patients, and also impact upon them physiologically, socially and psychologically. Moreover, glucose levels are a spectrum and fluctuate over time, which makes the intervention and actions to address hypoglycemia difficult. Therefore, in order to minimize its impact, understanding diabetes patients' experience in hypoglycemia is important.

This study has considered the picture of Cambodian urban diabetes participants' lives with regards to hypoglycemia. There was no unified term for "hypoglycemia" in Khmer; four possible words were used and participants showed various interpretations of these words. The widely spoken term "low sugar" might have the meaning of "glucose levels in normal range." In order to indicate what they had experienced, participants would describe their discomforts, such as shaking and sweating, but these experiences differed from participant to participant. Usually the episode of hypoglycemia was an unpleasant and uncomfortable experience. Participants stated their fear of hypoglycemia because of the possibility of death whether they had experienced it or they had heard from others. However, if it was mild, once they knew how to intervene with the discomforts, participants would feel alright. Meanwhile, because of the experiences of attending regularly checkups in MoPoTsyo, figures from a glucometer were also used to refer to their glucose levels, including the abnormal glucose levels—hypoglycemia, even though everyone might understand differently about the figures. These examples showed the complexity of defining hypoglycemia in Cambodia that terminologies, the discomforts and the figures would be used together to indicate the episode of hypoglycemia. The meaning of hypoglycemia would change continuously according to participants' experiences.

Participants expressed how they intervene and prevent the episode of hypoglycemia in the research. They would eat something, usually sweet foods, in order to ease the discomforts. How they chose foods might be determined by their preferences, economic status, their experiences, cultural influences and family concerns. Participants would try to avoid the occurring of hypoglycemia through analyzing and made senses of what made it happen as Baglar (2013)

states “personal experiences of illness contribute to patients’ own epidemiological theories” (P.119). Daily activities in their lives were also explored. For instance, exercise was generally not linked to the episode of hypoglycemia while working was mentioned for some participants. Since medication might directly cause the episode of hypoglycemia, many would adjust or stop taking medication, with or without cooperation with MoPoTsyo. Because eating was one of the intervention methods, some participants would choose to eat more before it happened. These actions might make them become “non-compliant” from biomedical point of view; however, for participants, it was just a defense mechanism in order to intervene or prevent the discomforts. They might depend on their discomforts to determine whether their glucose levels were under control and their actions were appropriate.

Family members played essential roles in hypoglycemia intervention and other daily self-care management. Even though many participants stated the episode of hypoglycemia could not be seen or experienced by others unless they told explicitly, when the situation was extremely severe, such as sweating a lot, being weak and nearly unconscious, family members usually provided help upon recognizing the episode of hypoglycemia. Meanwhile, family members would also provide information concerning diabetes management to the participants. For instance, some family members bought the sweeteners for their diabetes family.

Last but not least, relationships between participants and biomedical knowledge were important. The checkups at peer educators’ place were organized mainly by the concerns of treatment from the biomedical perspectives. Participants got familiar with diebetological knowledge from the checkups; they were told to follow the “standard instructions” and they had to measure their glucose levels through glucometer at the checkups. The standard instructions of self-care created an explicit or implicit moral judgment when participants broke the rules. However, whether standard instructions existed is debatable since every individual is different. Chemical figures were the dominant language used in checkups, while personal experiences and feelings were generally not mentioned. Some participants would experience hypoglycemia repeatedly, trying to manage by themselves with either proper or improper methods, biomedically speaking, and the peer educator might know nothing about their situations, which might make the participants not get the information they needed and miss the chance to meet the doctor.

During the research period, research participants generally spoke highly of

MoPoTsyo, where the affordable and accessible health care and medications were provided in the reachable community. At the same time, MoPoTsyo helped the patients deal with their diseases by providing education and information of diabetes self-care. Most of the participants continued the treatments in cooperation with MoPoTsyo because it was the only choice for accessing diabetes treatments. They then accepted the rules of MoPoTsyo, such as going to the checkups at least once a month, in order to maintain their well-beings. Therefore, since both MoPoTsyo and diabetes patients aim to maintain well-beings and regain order in diabetes lives, some reflections on the setting in order to better the diabetes care are necessary.

Firstly, it is worthy considering whether chemical figures should play such a dominant roles in weekly checkups. Chemical figures are stressed in MoPoTsyo's activities probably, as I speculate, because the organization is founded biomedically; they need the figures to support and report their efforts in their services and get sponsors. However, as shown in the previous chapters, terminology, chemical figures and subjective feelings and discomforts were all important for participants to describe the situation. Most of the patients do not get the chemical figures at home in the Cambodian setting. Therefore, it is almost impossible for patients to mention their situations at home with figures. Meanwhile, when chemical figures are stressed, personal experiences and feelings are often missing. By doing so, the whole picture of how patients live and what kind of issues they deal with are failed to catch. Even though the peer educators do not work as health professionals, they serve important roles in this system; they provide advice in self-care and are the key bridges between health facilities and patients. Moreover, peer educators are also diabetes patients sharing the same social and cultural understandings and the experiences of having to adapt to the readiness of the disease. These are the advantages of them to create the communications, the discussions and share their own experiences with patients. As a result, in addition to figures, the language of subjective feelings and discomforts could be used and stressed during the checkups.

The other issue in relation to the checkups is the content of the discussed information. This weekly checkup is indeed a great place to exchange information and participants stated they got plenty information from the organization. However, it is also important to receive information from patients and discuss those issues. Participants mentioned several times about traditional and cultural healing during the interview. However, it was not widely discussed in the checkups as I observed. These aspects appear to be much closer to patients'

lives. Through discussions, they may learn more about whether this practice helps the condition for diabetes and how it helps. Moreover, some participants learned some self-care methods from other places. They can discuss those methods and the peer educators together with the organization can identify the possible rumors and also include the good information in the education program. By doing so, patients are not just the passive receivers; they can contribute to the organization and perhaps influence others' self-management.

This research also suggests that it could be useful to consider how to address the "standard instructions." As mentioned before, instructions for self-care are actually flexible in different conditions. In addition, every human being is different, and both MoPoTsyo and participants knew everyone practiced differently. When the "standard instructions" are created with such strong words—cannot eat, cannot stop, when someone breaks the instructions, they might feel morally judged no matter how they interacted with health personnel or peer educators, which may suppress the possibilities for communication. However, the transparent discussions in self-management and diabetic daily lives are important in terms of giving advice. Therefore, the way of addressing should be considered. For instance, instead of presenting dietary standards, principle of diet can be used. Patients learn about the relations between sugar consumption and glucose levels; the sugar contents and foods; and they can determine by themselves how to adjust their daily eating. By doing so, it is possible to open up a more dialogic or interactive relationship between the biomedical facts in patient education and the real-life considerations of the everyday lives of patients.

Diabetes is a disease needed both professional-care and self-care (IDF, 2012) and the peer educators system is the bridge between these two. The cooperation and communications between them are consequential regarding optimal control. The ideas of glucose levels are complex. Nonetheless, in addition to biomedical framework of diabetes, individual and cultural influences should take into account with respects and emphasis, and patients may be closer to the status of well-beings.

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Appendix 1- Thematic Guide for interview

- ◆ *Please tell me about yourself a bit.*
- ◆ *How long have you had DM? (if they don't mention in the previous)*
- ◆ *Since you have DM, how does DM affect to yourself?*

Probe

- ✓ In your opinion, what's the factor that makes those discomforts happened?
- ✓ If it's related to the sugar level?
- ◆ *Language: What do you think of when you hear the word "low sugar?" "extreme low sugar?" "too much low sugar?"*

Probe

- ✓ The understanding/interpretation of the language
- ✓ The experience in hypoglycemia (Can you share more.....)
- ◆ *Experience in Hypoglycemia*

Probe

- ✓ Sign and symptoms (discomfort)
- ✓ When
- ✓ Where
- ✓ Setting (who's there; what are you doing at the moment?/situation)
- ✓ The reason for happening? (interpret)
- ✓ Action for intervention (what do you do to make you feel better)
- ✓ Own perception/feeling about this experience
- ✓ Perception about witnessing (community/relatives)
- ✓ Action of prevention
- ✓ Discuss with others? (helpers)
 - ✓ Who? /where?
 - ✓ Perception when they hear HG
 - ✓ How do you describe it?
 - ✓ How do they feedback? (comments)
 - ✓ Your opinions of what they advise /instruction

◆ *Influence of hypoglycemia*

Probe

- ✓ Everyday life, integrate technologies (medicine, measurement, appointment with dr)? change (diet, exercise.....)? Balancing BS (how? Difficulties?)
- ✓ Feeling/psychological influence
- ✓ Relationships to others/social lives
- ✓ What is healthy/well-being/good health

◆ ***Personal details***

- ✓ Treatment
- ✓ DM d/x time
- ✓ Family status
- ✓ Social-economic status/occupation
- ✓ Education
- ✓ Religion belief
- ✓ Nutrition background (alcohol, cigarette, diet habit)

◆ Questions To relatives (if possible)

- ✓ Their experience in witness HG
- ✓ Their perceptions
- ✓ What's their actions/suggestions (prevention/intervention)
- ✓ Their interpretation of what happens
- ✓ Relationships with the participant
- ✓ How do they know HG happening? What makes them think so?

Appendix 2- Thematic Guide for Focus Group

- ◆ Invite everyone to introduce themselves, say anything they want to share with others..... **(10mins)**
 - ✧ Probe for occupation, family (children, marital status), which neighborhood, *If they wish, how long have they had DM, and how they manage it, something about the topic of discomfort related to low sugar; any experience about the way introduced the session.
- ◆ **OWN PERCEPTION (I) (10mins)**
 - ✓ Describe what comes to your mind when you think of diabetes?
 - ✧ Probe for tradition/facts of DM-related- living style, medication, signs, helps
- ◆ **UNDERSTANDING/PERCEPTION in COMMUNITY (I) (10mins)**
 - ✓ How does relatives/people surrounding think about DM?
 - ✓ How does the community think about DM?
 - ✧ Probe: reaction/ opinions/feeling (on examples from their own experience)
- ◆ **OWN PERCEPTION (II) (10mins)**
 - ✓ Describe what comes to your mind when you think of low blood sugar?
 - ✧ Probe: how DM affects them in everyday life, what kinds of discomfort they feel in consequence of their disease, what do they do for intervening and preventing these, and how they explain these feelings of discomfort, whether that is related to glucose levels or, perhaps, to something else entirely.
- ◆ **UNDERSTANDING/PERCEPTION in COMMUNITY (II) (20mins)**
 - ✓ How does people around you/family think about HG?
 - ✓ How does the community think about HG?
 - ✧ Probe: reaction/ opinions/feeling (on examples from their own experience)
 - ✓ Is it easy to talk to people about HG? Explain.
 - ✧ Probe: In your experience, who have you ever discussed with? What makes you do so?
 - ✓ How people seem to react when they witness HG? (perception)
 - ✧ Why do you think they react in this way?
 - ✓ Based on your experience, when do people think are you in HG?
 - ✧ Probe: Why do you think they think so? How do you feel?
 - ✓ In your experience, where do people get the information/learn about HG? Where do you get/learn the information about HG?
- ◆ **FACTS/TRADITIONS of DM-related topics in Cambodia (if have time?)**
 - ✓ As a Cambodian DM pt, you must know many different DM people. It

would be great if you can share where do DM p't usually go for health services/helps in Cambodia?

- ✓ If anyone mentions exercise before, then asking- What do Cambodian do for exercise? What do Khmer DM patients do for physical activity? (What do you do for exercise?) What are the possible challenges/facilitators for doing exercising?
- ✓ If anyone mentions diets before, then asking- What is the traditional Khmer food? What do Khmer DM patients eat? (What do you eat?)



Closing (5mins)

Before we finish, I'd like to ask if there's anything else you'd like to say about the topics we've discussed (Reflect on prior comments)

Thank you so much for coming. Your time is much appreciated, and your opinions and inputs have been very important and helpful.

Appendix 3- Timeframe

Time	Things	Research
Week 0&1 (Jul. 19 to Jul. 28)	<ul style="list-style-type: none"> ✓ Settle down ✓ Recruit the assistant ✓ Apply for ethical clearance 	<ul style="list-style-type: none"> ✓ Observation: MoPoTsyo orientation ✓ Observation: Palace, Wat Phnom, Tual Slang museum, National Museum, market, stadium, parks
Week 2 (Jul. 29 to Aug. 04)	<ul style="list-style-type: none"> ✓ After election tension- July 29. Stayed in guest house and read history. ✓ Assistant- training 	<ul style="list-style-type: none"> ✓ Observation: education system (university), health system (health center, hospital) ✓ Textual analysis: MoPoTsyo-related
Week 3 (Aug. 05 to Aug. 11)	<ul style="list-style-type: none"> ✓ Assistant-training ✓ Focus group: planning ✓ Ethical approval -Aug. 09 ✓ Broke the toe- Aug. 09 	<ul style="list-style-type: none"> ✓ Textual analysis: media ✓ Approach and observe patients in AK peer educator network on Aug. 10
Week 4 (Aug. 12 to Aug. 18)	<ul style="list-style-type: none"> ✓ Unexpected fever- Aug. 15 ✓ Focus group: planning, moderator- training. 	<ul style="list-style-type: none"> ✓ Recruitment and observation@ BK, BS, MoPoTsyo and BB peer network ✓ Observation: national hospital service; doctor consultation, pharmacy ✓ Textual analysis: media ✓ 1st focus group- Aug. 17
Week 5 (Aug. 19 to Aug. 25)	<ul style="list-style-type: none"> ✓ Translating and transcribing Focus Group ✓ Discuss Khmer transcription with MoPoTsyo 	
Week 6 (Aug. 26 to Sep. 01)	<ul style="list-style-type: none"> ✓ Interview: planning ✓ Interview pretest with staff ✓ Staffs' party 	<ul style="list-style-type: none"> ✓ Recruitment and observation@ BS, MoPoTsyo, BB and AK peer network
Week 7 (Sep. 02 to Sep. 08)	<ul style="list-style-type: none"> ✓ Translating and transcribing 	<ul style="list-style-type: none"> ✓ Interview P1-1, P2-1
Week 8 (Sep. 09 to Sep. 15)	<ul style="list-style-type: none"> ✓ Translating and transcribing 	<ul style="list-style-type: none"> ✓ Interview P3-1, P4-1
Week 9 (Sep. 16 to Sep. 22)	<ul style="list-style-type: none"> ✓ Political tension on Sep. 16 ✓ RA semester begins ✓ Translating and transcribing ✓ Travel: Kampot and Kep 	<ul style="list-style-type: none"> ✓ Interview P5-1

Week 10 (Sep. 23 to Sep. 29)	<ul style="list-style-type: none"> ✓ Consider interview variation ✓ Translating and transcribing ✓ Pchum Ben's tradition@ Hen 	✓ Interview P6-1, P4-2
Week 11 (Sep. 30 to Oct. 06)	<ul style="list-style-type: none"> ✓ National Holidays(Pchum Ben's) ✓ Primary analysis ✓ Translating and transcribing 	✓ Interview P3-2
Week 12 (Oct. 07 to Oct. 13)	<ul style="list-style-type: none"> ✓ Translating and transcribing ✓ Primary analysis 	✓ Interview P5-2, P7-1, P8-1
Week 13 (Oct. 14 to Oct. 20)	<ul style="list-style-type: none"> ✓ Translating and transcribing ✓ Primary analysis 	✓ Interview P9-1, P7-2
Week 14 (Oct. 21- Oct. 27)	<ul style="list-style-type: none"> ✓ Translating and transcribing ✓ Primary analysis 	<ul style="list-style-type: none"> ✓ Interview P3-3, P4-3, P5-3 ✓ Informal talk with potential P10
Week 15 (Oct. 28- Nov. 03)	<ul style="list-style-type: none"> ✓ Translating and transcribing ✓ Primary analysis ✓ Contact P1, P2, P8 	✓ Interview P9-2, P7-3
Week 16 (Nov. 04- Nov. 07)	<ul style="list-style-type: none"> ✓ Translating and transcribing ✓ Primary analysis 	✓ Preliminary presentation- Nov. 07

Appendix 4- REK



UNIVERSITETET I OSLO

DET MEDISINSKE FAKULTET

Chun-An Sun
P.O. box 1130
0317 Oslo

Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst B (REK Sør-Øst B)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: +47 22 84 55 11

Date: 05.06.2013
Your ref.:
Our ref.: IRB 00006244

E-post: post@helseforskning.etikkom.no
Nettadresse: <http://helseforskning.etikkom.no>

To whom it may concern

Exemption from ethics approval regarding the study *Experience and meaning of hypoglycemia in diabetes patients in Cambodia*

We hereby confirm that the Regional Committee for Medical and Health Research Ethics, section South-East B, Norway, has received the project *Experience and meaning of hypoglycemia in diabetes patients in Cambodia* on the 13th of May 2013.

The ethics committee system consists of seven independent regional committees, with authority to either approve or disapprove medical research studies conducted within Norway, or by Norwegian institutions, in accordance with ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act).

The abovementioned study is exempt from review in Norway, cf. §§ 2 and 9 of The Act. The project can be implemented without the approval by the Regional Committee for Medical Research Ethics.

Please do not hesitate to contact the Regional Committee for Medical and Health Research Ethics, section South-East B (REK Sør-Øst B) if further information is required.

Yours sincerely,

Stein Oppjordsmoen Ilmar, PhD (sign.)
Professor of Medicine,
University of Oslo

Chair, Regional Committee
for Medical and Health Research Ethics,
section South-East B

Høge Holde Andersson
Advisor

Regional Committee for
Medical and Health
Research Ethics, section
South-East B

Appendix 5- NSD

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org nr. 985 321 884

Per Kristian Hilden
Avdeling for samfunnsmedisin
Institutt for helse og samfunn
Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår dato: 20.06.2013

Vår ref:34741 / 3 / KH

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 12.06.2013. Meldingen gjelder prosjektet:

34741	<i>Experience and meaning of hypoglycemia in Cambodian diabetes patients</i>
Behandlingsansvarlig	<i>Universitetet i Oslo, ved institusjonens øverste leder</i>
Daglig ansvarlig	<i>Per Kristian Hilden</i>
Student	<i>Chun-An Sun</i>

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

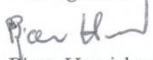
Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 31.08.2014, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Bjørn Henrichsen


Kjersti Håvardstun

Kontaktperson: Kjersti Håvardstun tlf: 55 58 29 53
Vedlegg: Prosjektvurdering
Kopi: Chun-An Sun, Trimveien 6 H305, 0372 OSLO

Avdelingskontorer / District Offices

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no

TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrre.svarva@svt.ntnu.no

TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@svt.uit.no

Appendix 6- NSD reply



Chun-An Sun <chunan.sun@gmail.com>

Prosjektnr: 34741. Experience and meaning of hypoglycemia in Cambodian diabetes patients

1 message

Kjersti Haugstvedt <kjersti.haugstvedt@nsd.uib.no>
To: chunan.sun@gmail.com
Cc: p.k.hilden@medisin.uio.no

Wed, Jan 15, 2014 at 2:53 PM

CONFIRMATION

With reference to your e-mail of 22.08.13, the Data protection official for research note that MoPoTsyo will have access not only to the final report but also to anonymized transcription. In this case, the Data protection Official for Research presupposes that every study participant (patient) are informed about the matter and have given their consent. We also presuppose that the data will be fully anonymised.

--

Vennlig hilsen
Kjersti Haugstvedt
Spesialrådgiver
(Special Adviser)

Norsk samfunnsvitenskapelig datatjeneste AS
(Norwegian Social Science Data Services)
Personvernombud for forskning
Harald Hårfagres gate 29, 5007 BERGEN

Tlf. direkte: (+47) 55 58 29 53
Tlf. sentral: (+47) 55 58 81 80
Email: kjersti.haugstvedt@nsd.uib.no
Internettadresse www.nsd.uib.no/personvern

Appendix 7- Cambodian Ethical Approval


ក្រសួងសុខាភិបាល
MINISTRY OF HEALTH
គណៈកម្មាធិការជាតិរៀបចំស្រាវជ្រាវ
សំរាប់ការស្រាវជ្រាវសុខភាពដែលទាក់ទងនឹងមនុស្ស
National Ethics Committee for Health Research

លេខ...០១២៩...NECHR

ព្រះរាជាណាចក្រកម្ពុជា
KINGDOM OF CAMBODIA
ជាតិ សាសនា ព្រះមហាក្សត្រ
NATION RELIGION KING

រាជធានីភ្នំពេញ, ថ្ងៃទី...០៧...ខែ...០៧...ឆ្នាំ២០១៣

Ms. Chun-An Sun

Project: Experience and meaning of hypoglycemia in Cambodian diabetes patients. Version N° 1.0, dated 24th June, 2013


Reference: - Your letter on 24th July, 2013
- Summary report of NECHR's secretaries on 01st August, 2013

Dear Ms. Chun-An Sun,

I am pleased to inform you that your study protocol entitled "Experience and Meaning of Hypoglycemia in Cambodian Diabetes Patients. Version N° 1.0, dated 24th June, 2013" has been approved by National Ethic Committee for Health Research (NECHR). This approval is valid for twelve months after the approval date.

The Principal Investigator of the project shall submit following document to the committee's secretariat at the National Institute of Public Health at #2 Kim Il Sung Blvd, Khan Tuol Kok, Phnom Penh. (Tel: 855-23-880345, Fax: 855-23-881949):

- Annual progress report
- Final scientific report
- Patient/participant feedback (if any)
- Analyzing serious adverse events report (if applicable)

The Principal Investigator should be aware that there might be site monitoring visits at any time from NECHR team during the project implementation and should provide full cooperation to the team. 

Regards,

Chairman


Prof. ENG HUOT

Appendix 8- Informed Consent English Example

Name of Principle Investigator: Chun-An Sun

Name of Organization: University of Oslo, collaboration with MoPoTsyo

Title of the study: Experience and meaning of hypoglycemia in Cambodian diabetes patients

Introduction: I am Chun-An, a Taiwanese student now study in University of Oslo in Norway. I am doing research on diabetes patients' experience in hypoglycemia with collaboration with MoPoTsyo. I would like to give you information and invite you to be part of this research.

Purpose of the research: The aim of this study is to contribute towards better diabetes care in Cambodia through an exploration of the experience and the meaning of hypoglycemia in diabetes patients and social networks.

Research methods: This research will involve your participation in repeated interviews that will take about 60-90 minutes each time.

Participant Selection: You are being invited to take part in this research because your experience as diabetes patients can contribute much to the study.

Voluntary Participation: You are freely to choose whether join the study or not. You can stop at any moment during the interview and ask for withdraw after the interview. All the services and cares you receive from MoPoTsyo will continue and remain the same if you decide not to participate in the research.

Procedures: I would like to ask you questions about your experiences in hypoglycemia and your lives with diabetes. You can choose the interview place, where you feel comfortable and safe to talk. Only translator and I will be present during the interview. Audio-recorded will be used if you agree. Otherwise, notes will be taken during the interview.

Duration: The research takes place around 17 weeks in total. During this period, I would like to visit you several times and each interview will last for about 60-90 minutes.

Risks: You will be asked to share your personal information and experiences, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question if you do not feel alright to do so, and that is fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits: There will be no direct benefit to you, but your participation is likely to help us understand and improve the diabetes care in Cambodia.

Reimbursements: You will not be provided any incentive to take part in the research. However, we will give you _____ for your time to participate.

Confidentiality: Your name will be replaced by codes once the interview finish. Only translator and I will know what your code is and access to your information. Raw materials, including recordings, field notes and personal information, will be locked and stored in a safe place. Anonymized data are only used for the research and the improvement of the service in

MoPoTsyo. Raw materials will be deleted once the master thesis is finished.

Share of results: Preliminary results in Khmer data, which is anonymized, will be given to MoPoTsyo during the research period. The result of the study will be published for the master thesis mainly. One copy will be given to MoPoTsyo after completing with a summary in Khmer.

If you have any concerns and questions about this research and the process, please feel free to ask me throughout the interview. You can contact me by [_____].

This proposal has been reviewed and approved by Cambodian ethics committees, which is a committee whose task it is to make sure that research participants are protected from harm.

If you wish to find out more about the IRB, contact [name, address, telephone number.]

Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

Signature of Participant _____

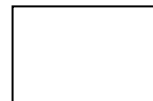
Date _____

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Thumb print of participant



Signature of witness _____

Date _____

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the context.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

