Cultural Care for Persons with diabetes in the community: An ethnographic study in Thailand

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Abstract: *This ethnographic study aimed to explore cultural care through the world view of persons with diabetes. Key informants were 30 diabetic patients from one rural community in Northeast Thailand. Data were collected using participant observations, in-depth interviews, with on 18 month period of fieldwork. The data was analyzed by content analysis.*

According to the results, it was revealed that the definition of DM, provided by persons with DM, is based on their perception, beliefs with their first-hand experiences. Providing a cultural meaning of DM will certainly contribute to cultural care management for persons with DM in the community.

The study shows that the cultural care management for persons with DM in the community occurs based on knowledge rooted in socio-cultural aspects as well as biomedical knowledge. The important goal of care management for persons with DM in the rural community context of E-saan is staying alive and living their lives normally without focus on cure or the control of blood sugar levels.

The result from the research is very useful for health personnel. It will help them become more aware of cultural differences and similarities when taking care of persons with DM. Hopefully, this can reduce cultural gaps between persons with DM and health professionals groups.

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Key words: *culture, cultural care management, diabetes*

Introduction

The prevalence of diabetes mellitus (DM) has escalated worldwide as a result of rapid economic development and associated changes in life expectancy. Contributing factors include changes of life style such as physical inactivity, unsuitable food consumption, and increased stress in daily living.[1] In Thailand, the incidence of DM has escalated. In 2000, 1.9 million people were estimated to have diabetes mellitus. Moreover, according to the latest survey, there are 3 million people with DM in Thailand.[2] The greatest number of persons with DM lives in the northeast region (E-saan).[3] DM is an incurable chronic disease. Without careful management, DM can result in various morbidities and complications.[4, 5]

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In the northeast of Thailand (E-saan), the Primary Health Care Unit tried to improve the service system for DM patients through establishing a diabetes clinic. However, it was unsuccessful as evidenced by uncontrolled blood sugar levels in the community. Some patients did not strictly follow the treatment regimen such as taking medication and missing follow up. In addition, patients had their own ways of managing the disease according to their experience. For example, they interpreted their diabetic status (hypoglycemia or hyperglycemia) differently from that provided by biomedical analysis.[6]

The literature review on DM indicates that nursing studies have focused on the efficiency of programs or projects supported by providing knowledge, developing self-care abilities[7-8] and self-management.[9] The reports provided no social cultural context in the design. All researches emphasized sample and setting focused on individuals rather than family, group and community. Therefore, the researches may have failed for lack of data reflecting the needs and the conditions of DM patients. A few studies have involved a cultural perspective of diabetes.[10, 11, 12] which understand that a cultural aspect is needed for self care management of the patients since each patient will have different view of their illness and self care in a particular socio-cultural context. However, studies of cultural care and management of diabetes by individual, family and community, using the socio-cultural context as a tool to construct knowledge for cultural care for persons with DM in rural areas, have not been conducted in Thailand. It is necessary that health care providers understand how persons with DM understand and manage their health.[13, 14, 15] With this information, suitable intervention strategies can be developed to help persons with DM to improve their life and control their disease.

Purpose of the Study

The purpose of this study is to explore cultural care through the world view of persons with diabetes, in order to understand the cultural meanings of diabetes from a lay perspective, and to explore cultural care management for persons with diabetes based on a socio-cultural context.

The method of study

Design

Ethnographic research, employing qualitative methodology, was used because this allowed a focus on the description and interpretation of community behavior and social or cultural systems.[16] Cultural perspective was used to emphasize the conceptual system of persons with DM, how they understand to diabetes, and how the process of cultural care management for persons with diabetes operates. The study was conducted over a period of 18 months from August 2004 to February 2006, in Northeastern Thailand. The setting of this study is one community in Chaiyapoom province.

Participants–Target groups

The participants were selected by purposive sampling, ensuring that those involved could provide suitable information and were willing to participate in the study.[17] The selection criteria included individuals who (a) were at least 30 years old, (b) were diagnosed as having Type II diabetes for at least 1 year, and (c) lived in the community at the study site. The 30 participants were persons with DM who had been diagnosed with Type II diabetes for 1 to 20 years. There were 24 women and 6 men ranging in age from 30 to 82 years old, and all participants were married. Twenty one participants had high blood sugar level (>120-200

mg %) and had one or more diabetes-related complications including nephropathy (1), retinopathy (5), and atherosclerosis (4). Their level of education ranged from no formal education (1) to elementary school level (29).

Data Collection

Data collection was guided by the processes specific to the qualitative method. Data were collected by using participant observation, in-depth interviews, field note records and photographs, and a review of formal documentation. Participant-observation characterizes most ethnographic research and is crucial to effective field work[18] and focuses on the meaning of human existence as seen for the standpoint of insiders in everyday life situations and settings.[16] In this study, the researcher used participant observation for understanding the behaviors of persons with DM in a natural context where social relationships within the community allowed useful access to the informant's world view. The interview format was based on open-ended questions (because we wanted) to encourage extended response. The researcher usually started each interview with general questions about the lives of participants, asking, for example, how life was before and after the onset of illness, or cause and effect of these illnesses. The study was approved by the Ethic Committee on Human Subjects of Khon Kaen University.

Data Analysis

Content analysis was mainly used in this study. The process of content analysis started when categories were defined, corresponding code created, and themes selected as statements.[19] Significant statements that were relevant to the cultural care for persons with diabetes were extracted from individual transcription. All data were checked by triangulation, through data gathered from different sources, at different times, using different methods in order to confirm and complete the data. Pseudonyms are used in this study for all participants to maintain confidentiality.

Result

The report of the study is divided into 2 parts: 1) providing cultural meaning of DM, and 2) the discovery of cultural care management for persons with DM in the community.

1. Cultural Meaning of Diabetes Mellitus

The understanding, belief and meaning of DM provided the primary information on self care management of the patients, especially understanding and belief in the socio-cultural context of E-saan. The result of the study shows that persons with DM derived meaning of DM based on their first-hand experiences. Furthermore, they also explained that their beliefs about DM in the aspect of etiology and the types of DM are separated according to the socio-cultural context as follows.

Diabetes Mellitus: Definition from first-hand experience

The definition of DM given by the persons with DM was generally based upon first-hand experience, either from their own battle with DM themselves or from their loved ones. Some patient with chronic DM revealed that at the beginning they had no clue about its symptoms, etiology and impact on their lives. After being diagnosed with DM for a period of time, they learned and understood more. Since a great number of community members have been diagnosed with DM, they have given their own definition of DM as the disease of:

Excessive Appetite (Kin Du)-Both patients and their care-givers noticed that the patients had excessive and insatiable appetites from the time they got DM.

> DM can also be called the appetite jack-up disease. Whatever I see, I would like to eat. Never get tired of eating. But without eating, I get really tired.

Laziness (Kee Klan)-Persons with DM view DM as a disease of laziness. From their point of view, whoever gets DM is unable to work as hard as they used to.

> "DM" is the disease of laziness. It just makes me tired, sleepy, and not wants to work at all.

Pancreatic Malfunction (Tub Noi Bor Dee)-After getting an explanation about DM from health personnel, both patients and caregivers offered their own definition of DM as: The disease caused by the pancreas malfunctioning and, as a result, increasing the blood sugar level.

> DM-is the decease where the pancreas does not work well.

No Cure-Almost every person with DM believed that DM is a chronic and incurable disease. But, they could still lead normal lives by taking care of themselves and strictly following doctor's orders.

> DM has no cure and it will stick and stay with me forever

Types and Etiology of Diabetes Mellitus Classified by Experiential Knowledge

The greater the number of community members being diagnosed with DM, the wider information on it was shared. As a result, based upon their experience and perception, they concluded the following:

Types of DM

There are 2 types of DM: Dry and wet. The symptoms and degree of severity varies. Generally, as far as severity is concerned, dry DM is less severe than wet DM. When having a skin wound or abrasion, the recovery rate among the dry DM group was faster than the wet DM group. Therefore, wounds or abrasions are more easily detected on wet DM patients. Because of the slow recovery, this may result in osteomyelitis and the need for amputation. Thus, wet DM patients require more attention to skin care and a strict diet than dry DM patients.

Etiology of DM

Persons with DM perceived that there are several factors leading to DM. Most of them believed that DM is a kinship disease. It also happens in fat people and people lack exercise. In addition, people also perceived DM through the socio-cultural context of E-saan, for example, one causes of DM is eating sticky rice, or Mono-sodium glutamate (MSG), or as a result of previous bad deeds (karma). Therefore, the factors that possibly cause DM are:

***Gene* (Genetic Inheritance)**

Community members concluded that DM is a genetically inherited disease. From their observation, if a family has a member diagnosed with DM, it is likely that another member of the same family will also have DM.

Food Consumption Behavior

Sticky rice causes DM. They believe that having sticky rice generates high blood sugar levels. Worse, for somebody with as existing unhealthy internal organ, eating sticky rice brings a higher risk of developing DM. ***Poor nutrition,*** such as lack of vegetables and fruits, can set off DM. ***Food with High MSG*** can bring on DM. ***Obesity*** is another DM indicator. Community members noticed that those with large bodies, who loved snacks, sweets, and soft drinks, usually had DM. ***Prepared foods,*** easily purchased in the market were generally are using coconut milk. Because of their poor diets, the number of community members diagnosed with DM has increased sharply.

Lack of Exercise

They believe that being a couch potato leads to DM. DM seems to attract those who lack physical activity or exercise more than those who do physical work or regular workouts.

Stress

Many persons with DM learned that stress can affect blood sugar levels. The more the stress, higher the blood sugar level.

Bad Karma

Some persons with DM believed that in their pervious lives they did something wrong. Therefore, being diagnosed with DM in the present life is like pay-back for their bad karma.

The result revealed that the definition of DM provided by persons with DM is based on their perception, beliefs and first-hand experiences. DM is wrongly believed to be caused by physical disorders, changing lifestyle and former deeds. Moreover, the definition of DM varied from one patient to another. Nevertheless, it can be concluded that the definition of DM is provided by the patients was based on 1) the symptoms and 2) pathology of the disease explained by health personnel.

The definition of DM which based on the perception and belief of the patients connects with the self care management which they considered to be the most suitable for themselves. For instance, some of the patients who believed that they had wet DM would take care of themselves more carefully than those who had dry DM. They had to strictly control their diet, take their medicine and avoid wounds by wearing gloves and socks when working outside.

2. Cultural Care Management for Persons with diabetes mellitus in the Community

The results of the study, revealed the context of cultural care management of persons with DM. The process of self care management is past of the learning process starting with asking about the causes of the illness and leading to the process of searching for and finding information for caring with DM. The goal of patients was to establish a "stable condition," meaning they can live normal lives and not focus on a cure. Persons with DM stressed health care based on their perception of the nature of the disease in terms of its type, etiology and care management. Cultural care management strategies included restricted diet, use of medicine or herbs, stress management, which can be seen as follows.

Restricted diet

Every person with DM was well aware that a restricted diet is crucial for their health and could tame its progression. Though not every patient had success in controlling or modifying their consumption behavior, most of them opted for the following methods to tackle the problem:

1) Avoiding forbidden foods (Ka Lum Naew Kin)

Some persons with DM had strong self-control and determination to omit some types of food from their diet-in particular fattening or sweet foods, such as durians, ripe mangoes, sweet tamarinds, ripe papayas, every kind of desert, coconut- based curry, and fatty meat are good examples.

2) Change meal serving patterns

Some persons with DM modified their meal servings to suit themselves and their family. Good examples are portion reduction, regular rice as a substitute for sticky rice, and even a special menu for persons with DM.

Medication

The majority of persons with DM understood the importance of medication. They also had positive attitudes toward medication and believed that following the doctor's prescription could prevent

its progression and any possible complications. Moreover, they agreed that medication could stabilize their blood sugar levels. However, some cases had problems with the "blue pills" (Chlorpropamide). They explained that after taking the blue pills, they always encountered side effects where they felt like "having a wrong medication." The symptoms would be loss of appetite, fatigue, and aches and pains. Because of its unpleasant side effects, some patients used various techniques to avoid taking the pills. Some gave them to their diabetic friends instead. Others modified the medication themselves, such as only taking the pills the day before their doctor's appointment.

Physical exercise

Both persons with DM and members involved defined physical exercise as any activity that involved body movement and perspiration. It could be working, farming, weaving, walking, wooden stick dancing, aerobics, or even chasing after grandkids. In other words, they could get physical exercise from their daily-life activities. For example, a farmer regarded his all-day farming as his physical exercise. However, moderation should still be a consideration.

Not every DM case can get physical exercise. Some patients, unfortunately, had poor health which prevented them from doing exercise, while others simply had various personal excuses, such as no exercise outfit, no workout companion, or no approval from their loved ones.

Stress Management

Persons with DM handled their stress in different ways such as: 1) talking to family members or neighbors 2) taking care of their grandchildren 3) having recreation such as watching TV for entertainment, or exercising for stress reduction and 4) using religious teaching for inner healing - some persons with DM discovered that when their minds were at peace and stress-free, their blood-sugar levels stabilized 5) seeking help and encouragement from family members 6) trying different stress management techniques and combine those that work.

Prevention of Complications

1) Safety precautions to prevent complications

Most persons with DM placed prevention of complications as their priority. Their biggest concern was glaucoma and next was chronic infection which may result in osteomyelitis and the need for amputation. Only a few patients were aware of other possible complications, such as kidney diseases, and high blood pressure. What made them realize the essence of complication prevention came from eye-witnessing "real examples" or "real cases" of other persons with DM in the community who suffered from complications. These examples were wake-up calls helping them become aware how easy it was to have complications, and complications would certainly complicate their lives.

Based on the perception of persons with DM and community members, there are two types of DM: and dry. For wet DM, whenever a patient gets any injury, cut or abrasion, it is very difficult to recover. "The wound in the wet DM group usually becomes festered quickly and leaves a big rotten hole on the skin." Thus, persons with DM do their best to prevent any skin cut while working. For example, they usually wear gloves when cutting sugar cane or picking hot chili. Before heading outdoors, they put their shoes on.

2) Hyperglycemia and Hypoglycemia Management

Persons with DM, especially chronic cases, were able to monitor and evaluate their condition. Whenever they detected a sign of either

hyperglycemia or hypoglycemia, they took control by themselves. They required help from family members, neighbors, or co-workers, only if the symptoms got worse.

> My sugar level took a nosedive once. My body was just soaked with heavy sweat and I almost passed out. After drinking half a cup of juice and lying down for a while, I felt better.

Health Seeking Behavior

The health care system and health seeking behavior of persons with DM and people in the community can be divided into 3 systems: 1) Cosmopolitan or Professional Medical System 2) Folk Medical System and 3) Popular System. The patients used all 3 systems mentioned above. All patients had been cured by health professionals and some of them had relied on folk medicine by buying herbs from folk herbalist. Eating herbs is the way agricultural people in E-saan cure disease. They believe that herbs can help relieve illness and reduce blood sugar levels. Furthermore, persons with DM also have good relationship with the popular system using their first-hand experiences, family and relatives to exchange information about caring for themselves.

Self care management of the patients is based on beliefs and the socio-cultural context. Although the state of society has changed, the way of life of people in E-saan is conducted according to religious beliefs, culture, traditions and Kalum. Kalum means strictly behaving appropriately according to the illness. Kalum in eating means strictly eat what is suitable for the illness and not eating foods that may be bad for health. Consequently, apart from following the advice of health professionals, patients had to respond to suggestions of family, neighbors and other persons with DM which were rooted the beliefs and culture of the patients themselves.

Discussion and Conclusion

The study result demonstrates how the nature of beliefs and understanding of DM by persons with DM affected cultural care management for persons with DM in the community. The understanding of DM starts with learning about its symptoms and etiology. From their understanding and real life experiences, persons with DM and members involved gave their own definitions of DM. These definitions and perceptions of DM care were formed from a combination of medical and socio-cultural aspects. From the medical aspect, DM is a disease of pancreatic malfunction, and it is a chronic and incurable disease. From the socio-cultural aspect, DM causes laziness and excessive appetite. As a result, it prevents patients from working as hard as they used to.

Providing a cultural meaning of DM will certainly contribute to cultural care management for persons with DM. For example, if persons with DM are provided biomedical information about DM, they will learn how to care for themselves in line with biomedical health care. For instance, patients who believe that DM is an incurable disease will not strictly control what they eat because they think they will never be completely cured. People, who believe that DM is karma, resign themselves to their fate and accept what happens to them.

DM has greatly affected their way of life. Those with DM, have experienced both different and similar events involving health care. Since first being diagnosed with DM, they have become patients rather than healthy persons. Their daily focus has shifted from working from dawn to dusk to sparing time for doctor visits at the hospital. Once they were happily surrounded by their family members, now they spend time in the hospital having their complications treated.

The study highlights the fact that the cultural care management for persons with DM in the community occurs out of the knowledge people have gained that is grounded in socio-cultural aspects of their lives and supplemented by scientific awareness which informs their particular approach to care for persons with DM. The important goal of care management for persons with DM is to stay alive and live their lives normally so they do not focus on cure or control blood sugar levels. On the other hand, the aim of heath professional treatment is to control blood sugar levels. This may lead to the difference of opinion between doctors and patients. In addition, it was revealed that there is no conflict between patient's perceptions and the biomedical aspects. They simply integrate the new knowledge into their ways of life instead. Moreover, people have sufficient potential to take care of their health in conformity with their life conditions and respond to the problems in time. For example, they can assess and cure complications such as hypoglycemia or hyperglycemia by themselves. Care management by the people is a way to get pass information from "insider" to "insider". This allows them to obtain detailed information that they can not get from health personnel.

The results of the research will be very helpful for health personnel. It will help them become more aware of cultural differences and similarities when taking care of persons with DM. Hopefully, this can reduce cultural gaps between persons with DM and health professionals. Therefore, in order to provide a service which can respond to the problems and the patients' needs appropriate for their socio-cultural condition, health personnel, especially registered nurses, need to vary their attitudes and modify their role from one with an emphasize on providing knowledge to one where they serve as coordinators and managers of the health care system aimed at enabling allow patients to live happily. Flexible attitudes, listening to others, understanding the patients' life situation and being ready to exchange information and learn from the patients, will lead the nursing service known for its "friendship therapy" and "generosity therapy"

This information is also useful for designing health care systems and activities that correspond to the needs of DM patients, their social environment, customs, culture and economy. The ultimate goal is to create a health care system that encourages the involvement of community members and delivers excellent customer service, and respects the rights and dignity of the patients.

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วัฒนธรรมการดูแลผู้ป่วยเบาหวานในชุมชน: การศึกษาเชิงชาติพันธุ์วรรณนาในประเทศไทย

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บทคัดย่อ: การวิจัยเชิงชาติพันธุ์วรรณนาที่ใช้ในการศึกษาครั้งนี้ มีวัตถุประสงค์เพื่อทำความเข้าใจวัฒนธรรมการจัดการดูแลผู้ที่เป็นโรคเบาหวานจากทัศนะของผู้ที่เป็นโรคเบาหวาน ผู้ให้ข้อมูลหลักเป็นผู้ที่เป็นเบาหวานจำนวน 30 ราย ศึกษาข้อมูลในชุมชนชนบทแห่งหนึ่งของภาคตะวันออกเฉียงเหนือ เก็บรวบรวมข้อมูลโดยการสังเกตแบบมีส่วนร่วม การสัมภาษณ์เชิงลึก ใช้เวลาในการเก็บรวบรวมข้อมูล 18 เดือน วิเคราะห์ข้อมูลโดยใช้การวิเคราะห์เชิงเนื้อหา

ผลจากการศึกษาชี้ให้เห็นว่า ผู้ป่วยเบาหวานในชุมชนให้ความหมายเกี่ยวกับโรคเบาหวานตามการรับรู้ ความเชื่อ และประสบการณ์ตรงของตนเอง และการให้ความหมายต่อโรคเบาหวานยังก่อให้เกิดการจัดการดูแลผู้ป่วยโรคเบาหวานภายใต้บริบททางสังคมวัฒนธรรมของชุมชน

ข้อค้นพบจากการศึกษาแสดงให้เห็นว่า วัฒนธรรมการจัดการดูแลผู้ป่วยโรคเบาหวานของชุมชนเกิดขึ้นจากความรู้ในสองกระแสหลัก คือ ความรู้เชิงสังคมวัฒนธรรมเติมเต็มกับความรู้เชิงชีวการแพทย์ เป้าหมายสำคัญของการจัดการดูแลตนเองของผู้ป่วยเบาหวานในชุมชนชนบทอีสานมุ่งเน้นที่การดำรงชีวิตอยู่ได้ ทำมาหากินได้ ซึ่งเรียกว่า “พออยู่ได้” หรือ “อยู่ดีมีแฮง” เป็นตัวตั้ง ไม่ได้มุ่งเน้นที่การรักษา หรือ การควบคุมระดับน้ำตาลได้หรือไม่ได้

ความรู้ที่ได้จากการวิจัยครั้งนี้ มีความสำคัญกับบุคลากรสาธารณสุข โดยจะก่อให้เกิดความเข้าใจในความเหมือนหรือความแตกต่างของวัฒนธรรมการจัดการดูแลผู้ป่วยเบาหวานของชุมชน ซึ่งจะช่วยลดช่องว่างทางวัฒนธรรมระหว่างผู้รับบริการกับระบบวิชาชีพด้านสุขภาพ

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คำสำคัญ: วัฒนธรรม วัฒนธรรมการจัดการดูแล โรคเบาหวาน

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