CARERS' PERCEPTIONS OF TYPE 2 DIABETES AND CAREGIVING IN NORTHERN THAILAND

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ABSTRACT:

Background: The number of people in Thailand who have Type 2 diabetes has increased dramatically making it one of the country's major health problems. Carers play an important role in looking after relatives with Type 2 diabetes but little is known about their perceptions of this condition. The present study aimed to examine the perceptions of carers in Thailand regarding Type 2 diabetes and utilise the findings to formulate a model for diabetes health education.

Methods: A grounded theory approach was used to recruit 22 carers from the outpatients department of 659 bedded public hospitals in Northern Thailand. Semi-structured face to face interviews explored their views of Type 2 diabetes and caring activities.

Results: Five explanatory categories emerged from the data. The core category was causing lifelong stress and worry and the others were wanting a normal life for the people in their care, finding their own ways of dealing with Type 2 diabetes, after a while changes occurred, and still cannot make things right. Carers were happy to care for their relatives because they loved them. Carers had some understanding of Type 2 diabetes although the accuracy of this varied as some did not regard it as a serious health problem. They tried hard to help their relatives follow heath professionals' instructions about diet, medication and exercise. Thai culture and Buddhist values influenced their thoughts. Carers who attended the patient education group at the hospital found group learning and learning from peers very helpful. Some carers bought traditional Thai medicines for their relatives especially if their blood glucose levels remained high. As their relatives' health deteriorated, carers' responsibilities increased and they experienced the social and emotional costs of caring: tension, worry, stress and loss of their personal lives.

Conclusion: Carers of people with Type 2 diabetes were constantly worried about the people in their care and spent a lot of time looking after them but were often socially isolated. Carers in Thailand needed respite from caring and better education about Type 2 diabetes.

Keywords: Type 2 diabetes; Carers; Caregiving; Thailand

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INTRODUCTION

The study reported here was part of a much larger investigation of perceptions of Type 2 diabetes among several groups in Thailand: patients, carers and health professionals. The overall aim was to identify educational needs and to formulate a model for patient education [1]. It was considered important to include carers as they might, potentially, provide new and different insights into the needs of patients. This paper reports on the perceptions of individuals who provided care for family members with Type 2 diabetes. Carers look after people on a daily basis, sometimes for many years and often with little or no help. They play important roles in enabling people to live, at home, with long-term illnesses or disability but they often do so whilst juggling multiple responsibilities such

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as earning a living and fulfilling other family roles. Carers need support and recognition for the work they undertake but in Thailand they have received limited attention. An extensive literature search did not yield any papers on this subject and consequently, carers were selected as the focus of the study.

Type 2 diabetes occurs most commonly in middle or later life, particularly among people who are overweight. It develops as a result of insulin resistance which causes a gradual rise in blood glucose levels to which the pancreas responds by producing more insulin until it eventually fails [2]. Symptoms of Type 2 diabetes often develop very slowly and the individual may feel quite well. Diagnosis may not occur until after serious complications have already arisen. In Thailand an estimated 4 million people have diabetes, mostly Type 2. Many more are likely to be undiagnosed and the incidence is increasing [3, 4].

METHODS

The aim of the study was to ascertain carers' perceptions of Type 2 diabetes. The absence of previous studies of carers indicated the need for a qualitative study. Strauss and Corbin's Grounded theory (GT) offered a systematic approach to the investigation of an under-explored subject [5]. GT also provided a method – Grounded Theory Method (GTM) which has a well-defined framework for data analysis and emphasized systematic coding techniques [6, 7]. GTM is a continuous process of simultaneous data collection and analysis in which the researcher becomes immersed. This process facilitates theoretical sampling, the identification of categories which are compared and checked against new data until saturation is achieved and progressive focusing as the researcher generates categories and an explanatory theory of the situation under study [8, 9].

Participants and setting

The study took place in the medical outpatients department of a 659 bedded public hospital in northern Thailand. It is the centre of a public hospital network covering three nearby provinces. On average, 50 people with diabetes attended the department every day. There was no specific diabetes clinic. The hospital is not identified here in order to ensure the anonymity of the participants.

The process of sample selection was based on purposive [10, 11] and theoretical [12] sampling. In a grounded theory study, purposive sampling facilitates the identification of people able to provide the required information. The criteria for recruiting the sample were that carers had looked after someone with Type 2 diabetes, usually a parent, for at least one year, were able to communicate in Central Thai language, and were able to consent for themselves. The characteristics of the sample are set out in Table 1.

Table 1 Demographic characteristics of participants

Characteristics	**N= 22**
Age (years)*	45.32 (31-64)
Gender (n)	
Male	3
Female	19
Length of time with caregiving (years)*	7.59 (1-15)
Marital status (n)	
Married	15
Single	6
Separated	1
Educational level (n)	
Illiterate	1
Primary school	8
Secondary school	7
Bachelor's degree	4
Master's degree	2
Relationship with people in their care (n)	
Daughter	11
Son	2
Grandchild	1
Sister	1
Wife	6
Husband	1
Working conditions (n)	
Self employed	2
Gainfully employed	8
Unemployed	6
Farmer	3
Seller	3

*Mean (range)

A total of 22 carers were recruited during a 6 month period of data collection at which point saturation was achieved. Their ages ranged from 31 to 64; their involvement with caregiving ranged from 1- 15 years. Informed consent was obtained from all participants.

Data collection

The data were gathered via semi-structured face-to-face interviews as this method is sufficiently flexible to enable in depth exploration of subjects. This type of interviewing allows the use of open-ended questions that encourage participants to give detailed answers. The researcher is free to probe and to clarify points raised [13]. The interview questions were based on the Health Belief Model which was developed by psychologists in the 1950s to explain health behaviours [14, 15]. This model has been further developed and applied in many fields. The essential elements remain: perceptions of the severity of and susceptibility to the specific condition, the consequences for personal life, the benefits of action, the obstacles to be overcome and the ability to do what is needed. These elements formed the basis of the interview questions.

Data analysis

All the interviews were transcribed verbatim and translated from Thai into English so that all members of the research team could read the data. Translations into English were checked by a member of the research team who could speak and read Thai. The complex data analysis process began after the first interview and continued concurrently with the data collection. Each transcript was analysed line by line in conjunction with the recording which helped to capture factors such as tone of voice or emotion. The emotions and tone of voice were discussed in team meetings regularly. The Thai speaker also provided help on this issue. The researcher engaged in constant interaction between sampling, data collection, the emerging analysis, and theory construction. All data were progressed and checked through systematic coding, memoing, categorizing, comparing and contrasting until a theoretical framework began to emerge. Member checking [16] was carried out with a small group of participants to check accuracy.

Ethical consideration

The study was approved by the Research Ethics Committee of the hospital setting (No. 3/2554 on 20th June 2011). The hospital is not identified here in order to ensure the anonymity of the participants.

RESULTS

The analysis generated a core category which revealed that participants perceived Type 2 diabetes as *causing lifelong stress and worry*. Around this core category were four related subcategories which provided more detail: *wanting a normal life for the people in their care, finding their own ways of dealing with Type 2 diabetes, after a while changes occurred, and still cannot make things right.*

Core category: causing lifelong stress and worry

Carers perceived Type 2 diabetes as an incurable condition that that would remain until the person affected had passed away. Type 2 diabetes was caused by high amounts of sugar in the blood or body which meant that people had to control their diet and take medication for the rest of their lives. If they did this then they could lead normal lives. Most of the carers stated that anyone could develop this condition; they knew many people who had done so. It was not a condition that could be caught like an infection; it was not serious like HIV/AIDS. Other carers worried because, after receiving a diagnosis of Type 2 diabetes, their relatives became mentally and physically weaker, with symptoms such as blurred vision or poor memory.

> *'During these 3-4 years, my mother was admitted to hospital several times because she was unconscious. The doctors told me that she was unconscious because her blood sugar was very low. I worry a lot about her. I worry that no one will know or help her, if she feels faint or becomes unconscious again' (Carer No. 17, daughter, 40 years old).*

More than half of the carers believed that Type 2 diabetes was caused by lack of exercise or eating large amounts of sweet food. Others attributed the cause to ancestors, malfunction of the human body or bad health behaviour such as smoking and drinking alcohol. A few carers disclosed that Type 2 diabetes might occur because of *kamma* (bad deeds in the past lives).

> *'I think my husband have diabetes because of kam. I believe that people who do not have any kam will not have any disease. For me, I do not have diabetes, hypertension, or any other diseases. I am fine and happy. I always wake up early in the morning and provide the monks with some food. This makes me happy' (Carer No. 20, wife, 59 years old).*

Almost all carers believed that it was their responsibility to look after family members when they got old or were ill because they loved them. Caregiving was a matter of *torbtaen boon koon* (doing and returning favours). As Buddhists, carers believed that looking after other people would bring them happiness in their present or future lives. However, caring affected carers' working lives; some had to stop working when their relative became too old or too ill to look after themselves. Even if they managed to continue working, carers faced loss of earnings when they had to take time off. This could affect not only their personal income but also that of the whole family.

This core category demonstrated a number of important issues about the ways in which carers perceived Type 2 diabetes and the effects of this condition on their own lives. The four categories presented below take up these issues in more detail.

Subcategory 1: wanting a normal life for the people in their care

Carers hoped that the people in their care would achieve normal blood glucose levels, be able to control their weight, and not suffer any complications because of neglected foot care, poor diet or some other factors. Type 2 diabetes was bad luck but not serious providing that the person affected followed professional advice and attended all medical appointments. Carers explained that they tried very hard to support the people they looked after.

> *'Everybody in my family try hard to help my mother to control her diet. We will not buy any dessert for her. We also do not buy it for ourselves. If we crave for it, we will go to have it outside. I explain to my mother that we do not want to be mean to her or anything. We have to do this because we love and want her to get better' (Carer No.17, daughter, 40 years old).*

Wanting these outcomes did not always mean success. Carers recognized that people could become very ill or even unconscious. These possibilities motivated carers to keep trying to help the people they cared for keep their Type 2 diabetes under control and lead normal lives.

Subcategory 2: finding their own ways of dealing with Type 2 diabetes

This category provided insight into the activities of carers. The majority believed that medication was very important. The majority of carers said that, every day, they prepared, and served medication, including insulin injections, to people in their care. Diet was similarly important. Most carers stated that they helped their relatives to reduce their consumption of food, especially sweet, fried or salty food and dishes containing coconut milk. This caused some to change their own eating habits. Carers reported feelings of guilt when they deprived the people they cared for of foods they enjoyed or limited portion size. Consequently carers sometimes served these foods because they felt sorry for the person concerned.

Many carers encouraged their relatives to exercise and sometimes went with them, walking or running in the park nearby. Most of the carers always accompanied people they looked after to their medical appointments because they were elderly, had difficulties in walking or had poor vision. They wanted to hear what the doctors advised and ask about abnormal symptoms in people they looked after. For carers, the main source of information about Type 2 diabetes was the hospital's health education programme. This was run by health professionals as a group activity. A few carers thought that this was the best way to educate people. They believed in healthcare professionals, learned from other people in the group and noted that their relatives enjoyed meeting other people and participating in the activities.

> *'My mother has some numbness in both of her hands. I meet one patient who has the same problem in the group. She told me to massage both of my mother's hands in warm water every day. I tried, and found that this way worked well. Some numbness in the hands of my mother was relieved' (Carer No.13, daughter, 39 years old).*

Most of the carers reported that their relatives' blood glucose levels did not improve. These carers sought information about alternative treatments such as herbs and traditional medicines. Some prepared herbs or traditional medicines, such as wild pepper or tinospora cordifolia, because they wanted their relatives to get better. Neither carers nor people with Type 2 diabetes discussed this with the health professionals at the hospital.

> *'I always find and buy my wife every kind of medication {traditional medicine} which my colleagues and other people have told me that it could cure diabetes. Recently, I buy her herbal juice for diabetes' (Carer No.11, husband, 56 years old).*

These findings show the range of activities performed by carers. They tried hard to ensure that people in their care followed the advice of health professionals with regards to managing medication, diet and exercise in order to reduce blood glucose levels. The hospital was a good source of advice although there was no education aimed specifically at carers. Despite the carers' efforts, some of the people for whom they cared did not improve. Carers then sought help through traditional channels but did not discuss this with the health professionals.

Subcategory 3: after a while changes occurred

Many carers found that, in time, their relatives got better and their blood glucose levels decreased to normal. Many abnormal symptoms, such as blurred vision, palpitations, dizziness and numbness, were also relieved. They completely changed their eating habits, exercised more, took their medication regularly, and were happy to come to the hospital for their medical appointments. They were less worried about Type 2 diabetes, felt happier in their lives and had more confidence in practising their self-management. Carers were pleased and felt they could relax a little.

Some carers found that the people they looked after deteriorated and experienced complications, such as retinopathy, nephropathy, and peripheral neuropathy. This increased the carers' workload and the time required for caring. In the following example the carer could no longer leave her mother in case she had a fall.

> *'My mother still cannot control her weight and blood sugar level. Now she has blurred vision and cannot walk properly. I need to help whilst she walks up and down the stairs. I really do not know what the best way to help my mother to control her weight and blood sugar level. She also does not believe what I have told her to do for her diabetes' (Carer No.18, daughter, 37 years old).*

This subcategory shows that increasing levels of dependence placed greater demands on carers. The people they cared for required a greater level of support as their physical and mental health declined. They could no longer manage Type 2 diabetes on their own.

Subcategory 4: still cannot make things right.

This category demonstrated the many personal difficulties that carers faced. Two factors emerged here. First, carers reported tension and frustration when the people they cared for became angry or refused to comply with taking medication or with dietary restrictions. Carers felt unable to do anything about this because they were younger than their relatives.

> *'I will not argue with my mother although I am very angry and feel highly frustrated with her. In this situation, I will go out somewhere for a few hours in order to calm down. Then, I will come back to talk and look after her as usual' (Carer No.14, daughter, 39 years old).*

Second, there was the lack of respite care for carers. As their relatives deteriorated, the carers' workload increased. They had to stop working and move into the same home as the person they cared for. Gradually their lives came to revolve more and more around that person. Carers were not free to spend time with friends or participate in social events. There was no break, no respite from caregiving. A few carers stated that, after many years of caregiving, they had lost their own personal lives and had no personal time.

> *'Looking after my mother is very hard work and very important. I spend most of my time in taking care of her. I do not often go out. Sometimes I will go out with my friends, if they come to pick me from home. In my view, taking care of my mother is more important than going out with friends' (Carer No.22, son, 31 years old).*

This subcategory reveals that, whilst carers were pleased to care, they experienced the social and emotional cost of caring. Their responsibilities increased as time went on and could last for many years.

DISCUSSION

Diabetes Mellitus (DM) is one of Thailand's major health problems and Type 2 Diabetes affects an estimated 1.03 % of total populations (64,955,313) in 2014. It is, therefore, important that those affected by this condition receive the best care possible and that those responsible for looking after them on a day-to-day basis receive support and appropriate education about diabetes. This study focused on the views and experiences of 22 carers. It showed that they looked after family members with Type 2 diabetes because they loved them and wanted them to have normal lives. Carers regarded caring as a way of giving back the care that those individuals had previously given them. These findings revealed that Thai culture and Buddhism had an influence on carers' thoughts and willingness to take on the task of caregiving. Similar findings were found in a study about stroke caregivers in Thai families [17]. Stroke caregivers were willing to care because, in Buddhism, it was of great merit to give and expect nothing in return.

This study of carers at one public hospital in northern Thailand reveals, for the first time, their perceptions of Type 2 diabetes. The core category showed that they had some understanding of the nature and possible causes of this condition although the accuracy of this varied. A previous study of patients' perceptions about Type 2 diabetes in Thailand [18] suggests some similarities with those of the carers in this study.

There were no resources aimed specifically at those looking after people with Type 2 Diabetes and so they had to find their own ways of providing care. This included the use of traditional Thai medicines and herbs which were believed to cure diabetes. This practice was not disclosed to health professionals possibly because carers feared rebukes. A previous study in Thailand [19] reported that patients and families worried about medical appointments and the attitudes of health professionals. It is therefore reasonable to surmise that, in the study reported here, carers did the same. The use of traditional Thai medicines and herbs to control Type 2 Diabetes requires further study particularly since some of these may interact with prescribed medication. Those who attended the health education programme at the hospital found it was a valuable source of information which helped both them and the people for whom they cared. Previous studies in Thailand, Japan and Sweden all reported the positive effects of group learning on quality of life and the ability to self- care [20-22]. The value of learning from peers has also been reported in Canada and several African countries [23, 24].

After a while, carers found that changes occurred. Sometimes, the health of the person for whom they cared improved but others reported deterioration and increasing dependence. It seemed that, despite their best efforts as carers, the people for whom they cared still had raised blood sugar levels and developed complications of Type 2 diabetes such as retinopathy and peripheral neuropathy. As a result carers had to devote more time and energy to caring, helping with daily living activities, medication and exercise but found that they still could not make things right. Carers bore a lot of responsibility. They lost their own personal lives and there was no respite care available to help them cope. Family relationships were strained by the constant demands of caring, particularly when the person being cared for was uncooperative. A previous study in Pakistan [25] reported similar findings. Caregiving roles put carers under a lot of strain, sometimes leading to great distress [26]. Previous research [27] also supported this study's reports of the psychosocial problems experienced by carers: social isolation, restricted social activities, anger, depression, anxiety, hopelessness, and disruption of professional life.

CONCLUSION

The aim of this study was to examine carers' perceptions of Type 2 diabetes in one outpatients department in northern Thailand. Carers had received little prior attention and so a GT approach was applied to facilitate exploration of this subject. The findings revealed their thoughts about caring, the aims and consequences of their caregiving, how they looked after people in their care, and the difficulties they faced. Carers experienced lifelong stress and worry as they struggled to provide care, particularly when the people for whom they cared. The study highlighted the importance of the carers in diabetes management and clearly indicates that carers need more information about Type 2 diabetes, psychological support and respite from caregiving.

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