

Glycemic control hassles for family caregivers of Sri Lankan adults with type 2 diabetes

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Abstract

Introduction: Type 2 diabetes mellitus (T2DM) is imposing significant complications and economic burden on adults worldwide. It is a leading cause of morbidity and mortality among adults in Sri Lanka. As adults with T2DM need to control their glycemic levels involvement of family caregivers increases the likelihood of successful glycemic control behaviors. Furthermore adults with T2DM develop complications and functional impairment; family caregivers become significantly important in supporting their relatives to have a better quality life. There is a limited data available on family caregivers' perspectives regarding glycemic control among adults with T2DM in Sri Lanka.

Objective: To explore the perceptions towards glycemic control among adults with T2DM as perceived by family care givers.

Design & Methods: A descriptive qualitative design was used to collect data. In-depth interviews with family caregivers (n=12) were conducted until data was saturated. Thematic analysis was used to analyze data.

Results: Findings were organized into three overarching themes: 1) feeling sad, burdened and stressed 2) knowing how to provide better care, and 3) improving family relationships and caring. Participants strongly agreed in knowing about the disease of diabetes and that its management is important to provide effective care for their relatives to achieve glycemic control.

Conclusions: Family caregivers perceived that their family member with T2DM faced lots of challengers while doing diet control, adhering to regular physical activities and taking medication properly for life. Moreover, family caregivers encountered many challengers when providing care due to their lack of knowledge about diabetes and its management. These findings can help health care professionals recognize family caregivers as a supportive group and also pave the way for developing awareness programs on diabetes for family caregivers in future.

Keywords: Type 2 diabetes mellitus, Glycemic control behaviors, Family caregivers, Qualitative research

I. INTRODUCTION

In the developing middle income country of Sri Lanka, T2DM is a major health concern of healthcare system and health policy makers. The national prevalence of DM in 2012 was 10.3% in Sri Lanka [1]. The highest prevalence of 18.9% of T2DM has been reported from the Western Province of Sri Lanka [2]. A hospital-based descriptive cross-sectional study (n=230) conducted in this province revealed that poor glycemic control (>126 mg/dl) was observed among the majority of the participants (71.3%) [3]. There is strong evidence that following glycemic control behaviors, namely doing diet control, regular physical activities, and taking diabetes medication, are key to achieving glycemic control among adults with T2DM [4]. Social and cultural influences, which include support of family members, play a large role in dealing with glycemic control behaviors among adults with T2DM. An ethnographic study conducted among participants with T2DM found that the Sri Lankan sociocultural context has a significant impact on glycemic control behaviors among adults and also suggested that this should be taken into consideration when health care professionals provide care for such people [5]. Thus focusing on family caregivers involvement in diabetes control is an important aspect of interventions for adults with T2DM in Sri Lanka. Another qualitative study conducted in Sri Lanka to explore perspectives of health care professionals regarding glycemic control among adults with T2DM revealed that lack of family support was a barrier to attain and maintain sustained glycemic control [6]. The importance of family support has been identified for regular exercise and medication taking behaviors [7], [8]. However, there is a paucity of data available on how adults with T2DM control their glycemic levels as perceived by their family caregivers in Sri Lanka, a matter which this study sought to reveal. Family caregiving is an important aspect of traditional Sri Lankan caregiving philosophy, and thus an underlying assumption for this study was that improving family caregivers' involvement in diabetes care as well as improving

their knowledge about diabetes, may promote glycemic control among adults with T2DM in Sri Lanka.

II. AIM & DESIGN

A. Aim

The study aimed to explore the perspectives regarding glycemic control among adults with T2DM as perceived by family caregivers

B. Design, Setting & Sample

A descriptive qualitative design was used. The study was conducted in the selected community settings in Sri Lanka. Family care givers were defined as family members who assisted the adults with T2DM. Inclusion criteria for the caregivers were: provided support/care for a family member with T2DM for more than one year, above 18 years old, and able to communicate in Sinhala or English languages. More than one year of experience was required for when recruiting family caregivers for the study because they needed experience in caring for adults with T2DM in order to understand their behavior. Emphasis was placed on trying to recruit an ethnically diverse sample to ensure culturally rich perspectives as Sri Lanka is a multiethnic country. Participants were recruited over a span of 9 months from an ethnographic study which was conducted among adults with T2DM in Sri Lanka. [5]. There were 12 family caregivers participating in this study.

C. Data Collection & Data Analysis

The required information was obtained by an interview guideline. The in-depth interviews had open-ended questions such as "What are your beliefs towards diabetes and its control?" and "How do you support your relative to perform glycemic control behaviors? Please explain". The principal investigator conducted in-depth interviews with 12 family caregivers until data saturation. The interviews were done at their home setting in a quiet room at mutually convenient times. Each interview lasted approximately 60 minutes and each was audio-recorded and transcribed for analysis.

Ethical approval was obtained by the Research Ethics Review Committees of the Faculty of Nursing, Chiang Mai University, Thailand; Faculty of Medical Sciences, University of Sri Jayewardenepura, and relevant community authorities. All participants were informed verbally and in writing about the study purpose and processes and their participation was voluntary. The study information sheet was reviewed with participants prior to the interview and any question that potential participants had about the study were addressed. Written informed consent was obtained from all participants and their privacy, confidentiality and rights were protected throughout.

Participants' characteristics were analyzed using descriptive statistics by using SPSS 16.0. Thematic analysis by Miles & Huberman [10] was used to analyze qualitative data. Firstly, qualitative data were verified, transcribed verbatim as soon as possible after each interview and read and re-read several times. Secondly, initial coding was done in the

preliminary analysis of the transcripts, then those codes were clustered and used to form preliminary subthemes and refined. Finally, further analyses were performed until themes emerged. Member checking was used to verify themes.

Demographic characteristics of family caregivers are presented in Table 1. There were 12 caregivers comprising husbands (n=3) and wives (n=3) daughters (3) and sisters (n=3). Most family caregivers were female (75%) and more than half were over 50 years age. The majority of the participants (85%) had more than 5 years of caring experiences for their relatives with T2DM. However, most of the participants (34%) were not aware the normal values of fasting blood glucose values.

Table 1

Characteristics of family caregivers of adults with T2DM (n=12)

Characteristics	Number (%)
Gender	
Female	9 (75)
Male	3 (25)
Age (Years)	
≤ 50	2 (17)
> 50	10 (83)
Ethnicity	
Sinhala	8 (66)
Tamil	2 (17)
Muslim	2 (17)
Educational status	
Grade 6- O/L	9 (75)
≥ A/L	3 (25)
Duration of caring for their relative (years)	
≤ 5	2 (17)
6- 10	6 (49)
11- 20	2 (17)
≥ 20	2 (17)
Knew the normal values of fasting blood glucose (mg/dl)	
Yes	4 (34)
No	8 (66)

Qualitative findings are presented as three themes: 1) feeling sad, burdened and stressed 2) knowing how to provide better care and 3) Improving family relationships. Relevant themes and subthemes are also presented. Quotes below are followed by the relationship of the participant to the person with T2DM.

Theme 1: Feeling sad, burdened and stressed

The most significant theme to emerge from interviews consisted of family caregivers' feelings about their relatives. Feeling sad and burdened reflected how the family caregivers committed their life to support their relatives. Adults with T2DM needed family caregiver support to help them adhere to a prescribed diet plan and medication regimen, especially to get insulin injections, to do foot care and to attend clinics for follow up visits. All these activities may provide a huge

burden on family caregivers in addition to their day-to-day activities. Family caregivers described how they feel sad about their relative as follows:

My wife has diyawadiawa (the Sinhala term for diabetes) and she cannot eat anything as she likes. How can she be happy? Don't eat this thing, that thing... everyone tell like that. (Husband)

I feel sorry for my mother. She likes to eat bread with butter and sugar but due to her diabetes she cannot eat this. (Daughter)

My husband has been suffering from this bad disease for nearly 15 years. He cannot do anything as he wants, cannot go out, cannot eat as he likes, needs to take insulin every day, and has painful dark patches on his arms, legs and belly. Earlier he was a nice man. (Wife)

Furthermore, some family members expressed their burden as follows:

I am highly worried about my wife's disease conditions now she is 40 years. Our children are still young. I know this disease gets worse in future, then what will happen to her and my family in future? If something happened to her, who will take care my children? (Husband)

My mother's one eye is already blind due to this diabetes, my father has to earn money for our family. I cannot support him as I have to stay at home with my mother (Daughter)

My husband (has been) admitted three times to the hospital due to high sugar, so I have to be very careful now about this diabetes. I have to prepare meals as nurses told me, but he doesn't like to eat them because they are less tasty. I have to go to work to earn money for my family living, it is very difficult now because I have to care for my husband. (Wife)

Participants also expressed how aspects of their relatives' diabetes exacerbated their stress.

I heard that this metformin causes kidney damage. Many people at the clinic talk about it. I am afraid what will happen to my mother's body in the future. (Daughter)

I have been giving insulin to her for many years, I cannot go for a job for full time because of this, (and) her insulin dose increases. I don't know what will

happen to her in future, when I think these things I get mad (Husband)

My elder sister got diabetes when I was small, she takes care of me a lot, now her children are not here to take care of her. Her husband passed away, so I have to take care of her all the time, no body to cook her meals, give medicines. If I get married, how to take care of her? I don't know (Sister)

Some family members expressed their stress because they were unable to support their relatives with diabetes due to their low economic status. Their family income was not adequate to buy insulin bottles, syringes, and recommended food, and to spend money to attend clinics for regular follow ups. Two expressed their ideas as follows:

Many times this hospital diabetic clinic doesn't have insulin so I have to buy it from the outside, it is expensive. My husband needs 2-4 bottles per month. Syringes, needles also I have to buy, we have only his pension. I also cannot go to work because I have to take care of him. I don't know how to find money for his disease. (Wife)

My father is the only person who works in my family. We don't have enough money to give good meals for my mother. Every month we have to take my mother to the hospital by a taxi. We cannot go by bus because she is not well. Sometimes there is no insulin at the hospital... sometime we ask money from our friends, sometimes we don't go to the clinic. (Wife)

Theme 2: knowing how to provide better care

The majority of caregivers did not have a clear idea about diabetes and its management, and the importance of adequate diet control and regular exercise. Especially, they did not know the normal values of fasting blood glucose and how proper diet and regular intake of antidiabetic agents had on blood glucose control. Four expressed their ideas as follows:

My wife takes insulin for many years but her sugar is not controlled yet. She used to eat a very small amount of meal, less sugar, but her diabetes gets increased every time. I don't know why. (Husband)

Sometimes people say eat this and its good for diabetic control. Sometime nurses said eat red rice and it is good for diabetes. The doctor said eat small amount per meal. Different people said different things. We get confused what is the good thing for diabetes? (Daughter)

My husband sometimes feels not well, feeling faint, then he refused to take metformin and says no need to take metformin because his sugar is very low, so I also don't force him to take metformin. (Wife)

... tell me what my sister can eat. What is good for her control? When can she stop taking this medicine? (Sister)

... blood glucose control and its necessity to manage ... family caregivers perceived that diet control was ... Most family caregivers did not know the meaning ... of input and output of calorie expenditure. Two participants stated:

... my wife doesn't take sugar for her tea since she got diabetes. She used to drink tea or other drinks without sugar but her sugar was not controlled at all. (Husband)

... I prepare meals for my husband, I do not put sugar into his tea. I don't give him any sweet things, but when we check his blood sugar it's not normal. (Wife)

... normally most participants were aware that metformin is ... to the body. This fear about metformin led the family ... to provide less support for compliance to health ... Some shared their ideas as follows:

... I heard this metformin is not good for the body, I am so afraid ... he is taking metformin for many years. Sometimes he didn't take metformin ... can we stop taking this? Is there any other medicine than this? (Wife)

... at this time when we go to the clinic, the doctor said that my mother's urine is not good and asked to do a test. I heard that metformin damage kidneys. I think it is the reason for this. (Daughter)

... after taking metformin my sister does not like to eat. In the past she ate a lot. She said that she doesn't feel any taste of food because the metformin makes her mouth like bad taste. (Sister)

... the other hand most caregivers tried to learn more about ... to control the glycemic level such as practicing the use of ... which are good for sugar control. They used to give ... herbs to their relatives, as highlighted below:

... I heard that thebu (costus speciosus, cheilocostus speciosus) is good for sugar control. I make thebu sambol (salad) for my husband every week, he also likes to eat it. (Wife)

... When I go to the Sunday fair I buy many herbs for my wife. I heard that they are good for sugar control. (Husband)

... In my home garden I grow thebu (costus speciosus, cheilocostus speciosus). I use this for my mother's meal. Many of our neighbors, newspapers and some TV programs said that these herbs are good to control sugar.

They are not chemicals ... so I think these herbs do not harm the body like metformin. (Daughter)

With regard to the medical advice about doing regular exercise to control diabetes, most caregivers were unaware of the benefits of doing this. They perceived that doing day to day activities are also difficult for their relatives and wondered how to engage in physical activities, for example:

Sometimes nurses said to do walking to control sugar, but I am afraid...even my wife cannot do household activities regularly. She feels faint (and has) weakness most of the time. (Husband)

One day my husband went to walk but he could not do it for 15 minutes. He felt so tired and came home with lots of sweating. I was so afraid that day, then how to do physical activities as nurses told him? (Wife)

My mother is already blind in one eye and she is so weak due to this diabetes, (so) she cannot do exercise at all. All day she feels weakness and pain in both her legs. (Daughter)

Theme 3: Improving family relationships and caring

In this theme most of the participants believed that due to their caring support they had improved their family relationships. Especially they perceived that their caring and support for their relative to control diabetes strengthened their family bond, for example:

My wife all the time pays her gratitude to me because she feels how much I care for her. Sometimes she gets angry with me when I asked her to take medicine, go to hospital... but later she says that she feels how much I love her. (Husband)

My mother sometimes cries, and says that she cannot live if she doesn't have me to take care her. All the time she says she has the most loving daughter in this world because I do all the things for her. I want her to live happily. (Daughter)

My husband sometimes whispers that if I am not here, who will look after him? Sometimes he says his loving thanks for me for caring him this much. He knows how difficult a life I have with his disease in addition to my role as a mother. (Wife)

Furthermore, family caregivers perceived that they got more opportunities to be with their relative due to the need to care, such as having meals together, going out walking, and going for clinical follow ups. They also felt that they had a

responsibility to take care of their relative to live without worries or complications:

I want my wife to be happy, she is my children's mother. She worked hard when she was well ... so now it is my responsibility to take care. My biggest concern is she does not suffer like this. (Husband)

My sister looked after me when I was a child so now it is my turn to take care of her. I want her to live without worries. (Sister)

My mother was a beautiful woman in the past, due her disease now she is not like that. I am the only child in this family, so it is my responsibility to look after her. I feel happy, I got a chance to pay back, even a little, for my mother. (Daughter)

When my husband was well he did everything for me and our children, now he cannot do like that. I want to support him as much as I can because this is my responsibility to look after him now. (Wife)

Discussion

As life expectancy increases in Sri Lanka, qualitative findings from the present study revealed that family caregivers of adults with T2DM experienced sadness, burden and the stress of caring for their relative. Their needed to know more about diabetes is this is an important aspect for them to consider glycemic control. Somewhat similar findings are reported in other studies [10],[11]. For example, a randomized control study conducted among family caregivers (n= 50) of relatives with T2DM and family caregivers (n= 54) of healthy relatives in Turkey revealed that depression is significantly more frequent among family caregivers of diabetes than among the control group (p<0.001). The same study concluded that family caregivers of relatives with diabetes tended to have a poorer quality of life [10]. The WHO has stated that "health care for chronic disease must be oriented around the patient and the family [11], hence healthcare professionals should be concerned not only the patients with diabetes but also their caregivers' health".

In the present study, lack of knowing about diabetes among family caregivers was associated with less support for adults with T2DM to help them adhere to their medication regimen. This has been observed in several other studies too [6], [12]. For instance, a study conducted to explore healthcare professionals' perspectives regarding glycemic control among adults with T2DM in Sri Lanka revealed that lack of family support acted as a barrier for medication adherence among patients with diabetes [6]. The same study concluded that diabetes awareness programs should target family members of adults with T2DM to enhance their knowledge about diabetes and its management. A qualitative study conducted in the

USA with 33 family caregivers of T2DM revealed that these caregivers needed information about the condition in order to provide better family care support [12]. The present study also concluded that in order to get adequate family support, diabetes awareness programs should be targeted towards family caregivers as well. This was confirmed in a quasi-experimental study conducted among adults patients with diabetes (n=36) and their family members (n=37) in North Carolina, USA, to examine the effects of a family-based intervention program on diabetes self-management in Hispanic adults with diabetes. This study concluded that including family members in educational interventions may provide emotional and psychological support to patients with diabetes to promote self-management [13]. Furthermore, the present study revealed that family caregivers' beliefs and practices regarding the use of traditional herbs to control blood sugar levels among their relatives with T2DM. These findings are supported by another study conducted among Sri Lankan adults with T2DM [5].

In this study, it is interesting that, though family caregivers perceived sadness, burden and stressors while providing care, they also perceived that due to this caring their family relationships improved. The caregivers felt that they have a responsibility to care for their relatives as well giving them an opportunity to improve their family bonding. In a similar fashion, a qualitative study conducted among family members (n=35) of relatives with serious mental illness in Midwest USA reported that due to their caring activities participants improved the family relationships with their relatives [14].

In conclusion, due to the increasing prevalence of T2DM and the need for the recommended glycemic control behaviors to be practiced in the day-to-day life of adults with T2DM in their home settings, identifying the hassles of their family caregivers is needed today than ever before. Awareness of The perspectives of family caregivers these adults is an essential prerequisite to designing culturally appropriate diabetes care interventions in Sri Lanka. The study also sheds light on the need for health care professionals and policy makers to obtain the cooperation of the family care givers of adults with T2DM when designing and providing care for adults with T2DM in Sri Lanka.

Limitations of the study

There are some limitations of this study. First the use of a convenience sample might not have recruited a representative sample. Second, the complexity of the medication regimen (oral diabetic drugs or insulin or both) and the severity of the present disease condition (amputated legs, having retinopathy or nephropathy) which might have influenced the issues that were perceived by the family caregivers when they provided care for their relatives with T2DM. However, whilst this was a small study, the findings provide rich data to help inform clinical practice and further research.

Conclusions and implications to clinical practice

The findings outlines that the family caregivers of adults with T2DM perceived that they face a lot of challenges while supporting their relatives doing diet control, adhering to regular physical activities and taking medication properly as a lifelong practice. Therefore health care providers as well as health policy makers should develop awareness programs on diabetes for family members of adults with T2DM in the future.

ACKNOWLEDGMENTS

The authors thank all participants for their time and commitment to this study. The authors gratefully acknowledge the funding from the Faculty of Medical Sciences, University of Sri Jayewardenepura to conduct the study (ref no ASP/MED/RE/06/2012/38). The first author wishes to express her gratitude to the National Center for Advanced Studies in Humanities & Social Sciences, Sri Lanka for financial support of tuition fees at the Faculty of Nursing, Chiang Mai, University, Thailand (ref no 11/NCAS/SJP/MdEdu/39).

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