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Using Photo-Elicitation Interviewing on Family-Based Intervention Experiences Among Informal Caregivers and Type 2 Diabetes Mellitus Patients

Tengku Mohd Mizwar[1*], Aini Ahmad[2], Puziah Yusof[3]
School of Nursing, KPJ Healthcare University, Negeri Sembilan, Malaysia
Corresponding author: tengkumizwar@gmail.com

ABSTRACT

Changes to the management of type 2 diabetes mellitus (t2dm), which are being developed, aim to meet the demands on the level of health and increase daily diabetes self-care management activities in family-based intervention which is increasingly challenging. Disharmony over the quality of life, conflict of experience and family roles that are still unclear have been used as contributing factors. Photo elicitation interviewing (PEI) is a method that combines photos and interviews, has gained traction in the exploration of family-based intervention experiences, and there is also a need for analysis to develop more effective health programs. The main objective of this study was to use the PEI method to explore family-based intervention experiences involving informal caregivers and t2dm patients in Malaysia. Qualitative phenomenological sampling involved eight families consisting of informal caregivers (n=8) and t2dm patients (n=8) aged 20–60 years as purposive sampling. Interview content was compiled and coded using Excel spreadsheets and ATLAS.ti V9 software to perform thematic analysis. Six main themes have emerged: (1) mixed reaction to insulin injection, (2) education transformation, (3) self-efficacy to self-care behavior, (4) efforts in family-based t2dm management, (5) treatment needs, and (6) perception to t2dm diagnosis. The respondents have responded positively to using photos to support in-depth discussions. This method has successfully revealed aspects of the occurrence of a conflict that becomes a burden to the daily management of diabetes between them. This observation shows that PEI has the potential for acceptability and feasibility to form an intervention module, and further evaluation is very appropriate for the module design and development phase and the quantitative study phase.

Keywords: Photo-Elicitation Interviewing, Family-Based Intervention, Experiences, Informal Caregivers, Type 2 Diabetes Mellitus Patients, Qualitative

BACKGROUND

Non-communicable diseases type 2 diabetes mellitus (t2dm) is one of the leading public health problems of the world and the Asian region, where the world has failed to understand the progress character of this disease and underestimate the accurate scale and threat of this disease [1.2]. T2dm is not like the pandemic situation that the world has experienced before, where there is hope for an end. In contrast to t2dm, every year, there is a dramatic increase in data followed by social media technology trends that often promote various dietary modifications [3,4].

The prevalence of t2dm is increasing in all regions of the world, especially in individuals aged ≥ 60 years [5,6], this is an effect of the previous increase in the prevalence of t2dm among individuals aged between 10 and 24 years globally involving Western countries [7,8] and the Southeast Asian region [9,10]. In Malaysia, the Malaysian National Health and Morbidity Survey reported in 2019 that the prevalence of diabetes among adults aged ≥18 years has increased from 11.2% since 2011 to 18.3%, which is 3.9 million, followed by 3.4 million patients who have two or more risk factors such as the combination of hypertension and dyslipidemia that often occur together [11].

As a result, the onset of failure to stabilize daily glucose management and good HbA1C readings contributes to other medical comorbidities with a variety of burdensome complications. This burden and conflict have been experienced by various parties, especially the patient's family members and the health system, where the health personnel try to provide treatment for this complication [12].

Through this phenomenon and statistical data, it has been essential to explore what is happening behind this situation, what the individual's experience is, the function and role of the family system, and the method required for analysis before developing a health intervention. The experience of family-based intervention (FBI) has been seen as a successful physiological and psychological management of chronic diseases [12, 13-15]. The selection of the FBI as an intervention is seen as the role of biological factors, family social influence [16], better interaction for various parties, and the role of the family system aimed at setting health goals together throughout life [17].

However, the role of FBI in the management of t2dm among informal caregivers and t2dm patients was given minimal emphasis, and FBI was often performed on one population only [5,12,18], compared to the dyadic concept of informal caregiver to t2dm patient. In addition, the emphasis of the FBI function is often emphasized only in type 1 diabetes mellitus (t1dm) patients compared to t2dm patients because it takes into account the young age factor, where stability and physical and psychological results require the encouragement of older caregivers [19] as well as their limited ability to perform daily diabetes self-care management maturely [20].

Modifying the qualitative methodology is necessary to achieve the goal of deeper exploration. Photo-elicitation interviewing (PEI) combines photos and an interview session capable of providing a powerful attraction and mechanism to obtain more meaningful information through individual reflection [21] PEI also provides an exploration that may not be easily communicated using only qualitative methods [22]. Exploration of these issues can also identify the opportunity to provide health interventions as a data source for modification of t2dm management interventions and quality of life together [21,23-25].

For this study, researchers have used the PEI method to explore family-based intervention experiences for inductive exploration related to beliefs, perception, actions, roles, behaviors, and practices among informal caregivers and t2dm patients. The results of this study can impact the development of more meaningful and quality interventions for the community from the health profession, both physiologically and psychologically.

METHOD

Study design and setting

This study was part of a 3-phase mixed-methods research project, and this discussion was one of the methodological aspects of this study in phase 1 as an analysis of the requirements for developing a web-based module.

This qualitative phenomenological study explored family-based intervention experiences related to daily diabetes self-care management activities and perspectives among informal caregivers and t2dm patients. The PEI method and semi-structured interviews are done together for a deeper exploration of a phenomenon [26] than verbally alone; this aims to meet the needs and complex exploration [27]. Previously, a systematic review [28] showed that this exploration has provided a privilege that can stimulate and narrative exploration contributes to the research agenda that can be expanded to respondents who have difficulty communicating verbally about a phenomenon [26,29,30].

Purposive sampling involved eight families, informal caregivers (n=8) and t2dm patients (n=8) aged 20-60 years, where t2dm patients are receiving treatment for the effects of t2dm complications. Meanwhile, informal caregivers are biological heirs or spouses of patients who have been directly involved in daily diabetes self-care management activities for at least one year. Only one informal caregiver was selected to participate in this study. These two groups of respondents should be able to speak either Malay or English. This study was conducted in a public hospital in Terengganu, Malaysia, the main referral hospital in Terengganu. This study has started from October 2023 to January 2024.

The study was approved by KPJ HealthcareUniversity(KPJUC/RMC/SON/ EC/2023/468) and the Medical Research and Ethics Committee, Ministry of Health, Malaysia (NMRR ID-23-03333-CDI (IIR)) before this study was conducted (Date approved: 09 October 2023)

Photo- elicitation interview procedures

Bates et al [29] have distinguished three formats in this situation, namely participant-driven (open), participant-driven (semi-structured) and researcher-driven (semi-structured/structured). For this study, for respondents who have met the inclusion criteria, the researcher has chosen a PEI researcher-driven (open) semi-structured interview to conduct a more specific exploration to meet the study's objectives [31]. A semi-structured interview was conducted face-to-face between the informal caregiver and the t2dm patient for real-time feedback experiences they had faced before.

A total of 12 photographs were taken by the researcher, involving the patient's environment and the patient's physical condition. The photo was shown to the respondent as consent and a narrative discussion to protect the confidentiality of the informal caregiver and the t2dm patient. In addition to signing the agreement to participate in the study, respondents also signed the intention of taking photos through the photography consent that had been prepared

Data Analysis

Excel spreadsheets and ATLAS.ti V9 software were used to collect data and analyse transcripts and photos. The transcripts and photos have been analysed into six levels (Table 1) to ensure that the selection and discussion of PEI are situated more effectively [29,32]. The majority of the discussion was using Malay; the researcher used the back-to-back translation method, and the resulting English text was analysed using thematic analysis, or deductive thematic analysis approach, which is a process familiar with the data by repeatedly reading the transcripts, generating initial codes, grouping and naming the data into codes, arranging codes into themes, reviewing and refining themes, defining and naming themes, and writing the report [23,33]. In addition to identifying key themes, it describes the essence and core commonalities of life experiences to be shared.

Researcher assisted with field notes to document body language and facial expressions during the interview, which were also reviewed. It is essential to obtain information about the expression of their life experiences where confusion and conflict between them can be revealed. In addition, this interview session was also recorded as a voice record, and each time, the completed voice record was shared with the respondent to be heard as a sign of agreement to share the information before being analysed

Table 1. Step by Step Photo- elicitation Interview Flow

Stage	Procedures	Purpose
1	Epistemological Decision - Researcher-Driven	More structured and objective based
2	Participant Briefing	Establishing a relationship through written consent and understanding of the content of the image.
3	Photos have been prepared by the researcher to be interviewed (move directly to Step 4)	Facilitate the patient during the acute phase
4	Interviews	Develop understanding of individual roles and events that have been experienced when outside the health area.
5	Analysis	Through photos, data was collected through interview sessions, and themes are formed.
6	Dissemination	Discussion and positive combination of themes that can be used for intervention module formation activities.

RESULTS

Demographic data of informal caregivers and characteristics

This study has involved eight families, informal caregivers (n=8) and t2dm patients (n=8) aged 20 - 60 years only. Table 2 summarizes the characteristics of the respondents in this study. The respondents also showed a positive attitude toward involvement in this study.

However, two informal caregivers do not want to be interviewed face-to-face with the t2dm patient because there are conflicts and conflicting opinions between them, such as rejection of modern treatment compared to traditional treatment and stigma against amputation treatment in tertiary care before. However, the interview session was conducted separately because they still agreed to be involved in this study.

Table 2. Demographic data of respondents

Family	Informal Caregivers		T2dm Patient's				
	Age	Relationship	Age	t2dm Duration	HbA1C (%)	Received education before	Diabetic management satisfaction
F1	54	Wife and husband	58	10	12.2	Y	Y
F2	56	Wife and husband	58	11	12.8	Y	Y
F3	26	Son and father	56	10	12	Y	N
F4	47	Wife and husband	49	12	6.3	Y	Y
F5	22	Daughter and father	58	15	13	Y	Y
F6	35	Wife and husband	39	8	12.6	Y	Y

F7	47	Wife and husband	49	10	11	Y	N
F8	55	Husband and wife	50	16	10.3	Y	Y

Y=Yes N= No

Thematic analysis

Six main themes and seventeen sub-themes (Table 3) resulted from data collection, including informal caregivers and t2dm patients, describing experiences in family-based intervention experiences for t2dm management. Both respondents showed efforts, perception, and conflicts that they had experienced during the t2dm treatment process and complications as experiences.

Table 3. Thematic analysis results

Themes	Subthemes	Example of respondent quotations
Mixed reaction to Insulin Injection	Stigma to insulin injection	*I feel that these insulin injections burden my ability to control daily glucose (F2: t2dm patient)* *Started with injectable medicine, probably forever will be injected (F6: informal caregivers)*
	Financial problem for insulin needle	*Hhrmm… in addition to buying insulin needles, I also need to purchase daily grocery items (F7: informal caregivers)* *I don't want to burden my family by buying insulin needles every month (F8: t2dm patient)*
Education Transformation	Education rejection	*I cannot receive information when I am tired and emotionally disturbed (F6: t2dm patient)*
	Time requirement	*I am too busy to accompany patients for health education sessions at the clinic (F3: informal caregivers)* *My condition is sick; I don't want to listen to this health session (F7: t2dm patient)*
	Variety of health information	*I often look for information on health blogs, but there are contradictions, and it does not fit the patient's condition (F5: informal caregivers)* *Sometimes, I feel that health information is not the same between health professions, such as the treatment of my leg wounds before and now (F4: t2dm patient)*
Self-Efficacy To Self-Care Behavior	Change of attitude towards problems	*Since the patient's leg was cut off (amputation), I am not sure and often feel guilty about past events (F7: informal caregivers)* *Not all health information I can receive at one time (F6: informal caregivers)*
	Action to support care	*I hope the health profession can take care of my father (F5: informal caregivers)*
Efforts In Family-Based T2dm Management	Emergency diabetes kit plan	*My children provide me with sweets if I feel low sugar in the body (hypoglycemic) (F5: t2dm patient)* *Previously, my father (the patient) was unconscious as a result of very low sugar in the body (hypoglycemic) (F5: informal caregivers)*

	Daily glucose monitoring	*I believe good glucose control can prevent complications from getting worse, but...I don't even know how (F3: informal caregivers)* *It's a bit strange if I check my glucose before eating at a restaurant (F4: t2dm patient)*
	Medication routine	*I often force the patient to take medicine and I expect the patient to understand (F6: informal caregivers)*
	HbA1c level understanding	*At least I know my normal daily glucose reading (F8: t2dm patient)* *It is written in the diabetes book (F1: informal caregivers)*
	Diet modification	*I am ashamed if my food is different from others (F6: t2dm patient)* *I often observe how to treat t2dm on patients to be practiced at home later (F5: informal caregivers)*
Treatment Needs	Motivation to change	*I know the patient has made a mistake, and I will try to change the patient's lifestyle after this (F1: informal caregivers)* *I don't want to burden my family, but I have been given a second chance to change (F4: t2dm patient)*
	Belief on hospital based intervention	*I did not attend the follow-up treatment clinic because I was afraid the finger would be amputated (F7: t2dm patient)* *My friends recommend traditional treatment first (F1: t2dm patient)* *I need a quick healing guarantee (F5: t2dm patient)*
	Face the challenge	*I often help patients with nail cutting, but I lack confidence because there are wounds on the patient's feet (F3: informal caregivers)*
Perception To T2dm Diagnosis	Family genetic	*This hereditary disease cannot be treated (F7: informal caregivers)* *I am worried that after me maybe my children will receive the same fate as me (F8: t2dm patient)*
	Adherence to Medication and Side Effect Prevention	*I'm not sure if I need to buy a glucometer to keep at home (F5: informal caregivers)* *It is difficult for me to take injection medicine during working hours, and the effect of the drug on me (F7: t2dm patient)*

Theme 1: Mixed Reaction to Insulin Injection

Stigma to Insulin Injection

Apart from complaints of pain reactions, confusion, poor injection skills, and medication side effects, the feeling of stigma towards the use of insulin injections has given a burden and rejection to the effective daily management of diabetes. Social stigma in t2dm treatment is a problem and a burden to the health profession to get better daily glucose and HbA1c readings among t2dm patients [34,35]. Meanwhile, the incorrect response from informal caregivers to insulin injection therapy has contributed to the failure of better t2dm management in their families.

'In the past, the doctor told me that this insulin injection was only temporary (Year: 2005), I did not want injection medicine and I made the choice to go to the

clinic to get my own tablet medicine. I'm afraid this injection medicine will be necessary forever' (F6: t2dm patient, 39-year-old, HbA1C = 12.6%)'.

'If the glucose reading is 7mmol/l, I don't inject, then the sugar will be low (hypoglycemic)... no need to inject, just eat as usual' (F6: informal caregiver, 35-year-old)'.

Informal caregivers also feel guilty and do not want conflict between them because of rejection from the patient himself. They prefer to follow the wishes of the patient rather than the complications that the patient himself will face in the future.

'My son often advises me to inject insulin... there's no need to tell me... I'll do it myself later' (F5: t2dm patient, 58-year-old, HbA1C = 13%)'.

'I don't want to force my father, I'm always scolded and my father says I'm still young and don't need to advise him...I think why argue about this little thing.' (F5: informal caregiver, 22-year-old)'.

On the other hand, there are still some who are not ready to accept this insulin injection treatment, and expect alternative treatment for their daily glucose control.

'Before starting this injectable medicine, the doctor did not get my consent to use an insulin pen' (F4: t2dm patient, 49-year-old, HbA1C = 6.3%)'.

'The doctor once told me at that time, to start insulin injections, the doctor did tell the husband (patient), but the husband refused' (F4: informal caregiver, 47-year-old)'.

Financial Problem for Insulin Needle

Financial problems are not something new in the issue of insulin needle purchases. In Malaysia, government hospitals only provide insulin pens for free, and the insulin pen needles must be purchased by the patient. The frequency of use over a long period makes them prefer to choose tablet medicine. Therefore, it is not surprising if the patient uses the needle repeatedly and causes pain, lipodystrophy [36,37], and the risk of infections such as staphylococcal epidermis occurs [38].

'I feel it's a waste to buy an insulin needle, I can get tablet medicine at the clinic for my wife (patient), the blood sugar reading remains under control' (F8: informal caregiver, 55-year-old)'.

'2 types of insulin pens given, and I have to buy twice as many insulin pen needles for frequent use' (F5: informal caregiver, 22-year-old)

'I usually use an insulin needle, one insulin needle for 3 days' (F2: t2dm patient, 58-year-old, HbA1C = 12.8%)'.

'I will change the needle if the husband (patient) complains of pain during the injection' (F2: informal caregiver, 56-year-old)'.

Figure 1 shows the insulin pen that was brought back when the patient was readmitted to the ward by the informal caregiver. The return of the insulin pen with the medicine in it clearly shows a refusal to inject insulin therapy.

Figure. 1. (a) (b) The returned insulin pen and the medicine in the pen are unused. Medicines are usually supplied for two weeks

Theme 2: Education Transformation

Education Rejection

Since the last pandemic, education methods have impacted changes in the education delivery system. However, the health education delivery system here has yet to be fully developed, and conventional methods are still the choice among health professionals for their patients.

'I am always exposed to t2dm health education whether at the clinic or social media. But after a complication, I hope the information delivered is more focused on

my condition and needs' (F1: t2dm patient, 58-year-old, HbA1C = 12.2%)'.

'I'm too tired taking care of patients in the ward, I can't receive any information at one time to practice when I'm at home later' (F7: informal caregiver, 47-year-old)'.

On a positive note, some informal caregivers appreciate the efforts of the health profession to provide health education, but the demand for innovation in education still needs to be developed in line with current technological advances.

'If possible, I need to get health information without going to the clinic such as daily notifications' (F3: informal caregiver, 26-year-old)'.

Time Requirement

Based on the complexity of daily diabetes self-care management that needs to be done, informal caregivers agree that the right time can form an understanding that is entirely related to what, how, and when daily diabetes self-care management in the family needs to be implemented.

'Even though my husband has been suffering from t2dm for a long time (8 years), I still do not understand why it is so difficult for my husband to control his blood sugar' (F6: informal caregiver, 35-year-old)

'Before I received health education advice at clinics and hospitals, with the age factor now, I quickly forget and need someone else to remind me' (F5: t2dm patient, 58-year-old, HbA1C = 13%)

'That's right...when I'm not there, the siblings have no guidance, just expect me to teach them over and over again' (F5: informal caregiver, 22-year-old)

Limited conventional health education (Figure 2) makes it difficult for t2dm patients to remember information; in addition, every piece of information received by t2dm patients cannot necessarily be fully conveyed to informal caregivers to be practised together at home after discharge from the hospital later

Figure. 2. Health pamphlets left after receiving health education before discharge from hospital

Variety of Health Information

Various health information sources, media influence, and surrounding individuals make them want to try. In addition, informal caregivers who want to take care of other family members by accepting views and opinions about medicine. Besides that, there are individuals around who take advantage of selling medicines that are promised to be effective.

'I used to buy traditional medicine from my aunt, I used to believe because family members would help' (F3: informal caregiver, 26-year-old)

'Sometimes I feel like wasting money getting treatment that is not commensurate with the results' (F1: t2dm patient, 58-year-old, HbA1C = 12.2%)

'I still remember, because we were late to decide on treatment, from 1 finger to 2 fingers turning black' (F5: informal caregiver, 22-year-old)

Difficulty with informal caregiver and t2dm patient making decisions and choosing treatment causes the delay of treatment intensification in t2dm on the patient.

Theme 3: Self-Efficacy to Self-Care Behaviour

Change of Attitude Towards Problems

Some things are difficult for the informal caregiver to change compared to the t2dm patient, such as the need for more confidence to influence the t2dm patient.

Recurring conflicts and complications have shown that the level of acceptance of previous t2dm treatment needs to be remembered and addressed (Figure 3).

'Outside individuals do not understand, it is difficult to take care of a t2dm patient, since the patient's leg was amputated (Figure 3), I am not confident and have a feeling of being blamed' (F7: informal caregiver, 47-year-old)

'Patients should be more responsible for their own health, I just help' (F2: informal caregiver, 56-year-old)

'It's not that I'm not responsible to myself, I want to be healthy just like everyone else' (F2: t2dm patient, 58-year-old, HbA1C = 12.8%)

Figure 3. Recurring complications for t2dm patients, where the history of surgery is ray amputation of the right leg, and most recently below the knee amputation of the left leg.

Action to Support Care

However, informal caregivers and t2dm patients work hand in hand and understand the importance of daily diabetes self-care management in the family, which is done through action rather than thinking about existing problems.

'I believe that a problem can be avoided by cooperating with the father (patient), this is also for the common good, because there is no need to face more problems in the future' (F3: informal caregiver, 26-year-old)

'Maybe I need to follow my son's advice so as not to burden him anymore' (F3: t2dm patient, 56-year-old, HbA1C = 12%)

'I often remind my father (the patient) to control his diet and help inject insulin before going to work' (F3: informal caregiver, 26-year-old)

Theme 4: Efforts in Family-Based T2dm Management

Emergency Diabetes Kit Plan

The availability of families and patients facing T2DM complications is deficient among respondents, primarily related to iatrogenic acute metabolic complications such as hypoglycemia [39-42] and not many provide 'sweet' as a diabetes kit when away from home or working outside the area. This situation has implications for the health system to develop more focused interventions.

'Since the incident where my father (patient) was almost unconscious, the effect of low sugar in the body (hypoglycemic), I learned to bring a sugar (Fig 4) wherever the patient goes' (F5: informal caregiver, 22-year- old)

'I always ask my wife to prepare sugar or sweet drinks' (F1: t2dm patient, 58-year-old, HbA1C = 12.2%)

Fig. 4. Sugar has become the choice of t2dm patients as a diabetes kit, easy to find and can be stored longer

Daily Glucose Monitoring

It is a failure of the majority of family respondents and t2dm patients who have repeatedly experienced complications to perform daily glucose monitoring activities. They often state that every food and drink taken is under control. They believe every food labelled 'non-added sugar' is safe to consume. But, they made a mistake by not looking back at this patient's glucose reading. This situation is known as stigmatization by self-good glycemic control.

'I work, it's a bit strange if I check my glucose before eating when I'm in a restaurant, I'll be made fun of by my friends' (F7: t2dm patient, 49-year-old, HbA1C = 11%)

'The health department has provided a glucose check service every time I go to the clinic, I don't need to buy a glucometer machine for myself' (F8: t2dm patient, 50-year-old, HbA1C = 10.3%)

'I don't take this matter so seriously because the patient can feel the feeling of low sugar (hypoglycemic), like blurry eyes and trembling hands... I don't have to worry' (F7: informal caregiver, 47-year-old)

'I believe every product labeled without added sugar was safe for patients to take.' (F5: informal caregiver, 22-year-old)

Medication Routine

Some families of respondents comply with taking medicine among t2dm patients, but anti-diabetic medicine requires glucose testing before taking medicine, especially insulin injections. Some families use coercion and threats to ensure that the patient takes the medicine at the right time and in the right way. In addition, no less common understanding between them failed to be formed to obtain medication management and a more systematic glucose check.

'I often force the patient to take medicine and I expect the patient to understand why I have to do that' (F6: informal caregiver, 35-year-old)

'In the beginning, I always advised the father (patient), sometimes I forced, I also felt tired ... I feel patient does not understand what I want from him' (F3: informal caregiver, 26-year-old)

HbA1c Level Understanding

Health education focuses more on routine daily glucose checks, and most families need to learn about the function of HbA1c. HbA1c is considered a biomarker for hyperglycemia, which is the risk of pre-diabetes among at-risk families, in addition to reflecting the practice of the past 2 to 3 months [32,42,43].

'It's written in the green book (diabetes examination book)' (F1: informal caregiver, 54-year-old)

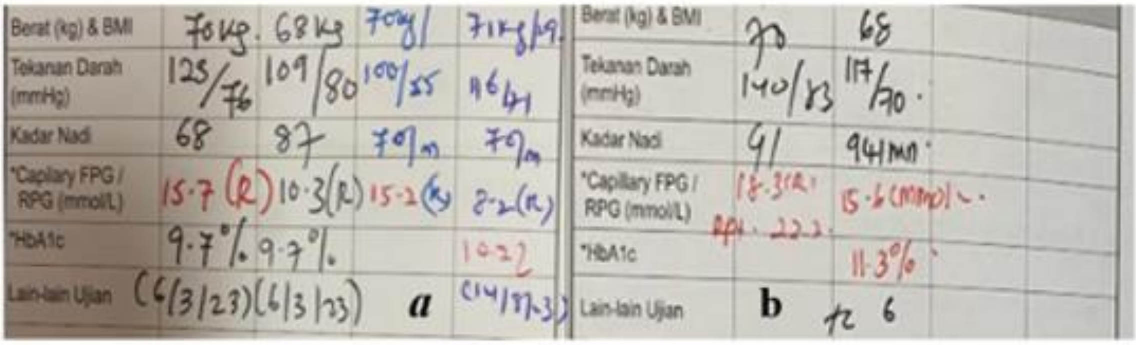
'Ooooo...I don't even know, usually, only daily sugar checks are emphasized' (F1: t2dm patient, 58-year-old, HbA1C = 12.2%)

For families at risk, it is necessary to undergo this examination regularly as an early preventive measure.

'I also thought about doing an examination, but I was afraid, I was afraid of becoming like my father (patient)' (F5: informal caregiver, 22-year-old)

'hhrmm...do I need to do a diabetes check? In that case, my siblings also need to be examined as well, besides my father (patient), my mother also has diabetes' (F3: informal caregiver, 26-year-old)

Figure 5 shows the follow-up treatment record book among t2dm patients. Shows HbA1c reading > 6.5%.



Berat (kg) & BMI	70kg.	68kg	70kg/	71kg/kg
Tekanan Darah (mmHg)	125/76	109/80	100/55	96/61
Kadar Nadi	68	87	79/m	79/m
*Capilary FPG / RPG (mmol/L)	15.7 (R)	10.3(R)	15.2(R)	8.2(R)
*HbA1c	9.7%	9.7%		10.2
Lain-lain Ujian	(6/3/23)	(6/3/23)		(14/11-3)

Berat (kg) & BMI	70	68
Tekanan Darah (mmHg)	140/83	117/70.
Kadar Nadi	91	94/mn
*Capillary FPG / RPG (mmol/L)	18.3(R) RPG. 22.2.	15.6 (mmol/L).
*HbA1c		11.3%
Lain-lain Ujian	12	6

Figure. 5. (a) (b) A t2dm treatment book where there is a variety of normal and abnormal reading information that informal caregivers and t2dm patients need to know

Dietary Modifications

The understanding of dietary modifications among respondents, which is a change to the style of daily food intake as the first step that needs to be focused on, such as drink intake is changed to the level of sweetness scale, types of food that have a lower glycemic index such as whole meal bread and cereal biscuits become the choice of t2dm patients.

'I knew about this bread for diabetes during health education at the clinic, when in treatment I still practice nutritious food' (F4: t2dm patient, 49-year-old, HbA1C = 6.3%)

'If my husband eats this bread at home, I will make sure my husband does not take bread or biscuits that are too sweet' (F4: informal caregiver, 47-year-old)

Figure. 6. Whole meal bread is the choice among informal caregivers and t2dm patients

Conversely, for t2dm patient dietary modifications give a feeling of food isolation among their family and social friends.

'I'm embarrassed if my food is different from other people's, especially when celebrating a party' (F6: t2dm patient, 39-year-old, HbA1C = 12.6%)

'That's it... sometimes I feel sorry too... but that's for my husband's daily glucose control too' (F6: informal caregiver, 35-year-old)

'If I eat at a shop with friends, they always make fun of me, forbid me to eat sweets and my legs will be cut off or tell me that I have diabetes in front of other people' (F5: t2dm patient, 58-year-old, HbA1C = 13%)

There are also families and t2dm patients learning through reflection related to diet modification about taste, quantity, and the effect of food intake on glucose readings. (Figure 7).

'If I'm at home, I'll try to cook what it tastes like in the hospital, I've tasted the patient's food when my husband (patient) was admitted to the ward before' (F2: informal caregiver, 56-year-old)

Figure 7. (a) (b) Between the quantity and quality of food provided to t2dm patients while in hospital to ensure optimal glucose control

Theme 5: Treatment Needs

Motivation to Change

To prevent disease complications from recurrence and frequent readmissions to the hospital, adherence to behavioral changes is important. The importance of maintaining a more stable and longer-term lifestyle begins with the motivation to change.

‘After 2 surgeries, I'm determined to change, I'm sad to see my wife's condition is so burdened. I have been given a second chance to change’ (F4: t2dm patient, 49-year-old, HbA1C = 6.3%)

‘I believe, the patient cannot do it alone...health is indeed his responsibility, but as a family, I need to help the patient to change so that he does not become a burden on the family even worse’ (F1: informal caregiver, 54-year-old)

Motivation has been identified as a factor to change and has had an impact on their family harmony [44]

Belief On Hospital Based Intervention

In managing increasingly complicated complications, caregivers expect treating t2dm patients to have a more significant impact. This is because every intervention the health profession delivers is a belief, alertness, and change to their mindset.

‘If I have surgery, will I not have surgery a second time? I need a guarantee of a quick recovery to take care of my family’ (F5: t2dm patient, 58-year-old, HbA1C = 13%)

The lack of trust in hospital-based care makes t2dm patients look for alternative treatment, and informal caregivers are not willing to see the loss of limbs among their families.

‘Apart from the doctor wanting to amputate my finger, hospital treatment does not guarantee a cure in treating me. My friends recommend traditional treatment first, because many have been cured’ (F1: t2dm patient, 58-year-old, HbA1C = 12.2%)

‘Even as a wife, if for surgery I also need to ask my children's opinion’ (F1: informal caregiver, 54-year-old)

Figure 8 shows a counselling session with specialist doctors for t2dm patients and informal caregivers. Counselling sessions will be conducted if t2dm high-risk patients refuse to undergo treatment. Mutual agreement is essential to ensuring that continuity in the treatment process is effective.

‘I don't want to force my husband (patient), if that's his choice, I'll just go along with it. I don't want to be blamed by the children later if anything happens later if the surgery fails’ (F2: informal caregiver, 56-year-old)

'My children tell me that if the wife (patient) leg is amputated, it becomes harder for the wife to move...the children

plan to get other treatment for their mother first' (F8: informal caregiver, 55-year-old)

Figure 8. T2dm patient is undergoing a counseling session by a specialist doctor about the pros and cons of not having surgery

Face the Challenge

Informal caregivers and t2dm patients believe that every treatment process and after treatment is a challenge to maintaining a healthy lifestyle. They must be prepared to translate confidence into action and knowledge into practice.

'I can't imagine how scared it was to see my father's wound before, I have to take my father to the health clinic every day to do dressing' (F3: informal caregiver, 26-year-old)

'The situation I am most afraid of is my husband experiencing symptoms of low blood sugar (hypoglycemic), he may faint and lose consciousness. I have experienced when giving medicine without checking sugar first' (F7: informal caregiver, 47-year-old)

However, the burden and challenge of treatment is increasing when the t2dm patient puts the burden and challenge only on the shoulder of the informal caregiver to do daily diabetes self-care management activities.

'I'm old, if my blood sugar goes from low to high (hypoglycemic and hyperglycemic) I can't do anything, my son is there to help' (F5: t2dm patient, 58-year-old, HbA1C = 13%)

'I like to eat food at wedding parties, there are many options' (F8: t2dm patient, 50-year-old, HbA1C = 10.3%)

'The food at the restaurant is tastier than the food cooked by my wife' (F2: t2dm patient, 58-year-old, HbA1C = 12.8%)

Theme 6: Perception to T2dm Diagnosis Family Genetic

Belief in genetic diabetes inherited by the family is very high and this situation is known as 'multigenerational legacy of diabetes'. This situation has disturbed psychological thinking on the ability, knowledge, and confidence to do daily diabetes self-care management activities in their families [45,46]

'My mother-in-law also died because of T2DM, 2 out of 7 siblings have T2DM. This hereditary disease is really difficult to treat' (F7: informal caregiver, 47-year-old)

'I worry that I will inherit this disease (t2dm) when I get older' (F3: informal caregiver, 26-year-old)

'I'm still young, maybe when I'm old I'll suffer from t2dm' (F5: informal caregiver, 22-year-old)

Apart from giving worry to the informal caregiver as a member of the patient's family, the patient also expresses concern about the future of their family about the risk to t2dm in the future.

'I'm worried that after me maybe my children will receive the same fate as me, as a mother I don't want them to have the same fate as me' (F8: t2dm patient, 50-year-old, HbA1C = 10.3%)

Apart from feeling anxious, t2dm patients also try to practice healthy eating in their family.

'I believe this T2DM disease can be inherited, to reduce the worry, I often cook healthy food at home that can be eaten with my husband and other family members' (F1: informal caregiver, 54-year-old)

Adherence to Medication and Side Effect Prevention

Each disease diagnosis will require a medication regimen that requires compliance. However, compliance was not taken as full responsibility because the side effects of the medicine and the situation experienced are difficult for them to tell and describe to the health profession.

'I am confused and afraid that if I take medicine it will cause dizziness and blurred vision, maybe I can reduce the dose of medicine, I usually do it myself without a doctor's prescription' (F6: t2dm patient, 39-year-old, HbA1C = 12.6%)

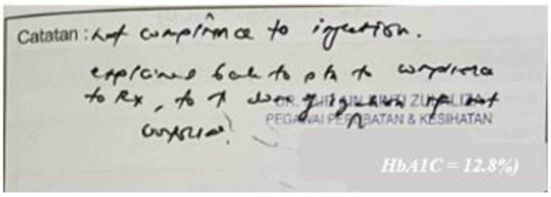
'My husband (patient) often feels sleepy after taking medicine, I think it's a side effect of the medicine, maybe my husband needs to rest' (F7: informal caregiver, 47-year-old)

Lack of knowledge on side effect prevention after taking medicine, t2dm has changed the medicine dose without knowing the exact glucose reading.

'The nurse always advises me to buy a glucometer machine, to make it easier to check when I'm at home, but my wife is not convinced to check my glucose' (F2: t2dm patient, 58-year-old, HbA1C = 12.8%)

'When it comes to medicine, I leave it to my husband (patient), I don't want to fight' (F7: informal caregiver, 47-year-old)

Figure 9 shows the health record book of the respondent t2dm patient, where adherence to medication management is low, with an HbA1C reading of 12.8%. Here, it clearly shows the fear and poor management related to side effects contributing to drug rejection factors in the daily glucose stability of t2dm patients.



Catatan : not compliance to injection.
[illegible]
[illegible]
[illegible]

PEGAWAI PERUBATAN & KESIHATAN

HbA1C = 12.8%)

Figure 9. Health reports show a very low level of adherence to medication intake, the main factor for good glucose and HbA1C control.

DISCUSSION

The main objective of this study was to use the PEI method to explore family-based intervention experiences among informal caregivers and t2dm patients in the same family.

To the best of the researcher's knowledge, this method was the first qualitative study involving a combination of PEI and semi-structured interviews to provide a new window for informal caregivers and t2dm patients to carry out daily diabetes self-care management activities in Malaysia. There are three main aspects that are very important to point out here.

First, the PEI method has provided a clear picture of health outcomes and actions from informal caregivers and t2dm patients in doing their daily diabetes self-care management activities. Through this method, they can provide a reflection of what they have done to be corrected in line with the health profession's views and health education services. Some respondents agreed to take photos, five informal caregivers refused to get involved in this study, and t2dm patients accepted it positively.

Second, the themes and subthemes formed are positive for preparing and developing web-based modules for the next study phase. Researchers have taken into account individual perspectives [47], basic needs from cultural aspects and the need to develop diabetes health education service facilities [48,49], and voices from those who expect changes for the next generation, especially for their family members. Systematic reviews have also documented that several factors must be considered when planning treatment to assess needs and priorities. This aims to provide a more optimal impact for each care between informal caregivers and t2dm patients and health professions to informal caregivers and t2dm patients [50].

The last point is the necessity of awareness of responsibility to form a coping mechanism that still needs to exist in informal caregivers and t2dm patients. Based on the themes and subthemes formed from the data transcripts, the practice of the five primary activities of daily diabetes self-care management is deficient, especially the changes to dietary modifications that are often discussed throughout this study. Dietary modifications are the main problem for more effective glucose control [51-53].

As this study is exploratory, these meaningful findings cannot be generalized. Therefore, quantitative studies must be conducted to create real effects, such as by constructing modules or intervention programs. For researchers, the results of this study will be extended to phase 2 of web module development and phase 3 of quantitative research

CONCLUSION

From the perspective of previous studies, it has been demanded that we explore more deeply what, who, where, and how problems in the health sector need to be eradicated profoundly and widely. One of them is further research on developing interventions to achieve collaboration and the goals of various parties. From the methodological perspective of this study, it can be used as a guide for other researchers to continue developing their studies using innovative and original data collection techniques to express experiences, beliefs, images, actions, roles, behaviors, and practices among informal caregivers and t2dm patients in daily diabetes self-care management.

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