

QUALITATIVE INSIGHTS FROM TYPE 2 DIABETES PATIENTS AND THE NEED FOR ESTABLISHMENT OF NURSE LED DIABETES CLINICS

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ABSTRACT

Diabetes is a complex progressive disease, and its treatment requires effective self-management strategies unique to each individual. The aim of the study was to explore the issues and challenges of patients living with type 2 diabetes. A Mixed method research approach was adopted to conduct the study in a tertiary care hospital. Convenient and voluntary participants were selected for the interview. The content was analyzed using Colaizzi's method of data analysis. Content analysis focused on five main themes. The transcribed data was divided into sub themes. Common issues and challenges faced by type 2 diabetes patients were identified. The identified issues of the individuals need to be channelized in effective patient education system and community nurse led clinics have to/ MUST be established to address the common problems faced by type 2 diabetes patients and reduce the hospital burden.

INTRODUCTION

Diabetes mellitus is non-communicable, chronic disease that can lead to serious complications and even premature death. The Global estimate showed that 465 million patients are suffering from diabetes in the world.¹ And in India is about 77million in the year2019 Diabetes mellitus is known to influence the patient's physical, social and psychological well -being .Poor diet, lack of physical activity, and poor self-monitoring of glucose levels are some of the most common issues faced by diabetic patients.²Better glycemic control can progressively prevent or delay complications and improve health status of the patients, on the other hand lack of attention, insufficient time to provide patient specific education and overcrowding opinions and advices by multidisciplinary health institutions creates a dilemma in patients to make choice of treatment best suitable for them.² A closer understanding of the diabetes mellitus patient's specific obstacles will provide a greater clarity of factors influencing their disease related health status and coping with daily life.²

Based on the previous study findings, many obstacles are reported by diabetes patients attending out-patient departments such as poor knowledge about the disease, poor relationship with health professional, lack of support from their friends, feeling lonely with their disease, non- availability of professional care team. This suggests that these are main obstacles faced by diabetes patients.

OBJECTIVES:

- i) To explore diabetes management experience, specifically the healthy lifestyle needs of diabetes patients and

- ii) To identify the challenges and barriers in managing glycemic control.

METHODS AND MATERIALS

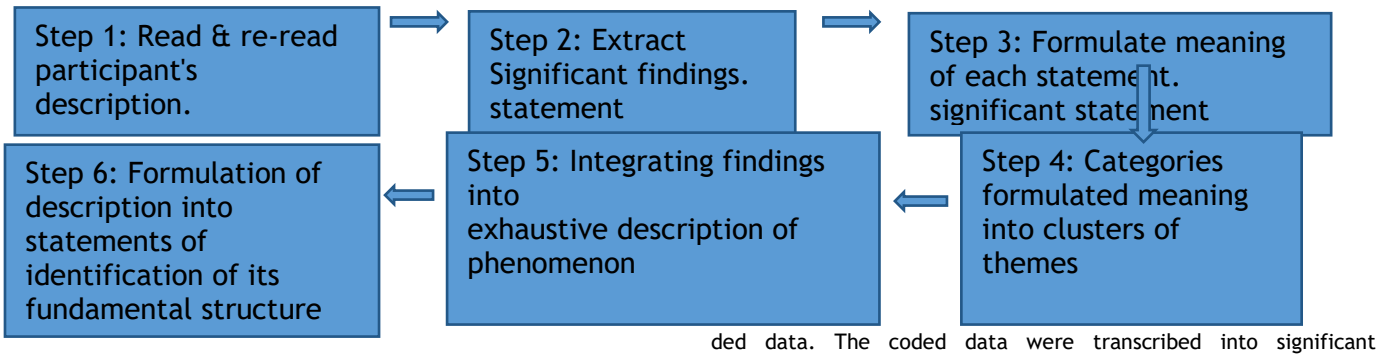
A Qualitative research design used in the study. Phenomenological approach adopted for this study was utilized to explore the diabetes self care management lived experience, semi structured interviews were conducted using a flexible semi structured guide with an open ended questioning approach in out-patient departments of Government hospital. In this study type 2 diabetes population was sampled by non-probability convenience sampling techniques.

The Inclusion criteria: Patients visiting OPD of Government hospital and diagnosed with type II Diabetes for more than 1 year and aged more than 25 years, willing to participate in the study in the OPD area by an audio recorded interview.

The Exclusion criteria: Those who affected with other diseases like Type 1diabetes, Gestational diabetes, Cognitive impairment (dementia) are excluded from the study.

Face to face interviews were conducted until thematic saturation was reached. The questionnaire consisted of total 30 questions. The main domains were on stress, coping, problem solving, diabetes knowledge, lifestyle intervention, healthy eating/ DD, and physical activities. There were open ended questions which encouraged participants to answer and any other topics which they would like to share about diabetes and question for patients with controlled and uncontrolled diabetes as per the review of case record of the patients were also explored.

Fig.1 The steps of Colaizzi's methods of Data Analysis



ded data. The coded data were transcribed into significant

Age (in Years)	
a. Less than 25 years	0
b. 25-35 years	11
c. 35-45 years	7
d. More than 45 years	7
Gender	
a. Male	3
b. Female	22
Married Status	
a. Single	0
b. Married	25
c. Living as Married	0
d. Separated	0
e. Divorced	0
f. Widowed	0
Education	
a. None at all	1
b. Elementary School	10
c. High School	6
d. College	3
e. Graduate/ Professional Degree	5
Employment status	
a. Employed	20
b. Unemployed	5
Health insurance	
a. Yes	2
b. No	23
Duration of Diabetes	
a. 1-5 Years	21
b. 6-10 years	3
c. 10-15 Years	0
d. More than 15 years	1

The researcher used Colaizzi's method of data analysis. The steps of the method includes: transcribing all the subjects descriptions by reading and rereading, extracting the significant statements, formulating the meanings, clustering into sub-themes and the main themes, developing an exhaustive description, producing the fundamental structure and seeking verification of the fundamental structure. All interviewed data was audio recorded with permission.23 participants participated in the study.Data were coded with help of two researchers who confirmed the statements and verif

statements and meanings were derived and categorized into themes.

RESULTS:

TABLE 1 DEMOGRAPHIC CHARACTERISTIC OF PARTICIPANTS

The study was conducted on 25 participants. The above table shows that maximum 11 participants were from the age group of (25-35)years, and7 participants age group was(35-45)years, the rest 7 participants were of(more than 45)years. Maximum participants were female (22) and the others were male (3). All

participants were married. Most of the participants studied till elementary school (10), 3 were graduates and 5 were Professional graduates. Mostly participants were employed (20) and remaining was unemployed. Only few participants had health insurance (2) and remaining had no health insurance. Maximum participants had diabetes for 1-5 years (21) and only 1 participant was diagnosed for more than 1 year.

THEMES

1. Adequate knowledge

Themes about perceived barriers to fulfillment of home care needs and maintaining behavior for management of type 2 diabetes at home emerged: "Insufficient information about diabetes", "Inability to accept diabetes", "Non-adherence to diet and exercise", and "Problems related to health care services", "Fear" and "Familial and social effects".

A. Knowledge deficit and symptoms experience

This theme included Subthemes.

Sub themes

The participant commented that they are aware about sign and symptoms of diabetes as they do regularly visit doctor and their family also supports them.

- Knowledge of symptoms
- Experience - All Patients Mother Tongue Was English, If Yes - Ok, And If Not Write The Wording In English Of Vernacular
- Management

Significant Statements

The participants admitted that they did not have sufficient information about Diabetes, but they have shared their experience such as:

- *When my frequency of urination is too much in a day.* "P.20,F"
- *I can feel my sugar level is high.* "P.18.30yrs, F"
- *I keep sweet in the bag in case I am tired as I can have.* "P.21.26yrs, F"

B. Lifestyle challenges and management

This theme included Subthemes.

Sub themes

Some of participants are worried as they know that diabetes is for life long and they have to control their eating habits and need to be physically fit and active.

- Lifelong management of DM."P.21, 26yrs, F"
- Controlling diet and exercise."P.2,30yrs, F"
- Weight reduction."P.21, 26yrs, F"

Significant Statements

The participants reported that they had problem in adjusting with diet and some had issues regarding health and weight as they were working people.

- "I am working; I do not know how will I carry forward but I try to manage with time". "P.9. 45yrs, M"
- I cannot eat what I want and have to give up sweets."P.5,35yrs, F"
- I have to give more time for exercise."P.2,30yrs, F"
- People comment on my weight and judge me wrongly. Looks like I am unable to reduce my weight "P.21, 26yrs, F"

2. Attention to self care management

A. Healthy eating habits

This theme included Subthemes

Sub themes

Some participant reported that they had problems related to access to health care services for diabetes resulting from either themselves or health care organizations, they also have problems related to fulfilling their practices on diabetes management, particularly dieting and exercise.

- *Healthy food choices to control DM.* "P.2, 30yrs,F"
- *Healthy ways of food preparation.* "P.21. 26yrs,F"
- *Diet and food limitations to remain healthy.* "P.21, 26yrs,F"
- *Cannot follow diet pattern.* "P.2, 30 yrs, F"
- *No control of diet.* "P.1,37 yrs, F"

- *Attitude towards healthy eating.* "P.21.26yrs,F"
- *Help to control the diet.* "P.21, 26yrs,F"
- *Health seeker.* P.21, 26yrs,F"
- *Fears of healthy eating.* "P.1,37 yrs. F"

Significant Statements

The participants admitted that they did not have sufficient information about measurement of blood concentration, but they reported that diabetes had negative effects on their daily life and habits and now they are trying to change their diet and lifestyle.

- *I have learnt to eat bitter gourd at least once a week.* "P.2,30 yrs, F"
- *I use less oil and sugar in food preparation.* "P.12,37yrs,F"
- *I restrict rice and sugar in the diet.* "P.1,37yrs.F"
- *I get tempted by looking at others in the family enjoying tasty food but I control.* "P.7,45yrs,F"
- *I eat junk food sometimes doesn't matter I say.* "P.4,47yrs,F"
- *I crave for sweets.* "P.13,35yrs,F"
- *I eat whatever I feel before I visit the doctor thinking tomorrow I will be treated by doctor.* "P.7,45 yrs. F"
- *I made up my mind because of my child to eat healthy diet.* "P.1.37yrs.F:"
- *Once I was admitted, I don't like to be in the hospital so I follow proper diet.* "P.3.39 yrs. F"

B. Being Active

This theme included Subthemes

Sub themes

Some participant reported that they are being doing regular checkups and consulting doctor as and when required, give time for exercise and yoga in their schedule. But at same time they want their leisure time so on weekend they don't do any excise.

- *Agree to be active*
- *Importance of exercise*
- *"I can't do without work it's a must Sunday I relax it is part of my life".* "P.3,39yrs,F"

Significant Statements

According to some participants, they made changes in their medications and did not take medications regularly or in the way recommend by their doctors due to their side effects. Some commented that they accepted their daily activities as a kind of exercise.

- *As per doctors advice I do the walk.* "P.3,39yrs,F"
- *I walk to reduce my weight I know my diabetes gets worse if I don't.* "P.21.26yrs,F"
- *I exercise very little because I get tired.* "P.3,39yrs,F"
- *I walk only if I get company to walk.* "P.3,39yrs,F"
- *Walking is important but instead I do all the household work and keep myself busy.* "P.3,39yrs,F"

3. Adequate facilities and support

A. Support system & health care professionals (No nurse is mentioned anywhere)

This theme included Subthemes.

Sub themes

Some participants reported that financial and work life related factors were barriers to fulfilling their practices of diabetes management, some participant also discussed that they were affected by attitudes of family members and poor health behaviour of people around them, friends and family.

- *Support is important.* "P.5.25 yrs ,F"
- *Family and friend health care professional.* "P.17,54yrs,F"
- *Help from support system.* "P.21.26yrs,F"
- *Family attitude and support.* "P.21.26yrs,F"

Significant Statements

Some participant reported that they have friends/family support to overcome from diabetes, on the other hand, there are some participants who responded that, they stay alone as they have no one to take care of the mind getting bored in adjusting with diet and health.

- *Support and help is required very much or else it is mental pressure and sometimes uneasy feelings.*"P.21.26yrs,F"
- *My mother is my close friend and doctors also take care.*"P.21.26yrs,F"
- *I have no one to help as I stay alone and no one can tell me or advise me.*"P.18.30yrs,F"
- *All encourage healthy food for me to control BSL.*"P.21.26yrs,F"
- *My family sacrifices a lot to have the same food with me and reminds me as I am forgetful about my care.*"P.19.30yrs,F"

4. Adjustment to barriers

A. Social Stigma

B. This theme included four Subthemes

Sub themes

Participants are mostly comfortable to express their signs and symptoms to family, friend and doctor. As they all guide them and motivate them.

- Toward Family
- Doctors
- Friends

Significant Statements

Some male participants reported that sexual problem arising after they had diabetes had a negative effect on their acceptance of the disease. And some participants do not have friends to discuss their issues related disease.

- *I cannot share my sexual problems to my family even to my mother.*"P.8,29yrs,M"
- *I don't discuss with my friends I don't want them to know also.*"P.8,29yrs,M"
- *I don't have friends.*"P.18,30yrs,F"

C. Cultural influence in self care (Lack of culturally relevant knowledge)

This theme included Subthemes

Sub themes

In India we have diverse culture in which we have to perform many rituals, and part of that are fasting and feast.

- Feasting
- Fasting

Significant Statements

The participants resorted to use traditional methods due to side-effects of their medications.

- *"I have weekend functions, feasts on Sundays, birthday parties and late nights after my food timing and to add to eat I have alcohol that's my culture"*"P.20.F"& "P.10.55yrs,M"
- *I have to do fasting on my rituals that time I know I have problems I can't avoid it and it affects me.*"P.21,26yrs, F"

D. Adjustments This theme included Three Subthemes

Sub themes

Some participants said that they are depressed and their primary care provider helps and guides them.

- *Effects of self and overcome depression.*"P.21.26yrs,F"
- *Overcome depression.*"P.21.26yrs,F"
- *Primary care provider.*"P.16,F"

Significant Statements

Some participant reported that they have mood swings and then prefer to have alcohol to overcome that, some participants believe that they divert their mind by spending their time with family and friends and some think that everything is in God's hand.

- *"I don't mind but I overcome with a couple of beers"*"P.10.55yrs,M"
- *I let it go by outings and destructions.*"P.5,35yrs,F"
- *I leave it to God he will take care of me.*"P.5,35yrs,F"
- *My husband is great strength for me to carry forward doctor's advice.*"P.16,F"

E. Appointments for self care behaviours

This theme include Three Subthemes

Sub themes

Some participants believe that they have issue in meeting the health professional for follow-up.

- *Regular check up*
- *Irregular check up*
- *Problems in meeting health professional and expressing problem*

Significant Statements

Most of the participants reported that they are conscious about health and visit doctor regularly according to their appointments and some participants reported that huge queue and rush at OPD's and hence either they don't get chance to meet their desired doctor and sometimes they have to go home without meeting doctors.

- *Every month I have been asked to come and I come.*"P.3,39yrs,F"
- *If I am well I visit after 6 months or even sometimes when I am not well or one year.*"P.12,35yrs,F"
- *I am late then I have to return home and my treatment is delayed.*"P.17,54yrs,F"
- *I have to wait in a big queue and rush is too much because too many people suffer diabetes especially after occasion one cannot enter the OPD's it's a headache to meet doctors.*"P.17,54yrs,F"

5. Acceptance to lifelong diseases and new lifestyle

A. Acceptance of new lifestyle

This theme included two Subthemes

Sub themes

Some participants have taken diabetes as a challenge and they want to overcome their disease

- *Positive attitude*
- *Negative attitude*

Significant Statements

Participants stated that they have craving for sweets and junk food. So they have to compromise on it. They know it's related for their health so they sad as well happy.

- *I do exercise regularly.*"P.12.35yrs,F"
- *I am 50% sad and 50% happy.*"P.12.35yrs,F"

B. Living with diabetes

This theme included Three Subthemes

Sub themes

Participants stated that life is very difficult with diabetes but after taking precaution and exercise it can controlled. And they have to adjust with diabetes and have to take proper medication and guidance by doctor.

- *Living healthy lifestyle.*"P.14.53yrs,F"
- *Living with life threatening risks, prone for complications or living with fears of life of complications.*"P.12.35yrs, F"

Significant Statements

Some participants said that they do not want to express their suffering to family as they will be worried about their health and on other hand some participants with help of family and friends they are trying to live normally with controlled DM .

- *Living with diabetes is like living life without sugar*"P.12.35yrs, F"
- *Complications like non healing wounds, hyperglycaemia are life threatening. I live with fears its difficult feeling and I cannot show family my sufferings.*"P.7,45yrs, F"

DISCUSSION

Controlling diabetes is a global need where the patient's suffering is increasingly rising. The current research focused on the difficulties among the type 2 diabetes. The study reveals various issues and challenges and expressed lived experience among the respondent the difficulties of the self care management includes procrastination to seek medical advice as it is perceived to be normal to time with diabetes. Adhering to a healthy lifestyle is a major obstacle.³ Counselling by health professional, support from family difficulty in medication identification, glucose meter handling, transportation from the peripheral and rural areas for consultation, were the

difficulties experienced are shared by the respondents. This current study focused on the difficulties in type 2 diabetes, patients and revealed the lived experience and derived five emergent themes from cluster of themes.

1. **Adequate Knowledge Deficit:** This theme had significant meaning from the respondent's statement and 3 clustered themes were formed. i) Knowledge of the disease, ii) the symptoms experience and iii) its management. In this study it was observed that the participant had idea of what is happening to them. Most of them expressed the same experience but the problem of frequent urination is expressed repeatedly. Some understand that their glucose level are high so, the urination is frequent but they keep seeking medical advice to reduce their symptoms which means that their pathological changes happening to them has to be focused and symptom reduction can be achieved only by controlling blood sugar level needs to be emphasized. Managing symptoms is also expressed by few participants. The participants do not understand its pathological changes. Newly diagnosed patients with diabetes can understand their disease; priority should be given to elimination of barriers to their education. Cues to action should be increased to improve effectiveness of the education programs.⁷

2. **Attention To self care management (Inadequate self care management)**

The theme had two sub themes: Healthy eating habits and being active .There are several studies pointing out that the patient cannot control their eating behavior.⁸

Overtime, as the patients are diagnosed they learn to control unhealthy dietary habit but it has been reported as a barrier to make dietary changes.⁹

Sugar craving is expressed mostly in all diabetic patients. A similar experience is shared by many participants.³ An alternative clue is not given to the patients and hence it is noted that there is no clue of action suggestive to patient. But patients who are self conscious about diet persistently try different remedies beneficial to their health and healthy eating. Constant reminder helps to make healthy calories choice, reading labels, and calories count can make a difference in ones choices. In the present study one participant shared that "I made up mind because of my child". Strong mind set is required.

Being active: All patients are aware that walking is important but finding excuses not to do has been seen equally, specially it is observed in females, who said that, 'household work is similar to being active', 'it's raining cannot exercise' is another complain.

Recommendations for walking are at least 30 minutes activity, but excuses are many shared in the study.⁶

Positive Outlook shared by patients should be encouraged in this study. One patient expressed that 'I can't do without walk it's a must, Sunday I may relax, it's a part of my life, then I can eat whatever I like.'

Apart from this, 2 components of self care management diabetic education should focus on foot care, regular eye screening and prevention of long-term complications in the kidney, nervous system and cardiovascular system.

3. **Adequate support system and facilities:** most of the participants agree and appreciated that the support is important for their care and it's given my family member, spouse, friends which is required.⁶ It was noted that there was no role of a nurses, dietitian shared by the patients which means doctor's advice the treatment and preventive measures and are burden. The primary care provider is the doctor for the patient, but issues of appointments and irregulating still persists. Hence the diabetic educator's role should be emphasized to reduce the burden (systematic review study)

4. **The facilities for diabetic patients are provided free of cost as reported by patients in government hospital.** The problem arises only when there are shortages of drugs, the patient's visits and transportation facilities become inadequate.

After being diagnosed, diabetic patients share that it affects not only self but the whole family gets affected because the food is common in the family, family has to alter the food preparation or separately cook is expressed by the one of the participant. Some patients do not want others or family members to know about the diabetic status specially sexual dysfunction, itching, elevated blood sugar are keep hiding or avoiding social gathering because of frequent urination they prefer to stay alone or at home. Emotional responses are similar to grief.^[13,14] Participants expressed mood changes and the adjustment by letting it go, distractions, one expressed by drinking alcohol as a cultural influence.

The recommendation suggested are individualize plan has to be tailored to the different patient, as the challenges of the individual varied in this study.

5. **Acceptance of diseases and living with diabetes**

These were 2 sub theme positive and negative patients indicate that advise are not easy to follow and so is this disease sacrificing what one likes and then accepting that the disease which can be fearful consequences is the expectation of diabetes. Most of the participants reported positive attitude if they can control the blood glucose they be happy and feeling of sadness only when the blood glucose is elevated.

Here the focus of diseases is only by checking blood glucose level, the happy or the depressed mood is observed.

Inability to accept diabetes can have lot of in advent affect such as non adherence to meditations using traditional methods can give adverse affects. Hence it is recommended to take proper advice and adhere to the advised regime than to resort additional method.⁷

Living normal life with diabetes:

It is recommended to live with preventive services to have normal life. Participants expressed normal living if regular check up and care is followed. Adopting healthy lifestyle, a person can live a long life without condition.

CONCLUSION

Is key to good diabetes care and it would be ideal to prepare individualized plan to help empower people with diabetes. Individual with diabetes learn to accomplish goals for healthy living. Healthcare professional support is required for lifestyle change which will increase personal needs control with regard to integration of diabetes self care into the work, family, personal needs and interest should be main goal for people living with diabetes.

1. **Information material**

✓ Patient needs to have access to adequate information.

✓ Health Care professionals need to prepare adequate and simple information as resource material that patients may take home message.

2. **Peer support** People suffering from diabetes are themselves good educators for others and can support by spreading awareness with similar experiences and can share their knowledge in groups in avoid loneliness.

3. **Nurse led clinics** can take major roles in curbing diabetes by motivating healthy lifestyle in communities.

4. **Patient educational resources** with necessary guidelines for practice can save time in the clinics.

5. **Diabetic nurse specialist training** is the need for diabetes patient's care.

A well integrated health care system is needed to reduce type 2 diabetes burdens.

Ethical approval:

1. Permission from Institutional ethics committee at GMC was obtained. Informed written consent was obtained from participants.

2. Participation was voluntary; they were informed that they could withdraw any time.

3. Confidentiality was maintained using code.

Note: All information regarding the patients data is kept confidential with the researcher and can get access with request.

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