ORIGINAL ARTICLE

Self-Care in Diabetes as perceived by diabetic patients – A Systematic Qualitative Approach

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ABSTRACT

Background: India is one of several developing nations where diabetes mellitus has grown to be a severe global public health concern. The individual, medical staff, and healthcare system are all subject to a heavy burden of care. As a result, there is a huge need of self-care practices in a variety of domains, such as nutrition, exercise, foot care, and blood sugar monitoring. **Objectives:** To determine perceptions regarding self-care management among individuals with Type 2 Diabetes mellitus following up at rural field practice areas of a tertiary care institute in Mangaluru. **Materials and methods:** Qualitative study using systematic technique by free listing approach was carried out on a total of forty patients confirmed type 2 Diabetes. By consecutive sampling 20 patients each from 2 field practice areas of a Tertiary medical institute were taken. **Results**: The general reason leading on to the diagnosis of diabetes stated was tiredness which had a composite salience of 0.48. The composite salience for self-care practice was 0.48. Participants stating that diabetes can be controlled had a composite salience of 0.3. **Conclusion:** Perception regarding self-care included diet, foot care, stress reduction and exercise with majority mentioning that diabetes can be controlled by these self - care mechanisms.

KEYWORDS

Diabetes; Self-Care; Qualitative; Perception

INTRODUCTION

India has 77 million people above the age of 18 with type 2 diabetes, and approximately 25 million are prediabetics according to statistics.(1) If diabetes is not diagnosed and treated in a timely manner, more than half of population will experience health issues as per report of World health Organization.(1) With diet, exercise, medication, regular screening and treatment, diabetes can be managed and its consequences can be postponed or prevented.(2)

Self-management is a dynamic process in which people actively control a chronic illness and necessitate a radical shift in lifestyle. Making wise decisions for one's health and way of life on a daily basis is part of daily management.(3) By strengthening self-care

practices, the diabetic patients can considerably lower their risk of long-term complications.(4) Since it is obvious andwidely acknowledged that self-care behaviors have a significant impact on the health outcomes of patients with chronic illnesses.(5)

Furthermore, the customized self-management program was successful when the participant received information about their challenges and their blood glucose level or level of current management, and received personalized feedback and management in accordance.(3)

Objectives:

1. To assess the knowledge regarding diabetes among type 2 Diabetes mellitus patients visiting the field practice areas of a tertiary care hospital in Mangaluru.
2. To assess self-care management among type 2 Diabetes mellitus patients visiting the field practice areas of a tertiary care hospital in Mangaluru.

MATERIAL & METHODS

Study Design: Systematic qualitative study using free listing approach.

Study Type: Crossectional study

Study Setting: Conducted among two rural field practice area of a selected Tertiary care institute in Mangaluru. This study was carried out from May 2023 to October 2023.

Sample size calculation*:* As the systematic qualitative method used in this study was free listing, the sample size is purely dependent on data saturation and a minimum of 20 participantsis required to achieve saturation point during interview.(6)A total of 40 participants which consists of 20 diabetics patients from each of two rural field practice area was taken to ensuregood quality data.

Sampling Method*:* 20 diabetics patients from each of 2 rural field practice area were taken by consecutive sampling method and interviewed.

Study Participants: All individuals who were diagnosed with type 2 diabetes mellitus more than one month of duration at the time of conduction of the study were included.

Data Collection Approach: The data was collected using a validated interview guide. The interviewer guide was translated to Kannada, the native language spoken and back translated to English. The interview from participants was conducted after obtaining their informed consent. The participants were asked to list out what they know based on the interview questions asked to them as per guide. The free list of items were generated from the answers provided by the participants. Free listing is a method of quantifying the qualitative data collected.

A total of 9 questions covering following areas were asked during the interview:

1. General reason leading to diagnosis with Diabetes.
2. Participant self-perception regarding reason for being diagnosed with Diabetes.
3. Perception regarding self-care in Diabetes.
4. Perception regarding living with Diabetes.
5. Participant's adherence to follow-up.
6. Diabetic care management measures undertaken.
7. Challenges faced by Diabetic patients.
8. Coping with the complications of Diabetes.
9. Self-perception regarding management of diabetes.

No cash or other forms of financial support were given to the study participants. We made sure that the responses were not duplicated and interviews were held according to the participants' level of comprehension in the local language. Also, Participants' confidentiality and privacy were maintained throughout the study.

Ethical clearance and study implementation: Ethical clearance from the Institution was taken and study conducted. Required permissions were taken from the officials at the rural health center medical officers. INST.EC/EC/065/2023 REG NO EC/NEW/INST/ 2022/KA/0174 dated 19-04-2023.

Data Analysis*:* The items for free listing were compiled from the answers provided by the patients from the interviews. Further analysis was done using the same.

The participant response was transcribed and translated into English using participant specific codes thus ensuring participant privacy. During translation it was ensured that meaning from the local language is not

deviated by having two coders coming up with free lists.

The analysis was performed in several steps: Initially the words /items/phrases raised from the interviews were listed out. As a first step two researchers grouped grammatical forms of the same words ("chapati" and "chapatis") synonyms ("Tensed" and "stressed") and words representing similar concepts ("tea without sugar" and "sugarless tea"). Under each questions the free list was combined and inverted rank was given to the items in each list so that the item mentioned first gets more points. For example, here in this study for the question -how an individual gets diagnosed with diabetes? the first participant has listed items in the order of vomiting, giddiness and burning sensation for which, the rankings are 3/3,2/3 and 1/3 respectively. Thus, the first item will have smith's=1 and the last item will have Smith's =0.3.

Smith's salience score (Smith's S value) computes the cognitive salience by taking the items' frequency and rank into account. It gives quantification to the qualitative data obtained. It is the weighted average of an item's inverse rank across several free lists, where the weight of each list is determined by the total number of items in the list.(7)

It involves identifying and prioritizing the items that are most relevant or noteworthy to the participants and salience helps researchers to identify the item which are most prominent or the experiences or perspectives of the participants. To calculate Salience of an item on a free list (smith's S), the Sum of item's percentile ranks was divided by the total number of lists. The salience score was calculated by using Microsoft excel.

RESULTS

General reason leading on to the diagnosis of diabetes (Table 1) the first and foremost item listed by participant was tiredness which consists of body ache and fatigue which has a highestcomposite salience of 0.48. Followed by most of participants were unaware of the diagnosis per se which has a composite salience of 0.33. And a vast majority of participant got to know the diagnosis by blood checkups followed by physician advice.

Table 1 Participants' general reasons & self-perception leading on to diagnosis of Diabetes mellitus

Item number	Items	Sum of item's percentile ranks	Composite salience= sum/n (n=40)
1	Tiredness	19	0.48
2	Do not know	13	0.33
3	By doctor checkup	12.9	0.32
4	Increased intake of sweets	11.8	0.29
5	Tension	10	0.25
6	Giddiness	7.8	0.19
7	Familial/ hereditary	5	0.12
8	Wounds will not heal faster	3.2	0.08
9	Increased urination	3	0.07
10	Increased thirst	2.3	0.06
11	Burning sensation in feet	2.3	0.06
12	Increased hunger	2.3	0.06
13	Side effect of other drugs	2	0.05
14	Vomiting	1.8	0.04
15	Part of old age	1	0.02
16	Reduced Vision	0.7	0.01

Most participants have followed food control as a self-care measures (Table 2). The food control includes reduced intake of rice and sugar, reduced intake of meat and fish items, increased intake of vegetables, lentils, and pulses. Also, the participants have replaced rice with chapathi and ragi items. Reduced sugar intake was also seen among them as a self-care measure as they reduced taking sweet food items and tea with sugar. A majority of participant did not do any self-care activity at all, the composite salience for the same is 0.48.

The other self-care measures undertaken were: proper adherence to medication, physical activity in terms of actively doing work around the house, such as walking and gardening which according to participants mentioning the same consisted of an average of thirty minutes, foot care, stress reduction and regular follow ups. Few of the participants did not take any measures stating that "I just eat like how I used to eat before." And some of the participants stated that they get tensed and stressed when the glucometer reading shows higher level of random sugar level and for that reason, they do not see the readings frequently.

Table 2 Perception regarding self-care on diabetes and management measures undertaken

Item number	Items	Sum of item's percentile ranks	Composite salience= sum/n (n=40)
1	Food control	55	1.38
2	Do not do anything.	19	0.48
3	Reduced sugar intake.	14.5	0.36
4	Adherence to medication	7.3	0.18
5	I just eat like how I eat before	4.4	0.11
6	Exercise	4.25	0.10
7	Gets tensed if sugar level goes high	2	0.05
8	Foot care	1	0.03
9	Stress reduction	0.8	0.02
10	Checkup on time	0.25	0.01

Diabetic patients' adherence to follow up listed by study participants are monthly once which has the highest salience of 0.97 followed by once in 2 months, every 2 month and twice a month.

Most of the participants (Table 3) did not face any challenges in regards to living with diabetes as the composite salience comes out to be 0.85. And some of them faced presenting symptomssuch as myalgia, burning sensation, increased thirst, headache, gastritis, blurring of vision, increased frequency of micturition and numbness over hand and feet. Few of the participants listed out fatigue as a challenge which includes tiredness, body ache, giddiness and unable to do any work. Few of the participant quoted that they must take care of the food what they are eating "I have to think before eating and I cannot have whatever food I used to have earlier. "Few of them quoted that "the life before diabetes was better and this life is not useful."

Table 3 Participant perception regarding challenges and living with diabetes

Item number	Items	Sum of item's percentile ranks	Composite salience= sum/n (n=40)
1	I do not have anything/nothing	34	0.85
2	Fatigue	14.7	0.36
3	Presenting symptoms	14.3	0.35
4	Food control	10	0.25
5	Stressful	6.8	0.17
6	Non-diabetic status was better	3.5	0.09
7	Reduced sleep	3.2	0.08
8	Other diseases take a lot of time for recovery	2	0.05

The complications listed by participants (table 4) were delayed wound healing, fatigue, blurring of vision, increased frequency of urination and burning sensation /pricking sensation over hands and feet. Most of the study participants stated that diabetes can be controlled/managed which has a higher salience of 0.3. Few of the participants mentioned that for burning sensation they use pain killers/ointment or stretching exercise. Whereas a 0.1 salience score is seen for the participants' who do not do anything for the complication as such.

Table 4 Coping mechanism with the complication of diabetes.

Item number	Items	Sum of item's percentile ranks	Composite salience= sum/n (n=40)
1	Diabetes can be controlled	31.3	0.78
2	Adherence to medication	14.1	0.35
3	I do not have anything	13.3	0.33
4	Food control	7.85	0.19
5	Diabetes cannot be controlled.	5	0.12
6	Exercise	4.25	0.10
7	Not doing anything	4	0.1
8	Use pain killer oil/ointment	2	0.05

DISCUSSION

In this current study the general reasons for diagnosing diabetes were found to be tiredness/body ache followed by diagnosis by treating physician/ or by blood investigation, delayed wound healing and increased hunger and thirst. Blurring of vision was mentioned by very few. The reason for being diagnosed with type 2 diabetes listed by participants included tension/stress, due to intake of refined sugars and drinks, ageing whereas the top most reason was not being aware of how the disease had occurred. These findings are consistent with the factors that are usually considered as ones that can be changed which include a sedentary way of living and/or inadequate physical activity, the rising prevalence of increase in weight leading to obese individual and unhealthy eating habits like inadequate consumption of vegetables, fruits and consumption of more refined sugars, grains, fat, and sweetened beverages, stress etc.(8) In another study nearly every participant (97.3%) stated that they had knowledge of diabetes, and accurately recognised predisposition due to family history and obesity as risk factors and a lower body weight (85.6%), a healthy diet (50%), and physical activity(32.8%) as protective variables.(9)

In our study participants listed exercise in terms of 30 minutes of walking and regular gardening at home and food control by reducing sugar intake, consumption of wheat and ragi instead of rice, reducing consumption of fish and meat items and incorporating vegetables and lentils in the diet as a measure undertaken to control diabetes. Whereas in another study 15.7% of respondents reported engaging in intensive physical activity, compared to over two thirds who reported moderate physical activity. About eating habits, the only intake that was noted was two to three servings of vegetables and one serving of healthy grains per day. Moreover, 50.6% of people ate fish 2-4 times each week and consumed red meat 1-4 times per month.(9)

In a study conducted in Moradabad, Uttar Pradesh, India, Goyal N et al(10) found that approximately 44% of participants had inadequate self-care practices, half of patients with diabetes followed a particular nutritious diet plan, among the participants, 47.6% reported consuming a minimum of five portions of fruits and vegetables, more than half of the participant reported exercising for at least thirty minutes every day on most days of the previous week, 14.2% routinely checked their footwear, and almost 80% had abstained from smoking for the previous seven days of the week.

In our study foot care was listed by only very few participants. A study done in Jharkhand showed patients' ignorance of proper foot care procedures was rampant, and low education and illiteracy were the most frequent causes of neglect in these areas.(11)Health literacy had a favorable effect on self-care practices specifically for exercise and foot care, but not for diet and blood monitoring.(12)

Numerous previous research has demonstrated that adopting appropriate self-care behaviors greatly reduced blood glucose levels and enhanced the general quality of life for diabetes. The following seven principles have been shown to be helpful in managing diabetes which are eating a good diet, exercising, monitoring, taking medicine, finding healthy coping mechanisms, and

lowering risks. Among these seven guiding concepts, primary care settings frequently evaluate physical activity, medication compliance, dietary intake, and routine physical examinations to discover self-care habits.(13) By increasing their self-care practices, most diabetic individuals can dramatically lower their risk of having long-term problems.(14) Despite this, it has been discovered that there is minimal compliance or adherence to these activities, particularly when considering long-term improvements.

Conclusion

The general reason leading to diagnosis of diabetes listed by the participants in this study are fatigue, giddiness, general health checkup by physician, familial and other symptoms like increased frequency of urination and increased thirst, increased intake of sweets and tension equating to stress are the leading reasons for diabetes as stated by participants. Knowledge regarding selfcare as mentioned by participants included diet, adherence to medication, foot care, stress reduction and exercise. However, majority of the participants were not translating this knowledge into practice. Complications listed by the study participants were myalgia, burning sensation, increased thirst, headache, gastritis, blurring of vision, increased frequencyof micturition and numbness over hand and feet.

Coping up mechanism listed includes proper adherence to medication, diet, and exercise. Whereas few participants stated that diabetes cannot be controlled. The free lists obtained from the study can be used as a tool for developing a validated questionnaire which can be used as a guiding tool for further research.

Recommendation

Encouraging the people to learn more about diabetes and adopt healthy habits will help lowerthe social and medical costs associated with the disease. Policy makers, healthcare management, and healthcare personnel can develop more efficient educational initiatives.

To improve diabetic patients' perceptions of illness and health literacy, educational initiatives that are suited to their educational background should be considered.

The healthcare system should prioritize managing chronic diseases, including diabetes self- care, and allocate greater resources to diabetic care.

Limitation of the Study

The study findings have been obtained using non random sampling and this could limit its usage to the particular study setting.

Relevance of the Study

Understanding diabetes self-care perceptions is crucial for improving patient outcomes. Such a study provides insights into individuals' beliefs and behaviors, thus helping in coming up with informed personalized interventions. By promoting positive attitudes towards self-care, healthcare professionals can enhance patient engagement, adherence to treatment plans, and overall diabetes management, contributing to better health outcomes**.**

Authors Contribution

All authors have contributed equally.

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Nil

Conflict of Interest

There are no conflicts of interest.

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Declaration of Generative AI and AI Assisted Technologies in the Writing Process

The authors haven’t used any generative AI/AI assisted technologies in the writing process.

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