

# Perceptions and Needs Among Diabetes Patients: A Qualitative Study

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**Abstract**—Diabetes mellitus is a degenerative disease that requires multi-dimensional management. Nowadays, the current phenomenon in the community happens that the patients only focused on pharmacological therapy without getting suggestions that describing the other dimensions. This study aimed at analyzing the patient's needs and the patient's perception of the condition of diabetes management. This study was designed in qualitative descriptive, the data collection was carried out through observation, in-depth interviews and focus group discussions for 3 months and involved 30 informants (patients and their families). The results of this study were qualitative descriptions that provide an overview of the needs and perceptions of patients and their families. The low level of knowledge about diabetes causes a bad perception of diabetes planning therapy. In conclusion, takes an equal perception between doctors and patients and their families about the management of diabetes which is not only limited to pharmacological therapy. There is a need for a practical guidance module to be a bridge in the sharing of knowledge and communication media for doctors and patients.

**Keywords**—diabetes; needs; perceptions; management guidelines.

## I. INTRODUCTION

Diabetes is a degenerative disease which until now has occupied the largest proportion as a type of degenerative disease in the world. The case of diabetes mellitus in addition to be a case with the largest proportion is also a case where the number of new cases is also very high. Diabetes caused 1.5 million cases of deaths in 2012. Additional data show that blood sugar higher than the maximum limit resulted in 2.2 million deaths, by increasing the risk of cardiovascular and other diseases. Forty-three percent (43%) of these 3.7 million deaths occurred before the age of 70 years. The percentage of deaths caused by diabetes that occurs before the age of 70 is higher in low and middle-income countries compared within high-income countries. [1].

WHO has estimated that, globally, 422 million adults aged over 18 years lived with diabetes in 2014. The largest number of people with diabetes is estimated to come from Southeast Asia and the Western Pacific, accounting for about half the cases of diabetes in the world. Around the world, the number of diabetics has increased substantially between 1980 and 2014,

increasing from 108 million to 422 million or about four times as much. Although the risk factors are often associated with lifestyle, the number of deaths from cardiovascular disease and diabetes tends to be more common in developing countries compared to developed countries. According to WHO data in 2008, the number of deaths due to diabetes mellitus and cardiovascular disease in developed countries such as Japan, the United Kingdom, Sweden, and the United States is less than in developing countries such as Laos, Cambodia and Myanmar [1].

Diabetes prevalence proportion, case of death attributable to diabetes, and health expenditure due to diabetes improving rise worldwide with the social, financial and health system implications followed it [2, 3].

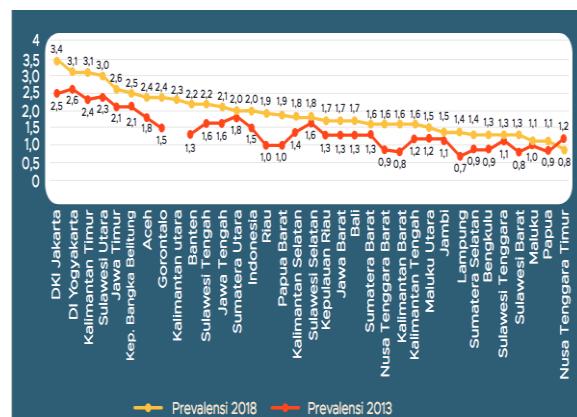


Fig. 1. Prevalence of Diabetes Mellitus Based on Doctor's Diagnosis in Population  $\geq 15$  Years by Province, 2013 and 2018 [4].

The core of this disease is theoretically influenced by several factors including genetics and lifestyle. By the two predisposing factors, the current lifestyle is the largest predisposing factor. The genetic factors are no longer the main feared factor for diabetes mellitus. Several studies show that an unhealthy lifestyle is a predisposing factor of 60% of the occurrence of diabetes mellitus. As predisposing factors thus are should be included as indicators in evaluation and monitoring of the positive results in diabetic management patients.

According to the observation and preliminary research by interviews with the patients and health workers, shown that predisposing factors only be the factors for diagnosed items a suspected patient. Thus, phenomenon pursued some issues about uncompleted management of diabetic. This study created in order to describe therapeutics needs among patients of diabetes mellitus. Thus, needs categorized as pharmacological, psychological and other needs according to equal therapy for diabetic patients.

## II. METHOD

The research was held in Buleleng, at the Internal Medicine Polyclinic of Sahabat Clinic, General Hospital in Kabupaten Buleleng and several private clinics of general practitioners in Buleleng. This study took four months from April to July 2019 until saturation data were obtained. The informants in this study were type 2M patients who came to the doctor's clinic to control or seek treatment. Informants should fulfill the inclusion criterion of this research study. Informants should be diagnosed for minimum 1 year as patients' diabetes, history of taking ant diabetic oral medicine, and agree to be involved in this study. Informants are divided into three groups based on the duration of DM disease. The sampling technique in this study used purposive sampling. Data collection techniques used was primary data through in-depth interviews (in-depth interviews) accompanied by in-depth interview guidance.

## III. RESULTS AND DISCUSSION

Twenty informants were obtained with a composition of 13 men and 7 women. The age of the informants ranged from 46-70 years old. According to the aims of this study, the focused of these descriptions results are divided into five key points.

### A. Self Perceptions

Several fears made some informants declared that they have been fear about few things about diabetes. Informants said that the things that cause stress when diagnosed with diabetes are characteristics of diabetic disease that seems severe, symptoms of DM that interfere their activity, complications that may occur due to diabetes, complex treatment rules, and fears of not being able to support the family due to chronic illness. The process of building perception that they have already suffered from diabetes requires a period of psychological acceptance stage. It took 1-2 years. This was stated in the following interview quotation:

*"When I was first diagnosed with diabetes, I felt that my life was over. Imagine the severe complications that would come to me in the fastest way. I became lazy to come to the clinic for control because the doctor did not explain as much detail as I needed. After 1 year, I began to realize, my life can still be running with things as usual that became my activity even though now I have to be with my new friends which called insulin."*

Other quotations explained that patients are needed to get explanation about their present and future condition.

### B. Family's Perceptions

Family has a companion roles in the treatment of patients with diabetes. The existence of the family as a companion so far is still limited to deliver patients to the clinic. Their family has not positioned itself as a companion to the efficacy of the management of diabetic patients. The family describes some reasons in this following quotation.

*"The time provided by the doctor for a consultation is very short. For guidance on follow up, consumption of drugs at home is also not given. Nutritional guidelines also don't exist. Then my parents already knew the injection method, the injection time and the time to take the medicine. Every time my control has never been asked or communicated how to be a facilitator taking good medicine. So, to be honest until now I only took my parents to the clinic and let my parents with the world of diabetes".*

### C. Nutrition needs

Another key point in this qualitative data is nutritional needs. It means that the name of sources food, portion per meal Dan per day and kind of food that listed as prescribed or limited. Patients and the family's patients do not seem to have adequate knowledge about the nutritional needs. The data are shown in this following quotation.

*"Every time while I go to control to the doctor, the doctor was explained only about the drugs that must be consumed. About the type of food is not explained in detail. Just explained not to consume a lot of sugar."*

Patients also commented on inadequate information that they got about their nutritional rules. They explained that all of that uncompleted information because of time limitation during their consultation with the doctor.

*"It because of the time limit. There are so many doctors we visited. Doctor's can be up to 100 people who must be served by 1 doctor. I guess everyone will be unsatisfied with the doctor's explanation."*

Subsequent statements stated the lack of understanding of the nutritional needs of diabetic patients. It was also found that lack of knowledge about food intake patterns that trigger diabetes.

*"I have read in the media that a diet high in sugar has a high risk of causing diabetes. Actually I do not really understand about what is meant by a diet with high sugar levels. Actually I rarely consume sweet drinks. I like foods like fried rice and fried noodles. My understanding at the age of 42 this year with the results of a laboratory check stated that my blood sugar is normal, so I am sure that the high sugar diet if we consume sweet drinks or cakes."*

The following excerpt raises another confusion which also has not yet received an explanation or proper guidelines.

*"I rarely accompany a parent suffering from diabetes to see a doctor. Every time after the control I always asked how the doctor ordered during the control, my parents said 'yes as usual you should not eat sweets, if the other food just eat as usual'. Actually I am confused what is meant by ordinary and unusual. I saw that my father had avoided sweets but ate twice the size of my meal. Before he was diagnosed with diabetes he ate a lot and now even with blood sugar that is never below 250 mg / dl, I see that he is eating more and more. I think that this is because there are no food menu guidelines."*

The following excerpt states that the diabetic patient's menu is not explained to his family or the person accompanying the treatment. Food menu was also not explained to patients.

*"What and how the arrangement of breakfast, lunch, snacks and dinner has never been explained by the doctor. I also never got an explanation of how I am at risk of heredity to avoid diabetes. Besides I want to gain knowledge about the diets of my parents who are diabetic, in fact I feel more important if the doctor explains how to eat well to my parents in language that is easy to understand."*

The statements above are excerpts of interviews obtained through in-depth interviews and FGD results with the community. The community is the target of health services and is the core of health sector development. Empowerment of community independence in improving their knowledge is needed as an effort to improve health status. Based on the above interview excerpts illustrate the low level of public knowledge about diabetes. Public knowledge about diabetes should be able to make people understand about how to deal with diabetes and how to prevent it.

#### D. Psychological needs

Psychology condition contributes to some effect of physiological state. Psychological conditions in the form of anxiety status affect hormone levels associated with emotion. This causes some psychological symptoms that affect the body condition physiologically.

Patient's guilty feelings were likely neglected by doctors because the guidance of evaluation management only describes the physical and laboratory results.

No guidance is found in the books for their medical record. This following quotation was taken from the doctor.

*"We have guidance from International Diabetic Federation and also from PERKENI. Both of them focused on pharmacological therapy-based monitoring program. We have no abundant time for checking all of the patients' conditions likely for psychological. Although we know that psychological and physiological are needed to monitor because they influence each other."*

Patients said that they needed more than just pills and injection because a kind of consultation about their physical condition is important too. Psychological condition as anxiety, depression, confusion, fear and other mood disturbance lead them to take bad nutrition intake.

Those are describing in this following quotation.

*"I realized without taking medicine my blood sugar would definitely not be controlled. But my motivation for taking medication is high and obedient, it turns out that my blood sugar is not controlled. I realized there was a psychological effect on me. Since I was diagnosed with diabetes, I feel that everything will be difficult. My life was worried even though I was doing a rejection in front of my family that I felt fine and was not burdened. Worries about complications and not being able to live long enough actually continue to haunt me. I think my stress must also be treated because it might be this stress that causes my blood sugar to be out of control even though I am taking medication with obedience."*

A small speech is taken from other quotations as followed.

*"Being a diabetic patient is not good. All become restricted. All must be with the rules. Indeed the rules make things better but without a good explanation actually, the rules make me stressed as a patient. I felt like I was imprisoned without knowing what my mistake was. This stress triggered me to reject rules like diet and taking medication or injecting insulin. Because I felt the doctor only asked for physical complaints without ever monitoring my psychological complaints."*

#### E. Physiological needs (Non Pharmacology)

Intake of food intake with high sugar content can affect the high and low blood sugar in the body, causing diabetes. Management of diabetic patients by health care workers should also pay attention to other dimensions besides pharmacological therapy. In addition to the nutritional dimension, there is a dimension of physical activity which also greatly affects the health status of diabetic patients. The type of exercise, the number of exercises performed, and the frequency of exercises are things that should be a concern of health workers as monitoring the success of diabetes therapy.

A useful result of descriptive data was giving some ideas to create a book as a module for caring diabetic patients. This study is conducted with explanatory qualitative method. The qualitative research in diabetes still in a bunch compare with the quantitative one. Over 85% of qualitative research articles on diabetes were conducted in North America and Europe [5, 6]. Meanwhile, over 80% of people with diabetes live in lower-middle economical country [6]. This study produces an output in the form of a draft of a module which had validated by an expert in diabetes (internist's).

As a keyhole of the management in diabetic patients, pharmacology should be accompanied by healthy lifestyle [7]. It is known that the most important treatment for

diabetes is to change lifestyle, especially to regulate a healthy and balanced diet [8]. The application of the diet is one of the main components in the successful management of diabetes, but often becomes an obstacle in the service of diabetes because it requires adherence and motivation from the patient himself [9].

Knowledge on dietary intake is very important for diabetic patients. This knowledge will help built a good perception to avoid unhealthy food in order to prevent any complications. As shown in some quotation in this study, the intervention is needed to increase knowledge about the pathomechanism of disease, the management or treatment protocols, diet, physical activity, and utilization of existing health facilities in the community (10). On the other side, few studies reported that basically a few diabetic patients whom already know about the dietary recommendation do not obey it, so they eat as they wish if they have not shown symptoms of complications (8).

Patient's diabetic knowledge is an important tool to guide treatment of diabetic patients themselves. Thus, it can be concluded that the better the patients' knowledge about diabetes, the better the treatment in handling the diabetes diet is (11). Furthermore, changing patient's behavior will also be able to control the prognosis of the disease, so that it can last longer, and the quality of life is getting better (12). A low level of knowledge about self-care results a worse health conditions and cause stress due to the inability to perform self-care (8). Stress experienced by diabetic patients can result in impaired control of blood glucose levels caused by excessive cortisol production, a hormone that reduces body sensitivity to insulin, making it more difficult for glucose in the body to enter cells resulting in increased glucose levels in the blood. Other studies indicate that someone who has low knowledge tends to be difficult to accept and understand the information received, so that the person will be indifferent to new information and feel no need for the new information (9).

Subjects of this study show some quotation which were indicate that the majority of diabetic patients have a low level of knowledge of the condition of the disease and also the treatment that are being taken. The diabetic patients in this study and their families had quite high stress levels because they felt anxious and confused in carrying out dietary recommendations and also medication. Patients who are the subject of research predominantly do not know diabetes information and do not get enough education among diabetes, so these patients do not know that diabetes is a disease that requires holistic management, especially drugs and non-drug therapy (diet, stress management and exercise).

This study found that lack of knowledge turned out to affect stress levels in patients. However, with a lack of education, poor understanding results in the patient experiencing a phase of rejection of the disease and leads to non-compliance with treatment management. In other

studies, more often said that the patient had accepted the condition of the pain suffered and accept the fact that diabetes is difficult to heal, so that patients try more positive thinking and not think too much about the situation (13).

The results mentioned several important emphases as patient needs. Statements that were obtained several times from informants in the form of:

*"I know that I have diabetes. And I also know that I have to exercise but there are many things that confuse me and consider me. I know the importance of the sport well, but I haven't done it because the gym is far away, and it can't be done at home."*

In this case the subject stated obstacles about the type of exercise that had not been carried out as well as its limitations to carry out the exercise independently at home.

*"If I choose to walk, I am often bored with the activity."*

The statement indicates the patient's need for an explanation of the type of exercise and variations in exercise so that the level of boredom can be suppressed.

Furthermore, it was found that, there is a building of patient thought in the form of patient perceptions of health services for patients with diabetes mellitus. Focus group discussions on patients who became the study sample revealed various communication and education obstacles that had been happening between doctors and patients.

*"I have never had a long chat, (the doctor) examined my chest then looked at the results of sugar, gave a was immediately, and suggested me to have a meeting once the drug's ran out."*

Submission of one of the quotes from the patient's statement indicates the limitations of quality and quantity in the service that should be very important in diabetes management programs.

*"I don't know what the food should be like, what complaints are experienced at this time, if you already have diabetes, don't stop the drug, that's all that is said every time control comes."*

These quotations provide sufficient data to bring up indications that corner health workers because they appear to be rushed, inaccurate, do not provide service and education to their patients holistically. Management of diabetic patients according to endocrinologists is currently with pharmacological and non-pharmacological therapies. Synergy between oral anti-diabetic drugs, stress management, diet and exercise menu settings are inseparable.

Diabetes is not only a problem of people in developed countries, in developing countries, especially Indonesia, diabetes is a health problem that really needs attention. This research is so important because the research idea is in line with the current world health problem. According to data

from the Ministry of Health in 2016, Indonesia ranked 7th in the world with the most diabetics in the world. Also added that the mathematical model of type II diabetes shows the prediction of type II diabetes patients continues to surge every year. The World Health Organization (WHO) predicts that diabetics in Indonesia will continue to increase until it is ranked 4th in the world by 2030. The distribution of this disease also spreads at all levels of society from low to high socioeconomic levels, at each race, ethnic group and region geographical. Buleleng Regency also records thousands of diabetes mellitus patients every year. Prevention of worsening quality of life is a problem that must be resolved in chronic patients such as diabetes.

Diabetes management starts with applying a healthy lifestyle (medical nutrition therapy and physical activity) together with pharmacological interventions with oral and / or injection anti-hyperglycemia drugs. Oral anti-hyperglycemia drugs can be given as a single or combination therapy that is obtained at the first health facility that is a private practice doctor, *puskesmas* and *pratama* clinic. In emergencies with severe metabolic decompensation, for example: ketoacidosis, severe stress, rapid weight loss, or the presence of ketonuria, should be referred immediately to Secondary or Tertiary Health Services.

Education is needed by patients to increase knowledge about independent monitoring, signs and symptoms of hypoglycemia and how to overcome them. Education with the aim of promoting healthy living, needs to always be done as part of prevention efforts and is a very important part of diabetes management. The need for education was raised in several quotations in this study. Some needs an understanding of the course of diabetes, the meaning and need for ongoing diabetes control and monitoring, complications, non-pharmacological and pharmacological interventions and treatment targets. Other knowledge needs are expressed by patients such as interactions between food intake, physical activity, and medication.

There are other needs that have not been revealed in the whole quote because indeed patients still have very minimal knowledge. The need intended by researchers is the need for patients to have simple problem-solving skills, and the need to join fellow diabetes groups and invite families to understand diabetes management. The next step that becomes necessary if education is to be carried out optimally is to pay attention to the results of psychological quotations in this study. These things are providing positive support and advice and avoiding confusion and anxiety. Patients need to provide information gradually, starting with simple things and in ways that are easy to understand. Health workers are also wanted by patients to approach the problem by discussing treatment programs openly and paying attention to the patient's wishes.

Knowledge about complications should also be given to patients and their families. Researchers assume that the

condition of complications in addition to aggravating the patient also affects the family. Complications will affect family support. The number of complications suffered by diabetic patients causes burden and drains family energy which ultimately impacts on family support so that the family cannot provide optimal family function and it is not uncommon for families and patients to stop treatment because of the burden felt due to complications of the disease. This causes the disease not handled properly and falls on the condition of organ failure.

Patients need to be given an explanation to be able to prevent complications of diabetes. Diabetes if not handled properly will result in hyperglycemia in the long run and it triggers complications in various organs of the body. There are various theories / hypotheses that explain that there is a relationship between complications and blood sugar levels. One of them is the theory of sorbitol. According to this theory, hyperglycemia will cause a buildup of blood sugar levels in certain cells and tissues that can transport glucose without requiring insulin. This excessive glucose will not be metabolized completely normally through glycolysis, but partly through the mediation of the enzyme aldose reductase will be converted into sorbitol. Sorbitol will accumulate in the cell / tissue and cause damage and changes in function. This explanation of sorbitol should be explained in plain language to patients and their families if the health care provider is able to allocate sufficient time to carry out communication and education.

This study shows that there are psychological factors between the length of time diagnosed with diabetes mellitus and the condition of blood sugar levels. Diabetes is a chronic metabolic disease that requires control throughout his life. This is not yet understood by the patients who were sampled in this study. The patient feels frustrated with medication and health services that corner the patient in the direction of a chronic chronic illness. As revealed by research subjects that when queuing in health services, many say that many become frustrated, frustrated or afraid of the conditions they experience because this disease requires strict self-control. Patients are more frustrated by regretting that they do not understand how to keep blood sugar levels within normal limits, even though they seem to have eaten less sugar.

*"Far from tasty and sweet. All without sugar, until I was confused about what to eat, how come my blood sugar has not been said to be stable, let alone to release the drug."*

The patient apparently does not have sufficient knowledge regarding matters related to diabetic patients' needs such as diet and food regulation, need to carry out regular physical and physical activities, need to consume hypoglycemic drugs regularly and stay away from psychological stress conditions.

The quotation above mentions the patient's lack of understanding of blood sugar which is not merely affected

by the matter of eating minimal carbohydrates. The patient appears to be currently in a state of stress that feels hopeless about his condition and this despair can actually cause instability in his blood sugar. Patients also do not yet understand that diabetes is not a disease that can be cured until it becomes a drug-free condition. Patients must understand that diabetes is a disease that cannot be cured but can be kept stable so that the function of other organs besides the pancreas can still work like people who do not suffer from diabetes.

In addition, researchers assume that the longer they suffer from diabetes, the need for an explanation of the condition of the patient has not been given individually.

*"My neighbor has been suffering from diabetes for 10 years and until now I see the same medicine as me who has only had diabetes for 1 year. Food recommendations are also the same as just saying "don't add too many sweets." We do not get any explanation on how many rice dishes a day, what should we do for the side dishes. So, I felt confused and never went limp because I was hungry. At that time, I was taken to the ER because he said I was lacking sugar. Actually, I was confused about how to take medicine and the distance between meals and portions."*

So far, the quotations in this study mention the impression that management is limited to drugs and does not provide holistic management. Food intake for each patient, of course, must be individualized as well as the reasons for drug intervention given. The need for explanation becomes crucial for the research subjects in this study for the successful management of the diabetes it suffers.

In studies conducted in Asia, it was concluded that psychosocial factors such as family support have important effects on glycemic control in adults with diabetes and also an important effect on self-management in diabetic patients (14). In a study examining the impact of family supportive and non-supportive behavior in relation to adherence and metabolic control in individuals with diabetes, it was concluded that individuals with higher levels of non-supportive family behavior have lower levels of adherence and poor metabolic control (15). Researchers assume that family support plays a crucial role in self-management compliance and will indirectly influence blood sugar control. But the research here does not reveal quantitative family support providers that are provided to patients.

#### F. Limitation of the Study

Data collection in this study was based on interviews with highly individual patients. However, this research seeks to ensure the validity of self-reports from informants. For example, informed consent is emphasized for the confidentiality aspect of research participation. In the informed consent explained that the authenticity of the interview data is strongly influenced by the honesty,

understanding and memory of the respondents regarding the knowledge and events that they have experienced.

#### IV. CONCLUSION

This research formulates several important and fundamental phenomena of the needs of diabetic patients. It is known that diabetes mellitus is a metabolic disease that can cause various complications as a final estuary in more than half the population of diabetes patients in the world. This situation greatly affects the quality of life of patients, so they need to get serious attention from all parties. Until now there has not been found a way or treatment that can cure diabetes.

However, diabetes can be controlled properly, by means of synergy between pharmacological and non-pharmacological therapies, namely diet, exercise and by using antidiabetic drugs. In every treatment for a diabetic patient, targets must always be set before reaching treatment. This aims to determine the success of the treatment program and adjust the therapeutic regimen as needed and avoid undesirable treatment results. Diabetes treatment is very specific and individual for each patient. By doing so, health workers must pay attention to the needs of patients individually. Services that are generalized will cause the quality of services that will not be able to reach the target treatment program. For patients, some of the quotations in this study mention the low quality of education in the advice of diet, exercise and psychological stress management. It is important to realize that there are 40% genetic factors for diabetes, so the patient's family also needs education about lifestyle modification to prevent diabetes. Lifestyle modification is very important to do, not only to control blood glucose levels but if applied in general, is expected to prevent and reduce the prevalence of diabetes, both in Indonesia and in the world in the future.

Diabetes and its complications bring huge economic losses for diabetics and their families, the health system and the national economy through direct medical costs, job loss and income. Included in the main cost components are hospital and outpatient care, another factor that requires large costs is the increase in costs for analog insulin 1 which is increasingly being prescribed despite little evidence that this type of insulin has a significant effect compared to cheaper human insulin.

Preventive action is the best programmed to reduce the prevalence and incidence of diabetes mellitus. The perception of diabetes mellitus patients and their families about the patterns of consumption of drugs, nutrition, and psychological stress management are part of the success of the treatment of diabetes mellitus.

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