# SELF-MANAGEMENT EXPERIENCE OF PATIENT WITH TYPE 2 DIABETES IN SUMBAWA BESAR, WEST NUSA TENGGARA: A QUALITATIVE STUDY

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#### ABSTRACT

**Background:** The number of patients with diabetes mellitus (DM) in Indonesia was reported to increase every year. Indonesia included into ranked sixth countries for diabetes (20-79 years) and ranked third as the deadliest diseases, (IDF, 2017; WHO, 2016). However, research about self-management experience for people with Type 2 DM is insufficient. **Objectives:** The purpose of this study was to explore the Self-management Experience of Patient with Type 2 DM in Sumbawa Besar, West Nusa Tenggara. **Methods:** Purposive sampling with one-on-one depth interview were used to obtain the participants experiences about self-management. six participants were selected randomly from 30 participants in community. Data saturation was achieved and analyzed by Colaizzi's (1978) seven-step method. **Results:** Six themes emerged from study were: dietary adjustment, using medicine to decrease blood glucose, taking exercise, taking care of DM by oneself, social support and looking for information regarding DM were consider as important theme for DM population in Sumbawa Besar, West Nusa Tenggara. **Conclusion:** the result of this study showed that each patient with DM has ability to carry out self-management based on their belief, value and knowledge. Basic information about diabetes was the most important aspect before patients can perform self-management successfully.

Keywords: Diabetes Mellitus, Experiences, Interviews, Nursing, Self-Management

# INTRODUCTION

Diabetes mellitus (DM) is a chronic disease that has become a major problem caused by number of populations and complications. Data suggest that the total number of patients with DM in the world are nearly 425 million people, an increase 48% from the year before. Prediction for 2045 are 629 million. Others data indicated that patients with DM in Indonesia are nearly 159 million people in 2017, an increase 15% from the previous year. Meanwhile, predicted for 2045 are that this number will increase to 183 million in, (IDF, 2017). Furthermore. Indonesia included into ranked sixth countries for diabetes (20-79 years), ranked third as the deadliest diseases and ranked forth for undiagnosed diabetes, (IDF, 2017; WHO, 2016). Lack of self-awareness, economic factor, health insurance, uneven reach of health services or facility, lack of knowledge and more trust with traditional medicine than modern medicine become the main reason why these condition can be occurred, (Pranata, 2017). As a result, patients with DM may do not know how to manage them self during sickness. This terminology was popular as self-management.

Self-management is the individual capacity of patient to handle his health problem such as, symptoms, physical and psychosocial consequences and lifestyle changes. (Barlow et all. 2002). Efficacy for self-management practicing properly encompasses patients ability to monitor their condition to achieve the cognitive, emotional and behavioral to maintain a satisfactory quality of life, (S. F. V. Wu et al., 2011; S. V. Wu, Liang, Lee, Yu, & Kao, 2013; S. V. Wu, Liang, Wang, Chen, & Jian, 2011).

In certain situation, patients with DM in Sumbawa Besar, West Nusa Tenggara more likely to control their health in community setting because caused by cost efficient reason. Several of them may not interested to process their health insurance and has low ability to manage them self. Sometimes there are not using footwear when doing activities, remain to consume diet with high glucose level and not exercise regularly, (Pranata, 2019; Pranata, Hs, & Sujianto, 2016). The patient's situation was not matched with health worker expectation.

Health worker expectations were patient able to practice self-management and improve their health condition by practicing the healthy behavior. However, majority of patients may feel over whelmed to control their blood glucose, diet, exercise and drug consumption regularly by disease complexity situation, (Grady & Gough, 2018; Pranata, 2019; Sassen, 2018). Life experiences and adaption process of patients to manage their disease need to be an aspect or attention for health worker before can be provided the right think intervention to provide the best solution based on patients need. Thus, it was assisted this study to capture and subjectively present information about selfmanagement among DM population. The purpose of this study was to explore the Self-management Experience of Patient with Type 2 DM in Sumbawa Besar, West Nusa Tenggara.

# **METHODS**

# **Study Design**

Oualitative research was used to obtain the participants experiences about selfmanagement. Qualitative research explores unknown areas of self-management of patients with DM. Phenomenology explores the meaning of a live experience from the individual's Qualitative perspective. researchers usually take a person-centered and holistic perspectives; seek people's life world and lived experiences to gain insight and extract the essence of the experience that human beings have in common beyond

personal cases. The cases objectively described the phenomena and obtained the truth of matters in the broadest sense, (Polit & Beck. 2015). Husserl defined phenomenology as "the science of essence of consciousness", and promoted the meaning of lived experience as a rigorous understanding of the world. way (Groenewald, 2004).

Phenomenological method analysis was developed based on Husserl's descriptive phenomenology, (Morrow, Rodriguez, & King, 2015). From this philosophical stance, the meaning of an experience of patients about self-management is described within emergent themes and common patterns specifically. Colaizzi's (1978) phenomenological approach was used because it provides a clear structure for analyzing data, (Gill, 2014).

### **Settings and Participants**

Through purposive sampling method, researchers recruited six participants in community at Sumbawa Besar, West Nusa Tenggara, Indonesia. Participants were recruited after researcher was checked the data in hospital regarding patients with DM and selected into inclusion criteria's, therefore, six respondents were selected randomly from 30 DM patients. Participants have gotten explanation about the study aims and procedures before started to interview. Eligibility criteria for participants were patients who suffer type 2 DM at least one year, living in the community, willing to participate in research, had signed the informed consent form, willing to express their feelings, thoughts and share their experiences via an in-depth interview.

### **Data Collection**

Semi-structured interview guide was used to explore participant experiences about self-management in community. The questions, such as:

- Would you tell me how long having the diabetes mellitus?
- 2) What kinds of experience changed since having the diabetes mellitus?
- 3) How do you deal with all the changed or experience regarding the diabetes mellitus?
- 4) What are your feelings and thoughts when you deal with your diabetes mellitus?
- 5) What difficulties do you experience during you manage your diabetes mellitus?
- 6) Do you have expectations regarding manage your diabetes mellitus?

7) Do you have more information to be shared regarding your experience to handle your diabetes mellitus?

Probing questions were also prepared to encourage the participants to give more information about their experiences, such as "Can you tell me more about your selfmanagement experiences?". At the end of interview, the question "Is there anything else you would like to tell me?" was a positive closure to interviews, (Polit & Beck, 2015). Interviews were conducted in patients' home, the patient's comfortability become researcher's consideration. Interviews lasted 15-20 minutes and were digitally recorded and transcribed verbatim.

### **Data Analysis**

The interview results were analyzed by the researcher according to Colaizzi's phenomenological analytic method, (Colaizzi, 1978). It consists of seven steps (Polit & Beck, 2015) such as:

- Read all protocols to acquire a feeling for them
- 2) Review each protocol and extract significant statements
- Spell out the meaning of each significant statement
- Organize the formulated meanings into clusters of themes

- Integrate results into an exhaustive description of the phenomenon under study
- 6) Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible
- Ask participants about the findings thus far as a final validating step

The first step was to acquire a sense of each transcript. In this study, each interview was listened to and checked for audibility and integrity as soon as possible when the interview was completed. The interview was transcribed verbatim and returned. therefore, the participants ensured that meaning was preserved. The interview transcript was written in Indonesian and translated into English by researcher. Each transcript was read several times until a sense of experience of self-management patients with Type 2 DM who live in community, Sumbawa Besar, West Nusa Tenggara was clear. All thoughts, feelings, and ideas were written during this stage.

The second step was to extract significant statements. Statements and phrases about the patient's experience were extracted from each transcript. These were debriefed and discussed with the research team. The third step was to formulate the meaning of each significant statement. The extracted statements related to self-management experiences among patients with type 2 DM who live in community, Sumbawa Besar, West Nusa Tenggara were interpreted into underlying meanings derived from the significant statements.

The fourth step was to organize the formulated meanings into clusters of themes, each cluster of which was coded, including all grouped formulated meanings. The fifth step was to integrate the results with an exhaustive description containing all the dimensions.

The sixth step was to describe the fundamental structure of the phenomena. At this stage, redundant descriptions were eliminated to establish the fundamental structure and generate specific relationships between clusters of themes and extracted themes. Transcripts were re-analyzed to confirm that themes represented the experiences of the participants to ensure consistency of the data analysis.

The seventh step was to return these research findings to the participants for discussion. All participants gave feedback that the results reflected the meaning of their experiences regarding selfmanagement among patients with type 2 DM who live in community, Sumbawa Besar, West Nusa Tenggara.

### Trustworthiness

Credibility, transferability, dependability, and confirmability were enhanced by using Shenton's framework, (Shenton, 2004). Questions were asked in a logical sequence in semi structured interviews; after each interview, the participant was given a copy of their transcript to affirm the accuracy of the data, and they could give any additional information after the interviews. The researcher attempted to remain as neutral as possible, be aware of presuppositions about how the self-management in community is. Together the research team discussed the findings during the analysis process to make sure that themes that emerged from narratives of participants' descriptions reflected their experiences. The provision of verbatim quotations provided a check to ensure that the researchers faithfully presented the participants' experience.

### **Ethical Approval**

Participants provided written informed consent procedures to participate in this study. This study was accepted in the hospital's review board and local government.

# **RESULTS AND DISCUSSIONS**

Six emergent themes were identified to illustrate the self-management experiences

among patients with Type 2 DM. These themes were: (i) dietary adjustment, (ii) using medicine to decrease blood glucose (iii) taking exercise, (iv) taking care of DM by oneself, (v) social support and (vi) looking for information regarding DM.

# 1) Dietary Adjustment

Dietary adjustment refers to patient's efforts to maintain dietary intake and ensure that dietary intake is a safe and sufficient to keep his blood sugar stable. When dietary intake is felt by patients to be unsafe and sufficient for their needs, further patients begin to look for other alternative food that are safer in keeping their blood sugar still stable. This theme included two subthemes: decreasing carbohydrate intake and decreasing sweet food.

# a) Decreasing carbohydrate intake

This study found that patients effort to maintain dietary intake and ensure that dietary intake is a safe and sufficient to keep his blood sugar still stable.

I only eat 1 meal each day. Usually 3 times a day but now it has become 1 time a day. I often drink milk... (participant 3).

*Eat 2 times a day, morning and afternoon. Afternoon no eat anymore until evening except drink water.* (participant 5)

In another words, patient also try to find other alternative food that are safer in keeping their blood sugar content stable:

I was limited my diet, I ate brown rice, now my condition is better. I'm eating with brown rice. (participant 1).

### b) Decreasing sweet food

I never drank sweet tea, sometimes I eat a little sweet cake but it's not every day. (participant 1). I thought that durian fruit is a big enemy hahaha. (participant 2).

# 2) Using Medicine to Decrease Blood Glucose

The theme using medicine to decrease blood glucose defines as the approach chosen by patients to reduce or stabilize their blood sugar levels. This theme included three subthemes such as: using herbal medicine, taking oral hypoglycemic drug and injecting insulin.

# a) Using herbal medicine

Patients choose to use herbal medicines because they feel safe and have few side effects. Moreover, the herbal medicine gives good effect to control their symptom:

I drunk herbal medication like daun salam or PKI...The gegereng powder is only small pieces of wood, sometimes I have added a ginger to get hot sensation, then the dizziness is gone. (participant 1)

I always consume herbal medicine like an insulin tree, I just drank the leaf. I only consume one leaf if I feel my blood sugar was rises. Sometimes 3 times a day, sometimes 3-4 times a week. I consume it as an addition. (participant 4)

*I take herbal medicine every morning*...(participant 5)

In another words, patients also use herbal medicines to decrease the doses of chemical drugs such as insulin:

> I routinely consume the herbal Mahkota Dewa. I tried to drink mahkota dewa while lowering my insulin levels, starting the insulin I used 12 units down to 8 units, 8 units down to 6 units, 6 units going down to 3 units and finally down in 2 units until I never used it again. I stopped taking insulin because there was mahkota dewa. (participant 3).

# b) Taking oral hypoglycemic drug

Patients choose to use oral hypoglycemic drug because they trust to recommendation by physician for using oral hypoglycemic drug to control their blood glucose level: I get a medicine from a doctor, I consume the medicine after breakfast, the reaction during the day. (Participant 2).

Usually my blood sugar is 300-400, to reduce it by drunk drugs which recommended by doctors (belidabet, metformin), I have both of them. I always consumption routinely. (participant 4).

Physician suggested me to drink metformin only for the last years (participant 6).

# c) Injecting insulin

Patients choose to use insulin injection because they trust to recommendation by physician for using insulin injection to control their blood glucose level. Moreover, the physician was recommended that insulin injection is safer for patient:

> Now I have used insulin. The doctor said insulin was safer. I'm using the insulin 3 times a day. Insulin was injected 5 minutes before eating. (participant 2)

> This month physician suggested me to stop consumption metformin but try to use insulin injecting at home (participant 6).

### 3) Taking Exercise

The term of taking exercise describes about patient's effort to control their blood glucose level by taking exercise. This theme included four subthemes, such as: taking exercise by waking, taking light exercise to decrease blood sugar, maintaining exercise habit and taking exercise with friends.

## a) Taking exercise by walking

In this sub-theme, the patient conveys the type of exercise was did, furthermore what the positive effects by doing exercise regularly for their body.

I traveled the distance of the farm by walking approximately 2 kilometers, if I use another road, the distance will be one kilometer... if I go there regularly, I feel more comfortable and healthier. (participant 1).

# b) Taking light exercise to decrease blood sugar

The patient conveys the type of exercise was chosen to control their blood sugar level.

I anticipate my excessive blood sugar with light exercise, such as running, playing ping-pong and walking in the morning. (participant 2)

### c) Maintaining exercise habit

The patient effort to control their blood sugar by maintaining the exercise habit, included when they were doing exercise, also how many times and frequencies for doing exercise:

It is necessary to do light exercise. There is a bicycle in my house. I was doing exercise by bicycle less than 5 minutes each day. (participant 3).

Every morning and evening I do exercise, approximately 3 km, at least 3 hours to stabilize my blood sugar. (participant 4).

*I am doing exercise after prayer in the morning...(*participant 5)

# d) Taking exercise with friends

This subtheme shows with who and what kind of exercise was did by patient for controlling their blood glucose level:

When afternoon I exercise with my friends, do tennis table. (participant 4)

### 4) Taking Care of Dm By Oneself

The term of taking care of DM by oneself describe about patient ability to make choices independently those how to deal with symptoms caused by diabetes and checked them self by considering with his physical, emotional, knowledge and believe.

### a) Checking blood sugar by oneself

The patient checks his blood sugar level independently to ensure his health condition:

I checked my blood sugar before drunk a mahkota dewa. After I drunk it, I measured my blood sugar 2 hours later and has down to 130 mg/dl. (participant 3)

### b) Injecting insulin by oneself

The patient shows his ability to make decisions about how to choose the location of insulin injection based on his physical, knowledge and believe:

> I injected it through my thigh or stomach, the location that is easily accessible. (participant 2).

### c) Controlling eat desire

This shows patient effort to take care of his self to keep his blood sugar still stable.

When I saw durian my desire to eat was very large. But when I remember I was suffering DM, I always tried to control myself. (participant 2).

### 5) Social support

Participants turn to their family, friends and their physician and or nurse for practical and moral support. They preferred their physicians to be aware of diabetes drug management and consistent to follow-up their condition (control blood glucose level, dietary adjustments, and listening to patient's personal stories). Further, participants discussed support from their family (wife and or Childs) and friends.

### a) Support from physician and or nurse

Physician talk to me, be careful drinking drugs without my recommendation. It's dangerous for your health. your blood sugar can drop immediately if you don't obey it (participant 6).

Nurse suggested me to check the blood sugar level regularly in his place (participant 1)

### b) Support from family

My wife supports me for the whole thing, I am happy and appreciate it. She says this is what you're going to eat. This is what you should eat; this is what you shouldn't eat. My wife control everything what I can and not eat (participant 6).

# c) Support from friends

My friend suggested me to use herbal medicine that he had been using. he

said it was effective and kept me always fit (participant 2). When in the office, my friend forbade me to drink soft drinks (participant 6)

# 6) Looking for Information Regarding DM

This term of looking for information regarding DM describe about the patient's efforts to find information about DM actively and passively from various sources and use it to understand the disease:

# a) Getting information from nurse

Patient get information about DM passively from nurse:

During this time, I often got information from nurse Lisa those reducing food - Sweet foods. (participant 1)

# b) Getting information from google

This study found that patient get information about DM actively from web:

I searched information from Google internet about how to make blood sugar always stable. (participant 3)

# c) Getting information from health worker

This study found that patient get information about DM passively from health worker: *I got information from health workers that diabetes is a genetic illness.* (participant 2).

# d) Getting information from physician

This study found that patient get information about DM passively from physician:

I had a discussion with my personal physician. I always consultation regularly. (participant 4).

This qualitative study was conducted to understand the self-management experiences of people with DM in Sumbawa Besar, West Nusa Tenggara. The participants reported that social support and valid information about DM are essential to their ability to self-manage their diabetes. Social supports may more easily make healthier lifestyle choices, regardless of social setting. Participants use of social support available from immediate family members. Based on previous studies and our results, Healthcare professionals should encourage the participation of family members, as well as other members of a person's social network, in diabetes selfmanagement education, (Mathew, Gucciardi, De Melo, & Barata, 2012; O'Brien, Van Rooyen, & Ricks, 2015; F. L. Wu, Tai, & Sun, 2019).

The information in education one was in this study was how to manage them self into food adjustment, exercise and medication. Valid information from educative process give great impact into self-management process will running well, (Ncama, 2011; Sassen, 2018). The study result showed that self-management affected by culture, social value and knowledge. It was match with study in other countries where increased understanding of diabetes care knowledge into the increased confidence and motivation necessary to improve patients' diabetes self-management, (Heisler, Piette, Spencer, Kieffer, & Vijan, 2005).

Strategies to provide information must be combined with other behavioral strategies to motivate and help patients effectively manage their diabetes, (Davies et al., 2015; Grady & Gough, 2018; Lorig, K.R and Holman, 2003). Information from health worker, web or patients experience has big effect to carried out a self-management in this study. However. doing selfmanagement without good knowledge may unnecessary and potentially even to unhealthy practices, (Atak, 2008; Sassen, 2018; World Self-medication Industry, 2010).

On the other hand, several participants had ability to manage them self very well. Although, it is depending on their knowledge, literacy and social economy, participant number three, four and five have shown that. Provide good, interesting and applicable information for patients become challenges in the future. As a result, patients may have good motivation to change their behavior and effect their selfmanagement, (A Bandura, 2004; Albert Bandura, 1978, 1986, 1989b, 1989a, 2002). In addition, the health, insurance and support systems of family must also be another consideration to make selfmanagement can be successful, (Vas et al., 2017).

Complementary therapy was popular used in Indonesia. Almost all participants from take this study to advantages of complementary therapy as an additional beside medical treatment. Patients got information about the function and usefulness of complementary therapy from various such television sources as advertisements, newspapers, google search, friends and family whose suffer diabetes. Communication between diabetes community, families and health workers are necessary in self-management, (DiNardo, Gibson, Siminerio, Morell, & Lee, 2012; Grossman, Roscoe, & Shack, 2018; Powers et al., 2015; Therapies, 2014).

Health professionals should give attention that complementary therapy was popular in DM patients who live in community, Sumbawa Besar, West NusaTenggara. Need intensive assistance by health workers, because if patients with DM continue to consume complementary therapy without basic knowledge of diabetes care, patients may risk at malpractice experience either hypoglycemia or hyperglycemia caused by medication dosage errors, (DiNardo et al., al.. 2012; Powers et 2015). complementary Misunderstanding of therapies selection will result in the wrong management, further complications in the future need to be aware.

This study was an in-depth interview only on six participants in Sumbawa City, West Nusa Tenggara. Therefore, they cannot be considered as representative population among experience of patients with DM in Indonesia. It might possible that patients who participate in this study have different experience from those who were not participate. The generalizability selfmanagement experience among patient with DM is unknown. Both quantitative and qualitative studies with big sample and multi-site in the future research are needed.

# CONCLUSION

This study is considered as the first research to explore the self-management experiences among patients with Type 2 DM at community in Sumbawa Besar, West Nusa Tenggara, Indonesia. Health workers should begin to realize that each patient has ability to carry out of self-management. The difficulties among patients were control desire to eat and availability of valid information from trusted sources. Basic information about disease becomes the most important thing before the patient with DM is able to perform self-management. Moreover, better understanding of disease and good awareness among patients with DM makes self-management will be successful.

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Nursing Current Vol. 8 No. 1, Januari 2020 – Juni 2020

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