Experience of patient's non-adherence to the treatment of diabetes mellitus (a phenomenology study on the context of nursing care in CM Hospital, Jakarta.

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Abstract— Diabetes Mellitus (DM) is a heterogeneous disorder with improvement of blood glucose. The disease can be treated by using four pillars of handling of DM. The pillars are health education, planning of diet, physical exercise, and the using of medicine which have to use for a lifetime. This qualitative study adopted phenomenological approach which goal was to explore various experiences of patient's non-adherence to the treatment of diabetes mellitus. Participants were selected according to certain criteria by using convenience method. Eight participants who participated in this study had experience of non-adherence to the treatment of diabetes mellitus in RSUPN Dr. CM Jakarta. Data were collected through in depth interview process in two phases and accompanied by field notes. The interview was recorded and converted in to verbatim transcript and then analyzed by using Collaizz's method. The results identified seven major themes which consist of unhappiness diet, not understand about the benefit of diet which made non-adherence, not understand about the benefit of physical exercise for the treatment of diabetes mellitus, the age is old, physical disability makes patient did not do physical exercise, incorrect understanding about the benefit of medicine, fail to adhere taking medicine because of economic reason. This study concludes that the most reasons of patient's non-adherence to the treatment of diabetes mellitus is "not understand the benefit of adhering the treatment of diabetes mellitus". The results of this research give implication about the necessary of giving health education continuously, especially in medical surgical nursing area to improve the adherence of patient with diabetes mellitus. Researcher suggests the need of nursing skills improvement about how to give a good health education, make a program to improve patient's adherence, and make other research to explore patient's adherence with four pillars specifically.

Keywords-component; Experience of non-adherence, patient with diabetes mellitus, the treatment of diabetes mellitus.

I. INTRODUCTION

Diabetes Mellitus (DM) is a heterogeneous disorder with improvement of blood glucose or hyperglycemia. Insulin is a hormone produced by pancreas which functions to control glucose in blood by controlling the production and its storage (Brunner & Suddarth, 2013). Body's ability to deal with insulin can be decreasing or pancreas can stop the production of insulin.

Changing in life style including eating habit can increase the number of patient. A survey done by WHO in 2013 said that Indonesia is on 4th place after India, China and the USA for the biggest number of patient in the world, with 8.5% prevalence of total population or about 17 million people. While in Indonesia, among other endocrine illnesses, the number of home-rest patient of Diabetes Mellitus has been on the 1st place with about 13 million people with DM (Depkes RI, 2013, Riset Dasar Kesehatan. http://www.litbang.depkes.go.id/sites/download.

Primary prevention to individuals which have life style modification is eating habit, physical activity, weigh loosing and joining related-seminar periodically. While the secondary is to prevent acute complication or in long term prevention, including checking blood pressure, checking feet and eyes regularly, the protein urine and stopping smoking habit. This illness is incurable yet we still can control it by obeying the four pillars of DM such as health education, diet program, do exercises regularly and take hypoglycemic or insulin for the rest of your life. Doing all of these is not an easy work for the patient so that many of them fail to do it.

A study in India reports that the number of patient who fails in diet program and glucose monitory is as much as 63% (Delamater 2006). A study in US shows about 48% of the patients failed to do the diet and physical activity programs. Anderson and Gustafson (in Delamater 2006) reports that 70% patients failed to have a diet on carbohydrate. A study in North California found 67% diabetic patients, type 2 did not monitor their glucose regularly as they should, 25% failed on the use of oral hormon, 63% in informal physical activity, 92.3% unorganized physical activity, 85% did not buy

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prescription. While a data from a survey done by public health faculty, Universitas Idonesia, shows that 80% DM patients did not have insulin injection hygienically, 58% had it in a wrong doze, 77% miss-interpretation and miss-read the glucose, 75% did not have a suggested eating habit (Darmayanti 2008).

In the 10th conference of North American Nursing Diagnosis Association-NANDA in 2013, the adherence issue itself had been listed on Nursing diagnosed that should be treaded specifically by the nurse (Doenges, 2013). A nurse, as one of professions that use nursing in handling patients, has a series of intervention to prevent and handle the adherence problem. The nursing intervention used to adherence as written in *Nursing Intervention Classification (NIC),* including health education, health system indicator, goal statement, nutrition control, having contact with patient, self modification aid, self responsibility facility and teaching patient (Dochterman & Bulechek, 2012).

National Public Hospital Dr.Cipto Mangukusumo (RSUPN Dr. CM), a pointed national hospital, has a great number of DM patients and it is increasing every year. Mostly, the patients have already been in critical complication like gangrene that needs to be amputated. When doing the nursing application in that hospital, the researcher discovered that some patients neglected the diet program, physical exercise, and taking oral medicine regularly. Looking at the big number of DM patients who have chronic complication like gangrene, blindness, stroke and some others, it can be said that this non-adherence phenomenon has been happening for a long time.

Interfering to this non-adherence can be classified as unique because it is more to psychological sense so that it should be researched intensely by using cumulative method through descriptive phenomenology approach. The purpose of the research is to seek for and answer and deep, and detail information from the patients about their perception, opinion and also the insight feeling of non-adherence's experience to the treatment of diabetes mellitus. This research is very important to see how they see about this non-adherence to the treatment so that nurses can find a better way to deal with them. Deeper interview is expected to make the patients realize how important the treatment is and to find new ways that are culturally more accepted by their society.

Method

This is an exploration research that uses descriptive phenomenon method emphasizing on the effort to understand human behavior based on the informant perspective (Creswell, 2013). The method can understand and explain naturally about DM patient's life experience of non-adherence to the treatment of DM at RSUPN Dr. CM Jakarta based on their perspective during the research. Since what the research does is exploring patients' experience, therefore this can also be applied in another place with different kind of illnesses.

Researcher got the expected response from medical report in nursing room. Approach through consensual decision making or informed consent methods (Streubert & Carpenter, 2007). Sampling procedure using convenience sampling is by using a group of people who are ready and willing to be the samples.

Another aspect that should bear in mind is the principle of autonomy which lets the sample decide whether they want to do it or not without any force and they can resign anytime they want without any penalties. The principle of justice will assure that informant or sampler will be appreciated and respected and any information regarding the sampler will be kept secret and confidential and anonymous (Streubert & Carpenter, 2007).

Eight people participated were from RSUPN Dr. CM Jakarta as follows: 1) Has been medically diagnosed as DM patient type 2 since at least two years ago; 2) Goes to those group of non-adherence to DM treatment with HbA1c point in the last 3 months is >7%; 3) Age >40; 4) Not in complication condition like coma etc; 5) Agree to join the research by signing letter of agreement; 6) Able to tell their experience clearly.

The data were taken twice through interview, first is to get the data and second one is to validate the data. Each interview was done in 60 minutes. The patient was free to choose the place which he thought was comfortable enough to tell the story. Even he was allowed to lie down during the interview. The interview finished when there was no more new information that could be obtained from them (Polit & Hungler, 2001).

Result

a. Demographic Data

Eight participants are all patients who are DM type 2 diagnosed since 2 years ago and were being hospitalized in 8th floor RSCM Jakarta when this researched were done. There are 6 female participants, 2 are males. Five participants are housewife the rest are teacher, security guard, and labor. The average of the age is 57,7 years old, the youngest is 48 and the oldest is 80. They were diagnosed by DM since about average 7,2 years ago, the earliest was 2 years ago the longest is 15 years ago. Their educational backgrounds are 3 participants Elementary, 2 Senior High School, 2 Junior High School, and the other 2 are Diploma and Teacher Training. Participants are majority Islam (7 participants) and one participant is Christian. All participants are married, 5 participants are widow/widower, 1 participant is left by his/her spouse, 1 is divorce, and 3 participants spouse were passed away. The average of HbA1c is 9.46% with the lowest value is 8,1% and the highest is 10,4%. The most race is Javanese which is 4 participants, and the rest are Sundanese, Batavianese, Ambonese, and Chinese.

b. Result

There are 7 main theme explaining participants' experiences to disobeying DM action, that is: unfavorable diet food, disobeying caused by the less understanding of the benefit of diet, disobeying DM action caused by the less understanding reason of doing the physical training, too old,, physical limit causes not doing the physical training, miss understanding about medicine, failure of drinking medicine caused by financial.

DISCUSSION

1. Unfavorable diet food

The study result found some of the participants has understood diet suggestion, but they did not obey the diet suggestion, some of them said that diet food doesn't meet their taste and their eating portion. Diet food tasted not good, plain, little portion, made hungry and pain, wanted to taste other food which is not on their diet suggestion, and feels suffered or sad by the limitation of their food. Patients often felt uncomfortable with their relatives' respond who reminded them about their diet food, in other side the patient really want to add some more food. Uncomfortable taste is one of the stressor itself which is mostly disobeyed by the patients. Consciously they often add some ingredients such as salt or sugar into their food or eat the common menu for the other family members. Participants also often add food portion and add some snacks between their meals.

This is like what Darmayanti found that 75% DM patients did not have the right eating habit. (Darmayanti, 2008, Patients' adherence, 3, http://64.203. 71.11/kompas.cetak/0507/01 /humaniora/1858574.htm on 19 Jun 2008). Same result was also reported by the DM Nursing Center RS Thamrin Jakarta, that 75% of the patients did not have diet because of some different reasons, if only they had taken the right therapy, they would have lived normally (RS Thamrin, 2008, Diabetes nursing center, 5, http:// www. thamrinhospital.com/old/services.html on 19 Jun 2008).

The participants eat because they still feel hungry and it's in line with Stutson & Plant research (in Delamater, 2006). It says that patients did not have the right diet, eating because of the suffer of feeling hungry or depress because of the limitation. People who do diet have adherence issue related with negative emotion like stress and depression. When they get more stressful, they tend to eat even more.

Researcher found that DM patients in Indonesia do not have enough willingness to have healthy life. Many of them still think that if it doesn't give them direct effect like skin burnt or hard to breath then they still need no help. It can be seen from patients who will eat as they like, as long as it won't cause them direct effect like coma. This also is influence by the believe of our culture that death is nature and it's God's will so that whatever the reason that causes death, including breaking diet rule, is simply because of destiny and its God's will. This believe that causes lots of patients do not have right eating habit.

2. Lack of understanding of having the right diet causes the non-adherence

Most of the respondents have miss-perception when they were asked about their bad eating habit. They are, that diet is to control glucose and this rule may be broken once in a while. What has to reduce is just sweet food or the sugar. Having snack is okay for just a little. Lack of knowledge of the right portion of eating. It is okay to have cookies as long as the sugar used is diet sugar. These miss-perception show how bad their knowledge about the right diet.

This also can be seen from the data taken from Thamrin Hospital Jakarta that patients who do not have enough knowledge about healthy life have 4 times the possibility to get complication (RS Thamrin, 2008, Diabetes Nursing center, 2, http:// www.thamrinhospital.com/old/services.html on 19 Jun 2008). Health education is important thing that should be given to DM patients. Beside the support from medical team, family, or people around them, patients also have an important role in managing themself. Socializing and telling them what they should do to DM patients not only be done by their doctor but also by some others like nurses, social workers, nutrients, and so on depending on their specialist. And also not mention researchers with their books, medical journals (Misnadiarly, 2008, Feet problem of Diabetes patient and the way to deal with. Badan Litbang Kesehatan, 5, http://www. tempointeraktif.com/medika/arsip/052001/hor1.htm, on 19 Jun 2008.

Poor knowledge will make the patients less care about their illness and end up with the non-adherence. This is because they do not communicate a lot with the experts and their education background that are still low. Most of the participants only finished from primary school and they do not often go to medical center to have their health controlled. The poor knowledge is also caused by their financial problem. Their income is only enough for meal, not only going to the medical center nor buying newspaper to seek for information. The poor have difficulty to access free information source like leaflet because they think they will have to pay if they come to medical center. Most of them are jobless so that there is no guarantee they get decent food. And they will eat everything they can whenever they attend a party even if it will break the diet rule. This is a confession from a participant who said that he would eat good food at the party and would only eat once a day on working days.

3. Fail to understand the advantage of physical exercise for DM treatment.

Almost all participants have wrong perception about the benefit of exercises. They only know that exercising is only needed for their health in general, that is to freshen up, clear the blood stream and build muscle. Specifically, the advantage of physical exercise that is to control patients' glucose has never been understood by them.

Most of the participants, based on the Delamater study (2006) found that gender has something to do with adherence. Male is physically more active than female, but they also consumes more calories, have worse eating habit and have more tendency to break the diet rule. Darmayanti also supports this and says that level of adherence of DM patients is varied. Some patients who had had medical education were still unable to do it. There're also patients who had heard and understood about the importance of adherence yet they still couldn't accept the program. And some others accepted the suggested program but failed to do it and there're patients who had done the program but discontinued. Some diabetes risk factors like overweight, age, bad eating habit, lazy life style, and stress happen mostly in big cities. Laziness increases the number of patients and also the number of complication (Darmayanti, 2006, Adherence of patient, 4, http://64.203.71.11/kompas cetak/0507/01/humaniora / 1858574.htm on 19 Jun 2008).

4. Patients' old age became the reason they neglected physical exercise

Their old age became the reason they did not do physical exercise. This is in line with Delamater (2006) that patients who have reached 25 will do exercise that will only burn less calories or in a way of recreation like going on vacation and exercise lesser every week. (Delamater, 2006, Improving patient Adherence, 28, www.clinical.diabetesjournala.org on 8 Jan 2008.

Most of the participants are female and in average, they are old and widows. This makes them think that physical exercise will only make them tired, loose passion, and they have no one to talk to so they feel lonely. This is influenced by Indonesian culture that farming is their common job, working in a farm without using any ergonomic equipment or body alignment when harvesting because they think it's exercising already and dry season is considered relaxing time. Having exercising is not common here only a subject that school kids have to do at school. This can be seen by the low number of gym or exercise club or their member in Indonesia for both health and sick people like exercise for healthy heart, exercise for old people, exercise for DM and so on. This miss-perception not only come from DM patients but also the healthy and intellectual. Exercise campaign declared by the President of RI Susilo Bambang Yudoyono which is bike to work only done by few people. The miss-perception that exercise is only for healthy people has made them not do the exercise well.

5. Physical disability made them neglected physical exercise

Participants in this research, some understood clearly about the function of exercise but being not able to do it because the disability of amputated foot, body immune that has getting weaker, and loose of balance. This limitation has made them disobey to suggested physical exercises. This is in line with Doenges (2013), DM patients with complication, often had sensor-perception disorder like endogen changes, imbalance glucose, and weak electrolytes, long healing process, dependence, missed the treatment, and depression towards physical disability. The complaint is usually about their disability to do their routine, they are so weak and has no passion.

They actually can do light exercise on bed like shaking heads, deep breathing, meditation, yoga or others. Lack of their understanding to exercise does not only happen to them, but also to those who are still healthy. This is indeed not Indonesian culture. The researcher sees that the foreigner mostly have more recognize to the importance of doing exercise. There where lot of sport public facilities can be found like in city park, town square and they are mostly visited by old people who want to do exercise in the morning and afternoon. They really enjoy walking around or doing exercise and they look very strong.

6. Misunderstanding the advantage of medicine.

Some participants said that they felt bored taking medicine for a long time. There are some who had been taking it for 15 years. The long time and their perception that there is no changes at all made them feel bored. They forgot or avoided taking medicine. This is supported by Glasgow and friends (in Delamater, 2006) that says duration of the occurrence of an illness has negative relation with adherence. The longer a patient has DM, the lesser the level of adherence to the treatment they could be. A related study in Poland and the USA found that illness duration also have a relationship with controlling insulin, like a kid who has been ill for a long time couldn't remember well their insulin injection compared with new diagnosed kid (Delamater, 2006, Improving patient Adherence, 24, www.clinical.diabetesjournala.org on 8 Jan 2008)

Most of the participants' age is elderly, and this is just like Delamater research (2006, Improving patient Adherence, www.clinicaldiabetesjournala.org, 29, on 8 Jan 2008), It said that older patients have a tendency to do mistake in controlling insulin that is forget to inject compared with the younger patients. This data is the same as that from RS Thamrin Jakarta where the level of adherence long term therapy of DM patients is only about 50%, where 58% DM patients has misused the medicine and 80% inject the insulin in a wrong way. (Diabetic Nursing Center, ¶ 5, http://www.thamrinhospital.com/old/services .html, on 19 Jun 2008)

Researcher found that the habit of not taking medicine is influenced by Indonesian culture that prefer to take traditional medicine like jamu even if it hasn't been scientifically research about the level of blood glucose in it. Moreover there are many fake jamu, traditional herbal medicine on the market that will possibly make the body less immune. For the last few years, the government through BPOM has announced that some traditional medicines or jamu are not allowed to be on the market. A lot of patients also get bored and choose a shortcut to go to traditional healer that claim can heal lots of kind of illnesses. They can easily believe that their illnesses can be cured and then they leave their insulin away. The fact is that the illness can never be cured, we can only control it for all life time.

7. Financial Reason

Some participants did not take the medicine because they did not have enough money. It can be shown by their effort to do the following things; taking medicine from other people's prescription which they thought having the same illness, buying medicine from their previous prescription without having checked their up to date condition, or postponing to buy the medicine until they have enough money. It is the same as Rietle's research (in Delamater 2006) which took patients from general medical setting in USA and found that the cost of medical was the greatest obstacle to deal with. Especially for patients who are in medication. (Delamater, 2006, Improving Patient Adherence, ¶ 34, www.clinicaldiabetes journala.org on 8 Jan 2008)

It was money that had become the reason why almost all participants did not take medicine regularly. Until the can afford the cost of medicine, their condition will get worse so that they have to be hospitalized. This situation forces them to apply for medical insurance. Even though there are lots of them got help with this medical insurance yet they are still in trouble because there are some others that aren't covered by

the insurance. This condition can cause stress and depression. This is in line with the finding from Delamater (2006), which says that depression related with high cost of DM treatment. There are a lot of people from developing countries including the poor and the minority, have to deal with the economic growth of the 20th century. They have become the victim. There is some environmental change and the high gap between the poor and the rich. Living poor causes the bad health. (Delamater, 2006, Improving Patient Adherence,¶ 34, www.clinical.diabetes journal.org, on 8 Jan 2008).

Based on these finding, the researcher recommend to have further phenomenology research to dig deeper about patient's non-adherence to the treatment of DM on each pillar specifically like factors causing patient's non-adherence to diet program, factors that make them too lazy to do diet program, diet experiences including type of meal, the portion, serving and cooking method, and other reason identification. Not to forget, identifying patient's need in order to follow the DM treatment right.

Conclusion

1. The existence of patient's non-adherence to the treatment of DM at RSUPN Dr. CM Jakarta are caused by 7 main themes as follows: unpleasant diet meal, failure in understanding the advantage of diet causes the non-adherence, failure in understanding the advantage of physical exercise to the treatment of DM, age reason, physical disability causes zero exercise, misinterpretation about the use advantage of medicine, failure in taking medicine because of economic reason.
2. Patient's non-adherence to giving nutrient or diet caused by unpleasant diet meal and lack of self-responsibility.
3. Patient's non-adherence to physical exercise caused by lack of understanding the advantage of physical exercise to the treatment of DM, and age reason and physical disability make them not exercise.
4. Patient's non-adherence to taking Oral hormone medicine regularly caused by the misunderstanding about the advantage of medicine and economical reason.

Suggestion

1. The Institute of Nursing

Based on the research where almost all the patients have the misunderstanding about the advantage of the DM treatment has caused non-adherence. Therefore nurses have to build a program that can improve the understanding and the adherence. This can be achieved by giving them some workshop about health especially the importance of diet, taste builder modification and reasonable portion, the importance of physical exercise, modification of physical exercise for those who have disability, the importance of taking medicine regularly, the advantage of medicine to DM patients and health check-up regularly using medical insurance, insurance for poor people if they cannot afford the cost. Nurses have to improve their ability to give health promotion, upgrade their knowledge, skill and caring behavior through formal education and workshops so that they are able to give comprehensive service to improve patient's adherence to the treatment of DM. Knowing the big number of patients who do not take medicine due to the cost reason, nurses in cooperation with the government are expected to give more accessible medical service for the poor and should be continuously watched.

2. Nursing Development

Consideration to make a program or nursing intervention for helping increase patient's level of adherence through giving workshops continuously, to ask patients and their family and also the society to care more and to motivate the patients to do the 4 pillars of DM treatment which are health education, diet, physical exercise, taking ORAL HORMON and also to do follow up on patient's behavior on that program.

3. The next research

Phenomenology follow up research is to dig deeper in term of patient's non-adherence to the treatment of DM on each pillar specifically, like some factors which influence the patient's lack of understanding to diet program. Factors which make patients fail to have a diet. Diet experience including type of meal, portion, and food making and serving should be examined so that some other reasons can be identified.

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