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Lay Perspectives on Diabetes Mellitus: A Qualitative Analysis in Indonesian Context

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Abstract— *The trend of prevalence of people at risk of diabetes is increasing in the world. In Indonesia, the number of at-risk people of diabetes is almost twice higher than the prevalence of diabetes. This study used qualitative descriptive design aiming at identifying lay perspectives on diabetes mellitus in North Sumatera Province, Indonesia. Purposive sampling was used to recruit 53 people at risk of type 2 diabetes mellitus, 2 village headmen, and 11 health volunteers. The open semi-structured face-to-face interviews and focus group discussion were used to collect data, and content analysis was employed to analyze qualitative data. There were five themes emerged: 1) meaning of diabetes mellitus; 2) diabetes mellitus risk factors; 3) low self-care; 4) insufficient activities to prevent type 2 diabetes mellitus; and 5) no community policy. The information from this study provided useful insight regarding opinion of diabetes mellitus in the community and served as ground evidence for action plan on type 2 diabetes mellitus prevention in the community setting.*

Keywords— *Perspectives, type 2 diabetes mellitus, qualitative study, Indonesian context.*

I. INTRODUCTION

One of largest global problem in the world at the 21th century is Diabetes Mellitus. Around the world, the prevalence estimated of 9% in 2015 and become of 10.4% in 2040 (IDF, 2015). In Indonesia, the diabetes prevalence people of age 20-79 years was 5.7% in 2007, and increased to 6.2% in 2015 (Soewondo *et al*., 2013). The trend of increasing diabetes prevalence is correspondingly followed by the prevalence of people with risk for diabetes. Approximately 318 million, or 6.7% of adults in the world are at risk to develop diabetes. By 2040, the number of these population will increase to 482 million, or 7.8% (IDF, 2016). A result of study throughout 33 provinces across Indonesia, showed that 10% of adult population was at risk for diabetes, which was almost twice higher than the prevalence of diabetes (Soewondo and Pramono, 2011).

Progression of risk people developed into type 2 diabetes is not happen acutely, develops gradually over time. A study argued that among newly identified impaired fasting glucose (IFG), the progression to diabetes took time in <3 years (Nichols *et al*., 2007). The percentage of progression of individuals at risk into diabetes can reach 70% (Tabák *et al*., 2012). Hence, prevention of diabetes is the ultimate opportunity to address the personal and societal burden of type 2 diabetes (Whittemore, 2011).

Many studies in clinical trial has disclosed that lifestyle change and pharmacological treatment can prevent or delay the progression of diabetes among risk people. The most effective prevention of diabetes was lifestyle change. Lifestyle change on healthy diet and physical activity can persist as long as 15 years to prevent or delay risk people develop into diabetes (Diabetes Prevention Program Research Group, 2015).

The increased prevalence of diabetes in Indonesia also the impact of urbanization that affecting their lifestyle (Novo Nordisk, 2013). Efforts to control diabetes, Ministry of Health of Indonesia has issued programs which implemented in health care system in Indonesia. Diabetes is one of nine diseases that become priority to overcome in Indonesia. Indonesia government has launched two programs in attempt to manage diabetes prevention, management, and complication. The first program, named the chronic diseases management program (*Prolanis, Program Pengelolaan Penyakit Kronis*) which is implemented to treat and prevent complication of people with diabetes (Indonesia Ministry of Health, 2012). The second program, the integrated coaching posts (*Posbindu, Pos Pembinaan Terpadu*), focus on diabetes and other non-communicable diseases prevention (BPJS Kesehatan, 2014). Even though Indonesia government has been implemented the *Prolanis* and the *Posbindu* program related to diabetes control and prevention, in fact, the programs cannot cover the whole area of Indonesia country. The prevalence of risk people of diabetes is still high. Health systems in Indonesia still focus more on the treatment of infectious diseases. Therefore, a need for a population-focused health care program become more important, and diabetes prevention programs are one of the challenges faced by public health services (Novo Nordisk, 2013). The aim of this research was to explore the perspectives on diabetes mellitus among risk people in the community of two sub-district of North Sumatera Province, Indonesia. This study was conducted as part of an ongoing action research project to develop a community-based care program for risk people to prevent type 2 diabetes mellitus in Indonesia.

II. OBJECTIVES

The aim of this research was to explore the perspectives on diabetes mellitus among risk people in the community of two sub-district of North Sumatera Province, Indonesia. This study was conducted as part of an ongoing action research project to

develop a community-based care program for risk people to prevent type 2 diabetes mellitus in Indonesia.

III. Methodology

This was a qualitative descriptive study, and was carried out by following the steps of qualitative descriptive study proposed by Sandelowski (2000). Sandelowski argues that qualitative descriptive study is appropriate for a research that describes a comprehensive summary of events in the everyday terms where the data are collected.

The setting took place at two sub-districts of Deli Serdang district, North Sumatera Province, Indonesia. Two villages were chosen as representative of each sub-district. The participants were 70 persons from the two villages, consisting of 53 at-risk people, 2 village headmen, and 11 health volunteers. The participants were recruited by employing purposive sampling technique. Participants' inclusion criteria were able to read and write in Indonesia language and willing to participate in the study. For those at-risk people for type 2 diabetes mellitus, other inclusion criteria was having risk score of ≥9 from screening process. The instruments used in this research were: the Finnish Diabetes Risk Score (FINDRISC) as screening tool for at-people for type 2 diabetes mellitus, which was translated into Indonesian; open semi-structured question guideline to conduct focus group discussion (FGD) and face-to-face interviews; and a sound recorder to record the conversation during FGD and interview.

Data collection was conducted by face-to-face interview and FGD. The data collected on sound recorder were transcribed by verbatim. The data analysis followed the step of qualitative content analysis proposed by Elo and Kyngäs (2008). The data analysis started by determining research unit of analysis, consisting of all words and sentences recorded during interview and FGD. The next step was open coding, and followed by coding sheet, grouping, categorization, and abstraction. All of the codes were collected and put in the coding sheets. The final step was generating categories, and each category with similar meaning was put together under higher level of headings. The categories with similar meaning were assembled to create themes. In this study, the researcher followed Guba and Lincoln's criteria to maintain rigorous of the study result (Schwandt, 2007). The techniques conducted for establishing credibility were member checking and triangulation. Transferability was established by purposive sampling and thick description. All data were well documented and the dissertation advisor suggestions was the techniques to establish dependability. The data in this study were interpreted based on the real data from all participants that included focus group discussion and in-depth interview to achieve confirmability.

This study was approved by Ethical Committee for Human Research of Khon Kaen University, Thailand (Reference No. HE602213). As guidance, the researcher followed ethical consideration guided by Koch and Kralik (2006) consisting of autonomy, beneficence and justice. Autonomy was employed by giving the information sheet and consent form for participants prior to their involvement in the study. Thus, the participant understood and had freedom to participate and withdraw from study process freely. Beneficence was applied by providing assurance for participants' personal identity by holding the principle of anonymity and confidentiality. To apply justice, the researcher explained the drawbacks and benefits to participants as well as a guarantee of their privacy and identity.

IV. Results

This study was conducted in two villages in Deli Serdang District, North Sumatera Province, Indonesia. In 2017, the population of village 1 and village 2 reached 12,144 people and 4,529 people respectively (Sussiatri, 2016; Tallo, 2016). There were five themes emerging from qualitative content analysis: 1) Meaning of diabetes mellitus; 2) Diabetes mellitus risk factors; 3) Low self-care; 4) Insufficient activities; and 5) No community policy.

Theme 1: Meaning of Diabetes Mellitus

Diabetes known as *penyakit gula* (sugar disease)

In this study, instead of diabetes, most of people in the community know diabetes mellitus as *penyakit gula* (sugar disease) or simplify as *gula* (sugar). The term of diabetes was not much understood by the community members. They call it sugar disease based on what they heard from friends' explanations, what they observed on the person who had diabetes in their community, the results of the explanation of their family members who had diabetes, and information from doctors.

"Here, we call diabetes as a sugar disease. Generally, we do not call it diabetes, but sugar disease. Diabetes is identic with sugar disease. Maybe blood sugar levels are excessive. People know diabetes more as sugar disease. There are some who call it as diabetes, but only 1 out of 10 people" (Village headman - Village 2).

"I think diabetes is a disease of sugar. I have never had diabetes before, so I want to ask about the symptoms of the disease" (Risk people, No. 1.2 - Village 1).

They call diabetes mellitus as sugar disease because the urine of diabetic person is sweet and when urine is left in an open place it will be surrounded by ants.

"According to people, diabetes is called sugar disease because the urine is sweet when tasted. That is why it is called sugar disease" (Risk people, No. 1.7 - Village 2).

Diabetes type: wet and dry

Most of the community members viewed diabetes into two types: wet and dry sugar disease. Wet type of diabetes refers to the presence of wounds that are difficult to heal; the wound is wet and produces exudate as well. When people with diabetes have a wound, then those people are included in wet type. Meanwhile, dry type of diabetes, demonstrate the criteria based on the thinness or fatness of the body of diabetic patients. When a diabetic patient is initially fat, and then their body become thinner, these diabetic patients are classified into dry type of diabetes.

"... but, what I understand is that diabetes is divided into two types, wet sugar and dry sugar" (Village headman - Village 1).

"People who experience wet sugar, when they are bitten by mosquitoes, the bite marks will become wound. When their legs stumble, their legs become rotten and even break. Well, it does not happen to people suffering from dry sugar. In dry sugar, their bodies are thin" (Health volunteer, No. 2 - Village 1).

"My father had a dry sugar disease, my mother had a wet sugar disease. My father, when he had a wound, his wound did not take a long time to heal. My mother, when she had a wound, the wound was wet and became pus as well. My grandfather had wet sugar as well. His legs were ever planned to be amputated. Because his leg sores could not heal, he finally passed away" (Risk people, No. 2.4 - Village 1)

Diabetes are frightening, terrible, and scary disease

They stated that diabetes is a deadly disease, especially for those poor people because they will not be able to affords treatment for diabetes. They also perceive diabetes as frightening, terrible, and very scary disease for many reasons. They believe that there is no cure for diabetes and sometimes it ends with death.

"Diabetes is a frightening and terrible disease, because eventually, diabetes will result in death to those who experience it. This is something that is real…Diabetes is a frightening disease because there are no drugs that can cure diabetes…We do not know exactly what diabetes is, what we understand is that it is a disease of sugar, a very scary and terrible disease because it cannot be cured. In this community, no person with diabetes has ever recovered. In fact, it ends with death" (Health volunteer No. 3 - Village 2).

"Diabetes is a deadly disease, especially for people who have no money" (Risk people, No. 3.7 - Village 2).

"Diabetes is a frightening disease. It must be prevented before the disease attacks our body" (Risk people, No. 1.1 - Village 1).

Diabetes disturbs husband and wife personal relationship

According to the experience of community members, diabetes could be complicated to body organs such as kidneys, eyes, diabetic wounds, and heart diseases. In addition, diabetes can also cause interference between husband and wife relationships. The sexual relationship of husband and wife becomes disrupted and could end in a divorce.

"…In addition, "nafsu besar tenaga kurang" (a proverb in Indonesia, which can be translated as "Big lust, less power"). Especially in men, when they have diabetes, their sex desire decreases…Based on the experience of a wife whose husband suffers from diabetes, in fact, his wife left her husband because her husband has diabetes, he could not satisfy (the sex desire of) his wife, so she left her husband" (Health volunteer, No. 1 - Village 2).

"In addition, people say, the routine of husband and wife relationship is also disturbed. But I do not believe it, because the one who speaks is not a doctor. I do not know" (Village headman - Village 1).

Theme 2: Diabetes Mellitus Risk Factors

Heredity is the most dominant

Community members argued that various risk factors of diabetes were unhealthy eating patterns and lack of activity. However, according to their understanding, the most dominant factor is hereditary.

"First, the greater factor is heredity, then, an improper diet. In my opinion, it may be more to heredity factor as well as, smoking, sleeping late nights and irregular rest. But, average cause is family factor" (Village headman - Village 2).

"I think diabetes is caused by heredity, diet and obesity. But, the most dominant factor is heredity" (Health volunteer, No. 5 - Village 2).

"Diabetes is a hereditary disease. My father had diabetes, so I participated in this discussion. My conclusion, diabetes is a hereditary disease" (Risk people, No. 2.2 - Village 1).

Eating before bed time

Community members highlighted a risk factor of diabetes is having dinner at late night and directly going to bed for sleep.

"It is probably caused by dietary factors such as eating too much. Often eating at night, at 10 or 11 pm and immediately going to bed may cause diabetes. If we eat at night, we should go to bed 2 hours after eating" (Health volunteer, No. 2 - Village 2).

"Factor of food such as eating at midnight" (Health volunteer, No. 1 - Village 1).

"It is caused by the habit of eating rice before bedtime. It is caused by eating rice before going to bed every night" (Risk people, No. 1.6 - Village 1)

Lack of physical activities

They also agree that the risk factor of diabetes is lack of activities, and suggest people do physical activity.

"Maybe physical activity. Indeed, we must always do physical activities. We cannot stop it immediately. So, what I told you earlier was like that. Once he does not work in the field anymore, he immediately experienced diabetes. Maybe sports should be done" (Village headman - Village 2).

"…Less physical activity, just writing, less energy burning in the body. For example, my father. My father worked in the office, he gradually developed diabetes. This happens because he lacks of exercise" (Risk people, No. 3.5 - Village 1).

Chemical ingredients in food

Community members also believe that another diabetes risk factor is the presence of chemical substances contained in daily food. These chemicals are food preservatives and substances that are used to accelerate the growth of animals and plants for human daily consumption.

"In my opinion, the cause of diabetes is the factors of food. The food we buy has been mixed with food preservatives…All bottled drinks and fishes contain preservatives. In addition, chicken meat…their growth (chickens) is accelerated by certain substances…In my opinion, it also affects the incidence of sugar disease" (Risk people, No. 1.1 - Village 2).

"…In addition, foods now contain lots of chemicals. For example, fried chickens which are sold in market. They come from chickens that have been injected by chemical substances. Chicks can reach their maturity within 23 days. Similar to plants, such as rice and chili, they are given chemical fertilizers. They are forced to grow fast" (Health volunteer, No. 1 - Village 1).

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"Both plants and the way of cooking. Food traders often use substances that can speed up the process of cooking food and beautify the appearance of their cuisine. They use food preservatives so that their foods become soft" (Health volunteer, No. 3 - Village 1).

Theme 3: Low Self-Care

Lack of awareness

Many community members were not aware of the importance of measuring blood sugar levels. This can be seen from the community members who have never checked their blood sugar levels. In general, they check blood sugar levels after their disease is severe and can no longer withstand the symptoms.

"I have never checked my blood sugar levels before. When I have headache I only go to a midwife. Then, one day, I could not sleep for a night for almost a month. I often urinated too. I experienced unconsciousness twice at home, and was eventually rushed to a hospital. I was hospitalized for 10 days" (Risk people, No. 1.8 - Village 2).

"It is because their sugar disease is already severe, and has many complications. Thus, they were recommended to be referred to a more advanced hospital…In fact, the patient's condition is already severe" (Village headman - Village 2).

Regarding taking care of diet and physical activities, the community member also show their unhealthy lifestyle. In addition, even though there is exercise activity held once a week in the village, they did not get involved in the activities.

"…My younger brother who has blurred vision, actually already knows that he has diabetes, but he cannot resist his appetite" (Risk people, No. 3.6 - Village 1).

"There is no time for exercise because we have to take care of the children, take care of husbands. No time for exercise. When the body is tired, I go to bed. That is all. Sweep and mop. Those things are equal with exercise" (Risk people, No. 3.1 - Village 2).

"I never participated (in exercise activities) because I needed to take a rest. Because I worked from Monday to Saturday" (Risk people, No. 2.2. - Village 2).

Physical activities depending on types of job

In terms of physical activity to prevent diabetes, there were no plan and regular implementation in both villages. Physical activity depends on their types of work. If they are housewives and housekeeping, their physical activities are related to cleaning the house and arranging home equipment. A lucky case is if they work in a multi-storey house, because they will go up and down the stairs in the process of carrying out their work. The same thing applies to those who work in their own fields or other people's fields. However, their physical activity depends on the stage of the field season. For example, during the harvest season they worked to lift crops, and in the growing season they worked to clear the fields of weeds.

"I work as a housekeeper in someone else's house. So, my sport is walking up and down stairs while working at his house. For example, I mopped the house from the first floor and then on the second floor. I do this every day, from Monday to Saturday" (Risk people, No. 1.8 - Village 1).

"My exercise is washing clothes, cooking, sweeping the house, mopping floors, and working in the fields" (Risk people, No. 1.8 - Village 2).

Diet pattern influenced by parent's eating habit

The people's diet in the community is significantly influenced by their cultural practice and followed by the next generation of their family member. The new generation follows their parents' diet habit. Their diet habits give them a sense of satisfaction of eating food.

"My parent's diet, after eating rice, they drank one large glass of coffee or sweet tea. After the meal, my parents said they were satisfied and relaxed. So, we, their children also make it as a habit by follow what our parents did. If we do not follow the diet, we are not satisfied" (Risk people, No. 1.8 - Village 1).

***Mentong* (eating after eat)**

In addition, one of the cultural practices in the communities in both villages is called *mentong*, which comes from the Javanese language. *Mentong* can be defined briefly as eating after having had daily meals. The basic principle of *mentong* is not to waste food. When cooked food is available, it must be consumed entirely. Otherwise, the food becomes wasted. So, even if they have lunch or dinner, but there is still food available, the food should be eaten before it becomes stale. The most common source of food for *mentong* comes from a party celebration in the village. Before the party is celebrated, in Javanese culture, food must be given first to community members, especially for close relatives or people who are considered influential in the village. Sometimes, in one week, more than one party celebrated in the village as well as the food they received.

"Mentong is dinner after dinner. Mentong time is uncertain. Dishes that are still available should be eaten before the they are stale. When food is available, if they are not eaten, the food will be wasted" (Risk people, No. 3.5 - Village 2).

"Mentong means eating again after eating. Extra eating. Mentong can be done at 4 pm. Mentong can also be done at night. I often have mentong too" (Risk people, No. 3.10 - Village 1).

"Mentong is a Javanese tradition. Usually, if anyone has a party, then rice and side dishes are delivered to our house. So, if there are five parties, then we will get five cooked rice as well, delivered to our homes. So, the food is eaten little by little. In the end, many foods are eaten" (Risk people, No.3.8 - Village 1).

Theme 4: Insufficient Activities to Prevent Type 2 Diabetes Mellitus

There were no activities in both villages which are specifically aimed to prevent type 2 diabetes. The community members conduct exercise only based on the initiative of community health center program which is held once a week. However, even though this activity is carried out only once a week, the level of participation of citizens is still low. Community members said that they need to rest after fully working from Monday to Saturday.

"Not available. In this community, there is no activity to prevent diabetes" (Health volunteer, No. 1 - Village 2).

"There is no specific activity to prevent diabetes. However, to find out if someone experience a sugar disease, there is a program called the posyandu for elderly. Everyone are allowed to come for a medical check-up. There is exercise activity in this village, but not specifically to prevent diabetes" (Village headman - Village 2).

"In this village there is no activity for diabetes prevention. Not available that I know. Diabetes prevention does not exist, it is only a check for blood sugar levels. There is no counseling to prevent diabetes" (Village headman - Village 1).

Counseling about diabetes has never been held, because there is not yet a team to carry out these activities. In addition, health volunteers are not confident in conducting counseling because they do not have accurate knowledge about diabetes and its prevention.

"…Counseling about diabetes has never been conducted here. I have *been here for a long time, now I have grandchildren, and there has never been any education about diabetes" (Health volunteer, No. 3 - Village 1).*

"…If the counseling is given by ourselves, they will not be convinced. Some will believe, but some will not believe in us. If we just do it ourselves, they just laugh. They do not believe it. If we were accompanied, maybe they would believe it. That is why counseling needs to be accompanied by a doctor" (Health volunteer, No. 3 - Village 1).

Theme 5: No Community Policy

Policies regarding the prevention of diabetes in both villages have never existed. They are entirely dependent on the policies of the primary health center (*puskesmas*). There was a program run by *puskesmas* called the integrated coaching post (*posbindu*), which focuses on the prevention of diabetes and other non-communicable diseases. However, the program could not cover the whole villages under its responsibility.

"Not available. About diabetes prevention does not yet exist. Once, we have done posbindu activities. But now, posbindu activity are combined with posyandu for elderly, because the activity of posyandu for elderly not only followed by elderly. Supposedly, the activity of posbindu are done separately with posyandu for the elderly, however, because our activity is very busy, thus, the posbindu activities are combined with the elderly posyandu activities" (Health volunteer, No. 1 - Village 2).

"…Posbindu activities are more often performed in community health centers. So, people are told to come to the community health center. The posbindu activity covers a wide range of diseases, so the implementation of their activities is carried out in community health center" (Village headman - Village 2).

V. DISCUSSIONS

This study results revealed low self-care on diabetes mellitus prevention. There was indication that low self-care was associated with the knowledge of community members regarding diabetes mellitus accurately, especially its risk factors, complication, and prevention. Even for those health volunteers, they have never received any counselling about diabetes mellitus, as one of them said "*I have been here for a long time, now I have grandchildren, and there has never been any education about diabetes*". These quotes indicated a gap of knowledge on diabetes mellitus among participants, which may lead to a low self-care.

According to Siguroardóttir (2005), knowledge about diabetes are prerequisites for effective self-care. Indeed, many studies have supported that lay persons generally lack of knowledge about diabetes mellitus. This issue is not only found in Indonesia, but also in other developing and developed countries around the world. A result of a study in Oman revealed that lay persons' knowledge about diabetes mellitus was suboptimal. It stated that only 17%, 21%, and 30% of participants understood that a positive family history, obesity, and physical inactivity, respectively, were diabetes risk factors (Al Shafaee et al., 2008). Even in developed country, adult people in Oregon who had high risk of diabetes were also unconcerned about their risk for developing the disease (Kemple *et al*., 2005). In addition, those people who have suffered from diabetes for many years, they still lacked of knowledge about the disease and self-care (Chavan et al., 2015).

Tuomilehto *et al*. (2009) stated that physical activity, body weight, and diet are the three main lifestyle issues that need to be noticed by people in attempt to prevent type 2 diabetes mellitus. In Indonesia, the impact of urbanization has affected two basic components of their lifestyle, a change in dietary patterns and lack of exercise. In terms of dietary patterns, almost half (45%) of Indonesians consume polished rice, and less high-fiber foods. Indonesian always consume carbohydrates twice as much as their body function needs. In terms of exercise, residents living in urban areas tend to adopt sedentary lifestyles (NovoNordisk, 2012). Indonesian people aged 18 years and above are found a lot to be not physically active with the percentage reaching up to 24% (Fountaine *et al*., 2016). Thus, any effort to increase their knowledge regarding diabetes mellitus will be the starting point to move into the next step to raise their awareness of the disease.

In Indonesia, studies on type 2 diabetes mellitus are mainly more on individual patients with type 2 diabetes rather than its prevention. A study was conducted to identify information on diabetes management, complication, awareness of self-control, and quality of life of patients with diabetes (Soewondo et al., 2010), a study was done to identify the physicians' awareness agreement, adoption, and adherence on type 2 diabetes mellitus guidelines (Widyahening *et al*., 2014), and a study was done to describe the prevalence and risk factor of type 2 diabetes in Indonesia. There was also limited study involving family as participants. Family member participation is important to increase self-care on diabetes. A study conducted by Wolde *et al*. (2017) found that there was a significant difference in knowledge and practice related to diabetes between those having diabetes family members and the control groups. The majority of those having diabetes family members demonstrated that they had good knowledge as well as practice compared to those who did not have diabetes family member. Hence, as a part of an effort to overcome diabetes problems as well as to meet the successful prevention of diabetes in Indonesia, a policy regarding type 2 diabetes

mellitus prevention is important to develop by involving in a bottom-up approach, participatory process, and involving and empowerment of people in the community.

VI. Conclusion

It was found out that the community members lacked of knowledge about diabetes and its prevention. As a result, their awareness of self-care to prevent diabetes was low. Self-care is the main domain for everyone to do health promotion and prevent various health problems. Community members still consider diabetes as a problem when they have experienced the disease and have complications. In addition, they still depend on government policies to do activities regarding diabetes mellitus. Community members need to increase their knowledge about diabetes mellitus through counselling sessions and workshop, which in turn will increase their self-care to achieve a better health status. The results of this study can be used as evidence-based participatory planning programs on the prevention of type 2 diabetes mellitus in the focus community.

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