

# **Qualitative Rural Indonesian Study of Diabetes** Knowledge, Health Beliefs, and Behaviors in **Type 2 Diabetes Patients**

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# Abstract

This study was aimed at understanding diabetes knowledge, health beliefs, and behaviors among type 2 diabetes patients in Balinese rural areas. The study used the Health Belief Model (HBM) in applied thematic analysis. It involved semi-structured focus groups with 20 patients (M = 49.95 years old, SD 6.7). Three themes formulated: poor diabetes knowledge, diabetes perceived as a life burden, and the factors affecting self-efficacy in practicing healthy lifestyle. The poor diabetes knowledge was due to traditional indigenous beliefs and low health literacy. The perception that diabetes is a life burden was related with physical and psychological condition. The factors affecting the self-efficacy were the perceived barriers and external influence. It is need to understand the traditional indigenous beliefs, burdens, and lacking internal intention as the modifying factors of health beliefs. This study suggests that the development of integrated health promotion of diabetes should consider the HBM's modifying factors in rural areas.

# **Keywords**

Type 2 Diabetes, Health Beliefs, Health Behaviors, Health Promotion, Rural Areas

# 1. Introduction

The number of adults with type 2 diabetes in the world is estimated to have reached 422 million in 2014 [1]. Indonesia ranks seventh in the world among the nations with the highest number of type 2 diabetes adults with an estimated number around 10 million in 2015 [2]. On the other hand, the number of undiagnosed cases of diabetes in adults in Indonesia is 5 million [3].

Indonesia experiences an epidemiological transition with increasing cases of non-communicable diseases every year, especially in the eastern provinces of Indonesia, Java and Bali [4]. This condition is exacerbated by difficulties in developing the preventive and curative health care system [3]. In Indonesia, only 41% of the type 2 diabetes patients are aware of their conditions, 39% get treatments, and only 0.7% have received appropriate treatments [5]. Knowledge and information on diabetes were still poor in Indonesia [3]. Ignorance causes diabetes patients to seek treatments only when they are in a serious condition [6]. Since they have a low level of education and do not have enough information about diabetes, they cannot detect their disease.

Bali is one of the provinces in Indonesia with the largest ethnic group that is the Balinese who still hold on to the belief that shamans can cure the disease including diabetes [7]. Diabetes becomes the second deadliest disease in Bali with 5365 cases in 2014 after hypertension [8]. Diabetes is one of the top ten diseases suffered in Buleleng [9].

## Health Belief Models (HBM)

HBM predicts the reasons people fail to practice a disease prevention behavior [10]. It has six constructs: perceived susceptibility, severity, benefits, barriers, self-efficacy and intention [11]. According to HBM, people will act to prevent, control or treat diabetes if they perceive its severity and consider that it will generate expected result [12]. If a high-risk community obtains proper knowledge on diabetes risk, they will perceive it as a serious disease and realize the importance of preventing it with healthy lifestyle. They will also try to adjust their behavior to keep healthy by practicing diabetes prevention action. When they have a belief in themselves that they can practice the diabetes prevention action and to overcome every problem, this will lead to a good self-management.

HBM has been used in cross-cultural studies, but its constructs need to be adapted to each cultural group [13]. Since Indonesia consists of various ethnic groups, an understanding on knowledge and health beliefs of diabetes may help in designing effective prevention programs for those at high risk of diabetes. In Indonesia, studies on diabetes have mostly been oriented on self-management for patients in urban areas [14] [15]. A study to explore the diabetes knowledge and health beliefs on rural areas is important to initiate.

Therefore, this qualitative study was conducted in rural Buleleng, Indonesia. It used HBM to explore the diabetes knowledge, health beliefs, and behaviors among type 2 diabetes patients there.

## 2. Material and Methods

## 2.1. Design

The study used HBM in applied thematic analysis to present the experiences of

participants as accurately and comprehensively as possible [16]. Semi-structured focus group was used to collect data. Focus group method is chosen because it generates broader understanding on the issues [17].

## 2.2. Ethical Considerations

This study was approved by the ethics committee of Hiroshima University, Japan (reference E-552), *Badan Kesbangpollinmas*-2016 (Nation unity, Politic and Community Protection Committee) Buleleng, and performed in accordance with the Helsinki Declaration. Written informed consent was obtained from participants. The participations are voluntary and confidential. All discussions in the focus group were recorded in audio with their approval and transcribed verbatim in Indonesian.

# 2.3. Participants and Data Collections

## 2.3.1. Inclusion and Exclusion Criteria

The participant, diagnosed with type 2 diabetes, were 20 years old up and can speak Indonesian. Those refusing to provide informed consent, pregnant, and adults diagnosed with cognitive impairment were excluded.

## 2.3.2. Sampling and Recruitment

The study was performed in *Puskesmas (community health center)* Buleleng 1, Bali, Indonesia on September 2016 to December 2016. The participants were selected through purposive sampling from *Puskesmas* Buleleng 1. It treats diabetic patients from some rural areas in Buleleng, Indonesia. The *Puskesmas* staffs, namely a doctor and five nurses were involved in the recruitment process. They provided the list of patients who met the inclusion criteria. The head of the *Puskesmas* wrote the study invitation. The invitees were 32, of whom 20 signed the informed consent document and joined the study. This sample size was to ensure sufficient variety of experience needed for saturation [18]. The participants jointed the study voluntarily. They were informed of their right to leave at any time and this will not affect their ongoing contact with the *Puskesmas* team. The confidentiality of personal identity was assured.

## 2.3.3. Procedure

The demographic characteristics were self-report. There were two gender-based focus groups discussion (FGD), consisting of 10 participants each. The discussions were conducted in *Puskesmas* Buleleng 1, with Indonesian language by the first author who is a native and assisted by a nurse. The discussions were 80 and 105 minutes. The participants were given IDR 50.000 (3.7 USD) for transportation expenses.

## 2.3.4. FGD Guides

The semi-structured FGD's guide was developed based on HBM's six constructs. A guide was piloted by a group of researchers experienced in qualitative research. It was to lead the discussions and ensure that similar topics are covered.

The doctor and nurse in *Puskesmas* Buleleng 1 conceived the language and the topics sequence on the pilot in local dialect. Further inquiries were used to explore in-depth information about their thoughts and feelings. See **Table 1** for FGD guides.

#### 2.3.5. Data Analysis

All discussions in the focus group were recorded in audio recordings with the approval of participants and transcribed verbatim in the Indonesian. The verbatim was back translated from Indonesian to English by two sworn Indonesian translators and then reviewed to verify the accuracy of the translations by the moderators. Data analysis process consisted of reading textual data, identifying codes within the data, sort codes into the themes, and interpreting the structure and content of the theme [16].

The textual data refers to the participant's statements that are related to the research questions. The themes identification was done by listening to the recording of the discussions and the re-reading of the verbatim transcript. Coding the themes was done based on the combined discussion of both focus groups. The interpretation of structure and content of the theme were described in the theme and sub-themes. Data was reprocessed with a deductive approach to determine utility of HBM to explain the participants' experiences on diabetes prevention. This ensured a better understanding of emerging themes based on HBM and checked for any generalized themes [19]. Comparisons were made between inductive derived data and deductively created categories. Inductively emerging themes that were not in accordance with HBM are retained if they are considered important for the description of the phenomenon.

#### 2.3.6. Trustworthiness on Analysis

To follow up the validity and reliability issues in analysis, several procedures were followed. First author assisted by nurses in community health center arranged the verbatim Indonesian translation of interview. All authors involved in the discussions for data extraction in a series of meetings. First step, the authors hold meetings for discussion findings. During the initial stages, the authors

Table 1. FGD guides.

Question		
What do you know about diabetes?		
What could happen to adults who already get diabetes?		
Do you think diabetes is serious problem?		
Do you think diabetes is common disease in Bali?		
How susceptible are adults in Bali to diabetes?		
Could you tell us what are, if there is, the benefits of healthy lifestyle?		
What would make it difficult for people to follow healthy lifestyle in your village?		
I am going to share you a story from another province. There is an adult who is told that unhealthy lifestyle could cause diabetes. He has the access to any healthy lifestyle resources. Do you think that adult would take the initiative to change his unhealthy lifestyle? What about you?		

compare codes and reach agreement. In the second steps, the authors sorted the codes into the themes. The interpretation of findings was compared between the first, second, and third author under the supervision of the fourth and fifth author until a consensus was reached. These steps served as a method of triangulation by multiple investigators [20]. The analysis ended with the interpreting the structure and content of the themes. The discussions about the themes were conducted with all authors to confirm that the researchers' assumptions were not reflected in interpretation. The themes were presented to a group of professional researchers unaffiliated with this study to get the advocate from them. The analysis steps were repeated to test for reliability. Each theme was described in the results with a quote. Participants' quotes are referred by number (P1-P20), sex, age, and last education level.

## 3. Results

## **3.1. Demographic Characteristics**

Twenty participants (M = 49.9 years old, range 33 - 58) were included in this study. The education levels were: Nine (45%) were elementary school (*SD*), nine (45%) were senior high school (*SMA*), two (10%) were junior high school (*SMP*). Average age when they were diagnosed with diabetes type 2 was 49.6  $\pm$  6.5 years old. The average of random blood glucose level in November 2016 was 184.3  $\pm$  75.7 (mg/dL). 60% participants did not have a family member suffering from diabetes. Fifteen (75%) participants had no history of non-communicable disease. See **Table 2** for Demographic characteristics.

# **3.2. Description of Themes**

Three themes were identified representing the six constructs in HBM:

Theme 1: poor diabetes knowledge

This theme explores the participants' knowledge and perception about diabetes and interpretations of perceived susceptibility from their experiences.

Subtheme 1.1: diabetes susceptibility caused by black magic.

45% participants believed that diabetes is related to black magic (*amah leak*). Diabetes susceptibility was believed caused by their bad relationships with another person. Participants considered diabetes to be curable by shaman (*ba-lian*).

I heard it is caused by *amah leak*, wound first then it develops into disease. Someone causes the injury. People said so. So, I go to *balian* (P1, Male, 53 y.o, *SD*).

Those believing this were the older generation. They only receive the health information from stories from their elders in the community. Limited access to health information makes them dependent on shamans while ignoring other advice.

That disease is because of *amah leak*. The elders usually think so, in the remote areas too. We lack information about it. It is not ordinary disease. So, we go to *Balian* (P10, Female, 55 y.o, *SD*).

Variable		N (%), unless otherwise stated
Total number of participants		20
Gender	Male/Female	10/10 (50/50)
Age (years) <sup>1</sup>	Range 33 - 58	$49.9 \pm 6.7^{1}$
Education level	Elementary School (SD)	9 (45)
	Junior High School (SMP)	2 (10)
	High School (SMA)	9 (45)
Body Mass Index (kg/m <sup>2</sup> ) <sup>1</sup>	Range 23.2 - 44.5	$27.9 \pm 5.4^{1}$
Body Mass Index Categorization $(kg/m^2)^1$	Normal (18.5 - 24.9) Overweight (25 - 29.9) Obesity (>30)	6 (30) 10 (50) 4 (20)
Age at diagnosis of diabetes (years) <sup>1</sup>	Range 33 - 57	$49.6 \pm 6.5^{1}$
Duration of symptoms (months <sup>1</sup> )	Range 1 - 24	$6.5 \pm 7.3^{1}$
Random blood glucose level (mg/dL) <sup>1</sup> in November 2016	Range 69 - 349	$184.3 \pm 75.7^{1}$
Family with diabetes	Yes	8 (40)
	No	12 (60)
History of non-communicable disease	Hypertension	1 (5)
	Hypertension and Hyperuricemia	3 (15)
	Hypertension and Hyperlipidemia	1 (5)
Blood Glucose test	Not at all	15 (75)
	Every month	6 (30)
	Every 3 months	3 (15)
	Rarely	3 (15)
	First time	8 (40)

Table 2. Demographic characteristics.

<sup>1</sup>Means ± Standard deviation.

#### Subtheme 1.2: diabetes susceptibility caused by unhealthy lifestyle.

In general, the younger participants got diagnosed with diabetes from the *Puskesmas*'information. They perceived that the followings are more susceptible to diabetes: those eating sweet foods and foods containing fertilizers.

If you are queuing in *Puskesmas* there are many people suffering from diabetes therefore, it is common in Bali (P5, Male, 42 y.o., *SMP*).

The food contains much fertilizer. The cattle are fed with some fertilizer, we eat the meat (P7, Male, 33 y.o., *SD*).

The participants mentioned heredity as a risk factor. Heredity is identified as the similarity in lifestyle in one family, particularly in eating habit.

If a parent had diabetes, their child must have too, it is inherited. They have the same eating habits; their lifestyles are the same (P4, Female, 47 y.o, *SMA*).

One participant was shunned by her husband. He thought that diabetes would

spread through physical contact.

My husband is scared that he will have diabetes too from the contact with me. At first, he stayed away from me. But now he is not (P 9, Female, 36 y.o., *SMA*).

Theme 2: diabetes perceived as a life burden

This theme explains about perceived severity and barriers. Those believing that diabetes susceptibility is caused by unhealthy lifestyle considered it as life burden and severe because it is not curable.

Subtheme 2.1: perceived severity on diabetes related to physical burden.

Participants explained some symptoms they felt before undergoing checkup in *Puskesmas*.

I kept urinating at night. I lost my energy. I just wanted to sleep. When I had a checkup in *Puskesmas* it turned out that my sugar level was 500 mg/dL (P 14, Male, 43 y.o., *SMA*).

They perceived diabetes as severe disease because of complications risk affecting their quality of life.

Male with diabetes will be impotent. This is serious. I am no longer strong. I do not have sexual passion any more. I feel weak (P 18, Male, 48 y.o, *SMA*).

My friend's kidney was dysfunctional because of too much medicine (P 6, Female, 36 y.o., *SMA*).

Subtheme 2.2: perceived severity on diabetes related to the psychosocial burden.

The perceived severity brings psychological burden upon them. They were stressed and worried when they first knew about the disease. Those with history of hypertension considered knowing the disease as extra burden, putting more stress, which might increase their blood pressure.

I would rather not know other diseases, which when I think of it I would feel stressed. I fear diabetes. The problem is every time I think of it I surely will have a high blood pressure. It is better not to know. We will live with a safe feeling, without thinking of weird things (P3, Female 45 y.o., *SD*).

They refused the diagnosis and blamed other factors when they were informed about their condition.

I did not believe about my blood sugar level or maybe the device did not work. I live a regular life. I eat regularly, my blood pressure is normal, my condition is OK, and none in my family has diabetes. Why do I have diabetes? (P 13, Male, 50 y.o., *SMA*)

Family members also felt psychological burden. They were afraid that the children would inherit the disease.

My families are afraid that my children later will have diabetes since we eat the same food. Thus, if I can have diabetes, they can have diabetes too. The meals are the same (P 20, Female, 49 y.o., *SMA*).

Theme 3: the factors affecting self-efficacy in practicing healthy lifestyle

It described the factors affecting the participants' self-efficacy.

Subtheme 3.1: shaman is a barrier to lifestyle change.

Participants believing in black magic considered that diabetes couldn't be

prevented because nobody knows when it will attack. Hence, the way is to go to a shaman and give the right offerings to cure the disease, giving them confidence that they do not need to change the lifestyle.

My neighbor believed *balian* very much and ask for an amulet, he did not want to go to *Puskesmas*. But if there is still a problem, he must give extra money to buy offerings (P 2, Male, 55 y.o., *SD*).

Subtheme 3.2: low self-efficacy to practice healthy lifestyle.

Participants believing the cause of diabetes is unhealthy lifestyle knew that it could be managed by practicing a healthy lifestyle.

I was informed to cut down on sweet foods, rice, and to eat less. Yesterday I had a checkup and my sugar level decreased (P 17, Male, 41 y.o., *SMA*).

However, most of them faced some barriers to change their diet practice. The irreplaceable of rice as staple food is one of them.

When I felt weak, I would eat some rice to make me feel strong again. Rice is compulsory. It is difficult to eat less rice (P 11, Female, 51 y.o., *SD*).

Another barrier was related to the person's culture and religion. The foods available at the community event (for both Hindu and Muslim community) were usually high calories and fat. They considered that the food served is expensive and rare, thus they will eat it despite being on a diet.

There will be a lot of food available as offering at temple anniversary. I always eat it. After it, I always have bad condition (P 8, Female, 52 y.o., *SMP*).

You are given food to take to your house after you finish attending a Koran recitation. Why will we not eat the food? Just eat it. It will be useless if you do not eat it (P 15, Male, 36 y.o., *SMA*).

Participants suffering from hypertension and hyperuricemia felt confusion in managing their diet. They were also afraid of medical treatment's cost.

I also have hypertension and hyperuricemia, I confused about the kind of vegetables and fruit that I can eat (P 17, Male, 41 y.o., *SMA*).

The problem is the cost to get medical treatment (P 8, Female, 52 y.o., SMP).

Intention to change their lifestyle was dominantly due to external influence. They lacked self-efficacy for self-management and to maintain the new healthy lifestyle. The internal intention to change their behavior only arises if the condition is severe.

There is an intention to change if the government supports it along with the people and facilities to care for them (P 13, Male, 49 y.o., *SMA*).

I eat a lot; I have good appetite. So, why do I have to eat like a sick person, regulating the menu? If complaints arise and I feel weak maybe, I will change my eating habits (P 7, Male, 33 y.o., *SD*).

# 4. Discussion

The result showed that three themes, according to HBM, emerged. They were: poor diabetes knowledge, diabetes perceived as a life burden, and the factors affecting self-efficacy in practicing healthy lifestyle. Regarding the poor diabetes knowledge, result showed that it was influenced by traditional indigenous beliefs. This was the case for the older generation graduating from *SD* living in a rural village with limited access to health information. The beliefs were important in their perception of diabetes severity and susceptibility. They believed that it was caused by black magic.

Balinese believe that a disease is caused by the interaction between *sekala* (physical world) and *niskala* (metaphysical world) in which black magic (*amah leak*) is one component in *niskala* [21]. They relied on shamans' treatment to deal with it [22]. Shamanism is a social phenomenon very close to Indonesian daily life [23]. The strong roles of shaman related to diabetes were also found in Igala community, Nigeria [12].

Poor diabetes knowledge was also related to low health literacy skills causing drug misuse and health information misunderstanding [24]. It was also significantly correlated to low education [25]. Family member of one participant also still considered diabetes infectious and transmitted through physical contact. This stigma can also be found in Taiwan [26].

The younger participants, graduating from *SMP* & *SMA*, believed they are susceptible because of their unhealthy lifestyle as informed by *Puskesmas* workers. This situation suggested that participants inclined to understand the scientific diabetes knowledge.

The second theme is that diabetes was perceived as severe and a life burden, for its possible complications, by those perceiving that it was caused by unhealthy lifestyle. This was in line with previous study [27] that mentioned diabetes not only burdened patients but also all family members.

In our study, male participants focused on the fear of disability in sexual function while the females focused more generally on dysfunctional of other organs associated with complications. However, they did not show positive behavior in diabetes self-management. Male participants rejected the condition and female participants felt better if they ignored it to avoid stress. They were unable to withstand the psychological burden. This was in line with the statement that diabetes is a chronic disease filled with the psychological and behavior factors [28]. Findings were reinforced by previous study [29] which showed an increase in the prevalence of depression and anxiety in patients with diabetes. Another previous study [30] also mentioned that the psychological burden contributed to the poor adherence of self-management in diabetic patients.

The third theme is the factors affecting self-efficacy in practicing healthy lifestyle. Both male and female participants faced barriers such as inadequate health information, irreplaceable of rice as staple food and eating habits in religious and cultural events. This research was linked to another research confirming that the cultural background also influences the diabetic diet and eating behavior [31] [32]. Other studies suggested that type 2 diabetes patients, facing a huge barrier to lifestyle change and lacked self-efficacy in self-management [33].

Lifestyle changes were associated with the internal and external influences [34]. The participants' intention to change the behavior was more dependent to

external influence, such as control and support from medical workers. Limited diabetes prevention and self-management education in Indonesia made it worse [3] and only less than 50% of medical cost was covered by government [4].

Studies exploring diabetes knowledge, health beliefs, and behaviors among type 2 diabetes patients in rural Indonesia are limited. This study can provide valuable insight for the health departments in rural Indonesia. It generally showed that diabetes knowledge, health beliefs, and behaviors were relatively poor in rural Indonesia. This study suggested the need to develop an integrated diabetes prevention program based on health beliefs in rural Indonesia. It can involve health workers and shamans in the village. Health promotion creating supportive environment correlated to the existing habits and beliefs will improve health literacy and overcome the problem of poor self-efficacy and maladaptive coping behaviors in diabetes.

# 4.1. Limitations

Even though the population of this study is Balinese people, coming from Hindu and Muslim communities, the results of this qualitative study may not represent the condition of entire Bali. It can however reflect the condition in rural areas of other regions with similar socio-demographic.

Further studies on health beliefs in diabetes should be explored. In the future, involving more patients from other rural areas in Indonesia could provide more in-depth information and knowledge about the experience and expression of diabetic patients. Quantitative studies on rural area should be conducted to gain a broader picture of diabetes health beliefs in Indonesia.

# 4.2. Conclusion

This study could contribute to a deeper understanding in exploration of diabetes knowledge, health beliefs, and behaviors among patients in rural Indonesia with HBM as the framework. The result showed that there was poor diabetes knowledge, poor health beliefs, and lack of healthy lifestyle in Indonesian rural areas. The existence of traditional indigenous beliefs about diabetes, burdens, and lacking internal intention in participants for practicing health behavior is the modifying factors exacerbating participants' health beliefs. Improving these modifying factors in diabetes prevention program in Indonesian rural areas could improve health literacy and positive self-management among diabetes patients.

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# **Conflicts of Interest**

The authors declare no conflicts of interest regarding the publication of this paper.

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