



## Research article

# The cultural beliefs and practices of diabetes self-management in Javanese diabetic patients: An ethnographic study



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## ABSTRACT

**Background:** It is important to assess the cultural beliefs and practices of diabetic patients since such beliefs and practices greatly influence how patients self-manage the disease. However, how cultural beliefs and practices affect self-management in Javanese diabetic patients in Indonesia is still unclear since research about it is very limited. Therefore, the purpose of this study was to explore the cultural beliefs and practices of diabetes self-management in Javanese diabetic patients.

**Methods:** An ethnographic study was conducted between July 2020 and March 2021 in Banyumas Regency, Indonesia. Forty-seven participants were included, consisting of 36 type 2 diabetes mellitus (T2DM) patients as key informants and 11 family members and health providers as general informants. Purposive and snowball sampling methods were used, and data was collected through in-depth interviews, observations, and the writing of field notes. The data were analyzed by thematic analyses using NVivo 12 software.

**Results:** Four themes emerged from the data analysis: (1) misconception about diabetes and management, such as the belief of there being dry sugar and wet sugar types of diabetes; the belief that consuming a lot of cold rice does not increase blood glucose; the belief that insulin causes organ damage; the belief that diabetes can be completely cured; and the belief that walking barefoot is good for the body; (2) cultural beliefs and practices regarding treatment regimen, such as use of medicinal plants to lower blood glucose and home remedies to treat foot ulcers; (3) coping influenced by a blend of culture and religion, such as managing stress by submitting to God and being patients in dealing with their disease; (4) cultural influence on diet management, such as facing difficulties managing their diets at cultural events and difficulties managing the habit of eating sweet-tasting food.

**Conclusion:** This is the first study to show that Javanese culture strongly influences how diabetic patients in Java self-manage their disease. Various aspects of Javanese culture were found to have either beneficial or detrimental effects on diabetic patients' health status. This study provides new insights for nurses in Indonesia and will help them design a culturally sensitive education program for their diabetic patients.

## 1. Introduction

The number of patients with diabetes mellitus (DM) is increasing, especially within developing countries [1]. There were 10,3 million DM patients in Indonesia in 2017 and that number is predicted to reach 16,7 million by 2045 [2]. Glycemic control in Indonesian diabetics is poor [3]. Consequently, mortality due to DM and its complication is high in Indonesia [4]. The complications that commonly occur in diabetic patients in Indonesia are retinopathy, nephropathy, cardiovascular

complications and diabetic foot ulcer [5, 6]. Considering these complications and the high mortality rate of DM, health care providers in Indonesia should take aggressive preventive measures to help their diabetic patients.

Diabetes mellitus is a chronic, progressive disease which needs proper management. To prevent complications, diabetic patients should self-manage their conditions [7, 8, 9]. Proper diabetes self-management has been shown to result in better blood glucose control and to improve quality of life for patients with DM [10, 11].

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Several studies showed that a key component of successful diabetes self-management is to implement an individualized approach that reflects an individual's cultural beliefs [12, 13]. Cultural beliefs play an important role in the diabetes self-management [14, 15, 16, 17, 18, 19]. For example, an African American may refuse to use insulin because of a cultural view that insulin can cause diabetes complications and damage to organs [20, 21]. Culture can also make patients choose traditional remedies over modern medicine, as has been seen in Mexico, and Myanmar [22, 23]. Cultural beliefs have been shown to lead to raised blood glucose levels [24], and to promote fatalistic beliefs about diabetes [25]. On the other hand, culture could be used to improve diabetes self-management, through spirituality and other means [26]. Each country has its own unique culture that determines diabetes self-management behaviors. Having an understanding of these cultural beliefs and practices is important for nurses to be able to design culturally-sensitive self-management strategies for their patients.

The largest ethnic group in Indonesia is Javanese, accounting for 40.2% of 236.7 million people [27, 28]. Members of this ethnic group live mostly on Java Island. Javanese people have strong cultural beliefs that may affect the way they engage with their disease [29]. In Javanese society, there is a strong culture of *tepo-seliro*, which means to put oneself in another person's situation. While such an attitude can be positive, it can cause patients to feel bad about spending a long time in consultation with their physician. The knowledge that many other people are awaiting in line for treatments often results in patients hurrying their consultations. This means many health-related questions are left unasked [30].

Furthermore, the cultural belief that traditional medicine is better than Western medicine means the use of traditional medicines is high among the Javanese population. Another cultural belief which causes many nutritional deficiencies in Javanese people is the proverb *mangan ora mangan waton kumpul* which means, 'living together is the most important thing, even if there is no food to eat' [29].

Although the ways in which culture impacts general health in Javanese patients have been studied, until now, the influence of Javanese culture has specifically on the diabetes self-management behavior is unclear, since there has been limited research on the subject. Every culture is unique and cultural beliefs tend to influence how patients manage disease. Investigating the impact that cultural beliefs and practices of diabetic patients in Java has on the self-management of their disease will help nurses in Indonesia create culturally sensitive education sessions for their patients in order to improve the self-management behaviors. The purpose of this study was therefore to explore the cultural beliefs and practices of Javanese diabetic patients on their self-management behaviors.

## 2. Method and design

### 2.1. Design

A qualitative design with an ethnographic approach was used to holistically explore what it means to be a Javanese diabetic patient and how the cultural beliefs and practices of such patients affect their self-management behaviors. The topic was also explored from the perspective of participants' family members and health providers. The use of ethnography allowed the researchers to capture data regarding participants' actual behavior rather than their reported actions [31].

### 2.2. Settings and samples

This study was conducted over a period of nine months between July 2020 and March 2021 in Indonesia's Banyumas Regency in Central Java. Patients were recruited from five primary health centers in Banyumas Regency with high numbers of diabetic patients. The health centers were those in South Purwokerto, East Purwokerto, North Purwokerto, Kebasen, and Sumbang. A purposive sampling method was used to recruit key informants. Key informants were accessed from patient registration

books in those public health centers. To obtain a varied set of key informants, we selected them by age, gender, duration of T2DM, employment status, and income level. The inclusion criteria were patients with T2DM (confirmed by a physician) of Javanese ethnicity residing in Central Java Province who were able to communicate verbally in either Javanese or Indonesian and were willing to participate and be recorded. Exclusion criteria were patients with severe ailments or those with cognitive or mental impairment recorded in their medical records. Eligible patients were contacted by telephone by a researcher, informed about the study, and asked if they consented to participate. Those who agreed were given an appointment for a face-to-face meeting. During the meeting, researchers explained the study again to patients, and those who consented were enrolled in the study.

General participants included the family members and health care providers (physicians and nurses) of T2DM patients. We used a snowball sampling method to ask key informants to nominate native Javanese health care providers and family members living in the same region. The key participants and health care centers choose those family members and health providers they deemed had the most knowledge regarding patients' experience in self-managing their diabetes and the effects Javanese culture had on this self-management.

The inclusion criteria for general informants were native Javanese family members and health care providers over the age of 20 who were able to speak Bahasa Indonesian or Javanese. They had to be knowledgeable with regards to the domain of inquiry, able to articulate their observations clearly, and willing to participate. Seven health providers and family members were included. Health care providers and family members were chosen in five health centers in which the key participants lived. The health providers and family members who agreed to participate were informed about the design and intention of the study. Those who showed a willingness to participate were scheduled a face-to-face meeting, during which the researchers explained the study again. Those indicating continued interest consented by signing the informed consent form.

### 2.3. Data collection

Data were collected through in-depth interviews, observations, and the writing of field-notes. The interview process was based on Spradley's (1979) ethnographic interviewing model which allows for the exploration of cultural factors which can influence diabetes self-management [32]. Interviews were conducted by three researchers, all of whom are experienced qualitative researchers. Before their interviews, participants were provided with information about the study. They were informed that participation was voluntary, and that they had the right to withdraw at any time. At this point, participants were encouraged to ask questions and their demographic data such as age, gender, education, employment, and duration of T2DM was noted.

A semi-structured interview guide based on literature reviews undertaken by the study team was created. The interview guide asked questions about diet, physical activity, monitoring of blood sugar, medication, foot care, and coping skills, and was reviewed by experts in diabetes and foot care. The questions were revised according to their recommendations and then pilot tested on 10 patients before being used in the study. No participant in the pilot study was included in the main study. The interview guide was created in both Indonesian and Javanese languages, and the Javanese version was translated and back translated by two professional translators.

Patient interviews were conducted in patients' homes and lasted between 30 and 45 min. Physician and nurse interviews were conducted either in their homes or in the primary healthcare centers in which they worked. Phone calls were conducted to clarify some responses after the initial interviews. During the interviews, all of which were conducted in either Javanese or Bahasa Indonesian, we also collected patients' demographic data. Saturation was reached at 47 participants.

Observations were conducted to gain an understanding of participants' cultural beliefs and how they self-managed their diabetes at home. Of particular interest was the use of traditional medicine, the performance of physical activity, diet management, the performance of foot care, and participation in cultural events such as community gatherings and weddings, with special attention being paid to how participants dealt with food served at such events. All researchers who conducted interviews had lived and grown up with the Javanese culture and language which allowed for immediate immersion in the field.

Researchers and assistant researchers took field notes to record the environment, behaviors, thoughts, and feelings during the research period. According to Creswell (2013), field notes are essential in a qualitative study since they enhance the data and provide rich context for analyses [33]. Figure 1 showed the overall research process through three distinct but connected ethnographic stages.

#### 2.4. Data analysis

Three of the investigators and research assistants are Javanese and are native speakers of the participants' local language. During the interview process, the research assistant took notes with participants' permission. Transcripts were written in combination of Bahasa Indonesian and Javanese, then translated into English by the investigators of

this study. They were then checked by people who are fluent in both languages. We translated the transcripts separately and discussed the words that have different meanings at great length to find the closest meaning. The words that are specific to Javanese which have no English translation were left as they were.

Interview transcripts and field notes were organized using NVivo 12 software. The data were analyzed using inductive thematic analyses [34, 35]. All transcripts were thoroughly read through several times to obtain a sense of the whole and were then reviewed using an inductive coding approach. Each transcript was compared with the field notes for the researchers to get additional context beyond the information written in the transcripts. The concept emerging from the data was then coded and constantly compared, and then themes and subthemes were developed [36]. Three researchers came together to compare their identified codes and to discuss the similarities and differences. When different opinions arose, discussions continued until a consensus on the emergent themes and sub-themes was reached.

#### 2.5. Study rigorousness

Criteria taken from Lincoln & Guba (1985) were used to confirm the rigorousness of the study, consisting of credibility, dependability, conformability, and transferability [37]. To ensure credibility, the

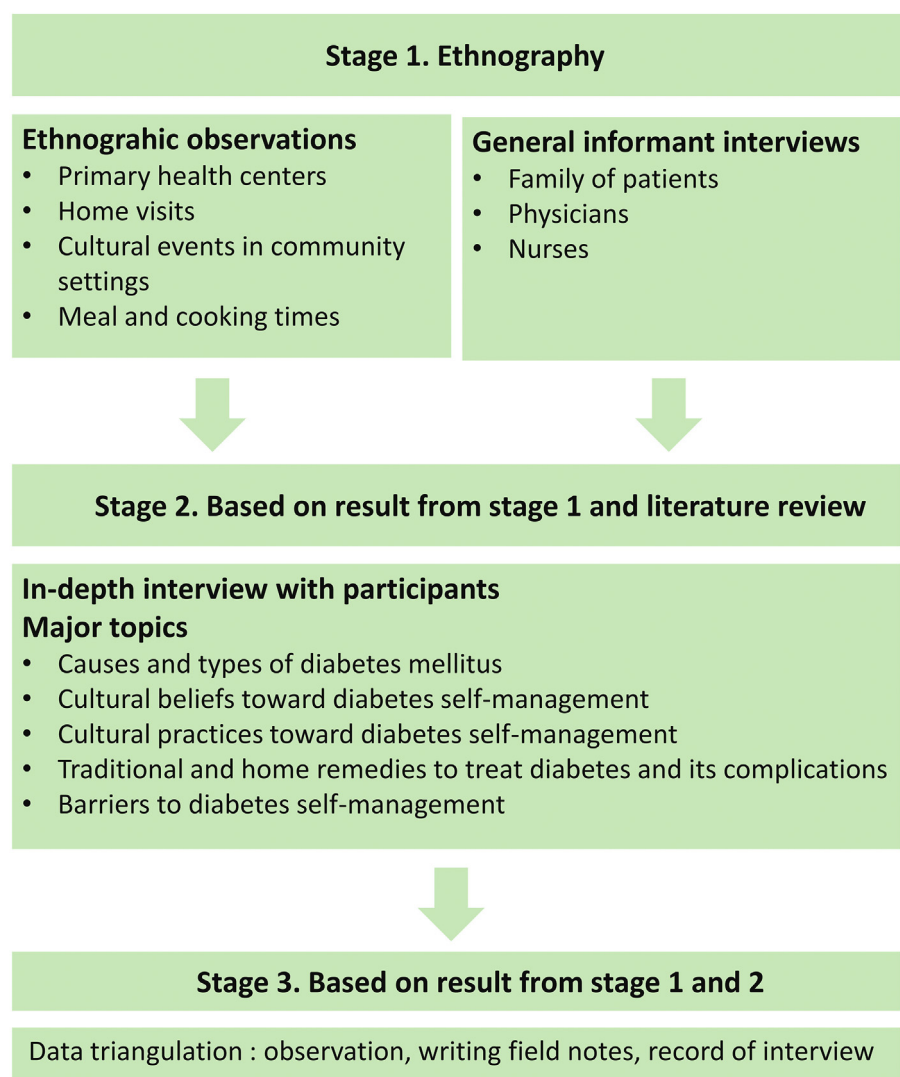


Figure 1. Three stages of ethnography.

**Table 1.** Demographic data of participants.

Code	Sex (F/M)	Age	Marital Status	Level of Education	Role	Job	Duration since diagnosis
R1	F	49	Married	No formal education	KI	Laborer	5
R2	F	58	Widow	Elementary	KI	Laborer	6
R3	F	52	Widow	Elementary	KI	Laborer	6
R4	F	50	Married	Bachelor	GI	Physician	-
R5	F	44	Married	Bachelor	GI	Nurse	-
R6	M	65	Married	High school	KI	Laborer	12
R7	F	50	Married	Elementary	KI	Laborer	8
R8	F	37	Married	Secondary	GI	Housewife	-
R9	M	38	Married	Bachelor	GI	Nurse	-
R10	M	65	Married	High school	KI	Housewife	9
R11	F	72	Widow	High school	KI	Pension	23
R12	F	62	Married	Elementary	KI	Housewife	12
R13	F	48	Married	Elementary	KI	Housewife	2
R14	F	47	Married	Elementary	KI	Housewife	2
R15	F	48	Married	Elementary	KI	Farmer	4
R16	F	47	Married	Bachelor	GI	Nurse	-
R17	F	42	Married	Secondary	GI	Housewife	-
R18	F	60	Widow	Elementary	KI	Housewife	3
R19	F	54	Married	Elementary	KI	Privately financed	4
R20	F	60	Widow	No formal education	KI	Housewife	4
R21	F	55	Married	Elementary	KI	Laborer	6
R22	F	70	Widow	Elementary	KI	Housewife	4
R23	F	29	Married	Bachelor	GI	Nurse	-
R24	F	20	Not married	Bachelor	GI	Student	-
R25	F	54	Married	Elementary	KI	Housewife	6
R26	F	57	Married	Elementary	KI	Privately financed	4
R27	F	47	Married	Elementary	KI	Housewife	6
R28	F	61	Married	Elementary	KI	Laborer	7
R29	F	66	Widow	Secondary	KI	Farmer	14
R30	M	63	Married	Secondary	KI	Privately financed	13
R31	F	44	Married	Elementary	KI	Farmer	1
R32	F	72	Widow	Elementary	KI	Housewife	4
R33	F	52	Married	High school	KI	Pension	6
R34	F	66	Married	Elementary	KI	Housewife	12
R35	F	38	Married	Bachelor	GI	Physician	-
R36	F	63	Married	Elementary	KI	Housewife	12
R37	F	41	Married	Elementary	KI	Housewife	9
R38	M	69	Married	High school	KI	Pension	15
R39	F	57	Married	Elementary	KI	Laborer	2
R40	F	52	Married	High school	KI	Housewife	2
R41	F	50	Married	Elementary	KI	Housewife	1
R42	F	48	Married	Elementary	KI	Housewife	4
R43	F	59	Widow	Elementary	KI	Housewife	2
R44	F	52	Married	Elementary	KI	Housewife	6
R45	F	60	Married	Elementary	KI	Privately financed	3
R46	F	52	Married	Diploma	GI	Nurse	-
R47	F	38	Married	Secondary	GI	Housewife	-

Note. F: Female, M: Male; KI: Key Informant; GI: General Informant.

researchers immersed themselves in the research field for long periods of time. All researchers are native Javanese and have lived in Central Java since birth. Researchers also used methodological triangulation including deep-interview, participant observations, and field notes. Triangulation sources were used to collect data involving diabetic patients, family members, and healthcare providers. Several investigators were involved in the projects, and three researchers were involved in the analysis and interpretation data (researchers triangulation). Data

triangulation was conducted by doing numerous interviews to validate the findings. We also conducted peer debriefing by reviewing and exploring the project with experts, and member checking by inviting participants to review, validate and confirm the findings.

To ensure transferability, researchers provided detailed demographic and clinical characteristic data so that the relevance to other situations could be considered. To ensure dependability, the researchers recorded the process of data collection and data analyses. To ensure

**Table 2.** The themes emerging from the data.

Themes	Subthemes
Misconceptions about diabetes and management	Types of diabetes: <i>dry sugar and wet sugar</i>
	Insulin causes organ damage
	Consuming a lot of cold rice will not increase blood glucose
	Consuming a lot of palm sugar will not increase blood glucose
	Diabetes can be completely cured
	Walking barefoot is good for the body
Cultural beliefs and practices regarding treatment regimen	Use of medicinal plants to lower blood glucose
	Use of home remedies to treat foot ulcer
Coping influenced by a blend of culture and religion	Managing stress by submitting to God
	Being patient in dealing with diabetes
Cultural influence on diet management	Difficulty managing diet at cultural events
	Difficulty managing the habit of eating sweet-tasting food

confirmability, the complete records of methodological description and related materials were retained to be used as an audit trail for future research interpretations.

## 2.6. Ethical considerations

Ethical approval was granted by the Institutional Review Board of the Faculty of Health Sciences, Universitas Jenderal Soedirman (Approval No 120/KEPK/VI/2020, 23 June 2020). The researchers received approval letters to conduct the study from the primary and private medical centers and from related government offices. All participants were informed of the purpose, potential risks, and benefits of the study. They were free to withdraw from the study at any time. Written informed consent was obtained from all participants who agree to participate in this study.

## 3. Results

### 3.1. Participant characteristics

The characteristics of both key informants and general informants are shown in Table 1. There were 36 key informants, most of whom were female. Ages ranged from 29 to 72 years old. Two participants had no formal education, 26 had completed elementary education, two had completed secondary education, and six had completed senior high school. Regarding employment, 18 were housewives, eight were laborers, three were pensioners, three were farmers, and four were privately employed. The mean length of time participants had had T2DM was 6.6 years. Four family members had experience in helping manage diabetes, and seven health care providers had been taking care of diabetic patients, consisting of two physicians, and five nurses.

Table 2 describes the themes and sub-themes. Four themes emerged from the data analysis: 'misconception about diabetes and management'; 'cultural beliefs and practices regarding treatment regimen'; 'coping influenced by a blend of culture and religion', and 'cultural influence on diet management'.

### 3.2. Theme 1: Misconceptions about diabetes and diabetes management

#### 3.2.1. Types of diabetes: dry sugar and wet sugar

Patients were found to believe in two types of DM: *dry sugar* and *wet sugar DM*. The *wet sugar type* is thought to be more dangerous than the *dry sugar type*. It is thought that patients with the *wet sugar type* are at more risk of developing foot ulcers and that once a foot ulcer develops it will

produce a lot of exudate, be difficult to heal, and will likely lead to amputation. It is thought that patients with the *dry sugar type* are not at risk of developing foot ulcers, but that, if it does happen, it will not exudate and will heal easily. The belief is that a foot ulcer without exudate will heal easily without specific treatment. During their interviews, all participants reported feeling relieved to have the *dry sugar type* rather than the *wet sugar type*.

*"I have always believed that I am a dry sugar type since whenever I am bitten by mosquito, it never wounds me. Even when I fall over and get scratched, it always heals [nodding head]. But my younger brother, unfortunately, has the wet sugar type so it is easy for him to be wounded. Several months ago, he got amputated...."* (Participant 2).

*"One day I tried to get bamboo for my stove, but accidentally, the tip of the bamboo struck my foot and made it bleed [pauses while looking at soles of feet]. But I always knew that I was a dry sugar type, not a wet sugar type, so I knew my wound would heal quickly. As expected, ... not long after, it healed. It must be because I am dry sugar type. I am very fortunate because my neighbor who is wet sugar type, his wound was getting bigger and full of odor, and finally he died from a foot ulcer"* (Participant 6).

#### 3.2.2. Insulin causes organ damage

According to their interviews and fields notes, participants believed that insulin could cause deterioration of the body, making it easier for diabetes complications to occur. They also believed insulin use leads to dependence. For this reason, the health providers reported that insulin is not drug of choice in Javanese patients. They said that when doctors offer their patients insulin, most of them refused.

*"I use oral medication, I don't want to use insulin, .....when my doctor suggested I use insulin, I didn't want to (because) it will cause my internal body to deteriorate and I will depended on it for life,...no [shakes head], I don't want to use insulin, I had neighbor who used insulin, and then not long after, he was dead. I believe it must be due to his use of insulin (participant 7).*

Only two patients out of the 36 participants used insulin. They both said that they don't have any other choice because their health clinician told them their blood glucose was too high and that they must use it.

*"My blood glucose was very high at that time. My doctor told me I would be given insulin. I don't want to use insulin, but I have no other choice, and therefore I use insulin. But one day I want to change it for oral medicine, I don't want to use insulin anymore. I feel my body really depends on insulin and I feel unhealthy and always feel sick..., it must be due to insulin...."* (Participant 11).

*"I have been working for long time here [in a health center], and I can say that all diabetic patients here believe that insulin will cause dependence and destruction of the body. They refuse when we suggest they use it. This belief has been rooted for a long time (Participant 4).*

#### 3.2.3. Consuming a lot of cold rice will not increase blood glucose

Rice is a staple food in Indonesia. Many participants believed that consuming even a little warm rice would cause an increase in blood glucose while consuming large amounts of cold rice would not. The usual method of cooling rice is to leave the rice at room temperature for one day. This cold rice is called *nasi wadang*, or decaying rice. Some participants believed that the longer rice is kept at room temperature, the better it is at reducing blood glucose. Participants had no knowledge that keeping rice at room temperature can increase bacterial accumulation.

*"I don't know who first told about this. We believe we should not eat warm rice but old rice... I always eat yesterday's rice... diabetic patients should*



not worry about eating a lot of cold rice since it won't raise our blood glucose" (Participant 11).

### 3.2.4. Consuming a lot of palm sugar will not increase blood glucose

Most participants reported that adding a lot of gula aren, or palm sugar, will not increase blood glucose levels. Derived from the palm tree, palm sugar is thought of as being different to granulated sugar which is known to increase blood glucose levels.

"Before diabetes, I used granulated sugar in all my drinks and dishes. But when I got this disease I started using gula aren, ... it is safe to use gula aren. It will not cause high blood glucose even when you use a lot" (participant 15).

"I treat many diabetic ulcers in hospital and while giving wound care treatment, I talk with the patients. Most believe that adding a lot of gula aren in dishes will not cause hyperglycemia" (Participant 9).

### 3.2.5. Diabetes can be completely cured

Some patients thought that their diabetes will not last long and that it can be completely cured by good management. Some participants said that diabetes can be cured if it is God's intention.

"I believe that one day I will not have diabetes anymore...so I manage my diet...I believe with diet management, one day...I will free from this disease [nodding head]" (participant 38).

### 3.2.6. Walking barefoot is good for the body

Most key participants in this study realized they should perform regular physical activity to keep their bodies healthy and reduce their blood glucose. The physical exercise most performed by key participants was walking outside. Most of them stated that they usually go barefoot when walking since it is generally believed by Javanese people that walking barefoot is good for the body. Based on researchers' observations, participants tended to walk barefoot on the rough surface of the road.

"I have been told by many people that I need to do physical exercise as a diabetic patient. Many people told me to walk barefoot to stay healthy, so I walk barefoot twice a week in the morning." (Participant 17)

## 3.3. Theme 2: Cultural beliefs and practices regarding treatment regimen

### 3.3.1. Use of medicinal plants to lower blood glucose

In addition to using oral medicine, most patients in this study also used herbal medicine in an attempt to reduce their blood glucose levels. They believed that traditional plants such as the leaves of *Annona muricata* L., *Physalis angulata* L., *Andrographis paniculata*, and *Syzygium polyanthum* can help reduce blood glucose levels effectively. This belief goes back a long way in Javanese culture. Patients believed that a combination of such traditional medicines alongside modern medicines reduce blood glucose levels more effectively than modern medicine alone. However, according to researchers' observations and interviews, when using these traditional medicines, patients didn't measure them, simply basing quantities on their preferences. When they believed their blood glucose to be too high, they increased the dose of their chosen herbal medicine.

"Before I have my blood glucose checked at the health clinic, I always make a herbal drink containing daun sirsak (*Annona muricata*) to reduce my glucose levels. I do believe the Western medicine can lower my blood glucose, but its effects are just so-so. After I take this herbal tea, I feel my body get healthier" (Participant 13)

"I use cimplukan (*Physalis angulata* L.), sambiloto (*Andrographis paniculata*) and salam (*Syzygium polyanthum*) based on a recipe my dead mother taught me. It's usually three or four leaves of each plant but one day I wanted to reduce more of my blood glucose, so I added more leaves. It made me dizzy so now I always stick to using three or four leaves" (participant 20).

### 3.3.2. Use of home remedies to treat foot ulcer

Participants also used home remedies such as garlic to treat new wounds. The use of garlic to treat wounds has been around for many generations. Participants said they would go to hospital or a primary health center if the wound deteriorated.

"When my foot [points to the bottom of the big toe] get wounded I usually use garlic. I smear it over the wound... I never need to go to hospital, since it always heals. ...If my wound were to become severe, I would go to the primary health center (Participant 15).

## 3.4. Theme 3: Coping influenced by a blend of culture and religion

### 3.4.1. Managing stress by submitting to God

Most of Indonesia's population is Muslim. Javanese culture and Islamic religion are closely linked and cannot be separated. The way Javanese patients manage their stress is therefore influenced by a blend of culture and religion. All key participants stated that everything that happens is God's will and that diabetes is simply a trial from God. They believed that if they coped well they would be rewarded by God. This belief might have improved key participants' psychological conditions, helping them deal with distress.

"Everything in this world happens according to kersane gusti (God's will). I have accepted this disease as being kersane gusti Allah [points a finger to the sky], so, I am not too stressed thinking about it" (Participant 20).

### 3.4.2. Being patient in dealing with diabetes

Javanese people tend to be polite and avoid conflict with others. This influences the way Javanese patients manage their T2DM. According to the interviews and field notes, key informants believed that T2DM must be accepted with *ikhlas* (patience) since it is trial from God.

"I don't worry about my disease and what I should do every day to control it. As a human I have to be sabr (patient) with this disease and its management every day. I believe this disease is a trial from Allah (God) to test whether or not I have patience (Participant 20).

## 3.5. Theme 4: cultural influence on diet management

### 3.5.1. Difficulty managing diet at cultural events

In Javanese culture, the concept of social gathering is very important. Each social occasion has a different name. *Kondangan* is a marriage celebration. *Mitoni* is a pregnancy celebration. *Khitanan* is a circumcision celebration. There are special social gatherings for everything from members of a credit group to neighborhood associations. This can be a challenge for diabetes patients. Because Javanese people have strong relationships with their communities and neighborhoods, they tend to receive many invitations for gatherings. On such occasions, participants stated it is difficult to avoid eating many dishes, since in Javanese culture, it is considered impolite to refrain from eating and doing so can be considered as disrespectful or arrogant. Refusing to eat could also be interpreted as a suggestion that the dishes are not tasty. According to interviews and field notes, all participants found such situations challenging for their blood glucose management.

*"When I attend a kondangan (marriage celebration), I can't refuse food. I am afraid they will label me as being disrespectful. It always puts me in a difficult situation [frowning]." (Participant 38).*

### 3.5.2. Difficulty managing the habit of eating sweet-tasting food

Participants reported that dishes in Central Java tend to taste sweet because it is a habit in the region to add a lot of sugar to cooked food. This is challenging for diabetic patients who are taught by their health providers that sugar should be reduced or omitted from their food. Most of them want to change the way they cook but it is difficult for them.

*"My tongue feels strange when I taste dishes that are cooked without sugar. Of course we use salt, but when we cook dishes without sugar they taste a bit bitter... The doctor told me that I should not add sugar to my dishes, so I do try" (participant 23).*

## 4. Discussion

Our study is the first to show that some of Javanese cultural beliefs and practices have a detrimental effect on their health. This study also showed that culture had strong influence on diabetes self-management in Javanese diabetic patients. The four themes to emerge from our study were misconceptions about diabetes and management; cultural beliefs and practices regarding treatment regimen; coping influenced by a blend of culture and religion; and culture influence on diet management.

Several misconceptions about diabetes and management were uncovered in this study. Participants believed in two types of diabetes: *dry sugar* and *wet sugar* type. Most participants reported feeling fortunate to have the *dry sugar* type since they believed that they were not at risk of developing ulcers. They also believed that if they did get an ulcer, it would heal without aggressive treatment. Although this concept is not known in Western medicine, the idea of there being *dry* and *wet sugar* types has been rooted in Javanese belief for a long time. The reason for this is unknown since there is no available literature describing it, however the concept might come from the visual appearance of ulcers. Theoretically, there are three types of diabetic foot ulcers, and they are categorized based on their etiology. Foot ulcers are classed as being either neuropathic, ischemic, or neuro-ischemic [38, 39, 40]. One of the characteristics of neuropathic ulcers not seen in ischemic ulcers is the presence of wound exudate [40]. Wound exudate creates a wet-looking wound, and this might be why Javanese patients categorize it as *wet type DM*. In contrast, ischemic foot ulcers are caused by low perfusion due to peripheral arterial disease and they are often characterized by dry, necrotic tissue [40]. This may be what is known locally as *dry type DM*. The prevalence of ischemic ulcers is lower than that of neuropathic ulcers [40], and this could explain why Javanese DM patients believe *wet type DM* sufferers are more prone to foot ulcers than *dry type DM* sufferers. This belief can endanger patients, since those with ischemic ulcers are actually more at risk of needing amputation than those with the neuropathic type [41]. Such beliefs can mean Javanese patients act without caution and fail to perform appropriate foot ulcer prevention. Education is needed to teach patients that they are still at risk of developing foot ulcers despite believing they have *dry sugar DM*.

In this study, participants refused to use insulin since they believe that insulin is harmful to the body and can result in complications such as internal organ damage and may even cause death. This cultural belief has been reported in the other countries [42, 43], but it does appear to be more serious in Javanese. Every patient in this study said they would refuse to use insulin if offered, believing it can lead to death. Such beliefs may be caused by a lack of knowledge and poor communication between health care providers and their patients. One study showed that patients with low knowledge about insulin therapy were highly likely to refuse it [44]. Previous studies carried out in Indonesia have shown a significant correlation between communication and insulin use [44, 45]. Poor communication between health care providers and their patients may lead to

misunderstanding, with patients instead believing information derived from their communities. Poor communication might also lead patients to initiate insulin use at a later stage of their disease when their blood glucose has increased, and their health has deteriorated. This in turn may cause patients to believe that insulin is to blame for their deteriorating health, rather than the natural progression of the disease. Health care providers should therefore provide education and counseling and improve communication with their patients, working hard to create trusting relationships.

Participants also believed that consuming even large amounts of either cold rice or palm sugar will not increase blood glucose. These beliefs have existed on Java Island for a long time. Somewhat surprisingly, recent research found that cold rice is lower on the glycemic index (GI) than freshly cooked rice [46]. A recent study also reported that palm sugar has a lower GI value than cane sugar [47]. However, in previous study, the rice was cooled in the refrigerator, and was not left at room temperature. The diabetic patients in this study usually allow their rice to cool by leaving it at room temperature up to two days, turning it into *nasi wadang* or decaying rice. This habit can be dangerous since rice kept in such conditions may accumulate bacteria. In addition, despite the abovementioned study findings, excessive of consumption of cold rice or palm sugar will still increase blood glucose.

The idea that consuming a lot of cold food and palm sugar will not increase blood level was entrenched in participants, none of whom had access to a blood glucose checker. They are therefore unaware of when their blood glucose rises. Participants stated they would only go to a health provider if their condition or symptoms became very severe. Health care providers should provide adequate education, teaching patients that eating a lot of cold rice or palm sugar will still increase blood glucose and giving information on how to safely prepare cold rice.

Participants also stated believing that DM can be cured by self-management and by God's will. This corresponds to the results of a study in Myanmar, which found participants believed diabetes could be cured completely through the use of traditional medicine [23]. While such positive thinking may benefit DM patients, health care providers should educate their patients about the cause and management of the disease. This should be done in a culturally sensitive way, using educational materials appropriate to Javanese culture, in the locally spoken language, and involving community or religious leaders in the planning, delivery and implementation [48]. The community or religious leader can serve to liaise between health care providers and patients, helping DM patients more readily accept educational information.

Most participants in this study reported using medicinal plants alongside medicine for controlling their blood glucose. Medicinal plants have been used by diabetic patients for many years. A previous study showed complementary and alternative medicine use in diabetic patients is high in Indonesia, reaching 64.9 % [49]. Participants believed medicinal plants used alongside medicine would further reduce their blood glucose. However, combinations of medicine and medicinal plants must be supported by evidence. When educating their patients, health providers should confirm any medicinal plants they may be using has been adequately tested for safety and efficacy [50].

Our study shows that patients coping with stress are influenced by a blend of culture and religion. In Java, culture and religion are inextricably linked. Therefore, Javanese diabetic patients tend to cope with both stress and disease management by submitting to God and trying to be patient. Key participants considered their disease to be a trial from God, a belief that may help them not to become stressed about their condition. Our study supports the results of a previous study which showed that religiosity and spirituality could serve as coping mechanisms in patients with DM. People with higher religiosity had significantly better glycemic control than those with lower religiosity [51]. Furthermore, diabetic patients with higher religiosity and spirituality have been found to suffer less depression [52].

Our study also found that participants struggled with diet management when it came to attending gatherings. They reported feeling conflicted between eating for politeness and managing their blood glucose. If they choose not to eat at such gatherings, they fear being

stigmatized as being disrespectful or arrogant. This struggle to follow a healthful diet at social gatherings can cause pressure and frustration for diabetic patients since in Javanese culture, not attending a social gathering is not socially acceptable. In this study, most participants were able to recognize that people in Central Java tend to use a lot of sugar in their dishes. This custom puts the population at risk of hyperglycemia. Nurses need to design culturally sensitive education program to educate patients and community to help Javanese diabetic patients in managing their diet. In our study, most participants were educated by a nurse and therefore reduced the amount of sugar they put in their dishes.

#### 4.1. Limitation, and implication for clinical practice

The main limitation of this study was that it was confined to Java island. However, while we realize we cannot generalize the findings to all Indonesians, Javanese is the largest ethnicity in Indonesia, and therefore our participants are more likely to better represent Indonesian culture as a whole than other groups would. Although our sample was heterogeneous across a number of different sociodemographic and clinical variables, it was not fully representative of the overall population of diabetic patients in Indonesia. Another limitation of this study was that the participants were mostly female. While this could be seen as a shortcoming, it does represent the prevalence of DM in Indonesia, which has previously been shown to be significantly higher among females [53].

Despite the limitation, this study can be of benefit. We gained comprehensive data, having interviewed both families and health providers to gain a wide perspective of how culture and belief relate to diabetes management in Java. Considering the previous lack of available evidence in this area, our study provides an important insight which will help nurses in Indonesia to design culturally sensitive program for their diabetic patients. Our study also highlights the need for nurses to understand how Javanese culture affects self-management in order to create an effective self-management program for Javanese diabetic patients.

Another implication is that nurses should adequately educate their patients about misconceptions related to and self-management, since some of these misconceptions can be harmful for patients. Nurses also need to educate patients that the use of traditional medicines might have harmful effects for patients. Educational programs should be performed at the community level since people in the community need to understand that patients with DM find it hard to control their blood glucose due to worrying about being labeled as disrespectful or arrogant if they don't eat the dishes served at community events. Future studies are needed to investigate the effects of the application of a culturally sensitive program for patients on improving self-behaviors of Javanese diabetic patients.

## 5. Conclusion

This study offers new insights into how Indonesian culture influences patients' perception and management of DM. It has revealed some misconceptions about DM and its management among Javanese diabetic patients. Results show that DM patients find diet management difficult and are influenced by their cultural beliefs and practices. Furthermore, results show that patients coping with stress are influenced by a blend of culture and religion. This study provides important information that nurses in Indonesia can utilize in their creation of culturally sensitive education programs for DM patients to improve self-management behaviors. Future studies are needed to investigate the effects of the application of a culturally sensitive program for patients on improving the self-management behaviors of Javanese DM patients.

## Declarations

### Author contribution statement

Yunita Sari: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Wrote the paper.

Lita Heni Kusumawardani and Annas Sumeru: Performed the experiments; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Haryanto, Saldy Yusuf: Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data.

Eman Sutrisna and Saryono: Contributed reagents, materials, analysis tools or data; Wrote the paper.

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### Data availability statement

Data will be made available on request.

### Declaration of interests statement

The authors declare no conflict of interest.

### Additional information

No additional information is available for this paper.

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