

Live experience of people with diabetes mellitus on self-management during COVID-19 in remote area of Indonesia

Experiencia en vivo de personas con diabetes mellitus sobre el autocontrol durante el COVID-19 en un área remota de Indonesia

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SUMMARY

Introduction: People with Diabetes Mellitus (DM) are vulnerable to COVID-19. Therefore, it's important to maintain good self-management (diet, exercise, medicine, and health care visitations) during pandemics. Unfortunately, during the COVID-19 pandemic, it's difficult for them to maintain adequate self-management. Therefore, this study aimed to explore the self-management of people with DM during the pandemic, especially in a remote area of Indonesia.

Methods: This study is qualitative and uses the phenomenology method. The data was obtained from 10 people with Diabetes Mellitus using face-to-face interviews. Data collected was analyzed thematic using Atlas.ti software and statements from participants were presented verbatim to illustrate the themes realized.

Results: Participants' experience in self-management during COVID-19 was categorized into three themes

and ten sub-themes. The three themes emerged from the study: psychological distress of being vulnerable to COVID-19, preferring traditional over medical treatment, and prejudice toward healthcare workers and facilities.

Conclusion: Rural residents with DM experience psychological distress, leading to poor self-management and stigma toward healthcare workers and facilities. Therefore, it is important to do comprehensive care consisting of self-management, psychological care, and education on the stigma around COVID-19 for people with DM.

Keywords: Comorbid, COVID-19 pandemic, type 2 diabetes mellitus, psychology distress.

RESUMEN

Introducción: Las personas con Diabetes Mellitus (DM) son vulnerables al COVID-19. Por lo tanto, es importante mantener un buen autocontrol (dieta, ejercicio, medicamentos y visitas médicas) durante las pandemias. Desafortunadamente, durante la pandemia del COVID-19, es difícil para ellos mantener una autogestión adecuada. Por lo tanto, este estudio tuvo como objetivo explorar el autocuidado de las

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personas con DM durante la pandemia, especialmente en un área remota de Indonesia.

Métodos: *Este estudio es cualitativo y utiliza el método fenomenológico. Los datos se obtuvieron de 10 personas con Diabetes Mellitus mediante entrevistas cara a cara. Los datos recopilados se analizaron por temas utilizando el software Atlas.ti y las declaraciones de los participantes se presentaron palabra por palabra para ilustrar los temas tratados.*

Resultados: *La experiencia de autogestión de los participantes durante el COVID-19 se categorizó en tres temas y diez subtemas. Los tres temas surgieron del estudio: angustia psicológica de ser vulnerable a COVID-19, preferir el tratamiento tradicional al médico y el prejuicio hacia los trabajadores y las instalaciones de atención médica.*

Conclusión: *Los residentes rurales con DM experimentan angustia psicológica, lo que conduce a un autocontrol deficiente y al estigma hacia los trabajadores y las instalaciones de atención médica. Por lo tanto, es importante realizar una atención integral consistente en autocuidado, atención psicológica y educación sobre el estigma en torno al COVID-19 para las personas con DM.*

Palabras clave: *Comorbilidad, pandemia de COVID-19, diabetes mellitus tipo 2, angustia psicológica.*

INTRODUCTION

As of August 2022, about 6.3 million people in Indonesia are exposed to Coronavirus Disease (COVID-19), with 157 thousand of deaths. At the peak of rapid transmission in 2021 Indonesian government made lockdown regulations that affect many people, especially people with type 2 diabetes Mellitus (DM) and other chronic diseases who need regular checks on health facilities. In addition, people with chronic diseases are vulnerable to COVID-19. According to the WHO report, Diabetes Mellitus (DM) is a chronic disease that occurs in 422 million people worldwide (1). Centers for Disease and Prevention (CDC) revealed that the risk of death in people with DM increased by 11 % more than in people who did not have DM. As a result, 1.6 million people die from diabetes yearly (2). During COVID-19, people with DM have a high risk of dying (3–5). A previous study found that DM is a major risk factor for developing severe pneumonia and sepsis (6). In addition, the risk of death from COVID-19 is up to 50 % higher in people with DM than in those without (7), so it

is essential to maintain self-management during a Pandemic for people with DM.

Self-management in DM patients is crucial, especially in maintaining blood sugar levels and preventing complications (8-11). DM self-management includes medication adherence, maintaining a proper diet for diabetes, regular exercise, and regular medical check-ups (12,13). DM patients who do proper self-management can improve self-care behaviour in type 2 diabetes patients, especially in maintaining blood sugar levels (1,12,14). Self-management in DM patients can also affect the quality of life of patients and families (8,15-17). The purpose of self-care is to manage the factors that effectively influence the development and condition of the client so they can maintain a healthy condition. The client's abilities and knowledge influence self-care behaviours. Self-care is important because it emphasizes a person's active role. Unfortunately, during COVID-19, it's difficult for people with DM to maintain adequate self-management. Previous studies stated that quarantine and lockdowns impact people with DM self-management like worsening glucose control, limited physical activities, difficulty getting medicine, and people with diabetes mellitus would not have been able to visit their physicians for the routine check-up (6,18,19). This condition can worsen in remote areas with limited health care, especially during pandemics.

Manggarai, located in East Indonesia, is one of the remote areas. Most of the locals worked as a farmer. There are only two hospitals and 21 public health centers for more than 312 thousand residents. In 2022 according to the health district of Manggarai, there are 9021 cases of COVID-19 and 21 dead. The most causes of the dead are comorbid illnesses like hypertension, diabetes mellitus, stroke, and heart disease. The lack of a healthcare system can be challenging for people with DM, especially during the pandemic. Previous studies stated that people with diabetes in remote areas in India face difficult challenges in self-management during the COVID-19 pandemic (20,21). Another study in Indonesia revealed that people with DM struggle to do self-management during pandemics and also experience psychological distress, but there is still limited qualitative study about the self-management of people with DM in remote areas

in eastern Indonesia (22). This study aimed to explore the experience of rural residents with DM in self-management during COVID-19.

METHODS

This study is a qualitative study that used a phenomenology approach. The goal of phenomenology is to describe the meaning of this experience—both in terms of what was experienced and how it was experienced (23). The participants in this study were 10 people with Diabetes Mellitus who were recruited using purposive sampling and interviewed face-to-face during their visit to the public health center in August of 2021. The interview questions focused on how people with DM maintain adequate self-management during COVID-19, the challenges, and the impact of the pandemic they experienced during COVID-19. Data was recorded and transcript verbatim. All the data were transcript anonym. Data were analyzed using thematic analysis with the help of Atlas.ti software. This study has been approved by the Committee Etic of Unika Santu Paulus Ruteng with number No.07/SK-IIIa/WAREK I-02/k/07/2021.

RESULTS

Participants in this study are 10 participants (7 female and 3 male) aged 41-65 years old. Most participants pursued formal education until high school (60 %) and the rest were elementary graduates. Most participants didn't work (60 %) and the rest worked as farmers and fishers. All the participants live with DM for about 3 – 13 years. Data analysis using Atlas.t resulted in 10 sub-themes and three themes. Three themes emerged from data analysis, namely Psychology distress of being vulnerable to COVID-19, preferring traditional over medical treatment, and prejudice toward healthcare workers and facilities

Theme 1 Psychology distress of being vulnerable to COVID-19

Psychology distress of being vulnerable to COVID-19 consists of afraid of death if got

COVID-19, paranoid about a family member who got COVID-19 or ignoring transmission prevention, anxiety and trouble sleeping if hearing other people with DM die because of COVID-19, Fear of going to the hospital because it can make them get COVID, and Ask a family member to go to the hospital or public health center to take their medicine.

Afraid of Death if Got COVID-19

Participants stated that people with DM are afraid they will die if they get COVID-19. Therefore, they realize DM will increase the risk of death.

“To be honest, I was afraid of death if I got COVID-19. We who have DM have a high risk of death if got COVID-19. If I hear my Neighbour or people from my circle got COVID-19, I am so afraid and don't want to go outside” (P2)

“One thing I am afraid the most if I got COVID is I will be dead. I feel so helpless with this condition” (P5)

Being paranoid about a family member who got COVID-19 or ignoring transmission prevention

Because of their condition, participants were afraid if a family member got COVID or merely ignored transmission prevention.

My daughter got COVID, and I asked her to stay outside the house and never meet me until she recovered. We communicate via video call as a mother, I want to take care of her, but my daughter and I don't want to take the risk if I got COVID-19 (P3)

I have to make sure my family member always does transmission prevention; they have to wear a mask if they go outside and do not meet me directly after going outside (P2)

Anxiety and trouble sleeping if hear other people with DM die because of COVID-19

The participant stated that they feel anxious and have trouble sleeping if they hear other people with DM die because of COVID-19.

One of my relatives who have DM died because of COVID-19. It makes me so anxious, and I can sleep for about three days. It also makes my blood sugar high. It is so frightening (P1)

Every time I read the news or watch TV about people with DM or hypertension who died because of COVID-19, I am so panicked and afraid. It makes me dizzy and sometimes fatigued (P4)

Fear of going to the hospital because it can make them get COVID-19

The participant stated that they were afraid to go to a hospital because it can make them get COVID-19

I am afraid to go to the hospital because I can get COVID-19 from them. Every time I want to go to the hospital or public health care, I am scared and can sleep at night (P4)

Public health centers and hospitals are the sources of COVID-19, and I am too afraid to go there. What if I got COVID-19 and died? (P7)

Ask a family member to go to the hospital or public health center to take their medicine

The participant stated that they are afraid to go to the hospital or public health, so they ask a family member to take their medication.

I never go to the hospital or public health care during this pandemic. If I run out of medicine, I just ask my son to go to the hospital or public health center to take medicine. (P2)

I am afraid to go to the hospital, so I ask my daughter, who is healthier than me, to take medicine for me. (P6)

Theme 2: Preferring alternative over medical treatment

Preferring alternatives over medical treatment consists of consuming herbal medicine to maintain blood sugar, drinking herbal medicine because they are afraid to go to the hospital, and consuming Afrika leaf (*Vernonia amygdalina*), which traditionally believed to maintain sugar blood

Consume herbal medicine to maintain blood sugar

The participant stated that during the pandemic, they chose to drink herbal medicine, which they got from a herbal store.

I read in the news that herbal medicine from China can improve the immune system of people with DM. So, I consume it. It is easy to get also. (P5)

I drink a lot of herbal medicine during COVID-19 because people say it is good for me and can prevent me from dead if I get COVID-19 (P3)

Drink herbal medicine because they are afraid to go to the hospital

Some participants stated that they choose herbal medicine because it's easier to get and they are afraid to go to a hospital

I drink a lot of herbs because I run out of medicine and am too afraid to go to the hospital or public health care. I will go to the hospital if this COVID-19 ends (P1)

Using alternative medicine is safer than going to the hospital or public health to take medicine. You just take some leaves from the garden and produce the medicine. No contact with people or COVID-19 (P9)

Consume Afrika leaf (*Vernonia amygdalina*), which traditionally believed to maintain sugar blood

The participant stated they consume Afrika leaf (*Vernonia amygdalina*) to maintain their sugar blood.

During the COVID-19 pandemic, I always drank Afrika leaf three times a day. It can help decrease sugar blood and is also easy to get. (P2)

People in my village used Afrika leaf to cure diabetes Mellitus. During COVID-19, I drink the leaf every day, and it helps me (P10)

Theme 3: Prejudgment toward healthcare workers and facilities

Prejudgment toward healthcare workers and facilities consist of refuse to go to hospital and

public health center because they were the source of COVID-19, avoid meeting doctor or nurse directly because they can transmit COVID-19, and believing in conspiracy and hoaxes about COVID-19.

Refuse to go to hospitals and public health centers because they believe that the places are the source of COVID-19

Participants stated that they don't want to go to hospitals and public health centers because they believe hospitals and public health centers are the sources of COVID-19.

I don't want to go to the hospital or public health center because that place is the source of COVID-19. I hear some people got COVID-19 because they go to public health care. So why bother to go there (P4)

I am afraid to go to the hospital or public health center because people who got COVID-19 are there. We can make sure the doctor or nurse didn't transmit the virus to me. (P5)

Avoid meeting doctors or nurses directly because they can transmit the COVID-19

Participants stated they don't want to meet a doctor or nurse because they can transmit the COVID-19

I never go to the doctor or nurse during this pandemic because they can transmit the virus to me. They spend their day caring for people with COVID, and we don't know how safe their prevention is. It's better to avoid them. (P5)

Doctors, nurses, and hospital workers are the source of COVID-19. I think I will be safe. I didn't go near them, so I don't want to go to the hospital or public health center during this COVID-19. If I need medicine, I ask my son to buy it in a drugstore (P6)

Believe in conspiracy and hoaxes about COVID-19

Participants stated that they believe COVID-19 is propaganda made by healthcare and government

I think some people didn't have COVID-19, but the hospital and public health center say he got COVID-19 to make us afraid. (P4)

COVID-19 is a hoax, and it is propaganda made by the government and health staff, so we spend money on the health system and pay for BPJS (public health insurance) (P6)

DISCUSSION

Participants in this study stated they feel psychological distress like being afraid of death if they got COVID-19, being paranoid if they know a relative who got COVID-19, and anxiety thinking about other people with DM who died because of COVID-19. Previous studies also found This belief happens because they read the news, are told by a healthcare worker, and also have relatives with DM who died because of COVID-19. Psychological distress has reduced the immune system, making people vulnerable to COVID-19 (24-28). Stress in diabetic patients also can decrease adherence (29). A previous study found that stress management in people with DM can also reduce the level of glucose (30,31). So, it's important to maintain stress management during COVID-19, especially for people with DM during a pandemic. It is important to meet not just the physical but also the psychosocial needs of people with DM.

Participants in the study stated that they prefer alternative treatment to medical treatment during COVID-19 because it is easier to get. They chose alternative treatment because they were too afraid to go to the hospital or public health, which they assume is the source of COVID-19. The practice of alternative medicine during COVID-19 is commonly known in Indonesia. The consumption of Jammu during the COVID-19 pandemic is believed to improve the immune system (32). In this study, a participant stated that they use Afrika leaf or Vernonia amygdalina to reduce sugar blood levels. A previous study has found that vernonia amygdalina has little effect on decreasing glucose in diabetic rats (22), but there is still no study on humans. The practice of herbal medicine to treat DM has also been known globally. In a remote area in India, people used plants like begonia roxburghii, calamus tenuis, and many more (33). But there is no evidence of the effect of herbal medicine on humans, so the best treatment to control sugar blood levels is medical treatment. Therefore, it is important to

emphasize the importance of medical treatment to improve the quality of life of people with DM. Public health facilities must find a way to make medical treatment accessible and affordable.

Participants in this study stated that they don't want to go to a hospital or public health center because they assume that hospitals and public health centers are the sources of COVID-19. During COVID-19, healthcare workers often experience stigma from the public, especially because they take care of and have close contact with COVID-9 patients (34,35). Stigma and prejudgment happened because of fear, anxiety, and limited knowledge (36). In this study, participants refuse to go to the hospital due to irrational fear of COVID-19. This can worsen the diseases, as medical check-ups are important to maintain blood sugar and prevent complications. Therefore, education about COVID-19 is important for chronic patients. Previous studies suggested that having better knowledge will diminish irrational fear, anxiety, and stigma and is associated with a less stigmatized attitude (37), so it's important to provide health education not only on self-management during COVID-19 but also to reduce stigma toward health care workers and facilities.

CONCLUSION

People with DM experience psychological distress, which leads to poor self-management and prejudgment toward healthcare workers and facilities. Therefore, it is essential to do comprehension care consisting of self-management, psychological care, and education about COVID-19 for people with DM.

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