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Malnutrition: Undernutrition or overnutrition?

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Abstract

The definitions and terminology related to malnutrition need to be clarified. The Academy of Nutrition and Dietetics (Academy) and the American Society of Parenteral and Enteral Nutrition (ASPEN) have classified clinical nutrition into malnutrition (undernutrition), sarcopenia, frailty, and overnutrition (overweight and obese). In addition, determining indicators for determining diagnoses related to malnutrition also needs to be clarified. Thus, this information can be used by nurses and other health workers to be able to provide appropriate planning and interventions for patients with malnutrition.

Keywords: malnutrition; nurse; overnutrition; undernutrition

Main Text

Adequate nutritional needs are needed by patients undergoing treatment at the hospital. Not only that, but the monitoring of patients undergoing outpatient care or community settings also needs attention. Nutrition is an important requirement and impacts the healing process of disease. Nutritional disorder experienced by many patients with chronic diseases such as diabetes mellitus, cardiovascular, renal, and others (Gosmanov & Umpierrez, 2012; Zahangir et al., 2017). Not only that, patients with critical illness who are hospitalized in the intensive care unit (ICU) also require serious attention to their nutritional needs (Havens et al., 2018). In other conditions in the community, someone who is overweight or obese also does not realize that they need therapy and serious attention to their nutritional needs. For this reason, the understanding of undernutrition and overnutrition need to be clarified.

The World Health Organization (WHO) states that malnutrition is a condition in which the body experiences a deficiency or excess of nutrients (Organization, 2020). This means that malnutrition is included in the category of undernutrition and over-nutrition. The definition related to malnutrition is still being debated because some argue that malnutrition refers to a condition of undernutrition. The European Society of Clinical Nutrition and Metabolism (ESPEN) provides definitions and terminology regarding clinical malnutrition (Cederholm et al., 2017). Clinical malnutrition consists of malnutrition (undernutrition), sarcopenia, frailty, and over-nutrition. ESPEN classifies these according to the needs of the patient's condition with nutritional disorders. ESPEN defines clinical nutrition based on nutrition-related concepts, procedures, and developments in practice and research (Cederholm et al., 2017). Thus, it can be concluded that malnutrition conditions refer more to nutritional deficiencies that impact the quality of life and well-being.

Instruments used for assessing malnutrition have been developed. WHO states that malnutrition can be evaluated based on Severe Protein-Energy Malnutrition and or Body Mass Index (BMI). Severe Protein-Energy Malnutrition refers to conditions such as marasmus, kwashiorkor, or a mixed form, marasmus kwashiorkor. Meanwhile, BMI refers to adult conditions that are classified into normal (>= 18.5), mild malnutrition (17.0-18.49),

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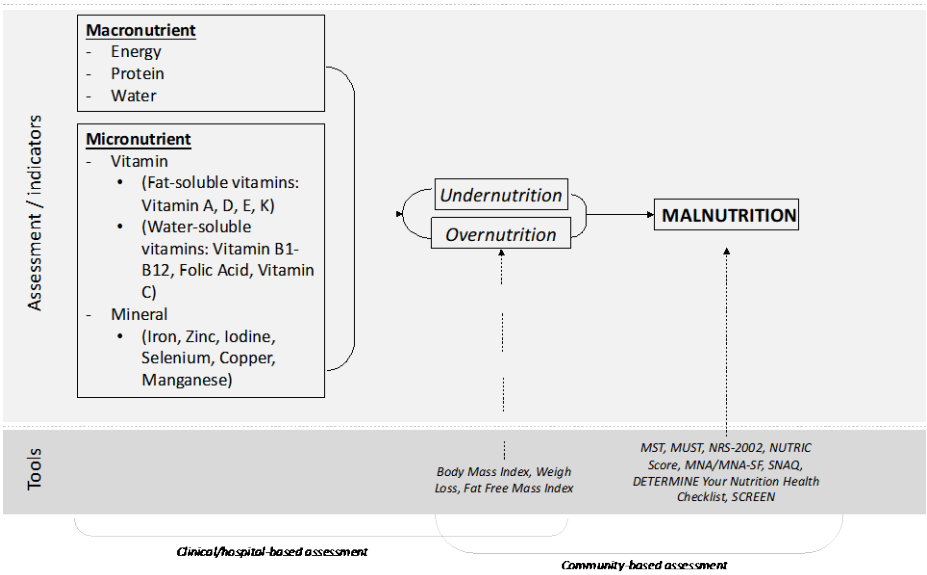

Figure 1. Malnutrition

moderate malnutrition (16.0-16.99), and severe malnutrition (<16) (Bailey & Ferro-Luzzi, 1995). Additionally, The Academy of Nutrition and Dietetics (Academy) and the American Society of Parenteral and Enteral Nutrition (ASPEN) identify and classify malnutrition based on 1) Insufficient energy intake; 2) Weight loss; 3) Loss of subcutaneous fat; 4 Loss of muscle mass; 5) Localized or generalized fluid accumulation that may sometimes mask weight loss; and 6) Diminished functional status as measured by hand grip strength (White et al., 2012). In addition, there are two alternative methods used to diagnose malnutrition 1) BMI < 18.5 kg/m2, and 2) weight loss > 10% indefinite of time, or > 5% in the last three months combined with either BMI <20 kg/m2 if < 70 years , or < 22 kg/m2 if >=70 years or fat-free mass index (FFMI) < 15 and 17 kg/m2 in women and men, respectively (White et al., 2012). Moreover, the identified malnutrition also refers to macronutrients and micronutrients (See figure 1).

In addition to the criteria above, there are several screening tools used to identify patients with nutritional disorders 1) Malnutrition Screening Toll (MST) for adults, including elderly in hospital and outpatient care facilities; 2) Malnutrition Universal Screening Tool (MUST) for adult in hospital and community settings; 3) National Risk Screening (NRS) for adults in hospital settings; 4) NUTrition Risk in the Critically ill (NUTRIC Score) for patient in the critical care; 5) Mini Nutritional Assessment (MNA) for elderly in the community, sub-acute, long-term care, or any residential with dementia; and 6) Short Nutritional Assessment Questionnaire (SNAQ) for older adults in the community-dwelling settings. Those screening tools can be used as patient characteristics and conditions (Doley & Marian, 2022).

Nurses have an important role in providing for patients with malnutrition in providing nursing care (Moyles, 2022). Observing, monitoring related nutritional needs, intake and tolerance, and communicating with patients and families are actions that nurses must carry out. Also, collaboration with doctors and nutritionists is carried out to obtain nutritional needs and proper diet information. In addition, physical assessments such as anthropometrics, appetite, intake, and tolerance can be carried out by nurses. Then, nurses can determine nursing diagnoses that refer to nutritional needs. Nurses have an important role. So proper education needs to be given to patients and families with malnutrition.

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The essence of surviving COVID-19: A phenomenology study

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Abstract

Background: COVID-19 is a respiratory infection that has claimed the lives of many people. It caused many changes in society; it impacted physically, emotionally, and most of all socially. The impact can be light or severe, depending on the severity of the diseases and the individual ability to cope with the disease. Although many died from this disease, many also survived.
Purpose: This study aims to explore the experiences of COVID-19 survivors. The results of this study can be used as actual information to all levels of society in understanding the COVID-19 phenomenon.
Methods: This study is a qualitative study with a phenomenological approach. The population is COVID-19 survivors with 14 participants that have been selected by snowballing technique.
Results: Survivors of COVID-19 experience physiological, psychological, social and spiritual impacts. The treatment received by the survivors is based on the symptoms experienced and fluid therapy to maintain fluid balance for patients who do not have a good appetite, and as a course of injection drugs. Survivors received support and comfort from doctors, nurses, family, friends, co-workers, superiors, and even from students. It was also found that the survivors admitted that suffering from COVID-19 they experienced a closer relationship with their family, more care and attention. It was also found that there was a last request if the survivor died. Survivors express the meaning of life felt by survivors of COVID-19 as a bitter experience, and a second chance that must be used to as full an extent as possible. There were also recommendations from the survivors.
Conclusion: There were 19 categories e found and put into six themes, namely the impact of exposure to COVID-19, treatment and remedies, support and comfort, interpersonal relationships, will and the essence of life

Keywords: COVID-19; essence of life; survive

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Introduction

Corona Virus Disease (COVID)-19 is an infectious disease that attacks the respiratory system acutely. This disease is an infectious disease that spreads very quickly. Since it was discovered in Wuhan at the end of December 2019, the spread of this disease has been very fast. In March 2020, the spread of this disease increased very rapidly. As of early June 2020, it had spread to 215 countries with 6,294,072 cases and 374,405 deaths. The ten countries most affected by the spread of this virus from the highest ranking are the USA, Brazil, Russia, Spain, the UK, Italy, India, France, Germany and Peru (Worldometer, 2020).

The spread of this virus occurs from person to person through the nose or mouth where splashes of saliva and mucus called droplets from someone infected with COVID-19 spurt when they cough, sneeze, or talk. These droplets can directly hit other people at a close distance, for example, less than one meter, or these droplets fall to the ground, onto nearby objects, such as on a table or doorknob. When someone touches an object that contains this virus, transmission can occur if that person touches his nose, mouth, or eyes (World Health Organization, 2020).

According to Centre for Disease Control (CDC) stated that symptoms of COVID-19 are fever or chills, cough, shorthnes of breath or difficulty

breathing. Patients reported fatique, headaches, aches in muscle and body. Another symptoms were loss of taste or smell, sore throat, congestion or runny nose, nausea or vomiting, and also diarrhea (CDC, 2022).

COVID-19 has claimed many lives and has changed the life of the global community, both psychologically, spiritually, and also affect social life. Individuals infected with this virus must be isolated from their families. In the hospital, the patient is placed in a room that cannot be visited by their family. This makes the infected persons very afraid and lonely. Even when death comes, the family cannot carry out the funeral according to the customs and beliefs that should be. Funerals can only be watched from afar because the funeral protocol for a COVID-19 corpse has been regulated. This of course is very sad and hurts the family members. Grief is often heart-wrenching where families are unable to attend the funeral of their family member who is infected with this disease. The community was hit by fear, especially throughout 2020. Although COVID-19 has taken many victims, fortunately, many of them also survived. They struggle to beat the damage to physical function caused by the viciousness of this virus. Surviving and recovering from COVID-19 is certainly an extraordinary experience, especially for survivors who experience severe symptoms.

People have often heard the quote that says that experience is a very valuable teacher. Experiences when interpreted correctly will result in something good that brings success. Likewise, with these experiences about COVID-19. If people are willing to read about the experiences of other people who have survived COVID-19 and interpret them well, they will have sufficient knowledge to prevent being infected with COVID-19. If infected, they can recognize symptoms quickly, get the test diagnostic early, so that they can be treated more quickly so that symptoms can be minimized so as not to cause severity, deformity and even death. Since the emergence of COVID-19, the government has encouraged scholars to conduct research related to this disease. There is a lot of information that can be obtained through social media, television, and journals both nationally and internationally, but rarely written as phenomenology study. This article in particular will provide scientifically factual information about the experiences of COVID-19 survivors.

In connection with the information mentioned above, this study aims to explore the experiences of COVID-19 survivors while undergoing isolation either at home, in isolation centers or in hospitals. It is hoped that, based on these experiences, essential themes can be found that can be used by all levels of society in understanding what is experienced by COVID-19 sufferers from feeling symptoms to being declared cured of COVID-19. Accurate information can encourage people to be more confident in carrying out COVID-19 prevention and handling practices without being enveloped by anxiety, fear or panic. In addition, to help the community to be better prepared if waves of COVID-19 appear with different variants.

Materials and Methods

Design

This study is a qualitative study with a phenomenological approach.

Participants and Setting

The population was COVID-19 survivors. Samples were selected through the following inclusion criteria living in the territory of Indonesia and able to use Indonesian properly and correctly, men and women aged 18 years and over, tested positive for COVID-19 based on the results of nasopharyngeal swabs and PCR. Other criteria were experiencing symptoms ranging from mild to severe, undergoing the isolation process either independently at home or being treated in hospitals or COVID-19 control centers. The sample was selected with the snowballing sampling technique. The researcher asked the first informant to introduce his acquaintances who had experienced COVID-19. In this study there were informants who introduced one person and there were also those who introduced two people. The introduced person is taken as a sample if he meets predetermined criteria. In this way the researcher obtained a larger sample. The selection of samples was stopped at the fourteenth informant to enrich the data. Sample size for phenomenology may be different from one author to another. Creswell (2013) recommended between 3 to 10 samples are adequate for phenomenology, whereas Marshall, Cardon, Poddar, and Fontenot (2013) belived that 6 to 10 is enough, and Ellis (2016) stated that 6-20 will be sufficient.

Ethical Consideration

Data collection was from December 2020 until October 2021 after receiving a letter of passing ethical clearance with No.086/KEPK-FIK.UNAI/EC/VI/20 and the respondents were given an explanation of the research objectives, and the benefit by which the participants can share their valuable experience to the community. There is no risk that can occur in this study. After the understanding, each respondent was asked to sign informed consent. In the participant's information sheet, the participant was also given autonomy to choose to participate or not to participate, or if they chose to participate, participants were allowed to withdraw at any time. Most of all, the participant's identity is treated as confidential.

Data collection

Data collection was done through in-depth interviews with online platform using the Zoom meeting application. Duration of interviews was between 30-45 minutes. Interviews were recorded after obtaining the consent of the respondents.

Table 1. The Themes and Categories Description

Themes	Categories
Impact of Exposure to COVID-19	Physiology Impacts
	Psychology Impacts
	Social Impacts
	Spiritual Impact
Therapy and Remedies	Medication
	Infusion Therapy
	Oxygen Therapy
	Supplements and Vitamins
	Alternatives Therapy
Support and Comfort	Support from Health Care Team
	Support from the family
	Support from others (friends, co-worker, students, and others)
Interpersonal relationship	Family's Ties
	Care
	Strength Resources
Wills	Last Wills
Life Essence	Bitterness
	Second Chance
	Recommendation

Personal data protection has been considered by blurring the participant's identity during the interview in Zoom meeting. The questions asked were open-ended questions. To initiate the interview, the researcher asked participants to explain their experience since they experienced the symptoms, being tested positive for COVID-19, undergoing isolation and treatment until they were declared cured and negative for COVID-19. The data from the audio-visual recording were listened to and typed at the end of each interview. The transcriptions were done by another person to avoid bias. To ensure the accuracy and quality of the data, a third person was asked to listen to the audio-visual records and to recheck the transcriptions. Both audio-visual and transcriptions were saved in a secure password protected device.

Data analysis

Transcriptions were read and checked repeatedly and compared with the recorded results. Coding process was conducted using Hilal & Alabri (2013) step-by-step guideline for NVivo. All of the 14 transcriptions were dragged in to the NVivo software to start the coding process. The first transcription was coded based on the participant's statement. Different statements were sorted into nodes form. The same process was repeated for the second until the 14th transcription. New nodes were added as new code emerged in each transcription. Following the coding, thematic analysis was formed. The similar nodes were placed in one related theme. So, in this stage, each theme contains one or more categories or sub-themes. The next step was to link each category or sub-theme within the theme with the participant's statement. If the statements among participants were similar, then author selected the most complete statement to be quoted.

Trustworthiness

The researcher ensured that all stages of qualitative data collection and data analysis have been carried out in accordance with the stages of qualitative research. To ensure trustworthiness, the credibility, transferability, dependability, and confirmability (Cresswell, 2016: Manen 1984) were ensured. The credibility of the data from 14 participants was confirmed with one of the medical team, and also previous studies and other sources of literature. This triangulation process can be seen in Figure 1. The collected data are also available and auditable at any time when needed. To ensure the confirmability, the researcher has asked another researcher to check that data collection and analysis were in accordance with methodology.

Results

Based on data saturation, sample selection was terminated at the 14th participant. There were 10 women and four men, and their ages ranged from 24 to 60 years old. The study emerged six important themes, namely: the impact of exposure to COVID-19, treatment and remedies, support and

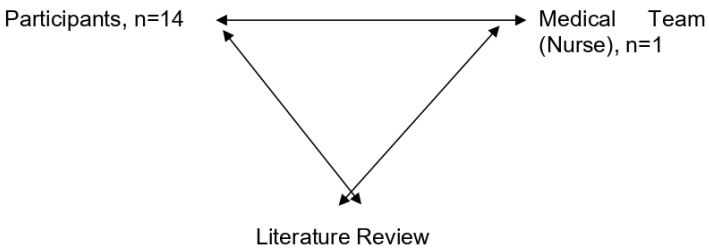

Figure 1. Triangulation Process to Ensure Credibility of the Data

comfort, interpersonal relationships, will, and the essence of life. These themes come from the results of coding that has been categorized. There are 19 categories found in this study. The description of themes and categories can be seen in Table.1. Based on Table 1, themes were complemented with the related categories and supported by the statements of the participants.

Theme 1: Impact of Exposure to COVID-1

There were four categories under the first theme, namely: physiological impact, psychological impact, social impact, spiritual impact.

Category 1: Physiological Impact

The first impact is the physiological impact. Survivors of COVID-19 experience physiological impacts in the form of physical symptoms, both mild and severe. Symptoms felt are in the form of fever (participants 3,4,6,7,10,12,13,14) feverish body and chills (participants 9, 11, 12, 13, 14), headache (participants 4,7,8, 10,11,12,13,14) even all parts of the body (participants 7,9,12), body shaking (participants 8,12), weak, powerless and unable to do anything (participants 3,8,10,12,14). The body aches, especially in the bones (participant 4,12), headache feels like the world is spinning (participants 6,12). The following are quoted statements from participants:

I have a fever, headache and body aches all over (participant 7).

I have a severe headache, the body is shaking, weak and unable to do activities (participant 8).

I have a fever and my body is very weak (participant 3).

The initial symptoms I felt were fever, extreme dizziness, it felt like the world was spinning (participant 6).

The symptoms were fever, and pain in my bones and also vertigo (pressing her head). The fever goes up and down, the fever can go up to 38.6 degrees (participant 4.

All body aches from head to toe (participant 9).

Survivors also experience symptoms of cough and shortness of breath ranging from mild to very severe. Severe symptoms need to be rushed to the hospital and treated in the Intensive Care Unit (ICU) and a breathing apparatus used. There were five participants who experienced light cough (participants 8, 10, 11, 13, 14). This is one of the participant's comments: *"it was just a light cough"* (participant 8). The duration of cough was different from one to another. Most of them recovered within days but there were four participants who experienced coughing for more than two weeks. This is their statement: *"my cough lasted for two weeks"* participant 3. The following are the statements of other participants:

When I cough my chest feels like it's going to burst and my eyes want to pop out because it's hard to expel the phlegm. I feel that phlegm deep down in my chest and almost three weeks the cough was present (participant 12).

I feel heavy when I breathe. Every morning I usually run for 30 minutes without stopping, but at that time it was only 10 minutes that I was already gasping for air and I was coughed about three weeks (participant 11).

There was one survivor who experienced severe symptom related to respiration. He had to be rushed into Intensive Care Unit from the COVID-19 isolation center because of his shortness of breathing. The following is one of their statements:

My breaths are getting short, it's very difficult to get air, uhmm it's very difficult to get air into the lungs. A few days later my breath became short. I had difficulty breathing and I ended up being transferred to the ICU, need to be placed with the ventilator. I was in ICU more than three weeks (participant 6).

Other symptoms felt by survivors were form of disturbances in the digestive system ranging from not being able to smell foods (participants 9, 11), no taste (9, 11), nausea (participant 1), vomiting (participant 1), no appetite (participants 6, 9, 110, 11, 12), and weight loss (participant 10). The following are the statements of the participants: *"I started to lose my sense of smell and have no appetite"* (participant 11); *"I was surprised that I didn't smell the foods and the food had no taste"* (participant 9); *"I've lost a lot of weight"* (participant 10).

Category 2: Psychological Impact

In addition to experiencing physiological impacts, the survivors claimed to experience psychological impacts. Once they received a positive result for COVID-19, most of them reacted similarly. The survivors experienced psychological symptoms such as denial, shock, panic, stress, worry, sadness, crying, and scared. One of the participants

denied that she was infected by COVID-19. This is her statement: *"I can't possibly be exposed to COVID-19. The results of the test may be wrong"* (participant 2). There were two of the participants who panicked and here are their statements: *"I was shocked and panicked, where did I get COVID-19 from"* (participant 4); *"as soon as the swab results came out and I was declared positive for COVID-19, I panicked and stressed. I thought that this is the end of my life* (participant 1)"; *"I am very worried"* (participant 3). The following are the statements of the participants:

Because my symptoms are mild, I am suggested to do self-isolating at home. My husband took foods to my room, and just gave the food without looking at my face for fear of being infected. I was very sad and cried (participant 9)

When the health workers came wearing full COVID-19 uniform. I could not recognize and see their faces clearly. It was as if they had come to pick me up and take me to the grave. It was fearful and I cried (participant 11).

In the middle of the night I cough, and couldn't breathe. I felt suffocate, and I had to sit or even stand up to enable me to grasp the air. I was scared that if I died no one will see me because my husband, my son, and assistants were in their own rooms (participant 12).

Category 3: Social Impact

Exposure to COVID-19 also has a big impact on social life. Being positive for COVID-19, the sufferers must undergo isolation either independently at home, or in isolation centers provided by hospitals or the government. Patients with mild symptoms are usually advised to self-isolate in their respective homes. Patients who experience severe symptoms are usually immediately isolated in the hospital. If the hospital is full, they will be directed to the COVID-19 control centers provided by the government. Participants responded that the isolation process was an unpleasant experience. They felt like they were being shunned, ostracized or abandoned. They felt distant from loved ones making this experience worse. The following are statements from participants about the isolation process they experienced: *"When I was placed in the isolation room, I felt like I was stranded on an island"* (participant 6); *"not being able to meet the people we love causes loneliness"* (participant 5); *"being in isolation is like being on another planet"* (participant 11); *"after a few days of isolation I felt stuffy, the room was hot and lacked ventilation"* (participant 3). The following are responses from another two participants:

Because there is no isolation room at the hospital, I was sent home to do self-isolation. My family was ostracized by the local community when they are informed that I was infected of COVID-19. Being ostracized is more painful than suffering from COVID-19 itself (participant 7).

The isolation room is completely closed. Only me in one room. I can't interact directly with anyone, even with the medical team. The nurse instructed me to take my temperature by cellphone, my food is placed in front of my door. There is no physical presence allowed to enter the isolation room (participant 2).

Because five of us (me, my husband, my son, my elderly mother and her care giver) in the family have been affected, so we did self-isolation together at home. My husband and my son were negative first. They always stepped aside and avoided me. They were afraid of being infected again (participant 12).

Category 4: Spiritual Impact

One of the positive impacts of being exposed to COVID-19 is the spiritual growth of sufferers. Suffering from COVID-19 changes the spiritual level. They experienced spiritual growth including more prayers and belief in God's healing. Participants also said that they surrendered themselves completely to God. They asked for God's help, and gave thanks when they were declared cured. The following are the statements of the participants: *"After being positive for COVID-19, I became more diligent in praying than before and I was sure that I would be recovered"* (participant 3); *"when I was very weak and helpless, I prayed, calling the name of God. Ask Him for help. I said if God wants, I will be healed"* (participant 10); *"I surrender all to God, I believe I will be healed"* (participant 7); *"I feel that God does exist, He is like touching my body. While in the hospital more than half of my time was spent for prayer"* (participant 11); *"Faith over fear. God gave the opportunity to pass the test"* (participant 6); *"God will surely heal, we always say this to reassure each one of us"* (participants 12, 13, 14).

Theme 2: Treatment and Remedies.

All survivors said that they did not receive specific treatment for COVID-19 because there was no specific drug to treat COVID-19. Treatment was given only to reduce the symptoms they were experiencing. There were five categories under the treatment and remedies theme, namely: medications, oxygen, fluids, supplements and vitamins, alternatives and other remedies.

Category 5: Medications

There were analgesic, couching medications, analgesic, antibiotic, sedative and nebulizer given under the medication category. Here are some examples of participants' statements: *"I was given anti pyretic"* (participants 4, 6,10,12,13,14); *"For coughing, I was given cough medicine"* (participants 3,6,10, 11,12,13,14); *"I only take headache medicine"* (participant 8); *"I was given antibiotics to treat a lung infection, I was given a sedative in the ICU because I panicked and so I could sleep"* (participant 6); *"I was given a nebulizer because of shortness of breath and there was a little fluid in the lungs"* (participant 6).

Category 6: Oxygen Therapy

To undergo shortness of breath, the survivors were given oxygen therapy. Here are their statements: *"I was given oxygen"* (participant 4); *"because of shortness of breathing I was given oxygen"* (participant 6); *"I asked for oxygen"* (participant 11).

Category 7: Fluid Therapy

Fluid therapy was given to maintain the fluid balance and the line for medication. The following are the explanation from participants regarding the fluid therapy: *"During the isolation, they gave me infusion"* (participant 4); *"the nurses injected the antibiotic through the infusion line"* (participant 6); *"because I lost appetite and couldn't eat, I was infused"* (participant 11).

Category 8: Supplements and Vitamins

These are kinds of supplement and vitamins consumed by the survivors. Here are the explanations from the participants: *"During self-isolation, I took 1000 mg Vitamin C and Vitamin D given by the doctor"* (participants 3, 4, 9, 10, 11, 12, 13, 14).

Category 9: Alternative Therapy and Remedies

Based on the recommendations from the family members, and friends, survivors agreed to use alternative therapies and remedies. There was a participant who inhaled the hot steam from boiling water and the result was helpful. This is the participant's statement, *"I breathe hot air from the thermos that my wife sent, this makes it easier for me to breathe"* (participant 6). Another participant drank a lot of water, especially orange and lemon juice, and also took nutritious food for energy. Their statement is: *"I drink a lot of warm water, orange or lemon juice, and have to eat nutritious food to give me energy"* (participant 8). According to the participant, to overcome low appetite, she provided plain food and broth from boiled chicken and this is her statement, *"plain rice porridge and warm soup from chicken broth that has been boiled for a long time are the only things that we can take"* (12,13,14). According to participants, based on their family recommendations, they consumed coconut water. There are four participants who consumed young coconut water during the exposure to COVID-19 (participants 10, 12, 13, 14). This is one of the statements: *"I drink young coconut water daily because it is recommended by families who have had COVID-19 previously"* (participants 10, 12, 13, 14). Participants 10, and 12 added eucalyptus oil in to boiling water and inhaled the hot steam, this helped them to breathe easily. This is one of the statements, *"I add eucalyptus oil to the water that I boil and then inhale it repeatedly three times a day. The result was very relaxing and made me easy to breathe"* (participant 10). One of the participants said that she took a good rest and increased the hours of sleep: *"just rest, and sleep more"* (participant 3).

Theme 3: Support and Comfort

There were three categories under this theme, support from the healthcare team, family, and others

Category 10: Support from the Healthcare Team

In a state of isolation where COVID-19 sufferers feel fear, worry, anxious, and stress, they received emotional support from health workers, both from the doctors and nurses. The emotional support provided a sense of comfort and enthusiasm to survive and follow the care and treatment program. Some respondents conveyed the words that doctors and nurses often told them. These words gave them strength and spirit to stay strong and fight for life. The following are their statements: *"Don't stress and panic, COVID-19 can be cured"* (participant 1); *"Let's keep positive thinking, because it can increase the body's immunity. Make yourself happy so that the immunity doesn't go down"* (participant 2); *"drink warm water as often as possible, keep your throat moist"* (participant 3); *"try to make yourself happy and happy huh. Keep in touch with family"* (participant 4); *"You have to be sure. COVID-19 can be cured, you need to fight for life, think positively. When we think positively, we get excited and our immune system increases"* (participant 6); *"PUSKESMAS (community health center) officers always monitor my health status and provide motivation to recover"* (participant 7); *"communications between families, doctors, nurses and patients are very positive, making me sure that I will recover"* (participant 10).

Category 11: Support from the Family

In addition to nurses and doctors, families play an important role in providing support, encouragement, and a sense of comfort to their family members who are exposed to COVID-19.

"My brother's words make me excited and think positive." (participant 4)

"I owe my life to my wife who has watched and monitored my condition during the isolation process at the hospital. This gives me strength and motivation to stay." (participant 1)

"My wife always tries to convince me that I can survive and recover. She also sent a water heater so I could breathe in the hot steam. It makes it easier for me to breathe." (participant 6)

"I had no appetite while in the hospital until I lost weight. But after being allowed to go home, my wife cooked my favorite foods and my appetite was improved." (participant 5)

"I am very grateful for the support and encouragement given by my wife, close family, friends, colleagues, even from my subordinates. It gives strength and motivation to survive." (participant 2)

"With the support of my family, I am sure I will recover." (participant 4)

"My family always monitors my nutritional intake and provides vitamins and herbal ingredients".

(participant 8)

Category 12. Support from Others

Likewise from the healthcare team and family, survivors also received support and comfort from friends, co-workers, superiors and subordinates. The encouragement received can be in the form of video calls, texts, even sending videos that provide important information about COVID-19 and funny videos that entertain sufferers. The following are the respondents' statements about the support they received from family, friends, co-workers, superiors and also subordinates in the office, even from students at school. *"I am thankful to my co-worker, boss and also my subordinates. They called me and ask my condition and gave me emotional support"* (participant 7).

"Every time I feel worried and panicked, my breathing gets heavier and I have difficulty in breathing. Luckily my students always send me funny and entertaining videos that make me laugh and this lessens my worries." (participant 11)

"I am very grateful to the health workers who are struggling to provide care to the sufferers. Never blame them or anyone else." (participant 6)

Theme 4 Interpersonal Relationship

In theme 4, there are three categories found: family's ties, care, and strength resources.

Category 13. Family' Ties

During treatment and isolation, the survivors always communicated well with their families. Either via WhatsApp chat, telephone, or video call. There are several respondents who say that by being exposed to COVID-19, family relations were getting better. They have more time to talk rather than before being infected with COVID-19. Participants who self-isolated at home committed to do household activities and tasks together. The following are their statements: *"during COVID-19 our family is closer and dearer to each other"* (participant 5); *"my sister is more attentive and always calms me down"* (participant 4).

Category 14: Love and Care

COVID-19 survivors admitted that they receive a very good care and attention from their spouse and family member. This is the way that they care for a family member infected with COVID-19: *"once I tested positive for COVID-19 then I had to do self-isolation. My husband took good care of me for 14 days"* (participant 5); *"because I am self-isolating, I live at home with my family, but all my activities are done in my room. I don't want other family members to be exposed. I really care and concern about them"* (participant 7). One participant expressed that, during the exposure to COVID-19, he received a large amount of love. This is his statement: *"from exposure to COVID-19, I received an extraordinary love from many people"* (participant 6).

Category 15: Strength Sources

Family members were the main strength sources. Survivors admitted that they strengthened each other, especially the family who were infected at the same time and isolated together at home: *"even though our rooms are separated, we chatted with each other, asking whether they needed help. We strengthened each other"* (participants 12,13,14). The following are also the participants' statements:

"My husband always strengthens me. He became more attentive to me. He always contacted me on video calls, prayed, and sent me abundant food that made me feel cared for and felt that they wanted me alive. My mother never missed calling me every day at night. He hung up the phone when I was asleep, I was strengthened" (participant 11).

Theme 5: Wills

Only one category was found under the wills theme. It was the last request.

Category 16: The Last Request

There was one respondent who was very worried after she experienced shortness of breath and began to have difficulty in breathing. She felt that she would end up in death. This worry was worse because her two young children were at home while her husband worked from place to place. She asked her brother temporarily to take care of her sons. She was very worried that her sons had no one to take care of them and would become neglected if she died. She expressed the last request to her husband. The following is her statement:

I have told my husband, if death comes to me, please hand over the children to your brother. He and his wife will take good care of them. If you want to go anywhere or want to get married again, it's okay for me as long as you leave our children to your brother and sister-in-law (participant 11).

Theme 6: The Life Essence.

There are three categories under this theme, namely: bitterness, second chance, and recommendation.

Category 17: Bitterness

Participants interpreted the experience of suffering from COVID-19 in different ways. Respondents said that suffering from COVID-19 was a bitter experience, and a heavy blow. Here are their statements: *"I need to emphasize that suffering from COVID-19 is a bitter experience"* (participant 6); *"experiencing COVID-19 was a heavy blow for me, what I remember is death"* (participant 11).

Category 18. Second Chance

Although some of the participants expressed bitterness, most responded positively. Participants said that being exposed to COVID-19 and being declared cured was a very valuable experience. It was like getting a second chance to live and even said it was like rising from the dead. The following are their statements: *"this experience is invaluable.*

I have a second chance at life" (participant 1); *"recovered from COVID-19, I felt like I had risen from the dead"* (participant 8); *"recovering from COVID-19 means I am given a second chance"* (participant 7); *"when I experienced COVID-19, I understand why people scared of it. And I was able to get through it"* (participant 11);

"God is very good, my family was saved from death, especially my 92-year-old mother. We all survived and healed" (participant 12).

Category 19: Recommendation

Based on the experiences felt by most of the participants, they said that there was no need to be panicked as recommended also by healthcare. It was not as scary as it was imagined. The most important thing is to know the symptoms earlier. When someone experiences symptoms such as fever, coughing, headache or feeling unwell, it is better to ask for help from the doctor or other healthcare team members. Ask for COVID-19 SWAB. The earlier the diagnosis, the faster the intervention can be made. The following are the participants' statements: *"this experience was not what other people feared, saying what if I got infected and died?"* (participant 5); *"everyone can be infected, focus on getting better and don't panic"* (participant 4); *"let's not avoid humans but avoid this virus as much as possible by following the health protocol"* (participant 10); *"hot water steam was helping to dilate my air way. It is recommended"* (participant 6); *"stay calm, and do deep breathing exercise often. This will make you more relaxed and able to have a good rest and sleep. Relax and sleep well to speed the recovery"* (participant 12).

Discussion

Patients with COVID-19 experience symptoms of a respiratory tract infection. Symptoms range from mild to severe. This is in accordance with what was stated by previous researchers that the common symptoms felt by patients infected with COVID-19 are fever, fatigue, and myalgia. Typical symptoms of breathing are dry cough, shortness of breath, sore throat, and even coughing up blood. In severe cases these are also accompanied by chest pain. In severe cases, the patient may develop acute respiratory distress syndrome. This happens because fluid fills the lungs and things like this can be fatal if not treated immediately using mechanical respiration in the ICU (Huang et al., 2020; Lapostolle et al., 2020; Lingeswaran et al., 2020; Nurhanisah, 2021).

Survivors of COVID-19 also experience some disorders in the digestive system such as diarrhea, nausea, and vomiting. This is similar to that found by Kumar et al. (2020), that patients with COVID-19 experience abdominal pain, diarrhea, nausea and/or vomiting. The neurological system suffers confusion and headaches. These headaches are often caused by fever and shortness of breath. This was also conveyed by Wu, Chen, and Chan (2020), that the symptoms that most often appeared were fever, cough, and shortness of breath or dyspnea. The exact cause of anosmia is not yet known, but it is possible that there is inflammation in the nasal cavity when the virus is in this area. World wide the prevalence of olfactory dysfunction was calculated to be 44.1 % (Butowt, & Bartheld 2021). How the virus effect olfactory still in ongoing investigation. Recently Bryche et.al (2020) explained that "virus localized exclusively to sustentacular cells and caused a massive degeneration of the olfactory epithelium and a widespread loss of the sustentacular cells, along with the olfactory cilia". Anosmia symptoms usually appear 2-14 days after exposure to COVID-19 and study revealed the median time time to recover from anosmia is 7 days (Lee, Min, Lee, & Kim, 2020).

Knowing that they are infected by COVID-19, some of the survivors experienced stress. This result is similar with a recent study that found participants felt psychological changes such as stress, shock and fear during the time they tested positive for COVID-19 (Kusuma, Soeharto, & Windarwati, 2022). It's not only ordinary people who are stressed because they are infected with COVID19, even health workers are (Rochanah & Nurbaety, 2021). Stress is a common reaction to different types of pressures, but it can damage health if it interferes with daily activities (APA, 2022). No matter how mild the stress situation, it needs to be overcome to reduce the negative impact. Many coping mechanism can be utilized (Angelica & Tambunan, 2021). One strategy to reduce stress related to COVID-19 is to get more information and to be updated with COVID-19 itself (Prasetyo, Setyamardina, Rahayu, & Huriah, 2021). It has been found that stress and anxiety are related with knowledge level. The higher the knowledge, the lower the stress or anxiety level (Sitohang & Simbolon, 2021).

According to the respondents, the therapy they received while exposed to COVID-19 was treatment to reduce the symptoms they experienced. Such as cough medicine, fever-reducing medicine, vitamins, and intravenous fluids to meet fluid needs when the patient does not have an appetite due to disturbances in the digestive system. This is in line with other scientific findings. According to Rusdi (2021), there is currently no cure for this virus. The only drug that is recommended is Remdesivir. In addition, corticosteroids are recommended for patients who experience severe symptoms who use a breathing apparatus or ventilator. Corticosteroids are useful for reducing the inflammatory response in the lungs. In addition, the provision of vitamins is also recommended as a supportive therapy. Among them are vitamin C, D, and Zinc, vitamin C functions as an antioxidant that binds to free radicals. In addition, vitamin C has an anti-inflammatory function and can affect immune cells. Although it is not known with certainty the use of vitamin D in the treatment of COVID-19, it is believed that vitamin D deficiency is associated with pneumonia. Zinc is also used in COVID-19 treatment.

The emotional support received by COVID-19 survivors came from health workers, family, friends, colleagues, and even from students. This gives strength and enthusiasm for COVID-19 sufferers to survive. Humans are social creatures who need other people to survive. The results showed that emotional support positively affects one's well-being while social disorders partially mediate the relationship between emotional support and well-being (Shaheen, Bano, & Amed, 2021). Many studies have been conducted to study the relationship of emotional and social support to physical and mental health and its impact on disease healing. Social support increases motivation to recover (Bau, 2019), and increases adherence to treatment (Muna & Spleha, 2018). The COVID-19 survivors in this study also experienced better relationships with family members. This is something that often happens. When a family member is sick, other family members choose to pay attention and this makes the family bond closer.

Most of the informants said that during their isolation and treatment they experienced an increase in their spirituality. They prayed more than before, surrendered their lives to God and believes that God will heal them. According to previous research, sufferers assume that what they feel is a trial by God and a test of one's faith. Sufferers tend to believe that illness is a lesson from God to make them appreciate the life that has been freely given to them. Thus, they use prayer in the hope of healing their illness, because there is a tendency to see everything spiritually and leave it in God's hands for better results (Witmer, Boccaro, & Henderson, 2011). Spirituality promotes individuals to cope better with life disruptions and allows them to view life more positively (Rathakrishnan, Singh,, Yahaya, Kamaluddin, & Aziz, 2022). Spiritual fulfilment is related to the motivation and high belief as to the healing effort and improving patient health (Wahyuni, 2014). Although the effect of this belief is not easy to evaluate, it can be observed by health workers where the individual can handle the severe physical distress they experience. In addition, surviving COVID-19, even though it is a bitter experience, has given an important message about what is meant by a second chance, namely by filling life with more meaningful things. Surviving COVID-19 has given meaning to the importance of praying and believing in God. God's help is very real. When you have faith that miracles exist, the spirit of life increases.

Conclusion

COVID-19 causes physical, psychological, social and spiritual impacts on survivors. The impacts were experienced differently by each survivor, depending on the severity of the symptoms. COVID-19 can be cured. It is encouraged to identify symptoms, carry out the diagnostic test and carry out basic treatment of existing symptoms so that symptoms do not become more severe. Although there is concern and anxiety for COVID-19 sufferers, they are confident that they will recover. This situation makes them pray more, ask for help from God and surrender themselves to God. In addition, the support provided by health workers, family, colleagues, superiors, subordinates, and even from students provides strength and comfort for COVID-19 sufferers. This makes them enthusiastic and persistent in undergoing treatment. Therefore, the community must place this pandemic situation not as a scourge or to stigmatize but use this situation as an important and valuable experience to always be ready to face the challenges of an uncertain future and most importantly quickly make the necessary adaptations so that the impact of the problem experienced does not become heavy. The important experiences that have been described by COVID-19 survivors can be an illustration of how the community must respond positively. They should take important steps to prevent it by actively participating in following and practicing the protocols that have been given by the government through the task force for the acceleration of the COVID-19 countermeasures both personally, with families and groups closest to their respective places of residence.

Declaration of Interest

There is no conflict of interest found in this study

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Barriers felt by nurses related to childhood basic immunisation in East Nusa Tenggara: A phenomenological study

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Abstract

Background: Immunisation barriers can increase morbidity and mortality associated with vaccine-preventable diseases. Understanding barriers to childhood vaccination is critical to informing effective interventions to maximise coverage.
Purpose: This study aims to explore the experiences of nurses involved in immunisation related to the obstacles they experience in immunisation activities.
Methods: This research is qualitative research with a phenomenological approach. Nurse participants who manage immunisation activities at the public health centre were recruited using a purposive sampling technique. In-depth interviews were conducted with 15 nurses who work in immunisation activities. Inclusion criteria are nurses who directly provide immunisation services and have managed the immunisation programme for more than one year. Exclusion criterion was nurses who were on leave. The study was conducted from August to September 2022, and face-to-face interviews were conducted. Interview transcripts were analysed using the thematic analysis method.
Results: Three major themes were generated in this study, namely: 1) barriers to immunisation governance systems, 2) barriers to vaccine recipients, and 3) policy barriers.
Conclusion: Interventions to overcome barriers to immunisation need to be carried out comprehensively at various levels, such as promoting the benefits of vaccines for the community, strengthening the capacity of officers' competence, reducing political bias, and funding supporting facilities for immunisation programmes.

Keywords: immunisation; nurse; qualitative; vaccine

Introduction

Efforts to increase immunisation coverage are critical because they can increase group immunity, reduce outbreaks and reduce healthcare costs (Ministry of Health Republic of Indonesia, 2020). Currently, there is a decline in immunisation coverage. Reports show that global immunisation coverage fell from 86% in 2019 to 83% in 2020. The total number of unvaccinated children in the same year increased to 3.4 million (World Health Organization, 2021).

According to the Ministry of Health Republic of Indonesia (2022), in October 2021, Indonesia's Complete Basic Immunisation achievement was only 67.9% of the national target of 93.6%. At the same time, the coverage of complete basic immunisation in East Nusa Tenggara is only 60.9%. Data from the Provincial Health Office show that the achievement of Complete Basic Immunisation in East Nusa Tenggara (December 2021) is still far from the target of 90%, where, in detail, the coverage of HB0 (<24 HOURS) is 72.9%, HB0 (1-7 DAYS) 3,8%, BCG 78.9%, POLIO 1 79.7%, DPT/HB-Hib

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79.2%, POLIO 2 80.2%, DPT/HB-Hib (2) 76.4%, POLIO3 78.1%, DPT/HB -Hib (3) 73.8%), POLIO4 76.8%, IPV 63.8%, Measles+RUBELLA (MR) 81%, DPT/HB/HIB 60.7%. Explicitly, in the East Nusa Tenggara Provincial Health Office report, the district in East Nusa Tenggara province with the lowest complete basic immunisation achievement, namely East Sumba, amounted to 51.9%% (East Nusa Tenggara Provincial Health Office, 2022). Meanwhile, based on Central Bureau of Statistics East Nusa Tenggara (2021) data from the East Nusa Tenggara province in 2020, it was recorded that East Sumba Regency was included in six of the 22 regencies that had the largest population of children under five after 0-4 years in East Nusa Tenggara, namely 33,079 people. Based on the data above, it can be predicted that the generation of children in East Sumba is at risk of experiencing morbidity and even death due to low immunity. Various reasons can cause low immunisation coverage.

A study conducted by Al-Salihi et al. (2019) indicated that the leading causes were missed opportunities for immunisation due to problems with health workers, issues related to parents, logistical issues, and service organisation. Other studies have shown that socio-demographic factors such as lower economic status, educational status, advanced age, religious and cultural beliefs, fear of adverse events, and misinformation about vaccines are some of the determinants that cause concern and refusal to vaccinate so that immunisation coverage is low (Rosen et al., 2021; Yufika et al., 2020). Studies on immunisation barriers and their achievements are still very minimal in East Nusa Tenggara, especially East Sumba Regency which is the Regency with the lowest immunisation achievement.

An understanding of immunisation barriers can assist nurses in determining a comprehensive strategy to increase immunisation coverage because of the nurse's role as the leading advocate for immunisation programmes (Bajnok et al., 2018; Wade, 2014) and supporters of efforts to increase the degree of community health (Hirani & Wüst, 2022).

This study explores the experiences of nurses involved in immunisation related to the constraints they experience in immunisation activities. A qualitative study approach is needed to understand the obstacles nurses feel so that a picture of the problem can be found for future improvements. Understanding nurses' perceived barriers will help inform decision-makers and other relevant actors involved in immunisation programmes and guide health interventions to increase immunisation coverage.

Materials and Methods

Design

This type of research is qualitative research with a phenomenological approach that aims to describe the essence of a phenomenon by exploring it from the point of view of those who have experienced it (Neubauer et al., 2019). In this study, the phenomenon experienced by nurses is related to obstacles in giving immunisations.

Participants and Setting

This study's participants were nurses assigned to provide immunisation services at health facilities such as public health centres. A total of 15 participants were recruited using a purposive sampling technique. The recruitment process began with an approach to the district health office to determine the number of immunisation management nurse personnel in each public health centre. Then the head of each public health centre was approached, who received a recommendation from the health office to be facilitated and meet with participants. The participant inclusion criteria are nurses who directly provide immunisation services and have managed the immunisation programme for more than one year. In comparison, the exclusion criterion was nurses managing the programme who were on leave. Before conducting the interview, the researcher explained the purpose of the research and the consent letter was given before the interview.

Data collection

Data collection was carried out in August-September 2022. The interview process was conducted face-to-face by a researcher with previous experience in conducting qualitative studies. An explanation of the research was submitted to the participants for approval. The semi-structured in-depth interview process was carried out in the study for 45-60 minutes using the interview guide that had been provided. Audio recordings and notes were used in the data collection process. Each transcribed datum was returned to the participants for review. Saturation was reached at the 15th participant.

Data analysis

A thematic analysis approach was used in analysing the data. Thematic analysis is an approach that involves searching for patterns of meaning that are explored further and determining how these patterns can be organised into themes (Sundler et al., 2019). The thematic analysis approach is carried out in several steps as follows; 1) two researchers looked at common themes that emerged by transcribing audio into text, 2) determining keywords from each participant's statement, 3) collecting keywords into sub-themes, 4) uniting sub-themes into several relevant themes. Each finding was returned to the participants for review, and triangulation of library sources was carried out to assess the suitability of the data with previous results.

Ethical consideration

Ethical approval (No.079/UCB.LPM/EP.25.08/2022) was obtained from the ethics committee of the Universitas Citra Bangsa Kupang.

Table 1. Demographic Characteristics (n= 15)

Demographic characteristics	F	%
Sex		
Female	9	60
Male	6	40
Age (Years)		
25-35	5	33,3
36-45	8	53,3
46-55	2	13,3
Educational Background		
3 Year Diploma	7	53,3
Bachelor of Nursing	8	46,6
Length of the service immunization program (years)		
1-5	11	73,33
5-10	4	26,6

Table 2. Overview of the Theme

Theme	Sub-Theme
Barriers to the Immunization Governance System	Cold Chain That is Not Yet Optimal
	Late Vaccine Supply
	Lack of Immunization Workers
	Distance
	Cooperation Across Sectors is Not Optimal
	Poor Recording System
Barriers to Vaccine Recipients	Parental Vaccine Refusal
	Lack of Knowledge of Parents
	False information regarding vaccination
	Negative experience from previous immunization
	Contrary to religious belief
Theme 3: Policy Barriers	Changes in the Regional Political Situation
	Lack of Training Support for Officers

Trustworthiness

In this qualitative study, we followed Sandelowski's (1986) method following four standards: 1) to maintain credibility, the researcher started with open-ended questions and allowed participants to talk about their experiences freely in their language. The researcher maintains neutrality without involving their own thoughts, experiences, and emotions, and the same questions are asked in different forms to allow for repeated identification during interviews and analysis. 2) Conformity is formed based on in-depth data collection until the participants' statements are saturated. In this study, the researchers extracted significant ideas from participants' descriptions of specific and vivid experiences. 3) In this study, the researcher received feedback from fellow co-authors on the study's results and carefully discussed the analysis and interpretation of the data. 4) For conformity in this study, we quote participants' comments so that readers can verify the interpretation and analysis of the data. For this purpose, we separately record the researcher's preconceptions, assumptions, and ideas about the topic during the entire research process. This is done by consciously comparing and analysing current interview data and the results of previous studies. As such, these findings reflect the experiences and opinions of the study participants as much as possible, minimising the researcher's prejudices. Finally, participants reviewed the summary of the study results to verify whether they captured the essence of their experience.

Results

Overview of participant

The number of participants in this study was 15, consisting of six men and nine women. The highest age was 36-45 as many as eight participants.

Bachelor of Nursing dominates education with as many as eight participants. The longest working time to manage the immunisation programme was 1-5 years, with 11 participants (Table 1).

Theme

This study resulted in three major themes related to the barriers nurses felt: 1) barriers to immunisation governance systems, 2) to vaccine recipients, and 3) policy barriers. The overall description of the theme can be seen in Table 2.

Theme 1: Barriers to the Immunisation Governance System

Immunisation governance is closely related to many systems, such as cold chain management, vaccine participant data reporting, vaccine availability, vaccination officers, and facility availability. This study shows that there are barriers to immunisation governance which will be explained in the following sub-themes

Sub-Theme 1: Cold Chain that is Not Yet Optimal

The cold chain plays an essential role in ensuring that the quality of vaccines received by vaccinated participants remains good quality. Participants explained that the cold chain supply often experiences problems and is not optimal due to electrical issues and a lack of equipment.

"We have problems with electricity and equipment to store vaccines here. Our refrigerator has only one function; we have difficulty storing our vaccines because it does not meet the standards, and our vaccines are often damaged". (P13)

Sub-Theme 2: Late Vaccine Supply

The continuity of vaccination is strongly influenced by the timely delivery of vaccines to the vaccination service. There are still problems with delays in vaccine delivery due to transportation problems between regions.

"Our immunisation activities are sometimes hampered because of the absence of vaccines in districts that are sent from the province; if the ship does not sail, the vaccine delivery will be hampered, sometimes we write letters to provincial pharmaceutical supplies, and the response is also slow so often the vaccine delivery is not the on schedule". (P3)

Sub-Theme 3: Lack of Immunisation Workers

During the COVID-19 pandemic, vaccine officers were focused on handling COVID-19, so the number of immunisation officers was reduced, affecting immunisation activities. One participant explained this statement.

"We are immunisation officers during the COVID-19 pandemic; some people are divided into the activities of the COVID-19 task force so that immunisation service personnel are reduced". (P14)

Sub-Theme 4: Distance

Access to immunisation services is related to the distance between the community's residence and the place of immunisation service. This is reflected in the statement.

"The distance from where our community lives with immunisation activities is too far, people who live in plantation areas find it difficult to get to the village for immunisation activities, and there are no adequate means of transportation". (P2)

Sub-Theme 5: Cooperation Across Sectors is Not Optimal

Cross-sectoral cooperation is an essential element in supporting the continuity of immunisation activities. Participants revealed that cross-sectoral cooperation in making vaccination activities successful has yet to run optimally.

"We are rarely invited to meetings to decide on immunisation service activities at school, even though it is good, so we can adjust the time for the children and discuss it with the school principals; we only get a notification letter if there is an immunisation activity". (P13)

Sub-Theme 6: Poor Recording System

Recording and reporting systems are an essential part of vaccine governance. The reporting and recording system allows data on the number of immunisation participants and coverage to be available.

"Our records are problematic, data from cadres, health centres, schools, and private practice for children who have been immunised or data on immunisation participants are often out of sync, so reporting is often based on invalid data". (P4)

Theme 2: Barriers to Vaccine Recipients

The direct beneficiaries of this vaccine are children; however, parents play a central role in including their children in vaccination programmes. Many complex problems can affect parental involvement in immunisation, such as lack of knowledge, negative experience with previous vaccines, trust issues, and the inability to access immunisation services due to geographic distance. Barriers to vaccine recipients, such as parents, are described in the following sub-themes:

Sub-Theme 1: Parental Vaccine Refusal

The fear of vaccines arises because of AEFI (Adverse Events Following Immunisation) developing in the community. Hence, parents are reluctant to take their children to take immunisations.

"We were chased away with sharp weapons when giving vaccines. Previously, the family objected to cases of AEFI such as fever and swelling in the former immunisation area, and they considered the vaccine dangerous for their child's health". (P7)

Sub-Theme 2: Lack of Knowledge of Parents

Lack of knowledge contributes to parents' desire to involve their children in immunisation activities.

"When we arrived at the vaccination site with the team, none of the participants were present. After we checked, they asked what the immunisation was for. When we were little, we were not immunised and are still healthy until now; immunisation is only for you city people". (P11)

Sub-Theme 3: False Information Regarding Vaccination

Fake news on the internet sabotages immunisation coverage because parents are reluctant to take their children to immunisation services.

"We identified parents in the city who were reluctant to take their children to take immunisations because there was information that vaccines were a tool to control a person's body and weaken the ability to think, and this developed in the family's WhatsApp group making it difficult to identify and control". (P9)

Sub-Theme 4: Negative Experience from Previous Immunisation

Negative experiences of previous vaccines in their children make it difficult for parents to let officers immunise their children.

"Once, their first child in 2015 was vaccinated and had seizures and fever for a few days; after we checked, it turned out to be malaria too, but after that, they did not allow the second and third children to get the vaccine". (P15)

Sub-Theme 5: Contrary to Religious Belief

The problem of belief that affects immunisation actions is the most severe challenge in Indonesia, even in rural areas such as in East Sumba.

"We are here, sir, there are still families from certain belief groups that do not believe in vaccines, and there was the issue of pork serum in the vaccine yesterday; it is getting more difficult; most of them are in the city of this group, we have also made an approach with religious leaders who exist, and there has been an appeal letter issued". (P10)

Theme 3: Policy Barriers

Immunisation policies set by the government have an essential role in determining immunisation coverage, especially facility support and the provision of competent vaccine staff resources. The analysis in this study shows that there are still policy-related barriers reflected in the existing sub-themes.

Sub-Theme 1: Changes in the Regional Political Situation

Regional political changes, such as the change of regional heads, will affect the vaccine management structure at various levels.

"Here, every time there is a change of regent, there must be a change of officers due to political opponents; there are two health centres whose officers have just been replaced and transferred to other parts that are not their fields and replaced by new officers who do not understand vaccine management or are poorly trained". (P10)

Sub-Theme 2: Lack of Training Support for Officers

The training allows the competence of officers to be better and optimal so that they can manage the immunisation program better, but participants reveal the lack of training obtained.

"It has been five years I have been the immunisation manager at this community health centre; I have never received any immunisation training, especially about the cold chain; we only got a guidebook, so I often had trouble interpreting the contents in the book, other friends complained about the same thing" .(P14)

Discussion

Immunisation Governance System Barriers

In this study, participants revealed several obstacles related to the low immunisation coverage influenced by problems in immunisation governance, such as the non-optimal cold chain system to ensure the quality of vaccine delivery from producers to users. This is in line with the study Bangura et al. (2020) conducted on 76 articles related to immunisation barriers in sub-Saharan Africa, where one of the causes of low immunisation coverage is caused by a broken cold chain. The broken cold chain decreases vaccine stocks and impacts low immunisation coverage (Gooding et al., 2019). Policy-making groups need to consider ensuring the quality of the cold chain from vaccine producers, especially cold chain equipment to users, to support immunisation coverage.

Another obstacle that arises is the delay in the supply of vaccines. A logistic regression study in 33 Sub-Saharan African countries conducted by Janusz et al. (2021) on children aged 12-35 showed that delayed vaccine scheduling because of delivery delays could reduce the coverage of immunisation programmes. It was scheduled effectively, so that vaccine delivery was not disrupted.

The shortage of immunisation personnel is a serious challenge faced during the COVID-19 pandemic due to the diversion of resources. The lack of vaccinators seriously threatens efforts to meet vaccination coverage. Studies in Pakistan show that a lack of vaccinators in rural areas contributes to low immunisation coverage (Sahito et al., 2020) and an increase in polio cases (Hussain et al., 2016).

The problem of access to health services due to distance is an obstacle related to governance found in this research. A mixed study of 311 childcare couples in Uganda explained that the distance for parents to reach several immunisation centres was quite far. This also means that health workers providing immunisation services must travel longer distances, which can be a challenge

when transportation facilitation is inadequate and geographical terrain is difficult to reach. This can lead to suboptimal immunisation services (Malande et al., 2019). The lack of cross-sectoral partnerships could be another challenge that hinders immunisation efforts. The report by Zhu et al. (2019) explains that cross-sectoral partnerships, cross-sectoral interactions, and cross-sector exploration are essential to overcoming public health problems. Stakeholders can come from the health sector, social services, community leaders, education, and religious leaders.

Poor record-keeping is a perceived challenge in assessing immunisation coverage levels. A study in Bali, Indonesia, conducted in six districts, showed that an ineffective recording and reporting system based on reporting at the community health centre could reduce the quality of data on immunisation programme achievements (Sawitri et al., 2021). Comprehensive information systems are needed to track immunisation uptake at the individual and population levels (Atkinson et al., 2020).

Nurses managing immunisation programmes need to be involved in advocating for work related to immunisation. Critical and supportive evaluation of institutional policies related to immunisation is a concrete step that nurses must take in overcoming obstacles to immunisation governance (Navin et al., 2020). The study conducted by Ogboghodo et al. (2018) explains that it is important for nurses to increase their knowledge and skills related to cold chain management in supporting immunisation efforts so that they become quality and effective. Another important thing that needs to be considered is nurses' commitment to making immunisation reports. Computer- and internet-based approaches to reporting can facilitate nurses' work and improve the quality of reports (Silva et al., 2020).

Vaccine Recipient Barriers

The biggest obstacle for vaccine recipients is closely related to fear of vaccines. In this study, the fear associated with AEFI developed in the community. Hence, parents were reluctant to take their children to take immunisations. A cross-sectional study of 440 parents/caregivers in Pakistan showed that fear of AEFI has hindered children's immunisation activities (Epaulard et al., 2022). Health workers need to educate parents/caregivers about AEFI; thus, health education will expand immunisation compliance and acceptance among those who refuse due to AEFI issues. This study also found that negative experiences due to previous immunisations affected parents' desire to immunise their children. This is in line with a study of 2,722 parents/caregivers in Ethiopia which showed that a bad experience related to a child's last routine vaccination was a predictor for parents not to take their child for immunisation (Porth et al., 2019). Everyone who comes to be immunised has their history, psychological strengths and vulnerabilities, and perceptions of the procedure and its social context. Nurses must take a holistic approach to educate and convince families to return to trust and engage in immunisation activities. In this study, the obstacle that arises from the side of the immunisation recipient is the complexity of immunisation scheduling, which confuses parents. Reports from Australia indicate that barriers to compliance with national immunisation programs include difficulty remembering whether children have been vaccinated, timing and location of care, and lack of awareness of vaccination schedules (Atkinson & Atkinson, 2021). A study of 5534 households with children undergoing immunisation in Australia explained that an approach to facilitate children's immunisation due to complex scheduling could be made through improving communication by sending letters and pamphlets directly from immunisation managers to parents regarding the child's immunisation schedule (Borg et al., 2018).

In this study, participants also explained the influence of parental beliefs that hinder children's immunisation activities. This is in line with the report written by Grandahl et al. (2018), where parents are the ones who decide whether to vaccinate their children based on attitudes, beliefs, knowledge, subjective norms, socio-demographics, as well as cultural and religious aspects. To shape parents' beliefs, the involvement of religious leaders and community leaders in setting social norms plays a crucial role in many parents' decisions to vaccinate their children. Religious leaders must be equipped with adequate information and involved in various stages of launching immunisation programmes to promote the positive benefits of immunisation for parents (Padmawati et al., 2019).

Nurses need to take a more significant role in educating religious leaders about the positive impact of vaccines, communicating effectively about the vaccine program, actively involving them in immunisation activities, building trust and accountability, and providing constructive feedback (Singh et al., 2019). This effort must be carried out on an ongoing basis and extend to the most minor elements of religious groups.

Policy Barriers

Changes influence problems related to policies in the regional political situation, such as the change of regional heads, which affect the immunisation management structure at various levels; this is because each official will replace the existing immunisation officer who will be moved to a different work location. Studies conducted in five middle-income Latin American countries, Argentina, Brazil, Honduras, Mexico, and Peru, show that political will at both the national and local levels greatly influences vaccine management, especially in terms of supporting policies for the provision and training of immunisation service personnel (Ropero Alvarez et al., 2021).

Participants also felt a challenge from a policy perspective related to the lack of training received for vaccine workers. Studies show that health workers

need additional training in vaccine governance to effectively manage immunisation activities, from injection techniques and reporting to vaccine storage (Feyisa et al., 2022; Nicol et al., 2019). Sustained policies to vaccinate children must continue in the changing healthcare environment. High vaccination coverage cannot be maintained with one-time or short-term efforts. A greater understanding of strategies to increase and maintain vaccination coverage is needed to create an effective and durable immunisation system.

Obstacles related to policies in immunisation programmes require strong efforts from nurses in advocating for existing stakeholders. The approach needs to be taken by nurses to regional heads to disentangle political influence into immunisation governance. Officer placement should be based on individual competency and experience. In addition, nurses need to design forms of training related to immunisation, such as cold chain management, web-based reporting, and vaccine administration skills.

Conclusion

Interventions addressing barriers to receiving vaccines should focus on educating and persuading parents to immunise their children using community leaders as additional facilitators. On an ongoing and scheduled basis, nurses must make health promotion efforts to the community regarding the positive benefits of vaccines and the side effects of vaccines. Nurses also need to design a form of vaccine schedule that is easily understood by the wider community.

From a policy perspective, it is necessary to provide customised training for service providers on an ongoing basis, eliminate local political bias, and encourage people to continue striving for complete immunisation despite obstacles. Physical and structural constraints as obstacles to governance, namely abandoned infrastructure and inadequate health supplies, must be addressed by providing tools and funds for maintaining the facilities. The role of nurse advocacy needs to be expanded not only to vaccine recipients but also to policymakers, especially to attract support for funding and policy alignments that can support immunisation activities.

Declaration of interest

We want to ensure that there is no known conflict of interest associated with this publication and that there is no significant financial support for this work that could affect its results.

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Data Availability

The datasets generated during and analysed during the current study are available from the corresponding author upon reasonable request.

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The life experiences of adolescent female students who use social media

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Abstract

Background: Social media is a place for students to follow trends. However, Islamic boarding schools limit students by prohibiting them from bringing cell phones; therefore, they are not influenced by the outside world, even online.
Purpose: The purpose of this study is to explore the experiences of female students as users of social media related to dormitory rules.
Methods: Using a qualitative research design with a phenomenological approach. The research was conducted by in-depth interviews with 8 female students at Madrasah Ulumul Qur'an Langsa aged 15-18 years. Interview transcripts were analyzed using the Colaizzi method.
Results: Six themes emerged from this study including: students bring cell phones to boarding schools because of the influence of friends and want to see updates, the use of social media as entertainment in their spare time, social media affects the way students follow fashion, the influence of the outside environment is more dominant on the behavior of students than the media in social media. The values instilled in the pesantren become a bulwark in the face of the outside world, and students want to make the best use of social media.
Conclusions: Female students want to make the best use of social media to atone for the violations committed. They also agree that the prohibition of bringing cell phones and access to social media in Islamic boarding schools is the right thing because it can cause negligence and jealousy in friends who do not carry cell phones.

Keywords: experience; students; social media; teenage girls

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Introduction

The phenomenon is currently found that many students bring cell phones to pesantren and access social media. Access to social media conducted by students causes changes in behavior in students including those who have followed fashion on social media so that they often violate the rules by using a hijab under 130 cm.

Regarding the change in students' fashion, Wardhani (2017) argues that at this time the students who viewed that fashion is not just to cover the aurat but become part of the lifestyle. Whereas the students who should have been equipped with more religious knowledge than in public schools have different grades. The phenomenon that occurs is that students are only dressed neatly just because there are rules. When they come out, they will adopt the dress style they see.

This can happen because not all students can apply discipline, which is usually easier to do when it arises from self-awareness. Many things can affect the behavior of these students, including students who are still teenagers, carry out self-regulation and perform self-efficacy, are individuals who interact with their environment and make adjustments (Rasyid, 2020).

In order not to be judged as different or old-fashioned from their peers, students often use social media as a medium for self-actualization. They want to appear and show that students can also follow the fashion that is developing, even though the pesantren has clearly imposed a ban on the use of mobile phones and access to social media in the pesantren. According to Bukhori and Mutminiati (2018), Hamid (2019), and Pradana (2019) this rule

is enforced because it can cause students to be negligent, tired because they forget to rest, do not participate in congregational prayers, find it difficult to concentrate and are lazy to participate in activities in the pesantren.

According to the ustadz and ustadzah, they also often see female students who behave differently when outside the pesantren, especially in terms of fashion. The ustadz said that the influence of friends outside was very large because students like to go with their friends so they are not considered old-fashioned, because it can make students feel inferior and embarrassed. From the parents' side, there is no further warning for their children. In line with that, the ustadzah also stated the same thing that parents had a part in the behavior of students like this because most students see the style of dress from their parents. There are even parents who forbid their children to wear headscarves or big clothes because they seem untidy.

Materials and Methods

Design

This study used a qualitative research design with a phenomenological approach. Data collection is done by using an in-depth interview technique which lasts about 30-60 minutes. The research procedure was carried out by implementing the Covid-19 prevention health protocol.

Participants and Setting

Participants were chosen with inclusion criteria of female students aged 12-17 years, bringing cell phones to pesantren and actively using social media. The study was conducted from May to June 2022 at the Ulumul Qur'an Madrasah (MUQ) Langsa.

Ethical Consideration

The study was approved by Health Commission Ethics from the Faculty of Medicine, Universitas Padjadjaran, Indonesia, with number 657/UN6.KEP/EC/2022. Before starting, the researchers explained the study to all participants, and then they were asked to sign the consent form manually.

Data Collection

During the Covid-19 pandemic period, regulations in and out of the pesantren environment were strictly regulated. Only interested people were allowed to enter pesantren such as ustadz and ustadzah, as well as employees or people who work in the pesantren. For this reason, before collecting data, the researcher submitted a research permit from the Secretary of the UNPAD Faculty of Nursing Study Program and the Ethics Permit from the Unpad Ethics Committee.

After the research and ethics permit were awarded, the researcher gave it directly to Mudir MUQ Langsa. Then the researcher coordinated with the head of care to be able to enter the dormitory and look for participants. After that, the researcher immediately searched for participants who matched the research criteria. Previously the researcher had been vaccinated twice using the Sinovac vaccine and continued to comply with the health protocol using a mask, washing hands with soap and running water before entering the pesantren environment, and kept a distance during the research process.

Data Analysis

Data analysis in the study used the Colaizzi method. There were seven steps taken, namely: In the first stage the researcher conducted a transcript of the results of the interview, then the results were read repeatedly to obtain the essence of the participant experience. In the second stage, the researcher reviewed each transcript and extracted important statements directly related to the phenomenon of the experience of female santri social media users. In the third stage, the researcher formulated the meaning of each important statement, put them into a table and sorted according to formulated meaning. In the fourth stage, the researcher regulated the meaning formulated into the theme group. In the fifth stage, the researcher integrated the results of the study into a complete description. For the sixth stage, the researcher formulated a complete description of the experiences of adolescent students of social media users as a statement of strict identification. In the last stage, the researcher referred to the findings so far as the final step of the validation (Polit & Beck, 2012).

Trustworthiness

To obtain reliable research results, data were validated with several criteria, namely credibility, dependability, confirmability and transferability. The techniques used to build credibility are Prolonged Engagement, Persistent Observation, Peer-Debriefing, Member Checking and Reflective Journaling (Connelly, 2016). The dependent test is carried out by audit by the supervisor of the research process series. If the researcher has a track record of research, then the dependability will not be doubted (Mekarisce, 2020). To get confirmation, the results of the study were prepared in full and tested in the forum, in this case the thesis session in front of the examiner and supervisor lecturer to get input and approval from the findings. Finally, transferability is obtained by making a clear finding description so that readers can understand the research result correctly (Sarwendah et al., 2022).

Results

We found five themes consisting of (1) students bring cell phones to boarding schools because of the influence of friends and want to see updates; (2) the use of social media as entertainment in their spare time; (3) social media affects the way students follow fashion; (4) the influence of the outside environment is more dominant on the behavior of students than the media in social media; (5) the values instilled in

the pesantren become a bulwark in the face of the outside world; and (6) students want to make the best use of social media.

Theme 1: Students bring cell phones to boarding schools because of the influence of friends and want to see updates

Based on the results of the transcript, most participants said that they brought cell phones to the pesantren because they saw friends and felt bored, jealous and isolated if they did not bring cell phones to the pesantren, as in the following statement:

"... look at friends also bring a cell phones, like jealousy. For example, a room is carrying, this person plays. So lazy, sometimes there are no friends, this person is busy with it " (P5.2).

"... sometimes we want to bring a cellphone even though it is prohibited because friends on playing cell phones, cool with their cell phones. We don't want it, so it's bored, I want to bring it too" (P8.26).

Other participants argue that cell phones make them more updated. Here's their statement:

"...it's important because nowadays everything is online,... information is from social media. If you have a stroke,…we lack knowledge" (P1.17).

"… more updates… able to communicate… find a lot of posts on Instagram…" (P3.10)

Theme 2: the use of social media as entertainment in their spare time.

All participants said that the reasons for students accessing social media were because of boredom during boarding school.

"Happy because yes there is a lot of entertainment too ... if for example again stress because of the school exam, if I play social media it feels like that ..." (P2.3).

"Yes, like which. Alright, just force it. Although it is prohibited to be silent. Because sometimes it is also in a pesantren, tired of learning. So it's like playing like that" (P5.3).

"Because in pesantren like a lot of free time. Because of the stubbornness, keep playing ..." (P6.7).

Using social media is also felt to be able to raise the mood of students. In accordance with the statement of participant 4 below:

"Sometimes, for example, I'm not in a mood like that, for example using social media at Islamic boarding schools, see what can lift my mood, from not being in a mood, to being in a mood." (P4.2).

Theme 3: social media affects the way students follow fashion

Social media provides all the things you want to find and enjoy by all groups, including in terms of fashion. In this case, some participants agreed that social media was able to change the fashion style of students, as follows:

"Social media changes fashion as possible. From what we don't know anything, for example, Ohh that is good, we change from fashion." (P8.13).

"... the impact of social media is more familiar with fashion now." (P4.13).

Santri who still maintain the style of dressing in the pesantren when they go out sometimes feel insecure when meeting friends outside because they feel less fashionable. This was expressed by participant 3 as follows:

"... it feels like wearing a long headscarf isn't cool, it's not fashionable. so I don't feel confident in terms of things like, for example, looking at fashionable people, why don't we just look like this." (P3.17).

Theme 4: the influence of the outside environment is more dominant on the behavior of students than in the social media

At present, students' cell phones can access anything including social media. It is not uncommon that things that are seen and heard from social media are very able to influence the behavior of students. But all participants , as in the following explanations:

"More effect on the real environment. If our online environment is like this, what are you following other people. " (P6.16).

"The environment that most influences behavior." (P8.17).

In addition to environmental influences, changes in behavior displayed by students are also due to social media and parenting styles. The following is participant 2's statement:

"From social media, from shows, from the upbringing of parents from a young age, maybe that will have an effect. What are our clothes, what are our behaviors?" (P2.23).

Theme 5: the values instilled in the pesantren become a bulwark in the face of the outside world

In some aspects, it turns out that even though they committed violations in the pesantren, when they came out they indirectly still hold the values taught in the pesantren. Here are some of the f participants who support:

"For example in terms of dress, also in terms of manners maybe sis. Then like the relationship with the opposite sex is also our more controlled. Or for example like here even if we are not 'Batat' (naughty), or many times violated the rules, so it is not as bad as that is because here the teachings of the religion are tighter. We have a little bit of influence even though we are stubborn." (P3.27).

"... if for example wearing pants like that, that's the shirt like for example above the knee. Not above, not short. Still know the limits ... " (P4.22).

Participants said that the students were more awake both from talking, socializing and clothing. This was expressed by several participants as follows:

"... It's not good to hang out outside... the students are more awake like that, because it's like that in a boarding school, you can't go out. If you go outside, you don't really get along with guys. After

all, I'm not in the same class as boys." (P5.18).

Theme 6: students want to make the best use of social media.

Based on the results of the interview, the students hope that social media will not have a bad impact on themselves, as per the following participants' statements:

"The hope is to be able to protect yourself from the influence of not whether social media or the environment ... does not close yourself ... utilize for positive values." (P3.26).

"The hope is not to be too carried away with the social media ... hopefully which can be different from what should be followed by the same ..." (P4.31).

Participant 7 instead hoped to be useful for others by posting productive content:

"The hope with social media is getting higher. It could be one that creates productive content... can provide benefits to other people through social media..." (P7.16).

Discussion

Sumaidah (2013) stated that students often commit violations in pesantren because students are adolescents who are growing up and in the search for identity. But violations committed will usually result in various kinds of problems that hamper the teaching and learning process.

All participants in this study were chosen because they brought cell phones into the pesantren environment. According to Rahmadhantie (2022), cell phones are used because adolescents do not want to be considered lacking slang, lack of knowledge of the outside world, and gaptek (tacky). Though the use of cell phones for students can cause many problems because students can only access cell phones during rest time, students often sleep late until midnight to use cell phones. Royant-Parola et al. (2018) said that the use of cell phones is proven to worsen sleep quality because the mobile screen delays sleep onset, melatonin secretion and stimulates the building system. Interaction with social media can also worsen the situation.

Behavior committed by students violating the rules can be caused by several things. Among these are not being very familiar with the benefits of the implementation of the rules, too accustomed to living freely, and also because of the characteristics of teenagers who do not like to be regulated (Suriana, 2016). All participants stated that they had several reasons why they brought cell phones to the pesantren. The main factor is because of friends. Seeing friends carrying cell phones causes feelings of jealousy, feeling isolated and also bored because of the large amount of free time in the pesantren. This supports the results of the research by Sumaidah (2013) that one of the factors of santri is doing things that are not good because they are influenced by friends and follow-up factors. Ibrahim et al. (2019) also explained that around 51.5% of respondents stated that peers have an important role in the lives of adolescents.

Rohmah (2022) argues that students also state that activities in the pesantren are boring, so they are looking for entertainment through social media. The use of cell phones is used only for entertainment (Mahfudhoh & Fatimah, 2019). Suryani et al. (2021) found that adolescent girls use the internet and access social media because they feel bored and are in a bad mood. Boredom after learning makes them not know what things can be done, so they end up playing the internet continuously.

Teenagers are currently too obsessed with social media, which will eventually have an impact on their behavior, one of which is that they tend to follow the development of fashion (Rosli et al., 2019). Based on the results of the study, participants said that social media affects the style of santri dressing. This is in accordance with Triananda et al. (2021) who said that social media today is very often used to show excessive self-existence because social media posts are benchmarked for students to display their lifestyles, both in terms of dress and others. For teenagers, fashion is a way to show their existence. They also compete to always be updated with trends or even become a trendsetter (Tyaswara et al., 2017).

Aliyah and Sutoyo (2016) state that students are strongly influenced by the environment and relationships between friends. This is caused by the life of the students who are always together with peers and far from parents, so that they have a very close relationship to peers. This causes the influence of friendly behavior patterns, such as attitudes, conversation, interests, appearance, and behavior, to be stronger than the influence of the family.

Under the influence of globalization, student behavior is currently changing. As a result, the behavior they show is often not in accordance with the values invested from the pesantren (Mundiri & Nawiro, 2019). Warto (2017) states that the rules set by the pesantren can shape the character of students based on religion and being increasingly directed. The problem of juvenile delinquency can be reduced and controlled by the pesantren by instilling character through the rules that are enforced. Based on Widara's (2021) findings, the regulations applied in the pesantren have a significant influence on the discipline of students.

Conclusions

This study concludes that although students bring cell phones to the pesantren to access social media, adolescent female students wish to make the best use of social media to make up for violations committed. The role of the mental health nurse is also needed to provide health promotion regarding the use of technology so that students can use social media wisely.

Declaration of Interest
The authors declare no conflict of interest.

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Artificial intelligence as an educational media to improve adolescent reproductive health: Research and development studies

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Abstract

Background: Cognitive accessibility, psychosocial accessibility, and geographic accessibility are all barriers to adolescent sexual and reproductive health services. Cognitive accessibility, as an educational medium, provides access to comprehensive adolescent reproductive health information.
Purpose: This study aimed to turn a textbook into a learning module for adolescent reproductive health using artificial intelligence (AI).
Methods: The study used the Borg and Gall Research and Development design. Purposive sampling was used to select the trial sample of students, teachers, and media experts at Muhammadiyah Junior High School 4 Margahayu, Bandung Regency. Interviews, validation sheets, and questionnaires were used to collect data. The data analysis technique was carried out based on the validation analysis results of media and material experts, as well as the module's feasibility according to students.
Results: At the research and information gathering stages, the research results were obtained by incorporating material from the previous module on menstruation and sexually deviant behavior, particularly LGBT. The planning stage included application aspects, materials, and usage instructions. With the addition of revised trial results in practice questions and adapted religious materials, the development results show that the module is ready for use.
Conclusion: According to the results of the study, the adolescent reproductive health learning module using artificial intelligence was appropriate as an educational medium. It is suggested that the press be improved in terms of media display and comprehensive material.

Keywords: adolescent; artificial intelligence; educational media; reproductive health

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Introduction

Adolescents account for approximately 16% of the total population (UNFPA, 2016), but their needs and rights to sexual and reproductive health are largely unmet. Discrimination and barriers to accessing sexual and reproductive health information, goods, and services contribute to this condition. Another barrier to accessing these services is the age limit, stigma, and social norms in society, particularly for young women seeking information about sexual and reproductive health. Biological and sexual maturity are typical in this period, forming a healthy character as an investment in the future. Individual profiles will be created that is also influenced by culture. Physical and sexual maturation can be the most difficult problem (Baker, 2017).

Adolescents must obtain the consent of their parents, guardians, or doctors to access sexual health and health information and services. Practically, there are barriers in the form of a lack of information for adolescents, which leads to a lack of understanding of their sexual and reproductive needs, which in turn leads to an inability to prevent unwanted pregnancies or sexually transmitted diseases. Because there is a lack of accurate and correct information about adolescent reproductive health, adolescents

are encouraged to explore on their own, whether through print, electronic media, or friendships, which can lead to risky behavior (Yusuf & Hamdi, 2021). Comprehensive sexuality education is essential for educating adolescents about reproductive health services, the right to access those services, and the right to make sexual and reproductive health decisions free of violence, pressure, or coercion. Access to reproductive health information is thought to reduce harmful reproductive health behavior (Susanto et al., 2016).

The results revealed that adolescents prioritized confidentiality and accessibility over medical accuracy, which are unlikely to exist in a clinical setting that frequently requires parental involvement. Other studies have found that adolescents prefer technological tools for sexual health education (Brayboy et al., 2018). Electronic devices in education, including information technology development technology, have become common due to the rapid development of information technology. The application of artificial intelligence in education/Artificial Intelligence for Education (AIEd) has advantages and disadvantages, with more opportunities than threats (Xie et al., 2022).

According to Ma et al.'s study, an intelligent guidance system is more effective than traditional learning tools. A learning environment using a web-based learning system positively influences academic achievement (Erdemir & Ingec, 2015), and artificial intelligence can help detect students' emotions. Teachers can adjust their teaching (Chung, So, Choi, Yan, & Wong, 2021). AIEd can change the way teachers and students communicate. Because of its ability to balance needs and address challenges associated with face-to-face communication strategies about adolescent sexual and reproductive health, digital technology has become a necessity for the twenty-first century (Guse, et al. 2012). Teachers and students have traditionally communicated face-to-face in a specific space and time. However, AIEd's emergence may limit opportunities for face-to-face communication. Furthermore, AIEd cannot function without the Internet and electronic devices. Youth are the most likely age group to use social media, with approximately 71% of those aged 15–24 online, compared to 48% of all people (United Nations Children's Fund (UNICEF, 2017)). This study aimed to develop an adolescent reproductive health education module using artificial intelligence (AI).

Wang et al. (2022) conducted a previous study on computers designed to simulate conversations with humans as users (chatbots) about adolescent reproductive health in India. They described how they used AI chatbots to educate adolescents about reproductive health. The objectives and methods of this study differed from those of the previous one, the purpose being to investigate the feasibility of Gibson's theory in assessing adolescent sexual and reproductive health in India and provide scientific guidance for AI chatbots to educate adolescents and young adults, promote sexual and reproductive health, and advocate for girls and women's health. In addition, the previous study used mixed methods with an instrumental case study approach, whereas this study uses an engineering method approach with mixed methods as well. For this study, the research team is already at the stage of designing and developing the media, which is a novelty of the research.

Materials and Methods

Design

This research design used the Research and Development (R&D) method which, according to Borg and Gall (Hermawan & Zuhrie, 2019) is used to develop or validate products used in education and learning. The researchers completed five of the ten stages of R and D in connection with the resulting product, which is still a sample product. The stages are as follows: (1) research and information gathering; (2) planning; (3) initial product development; (4) initial field trials; and (5) test result revision. In stage one, the researchers followed up on a previous study about the effect of the reproductive health learning module on knowledge, attitudes, and behavior by conducting interviews with teachers about the material to be added to the module using artificial intelligence.

During the planning stage, the researcher created a design for the software or hardware aspect, searched for an appropriate name for the media, and made an appealing user interface and user experience for teenagers. The researcher was assisted by media experts from the second to the fifth stages.

Sample and Setting The trial sample consisted of students, teachers, and experts, and the sampling technique was quota sampling. The study was conducted at Muhammadiyah 4 Junior High School in the Bandung District.

Variable

The only dependent variable in this study is the development of adolescent reproductive health education media using artificial intelligence.

Research Instruments

Interview guidelines, validation sheets, and questionnaires are examples of research instruments. Interview guidelines were used to interview teachers, validation sheets were distributed to experts, and a questionnaire was distributed to students.

Data Collection

In order to collect data, the researcher conducted interviews, solicited validation experts, and distributed questionnaires to students.

Data Analysis: The data analysis technique was conducted based on the validation analysis results of media and material experts, as well as the module's

Table 1. Reproductive Health Module Validation Test Results using Artificial Intelligence

Validator	Validity Percentage	Validity Category
Media Expert	84.6%	Fairly Valid
Material Expert	90%	Highly Valid
Media and Material Expert	87.3%	Highly Valid

Table 2. Feasibility Test Results of Adolescent Reproductive Health Module Using Artificial Intelligence

Group	Validity Percentage	Eligibility Category
Expertise	87.3%	Highly Eligible
Student	85.1%	Highly Eligible
Teacher	84.5%	Highly Eligible

Figure 1. Home Screen

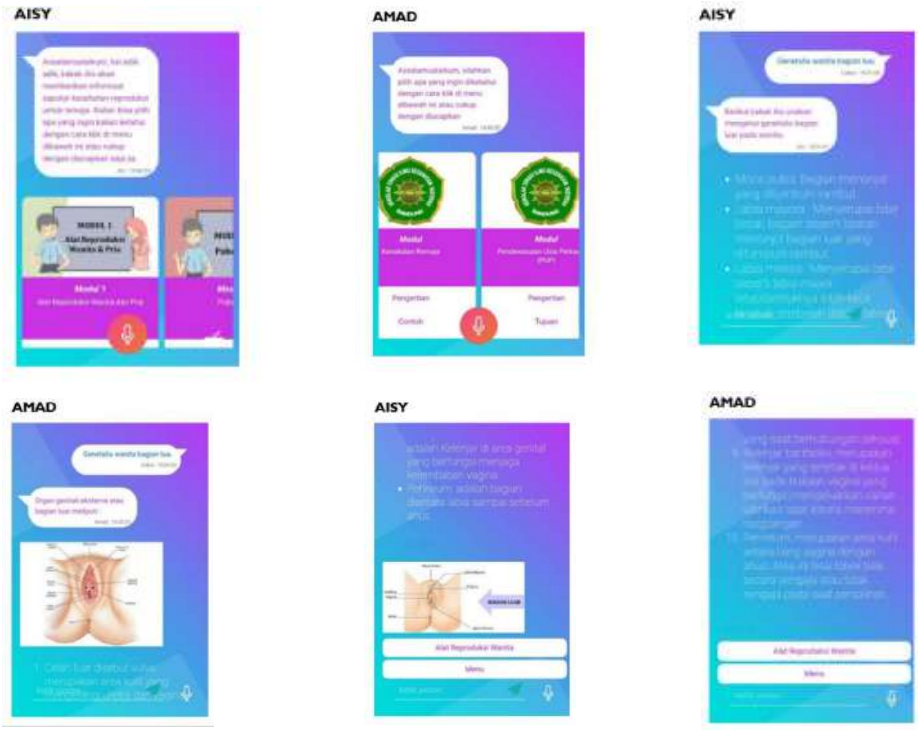

Figure 2. Screen After Login

feasibility according to students.

Ethical Approval

The Health Research Ethics Committee of the University of Aisyiyah Bandung granted ethical approval for this study in number 78/KEP.02/STIKes-AB/VI/2020. Students were given the opportunity to provide informed consent both orally and in writing. The researcher asked that students resubmit research information that will be carried out with informed consent so that permission for student participation can be obtained from the students' parents.

Results

The results of the study describe each stage in the order specified in the research method. Researchers designed and developed an artificial intelligence-based reproductive health learning module that replaced a paper-based module. The study focused on the planning and development of a learning medium for adolescents up to the fifth of ten stages in Borg and Gall's theory regarding priority needs and resource availability.

Development of Adolescent Reproductive Health Module Using Artificial Intelligence

The results of each stage of doing adolescent reproductive health modules using artificial intelligence can be described as follows:

Research and Information Collecting Stage

This study is a follow-up of a previous study in which the researcher created a textbook-based adolescent reproductive health learning module. After the investigation was completed, the researcher found no conditions that matched expectations, indicating that the module was not being used appropriately; for example, students rarely read the module, and the teacher rarely used it. To become more developed and capable of addressing broader adolescent reproductive health issues, the researchers relocated the study from 'Aisyiyah Junior High School Rancaekek to Muhammadiyah Junior High School Margahayu in Bandung Regency.

Based on these conditions, the researchers conducted further research to develop educational media modules into innovative media to answer problems in the field. Researchers conducted a literature study on Information Communication and Education (IEC) services for adolescent reproductive health, including male and female reproductive organs, puberty, clean and healthy life behavior, juvenile delinquency, maturation of marriage age, violence against children, and deviant sexual behavior, in this follow-up study, research results, and information collection. They added material on menstruation and sexual behavior deviations such as lesbian, gay, bisexsual, and transgender (LGBT) to the results of interviews with teachers and school principals. There were guidelines for developing teaching materials for teenagers, both boys and girls.

Identifying media needs indicated the need for adolescent reproductive health learning media with appealing designs that are not only text-based but also include pictures and videos, and that can help students obtain information or study independently. Previous study has revealed a lack of teachers or notable people who can provide systematic and structured data on reproductive health, as well as a lack of sourcebooks, media, and evaluation forms that can reflect students with a healthy reproductive capacity in terms of knowledge, attitudes, and behavior.

Planning Stage

The second stage in this study was product planning. Product planning includes 1) the required equipment, which includes software, hardware, application users, and introduction and training; 2) a general description of the system, which includes a general description of the application and a general description of application requirements; 3) how to use, which includes menu structure and user instructions; and 4) materials for adolescent reproductive health education. All product information is presented in the form of an application user manual Artificial Intelligence (AI) Adolescent Reproductive Health Module (Aisy and Amad). The names Aisy and Amad are icons for the names of boys (Amad) and girls (Aisy) derived from the terms of the Muhammadiyah and 'Aisyiyah organizations, respectively.

Early Development Stage

The application's initial development is based on a prepared plan and refers to several development elements, including 1) the purpose of making the product; 2) the qualifications of the parties involved; 3) the form of participation of the parties involved; 4) work procedures; and 5) the feasibility test.

The purpose of making the product is to create a learning module for adolescent reproductive health using artificial intelligence technology. Media experts, material experts, and students as test subjects are involved, with experts providing input for adolescent reproductive health materials and assessing the preliminary results of module products designed with students. The module's operation is documented in the form of a manual for using the AI Aisy and Amad modules. The module validation test was performed on media and material experts. The validation test results are shown in Table 1.

The validation test from a combination of media experts and material experts shows the validity category was very valid, with 87.3%. Validation tests were also carried out on teachers through open discussions and received positive responses.

Initial Field Trial Stage

Initial field trials were conducted on junior high school students who had smartphones and were willing to

become research participants and teachers. There were 20 participants in the module feasibility test with the test results shown in Table 2 below.

Based on Table 2, it can be explained that the feasibility of the adolescent reproductive health module with artificial intelligence, according to experts, is very feasible (87.3%), and according to students, it is also very possible with a percentage of 85.1%, and according to teachers, 84.5%. The results of the module development in the form of applications can be seen in the following pictures.

Test Result Revision Stage

Discussions with experts helped researchers revise the trial's findings. There was additional material in the form of practice questions in the results of the debate in the initial field test which was useful for evaluating students' knowledge of all the material in the artificial intelligence module. Experts also suggested that religiously charged material, the emergence of Eastern culture, and image visualization be included.

Discussion

According to Borg and Gall (Hermawan & Zuhrie, 2019), research and development is defined as an activity that aims to develop and produce good research products through cyclical and iterative processes or steps such as field testing, product revision, and finally producing products that meet the stated goals (Rabiah, 2015). The Organization for Economic Cooperation and Development defines research and development as "creative and systematic work carried out sequentially to increase the supply of knowledge about humans, culture, and society and design new applications of available knowledge." The. The research discussion can be summarized as follows.

Research and Information Collecting Stage

The artificial intelligence module is created by gathering information in the form of needs analysis and competency analysis. It requires examination to identify potential issues (Kamal, 2020). The researchers conducted research in accordance with the theory. They gathered data on adolescent reproductive health data acquisition problems in schools through needs analysis, literature review, and field observations. These results of this stage included material requirements for adolescent reproductive health and media created with artificial intelligence technology.

Based on Government Regulation No. 61 of 2014 concerning Reproductive Health, the IEC material contained in the module has not been fulfilled, namely material on mental health, family planning services, and behavior that hurts adolescent reproductive health, while there is additional material on menstruation and deviant sexual behavior, especially LGBT. There is a need for various media that can be accessed quickly, have attractive designs, and facilitate student interaction with the media when collecting information about media. The steps of research and information collection were carried out by researchers in systematic stages.

Planning Stage

Planning stage included the abilities needed in conducting this study, the formulation of the objectives to be achieved in the study, design and research steps, and the possibility of testing in a limited scope (Sa'diyah, Alfiyah, Tamin, & Nasaruddin, 2020). During the planning stage, the researcher devised a strategy that included transforming the textbook module into a module that used AI technology design and testing on a micro-scale. An application user manual compiled the method for using modules, techniques, and devices that users must know. According to theory, the module testing plan was conducted by researchers in collaboration with teachers, students, and media experts.

Early Development Stage

In the initial product development stage, the supporting components were prepared, guidelines and manuals were designed, and the feasibility of the tool was evaluated (Haryati, 2012). Researchers used AI applications to develop products, such as adding reproductive health materials and changing modules. At this stage, validation testing was performed, an activation process to determine whether the product design, in this case, the new AI module, can be more effective than the textbook module. Validation was said to be rational because it is based on logical thinking rather than field facts (Purnama, 2013). The test results demonstrating the application's feasibility indicated a type of evaluation of the tools' feasibility. Valid statements from media experts serve as the foundation for individual and group testing of products.

In this study, the AI application is part of the Virtual Assistant (VA). According to Guzman (2019) and Perdana and Irwansyah (2019), VA is a set of programming languages based on NLP (Natural Language Program) that allows users to speak and receive responses from applications in the same way that other people do. This AI module was created using the chatbot application, a VA derivative and component of AI which can integrate text-based input, and the presence of audio making it easier for users to get information from the database and quickly inform users. A chatbot is a computer program that simulates human conversations through artificial intelligence to allow machines to interact with humans in a closed area through written text or voice interaction, with or without human assistance. The presentation of the results of this study strengthened the design of the adolescent reproductive health module designed by the researcher.

Trial Stage

The initial trial was carried out individually to test the feasibility of the module. The trial involving students and teachers was then revised to complete and perfect the AI module product. Teachers have suggested that material about religion and its relationship to adolescent reproductive health be included in this trial. The manual also guided data collection during the trial stage for using the module described at the start of the meeting. Trials were conducted in Kamal (2020) after the product received expert advice and field findings.

Test Result Revision Stage

Sustainable development continues, and changes in the nation's economy are reflected in investments in science, technology, and investment. Investment is defined as the ability of a state to generate, utilize, and wisely apply scientific knowledge and technology related to innovation (Sibiya, 2011). Currently, research and development results are obtained through the collaboration of universities and other organizations, and they are then applied in a variety of ways in the industrial sector. This is done because research and development help humans better understand themselves and find solutions to health problems in a more straightforward and guided manner (Sibiya, 2011). In addition, theoretical reinforcement is that in research and development, thus a revision of the trial results is needed to make the primary product draft ready to be tested more broadly through the improvement of the initial product, and this improvement can be carried out more than once based on the initial trial results (Silalahi, 2017).

The usefulness of AI for human life can be used to assess its success. As a result, AI must be well -designed so that people become acquainted with the AI system, become a part of it, and develop trust. Public policy should make it easier for people to use AI, extending benefits while reducing unavoidable errors and failures (Grosz et al., 2015).

The use of artificial intelligence as a learning medium has allowed students to grasp information more quickly. Research on the use of artificial intelligence technology as a learning medium for adolescent reproductive health has never been conducted in junior high or high schools, particularly in the educational environment of the Muhammadiyah organization, Indonesia's largest educational charity. This study is expected to be a reference for the development of digital technology science to support adolescent health. In addition, the media design can be used by adolescents and related institutions in practice. This study has limitations in that it has only been done until the fifth stage or revision of the initial product has been tested in a limited environment, and has not yet been widely used by students.

Conclusion

Based on the evidence obtained from research and development in the field, it can be concluded that each stage was carried out properly, starting from the research and information gathering stage, planning stage, development stage, trial stage, and revision stage of the test results. It is suggested that the study be continued until it is widely used by students and lecturers.

Declaration of Interest

There is no conflict in this research.

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Data Availability Statement

none

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Preventive bacterial translocation and control of ventilator-associated pneumonia: A qualitative study

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Abstract

Background: Bacterial translocation is one cause of ventilator-associated pneumonia among patients treated in the Intensive Care Unit.
Purpose: The study aimed to observe critical nurses information about bacterial translocation prevention and ventilator-associated control in clinical settings.
Methods: A qualitative phenomenology design was undertaken from July to September 2021. We recruited 40 critical nurses in government and educational hospitals in Surabaya, Indonesia. The in-depth online interview was conducted during the interview process and analyzed using Colaizzi's technique.
Results: We emerged five themes that consist of 1) limited of nurse's competence, 2) unsupported work environment, 3) barrier of human resource management, 4) work motivation, and 5) development of bacterial translocation preventive tools.
Conclusion: Prevention of bacterial translocation is needed by developing tools and accessible by nurses, whereas, the capacity and ability need to be developed by training. Nurses and Hospital Managers should consider attention to evidence-based tools in clinical settings.

Keywords: bacterial translocation; ventilator-associated pneumonia; prevention; intensive care unit; nurse

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Introduction

The increased risk of nosocomial infection is one of the problems faced by patients treated in the intensive care unit (ICU) (Kózka et al., 2020), one of which is Ventilator-Associated Pneumonia (VAP) in the lower respiratory tract. Comprehensive efforts are needed to deal with the problem of VAP because it causes increased morbidity. VAP is caused by various factors, including improper infection control and the transfer of bacteria from the external environment into the body (Bacterial Translocation) (Vance et al., 2010). VAP occurs in 5–40% of patients on invasive mechanical ventilation for more than two days (Atashi V Mahjobipoor H, Yazdannik A.Atashi, Vajihe, 2018). High mortality is the greatest risk of patient mortality where VAP can reach 70% (Torres et al., 2017) and the incidence of VAP in the ICU is about 5-15% of total patients (Klompas et al., 2014). Proper prevention of VAP can reduce the length of stay, lower treatment costs and increase patient satisfaction (Samra et al., 2017).

The quality of health services is determined by the primary role of nurses (Koch et al., 2020). The skills of nurses in nursing care and preventive measures are very important factors to minimize complications. ICU care requires complex observation, therapy, high-intensity intervention, and continuous observation (Vance et al., 2010). Currently, nursing care must minimize complications, including bacterial translocation and micro aspiration in the airways.

Efforts to prevent bacterial translocation from the oral cavity to the external Endotracheal Tube (ETT) can prevent VAP. The ETT is a link between the patient and the ventilator, which can mobilize the oral microbiota, and can be colonized by oral bacteria or commensal respiration (Alagna et al., 2019; Jaillette et al., 2015). Leakage of fluid around the ETT cuff into the airway is a form of micro aspiration and bacterial translocation that can cause VAP. (Hamilton & Grap, 2012; Jaillette et al., 2015). When the ETT tube cuff balloon pressure is at its maximum level, micro aspiration and bacterial translocation can be prevented (Hamilton & Grap, 2012). However, nurses may not permanently anticipate reduced ETT balloon pressure due to the workload in the ICU and the limited equipment.

Based on an initial study conducted at two hospitals in Surabaya, Indonesia, it shows that nurses still do not fully understand the condition of bacterial translocation, especially in patients who are attached to ventilators. Of the 60 nurses who were interviewed, only 40 nurses had a thorough understanding of bacterial translocation and how to properly apply a ventilator bundle to prevent bacterial translocation from occurring. Meanwhile, the other 20 nurses still had superficial understanding because they had only been in the ICU for no more than two months and had not received formal internal training. These new nurses are also still learning based on the experience gained from senior nurses in the ICU.

Previous studies also have shown that the cause of VAP is more often due to a lack of cleanliness from the surrounding environment, nurses, and oral hygiene (Gupta et al., 2016; Hua et al., 2016; Karakaya et al., 2021). Nurses who always provide care to patients with installed should have more information and skills related to this evidence practice. Therefore, this study aims to seek information with a qualitative approach from critical nurses in the ICU about bacterial translocation and control of VAP in patients on ventilators.

Materials and Methods

Design

This study used a qualitative phenomenology design with a constructivist paradigm. Interpretative phenomenology was used to understand the experience and need of critical nurses about preventive bacterial translocation to prevent VAP (Mayer, 2015), while the constructivist paradigm involves the active role of the social and practitioner values in shaping the descriptions and statements expressed by the participants (Allen, 2008). The researchers were health professionals with expertise in the critical nursing and medical surgical nursing departments and had experiences in qualitative research. The research team consisted of men and women. No team member had a relationship with any participants in the study.

Settings and Participants

The study was conducted in the Non-Infectious Intensive Care Unit (ICU), Government and Educational Hospital in Surabaya, Indonesia. The data were collected from July to September 2021. The participants were recruited by purposive sampling. We collaborated with Nurse Unit Manager (NUM) to obtain the participants with the inclusion criteria being nurses in the ICU, working more than one year and having the clinical privilege to treat patients with ventilators from the hospital. Forty-four participants were recruited, and we asked informed consent to participate in the study.

Data collection

An in-depth interview was used to carry out the information from critical nurses, and four researchers conducted the interview process. Due to COVID-19 pandemic in Indonesia, and the higher incidence in the middle of 2021, we interviewed by online meeting with Zoom application. Before we conducted the interviewer, we sent the informed consent to participants to participate in the study. Furthermore, we asked for an agreement to record the Zoom meeting without video and only audio. All the recorded interviews were saved in the Zoom and only be accessed by the researcher to maintain privacy. The researcher designed the interview questions and got inspiration about the topic of study from clinical nurses who worked in the ICU. Before the questions were asked to participants, they were assessed by four experts (one expert in the critical nursing department, one medical doctor with a specialization in intensive care, and two nursing managers in the hospitals). To conduct the validity and reliability of the content of the questions, we performed interviews with three critical nurses. After that, we observed the question and where challenging to understand by participants, we revised them.

Furthermore, the interview process begins by building trust between the researchers and participants. Moreover, the research objectives were explained by the researcher. The questions during the interview process included *"How did you know about bacterial translocation and VAP?"; "How do you control the prevention of bacterial translocation?"; "What are the limitations faced to prevent VAP?"; "What is the hope for preventing bacterial translocation and VAP?"*. Each participant was interviewed for approximately 20 minutes.

After the interview process was completed, the researcher conducted it verbatim. Then, the researcher re-confirmed to the participants regarding information that was still unclear and to obtain the correct information. Triangulation of the interview was undertaken to enrich the data (Heath, 2015). Recruiting additional participants ceased when the data reached saturation.

Data analysis

The transcription and verbatim processes were

Table 1. Respondent Characteristics

Participant Code	Gender	Age	Occupation Status	Nurse Level	Latest Education	Experience of Work (Year)	Experience of Work in ICU (Year)	Marital Status
P1	F	41	Civil Servant	CN 3	Diploma	20	18	Married
P2	F	37	Civil Servant	CN 3	Bachelor of nursing	15	11	Married
P3	M	34	Civil Servant	CN 2	Diploma	9	5	Married
P4	F	33	Contract Employee	CN 2	Diploma	9	9	Married
P5	F	31	Civil Servant	CN 1	Diploma	8	1	Married
P6	F	45	Civil Servant	CN 3	Bachelor of nursing	20	17	Married
P7	F	36	Contract Employee	CN 3	Bachelor of nursing	12	4	Married
P8	F	27	Civil Servant	CN 1	Diploma	5	1	Married
P9	F	27	Civil Servant	CN 1	Diploma	2	2	Married
P10	F	31	Freelance	CN 2	Bachelor of nursing	7	4	Married
P11	M	30	Civil Servant	CN 2	Bachelor of nursing	7	2	Married
P12	M	28	Contract Employee	CN 2	Diploma	5,5	4,5	Single
P13	F	48	Civil Servant	CN 3	Diploma	26	1	Married
P14	F	29	Civil Servant	CN 2	Diploma	8	8	Married
P15	M	34	Freelance	CN 2	Diploma	13	1	Married
P16	F	48	Civil Servant	CN 3	Diploma	24	14	Married
P17	F	45	Civil Servant	CN3	Diploma	21	1	Married
P18	F	26	Civil Servant	CN	Diploma	3	2	Single
P19	F	29	Contract Employee	CN 1	Bachelor of nursing	4	1	Married
P20	F	42	Civil Servant	CN 3	Diploma	21	14	Married
P21	F	27	Civil Servant	CN 2	Bachelor of nursing	4	4	Married
P22	F	29	Civil Servant	CN 2	Diploma	7	1	Married
P23	M	35	Contract Employee	CN3	Diploma	12	9	Married
P24	F	35	Civil Servant	CN2	Diploma	14	7	Married
P25	M	26	Contract Employee	CN 1	Bachelor of nursing	2	1,5	Single
P26	F	29	Civil Servant	CN 1	Bachelor of nursing	5	1,5	Married
P27	F	25	Contract Employee	CN	Bachelor of nursing	1	1	Single
P28	M	27	Civil Servant	CN	Bachelor of nursing	3	1	Single
P29	F	31	Civil Servant	CN 2	Bachelor of nursing	7	5	Single
P30	F	25	Civil Servant	CN2	Bachelor of nursing	1	1	Sngle

Cont. Table 1. Respondent Characteristics

Participant Code	Gender	Age	Occupation Status	Nurse Level	Latest Education	Experience of Work (Year)	Experience of Work in ICU (Year)	Marital Status
P31	F	33	Civil Servant	CN 2	Master of Nursing	11	5	Married
P32	F	23	Contract Employee	CN	Diploma	1	1	Single
P33	F	29	Contract Employee	CN 1	Bachelor of nursing	6	6	Married
P34	F	27	Contract Employee	CN 1	Bachelor of nursing	2	1	Single
P35	F	30	Contract Employee	CN 1	Bachelor of nursing	6	2	Married
P36	F	24	Contract Employee	CN	Bachelor of nursing	2	1	Single
P37	M	27	Freelance	CN	Bachelor of nursing	3	1	Married
P38	M	29	Freelance	CN 2	Bachelor of nursing	5	5	Single
P39	F	27	Contract Employee	CN1	Bachelor of nursing	3	3	Single
P40	M	30	Contract Employee	CN 1	Bachelor of nursing	6	6	Married
P41	M	31	Contract Employee	CN2	Bachelor of nursing	7	6	Married
P42	M	25	Contract Employee	CN	Bachelor of nursing	1	1	Single
P43	F	25	Contract Employee	CN 1	Bachelor of nursing	5	5	Single
P44	M	29	Contract Employee	CN 1	Bachelor of nursing	5	3	Single

Abbreviation = P : participants; F : female; M : male; CN : clinical nurse; HCU : high care unit

carried out using Microsoft Word 365. After that, the researchers coded and analyzed using the NVivo 12 software (QSR International). The analysis of the interview results used Colaizzi's technique. The stages consisted of 1) familiarization with the transcript; 2) identifying significant statements; 3) formulating the meanings; 4) clustering the themes; 5) developing a detailed description; 6) producing the fundamental structure; and 7) seeking verification of the fundamental structure (Morrow et al., 2015). To enhance the quality and transparency of the study results and the associated reporting, the researchers applied the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

Ethical consideration

We received ethical approval from the Health Commission Ethics Committee of Haji Surabaya Hospital (No. 073/16/KOM.ETIK/2021) and Universitas Airlangga Hospital (No. 154/KEP/2021). Participants were required to give their written consent to participate free of coercion. They could withdraw from the study without giving a reason, and with no impact on their health care, and could decline to answer any of the questions. Furthermore, the researchers maintained their privacy throughout the interview process. All of the data were de-identified at transcribing, with participants being named according to a number such as P1, P2 and so forth. The study did not have the potential to harm the participants physically or mentally.

Results

Respondents Characteristics

Table 1 shows the characteristics of the research participants. The number of participants was 44 people consisting of 31 female participants and 13 male participants. All participants were at least 25 years old with the majority employee status being civil servants, while the other employee statuses were contract and honorary employees. As many as 26 participants were graduates of a bachelor of nursing and the rest were graduates of a nursing diploma. All participants had worked in the hospital for at least one year.

Analysis of the interview and the field observation

data resulted in the development of four main categories and fifteen subcategories which reflected nurses' perceptions to prevent bacterial translocation in order to control ventilator-associated pneumonia. Detailed explanations about the categories and subcategories are provided in what follows.

Theme 1: Limited of Nurse Competence

Nurses' understanding of bacterial translocation is still limited. This is associated with nurses' lack of knowledge about the term bacterial translocation and the mechanism of bacterial translocation. This theme is grouped into four subcategories, namely lack of knowledge, unexpected behaviour, lack of opportunity to practice new skills, and no standard VAP bundle.

Lack of knowledge of nurses regarding bacterial translocation and micro aspiration

The incidence of bacterial translocation is still not fully understood for most nurses, but nurses understand that bacterial translocation in patients who are on a ventilator is one of the triggering factors for the occurrence of VAP.

"Here, we rarely use the term bacterial translocation, so we don't really understand it. Maybe it means the transfer of bacteria from the mouth to the bottom, do you understand? Or how about it, basically it can trigger the occurrence of VAP if left alone." (P.12)

"I don't know yet, ma'am. Is that different from micro aspiration? As far as I know if it's the same as micro aspiration it can cause VAP." (P.19)

"As far as I know, bacterial translocation is the transfer of bacteria from A to B, from one patient to another. Maybe from poor oral hygiene then it could also be related to VAP because there are mucus that enters the lungs through small gaps." (P.2)

Unexpected behaviour from nurses

Nurse professionalism influences the implementation of VAP prevention measures. This action should still be carried out even though there are limitations of both time and energy. However, in some cases, VAP precautions such as measuring the ETT cuff voltage routinely can be missed or not carried out according to standards.

"We measure the air content, but it depends on the size of the contents. Usually there are those who report that the contents of the hot air balloon are 10 ml and some do not mention it."(P.15)

"… If the cuff meter doesn't exist yet, so we use instinct, we'll just estimate how many ml the ETT cuff balloon contains." (P.23)

"… it should be measured periodically, but in practice, only if there is an indication of the monitor." (P.5)

Have not received special training for ICU nurses

Information related to bacterial translocation is obtained from training that is routinely carried out from inside and outside the hospital. There are still many nurses who have just been placed in the ICU who have not received training.

"We have an ideal program for one nurse to have hours of education, so there is in-house training that needs to be done. So in-house training is often encouraged because during the pandemic it was neglected. So the facilities for the new siblings don't exist, so it's quite difficult." (P.11)

"Maybe it's more about socializing the VAP bundle because it's for new friends. We work with many people, but not all understand about the VAP bundle and I think there should be interference from the leadership either later to the PPI section to provide solutions so that we have the same understanding of VAP. I don't know how the PPI can find out, especially since there are a lot of new kids here and we can't teach them all" (P.23)

There is no standardized measuring of ETT cuff

Ventilator Associated Pneumoniae Bundle standards are needed so that nurses can act according to procedures and no action is missed. Checking the ETT cuff still has no standard, thus, the absence of a standard makes nurses have different ways of measuring the ETT cuff.

"In the ICU there has not been a clear standard, so we (nurses) only measure the ETT cuff according to each other's experience." (P.1)

"We usually do socialization via IPCLN and indeed there are no special tools to check the VAP bundle check list."(P.12)

"Yes, usually the VAP bundle is explained how the standard is, but at this time it has not been formally explained, only a few have just been submitted."(P.13)

Theme 2: Unsupported Work Environment

An unsupportive work environment includes several things that can hinder the work of nurses. There are four sub-themes including the situation during work, many workload, time constraints, and a lack of team approach.

Working situation during the pandemic

During the pandemic, the limited number of nurses and the available time became a barrier for nurses to be able to measure the ETT cuff. This action is often missed and is not a priority if the number of patients is large but the number of nurses is reduced.

"Yes, actually there are enough nurses, but because of the pandemic, some nurses have been transferred to the COVID isolation room, so there are more nurses in their work rooms. If we measure only occasionally, when there is an alarm on the ventilator, we will check it" (P.12)

"In this time of a pandemic, there are people who are basically not in the ICU, if their staff is limited and they really want to be admitted to the ICU, it would be better to hold in-house training first. So friends who enter the ICU already know what to do." (P.13)

"The problem was that before the pandemic we could enter at any time, there was no time limit to enter if after this pandemic we were on guard. In the past, oral hygiene could be done three times a day now two times." (P.19)

Excessive workload

The disproportionate comparison between the number of nurses and patients makes nurses only do the work they can do during shifts. As a result, there are nurses who do not take action according to procedures.

"In fact, if there are many patients, we ourselves do not do it. Usually if oral hygiene is three times a day, but if there are many patients, we can do as much as we can." (P.26)

"We should have worked according to the procedure every shift. But when we have a lot to do, we usually do what we can. Sometimes late to do, sometimes forget." (P.35)

Lack of team approach

So far, junior nurses have only received training through actions exemplified by senior nurses. However, this assistance is not always possible, because senior nurses also have the responsibility to treat patients.

"Yes, it is routinely implemented, but socialization to new nurses is only when taking action. So at the same time give an example. But if there are a lot of patients, the nurse we just asked to see." (P.14)

"But because the previous PPI person was from the ICU, we often get knowledge about the VAP bundle from him, if it's from a PPI hospital, it's very rare, we've never had it." (P.12)

"It is undeniable that there are now many new nurses in the ICU who may not be exposed to this VAP bundle. Senior nurses also don't always have enough time to guide them." (P.26)

Theme 3: Barriers of Human Resource Management

Human resource management is one of the obstacles in the implementation of routine ETT cuff measurements. This is related to the limited number of nurses, lack of training activities for nurses, lack of supervision from the leadership and lack of collaboration with other units.

Limited number of nurses

The limited number of nurses makes actions that should be routinely missed and even not carried out. Three participants said that the small number of nurses could not carry out all the actions completely.

"The comparison between senior and junior nurses is not balanced. There is still responsibility to the patient so other actions may be neglected." (P.12)

"Perhaps the frequency is not routine, so it should still be three times a day. During the night service, it is often done, but in the morning service it is rare. If there are many personnel on duty and not too busy, it can still be done." (P.29)

"From me, the ratio of nurses and patients is urgent. From me, the ratio of those in charge has an effect." (P.20)

Lack of supervision from the head of the room

The head of the room still often skips supervision for checking the ETT cuff. Supervision is more focused on other priority actions. If there is no alarm from the ventilator, then the ETT cuff balloon is considered not problematic and measurements are not always taken.

"The problem so far is the lack of reminding each other to check the ETT cuff pressure." (P.11)

"If the ETT cuff pressure is rarely asked, yes, because it is considered routinely done, or if the ventilator alarm does not turn on, then it is considered that there is no disturbance in the ETT cuff." (P.30)

Lack of collaboration

Collaboration with the Infection Prevention and Control (IPC) section is needed to provide information and supervise the implementation of efforts to prevent bacterial translocation and micro aspiration.

"Perhaps the important thing is the socialization of the VAP bundle. Because not everyone understands about bacterial translocation and microaspiration and bundle VAP. I think there should be interference from the leadership or the PPI section to provide a solution so that we have the same understanding of VAP." (P.39)

"It seems that the knowledge is still lacking, but we always set an example. I hope the IPC department can provide training soon." (P.40)

Theme 4: Work Motivation

Most nurses stated various sources of motivation at work. Motivation comes from outside and from within the nurse. There are three sub-themes of work motivation, namely moral responsibility as a nurse, empathy for the patient's condition, and reflection on one's own condition.

Nurse's moral responsibility

Nurses consider work is a responsibility that must be carried out to help patients.

"Because yes, the mindset is working and my job is like this. So you have to be responsible and later if you see a patient affected by VAP, I feel sorry for you. It really has to be taken care of." (P.14)

"The consequence of my job is to treat COVID patients like that. So it must really be done responsibly and sincerely." (P.31)

Empathy for the patient

Nurses' empathy encourages them to work earnestly to support the patient's healing process.

"Considering that patients are their own family. To avoid VAP, HAP or the other by doing the treatment

correctly and appropriately. Even though sometimes we forget and no one is watching for sure, we must still carry it out correctly." (P.25)

"Patients come in very hopeful to recover. Although we cannot promise to be cured, at least we must provide the best care. It's a shame his family is confused too." (P.32)

Reflection on self and family

The patient's condition gives the nurse the view that the condition experienced by the patient can also happen to themselves and their families.

"Yes, by helping patients recover, we can save ourselves too. So it's not only saving patients but also saving our lives like that." (P.26)

"I always imagined that it was my family who were sick. It's a pity if you have to stay in the hospital for a long time, so as much as possible you will be treated so that your condition will improve quickly." (P.29)

"The patient's family often asks me how the patient's condition is. I always feel sad when asked like that. Confused to answer how his condition." (P.22)

Theme 5: Development Bacterial Translocation Prevention Tools

Tool limitations

The tools used to measure the ETT cuff voltage are not yet available. The nurse only uses a syringe to fill the ETT cuff balloon by calculating the contents or size of the balloon volume.

"This check is carried out every time we take action. Usually when we are going to do oral hygiene or suctioning we also check the cuff, but we don't use a cuff meter and it's just an estimate that the cuff is inflated well or not." (P.14)

"Actually, it is measured using a tool, but here we don't have the tool so we measure it manually using an injection syringe," (P.17)

"There is a special tool to measure the ETT cuff balloon, but we don't have one. Usually we enter the air by looking at the plunger of the syringe. When the plunger has stopped it can't be pushed to enter the air, usually the volume is right." (P.19)

Easily accessible tools

Nurses want a tool that is easy to use and can ease the work, especially when there are a lot of patients in the ICU. The tool used is expected to be more accurate in measuring the ETT cuff voltage and can be monitored remotely.

"We want the tools not to be manual and the reporting is not manual either. If possible electronically at the same time with the recording." (P.25)

"Yes, I want to reduce contact with patients in order to minimize the incidence of infection. The hope can be easier by being able to see the cuff voltage from a distance, saving energy and time. Especially those in the ICU specifically for COVID, we cannot contact patients all the time, so being able to monitor remotely will be very useful" (P.28)

"I want a more advanced tool, the image is like the one that is pumped first, then the needle goes forward and then back again. It's better if the form of numbers is more accurate or like digital tension like that" (P.30)

"Actually, it doesn't really add to the workload. The hope is that we can have a tool that can be used simultaneously and to make it easier for me and my friends to control the ETT cuff. It also has a number of tools that suit your needs, so that my friends and I don't have to take turns and it saves work time too." (P.37)

Discussion

The intensive care unit (ICU) is for patients who are, at risk or likely to experience acute organ failure and life-threatening problems. Treatment in the ICU aims to prevent further physiological deterioration by treating the underlying disease (Marshall et al., 2017). Nurses who work in the ICU must have high competence (Rathnayake et al., 2021). The basic competencies that ICU nurses must possess are knowledge, skills, attitudes and values and experience (Lakanmaa et al., 2015). One of the nurse's competencies is to treat patients who use mechanical ventilators. Patients who are on a ventilator are at high risk for infection, one of which is vaping. VAP can be prevented by reducing bacterial translocation in the supraglottic due to decreased ETT cuff tension (Gatt et al., 2007).

The results showed that nurses' knowledge about bacterial translocation was still limited. Nurses do not understand about bacterial translocation, the mechanism of its occurrence and how to prevent it. This limited knowledge makes nurses measure the ETT cuff not according to the Standard Operating Procedure (SOP). Lack of knowledge about bacterial translocation triggered by ETT cuff is because measurement standards are also not yet fully available in the ICU and not all nurses have received training on VAP prevention, especially ETT cuff measurement. Increased knowledge of nurses can be done through training. Training is carried out periodically, namely during the orientation program when workers start working in the ICU (pre-employment check) and periodic training (Esin & Sezgin, 2017). Some of the nurses who work in the ICU are not ICU nurses and 19% of those who receive an introduction to the ICU COVID-19 (Bergman et al., 2021). Head nurses need to increase training opportunities for implementing nurses to increase competence in providing care to patients (Rahmah et al., 2022; Suhariyanto et al., 2018).

The COVID-19 pandemic has increased the number of patients being treated in the ICU. Some patients are classified as critical patients who have severe hypoxemia and require mechanical ventilation. Some of the problems experienced in

the ICU during the pandemic are the limited number of competent nurses, the low ratio of patients and nurses, the limited number of consumables, oxygen and medicines and PPE (Semedi, 2020). This study shows that the unfavourable work situation during the pandemic contributes to the quality of patient care in the ICU. The limited number of nurses and the large number of patients and limited working time make nurses not optimal in carrying out care, including patients who are on a ventilator. The ratio between the number of nurses and patients in the ICU is not comparable. In several hospitals in Surabaya, nurses who have never served in the ICU room before will be assigned to help in the room so that the workload can be evenly distributed. On the other hand, this can make it easier for nurses to work, but the expertise to provide care, especially for patients who are attached to a ventilator, is lacking. As a result, nurses who are at the CN 3 level must simultaneously teach new nurses in the midst of being busy caring for patients. In addition, supervision from the team leader during office hours is also considered to be lacking. During the pandemic, ICU nurses are responsible for caring for more than three patients in one shift. Patient safety during the early phase of a pandemic is compromised. Nursing care is highly prioritized during the pandemic, which is associated with a lack of time, resources, and required competencies (Bergman et al., 2021). The recommended nurse-patient ratio for patient care on a ventilator is 1:1 (Esin & Sezgin, 2017).

Nurses who work in the ICU need high motivation. In this study, nurses have a high motivation to treat patients. They think the job is a part of moral responsibility as a nurse. Feeling empathy with the conditions experienced by patients in the treatment room and reflection that caring for patients is considered as a taking care of yourself or your family. The biggest motivation that nurses have is that which comes from within themselves (internal motivation). In a study on "Nurses' perspectives of taking care of patients with Coronavirus disease 2019: A phenomenological study," it was stated that the motivation that underlies nurses to provide care for COVID-19 patients is professionalism as a nurse (Rathnayake et al., 2021). Motivation to work based on morality, empathy and a sense of responsibility, makes nurses comply with work procedures. So that even with a heavy workload, nurses still carry out their actions carefully and do not just carry out their obligations because they have considered the patients being treated as their own family. This is reflected in the large number of actions in patients who are attached to a ventilator.

Conclusion

Controlling VAP though preventive bacterial translocation is needed based on nurses' perspective. The development of real-time monitor tools to observe the pressure of ETT cuff can be promising to control the nosocomial infection especially VAP in the ICU and decreased the nurse's workload. This evidence could be a suggestion for the management in the hospital and clinical nurses to develop a new guide and tools. Further researchers are expected to create a prototype of ETT cuff censor monitor.

Ethics approval and consent to participate

We received ethical approval from the Health Commission Ethics Committee of Haji Surabaya Hospital (No.073/16/KOM.ETIK/2021) and Universitas Airlangga Hospital (No. 154/KEP/2021). Participants were required to give their written consent to participate free of coercion. They could withdraw from the study without giving a reason, and with no impact on their health care, and could decline to answer any of the questions. Furthermore, the researchers maintained their privacy throughout the interview process. All of the data were de-identified at transcribing, with participants being named according to a number such as P1, P2 and so forth. The study did not have the potential to harm the participants physically or mentally.

Consent for publication

Not Applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

None

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Author contributions

YSD

contributed to the conceptualization, investigation, and methodology.

AQ

contributed to data curation, resources, validation, visualization, writing – original draft, and writing–review & editing.

HA, ROP

contributed to formal analysis, software, writing – original draft, and writing– review & editing.

LSB

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The relationship between illness perceptions, self-management, and quality of life in adult with type 2 diabetes mellitus

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Abstract

Background: Few studies have examined the association between illness perception, self-management, and quality of life in adults with type 2 Diabetes Mellitus (DM), especially in resource-limited countries such as Indonesia.
Purpose: This study aimed to evaluate the relationship between illness perception, self-management, and quality of life in adult with type 2 DM in Indonesia.
Methods: The inclusion criteria were adults aged over 18 years old and diagnosed with type 2 DM. Convenience sampling was used in this study. A total of 351 patients with type 2 DM was recruited (response rate= 97.50%). This study used the following instruments: World Health Organization Quality of Life-BREF (WHOQOL-BREF), The Brief Illness Perception Questionnaire (B-IPQ), and Diabetes Self-Management Questionnaire (DSMQ). Hierarchical regression models were constructed by using the score of overall QOL and those for each domain as the dependent variables.
Results: The mean age was 54 (SD=8.14) years old and the mean time living with type 2 DM was 92 (SD=82.88) months. Higher illness perception score was significantly associated with lower physical health scores (β = -.395, SE = .096), psychological health (β = -.365, SE = .110), social relationships (β = -.363, SE = .138), and environment health (β = -.367, SE = .105).
Conclusion: The findings indicated that poorer illness perceptions are associated with a lower quality of life. The findings establish a foundation for future interventions aimed at altering illness perceptions in order to promote self-care and improved quality of life in people with diabetes.

Keywords: diabetes mellitus; illness perceptions; self-management; quality of life

Introduction

Diabetes mellitus (DM) is one of the most common health conditions, and its prevalence continues to rise, putting pressure on health-care systems around the world (International Diabetes Federation) (IDF, 2019). DM is estimated to affect 463 million people (9.3% of the global adult population (20–79 years) in 2019; this figure is expected to rise to 578 million (10.2%) in 2030 and 700 million (10.9%) in 2045 (IDF, 2019; Saeedi et al., 2019). In most countries, the number of adults with type 2 diabetes is rising; it now accounts for 90% of all diabetes worldwide (IDF, 2019; Saeedi et al., 2019). In total, DM killed over 4.2 million people, and at least USD760 billion in total medical spending was attributable to it each year in 2019 (IDF, 2019; Saeedi et al., 2019). Indonesia is the country with the sixth highest number of DM in the world (IDF, 2019). The prevalence of (DM) in Indonesia has increased from 6.9 % in 2013 to 8.5% in 2019. Many people with diabetes who do not routinely take anti-diabetes drugs or insulin injections, with the reason being more than 50% feeling healthy and only 75% of people with diabetes received a treatment (Ministry of Health, 2018). The World Health Organization (WHO) predicted that in 2030, there will be approximately 21,3 million people with DM in Indonesia (WHO, 2018).

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DM is a chronic disease that can have a negative impact on one's health as well as their quality of life (QOL) (Jing et al., 2018). QOL is defined as the individual perception of a person's physical, emotional, and social status (Dickerson et al., 2011; Rubin & Peyrot, 1999). Evidence shows that adults with DM have lower QOL than the general population (Bădescu et al., 2016; Norris et al., 2011; Petrak et al., 2015). Presence of complication, longer duration of diabetes, depression, non-adherence to medication and lack of self-care were associated with a worse QOL (Ali et al., 2010; Jing et al., 2018; Pozzo et al., 2016; Van der Feltz-Cornelis et al., 2010). In addition, people with DM suffer from low mental well-being due to fear of complications and the overwhelming complexity of self-management regimens (Pintaudi et al., 2015; Rubin & Peyrot, 1999). Incorporating QOL assessment in clinical practices is needed to provide a good estimate of disease control and preventing the patient's QOL to get worse (Saleh et al., 2015).

Many people who have DM struggle to meet the prescribed diabetes treatment guidelines (Gonzalez et al., 2016). The complex behavioral standards for diabetes self-management includes daily treatment, blood glucose self-monitoring (BGMS), adjustments in nutrition and physical activity, foot self-care and health care visits (Hunter, 2016). Previous study proved that previous research indicated that a low level of diabetes self-management practices was connected to poorer glucose control, increased hospitalization and mortality rate (Feldman et al., 2014; Hood et al., 2009)(Cho et al., 2011; Currie et al., 2012). Beliefs regarding disease and care have become a priority beyond the comprehension of various theoretical structures for understanding health behavior. A recent study of diabetes health beliefs found that the Common Sense Self-regular Model (CSM), which acknowledges the cognitive and emotional mechanisms involved in disease self-management, has a unique benefit among various theoretical models of health beliefs (Hagger et al., 2017).

The CSM is a self-regulatory model that views patients as agents acting in a socio-cultural sense, with their behaviors mediated by illness values such

Table 1. Demographic data for the respondents (n = 351)

Characteristics of respondents	n (%)
Age (years), Mean ± SD	54.12 ± 8.14
Range: 23-65 years old	
Sex	
Male	107 (30)
Female	244 (70)
Education	
No formal education	23 (7)
Elementary	64 (18)
Junior high	74 (21)
Senior high	120 (34)
University	70 (20)
Marital status	
Unmarried	6 (2)
Married	304 (87)
Widowed	41 (12)
Religion	
Islam	309 (88)
Christian	36 (10)
Hindu	2 (1)
Buddha	2 (1)
Confucius	2 (1)
Working status	
Employed	107 (30)
Unemployed	244 (70)
Time since diagnosed (months), Mean ± SD	92.20 ± 82.88
Range	3-576

Table 2. Distributions of means for domains of quality of life, illness perception, and self-management (n = 351)

Variable	Mean ± SD	Range
Quality of life (WHOQOL-BREF)		
Physical health	38.92 ± 15.92	13-88
Psychological health	38.34 ± 18.24	14-94
Social Relationships	33.14 ± 21.25	6-100
Environment health	45.53 ± 17.29	19-88
Illness perception (B-IPQ)		
Total score	46.73 ± 8.41	11-73
Consequences	7.00 ± 1.94	0-10
Timeline	7.16 ± 1.87	0-10
Personal control	3.77 ± 2.52	0-10
Treatment control	3.58 ± 2.64	0-10
Identity	6.79 ± 1.92	0-10
Concern	7.28 ± 1.80	0-10
Understanding	4.22 ± 2.55	0-10
Emotional response	6.91 ± 2.45	0-10
Patient's self-management (DSMQ)		
Total score	28.67 ± 5.34	12-42
Glucose management	9.17 ± 1.99	2-15
Dietary control	7.14 ± 1.84	1-12
Physical activity	4.37 ± 1.66	0-9
Healthcare use	6.25 ± 1.54	0-9

as recognition (symptoms and labels), presumed cause, anticipated timetable, consequences, and anticipated controllability, as well as measured feedback on the outcomes of their coping behavior (Gonzalez et al., 2016). The CSM is a framework for investigating the processes that individuals use to manage ongoing and future health threats. A critical component of the CSM is illness perception, which relates to the emotional or cognitive recognition of a health threat. Illness perception encompasses five different dimensions: (1) consequences, (2) causes, (3) identity, (4) timelines, and (5) control or cure (Broadbent, Petrie, Main, & Weinman, 2006; Hagger & Orbell, 2003). Addressing illness perception could be an important information to understand its effect on self-management and quality of life. If it has positive impact, then the healthcare providers need to pay more attention on patients' belief and understanding of a medical condition and its potential consequences in order to improve their quality of life.

Evidence suggested that negative illness perceptions were associated with psychological well-being, adherence to DM management program, and quality of life, (Hudson et al., 2014; Skinner et al., 2014); (Hudson et al., 2014; Scollan-Koliopoulos et al., 2013). Empirical research found that better compliance was related to perceptions of necessity and fewer health problems (Horne et al., 2013). A number of studies previously have examined perceptions of illness, self-care, adherence, and well-being separately. However, few studies have tried to look at the perception of illness and self-management, in resource-constrained environments such as Indonesia, where the literacy, access to the healthcare facilities, and financial burden are still the major issues. Based on the CSM, it was predicted that worse disease perceptions will be linked to poorer self-management and QOL. Thus, we sought to assess the relationship between illness perception, self-management, and QOL, as well as self-management and QOL among adults with type 2 DM in Indonesia.

Materials and Methods

Design

A cross-sectional design was used in this study. The data collection period was June to August 2019. The target population was adults diagnosed woith type 2 DM in Jakarta, Indonesia. Patients in Jakarta have a significantly higher prevalence of diabetes than the national average in Indonesia. Participants were invited to participate in this study if they visited one of four referral hospitals in Jakarta, Indonesia.

Sampling

All participants had been diagnosed with type 2

Table 3. Beta Coefficients (Standard Error in Parentheses) of QOL Scores Based on a Hierarchical Linear Regression in People with Type 2 DM (n=315)

	Quality of life							
	Physical health		Psychological health		Social Relationships		Environment health	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Education	-0.068 (0.783)	-.070 (.720)	-0.114 (0.888)*	-0.120 (0.832)*	-.130 (1.034)*	-.133 (.965)*	-.077 (0.845)	-0.081 (0.789)
Occupation	-0.107 (2.071)	-.031 (1.873)	-0.150 (2.286)*	-0.08 (2.164)	-.148 (2.663)*	-.078 (2.511)	-.158 (2.175)*	-0.087 (2.053)
Time since diagnosed	-0.128 (0.010)*	-.100 (0.009)*	-0.096 (.012)	-0.065 (0.011)	-.068 (.013)	-.041 (0.013)	-0.108 (0.011)	-0.080 (0.010)
Illness perception		0.395 (0.096)**		0.365 (0.110)**		0.363 (0.138)**		0.367 (0.105)**
Self-management		0.057 (0.150)		0.009 (0.173)		0.042 (0.201)		0.031 (0.164)
R2	0.038	0.201	0.058	0.188	0.059	0.194	0.051	0.187
R2 change		0.163		0.130		0.135		0.136

diabetes mellitus and met the following criteria for inclusion: (a) over the age of 18, and (b) capable of understanding written and spoken Bahasa Indonesia. Patients with psychological disorders or cognitive issues, as well as pregnant women, were excluded from the research. We chose not to include in this study as those people with special concerns for diabetics and diabetes management are already represented. In this study, convenience sampling was used. With these procedures, we gained 351 patients with type 2 DM (response rate= 97.50%).

Data collection

Ethical permission was obtained from the study hospitals (098/ETIK/IIV). Adults with type 2 diabetes were recruited when they went to the outpatient department for a routine check-up. The hospital's manager assisted in identifying prospective applicants who met the recruiting requirements. For data collection, two research assistants (clinical nurses) were qualified and standardized. Researchers obtained written consent from every person who agreed to participate in the questionnaire. This questionnaire took about 30 to 45 minutes to fill out.

Measurements

The following information was collected: age, time since diagnosis, sex, marital status, education, religion, occupation. Information about time since diagnosis was confirmed with their medical records.

The World Health Organization Quality of Life-BREF (WHOQOL-BREF) was used to assess patient's quality of life specific for diabetic patients in the Indonesian version (WHO, 1998). This instrument has been widely used internationally and translated in Bahasa Indonesia (WHO, 1998). The questionnaire consists of 26 items, two questions from perspective participants about their general quality of life and general health with the other 24 questions were divided into four domains: physical health, psychological health, social relationships, and environment health. The answer of each question was being rated on a 5-point Likert's scale. Raw score in each domain was then transformed to 1-100 score according to WHOQOL-BREF guideline (WHO, 1998). Highest score is indicated better QOL. In the current study, the Cronbach's α coefficients ranged from 0.79 to 0.84.

The Brief Illness Perception Questionnaire (B-IPQ) was used to assess the illness perception of adults with type 2 DM developed (Broadbent et al., 2011). This questionnaire was used to assess illness perception. It contains nine questions, eight of which use a single-item scale from 1 to 10, and one of which is an open-ended question to which the participants may react with what people perceive to be significant factors contributing to their diabetes (Broadbent et al., 2011). The B-IPQ measures nine domains: consequences, timeline, personal control, treatment control, identity, concern, understanding, emotional response, and causal representation.

The overall score of B-IPQ is the sum of each domain score, with the exception of the 9th area. The B-IPQ score is 8-10, when higher scores show a more destructive view of disease. The B-IPQ has a standardized Indonesian version that has been used for people with type 2 DM with Cronbach's α coefficients ranging from 0.79 to 0.85 (Indrayana et al., 2019).

Self-management. Diabetes Self-Management Questionnaire (DSMQ) was used to measure self-management in patients with T2DM, developed (Schmitt et al., 2013). The DSMQ is a reliable and valid instrument for efficiently assessing self-behavior associated with glycemic control (Schmitt et al., 2013). These are all self-administered questionnaires. They consist of 16 individual items in four subcategorized into four separate domains. The measured subdomains include glucose management, control of diet, physical activity and health. An overall measure of the self-care was derived from a sum score. Each item was scored on a four-point Likert type scale, ranging from 0 (does not apply to me) to 3 (applies to me very much). The highest score indicates greater self-control. This questionnaire has been translated into an Indonesian version and used for people with type 2 DM with Cronbach's α coefficients ranging from 0.81 to 0.86 (Ramadhani et al., 2019).

Statistical analysis

The demographic data, the quality of life, the perception of illness, and self-management were analyzed using a descriptive analysis. A QOL was computed using hierarchical regression models with overall QOL as the dependent variable and domains of QOL as explanatory variables. Included variables in the hierarchical regression analysis was decided based on p value of 0.25 (Hosmer & Lemeshow). In the first model, significant demographic data in bivariate analysis were entered. The second model included illness perception and self-management. The regression model produced the total score and scores for each domain of QOL. To determine the significant association, a 2-tailed alpha of 0.05 was used to determine statistical significance. The Statistical Package for the Social Sciences (SPSS) version 22.00 for Windows was used to perform the analyses.

Results

A total of 351 patients with type 2 DM agreed to participate in this study with response rate was 97.50%. The majority of the participants were female (n=244 ; 70%), married (n=304; 87%), 45% (n=56) had less than senior high education (7% no formal education, 18% elementary, 21% junior high), Islam (n=309; 88%), and unemployed (n=244; 70%). The mean age was 54 years old (SD=8.14), ranged from 23 to 65 years old. The mean time living with type 2 DM was 92 months (SD=82.88), ranged from 3 months to 576 months (Table 1).

The average score for four domains of quality of life was 38.98. The highest mean score of QOL domains was environment domain (45.53 ± 17.29) and the lowest domain was social relationship (33.14 ± 21.25). The mean score of illness perception was 46.73 (SD=8.41), ranged from 11 to 73. The highest mean score was concern domain (7.28 ± 1.80), while lowest mean score was treatment control (3.58 ± 2.64). The mean score of patient's self-management in this study was 28.67 from possible score of 42, with each domain average of 6.73. Glucose management domain was the highest with average score of 9.17 (SD=1.99), while physical activity was the lowest with mean score of 4.37 (SD=1.66) (Table 2).

In the bivariate analysis using t test for categoric data and Pearson correlation for continuous data was reported no significant association in terms of age (p value=.56), sex (p value=.72), marital status (p value=.43), and religion (p value=.33) with all domains of QOL. Only occupation (employed vs unemployed) and education (≤ 9 years and >9 years) were significantly associated with all domains of QOL. Also, time living with type 2 DM was significantly correlated with all domains of quality of life (Table did not show).

Table 3 shows a hierarchical regression of the relationship between illness perception, self-management, and quality of life. Higher illness perception score was significantly associated with lower physical health scores (β = -.395, SE = .096), psychological health (β = -.365, SE = .110), social relationships (β = -.363, SE = .138), and environment health (β = -.367, SE = .105). In addition, education was negatively associated with psychological health and social relationships (β = -.120, SE = .096; β = -.133, SE = .965, respectively), and time since diagnosed was also negatively associated with physical health (β = -.100, SE = .009). We did not find a significant association between self-management and quality of life (Table 3).

Discussions

The majority of people with type 2 DM in this study reported moderate level of illness perceptions with the highest score being the concern domain and the lowest score the treatment control. A previous study conducted in China found that the timeline dimension had the highest mean score of illness perception domain, while the coherence dimension had the lowest (Nie et al., 2018). Several studies have shown that illness perception is important in diabetes self-management and well-being (Abubakari et al., 2011; Nsereko et al., 2013). In our study, it was shown that illness perception is associated with self-management. According to the common-sense self-regulation model (CSM-SR) (Hagger et al., 2017), people facing a health risk like being diagnosed seem to develop affective and psychological perceptions that decide how to gather coping processes and behavioural patterns, and how

to evaluate the results of treatment in reaction to the health condition perceived. Thus, people may also believe these concepts because they have limited diabetes-related health literacy (Hu et al., 2013), despite the fact that the majority of participants were unemployed and had low education. Therefore, it' s very important for healthcare professionals to provide a comprehensive education package to not only improve their knowledge but also their perception and belief toward type 2 DM.

This study found that the majority of people with type 2 DM have sub-optimal self-management with the highest score in glucose management and the lowest was physical activity. The findings from previous systematic reviews showed that Sub-Saharan Africans were less likely to self-monitor their glucose levels, had low level of activity, and adhered to moderate recommendations about diet and medication routines (Stephani et al., 2018). The American Diabetes Association (ADA) reported that good glycemic control is associated with a reduction of complication (Shrivastava et al., 2013). While glucose management appears to be better, it is correlated with multiple individual and environmental factors that either encourage or impede good self-management but are still sub-optimal self-management. Lack of physical activity, however, poses a significant challenge to healthy glycemic regulation. The previous review reported that the most commonly encountered barriers to getting more physical activity are lack of space, fear of making exercise problematic, and bad weather conditions (Adeniyi et al., 2016). Therefore, further study investigating physical activity among people with type 2 DM is necessary in order to promote concordance with the treatment regimen and improve glycemic control.

Poorer illness perceptions were associated with poorer QOL. These findings are consistent with past research demonstrating that poorer illness perceptions are associated with poorer QOL (Knowles et al., 2020; Scollan-Koliopoulos et al., 2013). The correlation between understanding of illness and health outcomes may be due to the fact that engaging in self-care activities requires nuanced decision-making that relies on the patient's interpretation of their disease as to whether or not it is controllable, understandable, curable, cyclical and serious (Kugbey et al., 2017). The findings of current studies show that QOL is associated with the way people view their diabetes. Thus, intervention to enhance the understanding of disease is required in order to improve the quality of life of the patient. Previous study has shown that techniques such as mindfulness, intended to help people be more aware and interested in their symptoms, will result in improved symptom control. Research has found that meditation interventions could have a positive impact on general well-of-being and quality of life for people with type 2 DM (Schroevers et al., 2015; Van Son et al., 2013).

Surprisingly, this study revealed no association between self-management and QOL. Previous study has reported that self-management in terms of blood glucose testing, diet, and exercise was significantly associated with QoL (Kueh et al., 2015). Differences in this finding may due to the instrument that was used to measure QOL was not specific for people with diabetes. Previous study emphasized that combination of dietary factors such as fat and sugar, and increased exercise not only improved glycosylated hemoglobin measures, which indicate positive control of blood glucose levels among people with diabetes, but these lifestyle changes also significantly improve general QOL by using a different tool (Feldman et al., 2014). The combination of diet and exercise may improve quality of life throughout symptoms control, HBA1C level control, or other diabetic complications. About 95% of diabetes care has been reported to be self-treatment or self-management (Gonzalez et al., 2016). Individuals have to control their regular lifestyle activities to regulate diabetes, and sometimes have to adjust long-held habits.

Study Limitation

For this analysis, all variables have been subjectively evaluated using self-report questioning so that reporting biases like the influence of an acceptable social response can occur (Marchini et al., 2019). Furthermore, the lack of administration consistency may have affected the participants' willingness to fill out questionnaires when they were willing to do so was acceptable. The findings' generalizability is limited due to a lack of evidence on disease characteristics (e.g., HbA1c). However, this study was conducted in the capital of Indonesia, which included various ethnicity that could strengthen the findings of this study. Future work should include research into possible mediators that influence psychosocial factors, like social support, medication adherence, and trust in providers.

Clinical Implications

The findings from this research have some practical implications for healthcare delivery of diabetes. To support individual self-management, nurses and doctors should be provided with tools to meet the self-management needs of diabetes patients in the form of information leaflets and other related materials, particularly in Indonesia where such are not available in all healthcare settings. Such research on self-management may provide research on the causes, prognosis and techniques for management. Finally, since community education is commonly conducted in the different units of diabetes, it is advised that individual needs should also be taken into account due to differences in educational rates and understanding of educational content, especially related to the culture, belief, and religion regarding diet and care belief which is part of illness perception and self-management.

Conclusions

In conclusion, this research reveals an association between illness perception and self-management and QOL in adults with type 2 diabetes in Indonesia. However, there has been found no statistically significant relation between self-management and quality of life. The results lay the groundwork for potential initiatives aimed at changing people's views of the disease in order to encourage better self-care and QOL in diabetics.

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The impact of domestic violence on cognitive and psychological development of children: A scoping review

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Abstract

Background: Domestic violence is an incident that affects all family members, including children. The impact of domestic violence needs to be identified from the beginning, so that early treatment can be given. The purpose of this study was to describe the impact of domestic violence on child development.
Purpose: The purpose of this study was to explore the coping strategies of adolescents with divorced parents.
Methods: This study used the Scoping Review method. Literature were sourced from CINAHL, PubMed, and Scopus. The keywords are "domestic violence" AND "child" AND "impact". The criteria for articles in this study are full text, free access, English language, and the publication period of the last 10 years (2013-2022).
Results: Nine articles were found discussing the impact of domestic violence on children's development, namely the psychological impact, social impact, and the impact on school life. Several samples from UK ranged from 8-336 respondents. These impacts occur due to trauma events in children that are not treated immediately. The impact will be even worse if there is no immediate intervention to reduce the impact of domestic violence.
Conclusion: Domestic violence can cause disturbances to the development of children including psychological impacts, social impacts, and impacts on school life.

Keywords: children; domestic violence; impact

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Introduction

Domestic violence has experienced a significant increase. Domestic violence is behaviour that hurts and injures physically and psychologically, resulting in unwanted pain and distress (subjective suffering) for the injured party within the family (household). Domestic violence can occur between intimate partners, or against children or other family members, or against people who live in the same household (Lamela et al., 2018; Pamungkas et al., 2022). According to a study, the number of victims of violence against children reached 2.29 million (3%) with rural areas having a higher number of cases than urban areas. When viewed from the side of the perpetrators of violence, then 61.4% such acts were committed by parents (Macniven et al., 2020).

In general, the factors that cause domestic violence can be classified into two categories, namely external factors and internal factors (Lamela et al., 2021; Yosep et al., 2022). External factors are factors that come from beyond the perpetrators of violence. An offender who initially is normal or does not have aggressive behaviour and attitude may be able to commit acts of violence if faced with a situation under pressure (stress), for example, prolonged economic difficulties or infidelity or being abandoned by a partner

or other events (Stanley & Boel-Studt, 2021; Yosep et al., 2022). While internal factors are factors that originate from the personality of the perpetrator himself, which causes them to be easily provoked to commit acts of violence, even though the problems they face are relatively small (Lawson & Quinn, 2013).

The two factors above can have a negative effect not only on perpetrators and victims who experience acts of violence in the form of physical or verbal (Christian, 2015; Yosep, Hikmat, & Mardhiyah, 2022). Some research results show that children who are indirect victims of violent events, such as bickering between their parents at home, also have a vulnerability to psychological trauma, so that in the end the child has the possibility to be involved in or imitate doing the same thing in adulthood (Graham et al., 2021; Hikmat et al., 2022; Ristia et al., 2018). In other words, victims of domestic violence, either directly or indirectly, have the same trauma effect depending on their age and gender (Saltmarsh et al., 2020).

Domestic violence victims are frequently children who are victims of their own parents' actions. Domestic violence has a very bad effect on children (Ragavan et al., 2018). As for children who are raised in families or environments that experience domestic violence, they will experience stunted development, for example in terms of social maturity (Miranda et al., 2022). Children will tend to find it difficult to develop feelings of peace and calm, will always feel afraid, find it difficult to interact with other people, and tend to be more aggressive when playing with their peers (Lamela et al., 2021).

The impacts of domestic violence need to be a shared concern, especially for families. By knowing the impact early on, nurses and families can collaborate to prevent these impacts from becoming more complex. Therefore, the authors are interested in conducting research related to the impact of domestic violence on children.

Methods

Design

This study was designed with a systematic scoping review framework. Systematic scoping reviews are a methodological technique to explore and discuss a topic that is currently developing (Tricco et al., 2018). This methodology has a wide conceptual range to discuss various research results to achieve research objectives (Peterson et al., 2017). The framework used has five main steps: finding research questions, finding relevant study results, choosing a study, mapping data, putting together results, and reporting study results (Bradbury-Jones et al., 2021). The PRISMA Extension for Scoping Reviews (PRISMA-ScR) is used in this literature review to find different topics that talk about how domestic violence affects children.

Search Methods

Publications were searched using three databases, CINAHL, PubMed, and Scopus. The keywords used are: "domestic violence" andD "child" and "impact". After the authors obtained articles based on keywords, they eliminate them based on inclusion and exclusion criteria (Acob, 2022). Then they selected based on the title and abstract. The next step was to read the full text to determine the feasibility of the article for analysis. The research question is: What is the impact of domestic violence on children? Article search strategy used several relevant keywords based on PCC's Framework (Table 1).

Inclusion and exclusion criteria

This literature review uses the PRISMA Extension for Scoping Review (PRISM -ScR) which serves to identify various topics that discuss the impact of domestic violence on children (Figure 1). Articles were selected based on inclusion and exclusion criteria. The inclusion criteria for this study were that the patient was a sample of children or adolescents, the article was an original study, used English, full text, and was set in the last 10 years (2013-2022).

Data extraction

The articles were extracted using a manual table by authors. The contents of the table include author, year, country, research design, population and sample, scale, and results of the study. Filling in the table is done based on the summary results that have been discussed by the author.

Data Analysis

The articles collected were then read in full and analysed by all the authors. After being analysed, the impact of domestic violence on children from the articles reviewed was classified based on similar effects and then described.

Results

The number of articles obtained from the search is 468. After removing duplicates, 408 articles were obtained. Furthermore, after elimination based on the inclusion criteria, there were 372 articles remained. Then, after checking the title and abstract, nine articles were found. Articles were analysed with all authors based on criteria and topic relevance.

There are nine articles that discuss the impact of domestic violence on child development. Of the nine available interventions, they are classified into three types, namely: psychological impacts, social impacts, and impacts on school life. The results of the analysis are shown in the following table (Table 2).

Discussion

Domestic violence is an incident involving family members, including the wife, husband, children, and

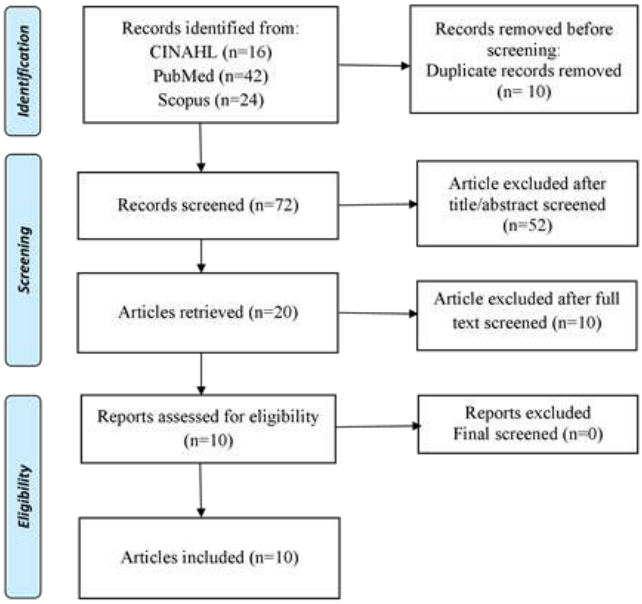

Figure 1. PRISMA Flow Diagram

Table 1. PCC's Search Strategy

PCC's Framework	Search Strategy
Populations	Children with domestic violence
Content	Impact of domestic violence
Context	Cognitive and Psychological Development

other family members (Thornton, 2014) and takes the form of physical and/or verbal violence. For example, physical violence in the form of slapping, hitting and torturing, while verbal violence takes the form of insults and threats. Domestic violence can occur due to economic problems, infidelity, incompatibility, and others (Rollè et al., 2019).

Domestic violence affects all family members, including children. Children can suffer trauma due to unpleasant events that they feel. Although they are not victims directly, children who see incidents of domestic violence can also feel the negative impact of domestic violence. The following is the impact of domestic violence on child development:

Psychological Impact

Children who have been victims of domestic violence since childhood suffer mental disturbances, so that the idea arises that children only deserve to be sacrificed (Lamela et al., 2021). If you have a mindset like that, your child will continue to be a victim and surrender to the situation. In addition, children who are victims of domestic violence can have low self-esteem due to the fear that they will do something wrong and experience violence again (Lamela et al., 2021). This will cause the child's development to be hampered. Children will find it difficult to show an attitude of initiative in solving problems and have difficulty getting along. Children are also prone to stress, depression and anxiety (Wang & Pannell, 2019). This has the impact of disrupting child development. The violence experienced by children will cause them heartache and trauma. The impact on the child's later life will be very large, resulting in depression, stress, and other psychological disorders that can interfere with social life and daily activities (Gustafsson et al., 2015). Children will also become afraid of all forms of violence, even the smallest ones, for example, loud voices, high-pitched speech, and others (Chung et al., 2021).

Social Impact

The impact of domestic violence on children can lead to new violence caused by the victim. Children who are victims of domestic violence can become perpetrators of violence. The results of the study reveal that violent behaviour is actually carried out by those who have been victims of domestic violence (Gurtovenko & Katz, 2020). The impact of violence also causes quite drastic changes in the emotional condition of children, which will be immediately visible. Greene, Chan, McCarthy, Wakschlag, and Briggs-Gowan (2018) describe such a child as quiet, moody, and prone to crying. The child won't have a good opinion of him or herself because they won't be able to deal with stress and take their mind off of things. Children who experience violence feel they have lost an adult figure who can protect them, that's why, little by little, their trust in others will begin

Table 2. Extraction Data

Author & Year	Outcome	Country	Design	Sample	Scale	Result
(Swanston et al., 2014)	Dual perspectives of school-aged children of experiences of domestic violence	UK	Qualitative research	8 participants	Research questions: How do school-aged children make sense of their experience of domestic violence? How do mothers perceive their school-aged child's experience of domestic violence?	The impact of domestic violence on children is that it can cause stress and depression; the impact can also have consequences in adulthood such as anti-social behaviour and difficulty communicating with others.
(McDonald et al., 2016)	Contextual risk and protective factors	Franklin Street	Mixed-methods study	289 participants	Child Exposure to Domestic Violence Scale	The impact of domestic violence on children is not being able to adapt to their environment. This is because children are less sensitive to their environment. In addition, children also experience a decline in cognitive abilities.
(Fusco, 2017)	Emotional harm	USA	Empirical studies	336 students	Patient Health Questionnaire-9	The impact of domestic violence on children is that there are socio-emotional problems where children have difficulty communicating with their environment and difficulties in controlling emotions. This causes the child's cognitive development to be disrupted and it is difficult to make friends.
(Lloyd, 2018)	domestic violence impacts the lives and education of children	UK	A case study	10 students	-	Children who are victims of domestic violence face emotional trauma, physical and psychological barriers to learning, and display disruptive behaviour at school.
(Callaghan et al., 2017)	Emotional Competencies and Relational Contexts	Italy	Interpretive Interactionism	107 students	Constrained Articulation – Expressing Emotions	Domestic violence has an impact on children's emotional conditions, that are unstable and subject to anxiety; children are also prone to depression which causes children to become anti-social.
(Waldman-Levi et al., 2015)	childhood post-traumatic stress disorder (PTSD) and attachment security	Israel	Quantitative research	54 children	Post-Traumatic Diagnostic Scale	Traumatic events, namely domestic violence, cause children to experience anxiety, stress and post-traumatic syndrome disorder.

Author & Year	Outcome	Country	Design	Sample	Scale	Result
(Callaghan et al., 2018)	Learning difficulties, economic difficulties, and anxiety	UK	Interviews: interpretive interactionism	21 children	-	Children with domestic violence have difficulties in learning, have difficulty communicating with others, have economic difficulties, and experience anxiety about the future.
(Kithonga & Mbogo, 2018)	Educational performance and behavioural problems	South Africa	Descriptive Design	56 students	Interview	The results showed that children with domestic violence experienced slowness in the learning process.
(Pang & Thomas, 2020)	Learning achievement	UK	Interpretive interactionism.	21 children	Interview	The results of the study show that, due to domestic violence, children experience decreased learning achievement due to trauma.
(Chester & Joscelyne, 2021)	Motivate learning, anxiety	England	Interpretive interactionism.	14 children	Interview	The results of the study show that domestic violence impact was anxiety, difficulty in the learning process, and less motivated to learn.

to erode, and children will find it difficult to put trust and confidence in others again (Callaghan et al., 2017). They will assume that there is no one who can be relied on to provide protection for them, because there is no one who is worthy of their trust (Kh et al., 2014).

Impact on school life

Pressure due to violence that children receive can also damage a child's ability to concentrate and focus on something. For example, on school activities and school lessons (Joseph et al., 2006). It could be that the interests and talents of children that once seemed great and promising will disappear drastically along with a decline in their ability to concentrate (Waldman-Levi et al., 2015). Violence can suppress the process of a child's development. Children's IQ development will tend to be static, and IQ levels can even decrease (Swanston et al., 2014). Children's cognitive development will also deteriorate and not be as it should be (Lloyd, 2018). In other words, the condition of children's intelligence will be hampered by the constant violence continuously experienced by children.

The limitation in this study is the lack of previous studies discussing domestic violence. So it is quite difficult for researchers to discuss the impact of domestic violence on child development. In addition, the research methods in this study are quite diverse, so the discussion is not comprehensive.

Conclusions

Domestic violence is an unpleasant incident in the family that affects every family member, including children. Children who are in the process of development are prone to disturbances due to stressors and developmental disorders. The effects of domestic violence on children include psychological effects, social effects, and school-related effects. The experience of trauma due to domestic violence needs to be a shared concern among people such as parents, teachers, and health workers, including nurses, to provide interventions to prevent a more severe impact.

The suggestion from this research is that there is a need for further research on interventions to reduce the effects of domestic violence. The impact of domestic violence has an impact on the development of children to adulthood, so interventions are needed to prevent the impact of continued domestic violence. Nurses can work with families and other health workers to prevent and lessen the effects of domestic violence on children.

Declaration of conflict of interest

The authors declare no conflict of interest.

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Data Availability

Not applicable.

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Sleep disorder among patients with breast cancer: A concept analysis

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Abstract

Background: Sleep disorders are a long-term issue for breast cancer survivors (BCS). Sleep disorders are among the top five most bothersome lasting difficulties in BCS, and they have a greater risk of sleep disorders than healthy persons and other cancer patients. Failure to understand sleep disorders in breast cancer patients causes nurses to be unable to give interventions appropriately.
Purpose: To clarify the definition of sleep disorders in breast cancer survivors.
Methods: We comprehensively searched electronic databases from CINAHL, PubMed, and Ovid-MEDLINE. We used the eight steps from Walker and Avant to conduct a concept analysis. This approach was chosen because it gives a philosophical understanding of the concept using linguistic philosophy techniques. Model case and other cases were provided to give a conceptual definition of sleep disorders.
Results: Finally, 62 studies were included. We found five antecedents of sleep disorder in breast cancer patients: psychological and emotional stress, physical symptoms, cancer treatment, lack of social support, and sociodemographic factors. This study found four common attributes of sleep disorders 1). abnormal sleep pattern, 2). troubling complaint, 3). persistent complaint, and 4). sleep difficulty. Finally, we found a reduction in quality of life as consequence of sleep disorder in breast cancer patients.
Conclusions: Sleep disorders in breast cancer need attention and must be integrated into regular palliative care practices.

Keywords: breast cancer; concept analysis; sleep complaint; sleep difficulty; sleep disorders

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Introduction

Breast cancer (BC) is becoming more common worldwide, with high and high-middle-income nations having the highest incidence. In contrast, parts of Africa and Oceania have the most outstanding BC's mortality, mainly in low-income and low-middle income countries. It is estimated that there are 2.3 million women who will have BC in 2020, and 685,000 people died worldwide. Breast cancer will be diagnosed in 7.8 million women by 2020, making it the most frequent cancer worldwide. Breast cancer results in the greatest overall loss of disability-adjusted life years (DALYs) in women (Lima et al., 2021; World Health Organization, 2021).

Breast cancer survivors (BCS) are experiencing a terrible event. They begin to think negatively about life and death, which hurts their daily physical activities, emotional state, or psychological alterations (such as anxiety and depression levels), social interactions, and general quality of life (QoL) (Hajj et al., 2021; Putri & Makiyah, 2021). Sleep disorders are among the most common concerns in BCS, ranking as one of the top five most bothersome long-term issues. They may develop sleep disturbances, depression, or

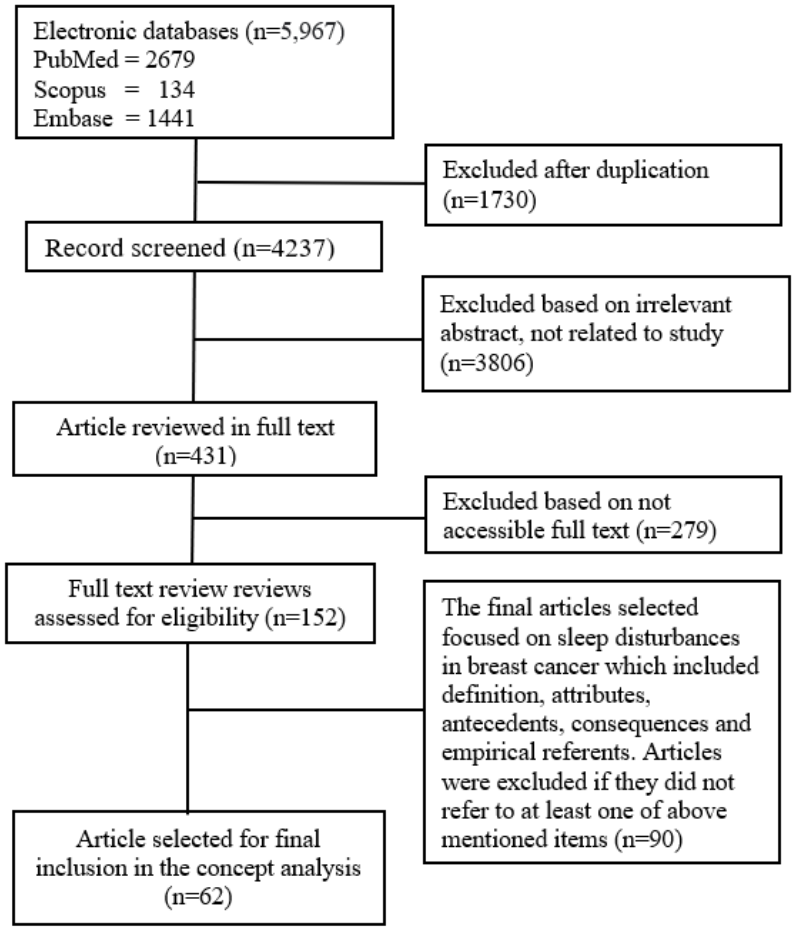

Figure 1. Flowchart of literature search and article extraction

anxiety at any stage of breast cancer in their therapy after being diagnosed. As many as 67–90% of BCS have sleep issues. Moreover, sleep issues are twice as common in BCS than in the common population. Breast cancer patients have a greater incidence of sleep disorders than healthy persons and other cancer patients (Kim et al., 2019; Tejada et al., 2019; Van Dyk et al., 2021; Vin-Raviv et al., 2018). A study by Fiorentino et al. (2011) found the most prevalent psychological disorders in women with breast cancer are sleep problems, fatigue, pain, depression, and anxiety. In addition, insomnia affects 20% to 70% of BCS (Fiorentino et al., 2011).

Among BCS, sleep disorders are a long-term issue and have become a persistent problem (Jefford et al., 2017; Otte et al., 2016). Breast cancer survivors are most likely to have poor sleep quality compared to those with other types of cancer. Their sleep quality becomes poorer between four months to approximately one year after the beginning of treatment (Chang & Chang, 2020). Up to five years after diagnosis, signs such as difficulty concentrating, insomnia, constantly feeling tired, and fear of cancer recurrence persist. Breast cancer patients can experience sleep complaints for as many as ten years after post-treatment (Jefford et al., 2017; Otte et al., 2016). Another symptom experienced by BCS is fatigue, which is linked to sleep issues, anxiety, depression, and a reduction in survivors' quality of life (Jang et al., 2021; Lai et al., 2018; Lee et al., 2019). Failure to understand sleep disorders in breast cancer patients causes nurses to be unable to give interventions appropriately. A lack of quality sleep is related to decreased quality of life, reduced function, more pain, reduced energy, and more mental and health problems. Moreover, insomnia and depression in breast cancer patients will increase their likelihood of cancer morbidity (Jefford et al., 2017; Kim et al., 2019; Wang et al., 2016).

Therefore, exploration of sleep disorders in breast cancer patients needs to be developed better. Thus far, to my knowledge, no article on the topic has been published. A previous stud examined in sleep disorders in diabetic patients (Zhu et al., 2018); however, this study used a different conceptual analysis approach, and there is no previous study about sleep disturbance in breast cancer patients. Furthermore, although diabetes and breast cancer are both chronic diseases, sleep problems have

other causes. Thus, the concept analysis aims to define the meaning of sleep disorders in BCS. The current concept analysis is expected to understand sleep disorders better to give holistic interventions.

Methods

The eight steps from Walker and Avant (2018) guide to conducting concept analysis were followed and the approach is recommended because it employs linguistic philosophy strategies to provide a philosophical comprehension of the idea. Furthermore, it provides simple instructions. The steps of this method are: (1) choosing a concept, (2) figuring out the objectives or goals of analysis, (3) figuring out all the possible applications of the concept, (4) figuring out the defining attributes, (5) choosing a model case, (6) figuring out borderline, related, opposite, invented, and illegitimate cases, (7) figuring out antecedents and consequences, and (8) defining empirical referents.

Literature Search and Data Analysis

A comprehensive literature search used the electronic databases of CINAHL, Ovid-MEDLINE, and PubMed without time restraint to attain as many relevant studies as possible and enable to overview the use of the concept over time. We used the following keywords in our search and included free text, as well as MeSH and Emtree controlled vocabulary: population (breast cancer OR Breast Neoplasms), outcome (sleep disorder OR sleep deprivation OR insomnia OR sleep-wake disorder OR sleeplessness OR early awakening OR insufficient sleep OR insufficient sleep syndrome OR sleep fragmentation, inadequate sleep OR sleep insufficiency OR sleep insufficiencies OR REM sleep deprivation OR subwakefullness syndrome). We also used Boolean operators AND and OR. The title, abstract, and keyword sections of studies were searched for these terms.

Studies were included according to the following criteria: related to the concept of breast cancer; sleep disorders; peer-reviewed journal, proceeding, or literature review published in English. Endnote software version X20 was used to manage references. In total 5,967 studies were identified from databases, of which 1,730 duplicate studies were excluded. Next, the remaining 4,237 were screened based on abstract and title, and 152 studies were identified for the full-text check. From 152 studies, we excluded 90 studies since they did not discuss antecedents, attributes, and consequences. Finally, 62 articles met the criteria. A detailed explanation is show in Figure 1 and Table 1.

Results

Uses of the Concept

Sleep is an essential basic need for humans. Sleep serves a crucial purpose in recharging the body and mind. In addition, getting enough rest helps the body stay healthy and avoid disease. The brain cannot function effectively without enough sleep. The definition of sleep, according to the Oxford Dictionary of English, is “a state of body and mind that generally lasts many hours every night and in which the neurological system is largely dormant, the muscles supporting the spine are relaxed, the eyes are closed, and consciousness is essentially suspended” (Giddens, 2021).

Poor sleep quality impacts physiological, psychological, and social functions. Sleep is essential for metabolic regulation, cognitive function, QoL, mood, and all other aspects of life. Good sleep quality is required to reduce the chance of developing life-threatening chronic illnesses that influence the cardiovascular, respiratory, metabolic, and endocrine systems. In both otherwise healthy people and those with underlying medical issues,

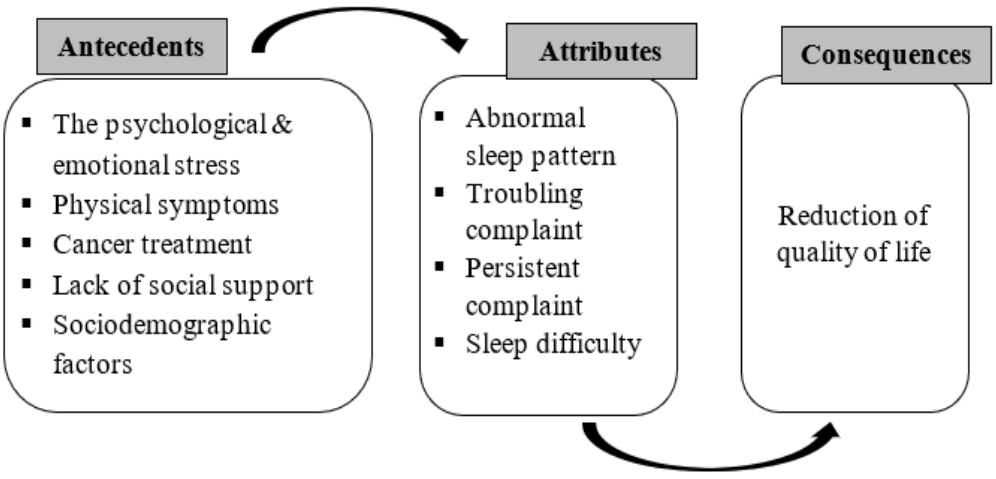

Figure 2. Association between antecedents, attributes, and consequence

Table 1. Summary of the articles included and components of the concept analysis to which they contributed

Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Posttreatment anxiety, depression, sleep disorders, and associated factors in women who survive breast cancer	Aggeli et al. (2021)	Cross-sectional	Sleep disorders were associated with factors such as profession, income, the number of minor children, and the number of pathological problems. BCS experience negative effects on their physical and mental health, including sleep disorders, insomnia, depression & anxiety after completing treatment.	Antecedent, attributes, consequences
Stress and quality of life in cancer patients: medical and psychological intervention	Barre et al. (2018)	Experimental	Fear of disease progression, especially due to lack of information can cause stress in cancer patients.	Antecedent
Breast cancer collaborative registry informs understanding of factors predicting sleep quality	Berger et al. (2019)	Cross-sectional	More than 50% of our large sample of women with a mean time of over 3 years since BC diagnosis self-reported poor sleep. Our examination increases understanding of associations between self-reported sleep quality with demographic, medical, tumor, lifestyle, and environmental variables and quality of life subscales.	Attributes
A qualitative examination of the factors related to the development and maintenance of insomnia in cancer survivors.	Garland et al. (2019)	Qualitative	Participants described a number of factors that they felt might predispose them to insomnia including family traits, an anxious temperament, and the inability to relax.	Attributes
Assessment of quality of life of women with breast cancer.	Gavric and Vukovic-Kostic (2016)	Cross-sectional	Symptoms of fatigue, insomnia and pain have the most important influence on these domains of quality of life in breast cancer. Breast cancer affects all the domains of quality of life.	Attributes, consequences
Clinical and genetic factors associated with anxiety and depression in breast cancer patients: A cross-sectional study.	Hajj et al. (2021)	Cross-sectional	Higher anxiety and depression levels in breast cancer patients suffering from cognitive impairments and worse sleep quality/insomnia.	Antecedent, attributes
A Longitudinal study of depression, fatigue, and sleep disturbances as a symptom cluster in women with breast cancer.	Ho et al. (2015)	Longitudinal studies	Depression, fatigue, and sleep disturbances were correlated.	Attributes
Quality of life in long-term premenopausal early-stage breast cancer survivors from spain, effects of surgery and time since surgery.	Arraras. et al. (2016)	Cross-sectional	Younger patients tend to have more insomnia. moderate global QoL in sleep disturbance, future perspective, sexual functioning and enjoyment, and hot flashes.	Antecedent, attributes, consequences

Cont. Table 1. Summary of the articles included and components of the concept analysis to which they contributed

Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Sleep quality and fatigue among breast cancer patients undergoing chemotherapy	Imanian et al. (2019)	Cross-sectional	Patients with breast cancer undergoing chemotherapy experience different degrees of sleep disorders and fatigue.	Antecedent, attributes
Innovation in the treatment of insomnia in breast cancer survivors	Irwin (2018)	Literature review	Breast cancer survivors show a prevalence rate of insomnia that is twice that found in the general population. literature suggests that persistent sleep difficulties in cancer survivors lead to daytime impairments, reduce quality of life.	Attributes, consequences
Sleep disturbance, inflammation and depression risk in cancer survivors	Irwin et al. (2013)	Literature review	In cancer survivors, sleep impairments are primarily characterized by problems falling asleep, with difficulties of sleep maintenance and duration also reported.	Attributes
Well-being of newly diagnosed women with breast cancer: Which factors matter more?	Ivanauskiene et al. (2014)	Cross-sectional	Poor financial situation and different treatment modalities increased the relative risk of increased pain, insomnia, and financial difficulties.	Antecedent, attributes
Pre-treatment and post-treatment anxiety, depression, sleep and sexual function levels in patients with breast cancer.	Izci et al. (2020)	Cross-sectional	Our study finds that the Patients with breast cancer have higher anxiety, depression, sleep disorder	Attributes
Association between sleep disorders and the presence of breast cancer metastases in gynecological practices in Germany: A case–control study of 11,412 women.	Jacob et al. (2018)	Case control	Sleep disorders were associated with a significant increase in the presence of breast cancer metastases in the overall population.	Attributes
Are there efficacious treatments for treating the fatigue–sleep disturbance–depression symptom cluster in breast cancer patients? A Rapid evidence Assessment of the Literature (ReAL)	Jain et al. (2015)	Literature review	Fatigue, sleep disturbance, and depression are problem which is faced by breast cancer patients.	Attributes
Comparison of fatigue and fatigability correlates in Korean breast cancer survivors and differences in associations with anxiety, depression, sleep disturbance, and endocrine symptoms: a randomized controlled trial.	Jang et al. (2021)	Eksperimental	Fatigue and fatigability were significantly associated with anxiety, depression, sleep disturbance, and endocrine symptoms.	Antecedent, attributes

Cont. Table 1. Summary of the articles included and components of the concept analysis to which they contributed

Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Patient-reported outcomes in cancer survivors: A population-wide cross-sectional study	Jefford et al. (2017)	Cross-sectional	Symptoms such as trouble sleeping, always feeling tired, trouble concentrating and fear of cancer recurrence persisted up to 5 years post diagnosis. Difficulties with all QoL domains were more prevalent amongst cancer survivors compared with the general population.	Attributes, consequences
Longitudinal association of poor sleep quality with chemotherapy-induced nausea and vomiting in patients with breast cancer.	Jung et al. (2016)	Prospective observational	Chemotherapy-induced nausea was significantly associated with poor sleep quality.	Antecedent
Impact of changes in perceived attentional function on postsurgical health-related quality of life in breast cancer patients awaiting adjuvant treatment.	Jung et al. (2020)	Descriptive pre-post design	Health related quality of life was associated with symptom distress. Specifically, lower health-related quality of life was associated with lower perceived effectiveness on daily tasks requiring attention and memory function, depressed mood and poorer quality of sleep.	Attributes, consequences
Social Support, Insomnia, and Adherence to Cognitive Behavioral Therapy for Insomnia After Cancer Treatment.	Kamen et al. (2019)	Eksperimental	Insomnia disorder may occur as a stress response to receiving a cancer diagnosis, or as a side effect of treatment. social support was negatively correlated with insomnia severity.	Antecedent, attributes
The effect of massage therapy on the quality of sleep in breast cancer patients.	Kashani and Kashani (2014)	Eksperimental	43.35% in the experimental group and 39.78% in the control group were suffering from sleep disorders.	Attributes
Relationship between sleep quality and spiritual well-being/religious activities in muslim women with breast cancer.	Khoramirad et al. (2015)	Cross-sectional	In a study conducted on cancer patients in Tehran, it was shown that 71.7 % of patients had poor sleep.	Attributes
A prospective longitudinal study about change of sleep, anxiety, depression, and quality of life in each step of breast cancer patients.	Kim et al. (2019)	Prospective longitudinal	Chemotherapy can change the quality of sleep (QoS), anxiety, and depression of cancer patients. Breast cancer patients experience sleep disturbance, anxiety, depression, and loss of QoL.	Antecedent, attributes, consequences
Evaluation and management of insomnia in women with breast cancer	Kwak et al. (2020)	Literature review	Multiple factors contribute to insomnia among patients with breast cancer including endocrine therapy and hot flashes, pain and discomfort from local therapy, and fear of recurrence.	Antecedent, attributes

Cont. Table 1. Summary of the articles included and components of the concept analysis to which they contributed

Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Relationships among personality, coping, and concurrent health related quality of life in women with breast cancer.	Lai et al. (2019)	Cross-sectional	About 60% patients with breast cancer have poor sleep and sleep disorders having a negative association with HRQOL.	Attributes, consequences
Resilience and coping styles as predictors of health outcomes in breast cancer patients: A structural equation modelling analysis.	Lai et al. (2018)	Cross□sectional	The prevalence of negative health outcomes among the participants was as follows: 70% had sleep disorders, 55% had depressive symptoms, and 27.4% had anxiety symptoms.	Attributes
The influence of sleep disturbance and cognitive emotion regulation strategies on depressive symptoms in breast cancer patients.	Lee et al. (2019)	Retrospective cohort	Cancer patient depression is associated with insomnia and the cognitive emotion regulation strategies used during their care.	Attributes
Genetic variants in circadian rhythm genes and self-reported sleep quality in women with breast cancer.	LeVan et al. (2019)	Cross-sectional	Studies have reported that 30–60% of breast cancer patients have poor sleep quality before receiving adjuvant chemotherapy	Antecedent, attributes
Disruption of sleep, sleep-wake activity rhythm, and nocturnal melatonin production in breast cancer patients undergoing adjuvant chemotherapy: Prospective cohort study.	Li et al. (2018)	Cohort	The first administration of adjuvant chemotherapy is associated with sleep disturbance and sleep wake activity rhythm disruption among breast cancer patient	Antecedent, attributes
Joint effects of multiple sleep characteristics on breast cancer progression by menopausal status	Liang et al. (2018)	Cohort	Poor sleep quality and impaired daytime function after breast cancer diagnosis were associated with an elevated risk of breast cancer progression.	Attributes
The relationship between insomnia and cognitive impairment in breast cancer survivors.	Liou et al. (2019)	Cross-sectional	We found that more than 50% reported insomnia and nearly 80% of patients were bothered by perceived cognitive impairment.	Attributes
An exploratory study of the effects of mind–body interventions targeting sleep on salivary oxytocin levels in cancer survivors.	Lipschitz et al. (2015)	Eksperimental	Cancer survivors experience high levels of distress, associated with a host of negative psychological states, including anxiety, depression, and fear of recurrence, which often lead to sleep problems and reduction in QoL. For the sleep measure, the analysis revealed that SPI-II change scores at post and follow-up were significantly lower in MBB.	Antecedent, attributes

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fatigue and sleep quality are associated with changes in inflammatory markers in breast cancer patients undergoing chemotherapy.	Liu et al. (2012)	longitudinal	The results showed that during chemotherapy, fatigue was worse than pre- chemotherapy while sleep quality remained poor both before and during chemotherapy.	Antecedent, attributes
Sleep quality is associated with disability and quality of life in breast cancer survivors: a cross-sectional pilot study.	Lourenço et al. (2020)	cross-sectional	Breast cancer survivors with subjective poor sleep quality had more fatigue, less upper limb-related functional performance, more disability and worse quality of life.	Attributes
Randomized sham-controlled trial of cranial microcurrent stimulation for symptoms of depression, anxiety, pain, fatigue and sleep disturbances in women receiving chemotherapy for early-stage breast cancer.	Lyon et al. (2015)	Eksperimental	women receiving chemotherapy for breast cancer experienced multiple symptoms in the mild to moderate range including depression, anxiety, fatigue, pain and sleep disturbances.	Antecedent, attributes
Poor sleep quality, depression and hope before breast cancer surgery.	Mansano-Schlosser et al. (2017)	Longitudinal	The majority of women had tumors in initial stages (78.7%), reported poor sleep quality (58.9%), and had moderate to severe or severe depression (27.2%).	Attributes
Feasibility of a preventive intervention for insomnia in women with breast cancer receiving chemotherapy.	Marion et al. (2019)	Eksperimental	Breast cancer patients at high-risk of developing insomnia.	Attributes
Symptom clusters in women with breast cancer: an analysis of data from social media and a research study	Marshall et al. (2016)	Quantitative	After reviewing a random sample of 100 posts containing the keyword “sleep,” we found that approximately one-fifth of these posts described sleep-related difficulties. However, none of these posts contained the specific phrase “restless sleep.	Attributes
Sleep disturbances in patients with advanced cancer in different palliative care settings	Mercadante et al. (2015)	Observational	More than 60% of palliative care patients have relevant sleep disturbances. Hormone therapy and use of opioids and corticosteroids were positively associated with sleep disturbances, and there was a positive correlation of HADS-Anxiety and HADS-Depression scores with sleep disturbances.	Antecedent, attributes
Mapping unmet supportive care needs, quality-of-life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: results from the International STEP Study.	Molassiotis et al. (2017)	Cross-sectional	The top five symptoms present in the past week from the assessment day included fatigue (66.6%), loss of (Mansano-Schlosser et al., 2017; Molassiotis et al., 2017) strength (61.8%), pain (61.6%), sleep disturbance (60.1%), and weight changes (57.7%)	Attributes

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Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Sleep disorders in breast cancer survivors	Otte et al. (2016)	Cross-sectional	The majority of women had more than one possible disorder, with insomnia and circadian rhythm disorders being the two most frequent potential disorders. Interestingly, 79 % of the BCS had high symptom burden potentially related to sleep apnea.	Attributes
Factors associated with poor sleep in older women diagnosed with breast cancer.	Overcash et al. (2018)	cross-sectional	The final model from backward selection indicates that fatigue was the strongest predictor of poor sleep.	Antecedent, attributes
Sleep disruption in breast cancer patients and survivors.	Palesh et al. (2013)	Review article	Sleep disturbance is prevalent in patients with and survivors of breast cancer, and is associated with reduced quality of life and possibly shorter survival.	Attributes, consequences
Management of side effects during and post-treatment in breast cancer survivors.	Palesh et al. (2018)	Review article	Physical complaints, including headaches and muscle aches, as well as sleep difficulties are more likely to co-occur earlier in the disease stage.	Attributes
Who is managing menopausal symptoms, sexual problems, mood and sleep disturbance after breast cancer and is it working? findings from a large community-based survey of breast cancer survivors.	Peate et al. (2021)	Cross-sectional	Menopausal symptoms, sexual problems, mood and sleep difficulties are common after breast cancer and often not effectively managed.	Attributes
Sleep patterns, sleep disorders and mammographic density in spanish women: The DDM-Spain/Var-DDM study	Pedraza-Flechas et al. (2017)	Cross-sectional	Sleep disorders lasting at least one year were reported by 45.5% of the women, usually difficulties falling or staying asleep at night. Less than 1% of the women reported obstructive sleep apnea (n:23) or restless legs syndrome (n:6).	Attributes
Pre-diagnostic sleep duration and sleep quality in relation to subsequent cancer survival.	Phipps et al. (2016)	Eksperimental	Short sleep duration and frequent snoring were each associated with poorer breast cancer survival.	Attributes
Factors affecting sleep quality of breast cancer patients with chemotherapy.	Putri and Makiyah (2021)	cross-sectional	Breast cancer patients undergoing chemotherapy had poor sleep quality, and the factors related to sleep quality were age and with whom the respondent lived in the same house.	Antecedent, attributes
Sleep disorders in patients with breast cancer prior to a course of radiotherapy – prevalence and risk factors.	Rades et al. (2021)	Retrospective	Sleep disorders prior to radiotherapy for breast cancer are common. This applies particularly to patients with risk factors including distress due to emotional, physical or practical problems.	Antecedent, attributes

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Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Living with persistent insomnia after cancer: A qualitative analysis of impact and management.	Reynolds-Cowie and Fleming (2021)	Cross-sectional	Insomnia was found to have a detrimental and pervasive impact on cancer survivors' quality of life	Attributes, consequences
Contribution of cancer symptoms, dysfunctional sleep related thoughts, and sleep inhibitory behaviors to the insomnia process in breast cancer survivors: A daily process analysis.	Rumble et al. (2010)	Longitudinal study	Poorer sleep was related to nighttime pain and hot flashes in breast cancer patients. Time-lagged effects were also found. The current study identified higher levels of dysfunctional sleep related thoughts and sleep inhibitory behaviors during the day and night as antecedents of insomnia, and higher levels of pain, fatigue, and hot flashes and lower levels of positive mood and dysfunctional sleep related thoughts as consequences of insomnia.	Antecedent, attributes
Post-treatment symptoms of pain, anxiety, sleep disturbance, and fatigue in breast cancer survivors.	Schreier et al. (2019)	Descriptive correlational study	This study described the prevalence of three physical symptoms (pain, sleep disturbance, and fatigue) and one psychological symptom (anxiety) in breast cancer survivors.	Attributes
Cancer-related problems, sleep quality, and sleep disturbance among long-term cancer survivors at 9-years post diagnosis.	Strollo et al. (2020)	Cross-sectional	This study suggests that the residual effects of cancer may contribute to sleep difficulties in long-term survivorship. Heightened levels of cancer-related physical distress, emotional distress, economic distress, and fear of recurrence are associated with poor sleep quality and high sleep disturbance in long-term cancer survivors.	Antecedent, attributes
Evaluation of sleep pattern disorders in breast cancer patients receiving adjuvant treatment (chemotherapy and/ or radiotherapy) using polysomnography.	Tag Eldin et al. (2019)	Cross-sectional	In breast cancer patients, significant shortening of total sleep time, decrease of sleep efficiency, lengthening of sleep latency and rise of wakefulness after sleep onset as compared to healthy controls were registered (p=0.001).	Attributes
Identification of subgroups of chemotherapy patients with distinct sleep disturbance profiles and associated co-occurring symptoms.	Tejada et al. (2019)	Longitudinal	Patients in the High and Very High classes reported significantly poorer quality of sleep and higher scores for the two subscales associated with sleep maintenance (i.e. mid-sleep awakenings, early awakening).	Attributes

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Title	Author/Year	Methodology	Component of the Concept Analysis to Which the Study Contributed	How to Use in the Present Study
Sleep and endocrine therapy in breast cancer.	Van Dyk et al. (2021)	Review article	Sleep disturbance is a significant concern for women initiating endocrine therapy for breast cancer. Sleep disturbance similarly emerges as a pivotal issue across a number of outcomes, including non-adherence to these longstanding daily therapies.	Attributes
Sleep disorder diagnoses and clinical outcomes among hospitalized breast cancer patients: A nationwide inpatient sample study.	Vin-Raviv et al. (2018)	Cross-sectional	Among women hospitalized with a primary diagnosis of breast cancer, 2% (n = 1807) also received a diagnosis of a sleep disorder during hospitalization, the majority of which were sleep-related breathing disorders.	Attributes
Sleep difficulty mediates effects of vasomotor symptoms on mood in younger breast cancer survivors.	Vincent et al. (2014)	Cross-sectional	Vasomotor symptoms (VMS), sleep and mood disturbance are commonly experienced by younger women with breast cancer.	Antecedent, attributes
Experiences and insomnia-associated factors in Chinese breast cancer survivors: A qualitative study.	Wang et al. (2016)	Qualitative	Three themes emerged concerning the experiences of insomnia, including sleep neglect, insomnia perception and insomnia anxiety. Participants reported their own opinions on three insomnia-associated factors, including factors associated with hospitalisation, factors associated with breast cancer and the therapies.	Attributes
Sleep quality and related factors in patients with breast cancer: A cross-sectional study in Taiwan.	Weng et al. (2021)	Cross-sectional	Patients with breast cancer showed 67.6% prevalence of sleep disturbances after treatment. The patients with sleep disturbances were more likely to have previously experienced psychological disturbances, severe pain, depression within 5 years after diagnosis.	Attributes
The associations of self-stigma, social constraints, and sleep among Chinese American breast cancer survivors.	Wu et al. (2020)	Cross-sectional	Participants frequently reported poor sleep quality (44.9%), use of sleep aids (37.5%), and difficulty staying awake during the day (37.5%).	Attributes
Perceived stress as a mediator between social constraints and sleep quality among Chinese American breast cancer survivors.	Yeung et al. (2017)	Cross-sectional	This study implied that social constraints may worsen sleep quality among Chinese American BCS through increasing perceived stress.	Attributes

sleep disorders can have short and long-term adverse effects on their health (Giddens, 2021; Medic et al., 2017).

Compared to the general population, BCS experience a higher incidence of sleep disturbances. Different cancer patients report varying types and rates of sleep issues. Breast cancer patients exhibited an increased incidence of fatigue and insomnia, while lung cancer patients had the greatest or second-highest frequency of general sleep disorders. Reduced quality of life and breast cancer metastases were linked to sleep disorders. The American Cancer Society and American Society of Clinical Oncology advise comprehensive and targeted treatment for breast cancer patients' health and quality of life, including sleep problems (Jacob et al., 2018; Lourenço et al., 2020). Because of this, the issue of sleep disturbances in BCS requires attention and has to be included in the standard procedure for palliative care evaluation. Sleep disorders can cause problems with falling asleep, remaining asleep, waking up early in the morning, or having nonrestorative sleep patterns with poor associated sleep efficiency (Mercadante et al., 2015).

Defining Attributes

The definition of attributes is a critical characteristic of the concept that can help distinguish one concept from another related concept (Huda et al., 2021). Based on the literature search, the most common attributes of sleep disorders are 1). abnormal sleep pattern, 2). troubling complaint, 3). persistent complaint, and 4). sleep difficulty.

First, an abnormal sleep pattern, a sleep-wake pattern, is a biological rhythm that guides the body to sleep and wake. Short or extended sleep cycles and excessive daytime sleepiness are all signs of irregular sleep patterns. Short sleepers slept for fewer than five hours, while long slept for over nine. The National Sleep Foundation advises adults to get seven to nine hours of sleep, with six hours being the recommended minimum (Pedraza-Flechas et al., 2017; Phipps et al., 2016).

Second, BCS experience several problems, and sleep problems are among the top five most bothersome lasting difficulties for BCS. Sleep issues are twice as common in BCS as in other cancer and are perceived as disturbing compared to other complaints (Otte et al., 2016; Kim et al., 2019). Most BCS reported poor sleep in the initial stage (Mansano-Schlosser et al., 2017; Marshall et al., 2016; Molassiotis et al., 2017).

The third attribute, persistent complaint, is the expressions of discomfort and unease that continuously happen. Insomnia and fatigue are complaints that breast cancer patients often experience. According to Otte et al. (2016) and Jefford et al. (2017), sleep difficulties in BCS can last for up to five years after diagnosis and up to 10 years after treatment, and this issue is frequently not well-treated (Peate et al., 2021).

The fourth attribute is sleep difficulty. Breast cancer patients have difficulty sleeping, including difficulty falling asleep, staying asleep, or waking up too early. Insomnia symptoms include trouble falling asleep, frequent nocturnal and morning awakenings, and problems getting back to sleep are reported by more than 60% of BCS (Aggeli et al., 2021; Barre et al., 2018; Garland et al., 2019; Gavric & Vukovic-Kostic, 2016; Ho et al., 2015; Irwin, 2018).

Several substitute labels have referred to sleep disorders. Sleep problems are complicated problems probably brought on by several physiological, psychological, and behavioral factors. Many of these traits, such as chronic pain, may be the same in healthy individuals and those with diabetes, cancer, or musculoskeletal illnesses (Zhu et al., 2018). In some research, the term "sleep disorders" has been used to refer to sleep disturbance (Aggeli et al., 2021; Izci et al., 2020; Kashani & Kashani, 2014; Khoramirad et al., 2015; Lai et al., 2019; Liu et al., 2015; Overcash et al., 2018; Rades et al., 2021). Other conversely used terms are sleep problem (Lipschitz et al., 2015), sleep-disordered breathing, sleep apnea, sleep-related movement (e.g., sleepwalking, restless leg syndrome), circadian rhythm, hypersomnia, parasomnia (Otte et al., 2016), sleep deprivation (Pedraza-Flechas et al., 2017).

Another term that is also often used is insomnia (Aggeli et al., 2021; Arraras. et al., 2016; Barre et al., 2018; Garland et al., 2019; Gavric & Vukovic-Kostic, 2016; Irwin, 2018; Jain et al., 2015; Jung et al., 2016; Lee et al., 2019; Liou et al., 2019; Marion et al., 2019). Insomnia is a sleep disorder that affects as many as 35% of adults. One of the most common problems BCS face is insomnia, which is having trouble falling asleep, staying asleep, or getting up too early at least three times a week for at least three months (Kwak et al., 2020; Reynolds-Cowie & Fleming, 2021).

While the term sleep disorders used in the Diagnostic and Statistical Manual of Mental Disorders - fifth edition (DSM-5) is sleep-wake disorders, it encompasses ten disorders or disorder groups: hypersomnolence, narcolepsy, breathing-related sleep disorders, insomnia, circadian rhythm sleep-wake disorders, non–rapid eye movement (NREM) sleep arousal disorders, nightmare disorder, rapid eye movement (REM) sleep behavior, restless legs syndrome, and substance/medication-induced sleep disorder (American Psychological Association, 2013).

Antecedents

Antecedents are situations or events that precede the concept of interest (Zhu et al., 2018). Based on the literature search, the antecedents of sleep disorders in BCS can be identified: psychological and emotional stress, physical symptoms, cancer treatment, lack of social support, and sociodemographic factors.

The psychological and emotional stress

The term 'psychological' refers to studies on the human mind, whereas 'emotional' refers to the mood mixed with seriousness and sadness. Some psychological and emotional stress appears in BCS, such as anxiety, depression, fear of cancer recurrent, negative self-stigma, and stress.

The combination of depression and cancer synergistically disrupts sleep. Conversely, better sleep quality in cancer patients has been associated with greater physical and psychological well-being (Berger et al., 2019; Garland et al., 2019; Hajj et al., 2021; Kashani & Kashani, 2014; Lipschitz et al., 2015; Palesh et al., 2013; Patel et al., 2009; Rades et al., 2021).

Psychological stress leads to elevated inflammatory markers and sleep disorders (Irwin, Olmstead, Ganz, & Haque, 2013). According to Patel et al. (2009), depression will increase proinflammatory cytokine levels, for instance C-reactive-protein (CRP) and interleukin-6 (IL-6). Circulating cytokine levels interact with the hypothalamic-pituitary-adrenal axis to regulate sleep crucially. Cytokines can cause cortisol variations, then abnormal cortisol secretion shortens sleep duration and worsens sleep disorders (Kashani & Kashani, 2014).

Stress and sleep have a mutual relationship. Losing sleep can raise stress and vice versa. Stress can cause sleep loss. A part of the hypothalamic-pituitary-adrenal axis (HPA axis) regulates the 24-hour cycle of sleep and wakefulness. Long-term stress has been associated with HPA hyperactivity, shorter sleep duration, reduced REM sleep, and lower delta power, all of which can lead to poorer sleep quality, impaired memory, poor mood regulation more severe stress (Schreier et al., 2019; Strollo et al., 2020; Tag Eldin et al., 2019).

Physical symptoms

Breast cancer patients endure physical symptoms such as vasomotor symptoms, fatigue, and pain. The sign most frequently expressed by BCS is fatigue, linked to anxiety, depression, sleep disorders, and limitations on QoL (Jang et al., 2021; Rumble et al., 2010; Yeung et al., 2017). Physical discomforts experienced by cancer patients can be related to sleep disorders. This complaint can also arise due to the effects of chemotherapy (Palesh et al., 2013). Breast cancer survivors frequently experience vasomotor symptoms (VMS), particularly in younger women diagnosed before menopause. Higher depressive symptoms and sleep disruptions were linked to vasomotor symptoms (Accortt et al., 2015; Wang et al., 2016). Additionally, most younger breast cancer patients have VMS, which both directly and indirectly affects sleep difficulty and, in turn, indirectly affects mood, which is partly mediated by sleep difficulty (Vincent et al., 2014; Weng et al., 2021; Wu et al., 2020).

Furthermore, pain and anxiety, such as excessive anxiety that results in depression, affect the sleep quality of BCS receiving chemotherapy. In this anxious state, the sympathetic nervous system is activated, raising norepinephrine levels in the blood. This circumstance decreases the NREM level 4 sleep cycle, REM sleep, and the possibility of being awakened while sleeping (Putri & Makiyah, 2021).

Cancer treatment

Cancer treatments, including chemotherapy and hormone replacement therapy, are potential inducers of inflammation, which is associated with acute inflation of inflammatory indicators, increasing insomnia, and sleep disorders in BCS (Jung et al., 2016; Li et al., 2018). Kashani and Kashani (2014) reported short sleep duration, trouble falling asleep, frequent interruptions, and insomnia. Other treatments, such as sedatives (sleeping pills) used on BCS, will also disrupt sleep. Some studies show that long-term use of sleeping pills will interfere with sleep.

Furthermore, chemotherapy can influence QoL, depression, and anxiety through a sequence of procedures that begins with diagnosis and ends with treatment. Chemotherapy has been demonstrated in trials to worsen QoL, sleep quality, anxiety, and depression. Chemotherapy-treated BCS had less sleep efficiency, REM sleep, and deep sleep than the general population (Kim et al., 2019; Liu et al., 2015; Lyon et al., 2015).

Lack of social support

Family support is an essential factor for a person facing health challenges. It may contribute to the healthcare function for family members to gain optimal health. Family support will give patients a sense of security, comfort, and hope, resulting in a calm that will make it easier for them to meet their sleep needs (Putri & Makiyah, 2021). The severity of insomnia is adversely connected with social isolation. Social support in the general population and cancer survivors predicts insomnia severity (Kamen et al., 2019).

Sociodemographic factors

Sociodemographic factors, for instance, marital status, profession, age, education, income, and the number of minor children, can affect sleep disorders. The prevalence of insomnia rises in adults and the elderly. The circadian rhythm brings on age-related changes in sleep patterns. The hypothalamus suprachiasmatic nucleus (SCN) is the epicenter of circadian rhythm regulation. Aging is associated with decreased SCN function. A decline in SCN activity in the elderly will have a comparable impact on blockages in the circadian rhythm. One sign of circadian rhythm disruption is difficulty sleeping (Putri & Makiyah, 2021).

According to the research by Aggeli et al. (2021) women with a small number of children had higher levels of anxiety and sadness. This could be because these women felt a greater psychological burden

related to the rearing of their children. Women's financial circumstances significantly impacted sleep disorders; those with low earnings had the highest rate of sleep problems, while those with higher incomes saw a decline in these issues. An increased incidence of sleep issues was positively associated with poor income.

Consequences

Consequences are events or phenomena resulting from the concept (Zhu et al., 2018). The consequences of sleep disorders are a reduction in QoL. Quality of life is an individual's perception of their position in life, in the context of the culture and value systems they live in, and their objective, expectations, standards, and concerns (World Health Organization, 2021). Quality of life is assessed in at least three well-being domains: physical, emotional, and social (Kim et al., 2019). Breast cancer patients' sleep problems can negatively affect all elements of their QoL and ability to function during the day (Arraras. et al., 2016; Gavric & Vukovic-Kostic, 2016; Jung et al., 2020; Liang et al., 2018).

Quality of life reverses the individual viewpoints of satisfaction with life, and the measurement is divided into four primary QoL domains: physical, social or family, emotional, and functional well-being. Some literature says that QoL consists of well-being domains (Lipschitz et al., 2015; Pinto et al., 2017). Thus, in this analysis concept, we only use quality of life as a consequence. The relation between antecedents, attributes, and consequences can be seen in Figure 2.

Constructed Cases

This is the fifth step in concept analysis. The purpose of making cases is to help understand the concept (Walker & Avant, 2018). In concept analysis, authors use a case model (concept analysis), and additional cases including borderline case, related case, and contrary case.

Model case

A model case is a way to apply a concept that exemplifies all its defining characteristics and improves its meaning (Walker & Avant, 2018). This model describes circumstances where all concept properties are present, and it can be made up or drawn from actual experiences (Huda et al., 2021).

Mrs. L. is a 38-year-old diagnosed with breast cancer stage III B 2 years ago. Currently, Mrs. L is undergoing chemotherapy treatment. Since her illness, Mrs. L often complains of difficulty sleeping, especially after chemotherapy. Complaints were difficulty initiating sleep, frequent awakenings at night, and inability to fall back to sleep, and often waking up too early in the morning. Moreover, Mrs. L only sleeps 3-4 hours. These complaints are felt almost every day and are very disturbing. Thus, she feels fatigued.

Based on the example of the model case, Mrs. L experienced all attributes (four attributes and their characteristics), namely 1). difficulty to sleep which is characterized by difficulty initiating sleep, frequent awakenings at night, an inability to fall back to sleep, and often waking up too early in the morning, 2). abnormal sleep pattern (only sleep 3-4 hours, whereas usually adults sleep 7-9 hours per day), 3). persistent complaint (complaints felt almost every day) and 4). troubling complaint (this sleep problem bothers them). One of the effects of all these complaints is that Mrs. L feels fatigued. This complaint is not included in the attributes section only as an addition.

Borderline case

A borderline case contains most of the defining attributes of the concept, but not all of them are included in the idea (Huda et al., 2021; Walker & Avant, 2018).

Mrs. M (32-year-old) was diagnosed with breast cancer-stadium III four months ago. Lately, Mrs. M complains of difficulty sleeping, often wakes up at night, has an inability to fall back to sleep, and often wakes up too early in the morning. Mrs. M can only sleep 5-6 hours a day. But this complaint is not felt every day, the complaint is most prevalent especially after chemotherapy, and sometimes Mrs. M also manages to overcome her complaints by relaxing and listening to music before going to bed.

In the above case, Mrs. M only experienced two attributes, namely 1). difficulty to sleep which is characterized by difficulty initiating sleep, frequent awakenings at night, difficulty falling asleep again, and often waking up too early in the morning), 2). abnormal sleep pattern (only sleeps 3-4 hours), whereas usually adults sleep 7-9 hours per day). Meanwhile, Mrs. M did not experience persistent and troubling complaints because her complaints were not felt every day, and sometimes Mrs. M managed to overcome these complaints.

Related case

A related case reflects instances of concern associated with the concept under study but does not contain all the defining attributes. This case demonstrates similar ideas to the central concept of interest; however, we can see the two concepts are different (Huda et al., 2021; Walker & Avant, 2018).

Mrs. K, a 38-year-old, is a breast cancer patient. Mrs. K works as an employee. These days she often works overtime because she must complete her assignments. Sleep duration is only 3-4 hours, cannot sleep well, and usually wakes up thinking about the task at night. Thus, she is sleepy in the morning. But Mrs. K felt her condition was fine and could still concentrate while working.

In that case, Mrs. K's complaint is still related to the concept or attribute but with different causes. She is experiencing sleep difficulty and abnormal sleep patterns, but the causes are different. The sleep problem experienced is because she sleeps too late to finish her work. While the other attributes, troubling complaint and persistent complaint, were

not shared by Mrs. K.

Contrary case

None of the concept's attributes is present in a contrary case (Walker & Avant, 2018).

Mrs. L (40 years old) has come to the oncology polyclinic for a medical check-up. Mrs. L was diagnosed with breast cancer three years ago. Every month, she routinely controls the oncology polyclinic for examination and chemotherapy. She is always ready for chemotherapy and takes her treatment with pleasure. When she was initially diagnosed with breast cancer, Mrs. L experienced several complaints, especially those that were very disturbing, namely sleep difficulty. But at this time, Mrs. L has improved, there are no complaints of sleep disturbance, and she can manage her condition well.

In this case, although Mrs. L is still undergoing therapy, her condition has improved, with no sleep disorder. Thus, none of the attributes are experienced by Mrs.L. Moreover, she can manage her stress well. She is also prepared for the upcoming chemotherapy cycle. This patient was doing an excellent job of controlling her symptoms and was coping well.

Empirical referents

Empirical references further clarify the concept and its measurements (Walker & Avant, 2018). The measurement tools for measuring sleep quality are many: (1). the Athens insomnia scale (AIS) is used for assessing sleep quality. The instrument consists of eight items and is planned to measure the quantity and quality of sleep (Aggeli et al., 2021), (2). The Pittsburgh Sleep Quality Index (PSQI) is the gold standard and the most extensively used instrument for assessing sleep quality in various groups. PSQI was created to evaluate sleep quality, sleep duration, and sleep disruption frequency and severity (Berger et al., 2019), (3). The Insomnia Severity Index (ISI) has a seven-item self-report, is commonly administered, and is psychometrically validated, (4). Sleep diaries are used to self-report sleep continuity, pattern, and quality on a night-by-night basis, as well as their time into and out of bed (Kamen et al., 2019), (5). Cancer-related dysfunctional beliefs about sleep (C-DBS). The C-DBS is a 2-item tool to measure cancer-related dysfunctional beliefs about sleep. This instrument has two questions to measure sleep disturbance "my immune system will have serious problems if I don't go to sleep at a specific time (question 1)," and "If I don't sleep well at night, my cancer can recur or metastasize (question 2)." Every item has a score from 0 to 10. Higher C-DBS scores are associated with more severe insomnia (Lee et al., 2019), (6) The Epworth Sleepiness Scale (ESS) is an instrument used to measure sleepiness. Patients who experience insomnia or sleep difficulty will feel sleepy in the morning because of the lack of sleep duration at night. Therefore, it is necessary to assess patients with ESS.

The instruments used to measure QoL are (1). EORTC QLQ-C30, patients' health-related QoL was measured using the European Organization for the Cancer QoL Questionnaire version 3.0 (EORTC QLQ-C30 version 3.0) (Barre et al., 2018; Gavric & Vukovic-Kostic, 2016; Irwin, 2018), and (2). EQ-5D-5L (the euroqol-5 dimension-5 levels) and the EQ-VAS; the questionnaire included the quality of life (QoL). The instrument consists of five domains of QoL (personal care, usual activities, mobility, pain or discomfort, and anxiety or depression). The value range is from 0 (death) to 1 (perfect health). The EQ-VAS represents the participant's health today on a scale of 0 to 100, where 0 is the worst health the respondent can imagine, and 100 is the best (Jefford et al., 2017).

Discussion

This concept analysis, which follows Walker and Avant (2018) approach, provides a more profound knowledge of sleep disorders in breast cancer patients by identifying attributes, antecedents, and consequences. A definition of the concept is proposed. This concept clarifies the sleep disorders traits in BCS that may differ from sleep disorders in other patients. Sleep is a phrase used to describe a state of altered consciousness during which there is little to no physical activity and a general slowing of physiological systems in the body. Sleep is essential for physical and mental recovery (DeLaune & Ladner, 2011).

Breast cancer survivors have had sleep issues for a long time. Furthermore, sleep problems affect twice as many BCS as the population. Compared to healthy people and other cancer patients, those with breast cancer are more likely to experience sleep difficulties (Kim et al., 2019; Otte et al., 2016). According to data, breast cancer patients are more likely to experience insomnia and fatigue (Irwin et al., 2013). The incidence of sleep problems in BCS varies widely, from as low as 24% to as high as 95% (Mercadante et al., 2015). Therefore, one of the main problems for cancer patients is having trouble sleeping.

We identified five categories of antecedents of sleep disorders in BCS: 1) psychological and emotional stress, 2) physical symptoms, 3) cancer treatment, 4) lack of social support, and 5) sociodemographic factors. Screening for antecedent sleep disturbance in BCS will help identify those at risk and help develop appropriate prevention. Future interventions should be carried out holistically because of the complexity of sleep disorders in BCS.

According to the literature search, the most common attributes of sleep disorders are 1). abnormal sleep pattern, 2). the troubling complaint, 3). the persistent complaint, and 4). sleep difficulty. Complaints of sleep difficulty are synonymous with insomnia. According to estimates, insomnia affects

more than 60% of BCS (Aggeli et al., 2021; Barre et al., 2018; Garland et al., 2019; Gavric & Vukovic-Kostic, 2016; Ho et al., 2015; Irwin, 2018). For BCS, complaints of sleep disorders are the most frequently felt and disturbing physical complaints compared to other complaints. Several substitute terminologies have been used interchangeably with sleep disorders such as sleep problems, sleep disturbance, sleep-disordered breathing, sleep apnea, sleep-related movement (e.g., sleepwalking, restless leg syndrome), circadian rhythm, hypersomnia, parasomnia, sleep deprivation, and insomnia. In conclusion, sleep disorders in breast cancer patients are more complex than other diseases or cancer.

Each breast cancer patient may differ in perceiving symptoms (attributes), and sleep disorders symptoms may vary from other cancer patients. Therefore, a more detailed assessment is needed to determine the severity of the symptoms. The same symptom could be intolerable for some people but much less for others. To better understand how patients perceive their experiences and the meaning they attach to them, it is crucial to ask them how much the symptom bothers them. The breast cancer survivor's experience will also affect their outcome or consequences.

The present study identified one consequence of sleep disorders in breast cancer patients: reducing QoL (Arraras. et al., 2016; Chean. et al., 2016; Gavric & Vukovic-Kostic, 2016). There is a multi-dimensional domain of quality of life that includes physical, mental, emotional, ability to function daily, family relationships, social functioning domains, and overall life satisfaction. According to Lipschitz et al. (2015) and quality of life represents how happy a person feels about their life. Because the characteristics of the two concepts (well-being and quality of life) are the same, the measurement of QoL is separated into four essential QoL domains: physical, emotional, social, or family, and functional well-being.

Study Limitations

Only three databases were used and were limited to English, and there are very many terms in sleep disorders so that it is rather difficult to choose specific sleep disturbance symptoms in BCS.

Conclusion

This concept analysis provides comprehensive insights into sleep disorders in breast cancer patients; understanding the antecedents, attributes, and consequences. Moreover, understanding concept analysis will provide new insight to assess the rest and sleep needs of BCS before intervention. So that nurses can provide comprehensive and holistic interventions.

Conflict of Interest

The authors did not have any conflict of interest regarding this publication.

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Data Availability

none

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A rare case of Fahr's syndrome with dissociative amnesia

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Abstract

Background: Fahr's syndrome (FS) is a movement and psychiatric disorder characterized by symmetrical and bilateral calcification of the basal ganglia. Dissociative amnesia is a rare psychiatric disorder that occurs after stressful events and is classified as a dissociative disorder. In addition, dissociation is the process by which the mind conceals stressful events from consciousness. Several neuropsychiatric manifestations in FS have been reported. However, due to their rarity, FS and dissociative amnesia can be misdiagnosed.
Case: A 43-year-old female presented with Parkinsonian symptoms and an inability to recall important personal information. FS and dissociative amnesia were diagnosed after a thorough medical, psychiatric, and diagnostic investigation. Subsequently, correction of calcium and phosphate levels by α-hydroxy-vitamin-73 D3 and psychotherapy were administered for two-months until there were no neuropsychiatric symptoms reported.
Conclusion: This research highlights a rare case of FS with dissociative amnesia which pathophysiology is not completely understood due to limited research.

Keywords: basal ganglia calcification; dissociative disorders; fahr's syndrome; hypoparathyroid; movement disorders

Introduction

Fahr's disease (FD) is a neurodegenerative disease characterized by abnormal symmetrical and bilateral calcified deposits in the basal ganglia and cerebral cortex which causes extrapyramidal symptoms (Lee et al., 2018). Its various symptoms, ranging from extrapyramidal to psychiatric abnormalities have been reported, with Parkinsonism being the most common (Abubakar & Saidu, 2012; Ooi et al., 2019). It affects young to middle-aged adults with a prevalence of <1/1,000,000 worldwide (Saleem et al., 2013). The presence of parathyroid endocrinopathies is termed Fahr's syndrome (FS) (Perugula & Lippmann, 2016).

FS with depression, delusional-manic disorder, dementia, flattening of affectivity, hypochondria, and schizophrenia was reported in previous research (Calabrò et al., 2014; El Hechmi et al., 2014; Naqvi et al., 2017; Roiter et al., 2016; Samuels et al., 2018; Savino et al., 2016). Furthermore, parathyroid endocrinopathies and Parkinsonism can be pathognomonic, but FS has no pathognomonic psychiatric symptoms. In several cases, new and unexpected psychiatric disorders have been reported (Asokan et al., 2013). In this case, a 43-year-old female was presented with FS and an inability to recall important autobiographical information but no prior evidence of significant cognitive decline indicating unreported and unexpected psychiatric disorders of dissociative amnesia.

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Case Presentation

A 43-year-old female was presented to a hospital with resting tremors and gait disturbance for two years. The companion disclosed that the patient had a radical thyroidectomy 20 years ago and occasionally wanders away from home and does not recall self-identity. These occurrences became apparent after the passing of the patient's husband four years ago. The symptoms were causing significant social impairment, and if received condolences, the patient would relapse. The amnesia is retrograde and occurs abruptly. The patient is unaware of the amnesia and requires five minutes to recall all of personal information. Hallucinations, delusions, or mood disturbances have also not been experienced. There was no history of alcohol consumption, medication abuse, drug abuse, seizures, head injury, metabolic, systemic diseases, and neuropsychiatric disorders in the family. The patient's mini-mental state examination (MMSE) score was 29 out of 30 indicating no mild cognitive impairment was found and dissociative amnesia was diagnosed based on the signs, symptoms, and findings.

On observation, the resting tremor was pin-rolling and had a frequency of approximately 4 to 6 Hz. The patient struggled to get out of a chair and stood with a flexed posture. The gait shown was characterized by small-shuffling steps with a retained arm swing. A structural brain organic lesion and metabolic abnormalities due to the radical thyroidectomy were suspected. The results of a blood diagnostic workup showed 9,640/µl leukocyte, 12.2 g/dl hemoglobin, 119 mg/dl blood sugar, 35 mg/dl urea, 1.13 mg/dl creatinine, low parathyroid hormone (PTH) (7.9 pg/ml), low calcium (0.57 mmol/l), 3.27 mmol/l potassium, 144.14 mmol/l sodium, and 102.87 mmol/l chloride. As shown in Figure 1, the computed tomography (CT) scan revealed bilateral symmetrical large areas of calcification over the corona radiata, basal ganglia, and dentate nucleus, which was suggestive of FS. FS secondary to hypoparathyroidism was diagnosed in the absence of autosomal dominant inheritance in the family history.

Results

The treatment was focused on the patient's specific pathology as well as symptomatic therapy. The movement disorders resolved with the administration of α-hydroxy-vitamin-D3 5000 IU o.d. and corticosteroid dexamethasone 0.5 mg o.d. for two months. Furthermore, we implemented novel approach of supportive ventilation psychotherapy for two months or more as needed. This psychotherapy provides the widest possible opportunity for the patient to express what is in his heart so that he feels relieved and his complaints are reduced. Therapist attitude is to be a good listener and full of understanding. Topic of discussion is problems that become the main stress. Psychotherapy, hypnosis, family and group therapies were also used to treat dissociative amnesia. This was suggested so that the patient feels safe, and the companion was educated on the need to reacquaint her with personal memoirs and belongings. In addition, re-traumatization factors should be discussed with the family or relatives, as well as the importance of avoiding them. During the two-month post-treatment follow-up, the patient was still cooperative by showing good mental and emotional adaptation during ventilation psychotherapy, and her family, also reported that no amnestic symptoms. Furthermore, the post-treatment MMSE score was 29 showing no decline and indicating her cognitive remained alert and good.

Discussion

The diagnosis of FS must be distinguished from FD because of the differences in prognosis and

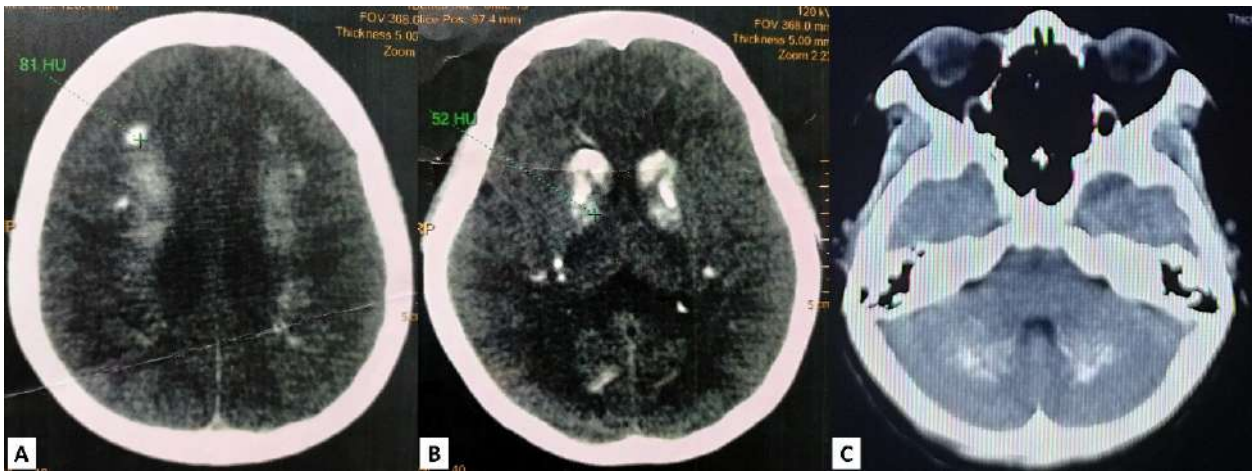

Figure 1. Axial non-contrast CT-scan depicts bilateral symmetric calcifications in corona radiata (A), basal ganglia (B), and both dentate nuclei (C).

treatment (Perugula & Lippmann, 2016). The age of onset in the fourth or fifth decade, a family history consistent with autosomal dominant inheritance, and the absence of metabolic systemic disorders are all diagnostic criteria for FD. FS should be considered in the presence of metabolic or other systemic disorders that could be explained as an underlying cause of calcification. The presence of metabolic or other systemic disorders that could be explained as an underlying cause of calcification should be considered as FS (Perugula & Lippmann, 2016). FD requires only symptomatic therapies, however, FS should be treated with symptomatic therapies directed at the underlying primary causes (Saleem et al., 2013).

The neurological manifestations of Parkinsonism are usually found in FS (Grover et al., 2011). The other common neurological signs and symptoms include headache, vertigo, stroke-like events, seizures, syncope, spasticity, dysarthria, chorea, dystonia, and myoclonus (Savino et al., 2016). Symptomatic or asymptomatic bilateral symmetric calcification can occur in various conditions. Therefore, clinicians should carefully exclude other potential diagnoses because the size of calcification affects manifestation, particularly dementia and extrapyramidal symptoms (Saleem et al., 2013).

Psychiatric disorders are common in FS, with 40% of patients presenting them as their initial symptom (Saleem et al., 2013). According to previous research, mood disorder, psychotic symptoms, and cognitive disturbance are the most common features (Calabrò et al., 2014; El Hechmi et al., 2014; Naqvi et al., 2017; Roiter et al., 2016). An incidental finding of FD in a hypochondriac patient was also reported in previous research (Samuels et al., 2018). In addition, there was an unusual and previously unreported presentation of fugue, retrograde memory loss, and autobiography amnesia in our case. The patient's amnesia was examined to see if it could be attributed to the calcification. The coincidental onset of amnesia following the patient's family loss, as well as the typical FS symptoms, increased the diagnostic difficulty. However, the coexistence of organic and psychological factors is common in amnesic patients.

Previous research recommended the identification of structural calcinosis-causing amnesia in the anatomical structure of the memory processing area (Lucchelli & Spinnler, 2002). The calcification of the patient's brain did not involve the declarative memory processing area, such as the hippocampus, medial temporal lobe, or diencephalon (Engelhardt, 2020). There has been an established relationship between brain calcification and psychiatric symptoms. The presence of brain calcification and progressive subarachnoid space dilatation is associated with widespread psychiatric symptoms (Lauterbach et al., 1998). Moreover, the stress trigger of her husband's death was believed to be the cause of neurotic psychiatric disorders such as dissociative disorders.

Movement disorders in PTH-related FS can be resolved by correcting the calcium and phosphate levels (Abubakar & Saidu, 2012). Corticosteroid therapy also reversed the neurological deficits (Saleem et al., 2013). Meanwhile, levodopa efficacy in FS with Parkinsonism is reportedly poor (Asokan et al., 2013). Psychotherapy has become the treatment of choice since no evidence-based treatments for dissociative amnesia are available. Medication can also be used to alleviate symptoms of anxiety and depression (Staniloiu & Markowitsch, 2014). However, lithium was not administered because it may increase the risk of seizures in the patient (Saleem et al., 2013).

Conclusions

We conclude that dissociative amnesia is a rare presentation of FS. Although the brain calcification did not affect the memory-processing area in this case, the history of family loss is a known cause of dissociative amnesia. There are no known cases in which these diagnoses coexisted. Therefore, further research is recommended to explore how brain calcinosis causes dissociative amnesia. We recommend the use of α-hydroxy-vitamin-D3, dexamethasone and supportive ventilation psychotherapy to alleviate the hypocalcemia-caused FS symptoms and dissociative disorders, respectively.

Declaration of Interest

All authors declare that they have no conflict of interests.

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Data Availability

Available on reasonable request from the corresponding author's email faizal9m@student.uns.ac.id.

Ethics statement

Written informed consent was obtained from the patient. The copies of the written consent and ethical approval (Health Research Ethics Committee of Dr. Moewardi General Hospital No.22/I/HREC/2022) are available for review by the Editor-in-Chief of this journal.

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