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ORIGINAL ARTICLE OPEN ACCESS

Navigating the Global Nursing Shortage: Collaborative Strategies for Education and Mobility

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Globally, nursing is a vital profession that contributes to the health and wellbeing of individuals, families, and communities. However, as the world emerges from the COVID-19 pandemic, there continues to be a global nursing shortage. Even before the pandemic, there was a shortage of nurses that varied considerably between countries (Drennan & Ross, 2019). Back in 2016, the World Health Organization (2016) predicted a shortfall of 7.6 million nurses by 2030, with the most severe impact in low- and middle-income countries. The COVID-19 pandemic has exacerbated the shortage of nurses (ICN, 2022).

There are many factors contributing to the global nursing shortage. Addressing the global nursing shortage requires collaboration between academic and practice partners to educate, support, and retain nurses in the workforce. This will involve increasing the total number of nursing graduates each year and improving the capacity to hire and retain those graduates (WHO, 2020). Therefore, investing in nursing education and nursing professional development is essential to increase the supply and quality of nurses, and to have a positive impact on the retention and satisfaction of nurses (Drennan & Ross, 2018). It will also include working together to assist global mobility. In this editorial, I would like to further discuss working together to support nursing education and global mobility.

The nursing workforce in many countries is becoming more culturally and linguistically diverse because of global mobility (Juntunen et al., 2024). Nurse educators in academic and practice settings play a role in facilitating the success of this diverse nursing workforce. To ensure patient safety and improve patient care, it is essential that this diverse nursing workforce is competent to work, in both their country of origin and the new country. To facilitate the assessment of nursing competence across countries, nursing curricula must provide the resources and structure to support global mobility (Juntunen et al., 2024). As there is variability in nursing curriculum, nursing licensure within country, and recognition of nursing licensure from other countries, there is a need for comparative analysis across countries to better understand these differences.

There are many reasons for nursing global mobility, i.e. family move, calling to serve, working conditions, etc. A way that academic and practice settings can support global mobility is to advocate for circular migration. In circular migration, the nurse would return to their originating country. By supporting circular migration, the nurse is exposed to training and different skills. The receiving country and hospital receive a competent nurse to work for a period of time, making an impact on the healthcare of that country. And finally, the originating country and hospital receive the nurse back, who can now share their training and experiences with others and continue to make an impact in the healthcare of their originating country.

In conclusion, addressing the global nursing shortage is a multifaceted issue that requires concentrated efforts from all stakeholders. By promoting collaboration between nursing academic and practice partners, we can educate, support, and retain more nurses in the workforce. We need to work together with policymakers and boards of nursing to facilitate and support circular migration. By working together, we can increase the nursing workforce and improve patient care to strengthen healthcare systems globally. Together, we can overcome the nursing shortage and create a healthier future for all.

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The development of an islamic nursing care model to improve patient satisfaction

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ABSTRACT

Introduction: Nurses are the determinants of patient satisfaction because the majority of actions involve nurses and provide holistic nursing care consisting of spirituality. Spirituality is an important key because it is one of the strong factors in assisting healing and recovery of the patient himself. Spirituality can be fulfilled through Islamic nursing care. This study aimed to the development of an Islamic nursing care model to improve patient satisfaction.

Methods: Cross-sectional design random sampling technique on 134 respondents, consisting of patients and nurses in the surgical inpatient room, internal medicine inpatient room, and postpartum and gynecology inpatient rooms, using simple random techniques. The variables of this study were the nursing factors, Islamic nursing care, and patient satisfaction and were collected using questionnaire. The data were collected using questionnaire in December 2021 at Islamic Hospital, Indonesia, and processed using a Smart Partial Least Squares (SmartPLS) analysis and Sommers' correlation test.

Results: The Sommers' test results show significant relationship between nursing factor (nurse knowledge, nurse's attitude, nurse competence, nurse personality) and patient satisfaction; nurse knowledge ($p=0.000$); nurse attitude ($p=0.000$); nurse competence ($p=0.000$); nurse personality ($p=0.000$; $\alpha<0.05$). SmartPLS test results show the nurse factor with Islamic nursing care has a strong significant influence (p value 0.000; β value 0.539; t value> 1.96). Then for Islamic nursing care with patient satisfaction, it has a very strong significant effect (p value 0.000; β value 0.753; t value> 1.96).

Conclusions: Islamic nursing care as a mediator of nurse factors with patient satisfaction can be described in this study model because Islamic nursing care is a real form of care by nurses that is felt by the patient and the application of Islamic values so that the form of nursing care makes patients feel satisfied. This model is a new breakthrough for the world of nursing and hospitals in improving the quality of nursing care.

Keywords: nurse, islamic nursing care, model, patient satisfaction, spiritual

Introduction

The current era shows that hospitals as health service industries are experiencing very tight competition. Competition between hospitals relies heavily on aspects of service quality, with the method used to improve the quality of health services, namely by developing Islamic-based services (Washeya and Fürst, 2021). A reflection of the Muslim population with the second largest population in the world, s about 1/3 billion, it can be used as an opportunity for hospitals to improve Muslim services. In India, Muslims account for about 25%, for the second most, namely Africa, there is 17%, then in Arab countries it is 18%, 10% in the Old Soviet Republic and the non-Arab Middle East and for

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Southeast Asia alone, there are 17% (Amir, 2020), In Indonesia there are 237,531,227 Muslims with Central Java alone having 35, 607,889 or 96,5with Islam as their religion (Statistic Center, 2021). It can be used as an opportunity for hospitals to improve Muslim services or Islamic health services. Islamic health services include all forms of management of activities including medical care and nursing care that are framed in Islamic principles. Nursing services are an important part of quality and safety in hospital care and are a determining factor in patient satisfaction with treatment outcomes, satisfaction is a happy state and means satisfaction with an action or an event after the patient uses the service (Aboosalehi *et al.*, 2022). Thus, nursing care is an important part in determining patient satisfaction (Dewi, Yanti and Saputra, 2020).

The reason why Islamic nursing care can increase patient satisfaction is because patient satisfaction is influenced by aspects of the patient's religion, as stated by Wardah, Usman and Wardani, (2020) in a qualitative study which showed that the majority of the population in Indonesia is Muslim, so society has strong Islamic values and ideology in daily life that are guided by the Al-Quran and Hadith (the teachings of the Prophet). The principle of patients following Islamic teachings plays an important role in decision-making, family dynamics in health practices, and service selection; therefore, this aspect is the basis for why Islamic nursing care can increase patient satisfaction. However, until now, there has been no research regarding the relationship between Islamic nursing care and increasing patient satisfaction, so further quantitative research is needed on this topic. Islamic nursing care is different from ordinary nursing care because it applies Islamic values, the application of which is as follows (1) Before carrying out the action the nurse reads *Bismillah* and invites the patient to pray to Allah SWT to ask for healing and after the nursing action the nurse reads *Hamdallah* or *Alhamdulillah*; (2) Remind and assist patients in carrying out the prayer service (3) Nurses in communicating with patients, families or fellow medical personnel must apply Islamic communication ethics, (4) The patient will be cared for by a nurse of the same gender as the patient, because the patient has the right to receive treatment based on his or her gender, (5) Nurses in providing nursing actions also apply Islamic values such as listening to the chanting of the Qur'an when the patient feels pain or anxiety so that the patient feels comfortable because he hears the chanting of the Qur'an. These values differentiate Islamic nursing care from ordinary nursing care, so that Islamic nursing care can meet the spiritual needs of patients. Aspects of spirituality cannot be separated from nursing care, which is an integral part of nurses' work with patients. This is because the spiritual dimension is one of the strong factors in assisting healing and for the recovery of the patient himself (Talibo, Kurniati and Widakdo, 2019). Patient satisfaction, in addition to being influenced by Islamic nursing care, is also influenced by factors related to nurses. This is because, when providing services to clients or patients, nurses with a good knowledge, attitude, competence, and personality can make patients feel nurses are working professionally and caring (Dehghani, Sobhanian and Jahromi, 2022).

Nurse knowledge can make patients feel satisfied; this has been proven in research conducted by Kartini *et al.* (2022) which shows that nurse knowledge has a relationship with nursing care because the patient feels that nursing care is carried out correctly because nurses have a level of knowledge that is reflected in good skills and competence, as well as problems that are resolved quickly. Another nurse factor that can influence nursing care is also formed by nurses' attitude indicators, as in the research by Belladona, Istichomah and Monika, (2020) which showed that nurses' caring attitudes influence nursing care. Nurses' attitudes can shape nursing care because they are influenced by their interactions with patients. Additionally, the services provided by nurses are among the various basic services available in health services or hospitals. This cannot be denied as the cause of nurses' interactions with patients becoming more intense, but there is no research on nurses' attitudes toward patient satisfaction (Kartika, Hariyati and Nelwati, 2018). Additionally, nurse competence can affect the quality of nursing care Takase, Yamamoto and Sato, (2018) showed that competence was related to nurse performance, which is the ability of nurses to effectively demonstrate a series of attributes, such as attitudes, knowledge, and skills, to professionally fulfill their responsibilities (Suprapto, Mulat and Lalla, 2021). Another factor that affects the performance of nurses, namely, personality, is evident from a study showing that the performance of nurses is influenced by personality (Sovia *et al.*, 2019). Personality is related to individual behavior, individual character of other people, and qualities that make them attractive (İspir, Elibol and Sönmez, 2019).

Nurse factors show that the spiritual dimension influences patient satisfaction, but there has been no research related to Islamic nursing services, even though Islam is the majority religion in the world; therefore, the spiritual needs of Muslim patients are very high. This research was conducted at an Islamic hospital located in Central Java. Regarding the role of nursing factors these are nurse knowledge, nurse attitude, nurse competence, and nurse personality, but there is no research as to Islamic nursing. Seeing the role of Islamic nursing care in patient satisfaction, the researcher is interested in researching about the role Islamic nursing care model as a key mediator of nurses with patient interaction in Islamic hospitals. Thus, the purpose of this study was the development of an Islamic nursing care model to improve patient satisfaction.

Materials and Methods

Design

This research is analytically observational with a cross-sectional design (Nursalam, 2020).

Setting

The study was conducted at an Islamic hospital in in Demak Regency, Central Java Province, Indonesia. Data collection was carried out in December 2021.

Population

The number of respondents in this study was 142. From the total sampling calculated with the Slovin formula, the total population was 71 patients and 71 nurses; after calculating the result was 67 inpatient nurses and 67 patients treated in inpatient rooms (Nursalam, 2020).

Data collection

The sampling was done using simple random sampling. The randomization system in this study uses a lottery that is shaken in a tube container, and the bed and room number listed in the lottery that comes out is used as the respondent. The inclusion criteria set for patients were patients in the inpatient room (in the surgical inpatient room, internal medicine inpatient room, and postpartum and gynecology inpatient rooms.), able to read and patients with Islam religion, with the exclusion criteria being outpatients to avoid research bias caused by outpatients only experiencing temporary services, unlike inpatients who experience it for more than 24 hours, patients in the intensive care unit, or patients with decreased consciousness. This was done to avoid bias research because the majority of patients in the intensive care unit experience decreased consciousness, so they cannot assess satisfaction with nursing care. In addition, exclusion criteria involved neonatal or pediatric inpatient rooms, because babies or children cannot assess patient satisfaction directly, they have to go through the family or parents, so that even though this research assesses satisfaction from patients not from the family, to avoid research bias, they were excluded. Inclusion criteria for nurses were determined as inpatient nurses with a minimum education for the associate degree in nursing at the first level and included people graduating from senior high school taking an associate degree in nursing for 3 years, at the second level graduating from bachelor of nursing, and at the third level graduating from master of nursing. Exclusion criteria were nurses in neonatal or pediatric inpatient rooms, intensive care units and emergency units, the reason being because this study assesses patient satisfaction with Islamic nursing care felt by patients, and patients in outpatient rooms, neonatal or pediatric inpatient rooms, Intensive care units, were not respondents in this study for the reason that patients in these rooms were excluded from this study as stated explained in the patient exclusion criteria, this was done to avoid research bias.

In quantitative research, the credibility of a study relies on the development of instruments used to measure the underlying concepts. The measurement of a variable is designed to achieve consistency, adequacy, accuracy, precision, uniformity, and comparability in assessing and explaining a specific concept. Therefore, the measurement approach encompasses testimony and confirmation variables that function as representations of constructs (Hair and Brunsveld, 2019). This study has exogenous variables of nurse

Table 1 List of questions for participants in in-depth interview

Variables	Indicator	Items	Sources
Nursing factors	Nurse knowledge	10	(DSN-MUI and Mukisi, 2017).
	Nurse's attitude	5	(Sunaryo, 2013)
	Nurse competence	8	(Sutrisno, 2011)
	Nurse personality	5	(Yuniarsih and Suwatno, 2008)
	28		
Islamic nursing care	Assessment	5	(Puspitasari et al., 2020)
	Diagnosis	5	(Puspitasari et al., 2020)
	Intervention	5	(Puspitasari et al., 2020)
	Implementation	5	(Puspitasari et al., 2020)
	Evaluation	5	(Puspitasari et al., 2020)
	25		
Patient satisfaction	Reliability	6	(Nursalam, 2020)
	Assurance	3	(Nursalam, 2020)
	Reality	5	(Nursalam, 2020)
	Empathy	5	(Nursalam, 2020)
	Responsibility	4	(Nursalam, 2020)
	23		

Table 2 Demographic characteristics of nurse and patient and distribution of variable frequency

Demographic characteristics of nurse and patient and distribution of variable frequency

Variable			**n**	**%**
Nurse	Age	17 – 25 years (late adolescence)	6	9.0
		26 – 35 years (early adult)	25	37.3
		36 – 45 years (late adulthood)	36	53.7
	Education	Associate degree of nursing	12	17.9
		Nurse profession	54	80.6
		Master of nursing	1	1.5
Patient	Age	17 – 25 years (late adolescence)	21	31.3
		26 – 35 years (early adult)	13	19.4
		36 – 45 years (late adulthood)	12	17.9
		46 – 55 years (early seniors)	3	4.5
		56 – 65 years (late elderly)	11	16.4
		>65 years old (seniors)	7	10.4
	Education	Primary school	11	16.4
		Junior high school	12	17.9
		Senior high school	33	49.3
		Associate degree	5	7.5
		Bachelor	5	7.5
		Master	1	1.5

Distribution of variable frequency

Variable		**Category scale**			
		Enough		**Good**	
		n	%	n	%
Nursing factor	Nurse knowledge	12	17.9	55	82.1
	Nurse attitude	13	25.4	54	80.6
	Nurse competence	16	23.9	51	76.1
	Nurse personality	17	25.4	50	74.6
Islamic nursing care	Islamic nursing care	14	20.9	53	79.1
Patient satisfaction	Reliability	15	22.4	52	77.6
	Assurance	16	23.9	51	76.1
	Reality	14	20.9	53	79.1
	Empathy	18	26.9	49	73.1
	Responsibility	15	22.4	52	77.6

factors, with endogenous variables being Islamic nursing care and patient satisfaction, with nurse factor indicators namely nurse knowledge, nurse attitudes, nurse competencies, and nurse personality, and patient satisfaction indicators consisting of Reliability, Assurance, Tangible, Empathy, and Responsiveness (RATER). Consequently, the study encompasses a total of 10 indicators representing its three latent variables. All variables in this study were assessed through the use of a questionnaire, and permission to modify or employ the instrument was obtained from the original authors.

The variables used a Likert scale, for nurses and Islamic nursing care factors with strongly disagree, disagree, neutral, agree and strongly agree, while patient satisfaction answers were very dissatisfied, dissatisfied, neutral, satisfied and very satisfied. All variables have a variable scale that is ordinal with an indicator rating of 76%-100% good, 55%-75% enough, and less than 55% (Nursalam, 2020). The validity test results for the nurse factor questionnaire have a validity value of 0.559 to 0.986 and reliability 0.928 to 0.953, and the results for the nursing care questionnaire having a validity value of 0.559 to 0.986 and reliability 0.928 to 0.953. Islam received a score of 0.656 to 0.933, and the patient satisfaction questionnaire received a score of 0.552 to 0.876, with a reliability of 0.906.

Attempts have been made to overcome research bias by providing multiple inclusion and exclusion criteria, which tightens the bias and ensures that the criteria are met for the respondents. The steps in the data collection sequence are: first, by taking care of licensing after obtaining ethical approval; then proceeding with submitting research at a hospital, and finally, after all permits, the research team has completed collecting data through a research questionnaire. The descriptive test uses a frequency distribution test with analysis using Smart Partial Least Squares (PLS).

Data analysis

The inferential analysis used is a structural equation model based on variations and components called structural equation modeling-partial least squares (SEM-PLS), namely Smart PLS. Smart PLS has the advantage because it does not assume that data must have a certain measurement scale. Small samples can also be used to confirm theory and allow testing a series of relationships between variables that are relatively complicated simultaneously. Smart PLS analysis is carried out using Smart PLS software which includes a measurement model (outer model), structural model (inner model), and hypothesis testing. So, seeing the advantages of SmartPLS, it is very suitable for this

Table 3 Analysis of nursing factors correlation with patient satisfaction care in Islamic hospitals

Variable nursing factors		**Patient satisfaction**				**Total**		**P value**
		Enough		**Good**				
Variable	**Category Scale**	**n**	**%**	**n**	**%**	**n**	**%**	
Nurse knowledge	Enough	8	66.7	4	33.3	12	100	0.000
	Good	6	10.9	49	89.1	55	100	
Nurse attitude	Enough	10	76.9	3	23.1	13	100	0.000
	Good	4	7.4	53	79.1	54	100	
Nurse competence	Enough	10	62.5	6	37.5	16	100	0.000
	Good	4	7.8	47	92.2	51	100	
Nurse personality	Enough	10	58.8	7	41.2	17	100	0.000
	Good	4	8.0	46	92.0	50	100	

research, thus o SmartPLS is used as a data processing device in research (Ghozali, 2021).

Guidelines for the outer model or validity test are namely an indicator that is said to be valid if it has an average variance extracted (AVE) value > 0.5 or shows all outer loading variable dimensions that have an outer loading value > 0.5. The second test is the structural model or inner model test, namely the structural model test is carried out to predict the causality relationship between latent variables. The structural model is evaluated by looking at the percentage of variance explained by R^2 (R square) for the dependent variable, then the prediction relevance test (Q-square) known as Stone-Geisser to measure how well are the observed values produced by the model and also its parameter estimates. If the Q-square value is greater than 0 (zero), it indicates that the model has predictive relevance or shows relevance when applied in different areas. Therefore, if the Q-square value is less than 0 (zero), then it has less predictive relevance. To see the magnitude of the structural path coefficient or the magnitude of the relationship or influence of latent variables, a bootstrapping procedure is performed. Hypothesis testing is done by testing the t-statistic or bootstrapping the significance of the hypothesis is obtained by comparing the values of the T-table and t-statistic. If the T-statistic value is higher than the T-table or $t > 1.96$ and the $p\text{-value} \leq 0.01$ (Ghozali, 2021). The second was the bivariate test to test the nurse factors of nurse knowledge, nurse attitudes, and nurse competence of nurses and nurse personality on patient satisfaction using the Sommers' correlation test.

The study was ethically approved by the Medical and Health Research Ethics Committee (MHREC) of the Faculty of Nursing Sultan Agung Islamic University Health Research Ethics Committee on December 8, 2021, under No. 918/A.1-S1/FIK-SA/XII/2021 and obtained the participants' consent through informed consent, thus patients first received an explanation from researchers about the research carried out in full orally and in writing. After the patient understands the research being conducted, the researcher is given informed consent in writing, and then the patient who agrees to be a respondent can sign the informed consent sheet, which is in accordance with the ethical principles of research, namely informed consent, anonymity, confidentiality, fidelity, and autonomy.

Results

The results characteristics of the nurses in the hospital in Table 2 show that the age of the majority of nurses is between 36 years and 45 years of age, or late adulthood (53.7%), with the majority of classified level of nurses' education (80.6%). The age majority is late adolescents aged 17–25 years (31.3%), with the majority education level being high school (49.3%). The frequency distribution test showed in Table 3 that the majority of the variables studied had good levels. This was reflected in the results which showed that the majority of nurses had good knowledge (82.1%). Then the variable on the attitude of nurses had good levels as

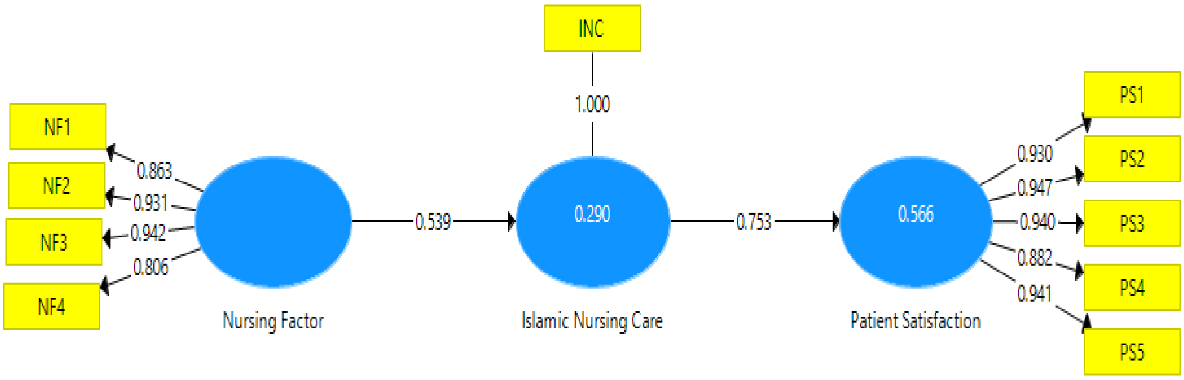

Figure 1. Measurement model evaluation

Table 4. Measurement model evaluation, coefficients of determination, and path coefficients

Measurement model evaluation

Latent variable	Items	Convergent validity		Internal consistency reliability		Discriminant validity
		Loadings	AVE	Composite Reliability	Cronbach's Alpha	HTMT <1
Nursing factor	NF1	0.863	0.788	0.937	0.909	Yes
	NF2	0.931				
	NF3	0.942				
	NF4	0.806				
Islamic nursing care	INC	1.000	1.000	1.000	1.000	Yes
Patient satisfaction	PS1	0.930	0.862	0.969	0.960	Yes
	PS2	0.947				
	PS3	0.940				
	PS4	0.882				
	PS5	0.941				

Coefficients of determination

Variable	R Square	R Square Adjusted
Islamic nursing care	0.290	0.280
Patient satisfaction	0.566	0.560

Path coefficients

Hypothesis	β	SD	t-value	ρ-value	Test result
Nursing factor ➔ Islamic nursing care	0.539	0.095	4.706	0.000	Supported
Islamic nursing care ➔ patient satisfaction	0.753	0.115	7.944	0.000	Supported

Smartpls Output

well. Then, in the third variable, namely the competence of nurses, the majority of nurses have a good level of competence (76.6%), and the majority of nurses have a good personality (74.6%), the nursing care variable shows the majority have good nursing care, (79.1%). Patient satisfaction has five indicators and shows that the majority of nurses have good reliability (77.6%), themajority have good guarantees (79.1%), then on empathy, the majority have good empathy (73.1%), and lastly, the majority have good responsibility (77.6%). There is an effect of nurse knowledge, nurse attitudes, and nurse competence of nurses and nurse personality on patient satisfaction in Islamic hospitals. The nurse knowledge variable shows there is a correlation with p value 0.000 <0.01. The nurse personality variable shows there is a correlation with a correlation p value 0.000 <0.01. The next analysis shows the effect of the nurse competence that there is a correlation with p value 0.000 <0.01, and the last analysis shows the relationship of the nurse personality and there is a correlation with p value 0.000 <0.01.

The interpretation of the measurement model in this test in Table 4 is valid because the reliability of the indicator for each part of the outer loading is higher than 0.7. The AVE value for all variables, was higher than 0.7. The reliability test in this study uses a reference to the value of composite reliability and Cronbach's alpha, which in all variables shows that the value of composite reliability and Cronbach's alpha is more than 0.7 with very reliable results because it is more than 0.80. In the Fornell-Larcker matrix, the square root value of the AVE (diagonal) is greater than all values, and the HTMT value is smaller than 1, so it can be concluded that the discriminant validity of the measurement model is confirmed.

The coefficient of determination in Table 3 shows that the nurse factor is able to determine Islamic nursing care by 0.290 (0.290x100 = 29) or 29% of Islamic nursing care is predicted or determined by the nurse factor while the remaining 71% (100% - 29% = 71%) is determined by other factors. The next coefficient of determination is the value for the ability of Islamic nursing care in determining patient satisfaction which shows the results of 0.566 (0.566x100 = 56.6) or 56.6% of patient satisfaction is determined by Islamic nursing care while the remaining 43.4% (100% - 56,6% = 43.4%) is determined by other variables outside this study.

The evaluation of the model structure in Figure 2 shows the results of the structural model analysis. The results of this study show the path coefficients along with the level of significance. The path coefficients contained in Table 3 are used to test the hypothesis; the path coefficient test shows a significant relationship between the nurse factor and Islamic nursing care, the nurse factors form a strong significant influence with a positive direction (p value 0.000 <0.01; value 0.539; t value> 1.96, then for the second hypothesis, namely Islamic nursing care with patient satisfaction, this is also accepted because having Islamic nursing care has an influence on patient satisfaction with a very strong significant effect in a positive direction (p value 0.000 <0.01; value 0.753; t value> 1.96).

There are several cultures and beliefs associated with the health condition of children in general. Particularly for adolescent mothers, the stigma of being pregnant is synonymous with the moral problem that they got pregnant before marriage, making them

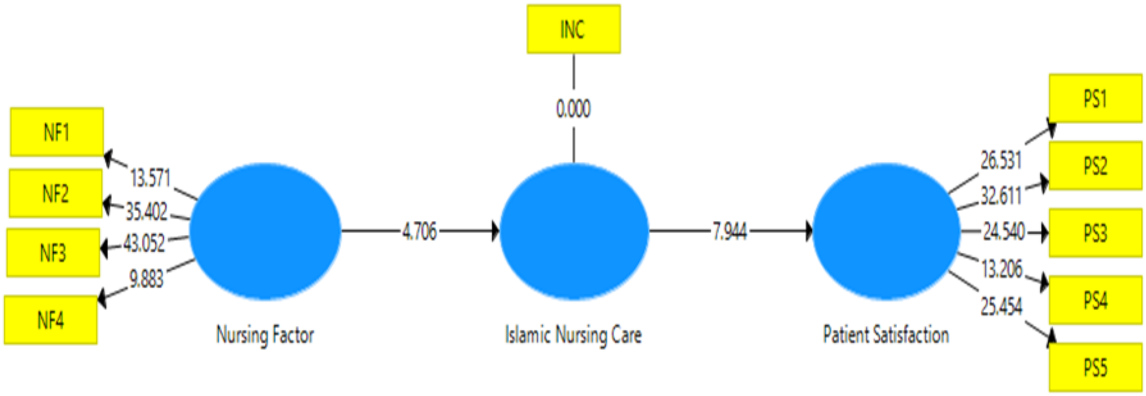

Figure 2. Structural model evaluation

reluctant to have an examination. Apart from that, their disobedience in consuming iron tablets, because of the belief that iron tablets will make the baby bigger, makes pregnant women the target of "kuyang" ghosts, and consuming iron tablets is a prayer so that pregnant women become sick, due to taking medicine.

Discussions

The majority of nurses in this study were 36–45 years old or in early adulthood, which shows that the majority of nurses were in the late adult age range, with female gender. These results are in line with a study which showed that the majority of nurses were aged 31 - 40 years with the majority being female. This study also showed that age and gender were not related to the implementation of nursing care. Age in this study does not form a construct of nursing factors because the knowledge, competence and skills of nurses or the performance of nurses in providing nursing care are not only influenced by the age and gender of a nurse but by various other influencing factors such as skills, length of work, and training (Andrew *et al.*, 2023).

The results of this study also show that nurse education is one of the indicators that is unable to form nursing factors. These results are in line with studies which show that the education of the majority of nurses is Diploma 3 and this level of education cannot be related to the implementation of nursing care (Furroidah, Maulidia and Maria, 2023). The results of this research show that the majority of nurses' education is still Diploma 3 so it still needs to be improved because a higher level of education can increase the knowledge and skills of nurses. But, because in this research the majority of nurses still have Diploma 3 education, they are unable to form a construct of nursing factors. Nursing factors can significantly influence Islamic nursing care and patient satisfaction. These results are in line with research which shows that nurse education can influence nurse skills (Tomotaki, Fukahori and Sakai, 2020). Nurse education can determine the skills and knowledge of nurses because nurse education is the basis for developing nurse competency, and through education, nurses can obtain the theoretical knowledge needed in clinical settings, and the knowledge gained can be applied to practice (Park, 2022). Clinics are needed to improve nurse competency and nurse attitudes, because in the nursing care process there is an integral relationship between patients and nurses and their respective emotions, and nursing education prepares students to handle their and the patient's emotions, so that when in clinical situations nurses can behave and control emotions in dealing with patients well (Dugué, Sirost and Dosseville, 2021).

Knowledge in this research was proven to be an indicator that forms nursing factors, and nursing factors are one of the elements that determine Islamic nursing care. This influence is in line with studies which found that knowledge was related to nurses' caring behavior. Knowledge can be related to Islamic nursing care; knowledge is the result of individual knowledge that individuals can obtain through learning or experience, so in behaving and acting in providing nursing care based on Islamic principles, nurses must know about Islamic nursing care which will later become the basis for behaving and providing nursing care to patients or clients (Kartini *et al.*, 2022).

The nursing factors in this study were also formed by indicators of nurses' attitudes. Nurses' attitudes can be related to Islamic nursing care because the attitudes and behaviors that nurses practice in relationships with patients and families greatly determine the success of nursing care. Nurses' attitudes depend on the nurse's spiritual intelligence which has a significant impact on service hospital and consists of eight components, namely honesty, openness, humility, kindness, generosity, tolerance, resilience, and the desire to meet the needs of others. This causes people with high spiritual intelligence to have more competence and greater flexibility, which is effective in improving the quality of work, so that nurses view work as an opportunity to help others. This causes patients to be more satisfied with nurses with a high level of spiritual intelligence. Nurses who provide nursing care are a multidimensional concept because it involves a set of dimensions and conditions that describe attitudes and behavior related to showing interest and appreciation for the patient's psychological, social and spiritual values (Agostinho *et al.*, 2023). Therefore, attitude is the key to the quality of nursing care and patient satisfaction (Alasqah *et al.*, 2023).

The results of this research show that nurse competency is one of the factors forming nurses, and is related to Islamic nursing care and patient satisfaction. The results of this study are in line with study which shows that competency is related to nurse performance (Suprapto, Mulat and Lalla, 2021).

Competence is a dimension of task actions, where these actions are used by nurses to complete tasks and provide patient satisfaction. This happens because competency is also a fundamental thing that determines a nurse's performance (Byre, 2021); therefore, hospitals that want to increase patient satisfaction must make nursing competency, a key that should not be overlooked (Acharya *et al.*, 2019). The competency of nurses in this study shows that there are still categories that are less than optimal; therefore, to increase patient satisfaction through Islamic nursing care, hospitals need to increase the competency of nurses, to increase patient satisfaction.

This research also shows that nursing factors are formed by the nurse's personality, and are related to Islamic nursing care. Personality is a trait related to individual behavior, and is an individual's character in how they behave toward other people and the qualities that make them attractive. Personality consists of four important elements, namely emotional intelligence, emotional stability, self-integrity and optimism, which are the elements important in the personality structure of nurses (Kuntarti *et al.*, 2020). Personality is one of the factors that influences the work of nurses, such as providing holistic services; the performance of nurses who can meet patient needs as a whole can make patients feel satisfied with nursing services (İspir, Elibol and Sönmez, 2019).

Nursing services are actions that occur because of the reciprocal relationship between nurses and patients; a good nurse's personality is the basis for nurses to understand the patient's situation accurately (Lee & Seo, 2022). This basis can explain why, in this study, the nursing factors can shape Islamic nursing care; nurses with good personalities can have good interactions which will increase patient comfort so that the better the attitude of nurses in providing nursing care, the more happy patients and families will receive the service.

This statement is in line with this research which found that nursing factors can influence Islamic nursing care, this is because various nurse indicators can form nursing factors nurses education is an important indicator in determining nurse performance, apart from knowledge, attitude, competence and personality which also play a role. It is important in determining Islamic nursing care, and when carrying out nursing care, nurses who have good personalities will treat patients with caring, so that high levels of concern and affection are reflected in the words and body language of nurses and nurses who always try to understand and care about their needs (Chachula, 2021).

Another study that examined the provision of nursing care with patient satisfaction was conducted in China and showed that the nursing care provided had a relationship with patient satisfaction (Zhi *et al.*, 2021). Feeling satisfied with the services provided by health facilities or hospitals is an important right for every patient. Patient satisfaction is defined as a basic criterion that can provide information about the level of patient values and expectations and show the quality of patient care (Lotfi *et al.*, 2019). Islamic nursing care can increase patient satisfaction because positive behavior carried out by health workers indirectly has moral meaning for patients and families, because they feel comfortable, calm and cared for because they get nursing care from responsible health workers, who believe and behave well based on Islamic norms and ethical values, thus motivating patient recovery. Therefore, Islamic nursing care can affect the level of patient satisfaction.

Exploring the role of nurses on the spiritual side is a very important topic to discuss because considering the role of nurses cannot be separated from the spiritual side. This is because nurses view individuals or humans holistically or have a holistic response to health changes. Therefore, giving nursing care that is carried out as a whole has a significant benefit or impact on the recovery of the patient or client. This is because the physical health condition of the patient or client has a relationship with the mental state and spiritual state. Therefore, nursing care cannot be separated from the spiritual side (Dewi, Nurrohmah and Fikri Rizki Fadlurrahman, 2020). This is the reason why patient satisfaction is influenced by Islamic nursing. Therefore, this study can show that Islamic nursing care modelling is a very important liaison mediator between the factors of nurses and patient satisfaction, so Islamic nursing care has a significant influence on patient satisfaction.

The strength of this research is that it has a significant positive impact because Islamic nursing care differs from conventional nursing care in its implementation. Furthermore, the interventions and implementations also differ significantly from ordinary nursing care, including practices such as murrotal al-Quran therapy, dhikr therapy, thaharah guidance, prayer guidance tailored to the patient's abilities. These distinctive features enable Islamic nursing care to fulfill all needs of patients and their families, ultimately leading to increased patient satisfaction. Therefore, this study has a positive impact on nurses, nursing students, and nursing practitioners, as it is closely related to the service system. Academic institutions can utilize this research to develop educational processes that teach students Islamic nursing care. Additionally, nursing managers and directors can benefit from this research by providing valuable information to nurses for designing training or workshop classes to improve the knowledge, attitudes, and competencies, as well as the personality of nurses in accordance with Islamic principles or values, which have implications for the quality of Islamic nursing care and patient satisfaction.

This increased knowledge enables nurses to deliver the best nursing services to patients, ultimately resulting in higher patient satisfaction. Moreover, this study positively impacts healthcare facilities by emphasizing the enhancement of nurse-related factors, which subsequently boost patient satisfaction. Ultimately, these benefits contribute to the improvement of society. This research, as has been stated, has many strengths, but in this quantitative research, it has a cross-sectional research design, so there is still a broader design, namely randomized controlled trials, systematic reviews, and meta-analysis to strengthen the findings in this research, so future researchers can carry out further research with this design to further strengthen evidence-based nursing.

Conclusion

Nurses with good knowledge, competence, who are supported by good attitude, and personality can form professional quality nurse work so that it is improving Islamic nursing care; thus, the patient feels that all his needs are met, the patient feels comfortable, and has patient satisfaction with nursing services. Thus, this research also has a positive impact on health facilities. Improving these nurse factors will increase nursing care. As a result, when patients are satisfied with nursing care, their loyalty can increase, and in turn this makes the health services better. This research is a study that produces and describes a model that explains Islamic nursing care as a mediator of nurse factors and patient satisfaction, by dissecting four nurse factors indicators that show a role in determining Islamic nursing care, and Islamic nursing care determines satisfaction. It is expected that future researchers are able to use other designs such as randomized controlled trial or quasi experimental design in a hospital setting. Hospital and nursing managers should be aware that nurse factors have a positive impact on nursing care and that the interaction between nurse factors and nursing care can improve patient satisfaction. Thus, nursing care can be implemented in Islamic hospitals as a key to hospital expansion.

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Conflict of interest

None declared

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ORIGINAL ARTICLE

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Low-birth-weight scorecard for early prevention: the accuracy for predicting low-birth-weight infants based on maternal risk factor

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ABSTRACT

Introduction: Babies with low birth weight (LBW) have a risk of complications and health problems. One of the efforts to prevent LBW births is to detect risk factors in pregnant women. This study aimed to test the accuracy of an early LBW detection scorecard based on maternal risk factors.

Methods: The research design used was observational analytical. The sample in this study was 177 mothers who were registered and delivered at hospitals and public health centers in Surabaya and were selected using a purposive sampling method. The research instruments used were LBW scorecard, maternal medical records, and baby's scale. The accuracy of the scorecard was measured with Mann-Whitney test, and Receiver Operating Characteristic (ROC) curve.

Results: The LBW scorecard which was based on maternal factors analysis can significantly predict LBW births (p = 0.000). Based on the ROC curve analysis, it was known that the early detection scorecard has a cut-off point of 3.5, and an accuracy of 88.70%, which indicated that the scorecard has high accuracy in predicting LBW.

Conclusions: The LBW early detection scorecards is able accurately to predict the incidence of LBW births. Through analysis and calculation of maternal risk factor, it can be seen whether the mother is at risk of giving birth to a LBW or normal weight baby. Early detection of LBW can improve services for at-risk babies, resulting in a positive impact on their health outcomes.

Keywords: low birth weight, scorecard, maternal risk factors

Introduction

Children's growth and development can occur optimally if the mother has good physical and psychological conditions (Park *et al.*, 2018). A child's growth and development begin at the beginning of conception and pregnancy; therefore, the physical, psychological and nutritional conditions expended by the mother need to be maintained because they greatly influence the growth and development of the fetus (Suryati, 2014). Mothers who experience malnutrition during pregnancy have a greater risk of giving birth to LBW babies and having health problems. Apart from that, the incidence of LBW also has an impact on several other health problems and increases the neonatal mortality rate (Tadese *et al.*, 2021). The World Health Organization (WHO) defines LBW as a newborn with a body weight below 2,500 g (WHO, 2014). LBW is a public health problem at a global level that has short-term and long-term consequences. It is estimated that between 15% and 20% of all births in the world are LBW births. The target set by WHO by 2025 is to achieve a 30% reduction in the number of babies born with a body weight of less than 2500 g (WHO, 2014).

One of the risk factors for LBW babies is the mother's history of high-risk pregnancies. The estimated number of pregnant women at high risk or complications in the city of Surabaya in 2016 was 9,496 people. Meanwhile,

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the coverage of high-risk pregnant women or complications treated at health facilities is 90.24% (City, 2016). The Infant Mortality Rate (IMR), Under-five Mortality Rate, and Maternal Mortality Rate (MMR) are important indicators to determine the level of public health. Indonesia is expected to be able to reduce MMR and IMR as an effort to support the achievement of the Sustainable Development Goals (SDGs) (Hapsari, 2019). There is a trend toward a decrease in the proportion of birth weights of less than 2,500 g. In 2013 the proportion of LBW decreased by 5.7% and in 2018 it was 6.2%. The 2019 RPJMN target is 8%; however, the results of the 2016 National Labor Force Survey are around 6.9% (Riskesdas, 2018), while the LBW percentage in Surabaya in 2018 is around 1.96 (Surabaya Health Office, 2018).

Babies with very low birth weight experience decreased cognitive, language and motor function (Endalamaw *et al.*, 2018). Previous research results explain that babies with low birth weight show an increased risk of death, growth retardation and neurodevelopmental delays, especially in children with very low birth weight (Hailu and Kebede, 2018). Additionally, newborns with low birth weight have a higher risk of stillbirth, low Apgar scores, admission to the neonatal intensive care unit, and early neonatal death (Wachamo, Bililign Yimer and Bizuneh, 2019). Apart from giving birth to LBW babies, pregnant women are at high risk, which can result in irregular/obstructed labor, fetuses dying in the womb, and pregnant women/mothers in labor dying (Utami, Purwanti and Aprilia, 2019). Several efforts have been made by the government to achieve child health targets from the time the fetus is in the womb until it is 18 years old. Some of these programs include integrated Antenatal Care (ANC), neonatal visits, immunizations, growth and development detection, and others. This effort aims to prepare healthy, intelligent and high-quality children. future generations and reduce child mortality (Riskesdas, 2018). Apart from that, various efforts are also made to prevent LBW births by controlling risk factors in pregnant women in the form of integrated ANC during pregnancy, providing additional food to pregnant women who experience chronic energy deficiency, and providing *roborantia*. Another effort that can be made is to detect pregnant women who are at risk of giving birth to LBW babies by scoring risk factors (Susilaningrum *et al.*, 2018).

Popular assumption states that LBW can be significantly reduced with special medical care during pregnancy. In previous study, risk factors in pregnant women that can be easily assessed using basic methods have been carefully examined throughout pregnancy and formed the basis of predictions. Early detection can help prevent the possibility of LBW and also provide several recommendations through diverse intervention mechanisms (Yarlapati, Dey and Saha, 2017; Porro *et al.*, 2020). Several risk factors in mothers that are considered to influence the occurrence of LBW are history of giving birth to LBW, maternal employment, parity status, gestational age < 37 weeks, gemelli pregnancy, educational history, experiencing pre-eclampsia or having levels of chronic hypertension history, maternal HB < 8 g /dl (Trimesters (TM) 1 and 3) or < 10.5 g/ dl (TM 2), and having a history of pre-gestational diabetes mellitus (Baker *et al.*, 2018; Wachamo, Bililign Yimer and Bizuneh, 2019). Early detection of LBW can improve services for at-risk babies, thereby having a positive impact on their health outcomes. Early detection of LBW helps mothers to better understand whether their condition during pregnancy is included in the risk category (Arsyi, 2021). The results of studies carried out at the previous stage found that there was potential for the developed scorecard to predict LBW in mothers through calculating risk factors (Utami *et al.*, 2023). However, the accuracy of low-birth-weight scorecard in predicting low-birth-weight infants is not yet known. This study aimed to test the accuracy of the LBW early detection score card based on maternal risk factor.

Materials and Methods

Design

This research used an observational analytical design to examine the accuracy of an early LBW detection scorecard based on maternal risk factors.

Sample

The research sample was 177 mothers who had registered and gave birth in hospitals or health centers in the city of Surabaya. Sample selection used a purposive sampling method based on inclusion and exclusion criteria. The inclusion criteria in this study

Table 1. Risk factor scorecard

Risk Factor	Score
There is past history of giving birth to LBW	10
Mother works (makes a living)	2
Current maternal parity status: Primipara (one delivery) or grande multi-para (≥5 times)	2
Gestational age at delivery <37 weeks	2
Gemelli/double pregnancy	1
Mother's last education < high school / equivalent	1
In this pregnancy experiencing pre-eclampsia	1
In this pregnancy, maternal HB levels < 8 g/dl (TM 1 and 3) or < 10.5 g/ dl (TM 2)	1
Have a history of chronic hypertension	1
Have a history of pre-gestational diabetes mellitus	1
Total Score	22

were 1) mothers who gave birth in a hospital or health center in the city of Surabaya, 2) willing to be respondents, and 3) cooperative. Meanwhile, exclusion criteria included 1) mothers whose babies died at birth, 2) mothers or babies experiencing serious complications and requiring intensive care.

Study Instrument

The instruments in this research were a demographic questionnaire and maternal medical records during pregnancy, infant weighing scale, and an early detection scorecard for LBW which had been developed in the previous study (Utami *et al.*, 2023).

Based on Table 1, the scorecard consists of several indicators, including history of giving birth to LBW, maternal employment, parity status, gestational age <37 weeks, gemelli pregnancy, educational history, experiencing pre-eclampsia or having levels of chronic hypertension history, maternal HB <8 g/dl (TM 1 and 3) or <10.5 g/dl (TM 2), and having a history of pre-gestational diabetes mellitus.

Data collection

The research began with the selection of research samples, namely mothers who gave birth in hospitals or health centers in the Surabaya City and were willing to be respondents. Mothers were assessed and scored on their maternal factors causing LBW based on several components on the scorecard. The scoring results were then adjusted to the cut-off point limit. If the risk factor scoring result was < 3.5 then the baby was predicted to have normal birth weight, whereas if the cut-off point result was ≥ 3.5 then the baby was predicted to experience LBW. The prediction results were then matched with the birth weight of the babies in each group. After that, the mother was followed until she gave birth, and the birth weight of the baby was measured using a scale. Mothers who had babies with a birth weight of < 2,500 grams were grouped in the LBW group, while mothers who had babies with a birth weight of ≥ 2,500 grams were grouped in the normal group.

Testing Scorecard Accuracy

At this stage, the researchers tested the accuracy of LBW scorecard in predicting LBW in 177 samples. The results of testing the accuracy of the scorecard are said to be effective if several calculation stages have been fulfilled: the results of the risk score comparison test between the LBW group and the non-LBW group were stated to be significantly different, the results of the ROC calculation using the AUC (Area Under Curve) graph have an Asymp. value. Sig (2-sided) less than 0.05, determines the cut off value, which produces a cut-off point number whereby sensitivity, specificity and accuracy values are close to 1.

Data Analysis

Analysis of the research data began by carrying out a normality test using the Kolmogorov Smirnov test with p value > 0.05. Next, the accuracy of the scorecard was tested by determining the cut-off point using the ROC curve. The ROC curve is a graphical representation of the relationship between sensitivity and 1-specificity. In medical research, ROC curves are widely used to describe diagnostic accuracy and determine optimal cut-off values. The accuracy of diagnosis is derived from the area under the ROC curve and optimal cut-offs are used to identify positive and negative conditions in diagnosis. ROC analysis is used to determine the ability of the score to classify or predict conditions (low birth weight or normal weight) (Ekelund, 2012). This analysis can also be used to determine the optimal cut-off point (optimal decision threshold). To find out whether this point is accurate, we also analyzed the area under the curve. The accuracy of the test depends on how well it separates the group being tested into low birth weight and normal birth weight groups. Accuracy is measured by the area under the curve, the ROC curve. Area 1 represents a perfect test; an area of 0.5 represents a worthless test. A rough guide to classifying the accuracy of a diagnostic test is the traditional academic point system: 0.90-1= excellent (A); 0.80-0.90 = good (B); 0.70-0.80 = sufficient (C); 0.60-0.70 = poor (D) and 0.50-0.60 = failed (F) (Nahm, 2022). The final stage of analysis is the effectiveness and sensitivity test employing the sensitivity and specificity diagnostic accuracy test using MedCalc. Next, the positive and negative predictive values (NPV and PPV) NPV and PPV are calculated, which are completed in the diagnostic accuracy test.

Ethical Clearance

It is confirmed that the research carried out has fulfilled several ethical principles and has received approval for ethical eligibility from the Health Research Ethics Commission dr. Mohamad Soewandie Hospital on June 7th, 2023, with ethical certificate number NO. 007/KE/KEPK/2023. Several ethical principles applied in this study were anonymity because we did not include the identity of the mother or baby in this study. Another principle is beneficence because we just included mothers and babies in a good condition and made sure that our study did not harm their health. The last principle is justice, whereby we made sure each

Table 2. Demographic characteristic of mothers (n= 177)

Indicators	LBW (n=59)		Not LBW (n=118)	
	n	%	n	%
Gestational Age				
< 37 weeks	32	54.2	0	0
> 37 weeks	27	45.8	118	100
Gemelli/Double Pregnancy				
Yes	3	5.1	0	0
No	56	94.9	118	100
History of LBW Birth				
Yes	10	16.9	4	3.4
No	49	83.1	114	96.6
History of Diabetes Mellitus				
Yes	8	13.6	0	0
No	51	86.4	118	100
History of Chronic Hypertension				
Yes	6	10.2	0	0
No	53	89.8	118	100
History of Pre-eclampsia				
Yes	11	18.6	5	4.2
No	48	81.4	113	95.8
Hemoglobin				
< 11 / < 10,5	16	27.1	26	22.0
> 10,5 / > 11	43	72.9	92	78.0
Educational History				
Under Senior High School	25	42.4	75	63.6
Senior High School/Equivalent	34	57.6	43	36.4
Job Status				
Working	24	40.7	45	38.1
Doesn't Work	35	59.3	73	61.9
Parity				
Primipara	28	47.5	35	29.7
Not Primipara	31	52.5	83	70.3

respondent in both groups received the same treatment.

Results

The research results include demographic data and risk factors for mothers, scorecard accuracy test results, and model accuracy test results, which are explained as follows.

Demographic Data and Maternal Risk Factors

Maternal demographic data. which include demographic characteristics and risk factor analysis based on components on the early detection scorecard, are displayed in Table 2.

Based on the results of the cross-tabulation analysis in Table 2, it is known that 59 mothers gave birth to babies with LBW, while 118 mothers gave birth to babies with normal weight. The majority of mothers with LBW babies have a gestational age of <37 weeks, apart from that, it is also found that mothers with LBW babies have a history of gemelli/double pregnancy, and a history of LBW birth in previous pregnancies. A history of diseases such as diabetes mellitus, chronic hypertension, and pre-eclampsia during pregnancy was also found in the group of mothers with LBW babies. Indicators of hemoglobin values for mothers that were below normal (< 11 g/dl) were also found to be the majority in the group of mothers with LBW babies. Meanwhile, indicators in the form of educational history, mother's type of employment, and parity number obtained equal results in both groups. The risk score comparison test from the score card between LBW and non-LBW subjects used the Mann Whitney test because the risk score data for the non-LBW group was not normally distributed. The following are the results of the risk score comparison test between LBW and non-LBW subjects.

Based on the risk score comparison test results in Table 3, it was found that for LBW subjects the risk score value was in the range 2 – 22 with a median of 10 and a mean ± SD value of 9.27 ± 4.34. Meanwhile, in the group of non-LBW subjects, the risk score value was in the range 1–4 with a median of 2 and a mean ± SD value of 2.25 ± 0.95. The results of normality test using Kolmogorov Smirnov test obtained that the p-value of the LBW group score was 0.062 which was stated to be

Table 3. Risk Score Comparison

Risk Score	LBW (n=59)	Not LBW (n=118)	p-value
Range (Median)	2 – 22 (10.00)	1 - 4 (2.00)	0.000
Mean ± SD	9.27 ± 4.34	2.25 ± 0.95	

Table 4. ROC calculation results

Area	Std. Error	Asymptotic Sig.	Asymptotic 95% CI	
			Lower Bound	Upper Bound
0.960	0.017	0.000	0.927	0.993

Table 5. LBW cut-off Point with LBW events

Cut-off point	Birth Weight		Total
	LBW	Not LBW	
≥ 3.5 (LBW)	52	13	65.0
	80.0	20.0	100.0
	88.1	11.0	36.7
< 3.5 (Not LBW)	7	105	112.0
	6.3	93.8	100.0
	11.9	89.0	63.3
Total	59	118	177.0
	33.3	66.7	100.0
	100	100	100.0

Table 6. Accuracy of test results of the LBW detection scorecard

Test	Value (%)	Confidence Interval (%)
Sensitivity	88.14	77.07 – 95.09
Specificity	88.99	81.90 – 94.00
Disease prevalence	33.33	26.44 – 40.80
Positive Predictive Value (PPV)	80.00	70.37 – 87.07
Negative Predictive Value (NPV)	93.75	88.18 – 96.79
Accuracy	88.70	83.09 – 92.96

normally distributed. Meanwhile, for the non-LBW group, the p-value was 0.000, which means it was not normally distributed. So, we used non parametric test (Mann-Whitney) to test the ability of the scorecard in predicting low-birth-weight. Based on the results of the comparison test using the Mann Whitney test, a p-value of 0.000 was obtained, which means there was a significant difference between LBW and non-LBW subjects based on the risk score obtained from the scorecard. The results of the analysis based on the mean value also showed that the risk score for LBW subjects was greater than the risk score for non-LBW subjects.

ROC Calculation for Determining Cut Off Point

Determination of cut-off points for risk classification were measured with the ROC curve. The results of the analysis using the ROC curve are shown in Table 4.

The test results in Table 4 using ROC obtained an AUC value of 0.960 with a significance of 0.000 ($p < 0.05$) with a positive curve direction, which means the top right point (1.1) represents a probability value that indicates a positive condition, namely the occurrence of LBW. The higher the AUC value indicates the greater the model accuracy. So, from the AUC value of 0.960, it can be said that the model produced by ROC is more accurate, as shown in Figure 1.

After the ROC calculation is carried out, the cut-off point value is determined, as shown in Figure 2.

In Figure 2, it is known that the results of calculations using a graph of the intersection between sensitivity and specificity values show that the cut-off point value is ≥ 3.50. The scorecard with a cut-off point value is 3.5, which means that if a mothers in her pregnancy has a risk score of <3.50 then her baby is not at risk of experiencing LBW. After classification is carried out, cross tabulation is shown in Table 5.

Based on the results of the analysis in Table 5, it is known that 105 mothers did not give birth to LBW as predicted (risk score < 3.50), and 52 mothers gave birth to LBW according to prediction (risk score ≥ 3.50). However, seven pregnant women who had a risk score of < 3.50 actually gave birth to LBW, and 13 mothers who had a risk score of ≥ 3.50 actually gave birth to babies with normal weight.

Model Accuracy Test

Calculation of model accuracy by calculating the sensitivity and specificity, and NPV and PPV values from the early detection scorecard for LBW incidents is described in Table 6.

Based on Table 6, it was found that the LBW scorecard had a sensitivity in predicting LBW births of 88.14%. The specificity result showed the ability of the scorecard to detect babies who are negative for LBW and the result showed that negative LBW is 88.99%. The PPV and NPV values showed that 80% of babies experienced LBW as predicted, while 93.7% of babies were proven not to experience LBW according to the results of the scorecard predictions. Overall, the scorecard had an accuracy of 88.70%. This value have a

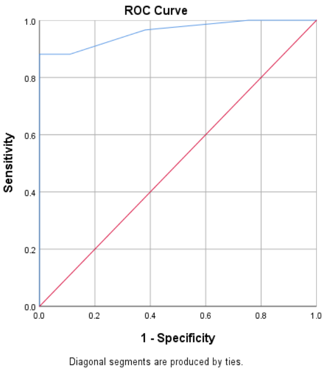

Figure 1. ROC Curve

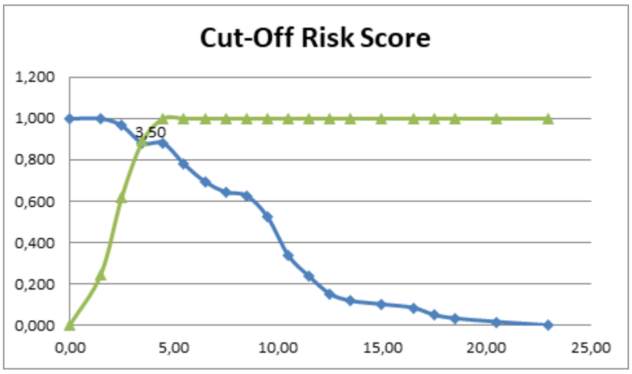

Figure 2. Cut-Off Risk Score

good interpretation because the percentage was more than 80% (Nahm, 2022).

Discussions

The application of the LBW early detection scorecard has high accuracy in predicting the incidence of LBW. Through analysis and calculation of risk factor scores for mothers, it is possible to determine the possibility of a baby being born with LBW. The results of the analysis of the LBW early detection scorecard that was developed also showed significant differences between the group of mothers with LBW babies and the group of mothers with normal birth weight babies. Several risk factors that are important to assess based on the score card developed include history of giving birth to LBW, mother's occupation, parity status, gestational age < 37 weeks, gemelli pregnancy, education history, experiencing pre-eclampsia or having chronic hypertension history, maternal HB levels <8 g/dl (TM 1 and 3) or < 10.5 g/dl (TM 2), and having a history of pre-gestational diabetes mellitus (Xi *et al.*, 2020; Utami *et al.*, 2023). Early detection of LBW can improve services for at-risk babies, thereby having a positive impact on their health outcomes. Early detection of LBW helps mothers to better understand whether their condition during pregnancy is included in the risk category (Bansal, Garg and Upadhyay, 2019; Toru and Anmut, 2020).

Midwifery services are an integral part of health services which focus on maternal, newborn and child health services in realizing quality family health (Ulita *et al.*, 2023). The state of maternal and child health is a national problem that needs to be given top priority because it determines the quality of human resources for the next generation. The high MMR and IMR figures and the slow decline in these two figures indicate that maternal and child health services are urgently needed to be improved both in terms of reach and services provided by health workers, especially midwives (Pramono and Paramita, 2015; Vos *et al.*, 2015). Obstetric services focus on prevention efforts, health promotion, assisting with normal childbirth, detecting complications in the mother and child, carrying out treatment according to authority or other assistance if needed, and carrying out emergency measures (Ford *et al.*, 2019). Through the development of an early LBW detection scorecard, health workers, especially midwives, have an important task in health counseling and education, not only for women but also for families and communities, especially in early detection of risk signs for LBW (Aryastami *et al.*, 2017; Ulita *et al.*, 2023).

Birth weight is an important indicator of a child's survival, future growth and overall development and, since it is not possible to provide expensive scales to community members and families, it is important to find alternative methods for estimating birth weight (Anil et al., 2020). Even though ultrasonic measurement techniques have been widely applied to measure fetal weight, only a small number of pregnant women are able to utilize maternity and child health program services due to limited economic resources and other social backgrounds (Rahfiludin and Dharmawan, 2018). Babies with a birth weight of less than 2,500 g can cause various health problems in the future. The high risk of death and health complications shows the importance of early prevention of LBW births (Huque and Hussain, 1991). ANC is a mandatory program in Indonesia with a minimum of four visits (Adawiyah *et al.*, 2021). The aims include preventing adverse birth outcomes, low birth weight, and detecting pregnant women who are at risk of giving birth to LBW babies by scoring. Many references state that pregnant women with anemia tend to give birth to LBW babies, but so far there has been no tool or scoring used to determine that pregnant women with a certain score are more at risk of giving birth to LBW babies (Kumalasari, Tjekyan and Zulkarnain, 2018). Through the development of this LBW early detection card, LBW births can be predicted more optimally (Utami *et al.*, 2023).

Efforts through ANC visits have not been able to predict LBW optimally, due to non-compliance with visits. Pregnant women make more antenatal visits when they have entered the third trimester; therefore, measuring body weight and risk factors in third trimester pregnant women is very important and plays a role in predicting LBW births. As a result of research that has been carried out, it is known that the early detection scorecard has a cut-off point of 3.5, which means that if the risk factor scoring results show a value of 3.5 or more, it can be predicted that the baby will be born LBW. By knowing the risk score, it is hoped that health workers can take optimal preventive and nursing steps for mothers and babies before delivery, to prevent worsening of the condition and death of the baby.

The study accurately reports the statistical significance of the data in predicting LBW through identification of maternal factors. The limitation of this study is that the sample of respondents is not representative and several other respondents are still needed. We recommend to do additional research to determine the best time to use this instrument to maximize its effectiveness in predicting the incidence of LBW and promoting healthier pregnancies.

Conclusions

The LBW early detection scorecard can accurately predict the occurrence of LBW births. Through analysis and calculation of risk factor scores for pregnant women, it can be seen whether the mother is at risk of giving birth to a LBW or normal weight baby. Early detection of LBW can improve services for at-risk babies, thereby having a positive impact on their health outcomes.

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Conflict of interest

There is no conflict of interest.

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Development of a self-care guideline to prevent rehospitalization in stroke patients: a modified Delphi study

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ABSTRACT

Introduction: Since 2007, the number of stroke cases in Indonesia has continued to increase. Stroke patients who have passed the acute phase of stroke still have a risk of recurrent stroke and rehospitalization. This study aimed to develop self-care guidelines to prevent the rehospitalization of stroke patients.

Methods: A three-round modified Delphi study was applied to a panel of 24 experts with different fields of expertise, consisting of doctors, nurses, families, and patients. In the first round, data were collected through a literature review and semi-structured interviews. In the second and third rounds, data were collected using a survey questionnaire on a 9-point Likert scale.

Results: The first round produced seven themes around self-care activities, including drug therapy, physical exercise, diet and nutrition, stress management, self-motivation, functional status screening, and control for risk factors. In the second round, all types of self-care in the first round were agreed upon for content in preparing the guidebook. The third round resulted in agreement on the guidebook that had been designed, with scores of 8 and above by 100% of the expert panel.

Conclusions: The development of a self-care guidebook to prevent rehospitalization of stroke patients through a three-round Delphi study has reached a consensus among the entire panel of experts. Further research by testing guidebooks in the healthcare system is needed to determine their effectiveness in preventing re-hospitalization in stroke patients.

Keywords: guidelines, readmission, self-care, stroke

Introduction

Stroke is the third-most frequent cause of disability and the second-greatest cause of mortality worldwide (American Stroke Association, 2019). The prevalence of stroke continues to increase globally every year. In 2019, there were 12.2 million new stroke cases and 101 million people struggling with stroke worldwide (Feigin *et al.*, 2021). Asia is the most significant contributor to the total cases in the world, with as many as 58.1 million cases. Indonesia has the second-highest stroke rate, following Mongolia, with 193.3 cases per 100,000 person-years (Venketasubramanian *et al.*, 2017; Mboi *et al.*, 2022).

Indonesia has experienced an increase in stroke cases of 2.1% in five years, based on Basic Health Research data for 2013 and 2018. East Kalimantan has the highest stroke case rate, namely 14.7‰ while the Province of Bali ranks 17th with 10.7‰ stroke cases. However, the number of stroke cases in Bali is very significant; it has more than doubled in five years (Riskesdas, 2018). Stroke survivors who survive the first attack are also still at risk of experiencing a recurrence. With stroke recurrence, stroke survivors are twice as

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likely to die from a subsequent attack as those who suffer a first stroke (Supriyadi, 2012). A stroke recurrence risk affects one in every four stroke patients (American Stroke Association, 2022). As many as 45.8% of the 238 stroke patients had recurrent strokes (Trisetiawati, Yuniar and Besral, 2018). Cases of stroke recurrence increased every year by 35% from 1995–1999 and increased rapidly to 67% for 2010–2015) (Flach *et al.*, 2020). One of the causes of high cases of recurrence is the lack of awareness among stroke patients about routine controls at health facilities. Stroke patients who do not regularly monitor their condition after the first attack have an 8.7 times higher risk of stroke recurrence than the first stroke (Trisetiawati, Yuniar and Besral, 2018). Only 39.4% of stroke patients in Indonesia routinely seek care at health facilities. Whereas in the province of Bali, the awareness of stroke patients to carry out controls is higher than the national average, less than, half of stroke patients carry out routine controls, namely 44% (Riskesdas, 2018).

According to the World Health Organization, one way to better control stroke is to involve patients in monitoring their own care. Self-care is the ability of individuals, families, and communities to improve their own health, prevent disease, maintain health, and overcome illness and disability with or without the support of health workers (World Health Organization, 2022). Many studies related to self-care have been conducted and have proven effective in improving quality of life and self-efficacy (Fryer *et al.*, 2016), resulting in improved conditions as well as the recovery of poor outcomes such as dependency and death (Parke *et al.*, 2015). Even though it has been proven to have a positive impact, in its implementation there are still obstacles that result in the not-optimal results expected, and recurrence in stroke patients still occurs frequently. In its implementation, at least four main obstacles were found, namely from the stroke patients, the health system, professional health, and the national health policy level (Baatiema *et al.*, 2017). Further research has been recommended to deepen understanding of the views of all stakeholders and address unmet needs during the transition period for stroke patients (Chen *et al.*, 2021).

To our knowledge, there has been no research related to the development of self-care guidelines to prevent rehospitalization in stroke patients using a Delphi study. By using the opinions of experts who have a high reliability value in obtaining agreement, the Delphi method is very suitable and important to use to explore, identify, compile, and obtain consensus in preparing guidebooks. This information is important for stroke patients and their families to use as a reference source for carrying out independent care at home. So, this study aims to compile and seek consensus regarding a self-care guidebook to prevent rehospitalization in stroke patients.

Materials and Methods

Design

The Delphi method was used to design and develop self-care guidelines to prevent stroke hospitalization. The Delphi study design has been widely applied to the health sector, especially to prioritize problems and needs (Suyasa and Sutini, 2021). This method has also been used previously in similar research, namely for developing guidelines (McMaster *et al.*, 2016; Virgara *et al.*, 2018). The application of the Delphi study in this study is based on three reasons. First, there is the suitability of the Delphi study design in utilizing expert opinion, which has a high reliability value in obtaining agreement on the self-care needs of stroke patients through a series of questionnaires accompanied by providing feedback on the agreement. Second, in expert groups, anonymity encourages participants' candor. Thirdly, it reduces the possibility of a "halo effect," in which the opinions of members of a dominant group or a higher-profile position are accorded additional weight (Winkler and Moser, 2016).

Population, Samples, and Sampling

The population of this study is a panel of experts with different areas of expertise who understand the need for self-care among stroke patients and consists of stroke survivors, families, doctors and nurses in Bali, Indonesia. This research involved 24 experts consisting of doctors, nurses, families, and patients who were recruited using purposive sampling and snowballing techniques. These two techniques are used to reach the most appropriate expert panel. The inclusion and exclusion criteria in this study were stroke patients who survived their first stroke > 3 months, family as the main caregiver who cared for stroke patients > 3 months, doctors and nurses who had or were caring for stroke patients for at least five5 years, skilled nurses who work in the stroke unit, and neurologists who work in the stroke unit. Such sample sizes have been shown to provide reliable and effective assessments (Akins, Tolson and Cole, 2005).

Instruments and Data Collection

The Delphi technique with three rounds was employed between September 2022 to February 2023 in this study: *Round One*: To gather expert opinions regarding the self-care required for stroke patients to prevent rehospitalization. Qualitative data were collected through semi-structured interviews using an interview guide prepared through a literature review and adapted to the research objectives. Feedback from the first round was used to develop the survey questionnaire for the second round; *Round Two*: Quantitative data were collected through a survey questionnaire containing the types of self-care obtained in the first round. A survey questionnaire via Google Forms was used to seek agreement on each type of self-care. The results of the second round of agreement were used as the basis or material for preparing the guidebook and were agreed upon in the third round; *Round Three*: Quantitative data collection was carried out using a questionnaire via Google Form to seek agreement regarding the guidebook that had been prepared.

The second and third rounds of survey questionnaires were prepared using a 9-point Likert scale ranging from 1 (not important at all) to 9 (very important). The nine-point Likert scale is a commonly used rating scale in Delphi studies (Blanco-Aparicio *et al.*, 2023; Guiguet-Auclair *et al.*, 2023). In filling out the questionnaire via Google Form, the researcher accompanied a panel of experts one by one to ensure the accuracy of the responses.

Data Analysis

Thematic analysis was used in this study to analyze and present the first round of data. Researchers found the responses of each expert separately. Researchers applied a deductive analysis approach to present relevant guidelines regarding the self-care of stroke patients to prevent rehospitalization. Data from the second round were analysed through descriptive statistical analysis with IBM SPSS version 27 to see the median, range, and interquartile range (IQR) values. The higher the median, the smaller the IQR and range, meaning the higher the priority level of the type of self-care needed. This analysis method is commonly used in Delphi studies (Suyasa and Sutini, 2021). After the agreement in the second round was obtained, it was used in the preparation of the guidebook and again agreed upon in the third round. Consensus was reached when scores were 7 and above by more than 70% of participants and scores less than 4 by less than 30% of participants (Pandor *et al.*, 2019). If consensus was not found, the questionnaire was be revised, and data collected again until consensus was met. Apart from that, comments submitted by the expert panel through the comments column in the questionnaire were also used as consideration for preparation and agreement.

Ethical Consideration

This study received ethical approval from the Research Ethics Commission of the Faculty of Health, Bali Institute of Technology and Health (ethical license number 04.0529/KEPITEKES-BALI/X/2022). All participants gave informed consent and were made aware of their right to disengage from the study without negative consequences. This research applies the ethical principle of anonymity to protect the identity and confidentiality of expert panel information by using codes or initials, deleting personal identification information, and monitoring data security.

Results

Characteristics of the Expert Panel

Based on Table 1, most of the expert panel of doctors and nurses were late adults with an age range of 36-45 years, namely five participants (83.3%) and three participants (50%), respectively. The expert panel from families was dominated by late adults and the elderly, namely two participants each (33.3%). All expert panels of stroke patients are elderly with the age category of 56-65 years. The proportion of gender on the panel of experts from nurses and families was dominated by women, namely five participants (83.3%) and four participants (66.7%), respectively, while the panel of experts from the majority of patients were men, namely four participants (66.7%). Judging from the level of education, the entire panel of expert doctors held a Master's degree, and the entire panel of expert nurses and most of the families held a Bachelor's degree,

Table 1. Characteristics of the expert panel

Characteristics	**Doctor (D)**		**Nurse (N)**		**Family (F)**		**Patient (P)**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Age								
17-25 years	-	-	-	-	1	16.7	-	-
26-35 years	1	16.7	2	33.3	1	16.7	-	-
36-45 years	5	83.3	3	50	2	33.3	-	-
46-55 years	-	-	1	16.7	-	-	-	-
56-65 years	-	-	-	-	2	33.3	6	100
Gender								
Male	3	50	1	16.7	2	33.3	4	66.7
Female	3	50	5	83.3	4	66.7	2	33.3
Education level								
Senior High School	-	-	-	-	-	-	4	66.7
Diploma	-	-	-	-	1	16.7	1	16.7
Bachelor	-	-	6	100	5	83.3	1	16.7
Masters	6	100	-	-	-	-	-	-
Duration of stroke/care/work								
5-10 years	6	100	2	33.3	6	100	6	100
11-15 years	-	-	4	66.7	-	-	-	-

Table 2. Types of self-care in the first round

No	Theme	Category	Excerpts
1	Physical activity	Physical activity to prevent complications	"*Patients with pneumonia or decubitus ulcers are very vulnerable to patients who only lie in bed, so physical activity in patients is very important.*" (D5)
		Physical activity guide	"*The problem is that our patients don't know what kind of movement is preferred.*" (D4)
		Light physical activity and not forced	"*We still ask the patients to socialize together, keep exercising, keep exercising as usual. Keep doing light and not forced example activities...*" (D3)
		Less interest in physical activity	"*Lazy to move, even though his condition had improved but he didn't make any movements.*" (F4)
2	Diet/Nutrition	Diet/nutrition settings	"*Make them a guide to their calorie needs, how much protein, how many carbohydrates, how many fats and all kinds of things.*" (D2)
		Decreased appetite	"*The doctor suggested a low-salt diet, but after we prepared the food, you didn't want to eat, my father's appetite went down so he didn't want to eat.*" (F3)
		Food recommendations and restrictions	"*Diet low in salt, then avoid fried or foods that contain fat / oil like that.*" (D6)
3	Drug therapy	Withdrawal from drug therapy	"*Many patients stop taking their medication for 2 reasons, because they are afraid to go to the hospital (pandemic) and feel that they are already healthy.*" (D1)
		Adherence to taking medication	"*…maybe that's starting from discipline in taking medicine.*" (F1)
		Fear of taking medication	"*Often patients ask how long should he take the medicine? Is it for life? When will I recover?*" (D2)
4	Control of risk factors	Hypertension control	"*That's why it's important for patients to stay under control so that the risk factors, for example blood pressure are stable*" (D2)
		Diabetes control	"*For example, blood sugar must be controlled, what is the target blood sugar and diligent control.*" (N2)
		Cholesterol control	"*Routinely check blood cholesterol levels.*" (N6)
5	Stress management	Depression with a state of weakness	"*They feel depressed because they themselves feel mentally healthy and strong but how come their body still has weakness.*" (D2)
		Stress worsens the condition	"*If the patient is easily anxious and stressed, sometimes they really don't want to be trained like that.*" (N1)
		Stress control	"*Always try to avoid emotions from occurring, and often pray so that stress can be controlled.*" (P5)
6	Self-motivation	Loss of motivation	"*For example, young people with stroke are still productive at work but are weak in half of their body, usually their motivation is lost.*" (D3)
		Awareness and motivation to improve conditions	"*Making patients aware and motivating about their condition and guiding them to be able to continue treatment is very important.*" (D6)
7	Functional Status Screening	Screening for severity	"*For self-care at home, we first look at when the patient is hospitalized or hospitalized, how severe the stroke is.*" (D2)
		Developmental screening	"*Knowing what the score was at the time of the stroke, then what the score was after the stroke, and after rehabilitation, what the score was like to see whether there was a change in progress.*" (D4)
		Adjustment of the patient's condition and ability	"*For independent treatment, perhaps the first thing we have to do is look at the patient's condition to determine whether it is possible for the patient to carry out treatment independently. So usually we first check the patient's functional status.*" (N5)

namely six participants (100%) and five participants (83.3%), respectively, while the expert panel patients were dominated by high school education level, namely four participants (66.7%). Based on experience, the expert panel of doctors and families all have experience treating stroke patients for 5-10 years. Most of the expert panel nurses had longer caring experiences (11-15 years), namely four participants (67.7%). The expert panel of stroke patients involved in the study had all struggled with their condition for 5-10 years. The expert panel in this study had different ages, educational backgrounds, and occupations. However, these different characteristics can enrich the point of view of each opinion, recommendation, and assessment of the book being prepared. So the potential bias from differences in these characteristics has been anticipated.

Round 1

The results of the first round of research were in the form of semi-structured interviews conducted with a panel of experts from October to December 2022. This produced a series of themes related to self-care to prevent rehospitalization in stroke patients. Based on the results of the data analysis, seven core themes of self-care were identified: physical activity, diet and nutrition, drug therapy, control for risk factors (hypertension, cholesterol, and hyperglycemia), stress management, self-control, motivation, and functional status screening (Table 2).

Round 2

The second round of research through a survey questionnaire was conducted in December 2022 and January 2023. The expert panel in the second round was the same expert panel as the first round, with a total of 24 expert panels.

Based on Table 3, most types of self-care scored 8–9 from a 100% expert panel. Only one type of self-care received a score of 3, namely blood sugar control, according to a panel of experts (8.3%). A score of 3 is given because it is considered situational, only needed when someone has diabetes. However, based on >70% of the expert panel giving an assessment score of 7-9 and <30% giving a score of 1-3 for each type of self-care, it was concluded that all types of self-care had been agreed to serve as material or content for the preparation of the guidebook.

Round 3

The results of the third phase of the research are the agreements in the guidebook that have been prepared based on the results of the agreement on types of self-care in the second round. The guidebooks and assessment questionnaires were distributed to all expert panels in February and March 2023, and after being analyzed, they yielded a median value of 8, IQR = 1, Range 1, with the highest score being 9 and the lowest score being 8. Based on the results of the assessment, 100% of the panel of experts gave a score of 8–9. It can be concluded that all expert panels agree with the guidebook that has been compiled, namely self-care to prevent rehospitalization in stroke patients. Several expert panels also provided input and considerations, such as larger font sizes to make them easier to read, especially for the elderly. A compact size and being available in an e-book are also recommended to make it easier for those who will read it.

Table 3 Descriptive analysis of self-care types

Types of Self Care	Median	IQR	Range (Max-Min)
Drug Therapy	9	0	0 (9-9)
Blood Pressure Control	9	0	0 (9-9)
Physical Activity	9	0	1 (9-8)
Diet/Nutrition	9	0	1 (9-8)
Stress Management	9	0	1 (9-8)
Self-motivation	9	0	1 (9-8)
Functional Status Screening	9	0	1 (9-8)
Cholesterol Control	9	0	1 (9-8)
Blood Sugar Control	9	0	6 (9-3)

Discussions

This study produced a self-care guidebook to prevent rehospitalization in stroke patients which had been agreed upon by the entire panel of experts. The contents in the guidebook are arranged based on the types of self-care that have been explored in the first round and agreed on in the second round. The agreed types of self-care were drug therapy, physical activity, diet/nutrition, stress management, self-motivation, functional status screening, and control for risk factor.

The entire panel of experts agreed that it is very important to include drug therapy as content in a self-care guidebook. Drug therapy such as anticoagulants and antiplatelets can help prevent excessive blood clots and reduce the risk of forming blood clots that can block blood vessels in the brain. It is recommended for individuals who have a high risk of recurrent stroke (Evans *et al.*, 2020; Paciaroni *et al.*, 2022). However, patient adherence to drug therapy is still low (Kronenberg *et al.*, 2017), and forgetfulness is the most common reason why participants do not adhere to therapy (Aparecida *et al.*, 2017). Therefore, it is essential to investigate and resolve the factors that contribute to noncompliance (Tene *et al.*, 2018). Good information about treatment, including potential drug interactions, potential side effects, and when to contact a doctor, is considered to improve patient compliance (Liu *et al.*, 2019). In addition, the use of technology, such as applications that can be used to provide reminders, combined with educational support, is also recommended to increase medication adherence. (Al-Arkee *et al.*, 2021). Consequently, it is essential to develop guidelines for the autonomous management of drug therapy, with the expectation that this will increase treatment adherence and prevent recurrent strokes or readmissions.

Physical activity is the next type of self-care that has received approval to be one of the contents in the preparation of the guidebook. Physical activity is believed to improve blood circulation, reduce systolic blood pressure, fasting glucose, and increase high-density lipoprotein cholesterol after a stroke or transient ischemic attack, and evidence supports the use of physical activity as a recurrent stroke prevention strategy (Love *et al.*, 2020). Stroke survivors who do light, regular, and long-term exercise (more than five sessions per week and lasting an average of 40 minutes per session) have a lower relapse rate (Pérez-de la Cruz, 2020). However, this is not in line with the low adherence to exercise in stroke patients, and a lack of knowledge about the importance of physical activity (Hussain *et al.*, 2022). This low adherence to exercise is influenced by several factors, namely physical disorders, balance, fear of falling, decreased self-efficacy, a lack of staff and support from health services, physiotherapists or gym trainers, transportation, and sports facilities (Tabah *et al.*, 2020). Based on this, the type of self-care physical activity is one of the important contents to be included in the preparation of this guidebook, so that it is expected to improve conditions and prevent rehospitalization of patients.

In addition to drug therapy and physical activity, all expert panels agree that diet and nutrition self-care play an important role for stroke patients. A diet rich in fruits, vegetables, and whole cereals, low in sodium, high in lean protein, and containing healthy lipids can help reduce blood pressure and cholesterol levels and enhance blood sugar regulation (Dearborn, Urrutia and Kernan, 2015). A Mediterranean-type diet is recommended to reduce the likelihood of stroke recurrence (Estruch *et al.*, 2018; Rees *et al.*, 2020). Patients with hypertension, stroke, or Transient Ischemic Attack (TIA) are advised to reduce their sodium intake by at least 1 g/day (2.5 g/day of salt) to reduce the risk of recurrent stroke (He *et al.*, 2020). However, this is not supported by practical knowledge and nutrition training that is less than optimal (Benameur, Gandrakota and Ali, 2022). In addition, the quality of diet in stroke patients was also found to be poor (Dearborn *et al.*, 2019). To increase compliance and motivation, nutritional care recommendations must consider patient lifestyle, preferences, and psychological aspects in the assessment, planning, intervention, and evaluation stages of nutritional care. Patients and caregivers must also have awareness of the basics of nutritional care and nutritional literacy capable of supporting decision-making regarding nutritional care. The possibility to understand why certain foods and fluids should be prioritized and to choose between different options helps shift responsibility from healthcare providers to older people, giving them the opportunity to feel more involved (and thus more compliant and motivated) in nutritional care (Batista de Lima and Eleuteri, 2021). Therefore, self-care by managing diet and nutrition is important for stroke patients to prevent recurrent strokes and rehospitalization.

Stress management is the next type of self-care that has been approved by a panel of experts for content in the guidebook. Stress is a prognostic factor in determining the quality of psychological and emotional recovery (Kronenberg *et al.*, 2017). Several epidemiological studies have shown that higher levels of post-stroke stress are associated with poorer long-term outcomes (Aparecida *et al.*, 2017; Tene *et al.*, 2018; Gyawali *et al.*, 2020). Several observational studies consistently report a significant correlation between stress and worse stroke outcomes (Liu *et al.*, 2019). Stress management with meditation (Love *et al.*, 2020), memory rehabilitation (Chouliara and Lincoln, 2016), aquatic therapy (Pérez-de la Cruz, 2020), and positive psychotherapy (Cullen *et al.*, 2018) are some examples of therapy considered effective in managing stress in stroke patients. However, lack of access, limited time, training, financial placement, resources, lack of self-confidence, negative beliefs about therapy, lack of desire, and the time-consuming nature of behavior change are some of the potential things that can hinder the progress of stress management therapy (Köpsén and Sjöström, 2020). So, by increasing self-awareness and identifying appropriate sources of stress, not feeling the need to overcome all obstacles at once, and seeking support from friends, family, or mental health professionals can help overcome obstacles and maintain motivation. Seeking professional help and time management are some steps that can be taken to carry out stress management therapy (Wabschall, 2023). Therefore, self-care in the form of stress management in stroke patients is indeed very important to be one of the contents in preparing a guidebook for preventing worsening of conditions up to recurrent strokes or rehospitalization.

The entire expert panel has agreed to include self-motivation as another form of self-care in the guidebook, in addition to stress management. Stroke is a condition that requires long-term or continuous care, so a high level of compliance and consistency is required from patients in the process of treatment or rehabilitation. In this achievement, motivation is considered an important point in the patient's intensive rehabilitation process (Pickrell, Bongers and Hoven, 2015; Gangwani *et al.*, 2022). Unfortunately, patients' self-motivation after stroke is limited (Connell *et al.*, 2015; Peters, Calvo and Ryan, 2018; Ezeugwu and Manns, 2020). Even after patients reach their physiotherapy training target, they lose motivation to practice further (Vourganas *et al.*, 2019), even though a study found a significant correlation between motivation and the prevention of recurrent strokes (Lilipory, Pattipelohy and Tuarissa, 2019). Seven strategies, including adjusting task difficulty and establishing rehabilitation objectives, have proved effective at boosting patient motivation (Oyake *et al.*, 2020). In addition, family support by paying attention to multidimensional aspects such as emotional, instrumental, and informational is one of the important points in increasing patient self-motivation (Kamaryati and Malathum, 2020). There are two strategies that can help in motivating, setting, and achieving goals. First, consideration of key goal characteristics (e.g., approach vs. avoidance goals, performance vs. mastery goals, level of difficulty) may result in more appropriate and feasible goal selection. Second, action planning can help individuals realize goals through action. Clinicians can help patients utilize these strategies to motivate, set, and achieve health behavior change goals (Bailey, 2019). Therefore, efforts to maintain and increase patient motivation in undergoing the rehabilitation process are very important to be discussed in the guidebook so that they can be implemented and improve conditions so that recurrent strokes or hospitalizations can be prevented.

Functional status screening was approved by all expert panels for content in the handbook. Functional status screening is considered important in terms of evaluating the success of the intervention and the progress of the patient's condition. Especially in the first three months of stroke recovery, because most of the functional recovery occurs during this period (Lee *et al.*, 2015). Functional status screening is important to determine the right time and what rehabilitation interventions will be given to patients (Selves, Stoquart and Lejeune, 2020). Functional Independence Measurement (FIM), Frenchay Activity Index, and Modified Rankin Scale (mRS) are some of the tools commonly used to assess patients' functional status (Rayegani *et al.*, 2016; Kim *et al.*, 2018). Although validated tools are available to assess functional status, they are typically administered by healthcare professionals. As far as researchers have conducted literature reviews, functional status screening is generally not carried out independently by stroke patients. Assessment of functional status in stroke patients is usually carried out by health professionals, such as physical therapists, occupational therapists, or other members of the rehabilitation team. Stroke patients who carry out functional status measurements independently indicate that self-assessment is less invasive than direct assessment by a health professional. Rather, asking about difficulty with activities versus the need for assistance are different and complementary concepts, and providing context is especially important when discussing sensitive topics such as functional impairment (Nicosia *et al.*, 2020). Knowing their functional status allows patients to be involved in setting goals and participating in their own rehabilitation. Therefore, screening for functional status is important as soon as possible to become a benchmark for when and what type of self-care the patient can do independently at home so as to reduce the risk of stroke recurrence and rehospitalization.

All expert panels have agreed that one of the contents of the guidebook should be the control of risk factors like hypertension, cholesterol, and blood sugar. Control of hypertension, such as routinely controlling blood pressure both independently at home and by coming to the nearest health service, administering drugs, and targeting blood pressure to be achieved is considered to reduce the risk of stroke recurrence and rehospitalization. A BP target of <130/80 mm Hg is recommended to reduce the likelihood of stroke recurrence and vascular events (Zonneveld *et al.*, 2018). In patients who have a mean office blood pressure of ≥130/80 mmHg, antihypertensive drug therapy is recommended to reduce the risk of recurrent stroke and other vascular events (Kitagawa, Yamamoto *et al.*, 2019). Individual drug regimens that consider patient comorbidities, patient preferences, and classes of pharmacological agents are recommended to maximize drug efficacy (Zhong *et al.*, 2016).

Cholesterol control, such as routinely checking cholesterol levels and paying attention to dietary adjustments and drug therapy, is considered important to prevent recurrent strokes or rehospitalization. LDL cholesterol levels <120 mg/dL and CRP <1g/L indicate a 51% reduction in the risk of recurrent stroke (Kitagawa, Hosomi *et al.*, 2019). Cholesterol is one of the three determinants of recurrent stroke (Rahayu *et al.*, 2019). According to a study conducted in China, there is a significant correlation between dyslipidemia and recurrent stroke (Akhtar *et al.*, 2019).

In individuals suffering from ischemic stroke or TIA and diabetes, achieving a goal HbA1c of ≤7% is recommended to lower the probability of microvascular complications (Nathan *et al.*, 1993). It has been found that treatment of diabetes with glucose-lowering agents reduces the risk of future adverse cardiovascular events (e.g., stroke, myocardial infarction, cardiovascular mortality) (Hernandez *et al.*, 2018; Gerstein *et al.*, 2019). To achieve glycemic goals and reduce stroke risk factors, multidimensional care (i.e., lifestyle counselling, medical nutrition therapy, diabetes self-management education, support, and medication) is recommended (Kleindorfer *et al.*, 2021). Acute hyperglycemia and diabetes are associated with worse outcomes after ischemic or hemorrhagic stroke, including higher mortality, worse neurological and functional outcomes, longer hospitalization, higher rates of hospitalization, and relapse (Lau *et al.*, 2019). Research conducted by Wahyuningsih and Kamaryati (2019) supports the results of this study that hypertension, diabetes, and heart problems are risk factors in stroke patients and must be controlled immediately to prevent recurrent strokes. Based on this, risk factor control is one of the important types of treatment included in the guidebook to be carried out or applied to stroke patients to prevent recurrent strokes and re-hospitalization.

This research is a study to develop self-care guidelines to prevent rehospitalization of stroke patients through the first application of the Delphi study method. This research involves multi-professionals (doctors and nurses), families, and patients to achieve the best quality guidelines that are applicable and according to user needs.

Although the number of expert panels or participants in this research is considered sufficient, the category of health workers involved in this research could be larger, such as involving nutritionists, physiotherapists, and other related health workers involved in the rehabilitation of stroke patients. Also, the expert panel in this research is only from Indonesia. Apart from that, this research has only reached the product design stage and has not yet reached the testing stage.

Conclusion

Consensus on the development of self-care guidelines through a Delphi study was obtained through three rounds. In the first round, the semi-structured interview method produced seven themes consisting of drug therapy, physical activity, diet and nutrition, stress management, self-motivation, functional status screening, and controlling risk factors. Through the second round, seven types of self-care from the first round were agreed to be included in the guidebook. In the third round, the results of preparing a self-care guidebook based on the contents of the agreement in the second round received consensus from the entire expert panel. The guidebook based on the results of this research can be integrated into the health service system. This manual is an integral part of the patient care process. This may include providing books to patients during visits, providing digital access, or placing them in health information libraries at care facilities. To improve this book, further research is needed by testing guidebooks in health services using an experimental study approach to maximize the quality of the guidebook. Apart from that, involving more complete health workers from across countries is also needed to obtain guidelines that can be applied globally.

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Conflict of interest

All authors in this article declared no potential conflict of interest.

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ORIGINAL ARTICLE

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Cultural care behaviors of multidisciplinary health workers in preventing neutropenic fever in children with leukemia after chemotherapy: an ethnonursing study

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ABSTRACT

Introduction: Neutropenic fever is commonly found in children with leukemia after chemotherapy. Fever occurs when children's immunity decreases after chemotherapy, and they are prone to infection. This study aims to describe the cultural care behaviors of multidisciplinary health workers in preventing neutropenic fever among hospitalized children with leukemia after chemotherapy.

Methods: An ethnonursing study was conducted at a cancer referral hospital in Central Java, Indonesia. Data were collected through observation in two Pediatric ward and chemotherapy unit for three months and FGDs and in-depth interviews with health workers who provided care services to leukemia patients post-chemotherapy. Data were collected from 14 informants: six nurses, four doctors, two clinical pharmacists, and two nutritionists. This study employed four phases of Leininger analysis for qualitative data to develop its thematic structures.

Results: The analysis of the entire data has revealed five themes: (1) performing antiseptic and aseptic techniques consistently, (2) nurse and dietician collaboration in handling eating difficulties post-chemotherapy, (3) collaborative interactions interdisciplinary in handling medication, (4) patient placement in an isolation room adjusted to patients' conditions, and (5) nurse's challenge to educate patients and their families.

Conclusions: Health workers from multiple disciplines play essential roles in preventing neutropenic fever by involving patients, parents, and other family members. It is necessary for the nurses to collaborate with other healthcare professionals and educate patients, and families to participate in the care interventions for these patients in minimizing the occurrence of infection among leukemia patients.

Keywords: behavior, health workers, preventing neutropenic fevers

Introduction

Neutropenic fever is one of the complications of chemotherapy in children with cancer and frequently becomes the leading cause of morbidity and mortality (Patel and West, 2017; Davis and Wilson, 2020). Neutropenic fever is more commonly found in blood cancers than in solid cancers. Moreover, neutropenic fever is primarily found in acute lymphocytic leukemia and acute myeloblastic leukemia at 54.2% (Nursyirwan and Windiastuti, 2018).

After chemotherapy, children with leukemia usually encounter various side-effects, including leukopenia and fever, caused by adverse drug reactions (ADRs) (Adade *et al.*, 2022). As neutrophils are one of the components of white blood cells or leukocytes, neutropenia can occur when someone has a low leukocyte count. Such a

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condition causes immunocompromising or decreased body immunity and makes children susceptible to fever (Rastogi *et al.*, 2021). Neutropenia is the most common side effect of myelosuppressive drugs and puts patients at risk of neutropenic fever due to infection (Tralongo *et al.*, 2020). Febrile neutropenia is most often caused by an infection in the bloodstream. Cancer patients with this fever are particularly susceptible to infectious complications, such as sepsis, which may lead to death (Davis and Wilson, 2020). To avoid deaths, appropriate multiple interventions for neutropenic fever must be delivered by multidisciplinary professionals before and after fever occurrence (Cennamo *et al.*, 2021).

Neutropenic fever is a body temperature reaching ≥ 38°C and a decrease in the value of the Absolute Neutrophil Count (ANC) reaching ≤ 500 cells/mm3 (Lucas, Olin and Coleman, 2018). Neutropenic fever is most often caused by an infection in the bloodstream. Cancer patients with neutropenic fever are particularly susceptible to infectious complications. Various effects that emerge after pediatric patients get chemotherapy include anemia, infection, leukopenia, and fever; this condition is known as adverse drug reactions (ADRs) (Adade *et al.*, 2022). To anticipate infection or complications, the multidisciplinary medical team will administer antibiotics to pediatric patients following chemotherapy. This effectively reduces the risk of infection (Davis and Wilson, 2020). Health workers, especially nurses, must strictly administer antibiotics on schedule and ensure that this administration in patients is in accordance with dosage and time using aseptic standards to prevent neutropenic fever. Administration of antibiotics is a preventive measure against neutropenic fever and are administered when neutrophils are < 500 cell/MCL or before the onset of fever is considered viable and safe (Melchionda *et al.*, 2013; Zengin *et al.*, 2017).

The Centers for Disease Control and Prevention recommends several aspects to prevent infection or neutropenic fever in children with cancer, which must involve multidisciplinary collaboration (Control, 2019). However, previous research has not comprehensively examined the collaborative works of health professionals related to nursing care in preventing neutropenic fever. Meanwhile, the number of neutropenic fevers in Central Java is still high. Among 101 patients with cancer who suffered from neutropenic fever after chemotherapy in Central Java, specifically in the Central General Hospital, 35 (34.7%) were pediatric patients (Pratiwi *et al.*, 2022). Thus, this study aims to describe the cultural care behaviors of multidisciplinary health workers in preventing neutropenic fever among hospitalized children with leukemia after chemotherapy. Such a condition was investigated using an ethnonursing approach to reveal the cultural care in preventing neutropenic fever in children with leukemia after chemotherapy through multidiscipline perspectives. Behavior is culture, and it is more appropriate to carry out research using ethnonursing because it will explore the actual natural condition of nurses and other health workers who work together with the nurses. This study was expected to understand the existing nursing collaboration culture in providing care to leukemia patients and its barriers to preventing neutropenic fever. Thus, the findings can underlie the establishment of a multidisciplinary team (MDT) model of care for post-chemotherapy among pediatric patients.

Materials and Methods

Design and Settings

A mini ethnonursing study was conducted to identify health workers' behavior in preventing neutropenic fever in children with leukemia after chemotherapy in a hospital. This study employed Leininger's theory of transcultural nursing or culture (McFarland and Wehbe-Alamah, 2019; Wehbe-Alamah and McFarland, 2020) as a guide frame. Qualitative study of multidiscipline health workers involved in leukemia therapy was conducted to gain facts regarding these workers’ care behaviors and to understand the potential and real phenomenon of nursing which needs to work collaboratively with other professionals in achieving goals. The aim of ethnonursing, as indicated in this study design, is to capture the expressions and meaning of patient care from similar and different perspectives (Leininger and Mc Farland, 2006).

This study was conducted for three months in two Pediatric ward and one outpatient chemotherapy unit. The data were collected through observation, FGDs, in-depth interviews, and document studies on medical records of leukemia patients and hospital protocols for leukemia and infection control. Data saturation was reached with 14 informants. The informants in this study were health workers, including nurses, doctors, clinical pharmacists, and nutritionists.

Ethical considerations

This study was approved by the Ethics Committee of the Central General Hospital of Central Java, Indonesia (No.1466/EC/KEPK-RSDK/2023). All observed and interviewed informants had given written consent prior to participating in this study.

Data collection

To obtain credible and rich data, three areas of the hospital, two Pediatric ward and one pediatric chemotherapy unit were chosen as the study location. Data were collected by the researcher with the assistance of two head nurses in the wards. Data were collected by observing participants during services, interviewing them, conducting FGDs, and conducting documentation studies. Both emic and etic data were studied to maintain objectivity and record relevant patterns (McFarland and Wehbe-Alamah, 2019; Wehbe-Alamah and McFarland, 2020) Informants comprised nurses, doctors, clinical pharmacists, and nutritionists. Before retrieving data, all informants had received an explanation of the research purposes. After receiving this explanation, they voluntarily participated in the study by giving consent. Data retrieval employed a semi-structured interview guide (See Figure 1).

Informant observations and interviews

Observations were made to obtain an authentic description of neutropenic fever prevention in pediatric patients with leukemia after chemotherapy. This study observed health workers' behavior and habits during services in the wards. The researchers observed health workers' behavior and habits in providing interventions and education for patients and their families. The researchers collaborated with nurses, doctors, clinical pharmacists, and nutritionists to conduct observations without involvement in the services. The researchers and health workers visited patients and observed the health workers' activities focusing on neutropenic fever prevention. Observations were carried out by following the service schedule of the nurses and doctors who were going to examine and treat the patients. Meanwhile, observations on dietitians and clinical pharmacists were conducted along with their duty time as informed by the nurse on duty. The researchers followed health workers during their visits to the patients and observed the health workers' activities. In the first and second weeks, the researchers used nursing uniforms to hold observations. Then, in the third and fourth weeks, we continued with interviews during observation for other informants. Finally, the observed health workers were interviewed. This study also analyzed documents related to the objective of this study. This study adjusted observation phases to those in an ethnonursing method, participation, and Leininger's reflection as observation protocols (Wehbe-Alamah and McFarland, 2020).

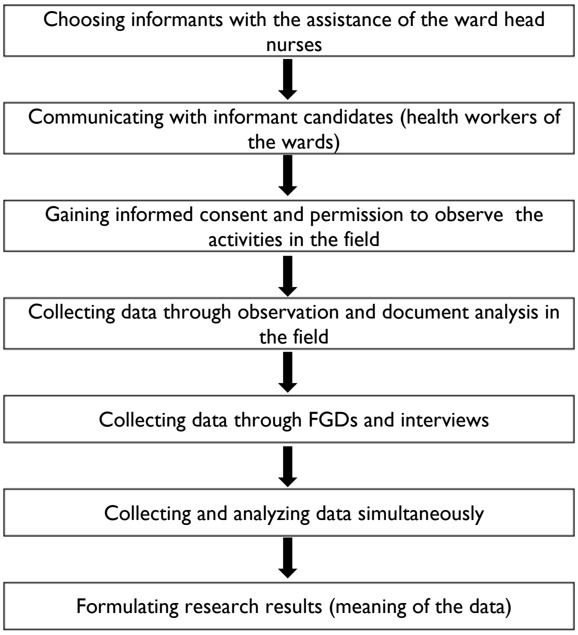

Figure 1 *Data collection process*

Recruitment of the informants

The purposive sampling technique was employed to recruit informants to achieve data saturation. Informants were selected by adjusting to the research question as a guide and following their informants during the observation. The informants were recruited using the inclusion criterion of health workers who care for and treat children with leukemia after chemotherapy. During the observation in the wards, four health workers participated in this study; they were nurses, doctors, clinical pharmacists, and nutritionists. Meanwhile, the exclusion criteria were: (1) health workers who were on leave or sick during the research time and (2) health workers who resigned from participating in this research. The researchers protected the informants' privacy during the observation, FGDs, and interviews.

Data analysis

Observation data were in the form of field notes and photographs. Meanwhile, the results of interviews and FGDs were recorded and transcribed. Afterward, the researchers analyzed the data to obtain a thematic view. This study employed four phases of Leininger analysis for qualitative data to gain the thematic structures of this study (Wehbe-Alamah and McFarland, 2020). First, the researchers consecutively focused on emic data, ethical data, and research objectives. Data from observations, field notes, photographs, interviews, and FGDs were copied. Second, the researchers described a process to encode all data. Then, the codes were classified according to the investigation domains, and each code's meaning in the context was analyzed. Third, the researchers ranked repeatedly reviewed data to find recurring patterns, similarities, and different meanings in contexts. In this phase, the data saturation was confirmed. The data were analyzed to show meaning patterns of the findings, considering further credibility and confirmation of the results. In this phase, the meaning of the text was described as categories. In the final phase, the data were unified and interpreted, and the formulation of new findings of this study was determined as a pattern of preventing neutropenic fever in children with leukemia after chemotherapy. The researchers analyzed the data repeatedly; each step was conducted repeatedly by confirming the data with the informants. Then, each step was reviewed, and the data were confirmed with informants at all stages.

Results

This study involved 14 participants aged 26 to 48 years old. The informants were mostly female and dominated by professional nurses and medical doctors with bachelor's degree backgrounds (See Table 1).

The observation, FGD, interviews, and document studies have revealed five themes: (1) performing antiseptic and aseptic techniques consistently, (2) nurse and dietician collaboration in handling eating difficulties post-chemotherapy, (3) collaborative interactions interdisciplinary in handling medication, (4) patient placement in an isolation room adjusted to patients' conditions, and (5) nurse’s challenge to educate patients and their families The summary of the themes and sub-themes of the findings can be seen in Table 2.

Theme 1: Performing antiseptic and aseptic techniques

The observation results showed that the mother and child service wards were equipped with a sink for hand washing near the entrance door, near the bathroom, and in the patient's room. A bottle of liquid disinfectant for washing hands was also available next to the patient room's door. Before entering the patient's room, some of the health workers washed their hands in the sink or applied alcohol-based liquids. However, some others did not always apply this hand washing before and after entering the patient’s room. In addition, they wore gloves during the treatment according to hospital procedure protocol. They also frequently reminded patients, families, and parents to pay attention to personal hygiene and hand washing. The observation has revealed that alcohol-based liquid disinfectant was regularly refilled because health workers, families, and visitors frequently apply it.

Table 1 Characteristics of the informants

Code	Age	Sex	Level of Education	Occupation
P1	48	Female	Undergraduate	Charge Nurse
P2	33	Female	Undergraduate	Charge Nurse
P3	31	Female	Undergraduate	Dietician
P4	35	Female	Undergraduate	Charge Nurse
P5	34	Female	Undergraduate	Charge Nurse
P6	41	Female	Undergraduate	Charge Nurse
P7	28	Female	Diploma	Charge Nurse
P8	56	Female	Undergraduate	Dietician
P9	32	Male	Postgraduate	Clinical Pharmacist
P10	33	Female	Undergraduate	General Practitioner
P11	52	Female	Postgraduate	Clinical Pharmacist
P12	32	Female	Undergraduate	General Practitioner
P13	29	Female	Undergraduate	General Practitioner
P14	48	Female	Postgraduate	Specialist: Pediatrician with Hematologist expertise

Table 2. Finding Themes and Sub-Themes

No	Themes	Sub-Themes
1	Performing antiseptic and aseptic techniques consistently.	Personal hygiene Healthy Living Behavior Sterilization and disinfection
2	Nurse and dietician collaboration in handling eating difficulties post-chemotherapy.	Optimizing nutritional intake Education on optimizing nutritional intake
3	Collaborative interactions interdisciplinary in handling medication.	Child’s condition after chemotherapy Intervention according to standard operational procedure
4	Patient placement in an isolation room adjusted to patients' conditions.	Criteria for isolated patients Cohorting
5	Nurses' challenge is to educate patients and their families.	Education on healthy living behavior Education minimizes the risk of infection from outside Education on infection prevention at home Educational media Educational evaluation

Almost all of the informants described that personal hygiene, especially hand washing, is a priority intervention for health workers to prevent infection and teach the patients and their families. Two of the nurse informants said:

"Our treatment should follow the SPO. We should prevent pediatric patients from being infected so that we wash our hands and use disinfectant." (P1)

"We wear PPE and wash our hands when visiting the patient. We collaborate with housekeeping staff to clean the patients' rooms. We educate the staff on how to clean the room. We also educate patients' families about patient rooms' cleanliness." (P5)

Meanwhile, one of the general practitioner (GP) informants emphasized the importance of conducting procedures with sterile techniques. He said: *“We always* *perform the aseptic technique and administer medicine sterilely*." (P10)

Theme 2: Nurse and dietician collaboration in handling eating difficulties post-chemotherapy

This study's observations found that some patients had mouth ulcers, nausea, and vomiting as the effects of chemotherapy and this caused eating difficulty. To manage this problem, the nutritionists assessed and offered types of foods that pediatric patients could eat. They informed the pediatric patients' parents of these types of foods. Therefore, their diet was replaced with milk because they refused to eat porridge or bread. The nutritional staff served a significant portion of meals three times a day. It also indicates that some pediatric patients with eating difficulties cannot eat one meal in one serving, so the meals, including fruit, were left. The interviews revealed that leftover food was supposed to be saved in the food storage so patients could eat it later. However, no food storage was available in the room, and the leftovers could be the sources of infection when eaten again by pediatric patients. The FGDs stated that nurses and nutritionists collaborated to discuss patients' nutritional needs, provide high-nutritional meals, and educate the patients and their families. This strategy aims to provide adequate daily nursing care and nutritional care. The dietician informants stated:

"After providing the pediatric patients with food, I ask their parents how much food the child can eat and what types of food the child eats. Then, I also ask them about symptoms of nausea and vomiting. Afterward, I will count the percentage of the food and decide if the amount can be added. I will increase the amount of food given. If the pediatric patients can only eat 30% of the provided food, instead of 50% as I target, I will remodify the diet and consider what types of food the child eats more, solid or liquid. For example, if they eat more liquid food, I will add the volume of the food or change into a higher calorie milk with the same volume." (P3)

Furthermore, a nurse informant said:

"For example, when leftover fruit, such as bananas or apples, is not discarded into the bin, family members sometimes eat it because they consider it unfortunate with the fruit. They just eat half of the fruit and leave it in the ward. If the other half of the fruit is eaten by pediatric patients with malignant diseases and chemotherapy, it will cause infections. Therefore, we educate the family to eat up the food and not leave over the food. If they cannot eat the food, they should throw it in the bin." (P1)

The medical records also showed that nutritionists educate patients about food or nutrition given to hospitalized patients. Implementation notes showed that nurses also provided education about balanced nutritional intake to increase patients' body immunity and prevent infection risk and informed the dietician and pediatrician about patients' eating problems.

Theme 3: Collaborative interactions interdisciplinary in handling medication

The observations indicated that a pharmacist comes with the medicine as prescribed for a number of patients. Medicine handover was held in a room by pharmacy staff and more than one nurse to check the medicine. An example of health workers' collaboration is as follows: a clinical doctor prescribes medicine for a patient, and then a clinical pharmacist assesses, dispenses, and counsels the prescription to monitor the side effects of the prescribed medicine. This assessment involves nurses because they interact with patients more. One of the pharmacist informants explained:

"We help doctors to review whether chemotherapy documents have already complied with established standards or protocols. If the documents are ready, pharmacists will prepare cytostatic. Afterward, the medicine is ready, the patient undergoes chemotherapy and he returns to the ward. Then, if the patient has chemotherapy repeatedly, he usually understands what he will feel every chemotherapy, even though the feeling is not the same. We help patients to conduct an initial assessment. For example, we ask, "How was the chemo yesterday?

"Patients usually say that they vomit after chemotherapy and suddenly have a fever. Even if the problem exists, it is fine so far. That is all that we are doing. We observe and monitor until the patient is discharged. However, some parents ask nurses to prepare medicine in case their child has a fever at home. We talk to the doctor and ask him to prescribe some medicine because the patient has a certain tendency.

"So I would definitely ask patients not to be bored because his medicine is a lot and not taste good. I also remind them if they did not take this medicine, their condition will get worse." (P9)

Theme 4: Patient placement in an isolation room adjusted to patients' conditions

The observation revealed that the maternal and child care wards only have one isolation room with a HEPA filter and one isolation room without a HEPA filter. The capacity of the two rooms is two patients each. Pediatric patients with leukemia after chemotherapy are often placed in these two rooms due to the risk of infection caused by decreased white blood cells, known as neutropenia and pancytopenia; however, many times the rooms were full while the demand for the rooms was higher. A high number of children conducting chemotherapy made the wards adhere to a cohort system. The informants described that this system aims to minimize the occurrence of infection due to limited existing facilities. The charge nurse discussed with the pediatrician about the patients to be prioritized in the isolation room and how prompt treatment should be delivered for these patients. One of the nurse informants said:

"This patient can be treated in positive pressure and must be isolated from other patients who have infections. Therefore, quick treatment aims to reduce further severity or infection transmission." (P7)

Theme 5: Nurse's challenge to educate patients and their families

Observation results indicate that each discipline provides health education to the patients by themselves, while documentation about specific information provided to the patients is not mentioned in the record. Thus, similar information was repeatedly delivered to the patients by different health workers. In addition, nurse informants explained their difficulties in managing patient's disobedience in following visiting rules to prevent nosocomial infection to the patients. This statement is supported by the observation data that some hospitalized children are accompanied by both parents. Once, an isolation room was occupied by six people, namely two patients with two companions each. Even though the hospital regulations showed in the electronic medical record stated that patients could only be accompanied by one family member and the family could not sleep on the bed, the nurses described that they were unable to enforce these hospital regulations to the patient's family as they did not want to have a conflict with the patient and his family. The results of the analysis of hospital administrative documents showed that there are no differences in regulations for visiting and accompanying pediatric patients. One of the charge nurse informants affirmed that:

"Many family members should not stay here in the ward. Therefore, they will not block housekeeping staff from cleaning the ward in the morning and evening. An isolation room has a room for companions, while others do not. Therefore, when a family member sleeps under the patient's bed, we will wake him up, especially during the handover. We will ask him to wake up and roll up the mat. Sometimes, some family members do not follow our instructions, so we must call security staff. In some cases, a pediatric patient from a village is accompanied by many family members, such as a mother, father, grandmother, and uncle. That is our challenge, especially when dealing with chemotherapy patients. We will educate the family members that the patient's companion staying in the ward should not change. Therefore, when the companion in the ward needs food, another family member outside the ward can help him find food. Unfortunately, it is difficult for us to educate them about this issue. Sometimes, we also rebuke a family member from another city who directly visits the patient in the ward wearing a jacket. We will ask him to put the jacket outside the ward. That is our effort. Then, we ask him to wash his hands before entering the patient's room." (P1)

The hospital services standard of infection prevention states that one only family could accompany one patient. However, because pediatric patients often experience hospitalization effects, such as anxiety and fear, the nurse permitted that a pediatric patient could be accompanied by both parents. In fact, this violates the provisions of infection control.

Discussions

In this discussion, cultural care related to neutropenic fever prevention carried out by multidisciplinary health workers at the hospital will be explained and compared to the previous studies according to Leininger's educational factors enabler. Generally, this ethnonursing study found that professional nurses should effectively work with other professionals, such as physicians, nutritionists, and pharmacists, and involve patients and their families in the fulfillment of patients' basic needs and health education to prevent neutropenic fever due to chemotherapy; however, according to the results of the observation, interviews, and FGDs, the MDT collaboration has not been established optimally.

This study found that hand washing was mandatory for health workers, patients, their families, and visitors, and information always reminds medical staff to wash their hands every time patients are admitted to hospitalization, including when carrying out duty or intervening in patients. However, some medical staff did not comply with this rule. From the observation and interview, some medical staff do not comply with this rule. In some cases, health workers do not wash their hands or use hand rub before touching patients. Consistent with previous studies, practicing hand washing has several obstacles, such as inconsistent supplies of hand washing materials, lack of training, adverse reactions after being reminded to wash hands, and lack of motivation (González *et al.*, 2016). Although health workers' infection prevention and control behaviors are key factors in infection prevention and management, many parties still have low adherence to prevention behavior, so the focus is usually on corrective interventions (Greene and Wilson, 2022). Lifestyle, personality, and organizational culture play a key role in hand-washing behavior (Ghaffari *et al.*, 2020).

According to this study's findings, many children with leukemia experienced post-chemotherapy side effects. They experienced anemia, nausea, and vomiting because of mucositis, which led to eating difficulties and low dietary intake. The roles of nurses and dieticians is important to maintain the oral intake and nutritional balance of the patients. These health workers collaborated in identifying problems and providing education and support for the patients and their families. Education about diet to meet nutritional needs during illness is crucial, especially for pediatric patients with leukemia after chemotherapy, as their immunity decreases (Adade *et al.*, 2022). Past research indicates that children with cancer presented undernutrition. In general, undernutrition rates were found in low- or low-middle-income countries. Malnutrition will affect the quality of life and the overall survival of the patient (Diakatou and Vassilakou, 2020). Proper nutritional assessment and nutritional intervention are necessary to maintain growth and development and improve the quality of life of children with cancer (Viani *et al.*, 2020).

This current study found that each health worker understood their part in patients' care services adequately. The nurse works are links with other professional work, and no single profession can prevent the occurrence of neutropenia; however, this study also indicates that most work is just a daily routine, while multidisciplinary consultation discussions or meetings for special or cases were rarely performed. Various effects that emerge after pediatric patients get chemotherapy include anemia, infection, leukopenia, and fever should be anticipated to prevent infection or complications by the medical team (Adade *et al.*, 2022). Furthermore, the medical team is supposed to give antibiotics after the pediatric patients have chemotherapy as administration of antibiotics effectively reduces the risk of neutropenic fever (Owattanapanich and Chayakulkeeree, 2019). However, this ethonursing study found that this antibiotic would not be prescribed for the patients if the infection has not to occur. A recent integrative review by Dunnack and Montano revealed that multiple health professional who works together towards standardize implementation for neutropenic fever will improve the patient’s outcomes, including reducing antibiotic duration, deaths, cost, and length of stay (Dunnack and Montano, 2021).

In this study, health workers are found to perform several health promotion sessions to the patients and their families to improve their knowledge and behaviors toward preventing neutropenic fever. Several patients and families’ behaviors, such as washing hands, wearing clothes that protect them from being contaminated by infectious fluids, not coming to visit patients if having respiratory tract infection symptoms, and hospital efforts to build private rooms with closed windows and install air filters that can filter the air efficiently are an important aspect in controlling the nosocomial infection (Bryant, Walton and Albrecht, 2014). Patients with neutropenia should be facilitated to occupy the isolation rooms to prevent them from infection (Naghdi, Forouzi and Dehghan, 2021), which is not fully supported in the hospital of this current study. One-time education is not enough and must be repeated and implemented for patients, parents, families, and visitors. Education is mainly about personal hygiene, hand washing, and hygiene. This education is crucial because some visitors often go in and out of patient rooms without washing their hands and bring various items from outside that can increase the risk of transmission.

Conclusion

Prevention of neutropenic fever depends on the collaboration habits of the nurse team. Sufficient and prompt multidisciplinary teamwork between health workers and optimal support of patients and their families can effectively prevent the neutropenia side effects. Health workers must collaborate to maintain antiseptic and aseptic techniques and a high standard of health education and treatment for the patients, while patients and their families should implement aspects taught by health workers. Prevention of neutropenic fever requires the cooperation of multidisciplinary health workers, patients, and their families since medicaments and health workers' preventive behaviors cannot necessarily reduce the risk of infection.

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ORIGINAL ARTICLE

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Self-care of chronic illness prevents the risk of diabetic foot ulcers in patients with diabetes: a cross-sectional study

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ABSTRACT

Introduction: Diabetic foot ulcer (DFU) is a serious and chronic complication of diabetes mellitus (DM). This study aims to explain a model of self-care of chronic illness on the prevention of DFU risk in patients with DM, including foot self-care of maintenance, monitoring, and management.

Methods: This study was an analytical study with a cross-sectional approach, with 300 patients randomly selected from six Public Health Centers in Surabaya, Indonesia, from June to August 2022. The inclusion criteria were individuals with DM and aged more than 26 years. Exclusion criteria were reading disabilities or having cognitive impairments Data were collected using a questionnaire. The correlation between variables was analyzed using the statistical method of Partial Least Squares.

Results: The risk of DFU in patients with DM was 40% with low risk, 38% with moderate risk, 8% with high risk, 5% remission, and 10% with DFU. This research shows that there is a significant correlation between foot self-care management and the risk of DFU, where the p-value = 0.000, while the indicators of foot self-care maintenance and self-care monitoring do not have a significant correlation with the risk of DFU, where the p-value is respectively equal to 0.350 and 0.844.

Conclusions: Foot self-care management was a factor that directly correlates with the risk of DFU. Autonomous self-care management behaviors still needed to be improved, because most patients still had these inadequate behaviors. Further research is needed to improve the behavior quality of patients with DM in managing foot care independently.

Keywords: diabetes mellitus, diabetic foot, self-care

Introduction

Chronic hyperglycemia in diabetes in the long term can cause microvascular complications affecting the eyes, kidneys, and nerves and an increased risk of cardiovascular disease (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013). Long-term complications of diabetes can be present at diagnosis in people with type 2 diabetes and can appear earlier (around five years) after the onset of type 1 diabetes (Federation International Diabetes., 2019).

Peripheral neuropathy is the most common form of neuropathy associated with diabetes. It affects the distal nerves of the limbs, especially those on their feet. It primarily alters the symmetrical sensory function causing the abnormal feeling and progressive numbness. This condition facilitates the development of foot ulcers, referred to as diabetic foot. DFU is one of the most severe and chronic complications of diabetes mellitus, including deep tissue lesions with peripheral vascular disease (PVD) of the lower extremities and peripheral neuropathy. Often patients with DM who

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have diabetic foot ulcers require amputation of that part of the body and bear medical costs five times higher than patients without foot ulcers (Federation International Diabetes., 2019 ; Elkashif, Mahdy and Elgazzar, 2021; Thotad, Bharamagoudar and Anami, 2023). Patients with DFU will experience limited life and require strong efforts to adapt to their conditions (Alfaqih, Kusnanto and Padoli, 2020).

In chronic disease, self-management refers to carrying out daily activities that serve to maintain or restore health and well-being, prevent complications, and manage chronic disease (Song, 2010; Costa, Tregunno and Camargo-Plazas, 2021. In patients with chronic disease, it may be necessary to organize and adapt self-care during the illness, for example, with an exacerbation of the disease, if comorbid occurs, or if continued treatment is required. Self-care of chronic illness is a construct built from three main concepts: self-care of maintenance, monitoring, and management, which are closely interrelated. Therefore adequate self-care performance must cover all three of these behaviors ; Ausili, Rebora and Valsecchi, 2020).

Regarding DFU prevention, one of the many ways is to involve patients in day-to-day self-management, which is a patient-centered approach to care. The results of qualitative research show that patients with DM who experience DFU have a passive role in foot care and they do not realize the importance of foot care (Costa, Tregunno and Camargo-Plazas, 2021). The results revealed that out of 100 patients with DM, 79% suffered from burning or tingling in the limbs; 74% complained of redness of the lower extremities, leg or leg pain during exertion, and loss of lower extremity sensation; and 80% had skin discoloration or skin lesions. Most of them had low knowledge and inadequate foot care behavior before the intervention. Self-care practices of diabetics are important to maintain and reduce diabetic foot complications, but commitment to self-care practices is still inadequate (Elkashif, Mahdy and Elgazzar, 2021).

DM sufferers must have proper self-care skills to prevent DFU from occurring or developing foot ulcers. These skills are necessary for individuals with DFU, who usually must apply daily self-management and be on top of their ulcer care to prevent the poor outcome of lower limb amputation. Many self-management models have been developed for patients with chronic disease, especially for patients with DM to prevent DFU. Poor diabetic foot self-care practices are identified as a factor in the occurrence of DFU and a high risk of amputation. However, until now, there has been no research that explains how self-care of chronic illness is implemented which consists of three components in daily self-management practices in patients with DM who continue to do diabetic foot self-care.

This study aims to explain a model of self-care of chronic illness on the prevention of DFU risk in patients with DM. Self-care of chronic illness in this study consists of three components, namely foot self-care maintenance, monitoring, and management hereinafter referred to as latent variability. The risk of DFU is a health outcome of this model, hereinafter referred to as manifest variables.

Materials and Methods

Study Design

This research was analytical study with a cross-sectional approach. This study determined the correlation between latent variables, namely foot self-care maintenance, monitoring, and management behavior and risk of DFU as manifest variable, and also explained the relationship between latent variables. In addition, this study also measured indicators or constructs that make up each latent variable. There were three indicators that make up the latent foot self-care maintenance variables were (a) Disease prevention behaviors, (b) Health promoting behaviors, and (c) Illness-related behaviors. There were two indicators that make up the latent foot self-care monitoring variable, namely (a) Body listening, (b) Symptom recognition. There were two indicators that make up foot self-care management, namely (a) Autonomous self-care management behaviors and (b). Consultative self-care management behaviors.

Population, Samples, and Sampling

The population in this study was patients with DM who visited six Primary Health Centers (PHC) in East Surabaya, East Java, namely Pucang Sewu, Tambak Rejo, Pacar Keling, Keputih, Medoka Ayu, and Tenggilis located in East Surabaya. The sample size was 300 adult patients with DM calculated using the rule of thumb formula and recruited using the simple random sampling technique. The inclusion criteria were individuals with DM and aged more than 26 years. Exclusion criteria were reading disabilities or having cognitive impairments. This study was approved by the heads of institutions participating and by all enrolled and willing patients by signing a consent form.

Data Collection

The research was conducted from June to August 2022 at six PHC in Surabaya, East Java, Indonesia. All eligible participants had to fill out a self-administered questionnaire on characteristics and foot self-care of chronic illness, consisting of foot self-care maintenance, monitoring, and management, all of which were written in Indonesian. Researchers distributed questionnaires to patients who visited the PHC face to face with them. Eight nursing students were involved as enumerators, where they had previously received training in filling out questionnaires. Before data collection, the researcher explained the purpose of the study to the patients and ensured that they had obtained written informed consent. Patient participation was voluntary. In addition, patients as participants could choose to remain anonymous and had the option to refuse or not fill out the survey questionnaire.

Measurements

Data collection used a questionnaire consisting of characteristic data, including age, gender, marital status, smoking history, Body Mass Index (BMI), duration of DM, family history, type of medication, co-morbidity, and random blood glucose levels. BMI categories are Underweight: < 18.5, Normal: 18.5 - 25.0, Overweight: 25 – 27, and Obese > 27 (Menteri Kesehatan RI (Indonesian Minister of Health), 2014). The instrument used to measure foot self-care maintenance, foot self-care monitoring, and foot care management was a modified and combined questionnaire from the Self-Care of Diabetes Inventory (SCODI) (Ausili *et al.*, 2017) and Diabetic Foot Management (García-Inzunza *et al.*, 2015; Kaya and Karaca, 2018; Schaper *et al.*, 2019 (Kaya and Karaca, 2018)).

The foot self-care questionnaire consists of three parts, namely (1) maintenance of foot care (13 questions) spread over three indicators, namely: (a) Disease prevention behavior (5 items), (b) Health promotion behavior (4 items), (c) Disease-related behavior (4 items). (2) monitoring foot care (15 questions) spread over two indicators, namely: (a) Body listening (11 items), (b) Symptom recognition (4 items). (3) Foot Self-Care Management (30 questions) which is spread over two indicators, namely: (a) Autonomous self-care management behavior (26 items) and (b). Consultative self-care management behaviors (4 items). The scoring of foot self-care maintenance and monitoring uses a Likert scale with the categories strongly agree, agree, and disagree, where the higher the value, the better the behavior. The scoring of foot self-care management used a Likert scale with the categories always, often, sometimes, rarely, and never, where the higher the value, the better the behavior. Meanwhile, the development of risk category questions from DFU comes from the Diabetic Foot Model of Care with a score range of 1-5, where the higher the score, the more risky (National Clinical Programme for Diabetes, 2021). Score 1 is mild risk, score 2 is moderate risk, 3 is high risk, 4 is remission, and 5 is active ulcer.

Because this research has used Partial Least Squares (PLS) analysis, the validity and reliability test values use structural model testing, namely convergent validity, construct validity, and discriminant validity), and reliability (composite reliability).

Data Analysis

The descriptive statistics used to describe patient characteristics are frequency, percentage, mean, and standard deviation. The PLS determined the relationship between foot self-care of chronic illness variables and the risk of DFU as a health outcome. This research uses data analysis methods using PLS (*Partial Least Squares*) which can simultaneously test measurement models (outer model) and structural model testing (inner model). Measurement models are used to test validity (convergent validity, construct validity, and discriminant validity), and reliability (*composite reliability).* The result of convergent validity can be seen from the value of the loading factor and the calculated t value. The factor loading value is said to be valid if it is more than 0.5, while the result of t count can be said to be valid if it is more than 1.96. Construct validity measured by looking at AVE values greater than 0.5 indicates the adequacy of good validity for latent variables. The validity of the description can be measured using the cross- loading value. If the high cross loading value is 0.5 in the dimension of a particular variable compared to the dimension value of another variable then the constructive validity of the latent variable is good. Construct reliability is measured by the value *of composite reliability* and *reliable construct;* if the value of composite reliability is above 0.70 then the indicator is called consistent in measuring its latent variable. Structural models are used to test causality (hypothesis testing with predictive models). Testing was carried out using the t test. A variable was said to have correlation if the calculated t value was greater than the table t value. The t table value in this study was 1.96 (Latan and Ghozali, 2012).

Ethical Approval

Ethical approval was obtained from the Poltekkes Ethics Institute of the Ministry of Health Surabaya: No.EA/ 901/KEPK-Poltekkes_Sby/V/2022, and administrative was obtained from the Surabaya Health Office for each selected CHC before data collection.

Results

Description of Characteristics

The mean age of the participants in this study was 59.03 ± 9.78 years, 69% were aged between 46 and 65, 55% were female, 37% were high school seniors, 55% were unemployed, and 75% were married. Clinical characteristics data indicate that 86% were not smokers, and 53% had overweight. The mean Duration of DM was 7.31 ± 6.52, 55% had a family history, 87% used oral drugs, and 65% had co-morbidities. The average random blood sugar level at the time was 207.18 ± 78.44, 45% ≥ 200 mg/d (table 1). The risk of DFU in patients with DM was 40% with low risk, 38% with moderate risk, 8% with high risk, 5% remission, and 10% with DFU (Table 2).

Table 1 Description of characteristics of patients with DM (n=300)

Characteristics	Frequency	
	n	%
Age (years) (Mean 59,03 ± 9.78)		
26-35	3	1
36-45	19	6
46-55	89	30
56-65	118	39
> 65	71	24
Sex		
Male	134	45
Female	166	55
Marital Status		
Yes	224	75
No	27	9
Widowed	49	16
Smoking		
No	258	86
Yes	42	14
BMI (kg/m2) (Mean 24.46 ± 4.04)		
Underweight	10	3
Normal	107	36
Overweight	159	53
Obesity	24	8
Duration of DM (years) (Mean 7.31 ± 6.52)		
1-5	162	54
6-10	80	27
>10	58	19
Family history of DM		
Yes	164	55
No	136	45
Type of medication		
Oral	261	87
Injection	15	5
Combination	24	8
Co-morbidities		
Yes	197	66
No	103	34
Random blood sugar level (Mean 207.18 ± 78.44)		
<200	166	55
≥ 200	134	45

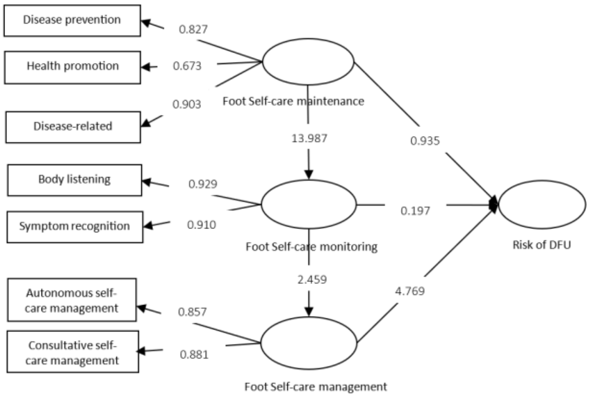

Figure 1 *The factor loading value of indicator and t-value of correlation between variables*

Description of Foot Self-care Maintenance, Monitoring, and Management

Variable foot self-care management has shown that of the three indicators, the highest proportion (47%) is indicated by inadequate disease prevention behavior. Variable the foot self-care monitoring showed that 64% of the patients had body listening and 59% had adequate symptom recognition. On the variable foot self-care management, the majority of patients (76%) had inadequate autonomous self-care management behavior, but 60% had adequate consultative self-care management behavior (Table 3).

The results of testing the structural model on each indicator for each latent variable can be seen in Table 2 and Figure 1. The convergent validity value of each indicator can be seen from the loading factor value, namely (a) Disease prevention behavior was 0.827, (b) Health promotion behavior item was 0.673, (c) Disease-related behavior is 0.903, (d) Body listening was 0.929, (e) Symptom recognition was 0.910, (f) Autonomous self-care management was 0.857, and (g) Consultative self-care management behaviors was 0.881. The convergent validity value was valid, because it was more than 0.5. The construct validity value could be seen from the AVE value, where the AVE value of this research is > 0.5. Sequentially the AVE values were 0.651, 0.846, and 0.756, so it could be stated that this indicator had a good validity value. The construct reliability value of each variable was expressed as a composite reliability value, where the value was declared reliable if the value was

Table 2 Description of risk of Diabetic Foot Ulcers (n=300)

Characteristics	Frequency	
	n	%
Risk of DFU		
Low	119	40
Moderate	114	38
High	23	8
Remission	14	5
Active ulcer	30	10

Table 3 Description of foot self-care maintenance, monitoring, and management (n=300)

Indicator	Adequate		Fairly adequate		Inadequate		Factor Loading	Composite Reliability	Average Variance Extracted (AVE)
	n	%	n	%	n	%			
Foot Self-care Maintenance								0.847	0.651
Disease prevention behaviors	45	15	115	38	140	47	0.827		
Health-promoting behaviors	159	53	132	44	9	3	0.673		
Illness related behaviors	98	33	160	53	42	14	0.903		
Foot Self-care Monitoring								0.916	0.846
Body Listening	93	31	192	64	15	5	0.929		
Symptom recognition	84	28	178	59	38	13	0.910		
Foot Self-care Management								0.861	0.756
Autonomous self-care management behaviors	21	7	52	17	227	76	0.857		
Consultative self-care management behaviors	180	60	41	14	79	26	0.881		

above 0.70. These values were respectively 0.847, 0.916, and 0.86 so that these indicators could be declared consistent in measuring latent variables (Table 3). Variable foot self-care management has shown that of the three indicators, the highest proportion (47%) is indicated by inadequate disease prevention behavior. Variable the foot self-care monitoring showed that 64% of the patients had body listening and 59% had adequate symptom recognition. On the variable foot self-care management, the majority of patients (76%) had inadequate autonomous self-care management behavior, but 60% had adequate consultative self-care management behavior (Table 3).

The Correlation between Foot Self-care Maintenance, Foot Self-care Monitoring, Foot Self-care Management and Risk of DFU

To determine the correlation between variables, a structural model (inner model) was tested. Testing was carried out using the t-test. A variable is said to have influence if the calculated t value is greater than the table t value. The t table value in this study is 1.96. This research shows that there is a significant correlation between foot self-care management and the risk of DFU, where the p value = 0.000, while the variable of foot self-care maintenance and self-care monitoring do not have a significant correlation with the risk of DFU, where the p value is respectively equal to 0.350 and 0.844 (Table 3). Based on these data, we conclude that foot self-care management is a variable that has a direct correlation to DFU risk, while foot care maintenance and monitoring is an indicator that correlates with self-care management.

Table 4 The value of the correlation between foot self-care maintenance, foot self-care monitoring, foot self-care management and risk of DFU

Correlation	Original Sample (O)	T Statistics (|O/STDEV|)	P-Values
Foot Self-Care Maintenance -> Risk of DFU	0.073	0.935	0.350
Foot Self-Care Maintenance -> Foot Self-Care Monitoring	0.650	13.987	0.000
Foot Self-Care Monitoring -> Risk of DFU	-0.017	0.197	0.844
Foot Self-Care Monitoring -> Foot Self-Care Management	0.197	2.459	0.014
Foot Self-Care Management -> Risk of DFU	0.296	4.769	0.000

Discussions

This research explains the correlation between foot self-care and the risk of DFU through the self-care of chronic illness model. We use the theory of self-care of chronic illness to analyze foot care abilities in patients with DM. The components of self-care of chronic illness consist of Foot Self-care Maintenance, Foot Self-care Monitoring, and Foot Self-care Management, which are the variables in this study. Based on research results, it shows that foot self-care management has a direct correlation with the risk of DFU. Meanwhile, foot self-care maintenance and monitoring have an indirect correlation with the risk of DFU. Treatment of foot ulcers is challenging behavior because the causes are multifactorial, become a burden for the patient, involve the healthcare system, and society. Meanwhile, for foot ulcers that have successfully healed, the risk of recurrence is still high (Netten *et al.*, 2020). Self-care practice is one of the most significant parts of self-management for preventing diabetic foot ulcers (Mekonen and Demssie, 2022)..

The risks of DFU discussed in this study are low, moderate, high, remission, and ulcer. The majority of participants had a low to moderate risk of DFU. However, based on data on foot self-care management it shows that the majority of patients with DM had low autonomous self-care management behaviors. This condition can be a risk for developing diabetic foot ulcers. Diabetic foot ulcers are usually caused by repeated stress on areas subjected to high vertical or shear forces in patients with peripheral neuropathy (Armstrong, Boulton and Bus, 2017). Diabetes can also involve Charcot's neuroarthropathy, which involves the progressive destruction of bones, joints, and soft tissue, most commonly in the ankles and feet. The combination of neuropathy, abnormal foot loading, repetitive micro-trauma, and bone metabolic disorders leads to inflammation, osteolysis, fractures, dislocations, and deformities (Mishra *et al.*, 2017).

This study shows that foot self-care maintenance does not directly affect the risk of DFU, but it does affect foot self-care monitoring. Patients with DM as a chronic disease must perform good and regular self-care to prevent complications (Ausili *et al.*, 2017). Self-care maintenance has a positive influence on self-care monitoring behavior. Patients with DM who carry out foot care independently have a positive relationship with the behavior of monitoring foot care. According to theory (Riegel *et al.*, 2019), self-care maintenance is directly related to self-care monitoring and self-care management. Theoretically, self-care maintenance is a complex and diverse dimension of self-care (Ausili *et al.*, 2017). Active symptom monitoring can provide awareness and interpretation of body changes as a symptom of a disease. Likewise, with the incidence of DFU in patients with DM, the ability to monitor the condition of the feet is essential to detect it early and prevent it.

The behavior of foot self-care monitoring in this study was not directly related to the incidence of DFU but influenced the behavior of foot self-care management. Even so, the data in this study indicate that most DM patients are quite capable of monitoring the signs and symptoms that occur in their bodies. Most patients experience foot abnormalities such as dry skin, callus, brittle toenails, and cracked heels. The self-observation of changes in signs and symptoms is the link between self-care maintenance and self-care management. Higher self-care monitoring was also associated with lower HbA1c in patients with diabetes (Ausili, Rebora and Valsecchi, 2020). Other studies have also indicated that self-management behavior is strongly associated with HbA1c (Thojampa and Acob, 2020).

Regarding foot care, careful inspection and examination of the feet is an integral part of the medical review that all individuals with diabetes can undertake (Boulton, 2022). Patients with DM who have no risk factors for DFU or have healthy feet should still receive general advice on foot hygiene, nail care, and purchasing footwear. Their DFU risk status should be checked annually (Boulton, 2022). Individuals with some risk factors should be checked more frequently and educated about preventive foot care (Joeliantina *et al.*, 2022).

So patients with DM who are not at risk and are at risk for DFU, still have to have the ability to recognize signs and symptoms or changes that occur in their foot. This ability can prevent early complications from DFU or the development of wounds that can lead to foot amputation.

The results showed that most patients with DM can't perform foot care independently or autonomously, but most patients were able to perform consultative foot care. DM patients have not been able to apply comprehensive foot care which includes recognizing symptoms, determining the risk of DFU, caring for the feet daily, caring for the feet if there are wounds, and carrying out foot exercises. Patients tend to choose consultative behavior to get treatment from doctors or other health workers. Other studies in line with this show that the practice of foot care which consists of examining the feet, drying between the toes, and cutting the toenails is still low (Khunkaew, Fernandez and Sim, 2019). It has also been found that self-care behaviors are effective in preventing DFU and are significantly associated with a lower risk of DFU (McInnes *et al.*, 2011; Chin *et al.*, 2014' Hemmati Maslakpak *et al.*, 2018))). Patients with diabetes who have poor foot self-care practices are 3.6 times more likely to develop diabetic foot ulcers than diabetic patients who have good foot self-care practices (Regas *et al.*, 2021).

Patients with DM must be sensitive to the signs and symptoms that occur. This response is in the form of behavior aimed at preventive action against DFU risk. Patient education plays an important role in the prevention of diabetic foot problems. The aim is to increase foot care knowledge, awareness, and self-protective behavior, and to increase motivation, skill, and adherence to foot care behavior.

Nurses should take part in preparing and implementing training programs to change patient behavior and improve patient quality of life. Nurses must have sufficient knowledge about foot care and provide appropriate information to DM patients about preventing the formation of diabetic foot and treating diabetic foot ulcers (Kaya and Karaca, 2018; Schaper *et al.*, 2019). There was a significant improvement, indicating that improved self- and family management from a three-month support program resulted in improvements in DFU patients (Subrata *et al.*, 2020). Health care workers (doctors or nurses) must be aware that one in two DM patients uses Complementary and Alternative Medicine (CAM) to manage their disease, so when evaluating patient they must ensure that the use of CAM is carried out correctly (Joeliantina, Norontoko and Anugrahini, 2021). This is so that patients can minimize the development of complications including DFU.

This study has some limitations. First of all, the researchers obtained data about the implementation of foot self-care through direct reports from patients, not through direct observation using concrete parameters. Second, the participants in this study were not specific to patients with foot ulcers, so they still had a bias in exploring foot self-care behavior. Third, the data were obtained through a cross-sectional survey. Based on the reasons above, patients with DM must get the right information so that patients can easily understand it. Patient independence in performing foot care can help to prevent DFU. These studies show that self-management support strategies can help individuals with DM avoid developing DFU as a clinical result, and they recommend incorporating these strategies into clinical care. Collaboration between nurses and other health professional teams is still needed to achieve successful DFU management. The Health Education Program about foot self-care must be continuous so problems don't develop more severely.

Conclusions

This research described a behavioral model of self-care of chronic illness to prevent the risk of DFU in patients with DM. Foot self-care management was a factor that directly correlates with the risk of DFU. Foot self-care maintenance and monitoring factors, although they did not directly correlate with DFU risk, should still receive attention, because they correlate with foot self-care management. Autonomous self-care management behaviors still needs to be improved, because most patients still had behaviors that were inadequate. This condition has a high risk of developing into a DFU. Further research is needed to improve the quality of behavior of DM patients in carrying out independent foot care management, both for those who do not have an injury and those who do. Research on the use of herbs also needs to be considered as an intervention to treat diabetic foot problems.

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Conflict of interest

The authors declare no competing interests.

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ORIGINAL ARTICLE

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Early patients' illness perception as a predictor of post-traumatic stress disorder and quality of life one month after mild traumatic brain injury: a prospective study

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ABSTRACT

Introduction: The illness perception of mild Traumatic Brain Injury (mTBI) patients before discharge from the hospital tends to be inappropriate. Apart from that, post-injury symptoms such as post-traumatic stress disorder (PTSD) are often experienced by patients, which can affect their quality of life. However, research linking patient perceptions with post-traumatic stress and quality of life remains scarce. This study aimed to examine patient's illness perceptions and their relationship with PTSD and HRQOL.

Methods: This study employed a prospective survey. Illness perceptions were measured before hospital discharge, and a follow-up of post-traumatic stress and health-related quality of life using an online survey was conducted one month later. The survey was administered from July to October 2023 at two hospitals, with a sample size of 72 mTBI patients.

Results: mTBI patients with older age (p= .001), negative emotional perceptions (p = < .001), more consequence (p = .045), more concern about their injury (p = < .001) are significantly related to more symptoms of post-traumatic stress. Patients with mTBI who felt more identity symptoms of IR (p = .001), worsened personal control (p = .041), and worsened treatment control (p = .011) are significantly related to deteriorated quality of life one month after injury.

Conclusions: This study produces evidence that mTBI patients' perceptions before leaving the hospital tend to be inappropriate and are related to post-traumatic stress and quality of life one month later. Based on these results, it is crucial for trauma nurses to identify patients' illness perceptions and initiate appropriate interventions to reduce PTSD symptoms and improve patients' quality of life.

Keywords: illness perceptions, post-traumatic stress disorder, quality of life, traumatic brain injury

Introduction

Mild traumatic brain injury (mTBI) is the most prevalent among Traumatic Brain Injury cases; an estimated 42 million people worldwide suffer from mTBI, and it is reported that around 302 people per 100,000 populations are hospitalized (Gardner and Yaffe, 2015; Skandsen *et al.*, 2019). Approximately 11.9%–44% of these cases worldwide, including the European and American continents and Indonesia, were related to traffic collisions (Dunne *et al.*, 2020; Majdan *et al.*, 2013; Ministry of Health, 2018). Studies showed that about 42 million people worldwide suffer from mTBI every year (Gardner and Yaffe, 2015; Skandsen *et al.*, 2019). However, literature reported that in the post-

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hospitalization period, when patients are discharged from the hospital to home, they experience vulnerability to symptoms following injury, impairments in cognitive and neurological functioning, and quality of life (Hiploylee *et al.*, 2016; Theadom *et al.*, 2016; van der Naalt *et al.*, 2017; Voormolen *et al.*, 2019). Patients with mTBI who experience symptoms after an injury have an increased risk of developing posttraumatic stress disorder (PTSD) (Stein *et al.*, 2019) and considerably lower health-related quality of life (HRQOL) (Fikriyanti, Kitrungrote and Songwathana, 2014; Voormolen *et al.*, 2019). Therefore, both physical and psychological problems and their relationship to quality of life in the early stages after discharge from the hospital should be given significant consideration to be followed up.

HRQOL is a crucial outcome metric for individuals with mTBI. A study found that, in comparison to their contemporaries who were not injured, older persons with mTBI had worse quality of life for up to six months after the injury (Hume *et al.*, 2023). Patients who simultaneously experienced somatic and cognitive postconcussion symptoms (PCS) had a lower HRQOL six months after injury (Voormolen *et al.*, 2019; Yousefzadeh-Chabok, Kapourchali and Ramezani, 2021). Another study reported that patients with mTBI experienced a decrease in quality of life at one year after mTBI (Theadom *et al.*, 2016). Furthermore, a detailed study reported that mTBI patients said they had problems in work/daily activities due to physical health (Voormolen *et al.*, 2019).

In addition, some symptoms following mTBI, including PCS and PTSD, contributed to a decrease in the patient's QOL after hospital discharge (Fikriyanti, Kitrungrote and Songwathana, 2014; Haagsma *et al.*, 2014; Yousefzadeh-Chabok, Kapourchali and Ramezani, 2021). For example, PCS was related to a decrease in QOL six months after discharge (van der Vlegel *et al.*, 2021; Voormolen *et al.*, 2019) and up to 15 months after discharge (Fikriyanti, Kitrungrote and Songwathana, 2014). Meanwhile, PTSD was associated with lower quality of life six months after injury (van der Vlegel *et al.*, 2021). However, most studies do not examine how these variables influence each other to influence quality of life immediately after discharge from the hospital.

PTSD is one of the psychological consequences for patients suffering from different traumatic injuries. Evidence reported that 8.8%-13.5% of head-injured individuals met the diagnostic criteria for PTSD (Lagarde *et al.*, 2014; Van Praag *et al.*, 2019). A study reported that PTSD complaints were experienced up to six months' post-injury (Stein *et al.*, 2019). Another study reported that patients with mTBI having PTSD tended to have higher pain intensity, maladaptive coping, and more PCS symptoms (Aase *et al.*, 2018). Furthermore, PTSD symptoms were significantly associated with consequences and emotions of illness perception components (Bahraini *et al.*, 2018).

The patient's illness perceptions or illness representations is a part of Leventhal's Common-Sense Model of Illness Representation (CSMIR) and plays a vital role in the early recovery of trauma patients (Mulyadi *et al.*, 2023; Tonapa *et al.*, 2022). This model proposes that individuals develop self-regulation and coping processes when faced with illness, symptoms, or situations threatening health (Diefenbach and Leventhal, 1996; Tonapa *et al.*, 2023). However, studies of trauma injury reported that patients' illness perceptions change over time and relate to their QOL (Chen, Yang and Lee, 2021). Specifically, in mTBI, a previous study reported a relationship between illness perceptions (IP) and QOL (War and Rajeswaren, 2013). Furthermore, a systematic review of mTBI patients reported that some dimensions of illness perception were found to have relationships to post-traumatic stress disorder and the quality of life of mild traumatic brain injury patients (Mulyadi, Tonapa, *et al.*, 2023). The phrases "illness perceptions" and "illness representations," which refer to people's perspectives when they come across health risks, are frequently used synonymously (Diefenbach and Leventhal, 1996; Tonapa *et al.*, 2023). Therefore, IP should be considered an essential variable in examining the relationship between PTSD and HRQOL post-mTBI.

Previous studies reported that trauma patients find it difficult to embrace the new reality of their changing capacities during transitional care and lack the expertise or experience to comprehend or manage their injuries (Goldsmith, McCloughen and Curtis, 2018). A recent study on extremity injuries in Indonesia emphasized the importance of illness perceptions in the early phase after being discharged from the hospital (Tonapa *et al.*, 2023). Considering the occurrence of post-traumatic syndrome and changes in quality of life in the early phase after discharge from the hospital, as well as the limited research on mTBI, this study proposes the following research questions: (a) what is the illness perception before hospital discharge? (b) what is the relationship of illness perceptions and PTSD and HRQOL one month after hospital discharge? Thus, this study aimed to determine patient perceptions of their illness and its relationship with PTSD and HRQOL.

Materials and Methods

Research Design

This study employed a predictive correlational design with a prospective survey. IPs was measured before hospital discharge (T0), and a follow-up of PTSD and HRQOL using an online survey was conducted one month (T1).

Participants

Data were collected from July to October 2023 at two hospitals in Manado, North Sulawesi. The inclusion criteria were patients with mTBI, 18 years old or older, and able to communicate using Indonesian. Patients having a history of significant medical conditions (often) or trauma-related injuries, hearing impairment, or deafness were excluded.

A power analysis was performed using software to estimate whether the present sample size achieved sufficient power (Faul *et al.*, 2009). Given that the present study produces a large effect size on the multiple linear regression, the number of predictors, the power, and the alpha value of .73, 12, .80, and .05, respectively, the sample size of 72 participants was deemed adequate.

Data Collection

Data were collected in the Emergency Department. After patients received primary treatment for their health problems, they were asked for their consent to participate in the study, and if they agreed, they were asked to complete a questionnaire. One month following their release, patients were phoned, and a verbal agreement was taken over the phone. One month following discharge, a survey was conducted regarding PTSD and HRQOL via a link (Google Link), and the author evaluated or checked the results via Google Drive.

Measures

Demographic and characteristics data

Data regarding age, gender, education level, and employment status, IP, PTSD, and HRQOL were gathered via self-administered questionnaires and were sent together in a link.

The Brief Illness Perception Questionnaire (BIPQ)

The patients' perceptions of their illnesses were evaluated using an eight-item BIPQ (Broadbent *et al.*, 2006). A timeline showed how long it would take them to recover from the injury, with personal control representing their capacity for self-control, treatment control representing the medical intervention/therapy that could control their injury, identity representing the number of symptoms following their mTBI, concern representing the patient's concern for their mTBI, coherence representing the patient's understanding of their injury, and emotional perceptions representing the person's adverse reaction to the injury were all included in the questionnaire. This instrument uses a rating scale of 0 to 10 to evaluate each dimension; a higher score indicates more serious damage that could be fatal.

The Post-Traumatic Stress Disorder Checklist (civilian version) (PCL-5)

A popular tool for measuring PTSD symptoms is the PCL-5. The 20 DSM-5 symptoms of PTSD can be evaluated using the 20 items on the PCL-5. It uses a 5-point scale in the range of 0 to 80 (Blevins *et al.*, 2015), with scores of 33 or above indicating experienced PTSD. (0 = "Not at all" to 4 = "Extremely") (Stein *et al.*, 2019; van der Vlegel *et al.*, 2021).

The Quality of Life after Traumatic Brain Injury Overall Scale (QOLIBRI-OS)

The QOLIBRI-OS was developed by von Steinbuechel *et al.*, (2012). It consists of six physical conditions: cognition, emotions, daily life, personal and social life, and current situation and prospect. A five-point Likert scale, with one representing "not at all satisfied" and five representing "very satisfied," was used to evaluate it. The scale means are transformed into a 0-100 scale by subtracting one from the mean and multiplying by 25, yielding scale scores of 0 to 100 representing the poorest and best QOL, respectively (Steinbuechel *et al.*, 2012).

Ethical Consideration

The study protocol was approved by the hospital's research ethics committee of RSUP Prof. Dr. R. D. Kandou Manado (No.109/EC/KEPK-KANDOU/VII/2023). Participant rights during the study were considered, their responses were protected, and a signed informed consent form was obtained from all participants.

Data Analysis

Data analyses were conducted with computer software. Descriptive analysis and simultaneous multiple regression were used in this study's analyses. Mean and standard deviation values were calculated for descriptive statistics measured as continuous variables, while frequencies were obtained for categorical variables. The force-entered multiple regression analyses were used to identify whether the demographic and IP domains could predict PTSD and HRQOL at one-month post-discharge. Statistical significance level was established at $p \leq 0.05$ for all tests.

Validity, Reliability, and Rigor

The BIPQ, PCLC-5, and QOLIBRI-OS instruments were chosen and used in this research because they are appropriate to the research context and meet validity, reliability, and rigor. The BIPQ has been examined for test-retest reliability and is reliable and valid (Broadbent *et al.*, 2006). The internal consistency and the test-retest reliability of the measurements were examined in Indonesia for patients with extremity injuries. The internal consistency of the BIPQ resulted in a Cronbach's alpha score of .85 and test-retest reliability with an intra-class correlation (ICC) of .84 (Tonapa *et al.*, 2021). Related to PCLC-5, the content validity index of the questionnaire used in Indonesia is 0.96, and Cronbach's alpha for the reliability test was 0.87 (Arnika, 2017). In the mTBI population, the PCLC-5 was re-examined for reliability (internal consistency), resulting in Cronbach's alpha 0.91 (Mulyadi, Harianto et al., 2023). In mTBI patients, the Indonesian version of QOLIBRI-OS' internal consistency reliability was examined, and Cronbach's alpha coefficient was 0.91 (Fikriyanti et al., 2014). In the present study, the Cronbach's alpha coefficient for BIPQ, PCLC-5, and QOLIBRI-OS were 0.84, 0.93, and 0.82, respectively.

Results

Descriptive Statistics of Participants

Participants in this study were 72 mTBI patients who were treated in the emergency department and followed up for up to one month after discharge from the hospital. The ages of participants were average 31.53 (SD 12.14) years, ranging from 18 to 56 years, with 60 (83.30%) males. Related to educational background, the majority received education over nine years (75.0%) and were not employed (52.40%) (Table 1). On average, participants had a negative perception of their condition (5.02 ± 1.95) before being discharged from the hospital.

Table 1 Demographic data of the sample (n=72)

Demographic data	n (%)	Mean ±SD
Age		31.53±12.14
Gender		
Male	60 (83.30)	
Female	12 (16.70)	
Education		
> 9 years	54 (75.0)	
≤ 9 years	18 (25.0)	
Employment status		
Not employed	37 (51.40)	
Employed	35 (48.60)	

Note: M= Mean; SD= standard deviation

Table 2 Descriptive statistics of illness perceptions, post-traumatic stress disorder, and health-related quality of life (N=72).

Variables	Hospital discharge Mean (SD)	1 month after discharge Mean (SD)
Illness Perceptions†		
Consequence	4.54 (1.73)	
Timeline	4.83 (1.42)	
Personal control	5.69 (2.34)	
Treatment control	5.65 (2.08)	
Identity	5.83 (2.49)	
Concern	4.15 (2.05)	
Coherence	4.57 (1.72)	
Emotional representation	4.88 (2.62)	
PTSD score†		25.65 (21.47)
Quality of life overall ‡		62.63 (19.88)

Note: SD= standard deviation; PTSD= post-traumatic stress disorder; HRQOL= health related quality of life
† higher score indicates worst while lower best;
‡ higher score indicates best while lower worst;

Some of the participants reported the presence of PTSD (25.65 ± 21.47) and reported HRQOL within the good range (62.63 ± 19.88) one month after discharged.

Predictors of Post-traumatic Stress Disorder

This study used simultaneous multiple regression to identify the significant predictors of PTSD one month after discharge from the hospital. There were no multicollinearity problems at any step of the regression analysis, as shown in Table 3. Four predictors were

Table 3 Predictors of PTSD at one month following mTBI (n=72)

Variables	1 month after hospital discharge				
	β	SE	95% CI	t-statistic	p-value
Demographic					
Age	0.53	0.15	[0.23,0.83]	3.49	.001*
Gender	0.31	4.98	[-9.65,10.28]	0.06	.950
Years of education	-7.63	4.01	[-15.66,0.41]	-1.90	.062
Employment	3.50	3.76	[-4.02,11.01]	0.93	.355
Illness Perceptions					
Identity	0.33	1.72	[-3.12, 3.77]	0.19	.851
Personal control	-0.51	1.75	[-4.00, 2.99]	-0.29	.773
Treatment control	-1.99	1.51	[-5.01, -1.04]	-1.32	.193
Emotional representation	3.41	0.81	[1.79, 5.03]	4.21	<.001*
Coherence	-1.02	1.06	[-3.15, 1.11]	-0.96	.342
Consequence	2.25	1.10	[0.05, 4.44]	2.05	.045*
Timeline	-1.50	1.22	[-3.95, 0.95]	-1.22	.227
Concern	5.39	0.95	[3.48, 7.30]	5.65	<.001*
R2 0.73					
Adjusted R2 0.68					

Note: SE=standard error; CI=confidence interval; PTSD= post-traumatic stress disorder
* p <.05;

Table 4 Predictors of HRQOL at one month following mTBI (n=72)

Variables	1 month after hospital discharge				
	β	SE	95% CI	t-statistic	p-value
Demographic					
Age	0.06	0.10	[-0.13,0.25]	0.61	.546
Gender	1.12	3.12	[-5.13,7.37]	0.36	.720
Years of education	2.88	2.52	[-2.16,7.92]	1.14	.258
Employment	1.74	2.36	[-2.97,6.45]	0.74	.463
Illness Perceptions					
Identity	-3.79	1.08	[-5.95, -1.63]	-351	.001*
Personal control	-2.28	1.10	[-4.48, -0.09]	-2.09	.041*
Treatment control	-2.48	0.95	[-4.37, -0.58]	-2.61	.011*
Emotional representation	0.04	0.51	[-0.98, -1.05]	0.08	.938
Coherence	-0.57	0.67	[-1.91, 0.76]	-0.86	.395
Consequence	0.00	0.69	[-1.38, 1.37]	0.00	.966
Timeline	0.68	0.77	[-0.86, 2.22]	0.88	.380
Concern	0.77	0.60	[-0.43, 1.96]	1.28	.008
R2 0.88					
Adjusted R2 0.85					

Note: SE=standard error; CI=confidence interval; PTSD= post-traumatic stress disorder
* p <.05;

found statistically significant related to PTSD one month after injury. mTBI patients' age significantly predicted PTSD (β = 0.53, *p* .001). This indicates that, on average, a one-unit increase in age will increase the PTSD score. Patients' emotional perceptions significantly predicted PTSD (β = 3.41, *p* =< .001), which indicates a one-unit increase in emotional perception will increase the PTSD score. Patients' perceptions about injury consequences significantly predicted PTSD (β = 2.25, *p* = .045), which indicates a one-unit increase in consequences will increase the PTSD score. Finally, patients' concern of their injury significantly predicted PTSD (β = 5.39, *p* =< .001), which indicates a one-unit increase in concern will increase the PTSD score.

Predictors of Health-related Quality of Life

There were no multicollinearity problems at any step of the regression analysis, as shown in Table 4. Three predictors were found statistically significant related to HRQOL one month after injury. mTBI patients' perception of identity symptoms significantly predicted HRQOL (β =-3.79, *p* = .001). This indicates that, on average, a one-unit increase in identity will decrease the HRQOL score. Patients' personal control significantly predicted HRQOL (β = -2.28, *p* = .041), which indicates a one-unit increase in personal control will decrease the HRQOL score. Patients treatment control significantly predicted HRQOL (β = -2.48, *p* = .011), which indicates a one-unit increase in treatment control will decrease the HRQOL score.

Discussions

This study aims to examine patient's illness perceptions and their relationship with PTSD and HRQOL. The results indicated that the average BIPQ results show a value more than or close to the median value; this represents the patient's mTBI perception, including more consequences, perceived long duration of their injury, worsened personal control, worsened treatment control, the concern of their injury, and negative emotional perceptions. The results of this study also showed that the IP domain is correlated with PTSD and QOL. Previous studies reported that, in the early phase after injury, patients' perception is important because it has been proven to be associated with health outcomes, including PTSD (Bahraini et al., 2018) and HRQOL (Mulyadi, Harianto, *et al.*, 2023). Therefore, nurses need to pay special attention to patient perceptions to reduce PTSD complaints and improve HRQOL.

Available evidence has reported that mTBI patients showed symptoms of PTSD before hospital discharge. Before leaving the hospital, patients with mTBI experience PTSD, and the PTSD lasts up to three months after leaving the hospital (Lagarde *et al.*, 2014; Mulyadi, Harianto, *et al.*, 2023). Another study in the United States even reported that PTSD symptoms continued to increase from three to six months among patients with mTBI (Stein *et al.*, 2019). A total of three domains of illness perception (emotional perception, consequence, concern) and age were predictors of PTSD.

The mean age of this study was 31.53 years. The average age in this group is relatively young, which is in line with studies on epidemiology, which have typically shown that elderly persons have a lower prevalence of PTSD than younger adults (Lee, 2019). A study reported that the age of traumatization was a predictor of post-traumatic stress disorder in young women (Becker *et al.*, 2004). However, another study of TBI patients reported that it did not differ significantly with regard to age of people who had either not lost consciousness during the event or were unconscious for less than one hour (Glaesser *et al.*, 2004). Despite the mixed findings from past evidence, the present study identified that older age was a significant predictor of PTSD one month after hospital discharge among mTBI patients. Therefore, nurses should pay attention to older mTBI patients when discharged from the hospital by providing them with precautions about the signs of PTSD and advising them to seek help from healthcare professionals when these signs appear.

Patients with mTBI who were relatively worried and concerned about their injury, their perception of the severity or negative influence of their injury, and their perception of negative emotions of their injury were predicted to have PTSD one month after injury. Considering that the increasing problem of post-injury depression is associated with a decrease in the recovery process (Kellezi *et al.*, 2017), nurses need to be aware of these psychological conditions, including PTSD. In this regard, existing predictor factors need special attention, including providing appropriate interventions.

Regarding HRQOL, mTBI patients with more identity symptoms of IP worsened personal control and worsened treatment control are significantly related to worsened HRQOL one month after injury. Patients with mTBI who felt many symptoms prior to hospital discharge had decreased QOL one month after. These results align with previous studies that identified identity as a predictor of QOL a month after injury of mTBI patients (Mulyadi, Harianto, *et al.*, 2023) and three months after injury of trauma extremity patients (Tonapa *et al.*, 2021). Patients with mTBI who thought they had little personal control over their injury reported decreased HRQOL one month later. These results corroborate previous mTBI research in India and extremity trauma research in Indonesia that found an association between personal control and HRQOL (Tonapa *et al.*, 2021; War and Rajeswaren, 2013). Patients with mTBI who felt that medical interventions or medications could not manage their injury tended to have lower HRQOL one month later. This is also supported by previous diabetes mellitus research conducted in Indonesia and France on lung cancer, which reported that patients perceived treatment control to be related to HRQOL (Masson *et al.*, 2020) (Perwitasari *et al.*, 2017). Given that injury symptoms encountered after mTBI are significant for postinjury quality of life, nurses may consider providing case management that covers symptom management approaches such as pre-discharge discussions to ease the symptom burden on patients in the early recovery phase (Hung *et al.*, 2023). In addition, nurses and other health professionals must empower patients to gain appropriate personal control and involve patients in the treatment plans.

This research has limitations. During the one-month follow-up period, there was still no information on patient visits after leaving the hospital, whether to hospital clinics or health centers or no visits. This allows them to obtain information and education linked to patient perceptions. In addition, the sample size of this study is quite limited; one of the reasons is that this study excluded mTBI patients who had several other cases of trauma that may have co-occurred with the event. So, further research can be recommended to continue identifying mTBI patients even though they have several other cases of trauma. Additionally, patients are categorized as having PTSD based on self-reported PCL-5 data, but the use of this survey is not sufficient to clinically diagnose patients with PTSD. This limitation can be overcome by providing a clear explanation regarding the self-reported PCL-5, ensuring that the filling is truly appropriate to the condition experienced by the patient. Early recognition of PTSD symptoms based on self-reported PCL-5 and appropriate interventions are expected to improve health outcomes of mTBI patients.

Conclusion

This study produces evidence that mTBI patients' perceptions before leaving the hospital tend to be inappropriate and are related to PTSD and HRQOL one month later. Patients with mTBI who were relatively worried and concerned about their injury, perception of the severity or negative influence of their injury, and perceived negative emotion of their injury were predicted to have PTSD one month after injury. In addition, mTBI patients, before going home, perceive more identity symptoms of IP, worsened personal control, and worsened treatment control, which are significantly related to worsened HRQOL. Based on these results, it is crucial for trauma nurses to identify patients' illness perceptions and initiate appropriate interventions to reduce PTSD symptoms and improve patients' quality of life. Potential developments in clinical practice are identifying patients' illness perceptions routinely (e.g. in outpatient clinics) and initiating follow-up trauma care programs for mTBI patients either in person or using communication media (e.g. digital, telehealth).

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Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Family skill development for attention deficit hyperactivity disorder behavior problem alleviation model in at-risk preschool children: a mixed methods study

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ABSTRACT

Introduction: Attention Deficit Hyperactivity Disorder is the most prevalent childhood mental health problem. This study examined families caring for children with ADHD and created a model to alleviate behavior problems in at-risk preschoolers.

Methods: This exploratory sequential mixed-methods study comprised two phases. Phase 1 included a qualitative retrospective survey that examined family experiences in caring for ADHD children. This involved in-depth interviews with 14 family caregivers (FCGs) and utilized thematic content analysis. Phase 2 involved creating, implementing, and evaluating a family skill development model using a quasi-experimental design. Thirty FCG- ADHD at-risk preschool child dyads, utilizing services at two Child Development Clinics, were paired and equally divided into experimental and control groups. Data analysis used repeated measures ANOVA and covariances (ANCOVA).

Results: The study FCGs reported that family-child interactions and positive parenting alleviated the ADHD at-risk preschool child's behavior problems. The Family Skill Development for ADHD Behavior Problem Alleviation Model was constructed and validated. Results from within-group comparisons showed significant improvements in the experimental group, with reduced behavior problems ($p<0.05$, $\eta p^2=0.28$) in ADHD at-risk children, improved caregiver behaviors to alleviate the child's behavior problems ($p<0.01$, $\eta p^2=0.37$), and enhanced family functions ($p< 0.001$, $\eta p2=0.42$).

Conclusions: The model significantly aids families in alleviating behavior problems in ADHD at-risk children, improving family functions and caregivers' efforts to address the children's behavioral issues. It is a promising parental intervention model for fostering healthy families and reducing behavior problems in ADHD-at-risk preschool children in northeastern Thailand and similar contexts.

Keywords: ADHD at-risk preschool children, a family skill development model, behavior problems, executive function, family function, family-child interaction, positive parenting

Introduction

Attention deficit hyperactivity disorder (ADHD) is one of the most common neurodevelopment disorders in children, characterized by symptoms of impulsivity, hyperactivity, and inattention. ADHD is usually diagnosed in school-age children, but several studies indicate certain symptoms can manifest as early as preschool age, typically between three and seven years (American Psychiatric Association and Association, 2013; World Health Organization, 2013; Aghebati *et al.*,

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2014). A longitudinal birth cohort study reported that pediatric predictors of ADHD were witnessed from the age of 17 months to 6-8 years, particularly high levels of hyperactive behaviors (Galra *et al.*, 2011). The global prevalence of ADHD ranged from 2.0% to 7.0% with an average of 5.0% (Sayal *et al.*, 2018), and it ranged from 4.2 to 8.1% in Thailand, with a maximum of one million affected children countrywide (Visanuyothin *et al.*, 2013). ADHD prevalence was higher in boys than girls, with a ratio of 2-3 : 1 (Sayal *et al.*, 2018), and increased with age (Danielson *et al.*, 2018). Childhood ADHD persisting into adolescence and adulthood increases the risk of mental health issues and negative long-term outcomes. Consequences include impaired working memory, daily living difficulties (Irwin *et al.*, 2021), academic underachievement (Arnold *et al.*, 2020; Condo, Chan and Kofler, 2022), problems with employment and relationships, and increased involvement in criminal activities (Sayal *et al.*, 2018). This can lead to family stress due to behavioral issues in affected children (Leitch *et al.*, 2019) and various burdens, particularly financial related problems (Lee *et al.*, 2019; Zhao *et al.*, 2019). Early intervention is crucial for understanding challenges in families with ADHD children and developing a model to alleviate behavior issues in at-risk preschoolers.

Early interventions, especially for preschoolers at higher risk, are vital for children with ADHD. Previous studies indicated that effective interventions significantly improved their behavioral problems (Charach *et al.*, 2013; Wolraich *et al.*, 2019). However, a key challenge lies in identifying ADHD in preschool children, as symptoms like inattention, hyperactivity, and impulsivity are often considered typical developmental traits, making early diagnosis challenging (Tarver, Daley and Sayal, 2015; Miller *et al.*, 2021). Early monitoring and screening are crucial to identify and treat behavioral problems in children before a full ADHD diagnosis. Delayed recognition can result in cumulative impairment in overall functioning and development (Cabral, Liu and Soares, 2020). ADHD is usually diagnosed around age six (Visser *et al.*, 2014). At-risk preschool children with unresolved ADHD-related behavior problems face a higher risk of future mental health issues (Bornstein, Hahn and Suwalsky, 2013). Caregivers' knowledge consistently influences the association of ADHD symptoms, as it is closely linked to ADHD-related problems (Dekkers *et al.*, 2021). In a comparative ADHD study, child caregivers had less knowledge than teachers (See *et al.*, 2021). Caregivers faced challenges handling children with impaired functioning due to ADHD symptoms. These difficulties present a unique caregiving challenge distinct from other childhood mental illnesses (Ching'oma *et al.*, 2022). Evidence-based parent training programs for preschoolers with ADHD, such as those modifying caring behaviors and improving symptoms and emotional, behavioral and social functioning (Feng *et al.*, 2023), are crucial. Essential support includes guidance on interacting with children based on understanding and using helpful information from caregiving experiences, providing good evidence to alleviate behavioral problems.

This study aims to develop a family skill training model to prevent and alleviate behavioral problems in ADHD at-risk preschool children. It combines research methods to modify caregiver behaviors using the unified theory of behavior (Lindsey *et al.*, 2013), positive parenting techniques (de Graaf *et al.*, 2008), and ecological concepts (Bornstein, Hahn and Suwalsky, 2013). Families significantly impact the well-being of ADHD at-risk preschool children both internally and externally. Changes in the family's immediate environment can lead to behavioral and developmental issues in the children, influenced by their ecological surroundings. Families are emotional bonding systems for all members. When dealing with preschool children experiencing ADHD-related behavioral problems, it impacts family emotional dynamics. All members play roles and fulfill duties to maintain their family system. FCG, as the key leader, is crucial in effectively addressing the behavioral problems of at-risk children with ADHD. This is achieved by having clear behavioral intentions and implementing appropriate strategies to alleviate the child's behavior problems. Consequently, families can foster positive development in vulnerable preschool children, helping them thrive and reach their full potential as capable adults, which are essential for the nation's future development. Implementing positive childcare practices early on promotes optimal child development and helps prevent potential complications. Positive parenting and the early adoption of effective childcare practices can mitigate behavior problems in ADHD at-risk preschool children, enhancing child development and preventing future issues.

Materials and Methods

Study Design

This mixed methods research study used an exploratory sequential design comprising two phases (Creswell and Clark, 2018).

Qualitative Study in Phase I

Participants

In Phase 1, a qualitative retrospective study explored family experiences caring for children with ADHD. The study involved in-depth interviews (n=14) and focus group discussions (n=4) with the family caregivers (FCGs) of children aged 6-9 years diagnosed with ADHD by physicians based on the DSM-5 criteria for at least six months. Participants were recruited from Hospital A's Child Development Clinic (CDC) of the Outpatient Department. Inclusion criteria for family caregivers (FCGs) included: 1) being primary caregivers of children aged 6-9 years who had been diagnosed with ADHD by physicians without other behavioral illnesses such as autism and cerebral palsy, 2) being able to communicate well in the Thai language, and 3) being able to voluntarily participate in the research project.

Instrument and data collection

Data collection was carried out by one of the researchers (KK) using the in-depth interview guide, observation checklist, and field notes. The in-depth interview guide has two parts. Part 1 includes the general characteristics and background of a child with ADHD, his/her FCG, and family information. Part 2 contains four open-ended questions about the child's behavior problems and the family's responding behaviors. These questions include: 1) "What are the behavior problems of the child with ADHD from the initial past up to the present?"; 2) "What behaviors do you and your family perform to alleviate such behavior problems of the affected child from past to present?"; 3) "Is there any change in your responding behavior(s) to alleviate the child's behavior problems from past to present?" "If not, please explain why it is so happening." "If yes, please specify why it is so happening,"; and 4) "What are the effects/consequences or outcomes of the family's general and specific responding behaviors?".

Data analysis

Data analysis was conducted concurrently with data collection using thematic content analysis (TCA), in seven phases with the use of ATLAS.ti (Friese, Soratto and Pires, 2018).

Data trustworthiness

For data trustworthiness in the qualitative phase, we employed the following procedures: 1) establishing rapport with four selected FCGs through initial questions before in-depth interviews, 2) conducting member checking with four selected FCGs during a focus group discussion, 3) peer debriefing with one specialist, and 4) triangulation to verify consistency between derived conclusions and data from in-depth interviews, observation checklists, and field notes (Lincoln and Guba, 1985).

Quantitative study in Phase 2

Participants

In Phase 2, a quantitative approach was taken to develop, implement, and assess the Family Skill Development (FSD) for ADHD Behavior Problem Alleviation (BPA) Model. The FSD-ADHD-BPA model was developed based on Phase 1 findings and extensive reviews of effective programs for reducing behavioral problems in ADHD at-risk preschool children (refer to Table 1). The study used a quasi-experimental design to implement the FSD-ADHD-BPA model over eight weeks in an experimental group, while a control group received routine care. Assessments included pretest, posttest, and 6-week follow-up from June to September 2022. The sample size for model implementation was determined by comparing behavior problems before and after the model implementation among ADHD at-risk preschool children in northeastern Thailand, using a priori power analysis available in the G*Power software version 3.1.9.2. Parameters included 95% power, 95% confidence level ($\alpha<0.05$), and a medium effect size ($d=0.31$). The G*Power analytic result in a minimum sample size of 30 FCG-child dyads (n=15 dyads per group). The researcher selected two specific groups from two hospitals based on the availability of a CDC with at least one pediatric psychiatrist providing service and recruited the study participants based on the inclusion criteria. The researcher allocated fifteen dyads utilizing services at Hospital A to the experimental group (E) and fifteen dyads at Hospital C to the control group (C). Group assignment was based on matching pairs of ADHD at-risk preschool children by age and sex. The inclusion criteria of the ADHD at-risk children included: 1) having the Thai ADHD Screening Scale scores of more than 51 points; 2) being in good health, with no current illness, or uncomfortable condition such as fever or infection; 3) having an FCG who can communicate well in the Thai language; and 4) willing to voluntarily participate in the research project both FCG and ADHD at-risk child.

Instrument and data collection

Data collection used five research tools as following: 1) The general characteristic questionnaire comprises three parts: a) family background, b) general information about an ADHD at-risk preschool child, and

c) general information about FCGs: 2) The Thai ADHD screening scale (THAISS) (Pornnoppadol *et al.*, 2014) was used for ADHD screening in preschool children aged 3 to 5 years by caregiver. The instrument has 30 rating scale questions, scored from 0-3 (none, rarely, often, more often), evaluating hyperactivity/impulsivity (15Qs) and inattention (15Qs). The THAISS demonstrates strong internal consistency with a Cronbach's alpha coefficient of 0.96. Additionally, it exhibits good sensitivity (0.90) and specificity (0.88) in detecting ADHD symptoms. In the current study, Cronbach's alpha coefficient was 0.92; 3) The Executive Functions (EF), developed by Vechmongkholkorn and Surakarn (Vechmongkholkorn and Surakarn, 2019) were employed by caregivers to assess preschool children's executive function. The assessment form comprises 25 rating scale questions, ranging from least to most proficient (rated on a scale of 1-4). It evaluates five aspects, each with five questions: inhibition (5Qs), working memory (5Qs), flexibility (5Qs), emotional control (5Qs), and systematic planning (5Qs). The form's reliability has been validated with a high Cronbach's alpha coefficient of 0.90. In the current study, Cronbach's alpha coefficient was 0.86; 4) The Behaviors to Alleviate Behavioral Problems (BABP), developed by the research team (KK), was employed to examine the BABP of ADHD at-risk preschool children by FCGs. It consists of 30 rating scale questions, rated from not at all to performing regularly (1-5 points). The questions assess positive interaction behaviors (15 Qs) and behaviors to develop EF of the children (15 Qs). This tool's content validity index (CVI) was 0.92, reflecting strong content validity. The reliability, as measured by Cronbach's alpha coefficient, was 0.86; 5) The Chulalongkorn Family Inventory, or CFI, developed by Trangkasombat (Trangkasombat, 2001), is a self-report questionnaire for caregivers to assess family function. The assessment comprises 36 rating scale questions (rated on a scale of 1 to 4). The questions gauge various aspects of family functions, including problem-solving (6 Qs), communication (5 Qs), role performance (3 Qs), emotional response (5 Qs), emotional attachment (5 Qs), behavioral control (4 Qs), and general functions (8 Qs). This assessment tool's content validity index (CVI) was 0.92, reflecting strong content validity. The reliability, as measured by Cronbach's alpha coefficient, was 0.86. In the current study, Cronbach's alpha coefficient was found to be 0.81, indicating a reasonably good level of reliability.

Data analysis

The study utilized SPSS Statistics version 22.0 for data analysis. Descriptive data include means, standard deviations (SD), frequencies, and percentages (%). General characteristic differences between experimental and control groups were compared using independent sample t-test and chi-square tests. The study examined differences in outcomes (behavioral problems, EF, BABP, and family functions) between groups at baseline using independent sample t-tests. Changes in outcomes within and between groups during three assessment phases (pretest, posttest, and 6-week follow-up) were assessed through repeated measures ANOVA with Bonferroni correction to account for time effects. For family function subscales (roles and behavioral control), analysis of covariance (ANCOVA) was employed, controlling for baseline values (pretest). Effect size interpretation followed Cohen's guidelines, with effect sizes (ηp^2) of 0.01, 0.06, and 0.14 considered small, moderate, and large, respectively (Field, 2013).

Ethical Clearance

This research was reviewed by the Research Ethics Committee of Mahasarakham University (Ref. No. 100-044/2021) and the research ethics committees of the three study hospitals: Hospital A Research Ethics Committee (Ref. No. MSKH_REC 64-02-007), Hospital B Research Ethics Committee (Ref. No. 007/2022E) and the Hospital C Research Ethics Committee (Ref. No. RE08/2565). The study was registered as a quasi-experimental Phase 2 trial with two groups (experimental and control), incorporating pretest, posttest, and follow-up assessments in the Thai Clinical Trials Registry (TCTR) (Ref. TCTR 20210921003).

Results

Qualitative study in Phase I

General characteristics of family caregivers of the children with ADHD

All caregivers of the children with ADHD were women (n=14), aged 22-60 years, with an average age of 42.0 years (SD=11.8). About 42.9% had secondary education, 57.0% were divorced, and 92.1% came from extended families. Children with ADHD (7 boys and 7 girls) were aged 6 years and 1 month to 8 years and 11 months, with an average age of 7 years and 1 month (SD=0.9). The average age of ADHD diagnosis was 5.6 years (SD=1.1), and the duration of diagnosis ranged from 8 months to 3 years, with an average duration of 1 year and 6 months (SD=0.6), as shown in Table 1.

Family experiences

Caregivers modified behaviors to alleviate behavioral problems in children with ADHD. In brief, it was found that the caregivers modified their behaviors to alleviate the behavioral problems of their children with ADHD by using family-child interaction and positive parenting, as shown in the following descriptions. Notably, detailed results of this part have been reported elsewhere. Based on the experiences of the caregiver's reflections, two themes emerged, namely: 1) Family-child interaction, and 2) Positive parenting.

Theme 1, family-child interaction, the caregivers reported modifying their behaviors to address the children's behavioral problems by engaging in activities together with them, aiming to improve family-child interaction and alleviate behavioral issues. The activities included: 1) promoting mindfulness and meditation by teaching the child to count from 1 to 10; 2) encouraging day-to-day self-help and household chores to involve the ADHD children in family activities and improve interaction; 3) promoting cognitive processes and creativity through playing with toys; and 4) promoting exercise as children with ADHD preferred to have physical activities with their families.

Theme 2, positive parenting, the caregivers acknowledged the need to modify their caregiving approach for children with ADHD by adopting the following positive parenting styles:1) promoting attachment through affection, closeness, and spending quality time with the child; 2) showing acceptance and respect by using polite language, apologizing when necessary, and encouraging the child's independence, particularly allowing them to perform daily activities without too closed supervision; 3) emphasizing proactive parenting by continuously self-studying child care topics and monitoring issues; 4) performing compassionate leadership by calmly admonishing wrongful behavior, showing sympathy, and providing reasons; and 5) implementing positive discipline by establishing family rules and avoiding physical punishment.

Quantitative study in Phase 2

Family skill development for ADHD behavior problem alleviation model

The FSD-ADHD-BPA model developed specifically for ADHD at-risk preschool children comprised three stages: 1) planning, 2) production, and 3) revision and completion.

Table 1 General characteristics of the primary caregivers of the children with ADHD and Children with ADHD (n=14)

General characteristics	n	%
General characteristics of primary caregivers of the children with ADHD		
Sex		
Female	14	100.0
Level of Education		
Elementary School	4	28.6
Secondary education	6	42.9
Diploma Degree	3	21.4
Bachelor Degree	1	7.1
Marital status		
Marriage	6	42.9
Divorce	8	57.1
Family characteristics		
Single family	1	7.1
Extended family	13	92.1
Average age family caregivers	42 years	SD=11.8
General characteristics of children with ADHD		
Sex		
Male	7	50.0
Female	7	50.0
Average age	7 years and 1 month	SD=0.9
Duration of diagnosis	1 years and 6 month	SD=0.6

Planning stage

The developed model in this stage is rooted in the ecological theory, incorporating the unified theory of behavior (Lindsey *et al.*, 2013). It views the family as a critical ecosystem for a child's psychological, emotional, and behavioral development (Haefner, 2014). Recognizing that the illness of one family member can impact the entire family, particularly the FCG, behaviors changes in the FCG can influence the behaviors of the entire family, including ADHD-at-risk preschool children. The FCG's intention to modify behaviors is complex and influenced by knowledge, environmental constraints, and habitual responses. Derived from qualitative research, the model underscores the necessity of enhancing FCGs' behavioral skills in family-child interactions and positive parenting. Engaging in activities with ADHD-at-risk preschool children is identified as crucial for their executive function development during this rapid developmental period (Anderson and Reidy, 2012). Positive parenting styles play a vital role in discipline and fostering strong relationships with children (Eanes, 2016). The model focuses on involving FCGs in family-based activities to promote positive parenting, alleviate behavioral problems, and enhance executive function skills in ADHD-at-risk children. Its goal is to empower FCGs with the knowledge and skills to effectively manage ADHD-related behavioral problems in preschool children while fulfilling their family responsibilities. The model

Table 2 The Family Skill Development for ADHD Behavior Problem Alleviation Model (FSD-ADHD-BPA Model) in ADHD at-risk preschool children

Component	Activity
Developing early family skills for ADHD detection	Workshop 1: Significance of appropriate child rearing in a family, assessing problems and risks of ADHD in preschool children. 1. A health education session on the significance of appropriate child rearing in a family. 2. A health education session on assessment of problems and risks of ADHD in preschool children. 3. Demonstrations and practice. Time: The workshop on Day 1 of Week 1 lasts for 60 minutes. Material: 1. A handbook entitled "Developing Family Skills to Alleviate Behavioral Problems in ADHD At-risk Preschool Children." 2. The Thai ADHD Screening Scales (THAISS).
Enhancing family skills for behavior problem alleviation	Workshop 2: Appropriate solutions to alleviate behavioral problems of the ADHD at-risk preschool children. 1. A health education session on appropriate solutions to alleviate behavioral problems of ADHD at-risk children. 2. Demonstrations and practice at the workshop. Time: The workshop on Day 1 of Week 1 lasts 60 minutes. Material: 1. A handbook entitled "Developing Family Skills to Alleviate Behavioral Problems in ADHD At-risk Preschool Children" on solutions to alleviate behavioral problems in ADHD at-risk children.
Promoting positive parenting through family-child interactions	Workshop 3: Promotion of positive interactions between families and children to enhance positive parenting skills. 1. Health education session on the development of positive parenting skills. 2. Health education on the development of children's executive functions (EF) through 4 activities: a) "Bottle of mindfulness," b) "Talented person can help oneself," c) "Think about what color," d) "Exercise to keep pace with the colors." 3. Demonstrations and practice at the workshop. 4. Practice at home. Time: 1. The workshop on Day 1 of Week 1 lasts for 120–180 minutes, with each activity lasting 30–45 minutes. 2. Continuous home-based practice Activities 1–4 during Week 1–Week 4, totaling 240–360 minutes or more. Spend 30-45 minutes on each activity per week, or more often if needed. All four activities are to be practiced. 3. Repeated home-based practice Activities 1-4 during Weeks 5-8, accumulating at least 240–360 minutes. Allocate 30-45 minutes per week to each activity or more frequently as desired. Choose activities flexibly. Material: 1. An activity book entitled, "Being mindful-Help-Cognition-Exercise." 2. Equipment 1 is a "Khuad-Hang-Sati," or mindfulness bottle, a DIY item. 3. Equipment 2 is a set of "Nine Square Step Exercises" consisting of a home-based exercise sheet, an exercise song, and a demonstration video.
Monitoring and assessing behavior progress	Activity: Self-review and home practice. 1. Review activities in Components 1, 2, and 3. 2. Caregivers monitor behaviors and record results. 3. Home visits or virtual support via video or phone calls. Time: 1. The pretest, posttest, and 6-week follow-up assessment are set in Week 1, Week 8, and Week 14, respectively, at the CDC. 2. The home visit activity in Week 4 was replaced by a phone call or video call, resulting from the COVID-19 social distancing regulations. Material: 1. A handbook for developing family skills toward the alleviation of behavioral problems in ADHD at-risk preschool children; 2. The Thai ADHD Screening Scales (THAISS). 3-5. Activity book and Equipment 1 and 2. 6. Equipment 3 is a free digital program application called "Happy Family Awareness of ADHD," created by KK. It was available on smartphone and the website, allowing easy download onto family caregivers' smartphones from the first day of the workshop training until Week 14.

emphasizes four intervention components for family caregivers, as outlined in Table 2.

Production stage

In this stage, the research team prepared for four workshop training activities to implement the model. The materials included: 1) A handbook titled "Developing Family Skills to Alleviate Behavioral Problems in ADHD At-risk Preschool Children"; 2) An activity book, "Sati-Chuay-Kid-Aoug" or "Being Mindful-Help-Cognition-Exercise"; 3) Equipment 1, mindfulness bottle named "Khuad-Hang-Sati"; 4) Equipment 2, a "Nine Square Step Exercise" set with a home-based exercise sheet featuring colorful squares. Additionally; 5) Equipment 3, a free digital program application named "Happy Family Awareness of ADHD," detailed in Table 2.

Revision and completion stage

During the revision and completion stage, the FSD-ADHD-BPA model underwent validation by five experts, including psychiatrists, maternal and child professional nurses, and special child educators, through a demand survey. They evaluated the model's objectives, content,

Table 3 Comparisons of general characteristics of the family caregivers (FCGs) and ADHD at-risk preschool children in experimental and control groups, 15 for each group (n=30)

General characteristics	**Experimental group (n = 15)**	**Control group (n = 15)**	***p*-value**
	mean (SD) or frequency (%)	**mean (SD) or frequency(%)**	
Family caregivers (FCGs)			
Age (years)	39.06(11.18)	38.93(13.84)	0.977[a]
Sex			0.409[c]
Male	5(33.3)	3(20.0)	
Female	10(66.7)	12(80.0)	
Education level			0.202[c]
Primary education	4(26.7)	4(26.7)	
Secondary education	3(20.0)	8(53.3)	
Diploma	4(26.7)	1(6.7)	
Bachelor's degree	4(26.7)	2(13.3)	
Marital status			0.166[c]
Married	10(66.7)	1(66.7)	
Separated	1(6.7)	4(26.7)	
Divorced or widowed	4(26.6)	1(6.7)	
Relationships with children			1.000[b]
Parents	10(66.7)	10(66.7)	
Grandparents	5(33.3)	5(33.3)	
ADHD at-risk preschool children			
Age (years)	5.23(0.81)	4.87(0.63)	0.189[a]
Sex			1.000[c]
Male	12(80.0)	12(80.0)	
Female	3(20.0)	3(20.0)	
History of past illnesses			1.000[c]
No	14(93.3)	14(93.0)	
Yes	1(6.7)	1(6.7)	
Family characteristics			0.885[c]
Nuclear family	2(13.3)	3(20.0)	
Extended family	12(80.0)	11(73.3)	
Single-parent family	1(6.7)	1(6.7)	

Note: Statistics: a *t*-test; b Chi-square test; c Fisher's exact test

language, design, and usability. Content validity, assessed by the CVI, was 0.93, meeting the acceptable threshold (0.70 or higher). After incorporating expert suggestions, the model was tested with five families at Hospital B's CDC by the research (KK) to ensure the appropriateness and clarity of content, activities, and time duration. Post-trial, the final activities and content of the model were fully developed.

Effects of model and impact evaluation

Baseline analysis

General characteristics of the study participants: The study focused on the FCG and ADHD at-risk preschool child dyads. Among the 30 FCGs, the majority were women (22 out of 30) with ages ranging from 21 to 60, with an average age of 39.0 years (SD=12.3). More than half were parents, and a significant portion had completed secondary education. On average, FCGs had been providing care for ADHD at-risk children for 4.03 years (SD=1.17), with a duration spanning from 1 to 6 years.

In the group of ADHD at-risk preschool children, the majority came from extended families (23 out of 30), with more girls than boys (20 vs. 10). Their ages ranged from 3 to 6 years, averaging 5.06 years (SD=0.74). Significantly, a substantial proportion of these children had mobile phones (24 out of 30), and among them, 24 used phones regularly for at least one hour daily.

Participants were divided into an experimental group (E) receiving the FSD-ADHD-BPA model and a control group (C) receiving standard care. Baseline characteristics in Table 3 indicate comparable demographics for both groups. Key factors such as age, sex, education level, marital status, and relationship with children for the FCGs, as well as age, sex, past illness history, and family characteristics of the ADHD at-risk children, showed no significant differences between the experimental and control groups (all p>0.05), as shown in Table 3.

At baseline, ADHD at-risk children exhibited a minimal to mild risk of having ADHD symptoms. The experimental group had slightly higher average scores (58.7 points, SD=9.8) compared to the control group (54.8 points, SD=10.2). Attention-related behavioral issues were slightly more prominent than hyperactivity/impulsiveness in both groups. Both groups displayed good to very good executive functions (EF). Regarding behavior to alleviate behavioral problems (BABP), the control group (118.8 points, SD=17.9) had a slightly higher total BABP than the experimental group (114.2 points, SD=19.8), indicating a high adoption of BABP strategies. FCGs reported moderate levels of performing family functions (71-110 points) in both groups.

Baseline measurements indicated no significant differences between ADHD at-risk children's behavior problems, total EF and EF subscales, BABP and BABP subscales, total family functions, and most family function subscales (including problem-solving, communication, affective responsiveness, affective involvement, and general functioning), except for roles and behavior control. These differences were not statistically significant (all p>0.50). However, FCGs in the experimental and control groups significantly differed in

Table 4 Comparisons of behavioral problems, executive functions (EF), behavior to alleviate behavior problems (BABP), and family functions in FCG-ADHD at-risk preschool child dyads at baseline (pretest) in experimental and control groups, 15 for each group (n=30)

Variables	Experimental group (n=15)	Control group (n=15)	*t*(df)	*p*-value
	mean(SD)	**mean(SD)**		
Behavioral problems				
Hyperactivity/impulsiveness	1.77(0.36)	1.60(0.42)	1.180(28)	0.248
Inattention	2.15(0.38)	2.05(0.42)	0.633(28)	0.532
Total	58.73(9.82)	54.80(10.26)	1.072(28)	0.293
Executive functions (EF)				
Inhibition	2.88(0.67)	2.62(0.60)	1.087(28)	0.286
Working memory	3.13(0.59)	2.87(0.42)	1.407(28)	0.171
Cognitive flexibility	3.12(0.42)	3.25(0.60)	-0.700(28)	0.490
Emotional control	3.33(0.55)	3.28(0.46)	0.284(28)	0.778
Planning and organization	3.13(0.94)	2.80(0.56)	1.168(28)	0.253
Total	78.00(12.07)	74.13(7.81)	1.042(28)	0.306
Behavior to alleviate behavioral Problems (BABP)				
Positive interaction development	4.03(0.53)	4.15(0.60)	-0.622(28)	0.539
EF skill development	3.73(0.76)	3.75(0.63)	-0.087(28)	0.932
Total	114.27(19.89)	118.80(17.97)	-0.566(28)	0.518
Family functions assessed using the CFI				
Problem-solving	3.13(0.28)	2.92(0.45)	1.273(28)	0.213
Communication	3.10(0.36)	2.92(0.52)	1.284(28)	0.280
Roles	3.76(0.34)	3.27(0.53)	2.966(28)	0.006**
Affective responsiveness	3.06(0.37)	3.05(0.40)	0.094(28)	0.926
Affective involvement	2.13(0.39)	2.27(0.33)	-0.993(28)	0.329
Behavior control	2.82(0.35)	2.47(0.35)	2.695(28)	0.012*
General functioning	3.20(0.41)	3.13 (0.49)	0.403(28)	0.690
Total	108.67(7.48)	104.00(10.70)	1.384(28)	0.177

Note: CFI, the Chulalongkorn Family Inventory; FCG, family caregiver; Scoring for subscales: Behavioral problems, 0-3; EF (Executive functions), 1-5; BABP (Behavior to alleviate behavioral problems), 1-5; and Family functions, 1-4; Data are significant at * p<0.05, ** p<0.01, *** p<0.001

family function subscales, specifically roles (p<0.01) and behavior control (p<0.05), as shown in Table 4.

Effects and impacts of the model

As per the Activity Book checklist, all FCGs in the experimental group consistently adhered to specified activities, engaging in play sessions with their young children at least four times a week. Consequently, the attendance rate for these intervention activities reached 100%. Data analysis revealed statistically significant main effects of time across three assessment phases for ADHD at-risk preschool children. This included total behavioral problems (F(2,56)=4.65, p=0.013, ηp^2=0.143) and all subscales, such as hyperactivity and impulsiveness (F(2,56)=4.65, p=0.012, ηp^2=0.193) and inattention (F(2,56)=9.69, p=0.002, ηp^2=0.257). Significant effects were also observed in some EF subscales, namely inhibition (F(2,56)=65.658, p<0.001, ηp^2=0.701), cognitive flexibility (F(2,56)=13.827, p=0.001, ηp^2=0.331), and emotional control (F(2,56)=4.268, p=0.04, ηp^2=0.132). However, there was no significant main effect of time on total EF (F(2,56)=2.793, p=0.079, ηp^2=0.171) and some EF subscales, namely working memory (F(2,56)=2.481, p=0.122, ηp^2=0.081), planning and organization (F(2,56)=3.054, p=0.083, ηp^2=0.098).

For FCGs, significant main effects of time were identified on BABP (F(2,56)=4.658, p=0.038, ηp^2=0.143) and all the subscales, including positive interaction development (F(2,56)=16.585, p<0.001, ηp^2=0.372) and EF skill development (F(2,56)=6.181, p=0.012, ηp^2 =0.181). A significant main effect of time was also found on total family functions (F(2,56)=8.764, p=0.004, ηp^2=0.238), and certain family function subscales such as problem-solving (F(2,56)=4.697, p=0.03, ηp^2=0.144), affective involvement (F(2,56)=10.832, p<0.001, ηp^2 =0.279), behavioral control (F(2,56)=8.123, p=0.001, ηp^2=0.225), and general functioning (F(2,56)=10.296, p=0.003, ηp^2=0.269). However, there was no significant main effect of time on family functions concerning communication (F(2,56)=0.153, p=0.726, ηp^2=0.005), roles (F(2,56)=2.422, p=0.13, ηp^2=0.08), and affective responsiveness (F(2,56)=1.980, p=0.155, ηp^2=0.066), with detail not shown.

Results from within-group comparisons showed that ADHD at-risk children in the experimental group significantly decreased in total behavioral problems (p<0.05, ηp^2=0.28) and all subscales, including hyperactivity/impulsiveness (p<0.05, ηp^2=0.25) and inattention (p<0.05, ηp^2=0.25). Two out of five EF subscales, inhibition (p<0.001, ηp^2=0.71) and cognitive flexibility (p<0.01, ηp^2=0.41), also showed significant

Table 5 Comparisons of the mean scores of each outcome measure in FCG-ADHD at-risk preschool child dyads within- and between groups in three assessment phases in experimental and control groups, 15 for each group (n=30)

Variables	**Group**	**Assessment phases**			**Within-group comparison**		**Between-group comparison**$^{s, b}$	
		Pretest	**Posttest**	**6-week Follow-up**				
		mean (SD)	**mean (SD)**	**mean (SD)**	***p*-value**	ηp^2	***p*-value**	ηp^2
Behavioral problems								
Hyperactivity/ impulsiveness	E	1.77(0.36)	1.33(0.56)	1.26(0.57)	0.02*	0.252	0.672a	0.007
	C	1.60(0.42)	1.46(0.35)	1.45(0.34)	0.720	0.026		
Inattention	E	2.15(0.38)	1.60(0.72)	1.51(0.78)	0.02*	0.250	0.688a	0.006
	C	2.05(0.42)	1.72(0.65)	1.70(0.65)	0.25	0.098		
Total	E	58.73(9.82)	43.87(17.72)	41.60(19.35)	0.01*	0.286	0.640a	0.008
	C	54.80(10.26)	47.73(13.07)	47.26(13.12)	0.35	0.074		
Executive functions (EF)								
Inhibition	E	2.88(0.67)	4.31(0.64)	2.87(0.99)	<0.001	0.716	0.300a	0.038
	C	2.62(0.60)	4.22(0.67)	2.60(0.64)	<0.001	0.759		
Working memory	E	3.13(0.59)	3.57(1.08)	3.49(1.05)	0.107	0.153	0.056a	0.125
	C	2.87(0.42)	2.83(0.66)	2.91(0.63)	0.891	0.008		
Cognitive flexibility	E	3.12(0.42)	3.68(0.72)	3.81(0.65)	0.001**	0.415	0.799a	0.002
	C	3.25(0.60)	3.60(0.51)	3.63(0.55)	0.142	0.135		
Emotional control	E	3.33(0.55)	3.77(0.80)	3.75(0.73)	0.093	0.161	0.165a	0.068
	C	3.28(0.46)	3.41(0.45)	3.43(0.40)	0.739	0.022		
Planning and organization	E	3.13(0.94)	3.73(0.80)	3.64(0.72)	0.070	0.179	0.002a**	0.295
	C	2.80(0.56)	2.81(0.52)	2.87(0.47)	0.795	0.017		
Total	E	78.00(12.07)	88.20(19.50)	88.70(17.61)	0.068	0.180	0.034a*	0.151
	C	74.13(7.81)	76.73(8.07)	77.13(8.10)	0.569	0.041		
Behavior to Alleviate Behavioral Problems (BABP)								
Positive interaction dvp	E	4.03(0.53)	4.54(0.34)	4.66(0.35)	<0.001***	0.519	0.275a	0.042
	C	4.15(0.60)	4.15(0.66)	4.35(0.57)	0.022*	0.246		
EF skill dvp	E	3.73(0.76)	4.31(0.43)	4.24(0.48)	0.008**	0.302	0.221a	0.053
	C	3.75(0.63)	3.92(0.62)	3.93(0.69)	0.65	0.031		
Total	E	114.27(19.89)	132.87 (10.84)	133.40(10.82)	0.002**	0.379	0.265a	0.044
	C	118.80(17.97)	120.27 (19.29)	124.20(17.87)	0.205	0.111		
Family functions assessed using the CFI								
Problem-solving	E	3.13(0.28)	3.54(0.55)	3.40(0.63)	0.002**	0.361	0.012a*	0.207
	C	2.92(0.45)	3.02(0.48)	2.90(0.45)	0.119	0.146		
Communication	E	3.10(0.36)	3.26(0.47)	3.20(0.48)	0.157	0.128	0.020a*	0.178
	C	2.92(0.52)	2.82(0.42)	2.81(0.39)	0.643	0.032		
Roles	E	3.76(0.34)	3.78(0.32)	3.78(0.32)	0.971	0.002	0.803b	0.002
	C	3.27(0.53)	3.47(0.61)	3.44(0.58)	0.131	0.140		
Affective responsiveness	E	3.06(0.37)	3.12(0.48)	3.28(0.36)	0.076	0.174	0.573a	0.011
	C	3.05(0.40)	3.07(0.43)	3.13(0.43)	0.636	0.033		
Affective involvement	E	2.13(0.39)	2.15(0.33)	2.55(0.48)	0.026*	0.236	0.248a	0.047
	C	2.27(0.33)	2.20(0.35)	2.64(0.38)	0.027*	0.237		
Behavior control	E	2.82(0.35)	2.45(0.49)	3.00(0.77)	<0.001***	0.433	0.812b	0. 058
	C	2.47(0.35)	2.38(0.55)	2.70(0.52)	0.081	0.170		
General functioning	E	3.20 (0.41)	3.64 (0.44)	3.60 (0.43)	0.015*	0.26	0.048a*	0.133
	C	3.13 (0.49)	3.22 (0.51)	3.20 (0.51)	0.82	0.01		
Total	E	108.67(7.48)	114.53(11.35)	118.07(12.02)	<0.001**	0.429	0.021a*	0.177
	C	104.00(10.70)	104.87(9.96)	107.87(10.39)	0.015*	0.269		

Note: CFI, the Chulalongkorn Family Inventory; dvp, development; FCG, family caregiver; Group, E=experimental group, C=control group. Scoring for subscales: Behavioral problems, 0-3; EF (Executive functions), 1-5; BABP (Behavior to alleviate behavioral problems), 1-5; and Family functions, 1-4. Statistics: a Two-way repeated measures ANOVA to compare means between- and within-group variations, b Repeated measures ANCOVA to perform some mean between-group comparisons, while controlling for the baseline values(pretest); Data are significant at * p<0.05, ** p<0.01, *** p<0.001; Effect sizes: ANOVA and ANCOVA analysis used partial eta square (ηp^2) and categorized into small = 0.01, medium = 0.06, large >0.14.

improvement with large effect sizes. However, from the model implementation until the end of the 6-week follow-up, the experimental group did not differ in total EF and EF subscales (working memory, emotional control, planning, and organization), all p >0.05. For the control group, there were no statistically significant differences in mean scores between the pretest, posttest, and 6-week follow-up, except for one EF subscale, inhibition ($p<0.001$, $\eta p^2=0.75$).

Results from within-group comparisons over three assessment phases for FCGs showed significant improvement in the experimental group. They demonstrated enhanced BABP with a significant decrease in total BABP with a significant decrease in total BHBP ($p<0.01$, $\eta p^2=0.37$) and improvements in all its subscales, including positive interaction development ($p<0.001$, $\eta p^2=0.51$), and EF skill development ($p<0.01$, $\eta p^2=0.30$).

The experimental group also experienced significant improvement in total family functions ($p<0.001$, $\eta p^2=0.42$), and four out of seven family function subscales, specifically problem-solving ($p<0.01$, $\eta p^2= 0.36$), affective involvement ($p<0.05$, $\eta p^2=0.23$), behavioral control ($p<0.001$, $\eta p^2=0.43$), and general functioning ($p<0.05$, $\eta p^2=0.26$). However, there were no differences in some family function subscales, such as communication, roles, and affective responsiveness, after completing the model implementation up to the 6-week follow-up, all $p>0.05$.

For the control group, there were no statistical differences in mean scores between the pretest, posttest, and 6-week follow-up, except for one BABP subscale, positive interaction development ($p<0.05$, $\eta p^2=0.24$), and total family functions ($p<0.05$, $\eta p^2=0.26$), along with one family function subscale, affective involvement ($p<0.05$, $\eta p^2=0.26$).

Between-group comparisons showed a significant main effect of the experimental group on the repeated measure averaged across time in total family functions ($p<0.05$, $\eta p^2=0.17$). Subscales, such as problem-solving ($p<0.05$, $\eta p^2=0.20$, large effect size), and general functioning ($p<0.05$, $\eta p^2=0.13$, medium effect size), also showed notable differences among FCGs in the experimental group compared to the control group. This effect was observed from the intervention through the end of the 6-week follow-up assessment phase, as presented in Table 5.

Results from data analyses indicated significant interaction effects of time (pretest, posttest, and 6-week follow-up) across groups (E, C) on total BABP ($F(2,56)=5.02$, $p=0.022$, $\eta p^2=0.152$), and BABP subscale, positive interaction development ($F(2,56)=7.64$, $p = 0.002$, $\eta p^2=0.214$).

Discussions

This was a mixed methods research study, employing an exploratory sequential design and utilizing a retrospective qualitative approach to investigate the experiences of families caring for children with ADHD. Additionally, a quantitative approach was used to develop, implement, and evaluate "The Family Skill Development for ADHD Behavior Problem Alleviation Model," abbreviated as the FSD-ADHD-BPA Model. This intervention model aims to tackle the challenges and requirements of ADHD at-risk preschool children and their families.

In phase 1, the qualitative phase, in-depth interviews and focus group discussions involved 14 caregivers of children aged 6-9 years diagnosed with ADHD for at least six months by a physician following DSM-5 criteria. This engagement took place at an outpatient clinic in a hospital setting. The study revealed two key themes contributing to model construction. First, caregivers adapted their behaviors through behavioral modification to address issues in children with ADHD. This was achieved through positive family-child interaction and effective parenting strategies. Second, caregivers described adapting their behaviors to improve family-child interaction and alleviate behavior problems in their children. This study uncovered how caregivers adjusted their approaches to support children with ADHD, showcasing the use of appropriate strategies in northeastern Thailand. Examples include 1) encouraging the involvement of ADHD children in day-to-day tasks, engaging in shared household chores, 2) introducing mindfulness and meditation techniques, 3) using playtime with toys to stimulate cognitive processes and creativity, and 4) promoting physical exercise, given the preference of ADHD children for such activities involving their families.

According to the caregivers, family-child interactions have a role in children's EF development. Prior research has suggested that children with higher EF appear to have fewer behavioral issues, while children with lower EF appear to have more behavioral external problems (Romero-Lopez *et al.*, 2017).

In phase 2, the quantitative phase, the model development integrated the ecological theory and the unified theory of behavior (UTB), viewing the family as a dynamic system close to preschool children. Informed by qualitative findings and effective interventions, the FSD-ADHD-BPA model was designed for ADHD at-risk preschool children and families, addressing their specific needs. The model included four key components: 1) developing early family skills for ADHD detection; 2) improving family skills to address behavioral issues; 3) promoting positive parenting through family-child interactions; and 4) monitoring progress. Implemented over eight weeks, the model involves pretest, posttest, and 6-week follow-up assessments. It serves as a tool for early detection by empowering the first-contact guardians such as FCGs, providing methods to address behavioral challenges in preschool children. The model also enhances FCG skills through positive interaction, emphasizing healthy relationships and effective parenting. With workshop training and resources, specifically a handbook, toys, and digital tools, the model has high potential to enable FCGs to assess changes in family behaviors related to alleviating behavior problems in at-risk preschool children.

Activities within the FSD-ADHD-BPA model were carefully examined. Preschool children with ADHD have deficits in multiple functions, activity level impairments, and significant executive functions (EF) impairments (Biele *et al.*, 2022). Interactions with families and other members were enriched by "Being mindful-help-cognition-exercise" activities, including: 1) "Bottle of mindfulness" aimed to calm emotions and enhance emotional control through mindfulness, crucial for early learning (Jean, 2020); 2) "Talented person can help oneself" activity fostered memory, cognitive flexibility, and routines, essential to counter ADHD-related memory deficits (Irwin *et al.*, 2021); 3) "Think about what color" encouraged memory and discernment, using the Stroop-effect concept, crucial for cognitive development, especially in ADHD at-risk preschool children (Okuzumi *et al.*, 2015); and 4) "Exercise to keep pace with the colors" therapy was designed to improve inhibition, movement control, memory, and emotional regulation, aligning with exercise’s benefits in ADHD management (Sun, Yu and Zhou, 2022). Preschool children’s behaviors evolve with cognitive development, becoming curious about their surroundings and interactions as they learn (Piaget, 1976; Aytkaliyevna, 2023). Contextual encouragement also aids learning and behavior adjustment.

In the FSD-ADHD-BPA model, caregivers acquire practical skills for addressing behavior problems of preschool children through workshops and education on understanding ADHD risks. Health education and practical exercises facilitate positive parenting and EF development. Resources like the "Handbook for Developing Family Skills," "Being Mindful-Help-Cognition-Exercise," and the "Happy Family Awareness of ADHD" program applications provide practical assistance. Equipped with knowledge, caregivers willingly tackle behavioral problems (Lindsey *et al.*, 2013). Parent training in behavior management supports the idea that parent and family environments influence ADHD symptoms. Reducing parenting challenges and increasing access to resources may improve children’s long-term developmental health (Claussen *et al.*, 2022). Positive family interactions, as indicated by studies, effectively decrease children's behavioral issues (Rincon *et al.*, 2018). Positive interactions between caregivers and children counter early ADHD (r=-0.58) (Taghizade *et al.*, 2022). Positive family parenting supports ADHD children, enhances family well-being, relieves stress, and improves overall care (Aghebati *et al.*, 2014).

Results from the quasi-experimental study showed that the FSD-ADHD-BPA model effectively enhanced the family functions of the FCGs, aiding them in better managing ADHD at-risk preschool children in northeastern Thailand. Notably, significant improvements were observed in the main effects from baseline (pretest) to posttest and 6-week follow-up in the experimental group. Specifically, significant effects were detected for total family functions ($\eta p^2=0.17$) and family function subscales, such as problem-solving ($\eta p^2=0.26$), with a medium effect identified for general functioning subscale ($\eta p^2=0.13$).

Contrary to expectations, the results revealed no statistically significant main effect of the intervention model on behavior problems, behavior problem subscales, and EF and EF subscales among ADHD at-risk preschool children. Similarly, no statistically significant effects were observed in BABP and all BABP subscales among the FCGs, with all p-values exceeding 0.05. Additionally, significant interaction effects were noted between the assessment time and the group. These interaction effects indicated that 15.2% and 21.4% of the variation in error scores of the BABP and the BABP subscale, specifically positive interaction development, were attributed to the model intervention, demonstrating large effect sizes. However, the other variables, such as behavior problems and EF, along with their subscales, did not show significant improvement compared to those in the control group at the end of the intervention (posttest) and 6-week follow-up.

Although no significant interaction effects were observed between the assessment time and the group, within-group comparisons indicated significant improvements in the experimental group. These improvements were evident in total behavior problems ($p<0.05$, $\eta p^2=0.246$), and all associated subscales, including hyperactivity/impulsiveness ($p<0.05$, $\eta p^2=0.252$), and inattention ($p<0.05$, $\eta p^2=0.250$). Notably, EF subscales such as cognitive flexibility ($p< 0.01$, $\eta p^2=0.415$), total BABP ($p< 0.01$, $\eta p^2=0.379$), and BABP subscale such as positive interaction development ($p<0.001$, $\eta p^2=0.519$) and EF skill development ($p<0.01$, $\eta p^2=0.302$), as well as total family functions ($p<0.05$, $\eta p^2=0.429$), family function subscales, such as affective involvement ($p<0.05$, $\eta p^2=0.236$), and behavior control ($p<0.001$, $\eta p^2=0.433$), all significantly improved from baseline to posttest and the 6-week follow-up. These improvements, all with large effect sizes, suggest that, while the experimental group did not significantly differ from the control group in the specified outcomes, the observed enhancements within the experimental group indicate promising potential for the FSD-ADHD-BPA model to achieve the desired study outcomes.

Our observed significant changes in outcomes through both between- and within-group comparisons, along with the identified interaction effects between the assessment time and the group, align with findings from many parenting intervention studies. Notably, an 8-week group-based behavioral parent training (BPT) intervention, carried out among 132 dyads of parent-ADHD at-risk preschool children aged 3-6 years, showed improvements in family functions, mirroring the results of our current study. However, the BPT intervention in the previous study also revealed additional significant improvements in peer and parental relationships, self-esteem, behavior, academic progress, and ADHD symptoms. These effects varied in size, from small to large (Risley *et al.*, 2020).

Based on a meta-analysis of 100 experimental studies spanning from 1980 to 2020 and focusing on children aged 2-12 years with behavior problems, parent-child interaction therapy (PCIT) demonstrated effective in treating issues such as disruptive, hyperactive, negative, and externalizing behaviors, showcasing large effect sizes (Valero Aguayo *et al.*, 2021). Additionally, in a randomized control trial titled “Incredible Years Parenting Intervention” (Overbeek *et al.*, 2021), which assessed immediate and long-term effects over a 2.5-year follow-up, involving 387 parent-child dyads (197 intervention, 190 control) with children aged 4-8 years experiencing conduct problems, through 15-week group sessions, parents learned relationship-building techniques, positive reinforcement methods, and non-violent discipline strategies to shift their focus from negative to positive child behavior. Results revealed that parents in the intervention group reported lower behavior problems in their children at a 2.5-year follow-up, with a medium effect size.

In this study, notable enhancements were observed among the FCGs in the control group, particularly in the BABP subscale focused on positive interaction development ($p<0.05$, $\eta p^2=0.246$), as well as in total family functions ($p<0.05$, $\eta p^2=0.269$), and family function subscale of affective involvement ($p<0.05$, $\eta p^2=0.237$). These improvements were significant, implying that the standard care services provided by the Child Development Clinic (CDC) in a Hospital Outpatient Department could have influenced the observed changes among FCGs in the control group. Furthermore, the progress in BABP and family functions within the control group could be attributed to an increased ability to foster positive interactions with their children, as highlighted by the FCGs in phase 1. These outcomes could be linked to external factors or heightened awareness of positive parenting practices.

There are limitations in this study that should be acknowledged. The unified theory of behavior underscores self-efficacy as a key factor influencing family caregivers’ (FCGs) practices in addressing behavior problems and managing family functioning. Nevertheless, factors such as income and marital status may either hinder or motivate family caregivers in addressing behavior problems among preschool children. The duration of model implementation and follow-up might not have been sufficiently long to initiate or sustain desired behavioral changes. Despite this limitation, the study utilized a control group and conducted repeated measures analysis of variance, enhancing the applicability of the results to ADHD at-risk preschool children and families in similar sociocultural contexts.

While existing literature often reports a higher prevalence of boys affected by ADHD. our study recruited a higher proportion of girls in the at-risk group. However, researchers employed the matching technique to assign participants to experimental and control groups, ensuring data to maintain comparable conditions between groups.

This study introduces a model that improves family caregivers’ capacity to recognize ADHD symptoms in at-risk preschoolers. Early detection helps minimize potential mental health effects on children, enabling caregivers to adapt and find suitable solutions for families and society. Utilizing assessments from different sources, such as teachers or health volunteers, can enhance accuracy. Researchers should collaborate to identify barriers hindering specific groups from adopting desired behaviors, with the goal of tailoring solutions to individual family needs and challenges.

Conclusion

The FSD-ADHD-BPA Model helps families in modifying and enhancing their functions and behaviors to alleviate behavior problems in ADHD at-risk preschool children. The observed improvements in the experimental group, including total behavior problems and specific executive function (EF) subscales, such as inhibition and cognitive flexibility, make the FSD-ADHD-BPA a promising parental intervention model. It shows potential for establishing healthy families while reducing troublesome behavior problems in ADHD at-risk preschool children, not only in northeastern Thailand but also in regions with similar sociocultural contexts.

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Authors’ contributions

KK and PH developed the research design. KK collected and analyzed the data. PH and KK wrote the first version of the manuscript. Both authors contributed to writing and completing the manuscript.

Conflicts of interest

The authors have no conflicts of interest.

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Disclosure statement

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ORIGINAL ARTICLE

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Experiences of nurses involved in air ambulance service: a qualitative study

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ABSTRACT

Introduction: Nurses undertaking air ambulance service encounter environmental, equipment, and personnel limitations during their work. Moreover, they must cope with various types of injuries and illnesses, as well as changes in patient conditions. These factors pose a significant pressure on nurses. Currently, there is a lack of qualitative research on the experiences of nurses performing air ambulance tasks. The purpose of this study is to explore the experiences of nurses undertaking air ambulance service, with a focus on capturing their personal perceptions regarding this field of work.

Methods: Twelve nurses were selected using purposive sampling, and semi-structured interviews were conducted to collect data. Content analysis was used to analyze the data.

Results: The analysis identified three major themes: "Ambiguous and risky emergency missions," "Challenges during air transfer," and "Nurses' personal limitations." Eight categories were formulated within these themes, including "Mission uncertainty," "Urgency of medical conditions," "Hazards at high altitude," "Cabin environment limitations," "Inadequate equipment," "Incomprehensive operating mechanisms," "Physical discomfort," and "Recognition of professional shortcomings."

Conclusions: Improving the performance and well-being of nurses engaged in air ambulance services necessitates the implementation of a psychological adaptation program. This includes the utilization of psychological stress assessment tools or engaging in role-playing activities. Successful patient rescues demand the establishment of comprehensive standard operating procedures, involving an interprofessional team. Supporting nurses in adeptly managing challenges during air ambulance services requires an expanded scope of education and training, facilitated through initiatives like situational simulation and similar approaches.

Keywords: air ambulance service, content analysis, experience, nurse

Introduction

Air Ambulance is a critical component of emergency medical services and has been demonstrated to deliver rapid treatment to patients in emergency situations, resulting in saved lives and reduced medical costs (Eskandari *et al.*, 2021). It can also efficiently transport patients who are in remote locations without adequate access to intensive care in hospitals (Kulshrestha and

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Singh, 2016). Comparable to many other regions or countries that require air ambulance as a vital part of the medical system (Edwards *et al.*, 2019), Taiwan faces similar issues regarding the health inequality of its offshore islands. Despite having relatively smaller populations on the islands, healthcare resources are severely limited. Residents of these islands are confined to basic medical services, necessitating air ambulance service for transferring patients to the main island of Taiwan, particularly in cases of severe conditions or advanced medical care needs. Tragically, in 2018, a Taiwanese rescue helicopter crashed into the sea off the coast of Orchid Island (Lanyu) during an air ambulance mission. This unfortunate incident claimed the lives of all six people on board, including three flight crew members, one nurse, the patient, and a family member (Li, 2018). Such events and the inherently dangerous nature of air ambulance services further heightened the psychological burden on flight nurses, posing greater risks compared to those working in general hospitals.

According to statistical data reported by the Nursing and Health Care Department of Taiwan Ministry of Health and Welfare (2022b), air ambulance missions averaged 230 per year from 2017-2018, and increased to 300 per year from 2019-2021. Notably, 40.58% of the flights during this 5-year period were conducted at night (Ministry of Health and Welfare, 2022a). The rising occurrences of natural disasters and infectious diseases in recent years have led to healthcare paralysis in specific regions around the world. Using Taiwan's data as an example, air ambulance rescues have become more crucial, especially in challenging and remote regions like offshore islands and inland areas. Patients in air ambulances are often critically ill and may require specific medical equipment before or during transport (Dyro, 2004; Zia *et al.*, 2019). When there is a need for higher monitoring capabilities during a mission, complications may arise if the medical equipment is not approved for usage in airplanes. This causes healthcare personnel to face a dilemma of having to choose between unapproved equipment or relying on transporting the patient with fewer monitoring resources (Frost, Kihlgren and Jaensson, 2019). This could mean a reduced ability to continuously track certain vital signs or health indicators during the transport process. While this may present challenges in comprehensive patient monitoring, it may be a necessary compromise in such situations.

Nurses undertaking air ambulance service face numerous challenges, including environmental, equipment, and human resource limitations, as well as managing patients with complex and changing conditions (Dias *et al.*, 2021). Working in the air means nurses are required to be patient-focused at all times, often at the cost of their own safety. The stark vulnerability experienced during prolonged transport also emphasizes the limitations on supplies and the absence of external assistance of air ambulance services as compared to ground ambulance work. All the above-mentioned challenges put significant burdens on nurses. In accordance with this, Aditya et al. (2022) identified patient handling before take-off, patient safety during flight, and preparing the handover of patients as key to the success of an air ambulance service. The distances traveled, climatic conditions, communication, and the precarious structure of some airports were also elements to be considered when planning transportation and screening the patient to ensure their safety (Dias *et al.*, 2021). To ensure both patient and nurse safety, nurses' work stress, perceived workload, and interpersonal teamwork skills play pivotal roles in air ambulance services (Pereira *et al.*, 2021).

Previous studies are centered on investigating aspects such as preparations, patient safety, work-related stress, fatigue, and team dynamics in air ambulance services. Nonetheless, there is limited research on nurses' personal perceptions regarding their experiences throughout the whole process of this work and its dangerous risks, particularly in the psychological aspect. The purpose of this study is to explore the experiences of nurses undertaking air ambulance services, with a focus on capturing their personal perceptions regarding this field of work. Although this study is conducted in Taiwan, the topic of air ambulance services remains globally significant. The research findings can serve as a benchmark for other countries, offering valuable insights into operational practices and contributing to the overall improvement of global air ambulance service quality.

Materials and Methods

Study Design

Content analysis and semi-structured interviews were involved in this qualitative research to gain a rich understanding of nurses' experiences in offshore-island air ambulance service.

Participants and Setting

This study employed purposive sampling, and the participants were selected from the air ambulance nursing departments of three hospitals designated by the Taiwan government. The inclusion criteria for this study were registered nurses (RN) with more than five years of emergency nursing experience and more than two years of experience in air ambulance services. They were also required to have participated in the initial eight hours of flight nursing training. The exclusion criterion was participants who had not been involved in air ambulance services within the last three months. The sample size was determined by data saturation, which refers to the point at which no new themes or codes emerge from the data (Guest, Namey and Chen, 2020).

Data Collection

This study adopted semi-structured interviews as the data collection method. Interview guidelines were carefully formulated through a comprehensive review of existing literature and panel discussions. These guidelines were specifically crafted to facilitate the interviewees in sharing their perceptions and the challenges they encountered during their experience in the air ambulance service (Table 1).

One researcher, KYW (an RN), who was responsible for visiting the hospitals during the study period to recruit participants for the study, has a PHD background and a sizeable experience in nursing. Equipped with qualitative research training, she highly focused on the air ambulance nursing experience, and had no prior contact with the participants of the study. After compiling a list of participants from three government hospitals, the researcher invited these nurses to join the study and encouraged them to refer additional potential participants. Recruitment involved outlining the research objectives, and participants were given one day to decide on their willingness to participate. Written informed consent was obtained from all 12 participants prior to interviews and data collection. Face-to-face, semi-structured interviews were conducted using the interview guidelines. Each participant was interviewed once in a private area within the hospital without any third parties involved. All interviews were conducted by the same researcher using a voice recorder, with each session lasting approximately 30–60 minutes. Limited demographic information was collected to ensure confidentiality. During the interviews, any ambiguous statements made by the interviewees are promptly clarified. Following the interviews, audio recordings were coded and transcribed verbatim in an anonymous manner. The data were collected from 15 November to 31 December, 2019.

Table 1 Interview guidelines

Questions	Prompts
What are the most profound experiences you have had during air ambulance duty? How did you feel at the time?	Sudden patient emergency, helicopter emergency landing, patient self-extubation, or patient having severe breathing difficulty.
What are your perceptions on air ambulance?	Work that involves helping others, is urgent yet important, or work that poses high risks.
What challenges do you encounter in air ambulance?	Adapting to the high-altitude working environment or being competent in providing air medical care.

Data analysis

The audio-recorded interviews were transcribed verbatim in Chinese within 24 hours post-interview and double-checked against the digital recordings. These transcriptions were then translated into English, back translated into Chinese, and returned to the participants for comment and confirmation. Afterward, two researchers (YFC and CYH) independently analyzed the transcripts using qualitative content analysis (Lindgren, Lundman and Graneheim, 2020) and discussed them with a third researcher (KYW) until a consensus was reached. The researchers immersed themselves in the transcripts and developed a list of data-driven codes. These codes were compared, labeled, and grouped into meaningful units to identify key themes in the data.

Trustworthiness

To ensure the accuracy and trustworthiness of the study, this research has adopted the criteria proposed by Lincoln and Guba (1985), which includes four aspects: (1) Credibility, in which the researcher has extensive interview experience and establishes a trusting and harmonious relationship with the interviewees prior to the interview. Additionally, qualitative research scholars and case members were invited to review the consistency of the text and the meaning units and to summarize the content. (2) Transferability, in which the interview content is faithfully presented in the text. The data were collected from nursing professionals with different disciplines, seniority, advanced levels, and marital status, providing multiple comparisons and richness to the data. (3) Dependability, in which the data collection was carried out by the researcher using in-depth interview techniques, and the audio content was transcribed verbatim into text. (4) Confirmability, in which all interview notes, text, and data analysis files were fully preserved.

Ethical Considerations

All study participants provided written informed consent, and the study protocol was approved by the

Institutional Review Board of the participating hospital (IRB No. 11MMHIS153).

Results

A total of 12 nurses were enrolled in the study. Their ages ranged from 28 to 50 years old (mean = 34 years) and 58% (n = 7) were married. They had 2–6 years of air ambulance working experience (mean = 3.8 years) and 58% of nurses (n = 7) had more than 10 years of emergency nursing experience (Table 2).

The analysis revealed three major themes. The content within these themes was formulated into eight categories and seventeen subcategories (Table 3).

Ambiguous and risky emergency missions

Working in hospitals involves clear and well-developed training, with a high degree of understanding of patient characteristics. However, air ambulance services are always pressing, unpredictable, and dangerous in nature. They fall under three categories: "Mission uncertainty," "Urgency of medical conditions," and "Hazards at high altitude".

Mission uncertainty (subcategories: anxiety during flight operations and apprehension about unclear patient progression)

Patients in need of air ambulance services are usually emergencies where the nurse has no way of knowing when they will be dispatched. They will also have limited access to patient information due to transfers commencing as soon as they receive the assignment. Nurses described these uncertainties as follows:

"I also wonder what kind of patient is being transported because I worry that if the patient is in a bad condition, our lack of equipment may endanger the patient's life." (F-1-031)

Table 2 Participant characteristics (N = 12)

Nurses	Gender	Age	Marital Status	Air Ambulance Experience	Emergency Nursing Experience
A	Female	35	Married	5	16
B	Female	33	Married	4	11
C	Female	32	Married	3	10
D	Female	28	Married	2	6
E	Female	29	Unmarried	2	6
F	Female	31	Unmarried	4	9
G	Female	31	Unmarried	4	9
H	Female	32	Married	4	11
I	Female	47	Married	5	25
J	Female	34	Unmarried	4	12
K	Female	31	Unmarried	3	8
L	Female	50	Married	6	23

Table 3 Air ambulance services experiences (*N* = 12)

Theme	Category	Subcategory
Ambiguous and risky emergency missions	Mission uncertainty	- Anxiety during flight operations - Apprehension about unclear patient progression
	Urgency of medical conditions	- Time pressure - Patient vital sign instability
	Hazards at high altitude	- Abrupt weather changes - Inherent risks of air travel
Difficulties during air transfer	Cabin environment limitations	- Difficulty to provide care in confined spaces - Low visibility during night flights
	Inadequate equipment	- Insufficient medical equipment - Lack of adequate heating devices
	Incomprehensive operating mechanisms	- Incomplete operational procedures - Absence of auditing procedure mechanisms
Nurses' personal limitations	Physical discomfort	- Discomfort during aircraft descent - Nausea due to the unpleasant smell of patients' blood and vomit - Ear discomfort caused by loud aircraft noise
	Recognition of professional shortcomings	- Limited training period - Inability to handle various situations due to lack of satisfactory training contents

"When we received the assignment for air ambulance transfer, I was quite nervous, as I do not know the patient, I was afraid I wouldn't have a grasp on the patient's condition. My fear only subsided once we arrived at the hospital and had access to the patient's information. Besides fear, I was also quite anxious, worried that I wouldn't be able to perform at my best." (A-1-001)

Urgency of medical conditions (subcategories: time pressure and patient vital sign instability)

Regardless of what they are doing at the time, nurses must be at the airport as soon as they are notified to avoid delay in departure. Moreover, the unstable conditions of the patient being transported can also add to their anxiety. Nurses described the urgency of time and patient instability as follows:

"We are required to arrive at the airport by a specified time, so the fear of being waited on by everyone is very nerve-wracking." (C-1-004*)*

"After disembarking from the aircraft, I really couldn't feel the patient's pulse in the ambulance, it was

very weak. So, I ended up urging the ambulance to speed up, and when we arrived at the hospital, the patient received CPR." (H-1-017)"

"I once had a patient with acute myocardial infarction (AMI), and I was worried about providing emergency care on board due to his irregular heartbeat." (G-1-020)

Hazards at high altitude (subcategories: abrupt weather changes and inherent risks of air travel)

The weather conditions are unpredictable, and the urgency of the situation demands a race against time to ensure the best treatment opportunities for patients. In addition to this, the flight itself carries dangers that can pose risks to the personal safety of the nurses. The following were the descriptions of each nurse regarding air ambulance service hazards:

"One time during a mission, the poor weather caused the tail section of the helicopter to hit a pillar at the port, causing damage to the rotor. The helicopter then crashed to the ground, and I was thrown around inside, hitting my head and suffering a slight concussion. The patient died thereafter." (J-1-005)

"The wind was strong at that time, and it was shaky, I kept looking out the window out of fear. It felt like the aircraft did not move even though it had been flying for quite some time. I was afraid that the helicopter might plummet to the ground." (H-1-018)

Difficulties during air transfer

Performing air ambulance services during nighttime can be extremely challenging due to low visibility and cramped space inside the helicopter, which makes it difficult to provide proper patient care and promptly assess physical symptoms for appropriate treatment. Effectively managing sudden patient behavior or air emergencies also proves to be a challenge due to the constricted space in the helicopters, limiting the carrying capacity for essential equipment such as medical and heating devices. This situation can lead to heightened anxiety for the personnel involved. Additionally, inadequate briefing on the helicopter's Standard Operating Procedures (SOPs) for the nurses, coupled with the absence of pre-flight audits, can result in non-adherence to the required protocols. Their difficulties were divided into three categories: "cabin environment limitations," "inadequate equipment," and "incomprehensive operating mechanisms."

Cabin environment limitations (subcategories: difficulty to provide care in confined spaces and low visibility during night flights)

The environmental characteristics of air ambulance services are difficult to control completely, such as small cabin space, vibrations in the aircraft due to turbulence, and low visibility during night operations. The following were the descriptions of such challenges as mentioned by the nurses:

"The helicopter cabin is narrow; it is difficult for us to move patients inside the cabin." (F-1-042)

"For patients with gastric bleeding, we must observe whether they have symptoms of anemia by the color and texture of their vomit. But, because of the low light conditions on the aircraft, it can be difficult to tell. Sometimes, things like the drip or the nasogastric tube can slip out without us noticing." (E1-048)

Inadequate equipment (subcategories: insufficient medical equipment and lack of adequate heating devices)

The helicopter's limited capacity, as it is not a conventional medical aircraft, restricts the availability of fully equipped medical and heating equipment that can meet all patients' needs. The helicopter can only carry simple or minimum-capacity equipment. The nurses described this issue as follows:

"The roof area of the helicopter compartment is empty, so there should be basic medical equipment like those in an ambulance such as a blood pressure monitor, oxygen equipment, and sputum suction unit…" (D-1-030) *"The stretcher is not made of plywood, but rather a kickboard-like material, and whenever a patient has to be moved, there is no point of force applicable to carry the patient onto it, so we can only pull the patient by the hem of their clothes."* (F-1-048)

"Conducting tasks at night means it can be quite cold. I didn't wear a jacket during my first night duty. It was freezing." (I-1-016)

Incomprehensive operational mechanisms (subcategories: incomplete understanding of operational procedures and absence of auditing procedure mechanisms)

Nurses heavily rely on the information provided by the handover personnel to assess and plan subsequent nursing care during the flight. Incomplete pre-transfer evaluation and missing medical information during transfer can significantly impact the nurses' ability to provide seamless care services. Therefore, implementing an audit process becomes essential to ensure the completeness and accuracy of the information exchange. The nurses shared the following descriptions in regard to this situation:

"On my first flight, the captain didn't give me any earmuffs, so I wondered how come it was so noisy up there. Also, I couldn't even buckle my seat belt when the helicopter was about to take off. But on the second flight, I was given earmuffs, and the captain helped me buckle my seat belt after I put on my life jacket. So, I thought maybe they didn't have a standard operating procedure." (B-1-018)

"Sometimes there is a discrepancy between the information received during a phone handover and what we see on the scene. Once we received a call about a conscious clear patient with abdominal pain who needed to be transferred. Yet the patient's breathing became increasingly labored during the flight and CPR was performed quickly." (E-1-005)

"Before takeoff, the handover personnel did not specify whether intubation was necessary. Later, the patient started to struggle to breathe and could not get enough air after boarding the aircraft." (E-1-021)

Nurses' personal limitations

The colder temperature, higher moisture levels, and stronger winds experienced in an air ambulance, along with flight turbulence, can induce dizziness and discomfort for nurses. The smell of blood or vomit during patient treatment can further add to the discomfort. In addition to this, even experienced nurses may find themselves inadequate in terms of knowledge and technical expertise when participating in air ambulance duties. All of this emphasizes the importance of providing sufficient training time for nurses to learn necessary coping skills and receive training content that adequately prepares them for the unique conditions of an air ambulance. This theme can be categorized into two areas: "physical discomfort" and "recognition of professional shortcomings."

Physical discomfort (subcategories: discomfort during aircraft descent, nausea due to the unpleasant smell of patients' blood and vomit, and ear discomfort caused by loud aircraft noise)

Nurses may encounter physical discomfort during air ambulance services, especially at high altitudes where intense winds can cause discomfort. Additionally, handling patients' wounds may result in olfactory stimulation, leading to feelings of nausea. Furthermore, the aircraft's descent can be accompanied by excessive noise and discomfort, adding to the challenges experienced by the nurses. The following were the descriptions of the nurses:

"I had to bend down while treating a patient's bleeding wound, and the blood smelled really strong. The helicopter was also descending at the same time, which made me nauseous." (H-1-039)

"The space inside the helicopter is very narrow. When I was taking care of a patient with head trauma who was constantly vomiting, I could smell the vomit and it made me feel nauseous too." (J-1-012)

"The helicopter is loud, and my ears would hurt." (B-1-012)

Recognition of Professional Shortcomings (subcategories: limited training period and inability to handle various situations due to lack of satisfactory training contents)

Nurses who have received only a short duration of training with subpar training contents may not have the necessary confidence or preparedness to handle the challenging and unpredictable conditions that arise during air ambulance services. Therefore, hospitals must maintain an ongoing, comprehensive training program that equips nurses for the demands of this particular work. The following were the descriptions of the nurses:

"Air ambulance service courses are usually not enough. I hope for more nursing courses to enhance nurses' abilities to provide care. It is important to receive relevant educational training." (L-1-028)

"During my first flight, I was not informed of the standardized safety procedures on the aircraft, and I did not know how to fasten the safety harness. One time, when I was administering intravenous injection to a patient, I found that the IV drip was not flowing properly and I was unsure if it was due to the high-altitude pressure." (B-1-061)

"Measuring vital signs is difficult. I couldn't get a reading on the electronic blood pressure monitor due to the shakiness and could only feel the pulse manually or use the oximeter to gauge his oximetry." (F-1-017)

"The original design of the program should have focused on selecting nurses with sufficient experience or qualifications in air ambulance service before allowing them to participate in missions." (K-1-060)

Discussions

Theme 1: Ambiguous and risky emergency missions

Air ambulance service is unique and distinct from ground ambulance service. The first theme revealed in this study was "ambiguous and risky emergency missions," which included "mission uncertainty," "urgency of medical conditions," and "hazards at high altitude." Interview participants reiterated the inherently high-risk nature of the job and the operational environment for air ambulance nurses. Not only must they contend with the pressure of patient care, but also external challenges during mission execution, such as dangerous weather conditions that can endanger crew members and result in the death of patients. Previous studies identified similar themes such as critical patient conditions, weather conditions during flights, and overall unpredictability of the work (Nolan *et al.*, 2020; Dias *et al.*, 2021; Aditya *et al.*, 2022). The complexity of non-hospital environments influences nurses' judgment and decision-making processes, emphasizing the importance of education and practical guidance to encourage reflection and feedback for better patient care (Perona, Rahman and O'Meara, 2019), as the experience of involved personnel will affect the operation of the air ambulance (Sorani *et al.*, 2018). In essence, the experience and qualification of the team will stand in as a safety net while providing professionals with security and tranquility to act under pressure, to some extent making immediate split-second decisions in adverse situations during air ambulance services (Alfes, Steiner and Rutherford-Hemming, 2016; Ericsson, Frenckner and Broman, 2017). To mitigate risks in the air environment, there is a need for an experienced medical team onboard, which is consistent with the results of previous studies (Miller *et al.*, 2016; Santos *et al.*, 2019). In other words, having ample practical experience and teamwork enables professionals to adeptly navigate the limited information available to them.

Air ambulance nurses require resilience and stress-coping abilities when dealing with challenging tasks (Langdalen *et al.*, 2018). This indicates that nurses aspiring to undertake this role require not only expertise but also strong psychological resilience to deal with the special working conditions. In fact, even experienced nurses may face heavy pressure and concerns about making mistakes. The numerous uncertainties arising from patients' conditions and high-altitude rescue operations make it essential for nurses to endure these factors and effectively perform their tasks. Adequate training is crucial in this regard. In the past, training courses in domestic settings have largely emphasized technical capacity building, with little attention paid to developing psychological mechanisms. To address this gap, this study proposes the development of a "psychological adaptation training for air ambulance tasks," which may include: 1) Utilizing psychological stress testing tools and self-observation records to help workers recognize physiological and psychological changes when confronted with stress, ultimately improving their resilience; 2) Incorporating activities like discussions on failures and successes, as well as role-playing to facilitate the learning of effective stress management strategies. This comprehensive approach aims to address both practical and psychological aspects crucial for those working in high-stress environments, particularly within the realm of air ambulance services.

Theme 2: Difficulties during the air transfer

The second theme summarized in this study is "difficulties during the air transfer," which includes three categories: "cabin environment limitations," "inadequate equipment," and "incomprehensive operating mechanisms." The study conducted by Chin et al. (2015) provided an all-encompassing review of air ambulance services in a regional hospital. Their findings were consistent with the results of this study, highlighting factors such as the lack of SOPs and auditing process mechanisms, insufficient medical and heating equipment, and cabin environment limitations. This theme emphasized the importance of handover before transport, injury assessment and patient preparation, transport and in-flight care, and follow-up reports, such as identified by Lo (2017). In other words, the SOPs should cover the period before the patient boards the aircraft, during the air ambulance process, and upon transferring the patient to the hospital on the ground. Clearly defining specific tasks and correct procedures for each period can effectively minimize human errors and their consequences. The study found that nursing training on the ground typically focuses on factors that can be controlled, but air ambulance care involves stressors that affect patients' and nurses' priorities differently.

As reported by the nurses in the present study, the challenges posed by limited space and visibility in nighttime missions make task execution especially difficult. Improving the understanding of operating procedures can lead to more precise and seamless actions. Thus, the establishment of SOPs for air ambulance missions can provide clear guidelines for nurses. The protocols may include patient handover, ensuring the safety of patients and air ambulance team through aeromedical checklists, as well as assessing air and ground conditions. Implementing an audit process mechanism also becomes crucial, as this systematic approach aids nursing management in examining, verifying, and adjusting all work processes. Operational efficiency could be enhanced by creating a comprehensive resource system for information linkage, ensuring a seamless flow of data accessible to the air ambulance team. Furthermore, conducting regular drills with an interprofessional team in the form of Crew Resource Management (CRM) training is key to effective communication and teamwork among healthcare professionals (Schwartz *et al.*, 2018).

Theme 3: Nurses' personal limitations

There are nine essential aspects that flight nurses' training content should cover, including experience, training, transport environment of care, psychomotor skills, flight nursing knowledge, cue recognition, pattern recognition, decision-making, and actions (Reimer and Moore, 2010). Based on the findings of the present study, the third theme, "nurses' personal limitations," revealed that flight nurses faced these challenges: "physical discomfort" and "recognition of professional shortcomings." Participants recounted stories of painful experiences and unfamiliarity with aircraft-related knowledge, stating, "*the helicopter is loud, and my ears would hurt…*" or "*…when I was administering intravenous injection to a patient, I found that the IV drip was not flowing properly and I was unsure if it was due to the high-altitude pressure.*" The former referred to the impact of environmental stimuli on their physical well-being, while the latter was attributed to insufficient time and training to handle clinical practice on the aircraft. Therefore, in addition to possessing professional aviation and nursing care knowledge, there is a need for more practical training courses. Moreover, high-fidelity simulation training is deemed necessary to facilitate adaptation, such as addressing issues like coping with the excessive noise present in an aircraft and other non-technical skills (Winkelmann *et al.*, 2016).

Sufficient training time and diverse learning approaches can enhance nurses' professional competence. Hospitals in charge of air ambulance services are advised to establish a specialized team to provide regular training for flight nurses. This training program may involve physical fitness and adaptation exercises for flight operations. To improve adaptation skills, nurses can engage in simulations of basic tasks such as receiving assignment notification, boarding the aircraft, performing in-flight operations, and disembarking, or emergency scenarios like aircraft malfunctions. Additionally, the training should include diverse patient cases, allowing teams to enhance their problem-solving skills by dealing with scenarios involving patients with varying conditions. Establishing a continuous feedback mechanism can also allow nurses to voice their experiences, helping them to update their service knowledge and reflect on the challenges encountered in practice. In short, the regular training program should incorporate characteristics such as physical operations, situational simulations, case-based teaching, and professional exchanges to effectively address the challenges of air ambulance services.

The participants of this study were nurses undertaking air ambulance services who were stationed in Taiwan's eastern offshore islands. However, nurses from other island regions were excluded, thus the results are limited in terms of lack of transferability. Building upon the existing foundation, the researchers suggest for future research on improvement plans to be approached from four different aspects: 1) The adjustment of participant criteria to enrich the experience feedback from various offshore-island flight nurses; 2) Employing a focus group research method that allows multiple participants to provide richer and more diverse perspectives through discussion and communication; 3) The development of quantitative research derived from the current themes to investigate the influencing factors on the safety operations of air ambulance services; 4) The assessment of work stress status among air ambulance team members, followed by the development of a work stress scale tailored to air ambulance personnel. The research results could then be utilized to propose future intervention strategies.

Conclusion

The nature of air ambulance service is characterized by unpredictability, urgency, and high risk. To ensure successful patient rescues, relevant units must remain vigilant about potential challenges that may arise during transfers, starting from cabin space limitations and lighting conditions. It is essential to prioritize the carrying capacity of sufficient equipment and establish comprehensive protocols for operations and auditing procedures. Additionally, nurses should be aware that air ambulance duties may entail physical discomfort and professional challenges, necessitating the development of appropriate education and training mechanisms to enhance their adaptability to the work environment.

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Conflicts of interest

The authors declare no conflicts of interest.

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ORIGINAL ARTICLE

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The effectiveness of case-based concept map to improve pathophysiology knowledge and critical thinking among first-year nursing students: a quasi-experimental study

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ABSTRACT

Introduction: Improving pathophysiology knowledge and critical thinking skills of nursing students remains as a challenge faced by nursing educators. To improve those, an innovative learning method is required. Concept map by adding cases might assist increasing students' pathophysiology knowledge and critical thinking skills.

Methods: A quasi-experimental study with pre- and post-test with control group design involved 104 first-year nursing students of Universitas Jenderal Soedirman, Purwokerto, Central Java from April to June 2023. Participants were divided into two classes at the beginning of the first semester and randomly allocated into the intervention group (54 respondents) and the control group (50 respondents). The intervention group was provided typical learning added with a case-based concept map development weekly for 7 weeks, while the control group underwent regular lectures based on the syllabus. Pathophysiology knowledge was measured by using Multiple Choice Questions, while critical thinking was evaluated by using the Critical Thinking Disposition Inventory questionnaire. Independent-t test and paired test were applied to evaluate the effectiveness of implementing the case-based concept map.

Results: The mean score for knowledge the pathophysiology of the disease in the intervention group was significantly higher than the those in the control group (t =5.24, p = 0.000). However, there was no difference in the average scores of critical thinking between two groups discovered in the study (t =0.90, p = 0.37).

Conclusions: Case-based concept map can be recommended as an innovative and effective learning method for teaching disease pathophysiology to nursing students. However, the case-based concept map in this study is still not consistent in improving students' critical thinking skills.

Keywords: critical thinking, nursing education, nursing students, pathophysiology understanding

Introduction

A comprehensive understanding of pathophysiology is fundamental to the clinical nursing practice, whether pathophysiology material is taught in a separate course or integrated with other courses in the nursing curriculum. The pathophysiology is part of bioscience knowledge becoming progressively more crucial due to the disease complexity (Taylor *et al.*, 2015). It provides patients safe, comprehensive care and establishes credibility with other medical professionals and patients (Ashelford, Raynsford and Taylor, 2016). Pathophysiology of disease also assists students to perceive patients more as the most affected parties by the disease process and entitled to receive qualified

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care to improve quality of life from their illness (Cheng, Zhao and Guo, 2016).

Although mastering pathophysiology and its application in clinical practice is a predictor of success in nursing, this material is challenging and tough. New nurses and nursing students have to put in a lot of effort to learn it (Dunn, Osborne and Rakes, 2013; Van Horn *et al.*, 2014; El Hussein, Salyers and Osuji, 2016a). Nursing students discovered the pathophysiology course was quite terrifying (due to the extensive content, the degree of difficulty degree, and the lack of connectivity between biomedical concepts, nursing subjects and subsequent nursing clinical practice. Therefore, students do not recognise the importance of disease pathophysiology in the undergraduate learning process (Craft *et al.*, 2013).

Pathophysiology understanding relates to critical thinking skills. The high pathophysiology knowledge becomes a foundation to increase the critical thinking skills and clinical reasoning among nursing students in providing nursing care (Fonseca *et al.*, 2020). The ability to think critically allows students to recognise important information and discriminate between issues that are life-threatening and those that don't require immediate attention (Shirazi and Heidari, 2019). The critical thinking in disease pathophysiology is essential in determining how to organise patients' nursing care, to encounter complicated issues and make quick decisions in order to determine the needs of patients and implement optimal nursing practices and patient safety (Kaddoura, Van-Dyke and Yang, 2016; Ali-Abadi, Babamohamadi and Nobahar, 2020).The American Association of Colleges of Nursing (2021) also concurs that it is crucial for recent nursing graduates to exercise critical thinking when resolving issues in various clinical settings. However, several studies reported that nursing students acquired low critical thinking skills (Shirazi and Heidari, 2019; Nemati-Vakilabad *et al.*, 2023). Moreover, Azizi-Fini, Hajibagheri and Adib-Hajbaghery (2015) found poor critical thinking skills in both first-year and senior nursing students.

Meanwhile, as nursing educator, escalating nursing students' pathophysiology knowledge and critical thinking skills is a challenge. Taylor et al. (2015) recommended that, to improve comprehension, application and integration of pathophysiology knowledge, a greater variety of biosciences teaching and learning techniques should be included. Ninety per cent of students agreed that the relevance of nursing learning to patients' disease process supported with bioscientists' teaching approach that prioritises on student needs is able to contribute increase students' knowledge of patient conditions and students' confidence for caring for the patients (Christensen et al., 2015). Numerous active learning techniques, both individual and group, encouraging students and teachers to engage in problem analysis and discussion, and encouraging self-directed learning are several strategies that could be employed to enhance critical thinking among nursing students (Shirazi and Heidari, 2019). Therefore, innovative learning methods in pathophysiology and critical thinking require to be improved and added in nursing education.

Concept map is a creative learning method that is able to link the theory and clinical practice. This method was first originated by Novak and Gowin (1984). Concept maps connect concepts with linkages and nodes that provide explanations, displaying ideas in a hierarchical graphical structure (Machado and Carvalho, 2020). The effectiveness of concept mapping for improving student learning quality has been consistently shown, and it has been well-received in higher education. This teaching method is repeatedly proven to have positive and significant effect in critical thinking skills of nursing students (Lee *et al.*, 2013a; Kaddoura, Van-Dyke and Yang, 2016; Bilik, Kankaya and Deveci, 2020). Meanwhile, there has only been limited research on the application concept map on the pathophysiology knowledge of nursing students. Previous studies applied visual narrative illustrations (El Hussein, Salyers and Osuji, 2016b), blended learning (Blissitt, 2016), and team-based learning ((Branney and Priego-Hernández, 2018) in escalating pathophysiological knowledge among nursing students. In addition, the current study applies a modification in concept map by adding vignettes or cases as triggers for students to compile a concept map consisting of signs and symptoms of disease experienced by patients as well as physical examinations and supporting examinations carried out and their results. Therefore, this research was conducted with the aim of evaluating pathophysiology knowledge and critical thinking skills after applying the concept map with the case among nursing students.

Materials and Methods

Design

This research was a quasi-experimental study with a pre-test/post-test with a control group design.

Setting and Sample

This study was conducted from April to June 2023. All 110 first-year nursing students who had registered for the Nursing Biomedical Science course were recruited to the study. Because of the large number of the students, all respondents were divided at the beginning of the first semester into two 54 and 56-student group classes for the four-year education programme. Both classes were randomly allocated to either an intervention or a control group through coin flipping. This study included all active first-year nursing students (110 students). Meanwhile, students who declined to participate were excluded from this study.

Methods

The study spanned a period of seven weeks. The control and intervention groups attended different classes. All respondents in both groups remained in each class until the research was completed. In addition, different day schedules for the pre-test, post-test and interventions were arranged for both groups The pre-test was carried out in week 8 of course learning because the disease pathophysiology material began to be taught in the Basic Science in Nursing course from week 9. The intervention and the control group filled out questionnaires via the Google Form and worked on questions through the University's Learning Management system (ELDIRU) on different days. The intervention group and control group filled out questionnaires and quizzes on different days through the learning management system site and online forms. Then, the intervention group was provided with training on making concept maps using the Cmaptools software. Concept map creation was carried out by the intervention group every week with different topics, while the control group attended usual lectures based on the course syllabus. In week 15, both groups completed the post-test on different days through the ELDIRU website and Google Form.

Measurement and Data Collection

Respondents filled out a respondent characteristic questionnaire and a Critical Thinking questionnaire through the Google Form. The critical thinking skills questionnaire used in this study was the Chinese Version of the Critical Thinking Disposition Inventory (Huang and Yeh, 2017). This instrument consists of 20 questions with a Likert scale of 1-6 (1 = never, 6 = always), so the score range for this instrument was 20 - 120. This instrument consists of four domains, which are systematic and analytic ability (9 questions); open-mindedness (4 questions); curiosity (3 questions); and reflective thinking (4 questions). The score range of this instrument was 20 -120, where the higher the score obtained, the better the critical thinking ability. This instrument was culturally adapted and translated into the Indonesian language by the researchers. This instrument has also been tested for content validity by Pearson correlation with a score range of 0.426 – 0.762 and the value of the reliability test using Cronbach's alpha was 0.904, so this instrument was valid and reliable.

To evaluate the understanding of the pathophysiology of the respondent's disease, the researchers compiled a quiz consisting of 30 questions in a vignette form. Quiz questions were completed within 30 minutes through the Learning Management System. Topic questions according to the disease were prepared with a concept map. The questions were created from the textbook *Pathophysiology of Disease: An Introduction to Clinical Medicine* (Hammer and McPhee, 2018). The vignette questions were arranged in the form of multiple-choice questions by the collaboration between the research team and course coordinator focusing on clinical manifestations and studies in patients with the disease. The score range for this quiz was 0 – 100; the higher the score obtained, the higher the level of understanding of the pathophysiology of the disease that the respondent owned.

Intervention

The control group followed lectures under the syllabus of the Basic Science in Nursing course from weeks 9 to 15. The intervention group attended the lectures according to the syllabus with the addition of the Case-Based Concept Map, and the concept map application was carried out from week 9 to 15 of the Basic Science of Nursing course. The intervention group was previously given training on creating concept maps using Cmap tools software (IHMC Cmap Tools, Florida). The intervention group was divided into six small groups. Each week, these groups carried out discussions and practised constructing a case-based concept map according to the available cases, which were facilitated by the lecturers within 100 minutes per session. There were six topics of disease pathophysiology arranged in the case-based concept map creation, including the endocrine system (diabetes mellitus), the cardiorespiratory system (tuberculosis), the haematological system (anaemia), the urinary system (chronic kidney failure), the immunological system (HIV-AIDS), and digestive system (Hepatitis B). Then, the facilitator provided feedback and suggestions related to the concept map that had been prepared and presented by the intervention group at the end of the session. The posttest was conducted at the end (week 15) of the Basic Science in Nursing course. Both groups filled out questionnaires via the Google Form and took post-test quizzes through the university's Learning Management system on different days.

Data analysis

The analysis in this study applied SPSS version 23.0, IBM Corp, New York. Frequency, percentage, mean and standard deviation were used to analyse univariate data. The chi-square test and independent t-test were performed to analyse the homogeneity of the characteristics between the two groups. To determine the difference score of pathophysiology knowledge and critical thinking between the intervention and control group, the independent t-test also was used in this bivariate analysis, while a paired t-test was used to analyse differences in data before and after treatment within the groups. The significance level considered in this study was $p < 0.05$.

Ethical Consideration

This research has received ethical clearance with number 1026/EC/KEPK/II/2023 issued by the Health Research Ethics Commission of the Faculty of Health Sciences, Universitas Jenderal Soedirman. The researchers explained the research procedure and then allocated the Google Form link for informed consent approval, respondents' characteristics questionnaire, and critical thinking skill questionnaire during the pre-test and post-test. For the control group, after the post-test was carried out, the researcher provided training on how to make a case-based concept map using the Cmap tools application and provided other cases as independent exercises. After data collection, all respondents were given a research souvenir, which was a stationery set.

Results

This study involved 110 research respondents of which104 respondents completed the study and were analysed, consisting of 54 respondents in the concept map group and 50 respondents in the control group with a participation rate of 94.54%. Two respondents declined to be involved in the research, and four respondents were excluded from the analysis due to filling out incomplete questionnaires (See Figure 1).

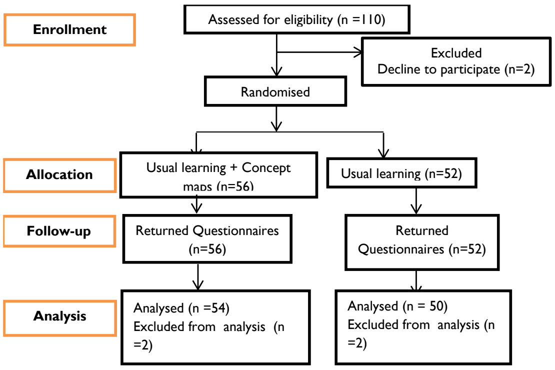

Figure 1. Participant Consort flow

Based on the respondents' characteristics, the majority of respondents were female students (85.58%), had a GPA of > 3.5 (75.97%), resided outside Banyumas (70.19%), had organisational experience (74.04 %), and had no experience in participating in student competitions at both the national/international level (88.46%). The intervention and control groups had similar characteristics (homogeneous), except for organisational experience. Respondents in the control group had more organisational experience compared to respondents in the intervention group ($t = 4.97$, $p = 0.026$). (See Table 1.)

The mean score of pathophysiology knowledge of the disease before intervention in the concept map group (49.57 ± 11.73) and the control group (47.80 ± 11.06) was not significantly different ($t = 0.79$, $p = 0.45$). Whereas, after the intervention, the mean score for the pathophysiology knowledge in the concept group was significantly higher than those in the

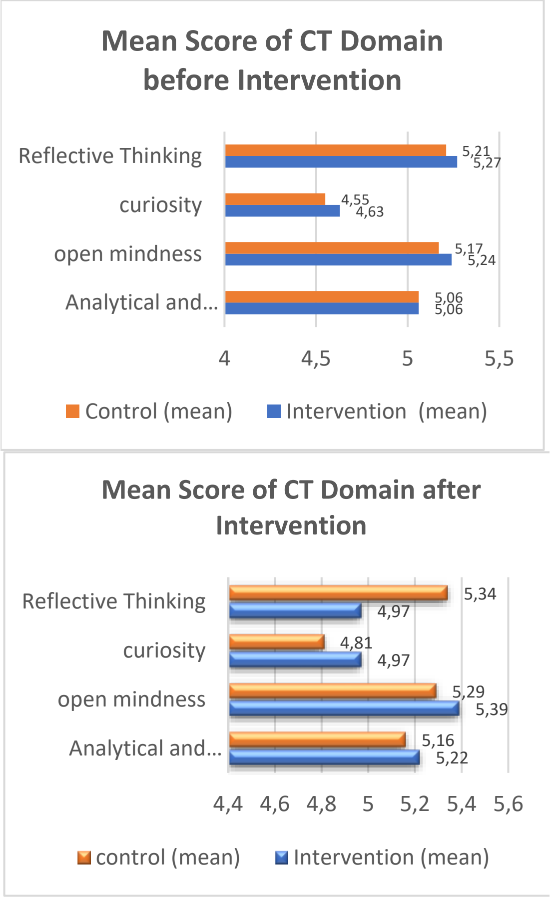

Figure. 2 Mean score of CT domains before and after intervention

Table 1. Demographic characteristics of research respondents (n=104)

Characteristics	Intervention (n=54)		Control (n=50)		Total	χ2/t	p
	mean ± SD	n (%)	Mean ± SD	n (%)	n (%)		
Age	18.67 ±0.67		18.68±0.621			0.12a	0.92
Gender							
Female		49 (47.12)		40 (38.46)	89 (85.58)	2.43b	0.12
Male		5 (4.81)		10 (9.61)	15 (14.42)		
Grade Point Average (GPA)							
3.51- 4.00		43(41.35)		36 (34.62)	79(75.97)	0.86b	0.65
≤ 3.50		11(10.57)		14 (13.46)	25(24.03)		
Origin							
Banyumas		15 (14.43)		16 (15.38)	31 (29.81)	0.22b	0.64
Outside Banyumas		39 (37.50)		34 (32.69)	73 (70.19)		
Organisational Experience						4.97b	0.026*
Yes		35(33.65)		42(40.39)	77(74.04)		
No		19(18.27)		8 (7.67)	27(25.96)		
Competition Experience						0.02b	0.89
Yes		6 (5.77)		6 (5.77)	12 (11.54)		
No		48 (46.15)		44 (42.31)	92 (88.46)		

SD = standard deviation, a = independent test, b = chi-square test, * = $p < 0.05$

control group (t =5,24, p = 0.000). Significant differences in knowledge scores before and after the intervention in the control group and the intervention group were also reported in this study (t = 9.05, p = 0.000) with a mean score difference of 14.58.

For critical thinking skill, before the intervention was conducted, the highest mean scores for critical thinking skills were in the domains of reflective thinking (5.24 ± 0.45) and open-mindedness (5.20 ± 0.40) (see Figure 2). The mean score of critical thinking skills in all domains before intervention in the intervention group was not significantly different (t= 0.85, p = 0.40). After the intervention, the highest score shifted to the domain of open-mindedness (5.34 ± 0.43), and there was no difference in critical thinking score in the two groups (t = 0.90, p = 0.37) (See Figure 2, Table 2). The results of the paired t-test showed a significant difference between the mean scores of critical thinking skills in nursing students before and after the intervention in both groups, except in the domain of reflective thinking ($p > 0.05$).

Discussions

Initial pathophysiology knowledge in the majority of nursing students was below average. Pathophysiology of disease, whether taught at the undergraduate or postgraduate level, is a subject that students and instructors fear and find most difficult (Craft *et al.*, 2013; McVicar, Andrew and Kemble, 2015; El Hussein, Salyers and Osuji, 2016b). This finding suggested that teaching pathophysiology was a challenge requiring innovative pedagogical teaching methods to assist lecturers and students (Colsch, Lehman and Tolcser, 2020). In this nursing department, disease pathophysiology was taught in the Basic Science of Nursing course in semester 2, which is a content-intensive subject, due to the combination of several disciplines including anatomy, physiology, microbiology, and anatomical pathology. In the second semester, nursing students still have minimal knowledge related to diseases and medical terms in nursing and health. This might contribute the minimal students' understanding related to the disease pathophysiology. Another possible cause was a change in nursing predominance from medical care to psychosocial aspects results in the bioscience reduction for nursing undergraduate programme. Taylor et al. (2015) reported that biosciences were taught for 20 –113 hours, mostly in the first year. This amounts to 0.24 to 2.4% of the 4600 hours that make up a preregistration nursing programme. It demonstrates that students continuously asked for additional time and emphasis on biosciences in their courses with various pedagogical teaching methods.

This study found that concept map was effective in increasing pathophysiology knowledge of nursing students. This was in line with previous studies (Saeidifard *et al.*, 2014; Kaddoura, Van-Dyke and Yang, 2016; Fonseca *et al.*, 2020). Case based concept map could be recommended as an effective learning method, especially for increasing understanding of challenging lessons or materials. Concept mapping is considered a valuable active teaching method because it encourages learners to make connections and build relationships between new concepts and previous schemata (Sadler, Stevens and Willingham, 2015). This learning methods provided more meaningful learning for the students. Meaningful learning was defined as the process of giving meaning to new knowledge by taking into account the personal

Table 2. Differences in Pathophysiological Knowledge and Critical Thinking Scores among the Intervention and Control Groups (n = 104)

Variable	**Before Intervention**		**After Intervention**		**Mean difference**	**t value**	**p****
	mean	**SD**	**Means**	**SD**			
Pathophysiology Knowledge Score							
Intervention Group	49.57	11.73	69.14	13.18		9.05	0.000
Control Group	47.80	11.06	57.00	10.11	14.58	4.67	0.000
t-value	0.79		5.24				
p*	0.45		0.00				
Domain 1: Systematic and Analytical Thinking							
Intervention Group	45.59	3.81	46.87	3.70	1.28	2.71	0.009
Control Group	45.02	4.64	46.40	4.29	1.38	2.34	**024**
t-value	0.69		0.60				
p*	0.53		0.55				
Domain 2: Open-mindedness							
Intervention Group							
Control Group	20.98	1.41	21.56	1.44	0.57	2.89	0.006
	20.68	1.79	21.18	2.02	0.50	2.06	0.045
t-value	0.95		1.09				
p*	0.34		0.27				
Domain 3: Curiosity							
Intervention Group	13.89	1.78	14.93	1.69	1.04	3.90	0.000
Control Group	13.66	1.91	14.42	1.86	0.76	3.19	0.002
t-value	0.63		1.45				
p*	0.49		0.15				
Domain 4: Reflective Thinking							
Intervention Group	21.09	1.74	21.46	1.99	0.37	1.72	**091**
Control Group	20.84	1.89	21.36	1.65	0.52	1.99	**052**
t-value	0.71		0.29				
p*	0.48		0.78				
CT Total Score							
Intervention Group	101.56	7.28	104.81	7.59	3.21	-4.10	0.000
Control Group	100.20	8.86	103.36	8.91		-3.17	0.003
t-value	0.85		0.90				
p*	0.40		0.37				

component in cognitive structures, as well as the assimilation of linkages connecting previous and current information formed in cognitive structures using an authentic and rational approach (Correia, Cicuto and Aguiar, 2014; de Sousa *et al.*, 2016). The meaningful learning was adapted from assimilating learning theory by Ausubel (1963) which is required to be arranged in a hierarchical manner according to how relevant they are to the topic at issue. This theory was agreed by creating the concept map (Suero López *et al.*, 2020)

The application of the concept map in this study uses the Cmaps tool software (Novak and Cañas, 2006). This software integrates technology, the internet and concept maps and permits users to modify text, files, photos, source links, and other items to add extra information to the concept map. These additional features lead the interactive and collaborative work among students (Cañas and Novak, 2014). It has an appealing graphical design and employs visual codes, which contributes to higher retention of material and understanding (Cañas, Reiska and Shvaikovsky, 2023). In addition, this application is appropriate in facilitating the high technology learning process for nursing students who are Generation Z. Future education for Generation Z is recommended to make close use of technology because it has proven effective in the learning process and experiences (Ziatdinov and Cilliers, 2021).

In addition, this study uses vignette cases to test students' understanding in the form of multiple-choice questions and cases to complete the construction of the concept map. Expertly designed vignettes linked with the phenomenon under investigation may assist in the capture of respondents' beliefs, resulting in a greater comprehension of the phenomenon (Leicher and Mulder, 2018). The vignettes in this study were created from case studies and then they were consulted with the bioscience experts to provide options for triggering patient information related to the clinical manifestations of the disease in cases. Students were required to construct the concept map according to signs, symptoms and physical examination and laboratory results. The vignette cases should allow for further questions related to doubts that arise during self-learning periods, and prove useful for promoting meaningful learning (Fonseca *et al.*, 2020).

In this study, researchers modified the concept map. Students created pathophysiology pathways with a concept map according to the available cases weekly; students had been given previous training on preparing the concept map. This modification aimed to bridge and connect pathophysiology with clinical practice, including clinical manifestations and patient outcomes in cases. Disease pathophysiology pathways accompanied by appropriate physical and supporting examinations were able to guide students in determining nursing diagnoses and interventions. The lecturers provided comments and feedback to students on concept maps that they had already constructed. Workshops and constructive feedback are essential in supporting the success of concept maps in teaching ((Harrison and Gibbons, 2013). Even though this learning method was successful, applying the concept map requires proper preparation, training for tutor lecturers, a training on creating concept map designs, and sustainable feedback for concept maps prepared by students to support its successful application.

This study found no significant difference in the improvement of critical thinking after the concept map application in intervention group compared to control group. This finding was in line with Lee et al. (2013) and Brune (2014). The high score of critical thinking of nursing students prior to intervention was a possible cause of this finding. Respondents in this study were second semester students who were still included in Generation Z, born between 1995 – 2010 (Bejtkovský, 2016). This generation has a tendency to focus on critical thinking in solving problems compared to memorising information, so that the learning process prefers concrete concepts compared to learning formulae (Gaidhani, Arora and Sharma, 2019). This is also supported by the nursing process and critical thinking courses which are also taught in the second semester at this Department of Nursing. This critical thinking ability becomes a student foundation to assist in formulating qualified and professional nursing care. Nursing students that can think critically are better able to handle complex data, plan and manage patients, and make sensible judgements (Kim and Lundberg, 2016; Berger *et al.*, 2021).

Additionally, due to the shorter application duration, low variations in critical thinking ability scores are also conceivable in both groups. Most studies reported that concept map needs to be applied within 15 – 20 weeks so as to foster critical thinking skills (Huang *et al.*, 2018; Wu and Wu, 2020). Moreover, Lee et al. (2012) reported significant differences in critical thinking skills after applying the concept map for four semesters, whereas this study was just carried out in seven weeks. This finding would suggest that developing critical thinking abilities through idea mapping takes more time and cannot be accomplished in a single semester. In order to derive conclusions from a concept map, students must first choose the key concepts and then arrange the linkages and hierarchical sequences between the key concepts and more specific concepts. This skill takes a long time to develop and cannot be achieved quickly (Lee et al., 2013)

During construction of the concept map, students worked in groups, so it was probable that not every student was actively involved in obtaining information and looking for connections between concepts, which could affect how reflectively they were able to think. Also, according to the syllabus, the control group also received other student-centred learning including case-based learning, cooperative learning, and group presentations in addition to traditional lectures. These teaching methods might assist nursing students to develop their critical thinking skills. Some studies demonstrated that case-based learning and other student-centred learning enhanced critical thinking abilities (Kong *et al.*, 2014; Zhang and Cui, 2018). Therefore, the intervention and control group have slightly different scores.

When determining the effectiveness of case-based concept map within the intervention group, the study has shown improving scores in all domains of critical thinking skills, with the exception of reflective thinking after applying a case-based concept map. Since concept maps made it easier for students to discover information, obtain and gather information from a variety of sources, and to explain the truth in the preparation of interrelationships between the drafted concepts, it therefore assisted students to be more open-minded (Yue *et al.*, 2017). In this study, students were given the chance to find and gather reliable sources connected to the disease in order to apply several pathophysiology-related ideas to the instances that were accessible, resulting in dense and varied materials to construct a concept map.

It has been demonstrated that concept maps enhanced analytical and methodical thinking. Students are required to manage the relationships between concepts that are linked both inductively and deductively, as well as to correlate general concepts with specific concepts or data that have been gathered from various references, which required analytical skills (Yue *et al.*, 2017). This increased demand for analytical skills as the result of these process. Concept maps also provided students the chance to comprehend and to assess the logical progression of every concept so that they could develop into systematic concepts. Students were able create a transition from a linear to a comprehensive and integrated cognitive process by connecting fundamental and clinical information using the concept map (Saeidifard *et al.*, 2014). In addition, the concept map was also able to increase student curiosity. For nursing students in this study, creating concept maps using the Cmaptools software was novel experiences. Students were encouraged by this novel experience to attempt creating a perfect concept map multiple times, which improved their interest in the process. Over time, students were able to relate the concept quickly and independently, thereby stimulating their curiosity to read more and investigate rather than relying on the instructions (Fawaz and Kavuran, 2021).

This study has some limitations that should be discussed. The shorter duration of concept map application in this study was unable to assist students' critical thinking skills. This was due to pathophysiology began to be taught after half of a semester on the Basic Science in Nursing course; most studies take one semester or more to foster critical thinking. Interventions that are delivered over a long period of time and have a gradual scaffolding of abilities are more likely to succeed in developing critical thinking. The process of selecting how to visually distribute the linkages and nodes (relationships and links between conceptual ideas) may necessitate extensive elaborative processing and longer time. Additionally, because the learning process in the control group was tailored to the syllabus, it used a variety of cooperative learning and case-based learning techniques in addition to traditional lectures to help the control group's critical thinking abilities. This could be the reason why there is no difference in the two groups' critical thinking abilities. The longer duration of concept map appears to be suitable in escalating critical thinking among nursing students.

Conclusion

This study informs that the application of case-based concept maps is effective in increasing understanding of the pathophysiology of the disease. However, the application of the case-based concept map in this study is still inconsistent in improving students' critical thinking skills. This method can be carried out for a longer duration so that it can better evaluate the improvement of students' critical thinking skills in future studies. This method allows it to be applied to other difficult and challenging nursing courses. By using this method, it is also possible to assess other things, such as clinical reasoning in students, particularly nursing students who will participate in clinical education, as a foundation for providing nursing care (assessment, data analysis, enforcement of nursing diagnoses, appropriate nursing care (assessment, data analysis, nursing diagnoses formulations, nursing intervention planning and implementation) while undergoing clinical education at the hospital.

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Conflict of interest

Authors declare no conflict of interest in this study.

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ORIGINAL ARTICLE

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Adherence to antiretroviral therapy, CD4 count, viral load and opportunistic infections in people with HIV/AIDS: a cross-sectional study

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ABSTRACT

Introduction: Globally, antiretroviral therapy (ART) has been successful in reducing the death rate due to human immunodeficiency virus (HIV). Different conditions in Indonesia mean the death rate due to HIV/AIDS is still high. The problem lies in the low compliance with ART. This study aimed to analyze the correlation between ART adherence with number of CD4, the opportunistic infection (OI) and viral load in PLHIV.

Methods: A quantitative survey with cross-sectional approach was conducted between August – September 2022. As many as 375 PLHIV were recruited and agreed to give consent as research respondents. All respondents completed a questionnaire about ART adherence, OI and had blood taken to check CD4 count and viral load. Analyses were performed using Chi-squared test SPSS version 21 with significance level p<0.05.

Results: A significant relationship was shown between ART adherence and OI (p value= 0.000 with <0.05). The respondents who reported adherence in ART also showed asymptomatic OI. The analysis also showed that ART adherence had significant relationship with CD4 count (p value= 0.000 with <0.05) and viral load (p value= 0.000 with <0.05), respectively. Respondents adherent to taking ART had better level of CD4 and suppressed viral load in the body.

Conclusions: Adherence of antiretroviral therapy is the important factor contributing to the immune status of PLHIV, which has an impact on reducing CD4 count and suppressing viral load, thereby preventing the emergence of OI.

Keywords: adherence, antiretroviral therapy, CD4, opportunistic infections, PLHIV, viral load

Introduction

Globally, antiretroviral therapy (ART) has been successful in reducing the death rate due to human immunodeficiency virus (HIV) by 48% (UNAIDS, 2017) and ART can effectively improve the immune status of people living with HIV/AIDS (PLHIV) with indicators of CD4 count, viral load and incidence of opportunistic infection (OI) (Wardhani and Yona, 2021). This condition is different from the situation in Indonesia, in contrast the death rate due to HIV/AIDS is still high. The problem lies in the low compliance with ART, which does not reach the national target from the Ministry of Health. Of the 96.69% of PLHIV who were recorded as receiving ART, unfortunately 22.89% experienced loss to follow-up on their therapy (Ministry of Health Republic of Indonesia, 2018). The low compliance of PLHIV is caused by low self-efficacy, hopelessness and perceived stigma (Andini, Yona and Waluyo, 2019; Nurfalah, Yona and Waluyo, 2019). The main impact that occurs in PLHIV leads to the increased number of CD4, preventing the

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OI and suppressing the viral load (Wardhani and Yona, 2021). The current phenomenon is that many PLHIV are absent from ART, causing them to have low immunity due to a decrease in CD4 counts, an increase in viral load and making it easy for PLHIV to get OI.

In 2021, 38.4 million people in the world were living with HIV with new cases reaching 1.5 million and 650,000 will have died from HIV complications due to non-adherence to ART (World Health Organization, 2021). By the end of 2022, in Indonesia, positive HIV cases had reached 543,100 people, around 393,538 people with HIV were aware of their condition, 160,249 people received therapy and only 14% reported that ART had reduced the number of viruses over the last six months (Ministry of Health of Republic Indonesia, 2021). This condition shows that ART compliance in Indonesia is still lacking. The low level of ART in Indonesia means that many PLHIV show low CD4 counts (< 350) and viral loads increase to ≥ 40 copies/ml, the impact of which is an increase in the number of OI (Sutini et al., 2022). The most common OIs found in patients were oral candidiasis (58.6%), pulmonary tuberculosis (41.4%) and pneumonia (41.4%). Other infections found were hepatitis C, toxoplasmosis, cytomegalovirus, chronic diarrhea, tuberculous meningitis, and cerebritis. So far, government programs have been concerned with breaking the chain of transmission by increasing early detection of HIV cases in endemic areas, high risk groups and screening during pregnancy. The Indonesian government is also increasing the provision and retention of ART, as well as chronic care and expanding access to CD4 and VL testing including early infant diagnosis (EID) (Asmarawati et al., 2018).

Several factors influence non-adherence to ART in PLHIV, such as low level of knowledge (Martiana, Waluyo and Yona, 2019), not caring about their health status (Sefah et al., 2022), low motivation (Shrestha, Altice and Copenhaver, 2019), tired of taking medication (UNAIDS, 2017), hopelessness and trauma with side effects from treatment (Nursalam et al., 2021). Another study found that non-adherence of ART is also influenced by peer support, family caregivers, health service providers (Nursalam et al., 2020) and stigma or discrimination that comes from the public (Shrestha, Altice and Copenhaver, 2019; Agnes and Songwathana, 2021). If ART compliance is allowed to be low, more PLHIV will experience loss to follow-up and cause their immunity to decrease based on indicators of CD4 number, the OI and viral load. Therefore, this study aimed was to analyze the correlation between ART adherence with number of CD4, the OI and viral load in PLHIV.

Materials and Methods

Study design and setting

A quantitative survey with cross-sectional approach was conducted in Dr. Soetomo General Hospital Surabaya, East Java, Indonesia. The study was conducted between August – September 2022 to evaluate ART adherence, CD4 count, viral load and the incidence of OI. This hospital was chosen as the research location because of its long experience in HIV/AIDS treatment, the large number of HIV experts conducting related research, and being one of the referral hospitals for ART therapy and HIV patients experiencing complications in Surabaya.

Participants

As many as 375 PLHIV were recruited and were willing to give consent as research respondents. Respondents were recruited directly by researchers with research assistants and assisted by doctors and nurses at the hospital to confirm data from PLHIV. Recruitment of respondents was carried out using a purposive sampling technique with criteria determined by the researcher as follows: 1) Having been diagnosed as HIV positive through three test methods (oncoprobe, intake and vikia) which were in accordance with the doctor's regulations; 2) Productive age, between 20 – 55 years; 3) Taking ART for at least six months; 4) Able to read and write well; 5) Able to communicate well with language; 6) Do not have mental illness; and 7) Do not have vision or hearing problems. Respondents who met the inclusion criteria were explained about the research procedures. After potential respondents agreed to participate in the research, they were asked to sign an informed consent form. All respondents agreed to sign the information form provided by the author and 100% of respondents filled out the questionnaire in accordance with the initial sample plan determined by the researcher. All respondents in this study were given souvenirs for their contribution.

Data Collection

Research data were collected based on the independent variable, namely adherence to antiretroviral therapy and the dependent variables were CD4 count, viral load and OI. All respondents who agreed to sign the informed consent to participate in this study were then asked to complete a questionnaire about ART adherence, OI and had blood taken to check CD4 count and viral load. They completed a questionnaire and had blood taken in a special room provided to maintain the privacy of PLHIV from other respondents. The questionnaire in this study includes socio-demographic characteristics which collect age, gender, marital status, ethnicity, religion, educational history, employment, and income (Nursalam et al., 2021). ART adherence was identified based on two measures, in the last one week and last three months. If they self-reported taking ≥ 95% of ART medication in a 7-day period, they were determined as adherent category, then if they missed ≥ 1 dose of ART medication within this time period this was determined as non-adherent category. The second measurements described if PLHIV were following an ART medication routine ≥ 95% , if this was for a 3-month period, it was indicated as adherent and if they missed ≥ 3 doses of ART medication within this time period it was determined as non-adherent (Murphy et al., 2004; Wasti et al., 2012). Respondents were identified about OI using HIV/AIDS staging criteria with the criteria for stage 1 asymptomatic, stage 2 mild asymptomatic, stage 3 moderate asymptomatic and stage 4 AIDS (Bhatti, Usman and Kandi, 2016). CD4 count and viral load were checked by taking venous blood samples; 5 ml of blood was taken and divided into two test tubes. The examination results if the CD4 count < 350 were categorized as poor and ≥ 350 categorized as good, while if the viral load was ≥ 40 copies/ml in the blood sample then the viral load was detectable, otherwise a viral load < 40 copies/ml indicates it was not detectable (Cassenote et al., 2018).

Data Analysis

Descriptive analysis was performed to provide an overview of socio-demographic characteristic data and specific variables of percentage of ART adherence, OI, CD4 count, and viral load. Chi-squared test was used to detect the correlation between ART adherence with OI, CD4 count, and viral load. The independent variable was coded as binary (1=adherent and 2=non-adherent), dependent variable also was coded as binary (1= poor and 2 = good for CD4 count; 1 = detected and 2 = not detected for viral load, respectively), OI was coded as ordinally (1 = asymptomatic, 2 = mild asymptomatic, 3 = moderate asymptomatic and 4 = AIDS). All analyses were performed using SPSS version 21 with significance level p<0.05.

Ethical Consideration

Ethics approval for this study was assessed and obtained from Dr. Soetomo General Hospital Surabaya with the approval number 070/0957/102.6.3.3/Litb/VII/2023. The researcher had first provided an explanation about research procedure to the research respondents and obtained informed consent by adhering to research ethical principles. Research data were processed by researchers and only data related to research were

Table 1. Demographic characteristics of the participants (N = 357)

Characteristics	Frequency	Percentage
Age		
20-25 years	28	7.5
26-35 years	140	37.5
36-45 years	134	35.7
46-55 years	73	19.5
Gender		
Male	196	52.3
Female	179	47.7
Education		
No school	7	1.9
Elementary School	43	11.5
Junior High School	78	20.8
Senior High School	209	55.7
University	38	10.1
Marital Status		
Single	116	30.9
Married	166	44.3
Divorced	79	21.1
Widowed	14	3.7
Tribes		
Java	332	88.5
Madurese	36	9.6
Dayak	2	0.5
Chinese	5	1.3
Religion		
Islam	349	93.1
Catholic	2	0.5
Christian	24	6.4
Work		
Self-employed	37	9.9
Private employees	150	40.0
Trader	27	7.2
Laborer	12	3.2
Housewife	123	32.8
Other	26	6.9
Income *		
≤ Minimum regional income	322	85.9
> Minimum regional income	53	14.1
Duration of ART		
1-5 years	358	95.5
6-10 years	6	1.6
>10 years	11	3.0
ART Adherence		
Adherent	248	66.1
Non-adherent	127	33.9
OI		
Stage 1 Asymptomatic	238	63.5
Stage 2 Mild asymptomatic	83	22.1
Stage 3 Moderately asymptomatic	52	13.9
Stage 4 AIDS	2	0.5
CD4 Count		
Less	185	49.3
Good	190	50.7
Viral Load		
Detected	101	26.9
Not detected	274	73.1

* Minimum Regional Income of Surabaya US$ 288 or IDR 4.375.479

Table 2. Correlation between ART adherence with OI, CD4, and viral load (n = 357)

Variable	Antiretroviral adherence				Total		OR	p
	Adherent		Non-adherent					
	n	%	n	%	n	%		
OI								
Stage I Asymptomatic	215	60.2	23	6.4	238	63.5	0.35	0.000*
Stage 2 Mild asymptomatic	23	6.4	60	16.8	83	22.1		
Stage 3 Moderately asymptomatic	10	2.8	42	11.8	52	13.9		
Stage 4 AIDS	0	0.0	2	0.6	2	0.5		
CD4 Count								
Less	61	17.1	124	34.7	185	49.3	0.29	0.000*
Good	187	52.4	3	0.8	190	50.7		
Viral Load								
Detected	0	0	101	28.3	101	26.9	0.44	0.000*
Not detected	248	69.5	26	7.3	274	73.1		

published. At the time of data collection, a respondent code was given to protect the confidentiality of the data and researchers did not force potential respondents, so that respondents participated in the research voluntarily.

Results

Table 1 shows the majority of respondents were aged between 26-35 years (37.5%), male (52.3%), senior high school degree (55.7%), married (44.3), Javanese by ethnicity (88.5%), Muslim (93.1%), private employee (40.0%), and income less than regional minimum (85.9%). Most of the respondents had been receiving ART for 1–5 years (95.5%) and the level of adherence just reached 66.1%. Of the 357 respondents, 238 (63.5%) reported being in stage 1 OI, namely asymptomatic, 190 (50.7%) had good category in CD4 count (>350) and 274 (73.1%) showed the viral load was not detected (< 40 copies/ml). Although the immunity level was good category, the level of less CD4 count was still high (49.3%) and viral load detected was 26.9%, it meant 22.1% of PLHIV had mild symptoms and 13.9% had moderate symptoms.

Table 2 shows the cross-tabulation and bivariate analysis between variables/ Based on cross-tabulation, PLHIV adherent category showed asymptomatic OI (60.2%), good CD4 count (52.4%) and not detected viral load (69.5%). A Chi-square test for the bivariate analysis demonstrated a significant relationship between ART adherence and OI (p value: 0.000, OR: 0.35). The respondents who reported adherent in ART also showed asymptomatic OI. The analysis also shows that ART adherence had a significant relationship with CD4 count (p value: 0.000, OR:2.9) and viral load (p value: 0.000, OR: 0.44), respectively. Respondents who were adherent to take ART had better level of CD4 and suppressed viral load in the body.

Discussions

The proportion age was slightly greater in 26-35 years, which is similar to a study from Bandung, Indonesia that reported the average age of PLHIV was in productive age (between 20-40 years) (Wardhani and Yona, 2021). Male patients were dominant in this study; this contrasts with study conducted in Lampung where HIV positive cases occurred in women (Irmayati, Yona and Waluyo, 2019). HIV is more dominant in males because of the potential for a high risk of HIV transmission, because males like heterogeneous sex, male with male relations, as well as job factors, injecting drugs and tattoos (Katz et al., 2018). Mostly, respondents had jobs as private employees and the salary was less than the minimum regional income, which is one of the factors that make patient compliance low. The cost of treatment for PLHIV is quite high, and even though ART in Indonesia receives a free program from the government, the need for medication and other immune-boosting supplements is also very large Which impacts on PLHIV compliance, because they need supplements and vitamins to increase their immune status so they don't easily fall into worse conditions (Sukartini, Nursalam and Arifin, 2021). Senior high school as moderate education level influences ART adherence because higher education determines the quality of respondents' knowledge, thereby increasing respondents' awareness. Adequate adherence contributes to the success of ART treatment and minimizes the prevalence of antiviral resistance during treatment. However, lack of knowledge makes respondents and caregivers not aware of this fact (Van Nguyen et al., 2021). The majority of respondents were Javanese and Muslims, both of which were related to the culture and religion adhered to by Indonesian society as a country with diversity; moreover, the cultural and religious values of Indonesian society encourage each partner to always be loyal to each other even in sick conditions (Gamarel and Golub, 2015; Eidhamar, 2018). Most of the respondents were married which makes a big contribution to the support system between partners of PLHIV; even though the partner has HIV in their body, the marital relationship makes them more accepting of each other (Wardhani and Yona, 2021).

This study revealed the level of adherence only reached 66.1%, although they had been receiving ART on average for 1–5 years. Many factors are related to the low adherence to ART among respondents, especially beginners and those who have been around for a long time, because ART will cause side effects that are considered by PLHIV to be excruciating when taken (Martiana, Waluyo and Yona, 2019) and when not taken it also causes more serious problems (Shi et al., 2022). PLHIV feel uncomfortable and reduce their coping, coupled with low support, stigma and discrimination from society. The level of lower CD4 count was still high and viral load was still detected according to the research results, affecting to low immunity status. ART as a means of suppressing the number of viruses means that PLHIV must consume every day; the existence of the treatment makes them have better health and live longer (Van Nguyen et al., 2021). Suppressing the number of viruses contributes to reducing the amount of the body's immunity that has to fight the virus, so that more of the body's immunity survives. The body's immunity that maintains this condition in PLHIV is CD4 (Shukla, Ramirez and D'Orso, 2020). ART compliance for PLHIV is key if you want to stay healthy and live longer, because one copy of the virus can produce tens of millions of new active viruses (Fauk et al., 2021).

The analysis showed that adherence to ART had a significant relationship with OI; the more PLHIV adhere to ART, the more minimal the incidence of OI will be, because their immune system is better. ART as a treatment for PLHIV does not function as a curative or curing disease, but rather the persistence of both residual viremia and long-lived cells carrying latent, intact proviruses (Hong and Mellors, 2015). Early taking on of ART makes PLHIV get life expectancy and quality of life close to normal persons (Walker and Hirsch, 2013). Non-adherent ART for a long time results in the patient's immunosuppressed condition which results in more frequent or more severe OI, and can be the cause of serious morbidity and even mortality (Duff, 2019). Preventing OI can be initiated by vaccination, such as meningococcal infection, pneumococcal infection, hepatitis A and B, influenza and varicella, but it is not the most effective solution (Cao et al., 2022). Other major OI requires prophylactic antibiotics or antiviral medications (Sangeda et al., 2018), so it is very important for them to increase ART. The adherence to taking ART had a significant correlation with CD4 count and viral load among PLHIV; the more they adhere to treatment, the more CD4 counts increase and viral load can be suppressed. Proper adherence to ART is sufficient to suppress viral load in plasma and it makes viral load not achieved ongoing viral replication and prevents progressive depletion of CD4 through direct and indirect roles (Sempa et al., 2020).

Our study has some limitations that need to be addressed. Our results were focused to patients from one hospital in Surabaya. Furthermore, due to the methodology design, it may not be generalized to all PLHIV in Indonesia. Future research needs to add sample size or conduct research nationally so it can find some heterogeneous characteristics of respondents and type of ART adherence.

Conclusion

Adherence of antiretroviral therapy is the important factor contributing to the immune status of PLHIV, which has an impact on reducing CD4 count and suppressing viral load, thereby preventing the emergence of OI. The correlation between ART adherence has statistical significance to CD4 count, viral load and OI. Furthermore, it can be implied in the hospital that improving the immunity level of the PLHIV should focus on improving the quality of ART adherence in PLHIV. Future research that focuses on HIV/AIDS ART adherence research is expected to examine the impact of ART adherence on other PLHIV outcomes. Research can also be carried out that focuses on therapy to increase ART adherence for PLHIV, because ART for PLHIV is very important and should not be missed altogether.

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Conflict of interest

The researcher declares that in preparing and carrying out the research there was no conflict of interest with any party.

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ORIGINAL ARTICLE

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A blended learning using contextual teaching learning: strengthening nursing students' procedural knowledge and interprofessional collaboration

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ABSTRACT

Introduction: The level of knowledge about the types of teaching instruction through blended learning in nursing education is still lacking. This study aims to develop blended learning using contextual learning and evaluate its effect on procedural knowledge and interprofessional collaboration.

Methods: A quasi-experimental study was conducted from January to March 2022. The total participants were 96 students from one of the nursing departments in Indonesia, who were equally divided into experimental and control groups. The experimental group received a blended learning method with a combination of contextual learning for 400 minutes for four meetings. Meanwhile, 48 students in the control group received traditional blended learning. Mann-Whitney U test to compare between treatment and control groups. The instrument used to measure the interprofessional education variable was the Nurse–Physician Collaboration Scale and procedural knowledge was measured through a test of 25 multiple choice questions about procedural knowledge.

Results: The implementation of blended learning based on contextual teaching significantly increased their procedural knowledge (pre M = 43.30 vs post M = 79.00), and interprofessional collaboration (pre M = 58.08 vs post M = 83.79) with p-value < 0.01.

Conclusions: Blended learning using contextual learning was effective for increasing procedural knowledge and interprofessional collaboration in nursing students. The application of this instruction is highly recommended for nursing departments in higher education institutions as an effort to achieve qualified health workers for sustainable development and well-being.

Keywords: blended learning, contextual teaching-learning, interprofessional collaboration, procedural knowledge

Introduction

The Covid-19 pandemic has created lessons for nursing education to develop a flexible learning process for students, which can substitute online learning for face-to-face learning in class. During Covid-19, face-to-face learning in class is limited to reduce the risk of transmission, so blended learning is needed (Rohendi *et al.*, 2020)

Smartphones have recently received tremendous attention for use in learning and they are evidently convenient and effective for educators and students in the nursing education field (Langford *et al.*, 2015, Liao *et al.*, 2015, Curran and Standage, 2017, Willemse *et al.*, 2019, Plotzky *et al.*, 2021). Existing scholarship has demonstrated that the use of smartphones benefits improving the learning process, especially during the Covid-19 pandemic (Banskota *et al.*, 2020, Huckins *et al.*,

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2020, Olum *et al.*, 2020, Yu *et al.*, 2021). Accordingly, researchers, particularly in nursing education, are actively developing new learning methods which are more effective and utilize technology, such as smartphones, in a contextual way: like the real context in clinical services (hospitals or other health centers) (Barbosa *et al.*, 2021, Ngenzi *et al.*, 2021). In line with developments in the use of information technology in learning, as well as dealing with learning problems during the Covid-19 case and in anticipating similar cases in the future, blended learning is needed (Rohendi *et al.*, 2020). The aim of this research is to develop an effective learning method for nursing students, as an effort to improve the professionalism of nurses through increasing knowledge and skills. This effort is more critical, especially in difficult times, such as during the Covid-19 situation.

Nowadays, one of the learning problems in Indonesia's nursing education is the low level of procedural knowledge of nursing students and interprofessional collaboration skills (Uliyah *et al.*, 2020). A recent study showed that collaboration between nurses and doctors at one hospital was poor (66.8%), and most of them were still at the negotiation level (Uliyah *et al.*, 2019). This is reinforced in previous research which illustrates that the nurse-doctor relationship has not been collegially established. The hierarchical interaction pattern between nurses and doctors is still visible in terms of disciplines (Arya *et al.*, 2010, Setiawan, 2013, Sinubu *et al.*, 2021). This collaboration problem is not only experienced by nurses in Indonesia but also in other countries. Two examples come from Turkey and China. Existing research finds that collaboration between nurses in Turkey is still minimal in terms of problem-solving, coordination, professionalism, and cooperation (Durmuş *et al.*, 2018), while, in China, the level of collaboration is lacking in terms of effective communication, perceived respect, and willingness to collaborate (Wang *et al.*, 2018).

Learning processes and methods in nursing education that do not apply collaborative and contextual learning principles by utilizing information technology can result in students not properly understanding collaboration skills and knowledge procedures when practicing in hospitals. The stronger this is evident when students come to practice in hospitals, it shows that interprofessional collaboration from nurses has not been so grounded. One way to develop it is through collaborative learning called "interprofessional education"; this approach can improve interprofessional competence, increase student roles and responsibilities, and increase student confidence and skills (Wagner *et al.*, 2011, Cunningham *et al.*, 2018). Smartphones are considered to provide enormous benefits in the field of nursing education, namely the ease of accessing e-learning. The use of e-learning technology makes learning more interesting and flexible so that the efficiency and effectiveness of learning are assessed (Zhampeissova *et al.*, 2020, Franco *et al.*, 2021). Face-to-face learning is also able to deepen their nursing skills; however, the digital era requires nursing students to master their knowledge and skills comprehensively from both sources: e-learning and face-to-face learning (O'Connor and Andrews, 2018). This shows how blended learning is very important to be applied in the field of nursing education.

Research shows that mixed learning instruction in nursing education is effective in enhancing new learning experiences (McCutcheon *et al.*, 2015, Jowsey *et al.*, 2020, Leidl *et al.*, 2020). However, the types of instruction that are useful for addressing the problems of procedural knowledge and interprofessional collaboration skills have not been revealed. A learning model that is appropriate for the learning objectives in each topic determines learning outcomes, including the achievement of procedural knowledge abilities and interprofessional collaboration. The models that currently exist are only blended learning, and contextual learning independently, not integrated, but with a combined model between blended learning and contextual learning. Each model will cover the other's weaknesses. Constructivism theory states that learning is building knowledge through real experience in the field, meaning students will easily understand and know what they are learning when their knowledge is based on real conditions that exist in the field. Elaborating on this theory, students will easily understand aspects of procedural knowledge interprofessional care and collaboration if they learn and knows directly the context of care services in clinics and hospitals.

Therefore, this study aims to develop mixed instructional instruction using a contextual teaching approach and examine its effect on students' interprofessional collaboration and procedural knowledge. The basic nursing course was chosen because this topic involves basic nursing skills and interprofessional cooperation in the health sector.

Materials and Methods

Research design and samples

A quasi-experimental design with pre-post was used in this study. Participants were separated into control and experimental groups and the same lecturer taught both groups to eliminate bias factors. The lecturer in charge had 10 years of teaching experience with a focus on basic nursing research. Lecturers are responsible for organizing teaching content and implementing current experiments. To ensure the accuracy of the current experiment, the participants were not aware of the existence of the experimental and control groups. The experimental group with blended learning used contextual teaching learning and the control group only used blended learning. The research sample was selected using simple random sampling, with the inclusion criteria being that students were enrolled in an active semester and were taking basic nursing courses in the nursing study program at Muhammadiyah University, Surabaya.

Intervention

Before the learning activities, students were given 100 minutes of basic nursing lessons. Students took part in learning using a blended learning system, with four meetings, each meeting held for 100 minutes. The first meeting conducted offline learning (face-to-face in class using contextual learning methods) while the second g was held for 100 minutes online using an e-learning system with contextual learning methods. The third meeting was conducted offline (face-to-face) with the contextual learning method and the fourth was conducted online using e-learning with contextual learning methods. All groups were pretested for 15 minutes to determine the level of procedural knowledge at the beginning of learning. At the end of instruction, a post-test was conducted on the level of procedural knowledge and measured interprofessional collaboration skills in both the experimental and control groups.

The control group involved students who received blended learning, but not with a contextual approach and comprised 48 students who were members of class B in the nursing study program, Muhammadiyah University, Surabaya. To minimize bias, strict grouping was not recommended nor was it recommended to discuss the material taught in the two groups, as well as performing statistical tests on other factors that might influence the results on procedural knowledge and interprofessional collaboration variables.

The two groups received the same material, but different learning methods. The topic discussed was fluid and electrolyte needs in basic nursing courses. Explanation of the topics was given at each meeting. The first meeting was the topic of systems that play a role in fluid and electrolyte needs, how body fluids move, human body fluid needs, regulation of body fluid volume. The second meeting was on the topic of types of fluids, problems with fluid needs, electrolyte needs, electrolyte regulation, types of electrolyte fluids, problems/disorders with electrolyte needs, acid-base balance, types of acid-base, acid-base balance problems, and all factors that influence fluid and electrolyte needs. The third meeting was the topic of nursing action procedures to fulfill fluid and electrolyte needs, the practice of measuring blood pressure, the practice of measuring pulse, the practice of rumple lead test, practice of giving oral fluids, the practice of collecting urine for examination material, the practice of collecting urine from patients using catheters, and the practice of inserting a catheter condom. The fourth meeting was on the topic of the practice of giving oral fluids, the practice of administering fluids intravenously, the practice of caring for IV wounds, and the practice of changing IV fluids. The selection of material for learning trials is related to the interprofessional collaboration variable because this material entailed many nursing procedures that require collaboration and nursing problems in this material are almost always experienced by patients admitted to hospital.

Participants

The participants were first year students who received basic nursing courses at the Bachelor of Nursing Program in one of the universities in Indonesia and who had never studied basic nursing before. As many as 96 participants were recruited and randomly assigned to either the experimental group (*n* = 48) or the control group (*n* = 48).

Measures

Procedural Knowledge

Procedural knowledge was measured by a test of 25 multiple choice questions about procedural knowledge, which consisted of three indicators; knowledge of techniques/procedures for meeting basic nursing needs, knowledge of skills related to basic human needs, and knowledge of when to use nursing procedures. Internal consistency of procedural knowledge (Cronbach's alpha 0.86 for the pre-test measure and 0.85 for the post-test measure).

Interprofessional Collaboration

The interprofessional collaboration questionnaire was adapted from two sources. The first was the collaboration measurement scale of doctors and nurses entitled *Nurse–Physician Collaboration Scale*. The scale measured three components: joint participation in the

Table 1 Participants' characteristics (n = 96).

Variable	**Group** **Blended Learning Using Contextual Teaching Learning (experiment group) n=48** **(n,% or sd)**	**Blended Learning (control group) n=48** **(n,% or sd)**	**Test of group differences***
Gender			p=0.402
Male	16 (33.3)	20 (41.7)	
Female	32 (66.7)	28 (58.3)	
Age (mean, SD)	19.17 (+0.964)	19.10 (0.660)	p=0.652

*Mann-Whitney U Test

treatment/care decision-making process, sharing of information, and collaboration (Ushiro, 2009, Hossny and Sabra, 2021). The second was a scale for managing collaboration between nurses called the Nurse-Nurse Collaboration Scale (NNCS). This scale measured collaboration in various ways, conflict management, common goals, communication and coordination, professionalism and autonomy (Liao *et al.*, 2015). Thus, the questionnaire of interprofessional collaboration used in this study consisted of five indicators: joint participation, information sharing, cooperation, scope of practice and common goals. Furthermore, a 5-point Likert scale was used ranging from 1 (strongly disagree) to 5 (strongly agree). Internal consistency of interprofessional collaboration was confirmed with Cronbach's alpha of 0.79 for the pre-test measure and 0.83 for the post-test measure.

Data Analysis

The first data analysis used was descriptive statistics. Pearson correlation was also carried out to examine the relationship between the study variables. The Kolmogorov–Smirnov test was performed to verify the normality of the data and showed that they were not normal. Hence, the Mann-Whitney test was performed to analyze possible differences between groups before the intervention. The second data analysis was the main analysis and was conducted to investigate the effect of the intervention in two ways. First, to verify intra-group differences between pre-test and post-test data collection, the Wilcoxon test was performed on each group. Furthermore, a new Mann–Whitney test was performed to analyze the in-group differences between the two groups after the intervention. SPSS 24.0 program software was used to process the data.

Ethical Consideration

This research received the Ethical Clearance Certificate No. 003570920 from Universitas Muhammadiyah Surabaya. This study has obtained signed consent from participants with informed consent. Participants were given information about the objectives, benefits, advantages, methods, and procedures to be carried out while being research respondents. In addition, participation was voluntary and posed no physical or mental harm. Researchers gave participants the freedom to leave if they wished and assured and the information provided would be kept confidential.

Results

Table 1 shows descriptive statistics. In the two groups, the largest gender was female, for the group that received the blended learning intervention using contextual teaching learning it was 66.7%, and for the control group it was 58.3%' based on different tests there was no difference between the groups. There was also no significant difference in age between the two groups; the age of the experimental group was 19.17 years and the control group was 19.10 years.

There was no difference before the intervention of the two study groups, as shown in Table 2. This can be seen in the calculated Z value for the two variables and the two groups have the same calculated Z value between + Z table (1.96). This shows that there was no difference before the intervention, as well as the test results. P > 0.05 for the two variables.

As shown in Table 3, significant differences were found between the groups before the intervention. There was no difference after intervention in the control group for the two variables; this can be seen with a value

Table 2 Differences between Groups before the Intervention

	Control Groups (*n* = 48) ***M* (*SD*)**	**Experimental Groups (*n* = 48)** ***M* (*SD*)**	***Z****	***p***
Procedural Knowledge	41.20 (15.95)	43.30 (15.27)	-0.746	.455
Interprofessional Collaboration	57.41 (6.68)	58.08 (7.15)	-0.554	.580

*-z table < z count < + z table (no difference), z table=1.96

Table 3 Comparison of Effects of Intervention

		Control Groups (*n* = 48)			Experimental Groups (*n* = 48)		
		M (SD)	***Z***	***p***	***M (SD)***	***Z***	***p***
Procedural Knowledge	Pre	41.20 (15.95)	-0.225	.822	43.30 (15.27)	-5,941	.001
	Post	41.37 (18.87)			79.00 (16.55)		
Interprofessional Collaboration	Pre	57.41 (6.68)	-0.203	.839	58.08 (7.15)	-6.033	.001
	Post	57.60 (9.46)			83.79 (6.60)		

of p=0.822 for the variable procedural knowledge, and p=0.839 for the variable interprofessional collaboration, but there was a difference in the experimental group with a value of p=0.001. The experimental group showed higher scores than the control group in the procedural knowledge and interprofessional collaboration variables.

Table 4 shows the effect of the intervention. In the experimental group, a significant difference was found between before and after the intervention of blended learning with contextual teaching learning on nursing students' procedural knowledge and interprofessional collaboration. This is shown in the p value = 0.001 for the two variables. In two variables, the score after the intervention was higher than before intervention.

Discussions

This study examines the effect of blended learning instruction using contextual teaching learning on nursing students' procedural knowledge and interprofessional collaboration. It was found that the nursing students experienced higher increase of procedural knowledge in blended learning instruction using contextual teaching learning than the traditional/general blended learning. This finding shows that blended learning with contextual teaching learning can be an avenue to build or construct nursing students' existing knowledge, such as knowledge on how to do nursing care, practice nursing care, and so forth (Pereira *et al.*, 2014, Rohendi *et al.*, 2020, Rohmah *et al.*, 2023).

In the study, there were no differences between the two groups before the intervention, but after the intervention there were differences between the two groups in two variables, namely procedural knowledge and interprofessional collaboration. In the procedural knowledge variable, there was an increase in skills in indicators of observational, therapeutic, educational and collaborative care activities, including assessment of skills at the primary intervention and supportive intervention levels. In the interprofessional education variable, there was also an increase in rates of 1) collaborative participation, e.g. exchange of opinions to solve patient/care problems; 2) exchange of information, e.g. exchange of ideas for further patient care and opinions and suggestions from doctors; 3) collaboration, e.g. mutual support with professional tasks and qualifications, sharing of tasks with representatives of other professional groups; 4) fulfillment of tasks according to the area of activity, e.g. knowledge of the patient's health status; and 5) joint achievement of goals, such as patient-centered guidance and negotiation of treatment goals.

This finding extends the existing related studies which only inform that blended learning instruction in the nursing education field gives nursing students new experiences in learning: such as the learning becoming more flexible, fun, and appropriate for the students (McCutcheon *et al.*, 2015, Jowsey *et al.*, 2020, Leidl *et al.*, 2020).

Procedural knowledge is defined as the ability to understand a series of steps that will be carried out properly and correctly (Evi-Colombo *et al.*, 2023);the knowledge of someone on how to do something. This knowledge is not only exerted verbally but also in behaviors such as acting and practicing the skills. Procedural knowledge is also associated with understanding, flexibility, and critical judgment. Individuals with low procedural knowledge can only use standard techniques, which may lead to a low ability to produce efficient solutions and possibly the inability to solve new questions. However, more flexible problem solvers (individuals) with deep procedural knowledge, who use techniques other than those that are usually practiced will find the best matching solution for different conditions and purposes. In terms of knowledge, it is also recognized that conceptual knowledge has a strong impact on procedural knowledge (Braithwaite and Sprague, 2021).

Table 4 Differences between Groups after the Intervention

	Control Groups (*n* = 48) *M (SD)*	Experimental Groups (*n* = 48) *M (SD)*	*Z*	*p*
Procedural Knowledge	41.37 (18.87)	79.00 (16.55)	-7.080	.001
Interprofessional Collaboration	57.60 (09.46)	83.79 (06.60)	-8.187	.001

The possible reason for the increase in the students' procedural knowledge is that blended learning using contextual teaching learning provides space and learning stimuli in the aspect of constructing knowledge by synergizing the existing context to strengthen the existing procedural knowledge of the students. This finding are similar with a recent study which found that blended learning based on contextual teaching-learning that uses appropriate approaches, strategies and methods for thinking needs to gain procedural knowledge is possible to occur considering the learning activities in both face-to-face and online are conducted with the same principles (Uliyah *et al.*, 2019, Uliyah *et al.*, 2020).

Activities in blended learning using contextual teaching-learning that have been prepared through lesson plans, teaching materials/books, as well as existing e-learning, with time flexibility can be the sources of building students' strong knowledge. It is because they can be done repeatedly to achieve learning competencies. Accordingly, the students can improve their thinking skills to gain new knowledge, ultimately procedural knowledge. This is in line with the notions that procedural thinking patterns are trained through the features available in e-learning so as to familiarize students with procedural thinking, including the content of nursing case study material whose completion is trained to follow the steps in solving nursing problems (Uliyah *et al.*, 2019, Chen, 2021). Moreover, feedback from students during the implementation of blended learning using contextual teaching learning may facilitate the students' increased nursing students' procedural knowledge.

Regarding interprofessional collaboration skills, the results indicate the effect of increasing collaboration interprofessional abilities of nursing students who experienced blended learning instruction with contextual teaching-learning. This result extends the existing previous scholarship, which again simply informs that blended learning instruction in the nursing education field gives nursing students new experiences in learning: such as the learning becoming more flexible, fun, and appropriate for the students (McCutcheon *et al.*, 2015, Jowsey *et al.*, 2020, Leidl *et al.*, 2020). Our result shows evidence that blended learning based on contextual teaching learning with existing learning characteristics meets the principles of increasing interprofessional collaboration. Interprofessional collaboration is defined as a form of cooperative relationship, open communication to share, and decision-making processes with the aim of maximizing the fulfillment of healthcare needs. It is also defined as a positive partnership between a team of healthcare professionals through a participatory, multi-disciplinary collaborative and coordinated approach to joint decision-making around health issues (Orchard *et al.*, 2005, Dahri *et al.*, 2021). This collaboration is formed from nine elements, including cooperation, assertiveness, responsibility, communication, autonomy, coordination, common goals, mutual respect and trust (San Martín-Rodríguez *et al.*, 2005, Dahri *et al.*, 2021).

Nursing students' interprofessional collaboration skills can be trained and grown during the students' professional lives in nursing education through blended learning instruction with contextual teaching-learning. This model has an influence on growing and training students' interprofessional collaboration skills. It can be seen from various learning activities which involve an element of collaborative learning. For example, various case study task activities in the context of nursing/clinical services are carried out in small groups. This can foster students' motivation, cooperation, responsibility, and mutual learning in each member of the group. It can also foster students' positive attitudes. as well as facilitate students' practice of mutual respect for diversity and understanding of individual differences. Collaborative learning activities with the completion of case studies conducted in groups with different backgrounds both in terms of culture, level of knowledge, gender, and personality, means that students learn from collaboration, which in turn increase students' interprofessional collaboration skills (Uliyah *et al.*, 2019, Uliyah *et al.*, 2020).

The existence of collaborative learning elements in blended learning instruction using contextual teaching learning can train the attitudes and basics of collaboration skills. It can also affect students' learning outcomes considering collaborative learning highlights more on specific tasks and sharing tasks in group work, comparing between groups and group procedures, and providing flexibility to students in groups (Apriyono, 2013). In addition, students giving feedback to one another may also be able to provide space for students to build awareness, positive attitude, responsibility, and cooperation which are the basis of interprofessional collaboration. Through case study discussions, interprofessional collaboration is also possible to happen because students learn from each other and exchange ideas, which can build collaborations. Blended learning instruction using contextual teaching-learning will provide opportunities to build interprofessional collaboration skills in the future.

Conclusion

It was found that the nursing students experienced a higher increase in procedural knowledge and interprofessional collaboration in blended learning instruction using contextual teaching learning than traditional/general blended learning. This finding shows that blended learning with contextual teaching learning can be an avenue to build nursing students' procedural knowledge and interprofessional collaboration. These findings are novel and extend the existing previous scholarship which merely informs us that blended learning instruction in the nursing education field gives nursing students new experiences in learning: such as the learning becoming more flexible, fun, and appropriate for the students.

This study has successfully addressed the gap of knowledge as mentioned in the introduction; however, in many respects, this study still has limitations. First, the blended-learning instruction using contextual teaching learning was implemented in one course in a short period of time, not a whole semester. Subsequent studies extending the time to one full semester and applying to other courses in nursing departments are welcomed. Second, the confounding variables may explain the effect of the instructions on students' procedural knowledge and interprofessional collaboration such as learning environment and the duration of intervention. Further research may examine these confounding variables.

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ORIGINAL ARTICLE

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Good health literacy leads to better quality of life and medication adherence among hemodialysis patients

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ABSTRACT

Introduction: In managing their conditions and achieving positive health outcomes, individuals with chronic kidney disease rely on health literacy (HL) as a crucial concept. Sufficient health literacy enables patients to maintain good medication adherence and experience an enhanced quality of life. The research aimed to investigate the correlation between health literacy levels, medication adherence, and quality of life among hemodialysis patients with chronic kidney disease.

Methods: The research employed a cross-sectional design. A random sample of 164 hemodialysis patients from two hemodialysis facilities in Padang, Indonesia, was collected between May and June 2023. Inclusion criteria were patients undergoing hemodialysis twice a week and aged over 18 years. Patients who experienced a decrease in consciousness and memory disorders such as dementia were excluded from this study. The questionnaires used to measure variables in this study were the demographic data questionnaire, the HLS-EU-Q16 health literacy questionnaire, the MMAS-8 medication adherence questionnaire, and the KDQOL-36 quality of life questionnaire for chronic kidney disease patients.

Results: The statistical analysis demonstrated a significant relationship between health literacy, quality of life, and medication adherence (p-value < 0.05). The high health literacy group (N = 73) exhibited a markedly superior quality of life compared to those in the mid-level (N = 48) and low-level (N = 43) health literacy groups. Multiple regression analysis revealed that, of the three components of health literacy, health promotion has the greatest influence on patients' quality of life, contributing 25.1%, while the aspect of healthcare has the greatest influence on medication adherence, contributing 43.3%.

Conclusions: Health literacy is essential in improving medication adherence and the patient's quality of life in a more optimal direction. Healthcare professionals should create plans for tailored and customized health information with the goal of providing patients with the knowledge about critical components they need to manage chronic kidney disease.

Keywords: adherence, CKD, health literacy, quality of life

Introduction

Chronic Kidney Disease (CKD) is a term that medical personnel use to describe damage to the kidneys that lasts more than three months and is progressive. A Glomerular Filtration Rate (GFR) of less than 60 ml/min/1.73 m^2 has implications for a person's health condition (Thomas, 2019). Patients with a GFR of less than 60 mL/min/1.73 m2 begin to experience sleep disorders, weakness, nausea, decreased appetite, and weight loss (Black & Hawks, 2009). This condition is due to the accumulation of toxic waste in the blood,

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especially urea (Black & Hawks, 2009). Chronic Kidney Disease (CKD) is a rapidly increasing global health and healthcare burden. Although Indonesia has the lowest prevalence, with 117–540 per million population (pmp) from worldwide statistics (Thurlow et al., 2021), likely due to under-diagnosis, the number of patients undergoing haemodialysis in Indonesia increases every year. In 2018, over 132,000 patients received haemodialysis (Indonesian Renal Registry, 2018).

Hemodialysis is the most commonly used renal replacement therapy modality for CKD patients in Indonesia. The number of patients undergoing routine hemodialysis increased from 2017 to 2018, reaching 132,142 patients in 2018 (Indonesian Renal Registry, 2018). Effective chronic kidney disease management requires medication adherence, with the primary treatment objectives being to delay the course of the disease, monitor and ameliorate disease-related consequences, and treat the underlying etiology (Nielsen et al., 2018). Based on several previous studies, high adherence to medication among chronic kidney disease patients needs to be increased (Karuniawati & Supadmi, 2016; Ozen et al., 2019; Wulandari et al., 2020). Non-compliance with medication in patients results in them not fully benefiting from the prescribed drugs. Medication non-compliance in patients with chronic kidney disease is also associated with an increased risk of premature death and hospitalization. Therefore, medication adherence is critical to effective management in patients with chronic kidney disease (Nagasawa et al., 2018). Previous research conducted by Ozen et al. (2019) on hemodialysis patients in Turkey found a 79.9% non-adherence in medication. According to Browne and Merighi (2010), several factors can influence medication adherence in hemodialysis patients, such as socioeconomic, pill burden, and demographic status, psychosocial factors, health literacy, patient satisfaction, and health beliefs. Health literacy is crucial because low literacy has been associated with worse health outcomes, including increased use of emergency services, hospitalization, and causes of death. In patients with chronic kidney disease, low health literacy has been linked to lower knowledge of kidney disease and higher mortality (Galura & Pai, 2017).

A person's health conditions, quality of life, and medication compliance are all impacted by their level of health literacy (Zheng et al., 2018). Health literacy is "The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions." This definition emphasizes the ability to not only acquire and comprehend health information but also to effectively communicate and apply that information in decision-making(Berkman, Davis and McCormack, 2010). Health literacy is contextual and, by assessing its multiple dimensions, it is more likely to identify the ways healthcare professionals can integrate health literacy in every encounter with patients. In this way, healthcare delivery becomes person-centered rather than disease-centered (Dinh, et al., 2021). Health literacy is seen to be crucial in motivating people to engage in healthcare, develop resiliency, and enhance their health and wellbeing (Qi et al., 2021).

People with end-stage chronic kidney disease have higher mortality rates when they have low health literacy because they know less about renal disease (Galura & Pai, 2017). According to Fatima et al.'s study (2022), there is a correlation between health literacy and medication adherence in patients with end-stage kidney disease, with higher health literacy levels being associated with greater treatment satisfaction and adherence. This is consistent with previous research on the relationship between health literacy and the quality of life of hemodialysis patients conducted by Alemayehu et al. (2019). It backs up the conclusions of the study by Stømer et al. (2020), which demonstrated a link between health literacy and the quality of life of patients with chronic renal disease, with higher health literacy levels being connected to better overall quality of life. Health literacy can serve as a measure for determining one's quality of life: individuals with good health literacy tend to have a higher quality of life, while those with low health literacy have a lower quality of life (Milufa & Wahjuni, 2020).

Suarilah and Lin (2022) reported that Indonesian patients with CKD have low health literacy. Qualitative studies have also shown that patients receiving hemodialysis got inadequate information and that physicians or nurses could not provide clear information (Mailani *et al.*, 2021). Nevertheless, most of these studies have relied on health literacy (HL) assessments that focus solely on measuring reading and numeracy skills related to health. However, in recent years, the notion of HL has expanded beyond a person's literacy and numeracy abilities to include more interactive, social, and vital factors, such as assistance from family and friends, collaboration with medical experts, and the capacity for critical thought (Batterham et al., 2017; Sørensen et al., 2012; van der Heide et al., 2018). Further study is required to acquire a better understanding of the relationships between broader health literacy components and outcomes, including quality of life (QoL) and adherence to long-term treatment, both generally and specifically among people with chronic kidney disease (CKD). The research aimed to investigate the correlation between health literacy levels, medication adherence, and quality of life among hemodialysis patients with chronic kidney disease. In this study, individuals with CKD and various levels of health literacy had their quality of life (QoL) and adherence to long-term treatment evaluated and compared. The study also aimed to pinpoint the precise health literacy elements that were related to CKD patients' QoL and adherence to long-term treatment.

Materials and Methods

Research design

This study was a descriptive correlation analysis with a cross-sectional design approach intended to determine the association between health literacy level, medication adherence, and quality of life among hemodialysis patients.

Participants

In Padang, Indonesia, 164 hemodialysis patients were randomly selected from two hemodialysis units in two tertiary hospitals. The inclusion criteria included adult patients who were at least 18 years old, frequently had hemodialysis twice per week, and could read and write Indonesian. The exclusion criteria in this study were patients who experienced a decrease in consciousness, a state of weakness and had memory disorders such as dementia.

Research variables

In this research, the variables are Health Literacy, Medication Adherence, and Quality of Life for chronic kidney disease patients undergoing hemodialysis. Health Literacy refers to an individual's ability or skill to access, understand, evaluate, and use health-related information to make judgments and decisions regarding their health. Medication Adherence is the degree to which hemodialysis patients follow their prescribed medication regimens. Quality of Life is the perception of each individual with chronic kidney disease as they navigate their life, potentially influenced by symptoms, perceived effects, disease burden, and both physical and mental health statuses.

Data Collection and Research Instrument

Four questionnaires were employed in the study, together with a demographic characteristics form to gather information about the patients' gender, age, marital status, level of education, duration of hemodialysis, and comorbidities. Understanding the composition of the study population is essential for generalizing the findings to a broader population or specific subgroups. The questionnaires used in this research were on health literacy, medication adherence, and quality of life. All instruments used in the study are standard questionnaires frequently used worldwide. Researchers in Indonesia have also used these questionnaires with good validity and reliability. These instruments have commonly been used in research settings involving CKD patients undergoing hemodialysis. Below is a description of the questionnaires.

Health Literacy

The Health Literacy Survey Europe Questionnaire 16 (HLS-EU-Q16) is used to assess respondents' levels of health literacy. This questionnaire consists of 16 question items and the adaptation process into Indonesian was taken from previous research by Nasriyanto (2018) and has been tested for validity and reliability with a Cronbach’s alpha value of 0.849. This questionnaire consists of 16 items divided into three scales: health care (items 1, 2, 3, 4, 5, 6, 7), disease prevention (items 8, 9, 10, 11, 12), and health promotion (items 13, 14, 15, 16), which are related to four dimensions, the capacity to locate, comprehend, evaluate, and use a variety of health information. Each item is rated on a Likert scale from 1 to 4, where 1 represents 'very difficult' and 4 represents 'very easy.' The scoring range of this questionnaire is from 0 to 16, with a minimum score of 0 and a maximum score of 16. A score of 0 is assigned to "very difficult" and "quite difficult" responses, while a score of 1 is assigned to "quite easy" and "very easy" responses. The final score is categorized into three levels: 0-8 is classified as low-level health literacy, 9-12 as mid-level health literacy, and 13-16 as high-level health literacy (Pelikan et al., 2019).

Medication Adherence

A survey called the Morisky Medication Adherence Scale-8 (MMAS-8) is used to gauge how well patients take their medications. This questionnaire consists of eight items, seven of which are yes-or-no questions where "Yes" is scored as 0 and "No" is scored as 1, except for question 5 where "Yes" is scored as 1 and "No" is scored as 0. Question 8 has answer choices on 5-point Likert scale: "never, rarely, sometimes, often, or always," with a score of 1 given for "never." The final assessment is calculated based on the total score and categorized as low adherence for a score <6, moderate adherence for a score of 6-7, and high adherence for a score of 8. This questionnaire is a standardized instrument whose validity and reliability have been confirmed, with item selection values ranging from 0.305 to 0.463 and a Cronbach's alpha of 0.675, indicating good reliability (Prabowo & Huwae, 2022).

Quality of Life

The RAND Corporation has developed the Kidney Disease and Quality of Life Short Form Questionnaire (KDQOL-36), a questionnaire for evaluating quality of life. This questionnaire is designed to evaluate patients' quality of life with chronic kidney disease. It consists of 36 items representing five dimensions related to the assessment of physical and mental functioning (SF-12), symptoms/problems, the impact of kidney disease on daily life, and the burden of kidney disease. The scores of the KDQOL-36 questionnaire are transformed into a score between 0 to 100, with higher scores reflecting better quality of life (Hays et al., 1994). This questionnaire has been tested for validity and reliability, with Cronbach's alpha values ranging from 0.706 to 0.886 (Supriyadi et al., 2019).

To collect the data, the researcher began by consulting the head nurse to obtain information on the overall count of hemodialysis patients and to provide an overview of the study's objectives and methodology. In the second stage, the head nurses assisted in identifying potential participants who met the inclusion criteria. Additionally, the researchers received support from the hemodialysis unit nurses in identifying individuals who matched the specified sample criteria. The process of collecting data through the completion of questionnaires was as follows: the questionnaires were distributed to the participants in the hospital according to the hemodialysis schedule. The respondents were supported in filling out the questionnaire, but still complying with the research protocol. The filling process took place during hemodialysis sessions, but was adjusted to the condition of the patient. Then, the questionnaire data obtained were recapitulated and analyzed.

Data Analysis

Bivariate and multivariate analysis were used in this study. The data obtained were processed and analyzed using statistical software, and categorical data presented as frequency and percentage. The Chi-square test was performed in the study to see if there is a connection between health literacy and medication adherence. The Kolmogorov-Smirnov test and the Levene test were formerly used to determine whether the data were normal and homogeneous. The data for each variable were not normally distributed. To compare scores on each quality of life dimension in each health literacy category, the Kruskall Wallis test was used where the p-value <0.05 indicates a relationship between the variables tested. The Mann-Whitney test was used as a post hoc test to identify where the

Table 1 Characteristics of Respondents in Total and Based on Each Category of Health Literacy.

Variable	Total group (no = 164)	LL- HL (no = 43)	ML- HL (no = 48)	HiL- HL (no = 73)
Age (Years) (%)				
17-25	6 (3.6)	3 (50.0)	2 (33.3)	1 (16.7)
26-35	7 (4.3)	1 (14.3)	4 (57.1)	2 (28.6)
36-45	31 (18.9)	6 (19.4)	7 (22.6)	18 (58.1)
46-55	49 (29.9)	10 (20.4)	16 (32.7)	23 (46.9)
56-65	51 (31.1)	15 (29.4)	14 (27.5)	22 (43.1)
>65	20 (12.2)	8 (40.0)	5 (25.0)	7(35)
Gender (%)				
Male	89 (54.3)	20 (22.5)	24 (27)	45 (50.6)
Female	75 (45.7)	23 (30.7)	24 (32)	28 (37.3)
Education (%)				
Elementary School	25 (15.2)	14 (56.0)	5 (20.0)	6 (24)
Junior high School	20 (12.2)	8 (40.0)	8 (40.0)	4 (20)
Senior High School	87 (53.1)	20 (23.0)	30 (34.5)	37 (42.5)
University	32 (19.5)	1 (3.1)	5 (15.6)	26 (81.2)
Duration on Hemodialysis (%)				
< 3 months	32 (19.5)	6 (18.8)	15 (46.9)	11 (34.4)
4-12 months	57 (34.7)	16 (28.1)	15 (26.3)	26 (45.6)
>12 months	75 (45.7)	21 (28.0)	18 (24.0)	36 (48)
Comorbid (%)				
None	18 (10.8)	4 (22.2)	4 (22.2)	10 (55.6)
1 Comorbid	88 (53.6)	22 (25.0)	30 (34.1)	36 (40.9)
2 Comorbids	35 (21.3)	6 (17.1)	7 (20.0)	22 (62.9)
>2 Comorbids	23 (14.02)	11 (47.8)	7 (30.4)	5 (21.7)
Job (%)				
Employed	22 (13.4)	5 (22.7)	2 (9.1)	15 (68.2)
Retired	16 (9.7)	2 (12.5)	3 (18.8)	11 (68.8)
Unemployed	44 (26.8)	19 (43.2)	9 (20.5)	16 (36.4)
Stopped due to health reason	82 (50.0)	17 (20.7)	34 (41.5)	31 (37.8)

Note: LL: Low-level; ML: Mid-level; HiL: High-level; HL : Health Literacy

Table 2 The Correlation of Health Literacy with Medication Adherence and Quality of Life

Variable		LL- HL (no = 43)	ML- HL (no = 48)	HiL- HL (no = 73)	p-Value	Compare p-value in different level HL
Medication Adherence	low (*f*)	28 (65.1)	20 (41.7)	16 (21.9)	< 0.001*	
	Middle (*f*)	11 (25.6)	15 (31.2)	22 (30.1)		
	High (*f*)	4 (9.3)	13 (27.1)	35 (47.9)		
Quality Of Life	Dimensions of physical (Mean Rank)	76.40	73.50	92.01	0.068	LL VS ML = not tested LL VS HiL = not tested ML VS HiL = not tested
	Dimensions mental functioning (Mean Rank)	68.16	79.52	92.90	0.022*	LL VS ML = 0.196 LL VS HiL = 0.09* ML VS HiL = 0.106
	Dimensions the burden of kidney disease (Mean Rank)	60.47	80.47	96.82	< 0.001*	LL VS ML = 0.018* LL VS HiL =0.001* ML VS HiL = 0.036*
	Dimension symptoms/problems (Mean Rank)	75.12	71.24	94.25	0.016*	LL VS ML = 0.670 LL VS HiL = 0.034* ML VS HiL = 0.010*
	Dimensions the impact of kidney disease on daily life (Mean Rank)	66.86	81.27	92.52	0.019*	LL VS ML = 0.095 LL VS HiL = 0.008* ML VS HiL = 0.154
	Rerata Keseluruhan (Mean Rank)	63.05	75.40	98.63	< 0.001*	LL VS ML = 0.141 LL VS HiL = 0,001* ML VS HiL = 0,005*

A nonparametric exam was administered to patients with varied levels of health literacy to evaluate their quality of life and adherence to long-term therapy scores. The relationship between health literacy factors and adherence of medication was examined using the chi-square test. The researchers employed the non-parametric Kruskal-Wallis test to examine variations among different health literacy categories, followed by the employed of the Mann-Whitney test as a post hoc analysis to pinpoint specific areas where score differences existed
* Statistically significant (p<0.05)

differences lie in each group tested. The study conducted a Spearman correlation test to examine the relationship between the health literacy scale and both quality of life and medication adherence. Additionally, a multiple linear regression analysis was carried out on the full patient population to identify relationships between the three HLQ scales as independent variables and the dependent components of overall quality of life and medication adherence.

Ethical Consideration

Medical Research Ethics Management of RSUP Dr. M. Djamil Padang granted ethical approval to conduct this research, number: LB.02.02/5.7/254/2023. This investigation was carried out in accordance with an authorized procedure prospective respondents were informed about the goals of the research and provided with the opportunity to give their consent before participating. Respondents had to sign informed consent forms as a declaration that they were willing to take part in the study.

Results

The respondents in this study comprised 164 patients with chronic kidney disease who routinely underwent hemodialysis. Most of the respondents were in the 56-65 years old age group, as many as 51 respondents (31.1%). More than half of the respondents were male, namely 89 respondents (54.3%), the majority of respondents had high school education, namely 87 respondents (53.1%), and 79 respondents (45.7%) had undergone hemodialysis for more than one year. The majority of respondents,88 (53.6%), had one co-morbidity, and most of the respondents had stopped working due to illness as many as 82 respondents (50%). The data can be seen in Table 1.

QOL and Adherence in Patients with Diverse Levels of Health Literacy

The patients were classified into three groups with comparable Health Literacy Questionnaire (HLQ) profiles using Wards' hierarchical cluster analysis. The health literacy levels in patients were categorized into three groups: Low-level, Mid-level, and High-level (Pelikan et al., 2019). There were 43 patients (26.2%) in the low-level group, 73 (44.5%) in the high-level group, and 48 (29.2%) in the mid-level group. Among the 43 respondents with low-level health literacy, 28 respondents (65.1%) had low medication adherence. Among the 48 respondents with mid-level health

Table 3 The Relationship between the Health Literacy Domain, Life Quality, and Medication Adherence

Domain of health literacy	Quality of life correlation coefficient	p	Adherence correlation coefficient	P
Overall health literacy	0.336	< 0.001*	0.425	< 0.001*
Healthcare	0.348	< 0.001*	0.471	< 0.001*
Disease prevention	0.263	0.001*	0.336	< 0.001*
Health promotion	0.266	0.001*	0.308	< 0.001*

Note: *Spearman correlation test, statistically significant at p<0.05

Table 4 Multiple Regression Analysis to Establish the Correlation between the Health Literacy Domain and both Quality of Life and Medication Adherence

Domains HL	**Quality of life**					**Medication Adherence**				
	B	**SE**	**β**	**t**	**p**	**B**	**SE**	**β**	**T**	**p**
(Constant)	47.631	2.368		20.117	< 0.001*					
Health promotion	2.501	.759	.251	3.295	0.001*					
(Constant)						3.337	.446		7.490	< 0.001*
Healthcare						.505	.083	.433	6.108	< 0.001*

Note: p-value is the result of the multiple linear regression test
* Statistically significant ($p < 0.05$).

literacy, 20 (41.7%) had low medication adherence. On the other hand, among the 73 respondents with high-level health literacy, 35 respondents (47.9%) had high medication adherence. In patients with chronic renal disease receiving hemodialysis, the chi-square test's statistical analysis yielded a p-value of 0.001 ($p<0.05$), demonstrating a substantial correlation between health literacy and medication adherence.

QOL and Adherence Associated with Different Dimensions of Health Literacy

The analysis using Spearman's test yielded substantial correlations between the domain of health literacy and both medication adherence and quality of life, as shown in Table 3 ($p<0.05$). With a positive direction of correlation, it means that the better the value of health literacy, the better the quality of life and patient compliance. Multiple regression analysis revealed that of the three components of health literacy: health promotion has the greatest influence on patients' quality of life, contributing 25.1%, while the healthcare that has the greatest influence on medication adherence is 43.3% (Table 3 and Table 4).

Discussions

The study findings show a positive correlation between higher health literacy (HL) and enhanced quality of life (QoL), aligning with the health literacy conceptual model proposed by Sorensen et al. (2012). The study also showed that patients with high levels of health literacy closely followed their prescription regimens and closely improved their quality of life. These findings align with some studies that high HL is associated with better QoL (Dodson et al., 2016; Skoumalova et al., 2022; Stømer et al., 2020a). Those studies revealed that those with higher levels of total health literacy had better physical and mental health than those with lower levels of total health literacy. Patients with lower levels of HL tend to have lower educational attainment, more comorbidities, increased medication intake, and higher levels of depressive symptoms, all of which may impact their QoL (Stømer et al., 2020a).

The result showed that adherence to medication was related to all dimensions of the quality of life except the physical dimension. Health literacy is associated with medication adherence among patients with chronic kidney disease receiving hemodialysis (Barbosa et al., 2021; Fatima et al., 2022; Stømer et al., 2020). A previous study revealed that self-reported low medication adherence was associated with an increased risk for CKD progression (Cedillo-Couvert et al., 2018). Low health literacy contributes to medication non-adherence and poorer health outcomes in chronic disease patients (Fredericksen et al., 2019). The lack of patient understanding regarding medications' indications and potential side effects can cause discomfort and make them more susceptible to non-adherence. Individuals with high-level health literacy likely find it easier to understand and comprehend the benefits and risks associated with medications, as supported by a study by Coskun and Bagcivan (2020), which found that patients with low health literacy may not fully understand the benefits and risks associated with a particular medication. Patients with chronic kidney disease who were well-educated about their health also adhered to their medications more consistently. An earlier study revealed that knowledge and education substantially predicted the self-management score (Mailani et al., 2023).

Multiple regression analysis in this study revealed that of the three components of health literacy, health promotion has the most significant influence on patients' quality of life, contributing 25.1%, while the healthcare with the most significant influence on medication adherence is 43.3%. This aligns with a previous study that showed lower health literacy proportions were found in domains related to healthcare providers' support and appraisal of health information. The study highlights the need for healthcare professionals to improve communication, education, and support for patients with CKD, particularly in the early stages and during kidney replacement therapy (Dinh et al., 2021).

Chronic renal disease management calls for substantial patient input in decision-making and the execution of treatment strategies (Peng et al., 2019).

Patients need adequate knowledge and information about kidney disease management due to its complexity and impact on various aspects of life. Healthcare professionals have an essential role in assisting patients in making treatment decisions by providing education tailored to their needs to improve their health literacy (Paterick et al., 2017). The capacity to interact with healthcare professionals and actively manage health is essential for patients' quality of life and has a role in drug adherence. However, lower levels of education, income, or living in rural areas were each significantly more likely to contribute to lower health literacy levels in multiple domains, and greater comorbidity severity was significantly associated with lower health literacy in two domains. Finding information, understanding health information, and critical appraisal of health information were reported as challenging activities for participants (Dinh et al., 2021).

Chronic kidney disease patients must get ongoing care to maintain their health; various issues might affect their quality of life. Therefore, patients with good health literacy in hemodialysis find it easier to self-manage their treatment regimens, reducing symptoms and improving their quality of life (Pratiwi et al., 2020). Low health literacy poses a challenge for individuals to understand received health information, which can significantly impact their quality of life (Stømer et al., 2020b).

Based on the findings of this study, it is essential for patients with chronic kidney disease undergoing long-term therapies such as hemodialysis to possess high-level health literacy. Chronic kidney disease patients need to improve their health literacy as one of the efforts to enhance their quality of life. This group requires special attention during hemodialysis, particularly for patients with low health or low-level literacy. It is essential to build effective strategies for healthcare providers to communicate and educate patients about kidney health, including building a patient-centered approach, utilizing a teach-back method, providing written materials, incorporating visual aids, leveraging technology, and collaborating with interdisciplinary healthcare teams. Further investigation is warranted to ascertain whether poor QoL stems from overall low HL or vice versa.

This study has several limitations, including a small sample size, single-center, and cross-sectional study design. In this study, we did not analyze associated characteristic demographics and comorbidities with domain health literacy, QOL, and medication adherence. Additionally, we did not evaluate specific cognitive impairment, which has been shown to limit individuals with advanced kidney disease's capacity for self-management.

Conclusion

The research findings showed that health literacy among patients varied in the high-level, mid-level, and low-level health literacy categories. The analysis established a significant correlation between health literacy, medication adherence, and quality of life in hemodialysis patients. Therefore, it is crucial to implement initiatives aimed at enhancing health literacy among these patients. Healthcare providers can play a vital role in achieving this by offering regular education tailored to the specific information needs of individual patients. Additionally, providing informational resources, such as books or leaflets, in a language that patients can easily understand would be beneficial in improving health literacy and overall health outcomes.

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ORIGINAL ARTICLE

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Quality of life for adult family caregivers of patients with dementia: a Systematic review

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ABSTRACT

Introduction: to evaluate problems and factors related to quality of life (QoL) for adult family caregivers (FCGs) of patients with dementia.

Methods: The study used a systematic review method with the guidelines of PRISMA 2020 and registered in PROSPERO CRD42023464726. The review focused on adult FCGs for people with dementia in the home setting. The literature was searched from four databases, including Scopus, Web of Science, CINAHL, and PubMed. This systematic review examined a subset of fifty-two out of a total of 2,263. The study used a narrative synthesis method to analyze the study.

Results: The result showed that the severity of a patient with dementia's condition had an essential role in the patient's state. It impacted the caregiver's condition indirectly. Personal strategies (coping, resilience, sense of coherence, and expressed emotion) had an essential role in the caregiver situation. A maladaptive strategy would increase the stress of the caregivers and lead to a burden and depression. Those conditions of the caregiver would affect their QoL.

Conclusions: Caring for patients with dementia is a huge psychological distress and burden on FCGs, which may negatively affect their quality of life in many aspects. Therefore, FCGs need education and support programs to maintain their overall aspect of quality of life and enable them to produce care for loved people.

Keywords: caregivers, dementia, quality of life (QoL)

Introduction

Global population aging is a reality. Additionally, as people age, the number of old-age persons with dementia (PwD) has increased. All disorders defined by cognitive and functional impairment fall under the umbrella of dementia, which is a chronic and complicated disease. The occurrence of this disease makes managing it a significant problem for social and health policies in wealthy nations. The significance of dementia issues on a global scale is seen in there were 46.8 million dementia sufferers worldwide in 2015, and by 2050, that number is projected to almost triple (Alzheimer's Association, 2017). Caring for these individuals is expensive, and their families also incur additional costs.

People with dementia suffer a severe lack of control, mental conditions, and behavioral difficulties (Yoro-Zohoun et al., 2020). Wandering behavior is a condition

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frequently displayed by PwD that entails regular, repeated, time-disordered, and/or spatially-disordered lapping activities, random and/or pacing habits and eloping, or getting lost unless accompanied (Algase et al., 2007). Previous reports showed that 6 out of 10 community-dwelling PwD have wandering activity (Alzheimer's Association, 2017); although incidence rates range by 17.4 percent for community-dwelling seniors, 50 percent for individuals with severe dementia, and 63 percent for community-dwellers (Cipriani et al., 2014). Dangerous wandering activities, such as eloping and getting lost outside (Algase et al., 2004), frequently lead to injuries (Pai and Lee, 2016, Rowe and Bennett, 2003). Family caregivers (FCGs) have the most challenging situation to care for their PwD due to their wandering.

Additionally, the provision of care for individuals with dementia imposes a significant burden on FCGs and is constrained by economic considerations, such as the reduction in productivity, which has a direct influence on the overall quality of life (Shikimoto et al., 2018). It has also been said that dementia is one of the disorders of burdening patients and the population of geriatric diseases (Matsushita et al., 2016). In comparison, the mental health status of older adult dementia FCGs is poor relative to that of older adult dementia-free caregivers. It is also believed that the stress caused by caring for them could be a factor in the collapse of home care and the neglect of the older-adults (Wang et al., 2014, Leggett et al., 2018). For the older adults with dementia, the value of informal human capital such as neighbors, colleagues, district groups and volunteers that will support their families in the neighborhood while strengthening public access is emphasized (Japan Ministry of Health Labour and Welfare, 2015).

Although the demand for caregivers is growing, there is a reality that only family members typically assume their responsibility for caring for the older adults living in their families. However, the strain of caring for the older adults can have a significant effect on FCGs' quality of life, contributing to social alienation, financial challenges, and psychological and physical fatigue (Knodel and Nguyen, 2015). FCGs face multiple challenges to maintain their other positions, including child-rearing, employment, and marriages. The impact on FCGs is very nuanced (Chaobankrang et al., 2019). Many FCGs are unpaid and have no bargaining power (Tamdee et al., 2019). According to the study, most over-stressed FCGs did not undergo any instruction before taking care of them (including those with dementia), and were self-taught mostly from practice, relationship, and appreciation. It has also been stated that the factors associated with stress of FCGs were the health status of FCGs, their faith in their treatment, the partnership between FCGs and the older individual adults, and the economic burden of care, as well as the condition of being elderly with dementia (Tamdee et al., 2019).

Therefore, the goal of this review was to evaluate different aspects of quality of life of FCGs affected by caring for elderly with dementia. As a consequence, it was expected to explain different factors that influence physical, psychological and social aspects of quality of life of community caregivers, especially unpaid caregivers.

Materials and Methods

The study used the systematic review methodology. The procedure involved including the formulation of a research question, establishment of criteria, development of a search strategy, exploration of relevant databases, registration of a protocol, evaluation of titles and abstracts, thorough examination of full-text articles, manual searching for additional sources, extraction of data, assessment of quality, verification of data accuracy, statistical analysis, double-checking of data, and composition of the manuscript.

Search Strategy and Screening

PubMed, Scopus, Web of Science, and CINAHL databases were searched for studies released between 2016 and 2022. Additionally, relevant studies were looked up in reference lists. There were no language restrictions, and translated foreign papers were available. There were both conjunctive and disjunctive relationships between the keywords and their combinations that were employed (and - or): “quality of life,” “family caregivers,” and “elderly/older adults/aged dementia.” The details of search strategy can be seen in Supplementary File 1.

First, the researcher screened for the titles that used the terms "quality of life" and "family caregivers of dementia." The selected articles were filtered using the inclusion criteria by all of the authors. Literature which did not fulfill the inclusion criteria were excluded, and the study population was other FCGs diseases. The study team debated the various findings until reaching an understanding over whether or not each research should be included.

Inclusion and Exclusion Criteria

Studies examining the quality of life of community FCGs of dementia patients were the inclusion criteria for articles. These articles discussed observational studies that were pertinent to the subject under investigation, including cross-sectional, correlational, and survey research. Additionally, papers addressing the burden of care and its impact on caregivers' physical and emotional health were looked for. Unpaid carers were among the specific inclusion requirements, and there was a connection between PwD and FCG (spouse, adult child, relative, and sibling).

Articles published prior to 2016, duplicate registrations, research involving formal (paid) carers, and patients receiving long-term care or in nursing homes were all excluded.

Critical Appraisal

There were 52 articles out of 2,263 articles that matched the inclusion criteria and were critically appraised with tools from the appraisal tool for cross-sectional studies (Alilyyani et al., 2018, Keyko et al., 2016). The dimensions, including introduction, methods, results, discussion, and others, were represented by 20 questions. The answers included yes, no, or do not know/comment. Critical appraisal was done by each author and the result for each article was discussed and categorized as low quality, medium, or high. All articles showed high quality, with scores ranging from 10 to 11. The details of the critical appraisal can be seen in Supplementary file 2.

Data Analyses

Narrative synthesis was employed in the study (Hinchcliff et al., 2012). Data were extracted and recorded using a table consisting of author names, year(s), methods, instruments, and findings, including factors related to, and variable dimensions. In addition, content analysis was used in this study (Nuryani et al., 2022). All of the authors read each article and labeled the meaningful context. Each important labeling was re-read by each author. Authors collected all of the labelings, then mapped and grouped them to categorize and sub-categorize.

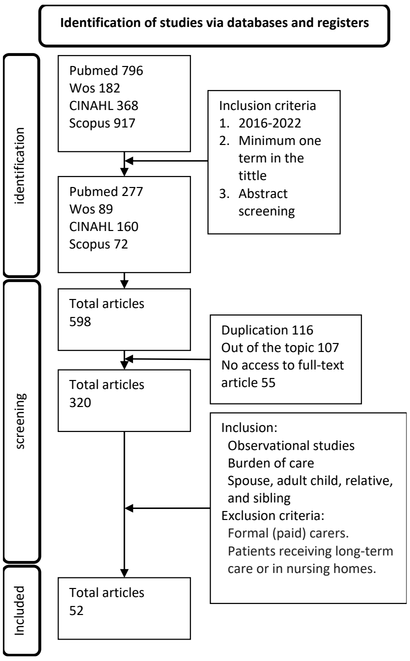

Figure 1 *Literature selection process*

First, researchers categorized problems and its factors. Specific terms were derived into subcategories such as problems were derived into mental and well-being, daily living, comorbid and overall quality of life. Besides, factors were derived into PwD factors and caregiver. PwD factors included type of dementia, impairment, and medication. Meanwhile, FCG factors included individual factors (demographic), health conditions, personality/traits, personal strategies, care activity factors, care activity knowledge, supports, and socioeconomic factors.

If the authors had different notions during categorizing and other opinions when grouping, these were discussed until reaching an agreement. The final results of categorizing can be seen in the results.

Results

A total of 2,263 articles were searched, although 1,665 of them were initially disqualified based on their titles, abstracts, and year published. The remaining 278 were rejected because they lacked full-texts, were out-of-topic, or duplicated. Two hundred and sixty eight studies were removed, leaving a total of 52 articles that met the inclusion criteria. Of the 52 research studies that were included in the final review, 20 studies directly examined quality of life, while the remaining 32 studies

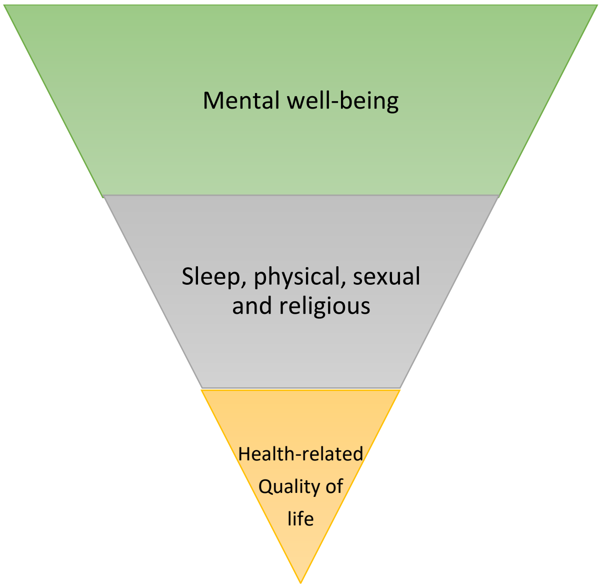

Figure 2 *FCG's problem.*

Table 1 Characteristics of the study

Country	Study
Asian	Chang et al. (2016); Chan et al. (2019); Yu et al. (2016); Kimura et al. (2019); Wang et al. (2020b); Morimoto et al. (2019); Honda et al. (2017); Tay et al (2016); Sittironnarit et al. (2020); Wang et al. (2020a); Liao et al. (2020); Ganapathy et al. (2020); Young et al. (2017); Koyama et al. (2017); Kim et al. (2017); Jeyagurunathan et al. (2017); Wong and Zelman (2020); Saffari et al. (2018); Liu et al. (2017); Khusaifan and El Keshky, (2017); Goren et al. (2016)
European	Joling et al. (2017); Oliveira et al. (2018); Zwingmann et al., (2019); Malak et al. (2016); Häikiö et al. (2020); Kerpershoek et al. (2018); Häusler et al. (2016); Clare et al. (2019); Tulek et al. (2020); Ruiz-Fernandez et al. (2019); Hvidsten et al. (2019); Millenaar et al. (2016); Välimäki et al. (2016); Parrotta et al. (2020); Konerding et al. (2018); Romero-Moreno et al. (2017); Rodríguez-Pérez et al. (2017); Borsje et al., (2016)
American	Polenick et al. (2019); Sutter et al. (2016); von Känel et al. (2019); Weisman de Mamani et al. (2018); Carletti Pessotti et al. (2018); Moon et al. (2017); Corey et al. (2020); Regier and Gitlin (2018); Aravena et al. (2018); Nogueira et al. (2017); Silva Leite et al. (2017b); Laks et al. (2016).
Multi-country	Five multi-country studies
Two eight-countries studies	Kerpershoek et al. (2018); Parrotta et al., (2020)
Two three-countries studies	Clare et al., (2019); Konerding et al. (2018)
One two-countries study	Joling et al. (2017)

were concerned with burden, psychological distress, sleep, and any negative effects of health on the physical, mental, and social aspects of quality of life.

Characteristics of the Study

The majority of the studies came from Asian countries which was 21 studies, followed by 18 studies from Europe and 12 studies from America (Table 1). There were five multi-country studies, including two eight-countries studies, two three-countries studies, and one two-countries study. Additionally, one review article did not include the characteristics of the study. The detailed summary of the studies can be seen in Supplementary file 3.

Analytical Findings

FCG's Problems

A total of eighteen articles consistently demonstrated a general decline in health-related quality of life. There were 15 specific problems that related to the quality of life (Table 1). The majority of FCGs problems were mental well-being problems, sleep,

Table 2 FCG's problems

Problem	Source
Mental well-being	
Mental health problems: psychological distress, psychological problems	Borsje et al. (2016); Goren et al. (2016); Laks et al. (2016); Malak et al. (2016); Millenaar et al. (2016); Sutter et al. (2016); Välimäki et al. (2016); Yu et al. (2016); Jeyagurunathan et al. (2017); Khusaifan and El Keshky (2017); Kim et al. (2017); Koyama et al. (2017); Liu et al. (2017); Rodríguez-Pérez et al. (2017); Romero-Moreno et al. (2017); Aravena et al. (2018); Carletti Pessotti et al. (2018); Regier and Gitlin (2018); Saffari et al. (2018); Chan et al. (2019); Hvidsten et al. (2019); Morimoto et al. (2019); Corey et al. (2020); Parrotta et al. (2020); Wong and Zelman (2020);
Burden/overburden	Sutter et al. (2016); Tay et al. (2016); Yu et al. (2016); Khusaifan and El Keshky (2017); Kim et al. (2017); Young et al. (2017) Liu et al. (2017); Silva Leite et al. (2017b);Young et al. (2017); Aravena et al. (2018); Regier and Gitlin (2018); Saffari et al. (2018); Wong and Zelman (2020); Hvidsten et al. (2019); Häikiö et al. (2020); Liao et al. (2020); Sittironnarit et al. (2020); Tulek et al. (2020); Wang et al. (2020a)
Life satisfaction	Rodríguez-Pérez et al. (2017); Romero-Moreno et al. (2017)
Well being	Konerding et al. (2018); Honda et al. (2017); Polenick et al. (2019)
Living well	Clare et al. (2019)
Health perception	Aravena et al. (2018)
Low self-competence for taking care of PwD	Millenaar et al. (2016)
Daily living	
Sleep problems (Insomnia/sleepiness/quality of sleep)	Goren et al. (2016); Laks et al. (2016); Honda et al. (2017); Liu et al. (2017); Corey et al. (2020)
Environmental problems	Rodríguez-Pérez et al. (2017)
Social problems	Chang et al. (2016); Konerding et al. (2018);Weisman de Mamani et al. (2018);
Physical problems (pain)	Goren et al. (2016); Laks et al. (2016); Kim et al. (2017);Konerding et al. (2018); Wang et al. (2020a)
Sexual problems	Nogueira et al. (2017)
Religious	Carletti Pessotti et al. (2018)
Comorbidity	
Hypertension	Laks et al. (2016)
Diabetes	
Overall quality of life	
Overall low health related-Quality of Life	Häusler et al. (2016); Millenaar et al. (2016); Tay et al. (2016); Välimäki et al. (2016); Jeyagurunathan et al. (2017); Kim et al. (2017); Moon et al. (2017); Oliveira et al. (2018); Saffari et al. (2018); Weisman de Mamani et al. (2018); Hvidsten et al. (2019); Ruiz-Fernandez et al. (2019); von Känel et al. (2019); Ganapathy et al. (2020); Häikiö et al. (2020);Liao et al. (2020); Tulek et al. (2020); Wang et al. (2020b)
Quality of Family Life	Kimura et al. (2019)

Table 3 Description of characteristics of patients with DM (n=300)

Factors related to FCG's problems			Sources
PwD factors	**Type of dementia**		
		YOD/EOD	Millenaar et al. (2016); Wang et al. (2020a)
		Type of dementia	Hvidsten et al. (2019) (FCG's QoL YAD worse than FTD)
		Severity of dementia Severity	Välimäki et al. (2016); Aravena et al. (2018); Carletti Pessotti et al. (2018); Ruiz-Fernandez et al. (2019); von Känel et al. (2019)
		Frequency neuropsychiatric symptom/behavioral symptoms	Borsje et al. (2016); Honda et al. (2017);Koyama et al. (2017); Aravena et al. (2018); Carletti Pessotti et al. (2018); Regier and Gitlin (2018); Saffari et al. (2018);Ruiz-Fernandez et al. (2019); Liao et al. (2020); Parrotta et al. (2020); Wong and Zelman (2020)
	Impairment of older adults		
		Cognitive impairment	Nogueira et al. (2017); Tulek et al. (2020)
		PwD physical condition	Ruiz-Fernandez et al. (2019); von Känel et al. (2019)
		Lower functional status	Liu et al. (2017)
	Medication		
		Number of medications	Tulek et al. (2020)
FCG's factor	**Individual factor**		
		Gender Female	Nogueira et al. (2017); Borsje et al. (2016); Sittironnarit et al. (2020)
		Male	Oliveira et al. (2018); Hvidsten et al. (2019)
		Age 50-70 years	Borsje et al. (2016); Oliveira et al. (2018); Tulek et al. (2020)
		Ethnic	Ganapathy et al. (2020) (Chinese)
	Health condition		
		Medical comorbid/chronic disease	von Känel et al. (2019); Liao et al. (2020); Tulek et al. (2020)
		Physical function/health	Clare et al. (2019); von Känel et al. (2019)
		Psychological health	Clare et al. (2019)
		Somatic well-being	Aravena et al. (2018)
	Personality/traits		
		Personal values	Romero-Moreno et al. (2017)
		Personality traits	Kim et al. (2017); Morimoto et al. (2019)
		Optimism	Sutter et al. (2016)
	Personal strategies		
		Coping (positive factor)	Häusler et al. (2016); Joling et al. (2017); Rodríguez-Pérez et al. (2017); Corey et al. (2020)
		Resilience (positive factor)	Sutter et al. (2016); Carletti Pessotti et al. (2018)
		Sense of coherence	Sutter et al. (2016)
		Expressed emotion	Weisman de Mamani et al. (2018); Wong and Zelman (2020)
		Burden	Hvidsten et al. (2019); Liao et al. (2020)
		Depressive symptom	Hvidsten et al. (2019)
	Care activity factors		
		Management skills	Aravena et al. (2018)
		Care hours	Silva Leite et al. (2017a); Oliveira et al. (2018); Sittironnarit et al. (2020); von Känel et al. (2019); Parrotta et al. (2020); Wong and Zelman (2020)
		Ability to carry out ADL	Ganapathy et al. (2020)
		Adaptability	Kimura et al. (2019)
		Having a limited space	Tulek et al. (2020)
		Caregiver pain	Polenick et al. (2019)
		Caregiving competence	Kimura et al. (2019)
	Care activity knowledge		
		Experience caregiving	Clare et al. (2019)
		Health literacy	Häikiö et al. (2020)
		Level of needs	Kerpershoek et al. (2018)
		Satisfaction towards psychiatric care	Sittironnarit et al. (2020)
	Support		
		Family	Clare et al. (2019); Ruiz-Fernandez et al. (2019); Ganapathy et al. (2020); Liao et al. (2020)
		Relatives	Wong and Zelman (2020)
		Informal social support	Khusaifan and El Keshky (2017) Morimoto et al. (2019)
		Formal social support	
		Religious	Wong and Zelman (2020)
	Social economy		
		Education (positive)	Sittironnarit et al. (2020)
		Job (positive)	Sittironnarit et al. (2020)
		Working hours	Wang et al. (2020b)
		Financial problems	Sittironnarit et al. (2020)
		Taking care of another dependent	Sittironnarit et al. (2020)
		Stigma	Chang et al. (2016)

physical, sexual and religious. Overall low health-related to quality of life was reported by 18 studies and one study reported quality of family life.

The highest problem was mental health problems followed by burden/overburden. Three studies found FCG's well-being, and two studies found life satisfaction were degraded. Living well, health perception, and low self-competence for taking care of PwD were found in one study for each category.

Daily living problems included sleep problems, environmental, social, physical (pain), sexual, and religious. The majority of daily living problems were sleep problems, and physical. Meanwhile comorbidities included hypertension and diabetes. However, the comorbidities were not clear because the studies did not identify whether FCGs got the comorbidity during taking care or before.

According to Figure 2, the major problems of FCG's are mental well-being, followed by daily living problems, including sleep, physical, sexual, and religious. All those problems would affect health related to quality of life. Mental health problems are psychological distress and psychological problems. Furthermore, the problems increased to be burden/overburden. Those situations impact FCG's daily living and health related to quality of life.

Factors Related to FCG's QoL

Factors related to FCG's quality of life involved two main factors, including PwD's and FCG's condition. PwD's condition included type of dementia, severity and impairments. On the other hand, FCG's factors are individual factors, health status, personality trait, personal strategy, care activity, support, and social economy.

FCG's Relationship

Nine studies found that the FCGs relationship was significant to their quality of life. On the contrary, six studies found that it was not significant (Liu et al., 2017, Regier and Gitlin, 2018, Hvidsten et al., 2019, Ruiz-Fernandez et al., 2019, Liao et al., 2020, Polenick et al., 2019, Chan et al., 2019). The majority of the studies did not identify and did not measure it, three studies focused on the spouse (Nogueira et al., 2017, von Känel et al., 2019, Häusler et al., 2016) and one focused on the child as caregiver (Wang et al., 2020b). Borsje et al. (2016) found being spouse has higher psychological distress than child. This was supported by Jeyagurunathan et al. (2017) and Clare et al. (2019) who found caring for spouse was significantly associated with lower psychological domain quality of life. A study from Turkey found spouse caregiver had higher burden and lower physical composite than non-spouse (Tulek et al., 2020). Otherwise, spouse caregiver with higher income had significantly impacted higher quality of life (Moon et al., 2017). Millenaar et al. (2016) found spouse YOD had significantly more impact than LOD.

PwD's Factors

Type of dementia

Type of dementia included age of PwD who was diagnosed with dementia (Millenaar et al., 2016); (Wang et al., 2020a) and the type of dementia (Hvidsten et al., 2019).

Severity

The majority of the studies found that severity (Välimäki et al., 2016, Carletti Pessotti et al., 2018, von Känel et al., 2019, Ruiz-Fernandez et al., 2019, Aravena et al., 2018) and frequency neuropsychiatric/behavioral symptoms have significant impact to FCG's quality of life (Borsje et al., 2016, Parrotta et al., 2020, Wong and Zelman, 2020, Koyama et al., 2017, Carletti Pessotti et al., 2018, Ruiz-Fernandez et al., 2019, Liao et al., 2020, Honda et al., 2017, Aravena et al., 2018, Regier and Gitlin, 2018, Saffari et al., 2018).

Impairments

Several studies found that impairment of the older adults had a significant influence to FCG's quality of life. The impairments were cognitive impairment (Nogueira et al., 2017, Tulek et al., 2020), PwD physical condition (von Känel et al., 2019, Ruiz-Fernandez et al., 2019), and lower functional status (Liu et al., 2017).

FCG's Factors

Individual

Individual factors were unmodifiable factors, including gender (Nogueira et al., 2017, Borsje et al., 2016, Sittironnarit et al., 2020, Oliveira et al., 2018, Hvidsten et al., 2019), age (Koyama et al., 2017, Tulek et al., 2020, Oliveira et al., 2018, Borsje et al., 2016), ethnicity (Ganapathy et al., 2020) (Chinese), and relationship status.

Health Condition

Health conditions included medical comorbid/chronic disease (von Känel et al., 2019, Liao et al., 2020, Tulek et al., 2020), physical function/health (von Känel et al., 2019, Clare et al., 2019), psychological health (burden and depressive symptoms) (Clare et al., 2019) and somatic well-being (Aravena et al., 2018) which were the health conditions of FCG's that influenced quality of life.

Personal

Personality of FCGs had significant impact to quality of life. Personality factors included personal values (Romero-Moreno et al., 2017), personality traits (Kim et al., 2017, Morimoto et al., 2019), and optimism (Sutter et al., 2016).

Personal Strategies

Personal strategies when facing the problem included coping (Rodríguez-Pérez et al., 2017, Corey et al., 2020, Häusler et al., 2016, Joling et al., 2017), sense of coherence (Carletti Pessotti et al., 2018, Sutter et al., 2016), resilience (Sutter et al., 2016) and expressed emotions (Wong and Zelman, 2020, Weisman de Mamani et al., 2018). However, their strategy might become negative if FCGs felt burdened (Hvidsten et al., 2019, Liao et al., 2020) and had depressive symptoms (Hvidsten et al., 2019).

Care Factors

Care factors were divided into two, including care activity and care knowledge. Care activity factors included management skills (Aravena et al., 2018), care hours (Silva Leite et al., 2017a, Parrotta et al., 2020, Wong and Zelman, 2020, von Känel et al., 2019, Sittironnarit et al., 2020, Oliveira et al., 2018), ability to carry out ADL (Ganapathy et al., 2020), adaptability (Kimura et al., 2019), having a limited space (Tulek et al., 2020), caregiver gain (Polenick et al., 2019), and enjoying spending time (Kimura et al., 2019). While, care knowledge is related to experience in caregiving (Clare et al., 2019), health literacy (Häikiö et al., 2020), level of needs (Kerpershoek et al., 2018), and satisfaction toward psychiatric care (Sittironnarit et al., 2020).

Support

Eight studies found that support can help FCG's struggle from suffering from their condition. Support includes social support (Ruiz-Fernandez et al., 2019, Ganapathy et al., 2020, Liao et al., 2020, Clare et al., 2019), family and relatives (Wong and Zelman, 2020), informal social support (Khusaifan and El Keshky, 2017), and formal social support (Morimoto et al., 2019). Additionally, religious found FCG's positive belief of their situation (Wong and Zelman, 2020)

Social Economy

Social economic situation was found in three studies. It included education (positive) (Sittironnarit et al., 2020), job (positive) (Sittironnarit et al., 2020), working hours (Wang et al., 2020b), and financial problems (Sittironnarit et al., 2020). Those are related to each other. Good education and flexible job working hours would help FCGs solve financial problems. Otherwise, low education and unemployment would bring negative impact. Additionally, stigma from environment has negative impact also (Chang et al., 2016).

Discussions

Quality of life exploration is important to human health and life. This study is the first systematic review that has explored FCGs' problems and the factors related to them. This systematic review found complex factors became FCGs' QoL problems, including mental well-being problems, sleep, environment, social, physical, sexual, and religious. Those conditions impact health-related QoL and quality of family life. Those problems could not be separated from the factors related to them. Generally, factors were divided into PwD's and FCG's factors. A PwD's condition has a huge impact to their FCG's QoL. The impact is not only limited to FCG, but also quality of family life (Steenfeldt et al., 2021).

The biggest problem for FCGs was mental health. Mental health problems become serious problems if they are not resolved as soon as possible. Unmodifiable factors, specifically PwD's severity, was the biggest problem. Otherwise, this study considered the modifiable factors, including support, social economy, and care activity, would give significant positive impact to mental health. Further longitudinal study might be needed to investigate over a long time period.

Meanwhile, burden as the second problem might appear, but it is not limited to knowledge, family or relatives' pressure, and financial situations. All of those situations if combined with negative coping would lead to mental health problems because FCGs could not solve them in appropriate ways. Additionally, this study considered social stigma was a slightly heavy factor that FCGs face from the life environment. The previous studies in Asian countries found social stigma has significant impact to FCGs because it is related to the culture and religion (Chang et al., 2016). A systematic review study (Nguyen and Li, 2020) found that individuals diagnosed with dementia, as well as their familial carers, have reported experiencing adverse perceptions, prejudiced attitudes, and discriminatory behaviors from both the general public and healthcare practitioners. Participants in the study exhibited self-perceptions characterized by negative effects and displayed a propensity to postpone seeking assistance. The self-stigma experienced by individuals with dementia and their family is mostly influenced by psychological issues, rather than sociodemographic factors.

Based on all those findings, this study assumed all the problems could not be separated, and the outcome was low health-related to quality of life. Three studies found that FCGs with comorbidities or chronic disease (von Känel et al., 2019, Liao et al., 2020, Tulek et al., 2020) had poor QoL, but it is not clear, when the FCGs started to suffer from their comorbidity. A further study related to FCGs' comorbidity is highly recommended. Mental, sleep, and physical problems would lead to disease (Kabaya et al., 2023).

FCGs' relationships are not really clear relationships with their problems. Local culture could influence this situation, because some studies found it was a significant factor, but some studies deny it (Liu et al., 2017, Regier and Gitlin, 2018, Hvidsten et al., 2019, Ruiz-Fernandez et al., 2019, Liao et al., 2020, Polenick et al., 2019, Chan et al., 2019). A meta-analysis study revealed that those who had a spouse had better QoL. A limited number of the studies, 12 of 50 studies, have limitations. Further study needs to explore FCGs relationship and culture.

Interestingly, religion and religious problems have become a problem and factor. This shows different perspective of FCGs would lead to different results. This problem cannot be separated into personality and personal strategies. Instead, it is important to acknowledge that religious beliefs and practices can greatly influence individuals' attitudes and behaviors (Teahan et al., 2018). Therefore, it is crucial to consider the role of religion in addressing and finding solutions to these problems. By recognizing the impact of religious beliefs, more inclusive and comprehensive strategies can be developed that take into account diverse religious perspectives and promote understanding and cooperation among individuals of different faiths.

Personality and personal strategies have an important role in FCG's problems. Those factors would lead to a positive or negative impact on QoL. Positive values will give a positive coping to solve their problems (Rodríguez-Pérez et al., 2017, Corey et al., 2020, Häusler et al., 2016, Joling et al., 2017). Otherwise, negative values will give maladaptive coping which in the long term might become QoL problems (Teahan et al., 2018). For example, in the context of developing inclusive strategies in a diverse religious community, a detailed example could be creating interfaith dialogue sessions where individuals from different faith backgrounds come together to share their perspectives and engage in respectful discussions (Chan, 2022). These sessions can help foster understanding, promote cooperation, and ultimately contribute to a higher quality of life for all individuals involved. This study encourages further study to explore these factors to increase FCGs' QoL.

This study found that there are several positive factors that would have a positive impact on QoL. Optimism (personality/traits) (Sutter et al., 2016), coping (personal strategies) (Corey et al., 2020, Joling et al., 2017, Rodriguez-Perez et al., 2017), resilience (personal strategies) (Carletti Pessotti et al., 2018, Sutter et al., 2016), support, education (social economy) (Sittironnarit et al., 2020), and job (social economy) (Sittironnarit et al., 2020). These factors were all found to significantly contribute to an individual's overall quality of life. This study revealed that individuals with an optimistic outlook, effective coping mechanisms, and resilience were likelier to experience a higher quality of life (Teahan et al., 2018). Moreover, having a solid support system, access to education, and a stable job were also identified as crucial factors that positively influenced one's quality of life (Farina et al., 2017).

Findings from this study can be used to prepare the appropriate interventions to maintain FCGs' QoL. Positive determinants become the concern of the intervention. Specifically, community nurses or public health nurses could prepare FCGs on how to face the dementia caring situation. They can provide education and support to enhance the FCGs' knowledge and skills in caregiving, as well as offer resources and referrals for additional assistance. Additionally, the intervention could involve creating a support network for FCGs, such as support groups or online forums, where they can connect with others who are in similar caregiving roles. By addressing the positive determinants identified in the study, the intervention can help improve the overall quality of life for FCGs and ensure they have the necessary support to continue providing care for their loved ones.

Policies related to FCGs should be well-prepared. By providing FCGs with knowledge and skills through structured training, they can better understand and accept their condition. This will enable FCGs to effectively navigate the challenges they face and improve their overall quality of life. Additionally, policies that are specifically tailored to address the unique needs of FCGs should be implemented to ensure they receive the necessary support and resources to adequately care for their loved ones. This holistic approach, combining professional healthcare and policy interventions, will contribute to maintaining FCGs' quality of life and well-being.

The scope of this review had several limitations. First, the majority of the investigations included in the current evaluation were carried out in Western nations. It is crucial to look at how cultural and religious differences affect carers and HRQoL. Family carers should receive support that is culturally sensitive since different racial and ethnic groups of caregivers may react to assistance differently or require varied forms of assistance. Second, this study searched literature from 2016, and earlier studies might have different problems that this study did not explore.

Conclusion

Mental well-being has become a big problem of carers. It is impacted by their PwD's condition, and specifically severity of dementia. Personal values, personality traits, and optimism would help carers to choose positive strategies for taking care of their PwD. In addition, formal or informal support would provide positive impact for carers. Findings of this study will help further study to employ the intervention of the modifiable factors, such as care factors and supports. Social stigma that is related to culture might need national health education of dementia. Education of carers in how to care for dementia relatives is related to country policy.

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Update: March 2022

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Table 1. Effects of plant growth regulator types and concentrations on embryogenic callus induction from leaf tip explants of *D. lowii* cultured in ½ MS medium supplemented with 2.0 % (w/v) sucrose under continuous darkness at temperature of 25 ± 2 °C after 60 days of culture

Table 3. Maternal and child health care-seeking behaviour for the last pregnancy in women aged 15 – 45 years old

Type of care	Age Groups (Years)							
	<30		30 - 39		40 - 45		All Age	
	n	%	n	%	n	%	n	%
Place for antenatal care								
Village level service (Posyandu, Polindes or Poskesdes)	1	9.1	1	4.6	1	3.5	3	4.8
District Level service (Puskesmas/Pustu)	2	18.2	7	31.8	1	3.5	10	16.1
Hospital, Clinics, Private Doctor or OBGYN	1	9.1	4	18.2	2	6.9	7	11.3
Private Midwife	7	63.6	10	45.5	25	86.2	42	67.7
Place of Birth								
Hospital	5	50.0	5	22.7	4	13.8	14	23.0
Birth Clinic/Clinic/Private health professional	5	50.0	15	68.2	21	72.4	41	67.2
Puskesmas or Pustu	0	0.0	2	9.1	0	0	2	3.3
Home or other place	0	0.0	0	0	4	13.8	4	6.6
Ever breastmilk								
No	1	9.1	1	4.6	1	3.5	3	4.8
Yes	10	90.9	21	95.5	28	96.6	59	95.2
Exclusive breastfeeding								
No	4	36.4	10	45.5	18	62.1	32	51.6
Yes	7	63.6	12	54.6	11	37.9	30	48.4

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(Nursalam et al., 2020)
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Reference to a Journal Publication:

Nursalam, N. *et al.* (2020) 'The effect of range of motion exercise on blood pressure, pulse and sleep quality among hypertensive patients', *International Journal of Innovation, Creativity and Change*. Faculty of Nursing, Universitas Airlangga, Mulyorejo Street, Campus C Unair, Surabaya, 60115, Indonesia: Primrose Hall Publishing Group, 13(6), pp. 220–234. Available at: https://www.scopus.com/inward/record.uri?eid=2-s2.0-85087361125&partnerID=40&md5=b7318712857248d9ea896f85f82d69c9.

Reference to a Book:

de Virgilio, C. & Grigorian, A. 2019, 'Surgery: A case based clinical review' in Surgery: A Case Based Clinical Review, pp. 1-689.

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Harper, M.S. 2021, 'Mental health and mental health services' in Services to the Aging and Aged: Public Policies and Programs, pp. 283-297.

Reference to a Website:

WHO (2021) *WHO Coronavirus Disease (COVID-19) Dashboard: Situation by Country, Territory & Area*.

Reference in Conference:

Yuarnistira, Nursalam, N., Rachmawati, P.D., Efendi, F., Pradanie, R. & Hidayati, L. 2019, 'Factors Influencing the Feeding Pattern of Under-Five Children in Coastal Areas', IOP Conference Series: Earth and Environmental Science.

Reference in Statute:

Pemerintah RI (2014) *Undang-Undang Republik Indonesia Nomor 38 Tahun 2014 Tentang Keperawatan*. Indonesia. Available at: https://peraturan.go.id/common/dokumen/ln/2014/uu38-2014bt.pdf.

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