

Data Collection

The data collection was performed using a website linked to the "DAHAGA" application for screening. The data were collected in a nursing college with the help of two research assistants. The researchers ensured that the research assistants had been given training for the procedures of the data collection. Their jobs were to facilitate the participants in filling out and using the "DAHAGA" application in the WhatsApp group. Each participant in the experimental group was asked to do a pretest before applying each feature of Islamic spiritual mindfulness in the app. The participants were asked to do the mindfulness exercise six times and then followed by a posttest. All data were recorded automatically in the app and could be accessed by the researchers and admin only.

In the comparison group, the pretest and posttest were conducted online using Google Forms. The research assistants also helped them via WhatsApp. After practicing mindfulness according to the book, the participants were asked to do a posttest.

Data Analysis

Data were analyzed using descriptive statistics and bivariate analysis. As data were normally distributed,

paired *t*-test and independent *t*-test were used to determine the effect of the intervention on depression in each group and compare its impact between the experiment and comparison groups. The significance level is set at 0.05.

Ethical Consideration

This study received ethical clearance from the Health Research Ethics Committee of the Department of Nursing, Faculty of Medicine, Diponegoro University, with a reference number of 99/EC/KEPK/D.Kep/IV/2020. The researchers also ensured that each student had signed a written informed consent prior to data collection. Each has a right to withdraw from the study at any time without penalty. Confidentiality of the data was also ensured.

Results

Seventy participants were able to join and no one withdrawn from the study. The majority of them were aged 18-22 years old and included in the category of early adulthood (Hurlock, 2009). The difference in depression levels among students can be seen in Table 1.

Table 1 Difference in the level of depression among students in the intervention and comparison groups (*N* = 70)

Group	Depression		Mean Difference	<i>p</i> -value ^a
	Pretest	Posttest		
	Mean±SD	Mean ±SD		
Experiment (<i>n</i> =35)	17.20±4.94	11.49±4.49	4.28	<0.001 ^a
Comparison (<i>n</i> =35)	16.49±4.11	16.34±4.92	1.80	0.861 ^a
<i>p</i> -value ^b	0.513 ^b	<0.001 ^b		

^aPaired *t*-test | ^bIndependent *t*-test

Based on the results of the paired *t*-test as shown in Table 1, it could be concluded that there was a significant effect of DAHAGA on the level of depression in the experimental group, seen from a significant difference in the depression level before and after the intervention (*p* <0.001). In contrast, there was no significant difference in the level of depression in the comparison group before and after the intervention (*p* = 0.861). This result is also supported by the statistical result of the independent *t*-test, which revealed a significant difference in depression level between the experimental group and the comparison group after the intervention with a *p*-value of <0.001. This finding indicates that the Islamic spiritual mindfulness combined with other features in the innovative app effectively reduces depression levels among students.

Discussion

This study aimed to examine the effect of DAHAGA application on reducing depression among nursing students. The results revealed a significant effect of the app on depression level in the experimental group seen from the dependent *t*-test analysis and confirmed by the

independent *t*-test analysis, which shows a significant difference in depression level after interventions between the experimental and comparison groups. However, the findings of this study support previous research (Asiah et al., 2019) that Islamic spiritual mindfulness intervention is effective not only for patients with depression who are admitted to a psychiatric hospital but also for nursing students, as indicated in our study.

An innovative intervention created in this study using the DAHAGA application helps the students identify problems that they have or the environment quickly through the detection feature. However, identifying the problems is essential for the prevention of mental disorders (Videbeck, 2008). The app also helps detect the bad behavior and independent healthy target plans (Dwidiyanti et al., 2019), which consequently awareness among the students will be increased, and they could cope with their problems independently and prevent mental disorders, especially depression. Additionally, the app allows the researchers to monitor and help the condition of the students, which is considered the benefit of the app. In contrast, the use of the Islamic spiritual mindfulness book alone was not effective in reducing depression levels

among students compared to app use, as indicated in this study.

Notably, the DAHAGA application is helpful and practical, especially during the pandemic. [Wei et al. \(2020\)](#) said that the provision of integrated internet-based interventions effectively reduced symptoms of stress and depression related to COVID-19. In this study, the DAHAGA application provides eight features: (1) problem, (2) bad behavior, (3) early detection, (4) independent health target, (5) pretest, (6) posttest, (7) mindfulness exercises, and (8) information. The problem feature contains questions about the problems faced, while the bad behavior feature contains questions regarding the user's experiences of the committed behavior. The early self-detection element consists of two forms of questions, namely, current feelings and physical conditions. The independent health target feature contains target choices/user expectations for independent health. The pretest and posttest feature includes questionnaires about depression that should be completed before and after mindfulness exercises. The mindfulness training feature contains mindfulness exercise guidelines that aim to help users consciously accept the committed bad behavior and try to correct it through independent health targets that have been planned earlier ([Sadipun et al., 2018](#); [Dwidiyanti et al., 2019](#); [Munif et al., 2019](#)).

It is noteworthy that Islamic spiritual mindfulness is fully emphasized in the app. Islamic spiritual mindfulness is an exercise that aims to help individuals aware of their current condition or experience by involving the presence of God ([Dwidiyanti et al., 2019](#)). It is also believed that Islamic spiritual mindfulness is able to change behaviors and build positive interpersonal skills through intention and self-evaluation ([Dwidiyanti et al., 2019](#)). According to [Yapko \(2016\)](#), for the healing of depression, a patient should be taught about (1) the ability to make effective decisions, (2) effective coping or stress management skills, (3) skills to build and maintain positive relationships, (4) problem-solving skills, and (5) building a realistic and motivating future. Such abilities are taught at each stage of Islamic spiritual mindfulness. The stages of mindfulness include the intention and self-evaluation that describe the decisions made effectively concerning the behavior to be changed. As for coping, stress management in Islamic spiritual mindfulness is taught through seven steps: intention, self-evaluation, repentance, body scan, prayer, surrender, and relaxation ([Dwidiyanti et al., 2019](#)).

Implications of this Study for Nursing Practice

Several implications of this study include: First, the findings of this study provide evidence to support Islamic spiritual mindfulness as a part of nursing intervention among mental health nurses or psychiatric nurses to reduce depression in their practice; Second, this study offers a new and innovative app called DAHAGA, which fit with the COVID-19 condition today where the utilization of the technology is necessary; Third, the results of the study provide additional knowledge for nursing science, which

the concepts of Islam, spiritual, and mindfulness merged in order to provide holistic nursing care, especially for the individuals who hold Islamic religion.

Limitation of the Study

We notice two limitations of the study. First, when installing the "DAHAGA" application, some participants experienced difficulties due to the device restrictions. As a result, there was a time difference in starting the mindfulness exercises using the application. Further study is recommended to encounter this issue, which the app could be used in any devices. Second, as the app specifically focuses on individuals who hold Islam; thus, it cannot be used in others.

Conclusion

There was a significant effect of using the DAHAGA-Islamic spiritual mindfulness-based app on reducing the students' levels of depression. The app can be used to detect and treat depression among college students. Also, it can be utilized as a part of the intervention in nursing practice. The extended application of the app with non-students and non-Muslims is a necessity to validate the findings.

Declaration of Conflicting Interest

The authors declared that they do not have a conflict of interest, either individuals or institutions.

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Authors' Contribution

All authors contributed equally to the drafting of the manuscript, revising the manuscript critically for important intellectual content, conception, and design of the study, acquisition of data, analysis, and/or interpretation of data. All authors approved the final version of the article.

Data Availability Statement

The research data could not be shared because they were saved by Diponegoro University's server. We strictly followed the research ethics to ensure the confidentiality of the data.

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“Accessibility”: A new narrative of healthcare services for people living with HIV in the capital city of Indonesia

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Abstract

Background: The progress of the fight against HIV is highlighted by significant change. HIV of the past is different from HIV of the present. Healthcare services have played an essential role in achieving the optimal goals needed to end the HIV epidemic. However, people living with HIV and those at risk of catching it (PLWH) often misunderstand the rapid growth of HIV healthcare service options.

Objective: This study aimed to explore the experiences of PLWH in the healthcare services featured in this study.

Methods: A qualitative phenomenological approach was used. Semi-structured interviews were conducted in 2017 with 12 PLWH who engaged with healthcare services in Jakarta, Indonesia, by using a purposive sampling technique. Semi-structured questions were asked which related to their experiences of using the services. Stevick Colaizzi Keen method was used to extract the thematic analysis of the study.

Results: The study developed four essential themes of PLWH healthcare use. They were accessibility, availability at all healthcare levels, comprehensiveness of service, and affordability.

Conclusion: Providing accessible healthcare services is considered essential by PLWH. It is also pivotal to helping people feel positive about the community-related healthcare services on offer. Nurse-led HIV services must maintain this progress by continuously evaluating the quality-of-service outcomes and promoting the accessibility of the services to the broader population.

Keywords

HIV infections; health services; patient acceptance of healthcare; nursing; Indonesia

United Nations Sustainable Development Goals demand sufficient progress in ending the epidemic of AIDS and also achieving universal health coverage by providing qualified essential healthcare services (United Nations, 2016). It is vital to establish quality HIV services that offer people-centered, safe, acceptable, appropriate, effective, and efficient care for PLWH (World Health Organization, 2019a). PLWH should be engaged in a qualified diagnostic and treatment of healthcare services (World Health Organization, 2016) and must be treated with Antiretroviral Therapy (ART) (World Health Organization, 2020).

In 2019, a total of 37.9 million people around the world was living with HIV and AIDS (US Department of Health &

Human Services, 2020). Global efforts have been made to reduce this, although the progress is not sufficient. The number of people who have tested positive for HIV may be reducing globally, but this reduction is not significant enough, and prevention strategies and programs still need encouragement. There is a significant gap between actual achievement and the 2020 target. Whereas the target was to bring the number of deaths down to 500,000, it currently stands at 770,000. Furthermore, the target for the number of patients acquiring HIV was 500,000, but in 2018 1.7 million people became infected (World Health Organization, 2019b). This is why HIV prevention programs continue to be encouraged.

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Patient experience and satisfaction are important to achieve better health outcomes (Leon et al., 2019). It is notably well-known that better healthcare services for PLWH will improve patients' retention with healthcare services, maintain patients' adherence to ART, and ultimately reduce the HIV viral load (Dang et al., 2013). Discontinuation of healthcare engagement and ART adherence will have adverse HIV consequences and increase a major public health problem (Pérez-Salgado et al., 2015; Anh & Thaweesit, 2019). ART non-adherence will contribute to the failure of the immune systems of PLWH. It will also lead to an opportunistic infection that threatens the quality of life, and in the worst-case, lead to mortality (Johnson et al., 2017). ART is the key to suppressing the viral load in the bloodstream, which is important to prevention strategies. It is well known that viral suppression will reduce the risk of passing the infection to others (Siedner & Triant, 2019).

The dream of an HIV-free world is facing critical gaps and barriers, including the optimization of healthcare services. Healthcare services sometimes have the limitations of poor performance and unequal treatments (Keller et al., 2014). Program collaboration and service integration are now considered vital to health departments to ensure a comprehensive approach, but this requires inter-sectional understanding (Bernard et al., 2016). Stigma also adds challenge to improving the accessibility of healthcare. Stigma disparaging is the equal access of all to receive appropriate services at all levels and circumstances (Moradi et al., 2014).

Within the ecological and policy factors influencing HIV healthcare engagement, the availability of surveillance, testing, prevention, medical and supportive services are crucial. Access within minimal distance, clinic culture, medical home, and the availability of appointments also lead to further and better performances and increased retention of services (Mugavero et al., 2011). Negative experiences between the healthcare providers and at-risk population sometimes detracts their relationship. The feeling of awkward interaction, irrelevant questions, blaming, pettiness, poor support, and confidentiality breaches were often experienced by patients during their treatments (Stutterheim et al., 2014).

In 2018, Indonesia had a total of 640,000 PLWH; 38,000 among them had died from HIV and AIDS-related illnesses, 46,000 people were newly infected in that year. Only 51% of the suspected population knew their status, and 17% of them living with HIV were receiving treatment (UNAIDS, 2018). Obviously, the number is very far from the target and needs intensive attention to improve achievement. Jakarta and parts of West Java, as one of the megalopolis cities in Indonesia, endure significant numbers of PLWH. Jakarta and West Java are both included in the top five most popular provinces that contained people who live with HIV. In 2017, Jakarta itself had around 6,626 people who tested HIV positive (Ministry of Health of Indonesia, 2018).

Indonesia's response to the HIV epidemic is considered

modest. The escalation of stakeholders' contribution is urgent and includes the public health service (Mesquita et al., 2007). The accessibility of healthcare services has to overcome a number of barriers. Stigmatization among healthcare is often high (Risal et al., 2018). It is recognized as a predictor of discriminatory attitudes towards PLWH who engage in healthcare facilities (Harapan et al., 2013). Indonesia also experiences the policy and practice implementation disjunction that will initiate the discrimination of treatment and care (Fauk et al., 2019). As a result, PLWH encounters difficulties in engaging healthcare access; it is also hard for them to adapt to their chronic disease (Senyurek et al., 2021).

Nurses play a major role in the eradication of HIV, providing optimal services starting from preventing transmission to promoting the health and well-being of PLWH (Gilks, 2019). Nurses achieve this by implementing friendly and approachable services within health services. Nurses make mutual collaborations with the population and ensure the continuity of care being provided. Nurses circulate the information about HIV healthcare services available to the people and seek to improve the quality and accessibility of these services. Advocating comprehensive delivery must be empowered by nurse-led HIV services to bring forth patient-centered care for PLWH (Rouleau et al., 2019).

Services for the wider population and PLWH are now broad and advanced. It can be accessed on both a static basis and a mobile one. The look of healthcare services is changing hand in hand with the efforts to move forward. Implementation faces financial obstacles and the progressive needs of the population. This is regarded as the key to widening the outreach of healthcare services (Falkenberry et al., 2018). HIV service delivery is now shifting from one size fits for all approach. It will accommodate comprehensive delivery across the prevention and care continuum through differentiated care (UNAIDS, 2018). HIV care continuum of HIV has been recognized as a progression from serotesting, medical and healthcare engagement, ART treatment and adherence to the ultimate goal that is viral suppression (Kay et al., 2016). The rapid shifting and continual efforts shall be followed by progressive evaluation from all perspectives. This study aimed to evaluate the experiences of PLWH who engaged with HIV healthcare services in Jakarta, Indonesia.

Methods

Study Design

This research used a qualitative phenomenological method. It describes the phenomena of progressive change within HIV healthcare services. Phenomenology is a type of qualitative research that focuses on the individual's lived experiences within a specific phenomenon (Creswell, 2013). This method was used to interpret the experience of the HIV healthcare use from the service user's perspective. This study explores the experiences of PLWH who used healthcare services in

Jakarta, Indonesia. Appropriate conditions help lead towards the successful achievement of objectives (Smith, 2018).

Participants

Participants in the study were PLWH who used HIV healthcare services in Jakarta, Indonesia. Purposive sampling is very commonly used in qualitative research. Purposive sampling allows the qualitative researcher to choose the participants and their characteristics for the study. It is essential for phenomenological study to accommodate participants who have experienced the topic of the research question. Furthermore, it will ensure the quality of the information provided by the research participants. Therefore, the criteria of participants in this study were PLWH who have engaged with HIV healthcare services and willing to share their experiences.

The number of participants was determined by reviewing available information and data saturation. Participants were recruited and selected through a designated HIV non-government organization around the city. This study evaluates the data collected from twelve participants. Saturation was achieved when no other bits of new information or issues emerged. Participants in this study were PLWH, who used HIV healthcare services, such as voluntary counseling, mother-to-child transmission programs, and methadone maintenance therapy clinics within hospitals, public health services, and prison clinics.

Data Collection

This study was conducted in two non-government organizations (NGOs) in Jakarta, Indonesia, which provide social support and engagement for PLWH during their life with the disease. Jakarta has 38 active NGOs and foundations in handling HIV/AIDS issues. The two NGOs provided the list of participants who matched the study inclusion criteria. The selection of participants for the research was based on the types of HIV healthcare services used by the PLWH, as it was expected to enrich the data collected. The researcher made an appointment with the participant before the interviews were conducted to develop emerging environmental situations and build trust. They then set the appointment to carry out the interviews. The study was conducted between July 2016 to January 2017. The study collated the data and information through semi-structured interviews. Two experts independently authenticated the interviews. All interviews were conducted by one person (MH). The other supervisors (WW and HPS) contributed to data analysis and validated the trustworthiness of the research. The interviews were conducted in the Indonesian language and then translated by MH to the English language after data analysis.

The interviews were conducted by questioning the participants through trigger questions and follow-up questions based on the initial responses. The first question in the questionnaire was, "Could you please tell me how has your experience in using HIV healthcare services been

so far?" Then, based on the participant's answer, the interviewer asked a followed-up question such as "Would you please describe to me what do you mean by easily accessed?" or "What do you mean by it was different from what you have ever expected? Could you please elaborate on what more you expected?". Other follow-up questions were asked until the data was confirmed and verified. The interviews lasted between 45-60 minutes. The oral data were recorded through secure tape-recording, and any non-verbal communication data observed were documented in field notes. Data were stored securely within a confidential folder on the computer. The recording results were then written as a transcript in verbatim form and combined with the results of the field notes.

Data Analysis

The stages of the data analysis process in this study used the Stevick Colaizzi Keen method (Speziale et al., 2011) by arranging the information of the interviews and transcribing the recordings into verbatim form. The data script was repetitively listened to and read to ensure the accuracy of significant information. Participant statements were marked to point out the important information relating to the objectives of the study. Finally, themes were formulated by identifying the important information, classifying it into data groups, and categorizing themes and sub-themes.

Trustworthiness/Rigor

The researchers ensured the trustworthiness of the data and results by comparing the results with other research and ensuring the participants provided trustworthy information. Environment familiarity was also confirmed by holding pre-interview meetings and advance contact with all participants. The researcher also discussed the results with fellow researchers and supervisors (WW and HPS) with upper-level degrees of education and expertise.

The transferability of the data was conducted by ensuring that other groups of participants fully understood the research results. The findings have been read by PLWH, who were not participants in the study but still fit the inclusion criteria. This study also surveyed a variety of participants. The reliability of the data is dependent on the saturation of the participant's information by preparing questions that provide accurate answers based on the topic or issue of the study. This study also used repeat questions with an expectation of the same response to clarify and maintain the trustworthiness of the information provided by the participants. Data and results were also presented back to the participants who were involved. The researchers then showed the principles of the results of the research documentation and findings to participants who engaged in the research.

Ethical Considerations

All activities within this research are strictly compliant with the relevant ethical guidelines and considerations. Ensuring that no one was at risk of harm or experiencing negative impacts from the research activities conducted

was crucial. By providing autonomy, beneficence, non-maleficence, confidentiality, and justice, this study was committed to protecting the participants involved. This study was reviewed by the Universitas Indonesia Ethical Council Committee and declared as ethically feasible to be conducted with ethical clearance number 0272/UN2.F12.D/HKP.02.04/2015.

Results

Characteristics of the Participants

There were 12 participants in this study who were PLWH that used healthcare services in Jakarta, Indonesia. The 12 participants participated voluntarily in semi-structured interviews conducted during the research process. All participants acknowledged their HIV-positive status, were open to being involved in the study, and cooperatively answered the questions during the interview. In addition, participants did not express objection or unwillingness to provide answers to any of the questions. The quoted text in this study was originally in Bahasa Indonesia and translated to English to fulfill journal requirements. The characteristic of the participants is displayed in Table 1 below.

Table 1 Participants' Characteristics

Participant Code	Age	Education	Year of Status	Risk Population
P1	29	High School	2005	PWID
P2	30	Elementary	2006	PWID
P3	31	Junior High	2008	Heterosexual Male
P4	32	Junior High	2008	PWID
P5	34	High School	2008	Prisoner
P6	34	High School	2008	PWID
P7	34	High School	2010	Prisoner
P8	34	Bachelor	2010	Heterosexual Female
P9	39	High School	2010	PWID
P10	41	Bachelor	2014	PWID
P11	22	High School	2016	MSM
P12	31	Diploma	2016	MSM

Note: PWID= People Who Inject Drugs | MSM=Men Who Have Sex with Men

Themes

The study developed four significant themes such as accessibility, availability at all healthcare levels, comprehensiveness of service, and affordability. Each theme is explained in the following.

Theme 1: Accessibility

Almost all participants stated that they had easy access to a healthcare facility. According to the participant's statement, the accessibility of the healthcare facility was determined by the proximity of the HIV healthcare facility and the transportation facilities to help them reach it. One of the participants stated that he had no complaints about

the HIV healthcare facility. His statement is documented below:

"Actually, there was no obstacle in order to reach out the facility, and the hospital was really nearby! The only problem I have is to provide a specific time to go. We didn't have to be worried; it is no big deal." (P5)

The other participant said the same thing; he said that the healthcare facilities are near his home. He also said that the facility could be reached while attending another activity. Along with fitting facial expressions, the participant stated the following:

"No, the public health center where I ran for regularly healthcare services was really close by. I can reach the place while I was going somewhere else. But the waiting was still taking some time." (P3)

Participants said that easy access to healthcare facilities was linked to the availability of transportation that they could use. There were so many transport choices in order to reach the services. Following is the relevant participant's statement:

"... the access was not too difficult for sure, it was easy! Lots of vehicles and public transportation to use." (P1)

Theme 2: Available at all healthcare levels

Six participants felt that the healthcare services are now available in all levels of healthcare facilities, from a primary level to a tertiary one. Participants recognized that the facilities are part of government efforts to broaden the range of available services. Two participants summarized their experience as the following:

"It depends on me, where do I want to go, which hospital do I prefer. It's completely up to me, even though I heard I could choose from the services in public health centers around me. There are so many facilities that I acknowledged, and I chose the hospital because I did not want to be recognized." (P5)

"Surprisingly, at first, I thought it only could be done at the hospital far from my house. But my peer navigator enlightened me it could also be done in the public health center near my house. It helps me a lot, you know." (P12)

Theme 3: Comprehensiveness of service

Participants are fully aware of their risk behaviors. It pushed them to start engaging with the healthcare services. Participants get sufficient knowledge and information from the facility, then complete serostatus checking and obtain the test results before starting ART and other behavioral therapy all in one place. Most participants admitted that all of the services for HIV care they experienced were simply done in one place. One participant stated that he felt relieved because the processes were comprehensively all in one place and helped fulfill all needs. Fluently speaking with a heavy tone, the participant expressed the following:

"I am fully satisfied with all of the services, which began with the registration., I can choose whatever name I want to respect my secrecy. They collected me with the others in a room and told us information related to HIV before asking us to express our feelings before getting the test. Some people were crying at the time, but I felt so comforted by the manner of the facilitators. I admired that. Then when I tested positive, they recommended me to start the ART. They looked after me when I disclosed my status. That was a big moment of my life, really." (P11)

The other participant felt the same thing with all the services provided by the healthcare facility. She experienced all the procedures she needed to in one place and only needed to think of her feelings at that time. With a calm tone and soft smile, she spoke as follows:

"...then they brought me to VCT. I was interviewed by the nurse, and he told me about HIV. I also ran the test there. When I came back, the doctor announced the result; I am positive. They counseled me when I reacted and checked how I was feeling, and then we planned the ART. They allowed me to ask as many questions and discuss as many things as I wanted to." (P8)

Theme 4: Affordability

Five participants stated that most of the HIV healthcare services they accessed were free of charge, but some specific services still cost them. For participants who had limited financial income, it sometimes increased their financial challenges. One participant said that the services cost him little but still caused a burden on his financial situation:

"Most of the services were free; I don't pay that much, only for the administration. I guess it might be for doctor service only. When I don't have any money, sometimes this fee was uncomfortable and hard to take." (P1)

The other participant stated that the affordability was convenient. The funding system did not burden him because it was just a small amount to cover. Compared to what he was getting, he felt it was quite cheap. With a confident tone, he said as follows:

"It was free, I guess, but there were some specific services for which I should pay, but that was okay; I think that was normal. At first, I thought it would be expensive, but it was mostly free. I feel grateful. (P10)

Discussion

The themes indicated that there is a significant growth in HIV services. Easy access to the facilities mirrors the success of the healthcare system to provide accessible and quality healthcare facilities for PLWH. A study of factors associated with access to HIV healthcare services stated that HIV-positive patients preferred the nearest place in order to more easily engage with services (Lubogo et al., 2015).

Distance to care will determine the ART compliance

among the PLWH. A study in Malawi found the ART retention increased, and the possibility of loss during follow-up decreased. The range of healthcare facilities on offer influenced PLWH's decision to maintain engagement with healthcare. It also improved annual visits in ART enrollment. Distance to travel was recognized as an obstacle for PLWH (Bilinski et al., 2017). Further distance between the healthcare facility and the patient will increase the cost for PLWH, who had a lower socioeconomic status (World Health Organization et al., 2013).

The distance to travel for the affected population in rural areas was also proven to increase transmission probability. Viral suppression is the key to slow HIV transmission. Viral load suppression will never be achieved if ART compliance could not be obtained. ART compliance requires routine access to reliable and available facilities. The need to travel farther will reduce the likelihood of ART enrollment (Smith et al., 2017). The longer the distance to healthcare facilities, the lower retention in care and viral suppression (Terzian et al., 2018). The longer distance is also regarded as a barrier for healthcare service use (Tafuma et al., 2018).

The availability of healthcare services within all levels of healthcare facilities is considered an advantage. All-level facilities will broaden the range of healthcare services available to the population. Decentralization of HIV services and facilities will also expand the range that HIV services can reach. A study of decentralization of HIV healthcare services experienced by the rural communities in Canada concluded that the PLWH prefers the services to expand to all clinics and public health centers. It provides them with a friendly and well-known environment (Cunningham et al., 2014). It is also cost-effective and reduces threats (Kolawole et al., 2017). A study from Yogyakarta, Indonesia, mentioned that the availability of services keeps the process simple and is convenient to the healthcare environments. The transgender women in this study recognized the positive attitudes of the healthcare professionals and friendly social relationships on both sides (Fauk et al., 2019).

Expanding ART services delivery helps to achieve the desired outcomes of HIV eradication in low and middle-income countries. The expansion of healthcare facilities increases the potential of retention and decreases the mortality rate (Haghighat et al., 2019). The expansion of primary healthcare facilities for HIV services is also associated with the reduction of loss in follow-up and fulfills the gap of incomprehensive healthcare services (Cunningham et al., 2014). Comprehensive care is not merely one type of essential service at a time. It covers all needs and is patient-centered, i.e., the provision of test results must be followed by emotional support. A primary setting has much more time to deliver good services, and this increases patient satisfaction. The satisfaction is also linked to the attitude from reception, waiting times, HIV education, and the comfortability of the service from healthcare professionals. Satisfaction of PLWH also varies with the extent of the facilities (Odeny et al., 2013).

Delivering comprehensive healthcare services for the PLWH will optimize the healthcare continuum. It is well known that comprehensive health services will evidence the strengths of HIV healthcare services. The comprehensive services also increase patient enrolment and retention (Wroe et al., 2018). Comprehensive care also boosts the reduction of HIV transmission in the community. Healthcare services focus on prevention and education. The preventive service scale up the HIV negative and unknown status to check their serostatus (Subramanian et al., 2019).

Comprehensive healthcare services for PLWH will optimize the coordination and communication between healthcare services. Comprehensive services will unify the strategies into efficient and effective actions (Watts et al., 2019). Comprehensive healthcare services lead to universal access to ART, improving patient-centered care, and scale up the baseline of HIV testing among the population at risk and PLWH (Havli et al., 2019).

The affordable cost of engaging healthcare services is helping PLWH to deal with their catastrophic life-changing condition. Low-cost access is believed to be the gateway to universal access for all of the population affected by HIV. Providing universal access will increase the impacts of HIV eradication efforts (Hill & Pozniak, 2016). Providing ART to all PLWH is mandatory for low and middle-income countries to achieve clinical prevention and programmatic benefit for all (Ford et al., 2018). The limitation of the study found some participants were not able to express the qualitative narration of their experience. It required the communication competency of semi-structured interviews. It was also found that there is no scoring system in validating the semi-structured questions. The importance of exploring more about HIV healthcare services literacy among PLWH is crucial.

The implication of this study can be seen that PLWH get fairly easy access to HIV healthcare services in urban and metropolitan settings. In fact, the healthcare services are now reaching the primary level and easier to access with good links to public transport. Equitable distribution of health services in urban and big cities shall be implemented in suburban areas, especially in concentrated epidemics by the government and policymakers. This study showed that the role of nursing is crucial in circulating the information of the availability of services to those PLWH.

Conclusion

HIV healthcare services are growing stronger and continuing to progress. The old paradigm of HIV being nothing but a death sentence is fading away. Precise and accurate information is increasingly being provided to all sectors, communities, and individuals. Healthcare providers and HIV activists are recommended to promote and campaign about the new perspective of accessibility: reduced travel to facilities and less financial hardship from using HIV healthcare services, especially within urban cities.

Declaration of Conflicting Interest

There is no conflict of interest in this study.

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Authors' Contribution

MM contributed to developing the research, collecting and analyzing data, presenting results, and drafting the manuscript. WW and HP contributed to the study concept and design, data analysis, and manuscript development. All authors agreed with the final version of the article.

Data Availability Statement

All data generated or analyzed during this study are included in this published article.

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Psychometric properties of Quality-of-Life Index for Vietnamese women with breast cancer three weeks postmastectomy

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Abstract

Background: The patient's quality of life immediately after mastectomy usually receives less attention than the quality of life after three months, six months, or a year. It is because the focus is mainly on surgical complications. Many instruments measure the quality of life from three months onwards. Still, the quality-of-life instruments right after postmastectomy are not yet verified.

Objective: This paper aimed to test the reliability and validity of the Quality-of-Life Index Vietnamese version (QOLI-V) in Vietnamese women with breast cancer three weeks postmastectomy.

Methods: The descriptive cross-sectional study was designed to analyze the psychometric properties of a Vietnamese version of the modified Quality of Life Index. The modified process was conducted after granting permission from the original authors. The content validity of the modified index was examined by five experts. Brislin's model was used for the translation process. The 26-item QOLI-V was tested in 265 patients with breast cancer stage II three weeks postmastectomy who expected to have a poorer quality of life score. The reliability of the index was measured using Cronbach's alpha. The construct validity was examined using confirmatory factor analysis (CFA).

Result: The content validity index results showed that the lowest I-CVI was .80 and the highest was 1.00. S-CVI/Ave was 0.95, and S-CVI/UA was 0.76. The Cronbach's alpha of QOLI-V was .84, which was considered acceptable. Most of the 26 items featured the correct item-total correlation of .30 to .60. There were only two items correlated with the total scale at .18, and the item with the lowest correlation (.06) was deleted from the item set. The CFA of model 1 with 26 items was not an ideal fit with the data, with Chi-Square/df = 2.15, CFI = .815, GFI = .853, TLI = .792, RMSEA = .066. After deleted an item #general quality of life, and the CFA of model 2 was conducted on the 25-item index. The final result indicated the improvement of the model fit, with Chi-Square/df = 2.26, CFI = .852, GFI = .814, TLI = .790, RMSEA = .069.

Conclusion: The 25-item QOLI-V version is considered valid and reliable to measure the quality of life of Vietnamese women with breast cancer three weeks postmastectomy. Nurses and midwives could use this instrument to measure the quality of life of the patients, and the patients could use it for self-assessment.

Keywords

quality of life; mastectomy; factor analysis; psychometrics; nursing; Vietnam

Patients with breast cancer feel considerable uncertainty when diagnosed with a life-threatening (or terminal) illness. Later on, patients facing the treatment process realize

these are events they could not foresee and are therefore wholly unprepared. From systematic reviews, the stage from mastectomy one month to initial chemotherapy

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represented a transition time of poor adjustment and decreased quality of life (Paraskevi, 2012). However, most of the studies focus on describing and providing support for quality of life as much as three months, six months, or over one year postmastectomy, but ignoring the immediate poor quality of life for the patients in the hours, days, and weeks after their mastectomy during the transition from hospital to home (Razdan et al., 2016). According to previous studies, it has been shown that decreased quality of life after surgery may predict early treatment discontinuation in patients with breast cancer (King et al., 2000; Richardson et al., 2007). The later poor quality of life will lead to reoccurrence, metastatic, or even death among this group (Coates et al., 2000; Mols et al., 2005). Thus, poor quality of life in patients with breast cancer postmastectomy exists as an urgent problem and requires effective interventions to reduce it. In addition to introducing a measure for the concept of quality-of-life postmastectomy, a reliable and valid scale must necessarily be established.

Definition of Quality of Life of Patients Postmastectomy

Quality of life (QOL) is the primary goal that most people attain during their daily life. Since this concept has been recognized, QOL is not separate from health because it is considered as the person's sense of well-being that stems from the satisfaction and dissatisfaction with aspects of life (Ferrans, 1990) or functional capacity, symptoms (physical and psychological) and perceptions of health (McCorkle et al., 1989). The quality of life in the nursing context is related to a specific illness, and it can be considered similar meaning with health-related quality of life. A concept analysis of nursing, based on the guiding theory of Peplau's, Rogers', Leininger's, King's, and Parse, is defined as a contextual, intangible, subjective perception of one's lived experience (Plummer & Molzahn, 2009). Cella (1994) identified four dimensions of quality of life in the context of cancer that encompasses physical well-being, functional well-being, emotional well-being, and social well-being. The concept of Cella (1994) and its four significant domains of quality of life help investigate the concept multi-dimensionally. Besides, (Padilla & Grant, 1985) describe the quality of life as five dimensions: physical well-being, social concerns, body image concerns, psychological well-being, and diagnosis/treatment response. In breast cancer, the concept of QOL describes the impact of breast cancer on the domains of physical, social, psychological well-being, and spiritual well-being (Ferrell et al., 1998).

Receiving a mastectomy also raises concerns about body image, uncertainty in the situation of illness, surgical symptoms, lacking nursing care or social support, and poor patient-physician communication impacting the patient's quality of life (Denieffe et al., 2014; Mandelblatt et al., 2003; Wronska et al., 2007). Thus, in patients with breast cancer postmastectomy, the concept of quality of life should be more specific, clearly describing the situation, which occurs among this group. That is why the definition of QOL defined

by Padilla and Grant (1985) as physical well-being, social concerns, body image concerns, psychological well-being, and diagnosis/treatment response remains the most suitable application for QOL postmastectomy.

Following Padilla and Grant (1985), physical well-being can be considered a strength, fatigue, ability to work, current health, and perceived usefulness. Psychological well-being implies happiness, satisfaction, fun, general QOL, pleasure in eating and sleep. The body image concerns mean the ability to look at the changes in one's body, the tendency to worry, and the ability to adjust and live with body changes. The social concerns focus on social rejection, social contact, or the need for privacy. Diagnosis/treatment response relates to surgical treatment symptoms, which are defined as the ability to have sufficient sexual activity, nutrition, weight, pain, and severity of pain, nausea, and vomiting (Padilla & Grant, 1985). In postmastectomy patients, the attributes of physical, psychological, and social concerns of QOL might be the same as other cancers; however, the defining attributes of body image and treatment response might differ. The body image in breast cancer patient postmastectomy relates to the ability to look at the changes of the body, worry over scarring, perceived femininity, and how easy it is to live with anybody changes (Barolia, 2008; Denford et al., 2011; Fobair et al., 2006; Lindwall & Bergbom, 2009; Toriy et al., 2013). The treatment response of mastectomy patients focuses on symptoms around the hand and shoulder such as the ability to raise the hand, any swelling of the arm, the sensitivity of the breast incision, sufficient nutrition, weight, as well as the severity and frequency of pain (Champion et al., 2014; Janz et al., 2007; Taghian et al., 2014). Operationally, the concept of quality of life on postmastectomy patients is defined as the perception of life experienced based on five domains: physical well-being, psychological well-being, body image concerns, social concerns, and treatment responses. Defining attributes of QOL consist of physical well-being (strength, fatigue, ability to work, current health and perceived usefulness), psychological well-being (happiness, satisfaction, fun/hobbies, eating pleasure and sleep), body image concern (look at the body, scare of scarring, perceived femininity, ability to live with losing a breast, the worry of future living without a breast), social concerns (family, friends or healthcare giver staff contact, social rejection, and privacy needs and treatment responses (ability raising the hand, swelling of the arm, sensitive of destroying breast, nutrition sufficient, weight, severity, and frequency of pain)

Existing Instruments

Most of the effective existing instruments measuring the quality of life for patients with breast cancer are all well-known instruments that have been used to examine QOL in many stages of breast cancer (Perry et al., 2007). Among those, FACT-B and EORTC-BC23 are specific for patients during chemotherapy treatment. QOL-BC23 focuses on physical function, whereas FACT-B

emphasizes emotional well-being (Nguyen et al., 2015). EORTC-QLQ30 and SLDS-BC or QOLI are suitable for QOL in general. Interestingly, the QOLI of Padilla and Grant (1985) is based on the concept of QOL across a range of cancers in women, though sharing similar circumstances to breast cancer patients, such as cervical cancer, colorectal cancer, and hysteric cancer post-surgery. The original QOLI of Padilla and Grant (1985) identifies 14 factors and has been validated in many studies measuring QOL; hence it has proven validity and reliability (Rukholm et al., 1998). Over time, the QOLI has been modified for colostomy patients by adding nine items focusing on some aspects of symptoms post-surgery. The dimensions of QOLI would seem to be closest to the

definition of quality-of-life postmastectomy with five domains of physical well-being, psychological well-being, social concerns, body image concerns, and treatment/diagnosis response. The length of 23 items with self-administer base on the visual line for the most concern in the past four weeks. Summarily, with the same aspects of colostomy and mastectomy on colorectal and breast cancer patients, the QOLI of Padilla and Grant (1985) covers most aspects of the operational definition of quality of life postmastectomy. Thus, this instrument will be selected to test the psychometric properties in the breast cancer population postmastectomy. The summary of the comparison of the tools measuring QOL is presented in Table 1.

Table 1 Summary of existing instruments measuring QOL for patients with breast cancer

Name & Authors	Purpose	Domains	Scale	Duration	Items	Type	Reliability	Validity
European Organization for Research and Treatment of Cancer QOL Breast Cancer-Specific Version (EORTC QLQ-BR23) (Sprangers et al., 1996)	QOL in the breast cancer population at various stages and with patients with differing modalities	5 (Therapy side effects; arm symptoms; breast symptoms; body image; sexual functioning)	Four-point Likert scale ranging from 1 (Not at all) to 4 (Very much)	Past week	23	Self-report (10 minutes)	Reliabilities ranged from .70 to .91	Discriminant validity of mutually exclusive groups based on their initial performance status scores produced medium to large effect sizes ranging from .43 to 1.1
European Organization for Research and Treatment of Cancer QOL Cancer-Specific Version (EORTC QLQ-C30) (Aaronson et al., 1993)	QOL in the general cancer population	9 (Physical; role, cognitive; emotional; social; fatigue; pain; nausea and vomiting; global health status and quality of life)	Four-point Likert scale ranging from 1 (Not at all) to 4 (Very much); 1 (Very poor) to 4 (Excellent)	Past week	30	Self-administered (Under 10 minutes)	Reliabilities ranged from .69 to .90 (Carlsson & Hamrin, 1996) Test-retest reliabilities ranged from .63 to .87 (Hjermstad et al., 1995)	The correlation coefficient between the QLQ-C30 and the Profile of Mood States (POMS) was .56 (McLachlan et al., 1998).
Functional Assessment of Cancer Therapy – Breast Symptom Index (FACT-B) (Brady et al., 1997)	Specific to breast cancer patients	6 (Physical well-being; social/family well-being; emotional well-being; functional well-being; relationship with doctors; additional concerns)	Five points Likert scale ranging from 0 (Not at all) to 4 (Very much)	Past week	37	Self-report or interviewer-administered (estimated 25 minutes)	Internal consistency was .90	Spearman correlations between FBSI and FACT ranged from .34 to .84
Functional Living Index – Cancer (FLIC) (Morrow et al., 1992)	Assess the effect that cancer treatment and symptoms on functional ability in all areas of life	5 (Physical functioning; mental functioning; social functioning; general health/well-being; gastrointestinal symptoms)	Answer questions by placing a vertical line at the point in the best present point	Past two weeks; Past month; Today	22	Self-administered (Under 10 minutes)	Reliability ranged from .64 to .87 (Morrow et al., 1992)	Correlation coefficients between FLIC and SF-36 ranged from .50 to .62 (Wilson et al., 2005).
Life Satisfaction Questionnaire (LSQ) (Carlsson & Hamrin, 1996)	Measure one's general sense of satisfaction with life as it relates to school, relationships, leisure time, religious practices, and overall health for women with breast cancer	6 (Quality of family relation; physical symptoms; socioeconomic situation; quality of daily activities; sickness impact; and quality of close friend relation)	Seven points Likert scale ranging from 1 (very much) to 7 (Not at all)	Past week	32	Self-report (estimated 20 minutes)	Reliabilities ranged from .62 to .92	Correlation coefficients between LSQ and EORTC QLQ-C30 were -.68 to .54

Table 1 (Cont.)

Medical Outcome Short Form Health Survey (SF-36) (Ware et al., 1993)	Developed to assess health-related QOL	8 (Physical functioning; role limitations due to physical health; role limitations due to emotional problems; energy/fatigue; emotional well-being; social functioning; bodily pain; health)	Scaled using various scales	Unspecified	36	Self-administered (5 minutes)	Reliability ranged from .74 to .98 (Hays et al., 1995)	Correlation coefficients between the SF-36 and the General Health Questionnaire (GHQ-29) were -.35 to -.61 (correlations are negative because the two scales run in opposite directions) (Faiide & Ramos, 2000)
Quality of Life Index (QL-Index) (Spitzer et al., 1981)	Assess health outcomes of those with cancer and other chronic diseases	5 (Activity; daily living; health; support; outlook)	Three points Likert Scale	Past two weeks	5	Interviewer administered or self-administered (Under 10 minutes)	Internal consistency of .78	Correlation coefficients ranged from .40 to .63 (32)
Satisfaction with Life Domains Scale for Breast Cancer (SLDS-BC) (Spagnola et al., 2003)	Developed for satisfaction with life among breast cancer patients	5 (Social functioning; appearance; physical functioning; communication with medical providers; spirituality)	Seven points Likert-type scale ranging from 1 (A "delighted" face) to 7 (A "very unhappy" face)	Unspecified	32	Self-report (estimated 20 minutes)	Reliabilities ranged from .90 to .93	Correlation coefficient between SLDS-BC and FACT-B was .59
World Health Organization Quality of Life – Brief Version (WHOQOL-BREF) (Whogol Group, 1998)	Designed to examine domain level profiles assessing the quality of life	4 (Physical health; psychological; social relationships environment)	Five points Likert scale with varying anchors	Past two weeks	26	Self-administered (estimated 15-20 minutes)	Reliability ranged from .66 to .84. Similar alphas have been shown for test-retest reliability ranging from .66 to .87	Correlation coefficients between the WHOQOL-BREF and SF-36 ranged from .36 to .78 (Da Silva Lima et al., 2005)
Quality of Life Index (Padilla & Grant, 1985)	Examine the quality of life of colostomy patients	4 (Physical concerns, psychological concern, social concern, body image concerns, treatments, and responses)	10 points analog scale. Patients placing a vertical line at the point in the best present point	Past one month	23	Self-administered 10 minutes	Reliability Ranged from .65 to .85	

Methods

Study Design

The descriptive cross-sectional study was designed to analyze the psychometric properties of a Vietnamese version of the modified Quality of Life Index (QOLI-V) on patients three weeks postmastectomy. The modified process was conducted by researchers after granting permission, acceptance, and consultation of the original authors.

Sample and Setting

The population of this study was the patients three weeks postmastectomy at the Breast Surgical Oncology Ward in the Oncology Hospital in Ho Chi Minh City, South of Vietnam. Convenient sampling was used to select the respondents. The inclusion criteria of the respondents were aged 30-60, could read and write Vietnamese, no other diseases, and normal surgical recovery process at seven days.

The literature suggests the estimated sample size of CFA should not be less than 200 to avoid violating the thumb rule of "too few degrees of freedom" (Hair et al., 2010). Other assumptions requested that the sample was > 200 for the theoretical model or ≥ 300 for the population

model for CFA in physical health care. A systematic review also proposed that the number of subjects should be equal to the number of items multiplied by 10 in the nursing field (Watson & Thompson, 2006). It is estimated that 265 patients were included to test the psychometric properties of QOLI_V, with 26 items modified from QOLI (Padilla & Grant, 1985) combined with the five domains.

Instrument Validation

The demographic form and the modified quality of life index Vietnamese version (QOLI-V) were used to collect data in this study. The demographic form was developed by the researchers asking about the characteristics of the respondents, such as age, marital status, occupation, education, income, and mastectomy type.

The QOLI_V was a 26-item questionnaire composed of five domains: physical well-being, psychological well-being, social concerns, body image concerns, and treatment response. Data were indicated by marking an X on the visual line equal from 0 to 10 score. Scores were presented as numeric rating scales. QOL was calculated by the sum of the scores divided by the sum of items with a low score indicating a low QOL. The original QOLI with 23 items retained with five domains. In reference to the concept of QOL in a mastectomy group, four items related

to the symptoms of patients with breast cancer postmastectomy, including swollen arms, the ability to raise hands, the sensitivity of breast incision was added to the section on treatment response and perceived femininity was added to the section on body image concerns.

Then the 27-item QOLI was sent to five experts for testing its content validity index following the recommendation of Polit et al. (2007): two surgeons with ten years of experience in the mastectomy process, two Ph.D. nursing lecturers, and one head nurse in the Breast Surgical Department. The results showed that the lowest I-CVI was .80 and the highest was 1.00; S-CVI/Ave was .95, and S-CVI/UA was .76, which implied good validity for this instrument (Osano & Grant, 2016; Polit et al., 2007). The CVI testing of 5 experts confirmed that for 26 items, most of all item was rated from 3 (relevant) to 4 (very relevant). The sum agreements of each item related to the quality-of-life postmastectomy were calculated. The result confirmed that most of the items correlated well with the quality-of-life postmastectomy, except the item of sufficient sexual satisfaction (.40). Experts rated this item with a lower score of relevancy and recommended researchers consider the meaning of this item on Vietnamese culture.

Instrument Translation

The 26 item-modified QOLI was translated into Vietnamese using Brislin's model. It was translated from English into Vietnamese and back-translated by two different bilingual experts at the Language Center, University of Medicine and Pharmacy, Ho Chi Minh City, Vietnam. Two translated versions were reviewed by a Vietnamese nurse responsible for teaching English to nursing students in the university, identifying ambiguous words and confirming the symmetry. The Quality-of-Life Index Vietnamese version (QOLI-V) was then assessed for its intelligibility in the Vietnamese context and culture with 5 cases of patients in the Surgical Oncology Ward. The piloting of QOLI-V also showed that most patients skipped the question asking about sufficient sexual satisfaction after mastectomy. When researchers discussed the reason with patients, the answer was that mastectomy treatment was terrifying and tiring. They and their partner did not want to have sex, or it was of no meaning in the postmastectomy period. Based on the Vietnamese culture, women often feel shame and become uncomfortable when asked about sexual activities, or they could not express the meaning of sexual satisfaction. In the stage of three weeks postmastectomy, sufficient sexual satisfaction was felt completely irrelevant to ask because patients were usually concerned with other aspects of their life than sexual satisfaction. Therefore, this item was deleted from the questionnaire.

Ethical Consideration

This study was approved by the Board of Ethical in Biomedical Research at the University of Medicine and Pharmacy and the Research Ethical Board of Oncology

Hospital. This study was an instrument development part of the Dissertation project for PhD education in the Faculty of Nursing, Chulalongkorn University, Thailand. After IRB approval, the researchers met patients and presented the objectives, procedures to collect data, and approximate length of time for data collection at the Surgical Oncological Ward. Patients who matched the inclusion criteria and wished to volunteer signed the consent form to prove that they agreed to answer the whole questionnaire.

Data Analysis

The input data were checked for errors before entering the analysis tests. The data were analyzed for the assumption of normal distribution and descriptive demographic data and reliability of the measurement by the SPSS program version 16.0. Then the confirmatory factor analysis was conducted by using the AMOS version 20.0. The process of conducting the CFA conducted by following standardized recommendations: (a) Initial data analysis to identify any problem of missing data or input errors, (b) Fix one-factor loading on each sub-construct to a specific value as equal to 1, (c) Factor loading higher .5 to .7, (d) Construct reliability .6 was accepted, (e) Standardize residual accepted (from 2.5 to 4.0), (f) Not using modification indices to adjust the model fit (Hair et al., 2010).

Results

Characteristics of the Respondents

Table 2 Characteristics of participants (*N* = 265)

Characteristic	<i>f</i>	%
Age		
30-39	60	22.6
40-49	125	47.2
50-59	80	30.2
Marital status		
Married	209	78.9
Widowed	29	10.9
Divorced	12	4.6
Single	15	5.7
Education		
Primary school	75	28.3
Secondary school	84	31.7
High school	63	23.8
University or higher	43	16.2
Occupation		
Housework	112	42.3
Small business	52	19.6
Worker	57	21.5
Officer	31	11.7
Retire	13	4.9
Monthly income (VND)		
< 3 million	137	51.7
3-5 million	107	40.4
5-10 million	21	8.0
Mastectomy type		
Simple	94	35.5
Radical	171	64.5

The demographic data of the respondents showed that most of them were in middle age (47%). Many of the women were married and living together as a family (78.9%). However, the respondents had low education (primary and secondary school, 60.5%), and income from the main family members was still low (<3 million and/month, 51.7%). The majority of the respondents were housewives (42.3%), farmers, or doing small business at home (19.6%). Only one-third of them were office workers or executives; 64.5% of the respondents received radical mastectomy (see Table 2).

Reliability of the QOLI-V

The reliability of the revised translation version, 26-item QOLI-V, was tested for its reliability with 265 Vietnamese patients three weeks postmastectomy. Cronbach's alpha of QOLI-V was .84, which was considered acceptable for the modified instrument (Polit & Beck, 2003). Most of the 26 items featured the correct item-total correlation .3 to .6. There were only two items correlated with the total scale at .18. Regarding the last item, "general quality of life," the total correlation was only .06, and Cronbach's alpha increased when it was deleted. Thus, it was considered that this item should be deleted from the item set or not (see Table 3).

Table 3 Item correlation of Quality-of-Life Index Vietnamese Version

Items	Scale Mean if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Strength	172.82	.525	.832
Tired	171.63	.209	.841
Sleep	172.22	.469	.833
Weight	171.22	.185	.842
Appetite	171.96	.557	.829
Food amount	171.71	.521	.831
Daily work	173.94	.514	.831
Current health	172.82	.603	.827
Fun	173.26	.393	.836
Useful	171.99	.552	.829
Happiness	171.36	.556	.830
Worry of future	171.32	.236	.841
Life satisfaction	171.97	.525	.830
Pain	172.06	.284	.839
Frequency of pain	171.77	.396	.836
Arm swollen	170.28	.284	.839
Raise hand	171.82	.165	.842
Breast sensitive	171.53	.291	.839
Adjust easy	171.66	.374	.836
Scare of scar	171.50	.360	.837
Femininity	171.98	.288	.839
Difficult to look body	171.68	.329	.838
Meeting	172.22	.355	.838
Reject	170.26	.367	.837
Private	171.99	.318	.840
General quality of life	171.98	.060	.847

Construct Validity - Confirmatory Factors Analysis

The construct validity of the instrument was tested using the confirmatory factor analysis (CFA). The model validity is assessed based on exact test fit, with Chi-Square/df <2.0 is considered good and <5.0 is acceptable, Root Mean

Square Error of Approximation (RMSEA ≤ .08), Standardized Root Mean Square Residual (SRMR ≤ .05), Comparative Fit Index (CFI ≥ .90) (Hair et al., 2010). The researchers also used other evidence to concern the appropriate model fit.

The initial model 1 was drawn up in the AMOS graphic program and run CFA with the data set. The first analysis showed that with 26 items based on the construct of 5 dimensions, model 1 was not an ideal fit with the data. The findings in detail were reported as Chi-Square/df 623/289 = 2.15, CFI =.815, RMSEA =.066. The model was presented in (Figure 1).

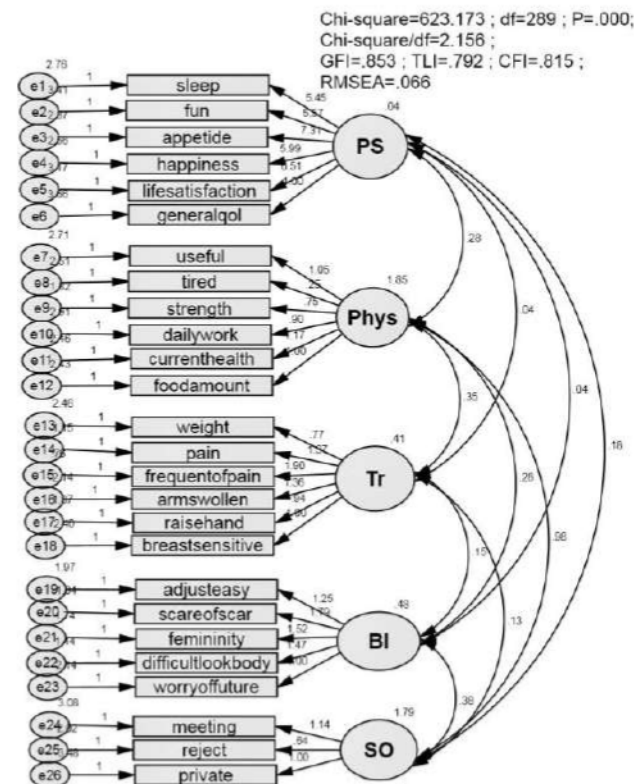


Figure 1 CFA Model 1

Note:

PS: Psychological well-being | Phys: Physical well-being | Tr: Treatment responses | BI: Body image concerns | SO: Social concerns

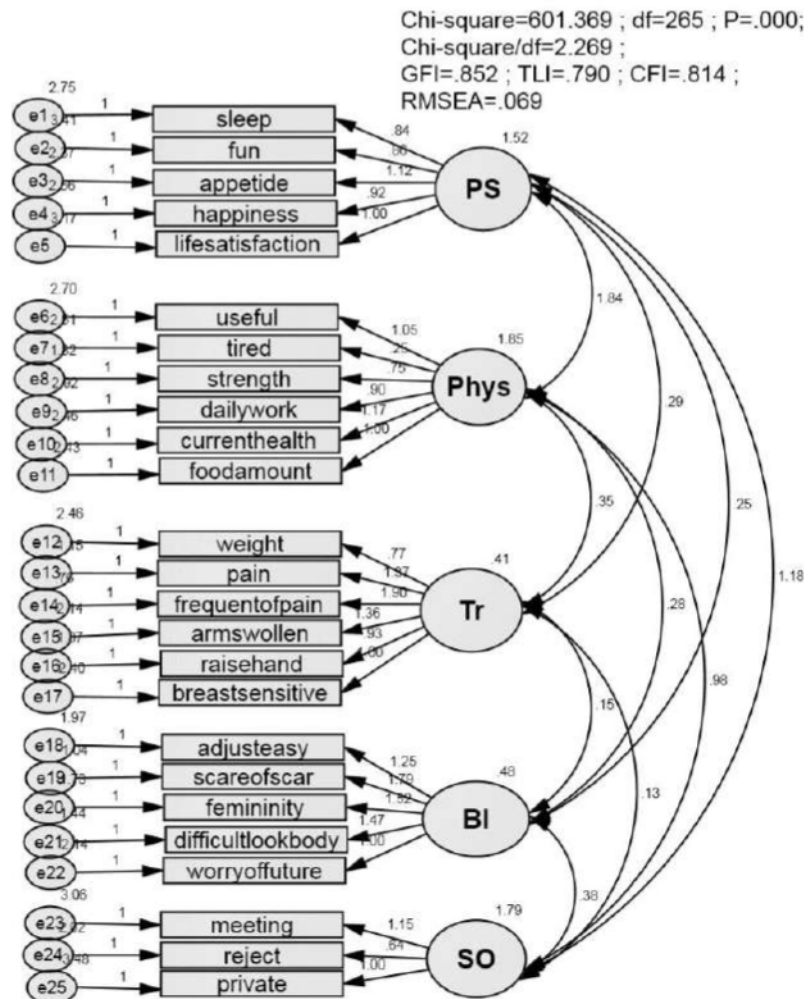
For most items, the standardized estimation (factor loading) was from .50 to .66. There is no estimation indicated the cross-loading factor. However, there were three items that the general quality of life, weight, and breast incision sensitivity were lower than .50, with the standardized regression weight estimated as .045, .48, .48, respectively. The residual estimation of 26 items ranked from 1.1 to 3.8 was acceptable based on the standardization rule. However, the residual estimate of e6 (general quality of life) exceeded the accepted level with the result at 4.2. The construct reliability of the measurement was high and exceeded the level of .6.

As for the modification indices, the general quality of life item is considered the cross-loading item. The

regression weight of these items was adjusted for the par change in every item or latent variable of the model. Therefore, this item was considered for deletion from the model.

Following the empirical evidence of the CFA in model 1, the general quality of life was deleted, and the CFA of

model 2 was conducted. The findings showed that the model fit improved, with the criteria Chi-Square/df = 2.269, CFI = .814, and RMSEA = .069. The construct reliability of the Psychological dimension was improved after deleted one item. The model was presented in Figure 2.



Note:

PS: Psychological well-being | Phys: Physical well-being | Tr: Treatment responses

BI: Body image concerns | SO: Social concerns

Discussion

Following Hair et al. (2010) to assess the model validity, we need the key value of Chi-Square/df, CFI, and RMSEA and other evidence to concern the appropriate model fit. Firstly, the confirmed factor analysis showed that the model of quality of life was acceptable as consistent with the concept. Although the Chi-square value was .00 (< .05) implied that the model might not fit. However, the Chi-square value may be influenced by the number of samples. In this study, 265 cases were higher than 250, as

referenced (Boateng et al., 2018). When we considered the Chi-Square/df in both models, the result was 2.15-2.26, less than 3 acceptable occasionally (Hair et al., 2010). The CFI, GFI, TLI of these models was over 8 compared to the standard of >.9 (Hair et al., 2010). Although it was not a perfect fit, the model was considered good for measuring the quality of life. Regarding RMSEA, both models were acceptable, with RMSEA were .06 (< .08) suggested the adaptable criteria for model fit.

Secondly, from model 1 to model 2, there was a slight decrease of CFI, GFI, TLI with increased Chi-Square/df.

RMSEA increase proved that the deleted item "general quality of life" was not contributed to the quality of life or considered redundant. Therefore, this item was deleted from the model. Thirdly, although model 2 was not also highly fit with the result of Chi-Square/df = 2.269, CFI = .814, and RMSEA = .069. The researcher did not try to rerun the model because this model was consistently based on CVI, Cronbach's alpha, and experts from a clinical view. Therefore, deleted more items did not help improve the model but ruin the construct of the quality of life in patients with breast cancer.

This study proposed the model for concept quality of life three weeks postmastectomy. The original model has been modified with four items and deleted two items through the process of developing the scale. The final 25-item QOLI should be tested in another group of patients with breast cancer in the early stage of treatment to conclude the validity and reliability of this scale. In addition, the construct of social concerns needs to be adjusted by adding the new constraints for increasing the decrease of freedom set up the tau-equivalent between each construct in the model following the suggestion of (Hair et al., 2010). The modification indices also suggested a high correlation between the appetite and food amount that may imply the redundancy of the item. This model should be considered for testing on a larger sample size to satisfy the assumption of the test and not violate the thumb rule of few degrees of freedom.

Conclusion

The findings of this study provided good reliability and validity of the QOLI-V among postmastectomy patients. The QOLI-V consisted of 25 items with five dimensions: physical well-being, psychological well-being, social concerns, body image concerns, and treatment response. Nurses and midwives can use this instrument to measure the quality of life of the patients with breast cancer postmastectomy, and the patients could use it for self-assessment.

Declaration of Conflicting Interest

There is no conflict of interest in this study.

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Authors' Contribution

HTNX designed the study, collected data, analyzed the data, wrote and revised the manuscript. ST designed the study, wrote and revised the manuscript. All authors contributed and agreed with the final version of the manuscript.

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Data Availability Statement

The datasets of this study are available from the corresponding author on reasonable request. The final instrument is available in appendix.

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Appendix

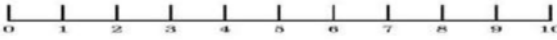
The Quality-of-Life Index for patients with breast cancer three weeks postmastectomy

Modified from Quality-of-Life Index of Padilla and Grant (1985)

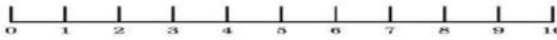
Instructions:

Please read each question and place an "X" on the line that most closely measures how you feel during the past weeks. The line level is measured from "Not at all" to "Completely/Extremely", with the score from 1 to 10. Please answer every question.

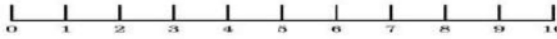
- How much strength do you have?

Not at all  A great deal

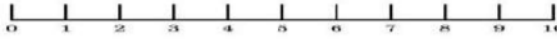
- Is the amount of sleeping time sufficient to meet your needs?

Not sufficient  Completely sufficient

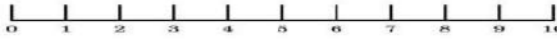
- Do you feel tired easily?

Not at all  A great deal

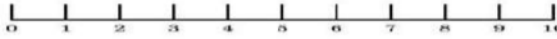
- Do you feel your current weight is a problem?

Not at all  A great deal

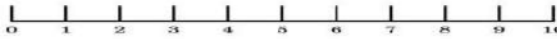
- Do you find eating a pleasure?

Not at all  A great deal

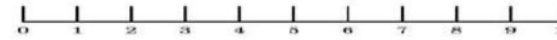
- Is the amount of food you eat sufficient to meet your needs?

Not at all  Completely sufficient

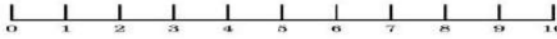
- How much can you do your usual tasks (homework, office work, and gardening)?

Not at all  A great deal

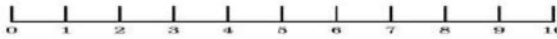
- How is your present stage of health?

Extremely poor  Excellent

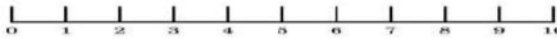
- How much fun do you have (hobbies, recreation, social activities)?

Not at all  A great deal

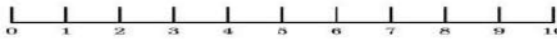
- How useful do you feel?

Not at all  Extremely useful

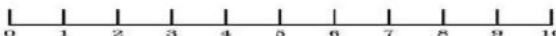
- How much happy do you feel?

Not at all  A great deal

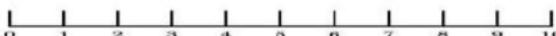
- How satisfying is your life?

Not at all  Extremely satisfying

13. How much pain do you feel in your arm and shoulder?

Not at all  Excruciating

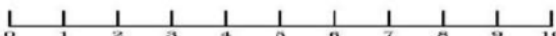
14. How often do you feel pain?

None  All the time

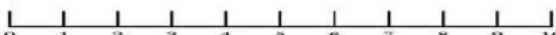
15. Do you have the arm or hand swollen?

Not at all  Extremely

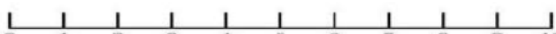
16. Is it difficult to raise your arm or move it sideways?

Not at all  Extremely difficult

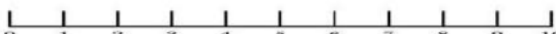
17. Is your devastated breast over-sensitive like tingling, itching, formication?

Not at all  Extremely sensitive


18. How worried are you about your future after mastectomy?

Not at all  A great deal

19. How easy is it to live with your devastating breast?

Not at all  Extremely fearful

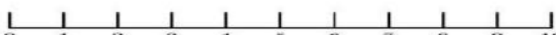
20. How difficult is it for you to look at your body postmastectomy?

Not at all  Extremely difficult

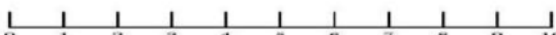
21. How fearful are you from the scar of devastating breast?

Not at all  Extremely fearful

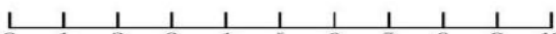
22. Do you feel less feminine as a result of mastectomy surgery?

Not at all  Extremely

23. Is the level of contact with your friends and family sufficient to meet your needs?

Not at all  Completely sufficient

24. Do you feel rejected by your family or loved one?

Not at all  Extremely

25. Is the amount of privacy you have sufficient to meet your needs?

Not at all  Completely sufficient

Common ethical dilemmas of family caregivers of palliative patients in Indonesia

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Abstract

Family caregivers, especially in Asian countries, have a profound role in caring for a sick family member. However, there are wide variations between the Asian and western world in terms of culture and facilities. Therefore, the problems and needs of family caregivers between those two regions may also be distinct, and it is important to explore and elaborate based on our empirical evidence. In Indonesia, motives and values in caregiving and religion become the wheel-power of the family caregivers in providing care. This affects action and consequences for caregivers. This paper attempts to elaborate on common ethical dilemmas that usually face by family caregivers in Indonesia. Unfortunately, family caregivers typically are not prepared to make those challenging decisions. Therefore, we recommend not only that family caregivers need to be involved in the caring process, but also their issues and ethical dilemmas should be assessed and addressed by health care professionals, especially nurses, who have the most frequent contact with patient and family caregiver.

Keywords

Asia; caregivers; religion; health personnel; caring; ethics; nursing; Indonesia

Prolog

Without a good understanding of what it is like to be overwhelmed by the experience of illness - one's own or that of a loved one - how can the doctor or ethicist (or other health care professionals) appreciate the human situation the doctor must address?" (Dresser, 2011).

This implies that understanding the lived experiences of patients and family caregivers is an essential key to take care of patients with a terminal illness. Accordingly, we would start this perspective essay by presenting three real cases.

Case one

Roy, 25 years old, a young man we interviewed in a chemotherapy clinic in Yogyakarta, Indonesia, was accompanying his mother, diagnosed with breast cancer.

He took it hard when we asked what his life activity was. Finally, he said: 'Well, I was a happy newly graduate entering my first day of work, but then mom called me almost every hour that day. She asked what time would I be home. That night I could not sleep. I thought it should be fine to postpone my life for 1-2 years to be her caregiver. My life can wait, but my mother's treatment cannot. I then submitted a resignation letter at the end of that week.'

Case two

Celine, 34 years old, who has been married for ten years, was looking forward to having a child of her own. She used to live in Singapore, but since last year, she moved back to Jakarta to take care of her mother, diagnosed with tongue cancer, and her father, a diagnosed Alzheimer's patient. Celine has an older sister who lives nearby; however, she said she was already too busy to take care of her own three kids. Therefore, it should be Celine who becomes their

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mom's caregiver since Celine has no kids. Coming from a wealthy family, they set up a proper home care plan fully equipped with nurses and a visiting doctor. However, it has been three months since she could go anywhere. One time she went to the gym, but she received a phone call from her husband asking how she could leave their parents at home in that condition. She was then stuck at home, bored and depressed.

Case three

Maria, almost 50 years old, decided to be her sister's caregiver, Anna, since five months ago. In doing so, she needed to leave her family and job in Kalimantan, Indonesia, which was such a tough decision to make. Anna, 36 years old, was diagnosed with breast cancer around three years ago. She has fought bravely, and now she suffered from constant pain and a large malignant wound on both of her breasts. She also suffered from anemia and needed to go to the hospital for a transfusion. Nevertheless, Anna is a cheerful lady with a bright personality. She knew exactly what is going on with her condition and was ready for the worst scenario. Her concern was only for her daughter, Lia (16 years old). Lia never knew who her father is since she was born. Since Lia goes to school and Anna was bound to bed rest, Maria's heart was moved. Actually, Maria and Anna had such opposite characters; they had argued in many ways since they were little. Maria decided to be Anna's caregiver because she could not be on her mother's side during her last moment in life. This guiltiness haunted her for many years. She was expecting that by becoming one of Anna's caregivers, her guiltiness would fade away. When we asked: *"With whom would Lia stay with when something happens to Anna?"* With her soft voice, she said that this is the most important topic, but she could not initiate it with Anna. She does not know how and when to start this discussion.

These cases illustrate that caring for the loved ones (who are ill) affects the patients and may also change the family caregivers' life. Accordingly, the [World Health Organization \(2010\)](#) defines palliative care as an approach to enhance not only the quality of life (QOL) of patients but also their family caregivers. This definition relates to the Indonesian situation where caring for the family member is considered part of Asian culture ([Funk, Chappell, & Liu, 2013](#)).

This perspective paper aims to elaborate experiences of family caregivers in Indonesia and to identify some common ethical dilemmas in their palliative experiences.

Family Caregivers

The family caregiver has various definitions. The most common meaning refers to people who provide care to their loved ones with or without blood relations, including in-laws and neighbors ([Kilic & Oz, 2019](#)). This person may or may not live with the care recipient, but they provide care for at least 6 hours a day. However, the most common differentiation with the formal caregiver is that there is no

financial compensation from the care recipient to this family caregiver.

Family caregivers' circumstances are varied between Western and Asian regions. In the Western world, independence (or lack of dependency) is highly appreciated. The government responds by providing various formal facilities such as long-term, hospice care, nursing homes, and many other institutions in order to maintain the individual sense of independence for people with chronic and terminal illnesses. On the other hand, in Asian countries, including in Indonesia, taking care of family members is part of the culture. In this setting, there are many important lessons that we have learned from generation to generation—taking care of our family, especially our parents, may be the only way we know how to appreciate life and our inheritance. In Javanese culture, for example, *tabon* is a term that refers to a child that is assigned to take care of a parent ([Keasberry, 2001](#)). According to this culture, *tabon* will be granted ownership of the house once the parents are passed away ([Keasberry, 2001](#)).

In relation to financial compensation, some developed countries have various schemes. For example, in the Netherlands, people are able to self-assign a '*mantelzorg*' (family caregiver in Dutch). They put this information on legal government documentation. When something happens to their health, this *mantelzorg* will provide direct care, including taking the patient to the hospital, facilitating their groceries, and other daily activities. The Dutch government offers a financial scheme to compensate for the time spent by the *mantelzorg* in providing this care. There is a limited amount of Euros per day that can be accessed by the *mantelzorg* and applied as an invoice ([Alice, Inger, & Mirjam, 2019](#)).

Considering the wide variations in the Western and Asian cultures, this implies that we need be careful about directly or thoughtlessly adapting ideas or interventions from the Western countries to Asian ones. Cultures are a form of intergenerational heritage that actively shapes people's lives, including the family caregiving condition. Since one of the most suitable policy types is supported by empirical evidence, research on family caregivers in Asia, including Indonesia, is essentially needed.

Family Caregivers in Indonesia

When one of the authors (MSK) started PhD study in 2015, funded by the Dutch government, evidence was limited concerning family caregivers in Indonesia. Fortunately, research on this topic has been growing progressively in the past five years. A study revealed that family caregivers have a profound role in patient care even during hospitalization ([Effendy et al., 2015](#)). This finding implied that family caregivers must have important tasks at home. They should be supported. They should be part of the care. The next question is, how can we provide the support and care that they need?

This initiated me to start my first study by comparing the experiences of family caregivers of patients with cancer and patients with dementia. We found more similarities than differences in the problems in caregiving, actions of caregivers, and beliefs in caregiving. Some differences were also identified (Kristanti, Engels, Effendy, Utarini, & Vernooij-Dassen, 2018). Family caregivers of people with dementia revealed that direct contact with health care professionals was highly appreciated. People with dementia are usually cared for by either gerontologists or neurologists, then the communication and coordination can be much simpler. On the other hand, care for most patients with cancer is done by multi-disciplines, including oncologists, internists, surgeons, and many other parties, depending on their needs. This lack of simple, one-to-one involvement increases the risk for friction and miscommunication issues.

However, family caregivers of people with dementia revealed that they sometimes felt a loss of connection with the patient even when the patient was still beside them. *"She doesn't know me anymore; she doesn't know anyone anymore"* [Husband].

Meanwhile, family caregivers of patients with cancer often described a stronger family cohesiveness. For example, one participant said that she (55 years old) had only talked to her older brother (57 years old), who lived in a different city once or twice a year since they were busy with their own life, family, and work. But since she has been looking after their mother, they keep in touch on a daily basis, sometimes just to ask how they are doing. As a result, they found a reconnection during this caregiving process (Kristanti et al., 2018).

The next study then elaborates on the experiences of family caregivers of patients with cancer (Kristanti, Effendy, Utarini, Vernooij-Dassen, & Engels, 2019). Data were collected from three major cities in Indonesia: Jakarta, Surabaya, and Yogyakarta. Belief in caregiving is the core phenomenon (Kristanti et al., 2019). It is the wheel-power of caregivers. It consists of spiritual and religion, values, and motives in caregiving. This wheel-power influences the actions of family caregivers and the consequences they received. The more constructive their belief in caregiving, the better the consequences it impacted on them. Those with this spirit eventually found themselves as a better person and vice versa.

Common Ethical Dilemmas

These empirical data can help us reflect on ethical dilemmas that the family caregivers must face in the caregiving process or their relationships with patients and other family members. In general terminology, extensive medical literature used ethics, dilemma, and moral distress interchangeably (Yildiz, 2019). In the nursing profession, an ethical dilemma may be alleviated by utilizing a scientific ethic, that is, by placing people (or the care recipient) at the center and interacting with family members and their

network, by considering their values, uniqueness, dignity, and inherent human rights (Yildiz, 2019).

In the case of the family caregivers' journey, based on our empirical data (Kristanti et al., 2019; Kristanti et al., 2018), one of the most frequent dilemmas was 'hiding'. Family caregivers tend to hide their emotions and burdens in front of the patient. They thought that their feelings were not relevant and should stay hidden. They would pose a cheerful, brave, and tough face in front of the patient. Another hiding is about revealing diagnoses. When the patient is younger (below 50 years old), the doctor mostly revealed diagnoses directly. However, when the patient is older and maybe illiterate (unable to understand), the family caregiver is the first to receive the diagnosis. The doctor then would request the family to inform the patient, or in some cases, the family would ask the doctor and nurses not to reveal the diagnoses until the patient is ready. When the patient was not aware of their diagnoses, the condition became the most problematic situation for the family caregivers. One of the participants in our study revealed that once she broke the news of the diagnosis to her mother, it felt like 'a mountain had been removed from her shoulders' (Kristanti et al., 2019).

The second ethical dilemma was the perception of voluntary vs. obligatory actions in the caregiving tasks. In many Western publications, Asian countries are framed negatively that caregiving is a mandatory action. Our study in Indonesia showed that we framed 'this obligation' in a positive way so that we see this as a chance to make some payback to our loved ones. It is described as 'a chance in disguise' or some opportunities and benefits while facing some challenges (Kristanti et al., 2019).

The third dilemma was that most caregivers were the so-called 'first-time players' with no training (Dresser, 2011), meaning that they are 'newbies' (in caregiving role), and they may need time to grasp information, to have second or third opinions, to make (some immature) decisions and/or to change their decision. It is because nothing is harder than making decisions about treatment and caring, resulting in life and death consequences. Family caregivers also felt like living as a shadow. Their presence was mostly overlooked by healthcare professionals or other family members. While all the spotlight is on the patient, the family caregiver is also the one who needs to be taken care of.

The decision-making process is another dilemma that we identified. Some caregivers need to decide to continue or stop treatment when the patient can no longer participate in this decision. The decision for resuscitation can be a life-long traumatic memory for them. The guilty feeling to stop the treatment can also become their burden of guilt for the rest of their life. In order to reduce unnecessary guilty feeling, British Medical Association reminds us to apply the ethical principles of ordinary and extraordinary. The obligation of healthcare workers is to provide ordinary care, while extraordinary care is not an obligation (British Medical Association, 2007). One is not obliged to use all resources to defend human life. Extraordinary care is a situation in

which we have to say “enough” and not prolonging treatment or care.

The last dilemma is the appreciation concerning the formal facilities. Some palliative care experts in Indonesia are still discussing if hospice care is suitable for our culture. Would we dare to let our loved ones stay in the hospital at the end of their life? Can we ignore what people say to us if we put our loved ones in a nursing home? or do we prefer to have them stay with peace in their familiar place: at home? What is the formal facility to support both patients and caregivers that suits our economic condition, social status, and culture?

Ethical Considerations in Involving the Family

As nurses, sometimes we need to decide to involve or not involve family caregivers as part of our caring team. Becoming part of the team means that we may have an equal number of tasks and responsibilities. One of the important tasks of healthcare workers (including nurses) is to foster autonomous decision-making of the patients or their proxy (Beauchamps & James, 2019). As healthcare workers, nurses have an ethical obligation to give all necessary information so that patients or their proxy may make autonomous decisions. In many cases, the final decision is a shared-decision making between family caregivers and nurses. We may refer to the four *prima facie* principles in making the decision: respect for autonomy, beneficence, non-maleficence, and justice (Beauchamps & James, 2019).

Principles of beneficence must take positive steps to help others, not merely refrain from harming them (nonmaleficence). It is an ethical obligation to do good for patients and their families, including family caregivers. Involving family caregivers in patient care will enhance the collaborative aspect. We then need to identify who is the daily ‘family caregiver’ and who is the ‘key person to make a decision for the patient’ because their roles are different. They can be the same person. But in Indonesia, this is not always the case. There are cases where the main decision-maker is living in another part of the world. They can be the one who is funding the treatment or the eldest ones in the family. Nurses need to identify this hierarchy so that they can speak the right topic to the right person.

Non-maleficence relates to the previous principles. The principle of nonmaleficence obligates us to abstain from causing harm to others. This principle is identical to the famous maxim *Primum non nocere*: “Above all [or first] do no harm.” Although this principle does not appear in Hippocratic writings, it is regarded as a fundamental principle in the Hippocratic tradition. It was found that that the most dilemmatic problem in family caregivers is their unbounded tasks (Dresser, 2011). They do everything every time. In some cases, family caregivers of dementia passed away when the patient was still alive. Nurses should assist them in setting up targets and boundaries to maintain the family caregivers’ own QOL.

The third *prima facie* is justice. Traditionally justice means that equals must be treated equally, and unequal must be treated unequally. This traditional definition is attributed to Beauchamps and James (2019) added an important notion, justice means fair, equitable, and appropriate treatment in light of what is due or owed to affected individuals and groups. This implies that services offered by nurses for caregivers should have the same quality and standard. We should provide the support that is systematic and structured. Intervention such as providing basic care training is effective to maintain the QOL of patients in terminal illness (Kristanti, Setiyarini, & Effendy, 2017). Also, interventions offered should not only be for the patient’s QOL but also maintain the caregivers’ well-being.

The last principle is respect for autonomy. Respect for autonomy is to acknowledge patients’ right to hold views, make choices, and take actions based on their values and beliefs. It means that nurses or other healthcare workers have to respect the autonomous decision of patients. The opposite is true: the decision by a non-autonomous person should not be respected. Respecting the autonomous decision of patients means that nurses should obtain people’s agreement for any decision and any medical interventions relate to them, keep confidentiality and promises, and not deceive others (Gillon, 1994). This principle may relate to the decision-making process in palliative care. Knowing how challenging the decision-making process in palliative care could be, advanced care planning (ACP) should be implemented soon in Indonesia. ACP is a discussion between the doctor, patient, and family (and nurses) for planning the treatment and future decisions. The patient should be in good condition physically and psychologically following a procedure. The discussion during ACP may include if the patient accepts or refuses resuscitation when it is needed. ACP will make the treatment and next step in the process easier for everybody and prevent a traumatic event due to the obligation to provide a decision in a short moment for family caregivers.

Implication for Nursing Practice

Nurses are part of health care professionals who have the most frequent contact and interaction with patients and families. Therefore, nurses have an important task to observe patient’s and family’s situations and needs. In addition, knowing some of the ethical dilemmas that may be faced by the family caregivers, nurses need to assess and provide sufficient support for them. Patients and families are one unit in caregiving. By providing care to the family caregivers, we support the patients in facing difficult moments in life due to their illness.

Conclusion

Family caregivers have profound roles in caregiving for patients with chronic and terminal illnesses. Some ethical dilemmas along the journey were identified as signposts. Accordingly, nurses can utilize the four primary ethical

principles of caregiving to provide support for family caregivers and enhance the family caregivers' sense of well-being.

Declaration of Conflicting Interest

None declared.

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Authors' Contributions

MSK was responsible for initiating the concept, writing, and drafting and had the ownership of data. K and CE provided important intellectual content and contributed feedback while writing a manuscript draft. All authors have provided final approval and agreement to be accountable for all aspects of the work regarding content.

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Developmental assessment and early intervention for children with developmental delays: A case study in South Australia

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Abstract

Background: Child development monitoring and screening have been mandated as a national health service worldwide, including Indonesia; however, a recent study found that Indonesian community health nurses experienced difficulties detecting and stimulating a child suspected of a developmental delay.

Objective: To explore and provide an example of how Australian community health nurses, along with other professionals, contribute to a Universal child and family health service (UCFHS), a similar programme name in Indonesia is child developmental stimulating, detecting monitoring and early intervention programme or SDIDTK.

Case study: This is a case study of a young Australian boy (4 years old) whom the mother reported that her son has unclear speech and he was not speaking as much as other children at his age. The researcher, as a nurse, delivered the child developmental assessment and play skills assessment and found that the child has subtle developmental gaps and was at risk for developmental delay. Several goal setting and programming ideas have been developed to meet the child developmental milestones. These include goals in fine motor skills, communication, problem-solving and personal-social skills which have been regarded as early intervention for the child. Together with the therapy from a Speech Pathologist, these goal settings and programming ideas have been collaborated with the kindergarten teachers and the family as well as the UCFHS nurses as part of the child developmental monitoring programme.

Conclusion: Developmental delays can be detected through developmental and play assessments and can be followed by developmental stimulation and early intervention programme by developing goal settings and programming ideas around the delays or gaps in play or development.

Keywords

child development; nurses; Indonesia; early intervention; play assessment

Child development monitoring and screening have been mandated as a national health service worldwide, including in Indonesia. Examples of the service are Child Find and Oregon Healthy Start in the US; Universal Child and Family Health Service (UCFHS) in Australia, and *Stimulasi, Deteksi Intervensi Dini Tumbuh Kembang* (SDIDTK, stands for growth and developmental assessment, stimulation and early intervention) in Indonesia ([Australian Health](#)

[Ministers' Advisory Council, 2011](#); [Macy et al., 2014](#); [Ministry of Health of Indonesia, 2021](#)). Indonesian Ministry of Health has regulated SDIDTK's Law number 66 by 2014 ([Ministry of Health of Indonesia, 2021](#)). This means that child developmental screening, stimulation, and early intervention should be provided regularly in Indonesian community health centres (*Puskesmas*). However, a recent study found that Indonesian community health nurses

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experienced difficulties detecting and implementing early intervention of a child suspected of a developmental delay (Mardiyanti et al., 2020). Meanwhile, other countries have delivered the programme successfully and may become an example for Indonesian health professionals, especially nurses. This article provides an example of how a child suspected of developmental delays has been screened, assessed, stimulated and intervened earlier so that the delay can be minimised or corrected before the child enters the primary school where the delays may become problems.

Australian Context

The Australian education system provides primary, secondary and tertiary education. Primary education starts from the foundation level (kindergarten or preschool from age 3.5 to 5 years) through year 6 or 7 (Department of Foreign Affairs and Trade, n.d.). Kindergarten or preschool are part of early childhood education which responsible for providing care and supervision for young children, preparing them for school, and ensuring that the children are able to effectively participate in subsequent learning opportunities (Department of Foreign Affairs and Trade, n.d.). This case study took place in South Australia kindergarten.

Case Presentation

Evan (not his real name), a 50-month-old male, was born prematurely on March 2010 at 36-week of gestation, with his birth weight of 3600 grams. During his first week of life, he experienced jaundice. He was breast-fed and formula-fed during the first 6-month of life because of reduced breast milk supply, then ceased breastfeeding completely at around 6-months. No feeding difficulties were reported during the infant period or at his current age. Physically, his weight and height are appropriate for his age, and he also looks taller than other children at his age. The only concern that his mother and teacher reported was his unclear speech. Dribbling sometimes occurs involuntarily during his speech. Mom reported a speech delay of 6-months, as diagnosed and assessed by the speech pathologist.

In March 2013 (aged 3), Evan's mother had referred him to a speech pathologist due to unclear speech as he was not speaking as much as other children at his age. Evan was assessed using the Diagnostic Evaluation of Articulation and Phonology (DEAP) (Dodd et al., 2006). It was found that his speech is relatively clear at the single word level, but when he tries to sequence sounds to say longer words and put words together, the clarity of his speech diminishes and becomes very difficult to understand. For example, he said: "hou" for a house, "sli" for slide and "muni" for "monkey". Dribbling and low oral muscle tone result in difficulty to precisely make and sequence the tiny movements necessary for connected speech (Rosemary & Usha, 2021). The speech pathologist reported that poor motor control in his mouth and motor

planning component becomes the issue to his imprecise speech. There were no other issues in developmental skills at the time, as she found Evan's play, attention and social skills, and receptive language were appropriate to age. Evan will become a successful verbal communicator if he has regular exercise on speech motor tasks, such as teaching precise movements for different speech sounds and sequencing sounds together to form words and sentences. In addition, she also recommended referring Evan to Ear, Nose and Throat (ENT) specialist to find out any structural issue which may impact his oral motor skills. The Speech Pathologist advised having a hearing test with an audiologist to find any hearing issues that may be impacting his processing of speech sounds. She also advised the mother to include Evan in the Early Entry Preschool Programme where he attended in July 2013 until now, in one of the well-known Adelaide Kindergartens.

The kindergarten principal said that she had made a referral to the Department of Education and Child Development to get support service, but to date, there has been no response. The family paid for private therapy as a result. After following all the recommendations from the speech pathologist, it concluded that he had not had any issue with hearing or structure disorder in his mouth. Currently, one teacher participates regularly in teaching different speech sounds as suggested by the speech pathologist. Since February'14, the focus has been on the speech of words ending with n, ch, f and c/k. Evan shows many improvements in his speech, as reported by the teacher and his mother.

During observation in the kindergarten, it was noted the teachers and his best friend (Nivedh) relatively understand what Evan's says, but it is likely difficult for other friends or adults who are unfamiliar with him. During free play, he pretended to be a spiderman with Nivedh excitedly. He can show others something that interested him, imitates others, join in a group if requested, seek adult assistance, and respond to questions. He also plays like others either inside (craft, puzzle, draw, and storytelling) or outside (climb the rungs, swing and slide). However, his unclear speech made the play assessment to some point hard for the assessor. For example, his verbalisation about the play scenario is hard to understand. In addition, the mother reported that he does not have any friends at home because there is no other child his age nearby. He usually plays with his little sister (Asley, 15-month-old) and his mother, who was not working at that time. Since starting Kindergarten, Evan was not attending other settings for early childhood programme, such as child care.

Methods

Structured observation has been performed two times; once at the kindergarten class and playground, and secondly observation at the child home. Informal interviews were also performed with the mother and the kindergarten teacher.

1. Child developmental assessment

Evan's developmental skills have been assessed using the Australian Developmental Screening Checklist (ADSC), Age and Stage Questionnaire (ASQ-3™) and Play skills checklist (Heidemann & Hewitt, 2010). ADSC is a professional-completed checklist developed by (Burdon., 1994), whereas ASQ-3™ is a parent-completed checklist developed by Squires et al. (2009). The play skills checklist is adapted from Heidemann and Hewitt (2010) and is an observational tool. The use of these tools combines both points of view (parents and professionals), which may differ in how they judge the child's ability. ASQ-3™ has been recommended widely in English-speaking countries because of its sensitivity and specificity (85% and 86%, respectively) (Mackrides & Ryherd, 2011). Many studies recommend ASQ as a standardised screening tool to be used during well-child visits in any clinical settings either in urban or rural settings (Hamilton, 2006; Rydz et al., 2006; Rybski & Wilder, 2008; Burns et al., 2009; King et al., 2010;

Guevara et al., 2013). The ASQ-3™ also utilised by the Child and Family Health Service (CaFHS) in the Adelaide region, which will subsequently be used if families or child health nurses are concerned about the child's development (Arrowsmith, May 28, 2014). Evan's ASQ-3™ results have been reviewed by Arrowsmith (May 28, 2014) from one local CaFHS in the Adelaide region. She suggested some sources and materials for developing Evan's stimulating programme.

Play assessments are often taken in screening children, as play is the central occupation for children (Lynch & Moore, 2016). Play is complex and may reveal many things about the child's development relative to others, including developmental status and functional skills (Casby, 2003) and cognitive ability (Fink et al., 2012).

2. Observation

The observation records can be seen in Table 1.

Table 1 Observation records

Date: 12/5/2014 Child's name & Age: Evan (49 month) Time: 09.15 Setting: Morning session in kindergarten Who is present: one group (23 children), one teacher (leader), and four facilitators		Observer: Yanti Background info: every morning, the one starts with a group session, singing, checking, and greeting each other's (±20 minutes). Other involved: one parent whose daughter was unwell.
Time	Observation	
09.15	T/ asking all students to come to the playground for the group morning session. E/ follow the instruction and sit down at the front corner closed to his best friend Nivedh. T/ greeting and student too, T/ asked all students to greet all teachers using other languages such as Spanish, French, Chinese, Vietnamese, and Indonesian. Some students follow the greetings; some were not. E/ does too. T/ then asked about the weather today, some students answered correctly, and some were quiet. E/ tried to give his opinion by raising his hand, but the T/ did not look at him as he sat down at the corner. Finally, he said something, but it was not clear. When another student gave a comment to the T/, Nivedh laughed and E/ laughed excitedly, T/ reminded them that there was not something funny, and they stopped laughing.	
09.35	Small group session (Reading story/storytelling) One facilitator with four students (two boys and two girls) sat down in the corner. F/ asked which book they wanted to read. The boys argued as they wanted to read different books, but finally, E/ agreed with his friend and chose to read his book later. F/ read a book about Charlie and Lola with the title "I like tomato" in front of the students. The boys actively questioned and answered with the F/, and the other two girls' students were very quiet. E/ sat beside the F/, which was not a good position as he needed his head to keep turn right to see the book. While being suggested to move, E/ was still in the same position. During the conversation, sometimes F/ understood what E/ said, sometimes not. It was noticed that E/ saliva sometimes splashed while he was talking. E/ looked frequently opened his mouth during storytelling. He pointed to specific pictures frequently and said some words such as "to..a..too" for "tomato"; "...at..is..nge" for "eat fish finger" etc. He asked for a specific picture in the book, and F/ explained it and replied with a question and E/ answered it correctly. It was noticed that his mouth sometimes kept open with the tongue coming out a little bit.	
09.50	Fruit time. E/ walked and grabbed his lunch book. Opened the bag's zipper with his left hand. He took the apple and brought it to the T/ asked for help to cut it and brought it back to the previous place where he left his bag. Together with Nivedh, he enjoyed his apple. I noticed again that E/ could not control his saliva while eating.	
Date: 13/5/14 Child's name and age: Evan (49 months) Time: 09.40 Setting: Kindy's office Who is present: One teacher (S) and Evan		Observer: Yanti Background info: every Tuesday (once a week), S stimulated E with a words card, asked E to mention the word and arranged it in the same group with other words with the letter ends with Ch, N, F and C/K. The programme has started on 26 February 2014. The cards consist of a picture of a word and its letters.
Time	Observation	
09.40	E/ came to the office room in the kindy as the T/ asked him to do so. E/ sat down in a chair, and S/ asked him to sit on the floor because it was for the observer. E/ asked why the observer came to the office, and S explained it simply, and E/ asked again, but the observer could not understand what he's talking about. S looked to understand what E/ said, and she explained and then shifted the focus to the activity. S started the intervention by explaining about talking at the right speed. She explained using a picture of three types of speed talking: slow (snail), just right and too fast (running people). She asked E/ to speak at the right speed. E/ looked at the cards and answered every question. S asked E/ to classify	

Table 1 (Cont.)

the card based on its sound. There were four groups for words ending with the sound n—ch—f—c/k. Examples of the word card are:

- Bee-Bean-Beach-Beak
- Win-witch-whiff-weck
- Lee-lean-leech-leak
- Tif-teen-teak-teach

S asked E/ to sound the words correctly, and E/ did it sometimes clear and sometimes unclear. E/ looked excited with these games, and he tried to sound the words and to put them in the correct group. Sometimes he kept busy on where to put the cards to the correct group and not follow S instruction; he sometimes asked "where to put this on?" and S kept remain E/ to sound it correctly and said, "you know where to put don't you" E/ looked enjoy if S looked a bit disturbed with his questions. S looked patient and asked E/ to "click them out" every time he finished grouping the cards. There was one word, "tea", which did not fit with those four groups, and E/ noticed that correctly.

The second games started. S asked E/ to close his eyes while she hid some words. After finished, S asked E/ to open his eyes. S asked E/ to find all the words and to pronounce them correctly. E/ could find most of the words, and when he looked difficult to find, S gave some clue of where the word was. S sometimes reminded E/ to speak just at the right speed if she could not understand what E/ said.

T/: Teacher S/: teacher responsible for Evan language therapy E/: Evan F/: Facilitator

Results from the developmental assessment

A summary of Evan developmental skills can be seen in Table 2.

Table 2 Summary of Evan developmental skills from ADSC and ASQ-3

No	Domain	ADSC	ASQ-3™
1.	Communication	Evan is able to name particular objects, join in songs/nursery rhymes, identify "same/different", ask WH- questions, respond appropriately to questions, and understand or verbalise physical needs. Apparently, his language skills are around the age of 44-49 month.	An overall score is 45, which is above the cut-off (30.72). Evan is able to answer common questions and act to three commands without pointing or repeating (give me the pen, open the book and stand up). Sometimes, he is able to name at least three items for common questions, such as "tell me the names of some animals". Sometimes , he is able to mention the ending of words (-s, -ed, -ing: such as I see two cats, I kicked the ball, I am playing) and uses all of the words in a sentence ("a", "the", "am", "is" and "are").
2.	Fine motor	Evan is able to pincer grasp, holds a pencil in hand, not a fist, draws horizontal and vertical lines, turns doorknob to open the door, cut paper with scissors, and draw a circle. Apparently, his fine motor skills are around the age of 44-49 month.	An overall score is 35, above cut-off (15.81) but close to grey areas. He is able to draw three shapes and a picture of people with at least three features (head, eyes, arms, legs). Sometimes he is able to put together a 5 to 7-pieces puzzle, cut a piece of paper using a scissor or unbutton one or more buttons of his clothes. However, he has not yet drawn or colour in within line.
3.	Gross motor	Evan is able to jump forwards: feet together, hops on foot: on the spot, balances on 1 foot for a few seconds, can sit on the floor cross-legged, walks a straight line. Apparently, his gross motor skills are around the age of 50-55 months.	An overall score is 60, which is above the cut-off (32.78). Evan is able to catch a ball, climb, throw a ball, hop up and down, jump forward and stand on one foot for 5 seconds, which are appropriate to his age.
4.	Problem solving/cognitive	Evan is able to tell the name of a friend or playmate, maintain interest or involvement for few minutes, refers to own gender accurately, understands 2: picks two objects, tries to count and understands 3: picks three objects. Apparently, his cognitive skills are around the age of 44-49 months	An overall score is 50, which is above the cut-off (31.30). He is able to repeat three numbers in order without repeating the request, distinguish items by their size, name five different colours, and count items. Sometimes he understands the concept of "under", "between" and "middle" and does pretend play.
5.	Personal-social	Evan is able to ask for help if needed, can tell his own first name, can wash and dry hands, recognise the gender of his friend Nivedh and himself, is able to go to the toilet by himself, sometimes joins in play with others. Evan is around 44 months development in this area.	An overall score is 45, which is above the cut-off (26.60). He is able to serve himself, wash his hands, and brush all his teeth without any help. Sometimes he is able to mention the names of two or more playmates and recognises his identity, such as his first and last name, age and sex.

Table 2 (Cont.)

6. Overall	Evan has strengths in the area of Gross Motor and is just under age appropriate for most other areas. There are some impacts of communication difficulties in his social and communication skills. There are also some slight delays in fine motor development.	No problems in hearing, vision, behaviour and medical problems in the last several months. Evan's mum worries about two things: "not talks like other children at his age" and "Others do not understand most of what your child says". Since under speech therapy last year, Evan's speech now shows many improvements.
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Play assessment checklist

Based on the play checklist, which looked at areas of social play, communication, pretence and problem solving, Evan does pretend play by using imaginary objects and uses verbal declaration approximation ("I am a Spiderman"). During observation, he enjoys and interacts with Nivedh, and they play together as they are Spiderman and others are the bad people. He enjoys playing in a group if an adult requests it. He is able to show others an interesting object by pointing, bringing the object or express verbally, and engaging in the activities for several minutes or until the activity finishes. He is able to negotiate with a peer about which book should be read during the storytelling group, although then he accepted the adult suggestion without arguing. There are some difficulties in his communication during a play episode, verbalising about the play scenario to his play partner, and being understood. He also tends to play with one (the same) play partner. However, due to parents' permission, the observation settings only happened in the kindergarten. Therefore, there is a need to observe the child's play skills in his house, where he spends most of his time.

Analysis

Overall, Evan's developmental level is relatively appropriate for his age. He still has many opportunities to improve the "sometimes" skills into his "routine" skills to help him reach his full potential. Evan's mother and the teachers are very good sources in shaping his development. During observation, the mother is very active in questioning and clarifying Evan's progress with the teachers. The teachers also persistently delivered the activity suggested by the speech therapist. It is believed that at the end of the kindergarten programme, Evan will be more than ready for his next primary school.

When looking at each domain in the checklist, more focus should be taken on the fine motor area, communication, problem-solving and personal-social. This means that more activities in these areas should be supported and created. His dislike to colour in should be addressed. In addition, given his unclear speech, this may lessen his motivation to participate in play with others or lessen his social interaction later when others respond unexpectedly or when he realises that his speech is different from other children. This can be seen during observation in the kindergarten; Evan spent his time mostly play with Nivedh and not with other children, though he is an active person and show excellent enthusiasm during group sessions and story-telling. He tries to participate and connect with others, but sometimes others do not respond to him due to his unclear speech. Therefore, we need to develop strategies not only for building his articulation speech but also for encouraging him to interact with other children.

Moreover, support should also be provided to help him achieve the kindergarten's learning outcomes so that he can build a strong sense of identity, feel connected and contribute to the world, a strong sense of well-being, feel confident, independent and involved learner as well as an active communicator (Pasaneda Kindergarten, 2012). Perhaps providing a positive experience will help him construct his strong identity, confidence and independence.

Goals setting

Goal setting aims to provide assistance for Evan and his family to optimise his child development. The goals have been created based on Evan's developmental level and his emerging skills that need to be strengthened to achieve his full potential. Please see Table 3 (Goals for Evan) and Table 4 (Goals and activities for the families).

Table 3 Goals for Evan

Fine Motor Goals	
Goal 1.	Evan will colour a picture in a colouring book mostly within the lines minimally three times a week in his time at home by July 30.
Goal 2.	Evan will unbutton one or more buttons while undressing his clothes every time he comes back from school or playing with a cloth buttoning strip by June 30.
Goal 3.	Using a child-safe scissor, Evan cuts papers in half on a more or less straight line 3 times a week at home by June 30.
Goal 4.	Using a minimum five- to seven-piece interlocking puzzle, Evan puts them together correctly three times a week by June 30.
Communication Goals	
Goal 7.	(Collaboration with the intervention from Speech therapy). Then requested to sound the words provided, 50 % of Evan's speech sounds are correct and clear by July 31.

Table 3 (Cont.)**Problem-Solving Goals**

Goal 8. When requested, Evan pretends to play with one different/new child partner (not Nivedh or his little sister) in the playground or during kindergarten free play minimally once a week by July 30 (collaboration with the teachers).

Goal 9. When requested to participate in socio-dramatic play, Evan can play with two or three children and interact with each other in the kindergarten play sessions 50% by July 31. (Collaboration with the teachers).

Personal-Social Goals

Goal 10. When asked by his mum after finish his school session, Evan mentions the names of two or more playmates (not including his little sister) by July 31.

Table 4 Goals and activities for the families

No	Goals Items	Activities Description
1.	Evan family will look for and use the services from one of the local CaFHS in Adelaide by June 30 (e.g., Kid's health and child developmental monitoring programme).	Explain the CaFHS services in South Australia that family may gain benefits. Provide the website address (www.cyh.com) or the CaFHS local address and contact number close to their area (Edwardstown CaFHS; 2 Vurness Avenue 5039, Call number 1300 733 606 between 9 am and 4.30 pm , Monday to Friday to make an appointment). Explain that Evan needs an-ongoing services from CAFHS to monitor his development closely (e.g., using ASQ-3™ developmental monitoring until 60-month-old), including the early childhood intervention programme and parenting support.
2.	Evan family will look for and use the services at Forbes children's centre for Early Childhood Development and Parenting by June 30.	Explain the Forbes Children's Centre services that the family may gain benefits, such as: <ul style="list-style-type: none"> • Sessional preschool for children for five sessions a week in the year prior to starting school. • Long daycare child care for Evan or Asley. So, the mother will be helped in raising the children. • Many programmes will benefit the family, such as Dad engagement, developmental play sessions, Saturday playgroup, Family service coordinator, Circle of Security, Premier's be active challenge, Mums of toddler group).
3.	Evan's family will read to Evan every day.	Offer article to the family about the risk for reading problems in children with speech sound disorders (Anthony et al., 2011). The Forbes Children's Centre also creates a programme, Let's Read, to support families reading with their children. Motivate the family to create a reading programme every twice a week at home.

Programming Ideas

Programming ideas aim to achieve those goals that are created based on Evan's emerging skills and the availability of resources. Play is extremely important for children's learning. It is regarded as an activity that helps develop the child's cognition, communication, socialisation, sensory-motor functions, problem solving and self-awareness ([Canadian Association of Occupational Therapist, 1996 cited in Stagnitti, 2004](#)). The activities should be integrated into the child's immediate interests

and ongoing activities, although he might avoid these (e.g. colour in) ([Johnson-Martin et al., 2004](#)). The strategy could be to rearrange the environment (e.g. remove the materials the child persists in using for a period during the day and offer other activities) or to become more directed (e.g. "We need to spend some time colour in first, and then you can play with trampoline"). One activity can be used for some or all domains of development; for example, storytelling in a group of children may involve cognitive, fine motor, gross motor, communication and social skills (Table 5).

Table 5 Activities for Evan

Goals	Activities	Description
Fine motor's goals	Colour in games	Provide "Spiderman colouring books" and colour pencils. Ask him to colour in. If he does not show interest, he will be attracted by modelling first and saying, "I am busy with Spiderman". Alternatively, guide his hand and later let him do it independently. Encourage him by stating, "can you cover all the white?" and "try and stay inside the lines."
	Unbutton games	Ask him to unbutton his cloth or another cloth strip from the dressing vest or doll, which has large, medium and small buttons. If he does not know how to approach this task, slowly demonstrate for him. Then try to assist him physically. He should hold and lightly pull the cloth next to the hole with one hand, grasp the button and push it through the hole with the other hand. Adapted from "The Carolina Curriculum for Pre-schoolers with Special Needs" (Johnson-Martin et al., 2004)

Table 5 (Cont.)

	Cut and draw games	Place a piece of paper and the safety scissors in front of the child. Draw a line from the left to the right side of the paper. Ask him to cut the paper in half or to cut all of the ways across the paper. Give him verbal cues if needed (e.g., "follow the line"). Or use tape by placing it on either side of the line to encourage the child to stay on the line. If he is able to do this, expand the games by cutting a circle, square or pictures that he made and coloured in. It may be helpful to trace around the outline of the picture with a marker before cutting it out. Encourage the child to stay on the line and not cut into a picture. Select pictures easily to cut, then stick them into a paper board. Ask him to put his name and date on it. At the end of June, the families can know how far his progress is. Adapted from "The Carolina Curriculum for Preschoolers with Special Needs" (Johnson-Martin et al., 2004)
	Puzzles	Choose a puzzle that has minimally 5 to 7-pieces. Encourage him to finish the puzzle. If he cannot do it, try to work together or one-by-one or backchain - do all but the last one and ask him to add the last piece. Next time do two last pieces, etc.
Communication	3-related items games	Choose three pictures from common categories (fruit, school items, food), then write the name of the picture on a piece of paper, place it close to the picture. Ask him to answer your question: "things that we eat", "things in the school", "things that are yellow". Encourage the child to choose three pictures and bring them together with the name. If he is able to do this, expand the games by only stating the name of the item. Encourage him to be familiar with the letters. Encourage him to verbalise the name correctly. Model the correct articulation of the words, then ask him to sound them out.
	Identifying the sound of words	Use the word cards from speech therapy or download the new one from www.bugbugkits.com.au/freebiesarticulation/ . Choose the letter of words that Evan needs to practice. Expand the games to "hungry for K's". Tell him and other children in a group that they are on a special diet and can only eat things that start with the /K/ sound. Ask them to put the things into their lunch box (e.g., carrots, corn, cucumber, ketchup). To make it more complex, add other objects that start with /k/ but cannot be eaten (e.g., cards, cat, key, cow). Alternatively, put some words that do not have any /k/ sound. Count to see how much they can put in their lunch box. Adapted from www.phonologicalawareness.org/#/phoneme/cr2d
Problem-solving	Spiderman shopping	Ask Evan to play "Spiderman shopping". Creates the situation like a shop. Evan becomes a Spiderman (provide Spiderman costume), and his friend pretends to be a clerk. Provide pictures as a cue to prompt, and ask Evan to buy things that start with the letter /f/. Encourage both of them to interact with each other.
	Spiderman Sick	Ask Evan to play "Spiderman sick" and go to a clinic and meet customer service, doctors, pharmacists, and other people who need help.

Discussion

Evan, who has speech delays, shows much improvement in his communication since he started the Early Entry programme in kindergarten and several session therapies since last year from the Speech Pathologist. Evan will be more than ready for his next school journey if he and his family join many community-based programmes and do a lot of activities, as suggested above.

Some articles show that Subtle Developmental Problems (SDPs) and Speech sound disorders are at high risk of academic failure, social-emotional disturbance and behaviour problems (Glascoe, 1999; Williams & Holmes, 2004; Anthony et al., 2011). These may be due to poor motor control and motor planning inadequacy that require much more intensive developmental stimulation. This stimulation may be hard to do if the family does not have enough resources and must deal with other demands such as work and other siblings. Therefore, it is important to refer all children with high risks of developmental delays to an early intervention programme, although they have not yet any diagnosis. It also important as well for CaFHS to

monitor the child development closely and support the family. Parent's willingness should also be supported so that they can participate in the programmes fully.

The case in this report might become a good sample where the child may show delays in the communication skills that may not intervene earlier if parents had not sought help from the speech therapist. Early detection of the developmental problem may allow an early intervention programme to reach children's full potential, academic success, independence, and confidence.

Nursing Implications

Nurses in the community health centres may be inspired by this case study and use the information for developing nursing care for children suspected of a developmental delay or subtle development. Evan's goals may also be used for developing nursing outcomes, and Evan's and family activities used for developing nursing interventions.

The developmental screenings (either ADSC or ASQ-3™) showed Evan's development was normal, although the mother's concerns about Evan's speech problem, therefore play skills assessment may be beneficial in finding which areas of development are specifically at risk

of delay. Therefore it is recommended to use play skills assessment, such as the Pretend Play Enjoyment Developmental Checklist (Stagnitti, 2017) combined with developmental screening tools such as *Kuesioner Praskrining Perkembangan* (KPSP) in the SDIDTK programme. It is also suggested that policymakers train community health nurses for developmental assessment skills and play assessment skills to improve the quality of child universal health service in Indonesia.

Limitations of this Study

There are several limitations to this study. Firstly, this is a single case study, and further studies would need to include more subjects. Secondly, ideally, child development skills and play skills should be assessed in three different areas (house, school and other public areas such as playground); however, this study only conducts observation in the school and public areas. And thirdly, this case study did not report on outcomes of the early intervention for the child, and further studies would do well to include both quantitative and qualitative outcome data.

Conclusion

Evan's developmental skills and play are relatively appropriate for his age based on the tools applied, although ASQ-3™ picked up parental concerns that need to be referred into an early intervention programme, followed by monitoring his development closely. Parents are strongly recommended to raise any concerns about their child development and seek help from professionals. Parents' concern and willingness should be encouraged for the success of the early intervention programme and the well-being of the child.

Declaration of Conflicting Interest

The authors have no conflict of interest to declare.

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Authors' Contribution

All author contributes to the study's conception and design. MM and MC conceptualized the study. MM performed data collection, MM dan MC drafted the original version of the manuscript. All author accepts the final manuscript.

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Reflections on International Nurses Day: Current status, issues, and the future of nursing in Indonesia

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Dear Editors,

May 12 is celebrated as International Nurses Day and as the birthday of Florence Nightingale, the founder of Modern Nursing ([International Council of Nurses, 2021](#)). For nurses around the world, this is a momentous occasion reflecting on the state of nursing and how nurses are advancing the profession. Highlighted by the International Council of Nurses are three issues; COVID-19 infections and deaths among nurses and other healthcare workers; stress and burnout in the nursing profession; and nurse shortage and retention ([International Council of Nurses, 2021](#)). Regarding issues affecting the discipline and professional practice of nursing, nurses in Indonesia are austere experiencing these issues because of the pandemic; of practicing professional nursing; and conducting research and enhancing nursing education.

First, with the COVID-19 pandemic, nursing practice has become more challenging. The invisible disease agent has caused untimely deaths of many healthcare professionals, making nursing practice much harder ([Chatterjee & Kagwe, 2020](#)) and less attractive as a profession. As of March 2021, the Indonesian National Nurses Association reported that more than 15,000 nurses were infected with COVID-19 and 274 have passed away ([Guritno, 2021](#)). Improvements in regulations related to COVID-19 management in hospitals and other healthcare institutions were imposed, such as increasing supplies of personal protective equipment (PPE) and prioritizing benefits for healthcare workers regarding staffing, including the nurses. This prioritized frontline healthcare workers, including nurses, to receive vaccinations against COVID-19 ([COVID-19 Handling Acceleration Force, 2021](#)).

Appreciations for nurses' dedication to their professional practice during the pandemic were many, but

still not significant enough, as nurses continue to risk their lives — sometimes losing their lives — in order to save their patients' lives and the lives of other co-workers. This appreciation points to the realization that nurses and their practice deserve political and social actions for their valuable work, supporting a deserved salary raise ([Gunawan, 2020](#)). While the risks to nurses' lives on the front lines is evident, the global society must finally realize the professional mandate that frontline nurses are soldiers-at-war, whose lives are valuable, therefore need protection by all costs from being uselessly exposed to an invisible organism and become patients themselves ([Chatterjee & Kagwe, 2020](#)).

Second, in Indonesia, there are various classifications of nurses based on education. The Indonesian Nursing Law No. 38 the Year 2014 described categories of nursing education into vocational education, academic education, and professional education. Vocational education is a three-year program, while the academic program prepares nurses for a baccalaureate degree in nursing, Masters in Nursing, and Doctor of Nursing. With an academic degree, professional nursing education qualifies nurses through internships in the nursing professional (*Ners*) and nursing specialty program ([Government of Indonesia, 2014](#)).

Despite the variety of educational levels and the limited number of graduate school programs, nursing education in Indonesia is steadily improving. With only 11 Professors of Nursing, there are now two Doctoral Programs in Nursing: a doctoral program at the University of Indonesia and the other at the Faculty of Nursing, Universitas Airlangga ([Casman et al., 2020](#)). Nevertheless, transforming the discipline to advance the professional practice of nursing requires more interdisciplinary collaboration, especially with expert nurse researchers from the international arena.

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Third, the regulations from the Indonesian Ministry of Higher Education require faculty members in academic positions to publish scholarly articles (Ministry of Research and Technology of the Republic of Indonesia, 2017), and for university students to also publish their final projects, theses, and dissertations in key scientific journals as a requirement for graduation (Ministry of Education and Culture, 2012). These requirements are clear evidence affirming the flourishing of nursing research and knowledge dissemination in Indonesia. Today, the requirement for enhancing scholarly articles authored by Indonesian nurses and nurse educators in international journals has increased manifold, instigating the establishment of more rigorous nursing journals. However, even with the increasing processes for knowledge dissemination as evidenced by the number of publications, journals indexed in reputable national and international indices are still few. As of March 2021, only three nursing journals were indexed in reputable international databases, such as Scopus, Web of Science, and EBSCO. These journals are *Belitung Nursing Journal*, *Nurse Media Journal of Nursing*, and *Nursing Journal of Indonesia* (Jurnal Keperawatan Indonesia).

While this letter briefly highlights three current conditions as the basic informational needs of nursing practice, education, and research, focused attention on education, practice, and policies influencing scholarly nursing endeavors in Indonesia requires more recognition and appreciation. Editors, researchers, and practitioners of nursing need to be influential and establish nursing science journals in order to disseminate ground-breaking and important nursing work. With the nursing academe, further progress and recognition of nursing as a discipline of knowledge and a practice profession will materialize.

Reflecting on the future of Indonesian nurses during this momentous International Nurses Day leaves us to realize that, while professional nursing practice in Indonesia is advancing, more disciplinary and professional 'homework' is needed to move nursing as a valuable and integral health care practice. This consideration is a significant step towards growing Indonesian nursing to a level of professional practice that is integral to human health and well-being.

Keywords

International Nurses Day; COVID-19; professional practice; delivery of healthcare; nursing; Indonesia

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