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# JKP

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# JKP

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Jurnal Keperawatan Padjadjaran

JKP

# Research Article

Volume 9 Issue 1

# Guidelines for Authors

Jurnal Keperawatan Padjadjaran (JKP) are a journal of scientific publications published every four months (quarterly) using a peer review system for article selection. Jurnal Keperawatan Padjadjaran intended for practitioners, academics, professionals, students or among the general public who are involved and interested in the development of Health and Nursing Science. It can receive relevant articles in the field of health and nursing, which includes research articles.

## General Instructions

The articles received are original works, have not been and / or are in the process of being published in other journals, all articles have been approved by the ethics committee and articles involving human subjects have obtained informed consent and written following the American Psychological Association (APA) ) Edition 6 of 2009. The author should ensure that all co- authors have agreed. All articles will be discussed and reviewed by experts and editorial boards. Articles that need improvement or revision will be returned to the author.

## Writing Article

Articles are written using Times New Roman font, size 12 with space 1.5. Distance of left edge 4 cm, right edge 3 cm, edge above 3 cm and bottom edge 3 cm. Article lengths of at least 12 pages and maximum 20 pages. Article submitted in the form of layout 1 (one) column. The article contains two references from JKP with Google scholar. Each page is numbered in sequence from the title page to the last page.

## Structure Writing

The structure of writing in JKP is as follows: Abstract, Introduction, Methods, Results of Research, Discussion, Conclusions, and Bibliography. The following describes the guidelines for each writing structure:

## Abstract

Abstract for each article written in English. The author's name (without academic title), affiliate author (department and institution name), email address, and institutional address include in the abstract. The abstract form is written in a concise and clear description of the background, methods, results, conclusions, and suggestions (implications) of the research. The abstract is accompanied by a keyword (key words) consisting of 3-5 keywords and the order is arranged alphabetically.

## Introduction

The introduction should clearly describe the background of the study. This also defines the novelty of the research. The manuscript is written with Times New Roman font size 12, 1.5 spaced, left and right justified, paper in one column and on A4 paper. Distance of left edge 4 cm, right edge 3 cm, edge above 3 cm and bottom edge 3 cm. Article lengths of at least 12 pages and maximum 20 pages. The article contains two references from Jurrnal Keperawatan Padjadjaran with google scholar. Each page is number in sequence from the title page to the last page.

## Method

This section presents the research design, population, sample and sampling technique, and the analysis method. The author should explain how the study was done in detail. All articles have been approved by the ethics committee and articles involving human subjects have obtained informed consent. Ethics, validity and reliability, or trustworthiness should be part of this section.

## Results

The study findings should be clear and concise. If the findings present in table or diagram, there must not be any overlap between findings shown in table/ diagram and description that written in text. The tables are arranged in a row, each table should be briefly titled and placed on top of the table, the title of the table is written in capital letters at the beginning of the word, except for the foreground. The maximum number of tables in each article is 6 tables. Photos, pictures, and diagrams are arranged in sequence, and given a short title and placed on the photo/drawing/diagram with a maximum of 3 pieces.

## Discussion

This should present the critical thinking and author's analysis of the study results. Interpreting and comparing between study's results and existing knowledge are significant in this section. Reasons for the results and implications to the Nursing knowledge should be discussed.

## Conclusion

Highlights of the study findings present in this section. Then followed by the main conclusion of the research. Limitations and future research should be mentioned.

## References

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**Online Journal**

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**Online Magazine**

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**Dissertation and Thesis**

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# Lived Experiences of End Stage Renal Disease Patients Undergoing Continuous Ambulatory Peritoneal Dialysis Therapy

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## Abstract

End stage renal disease (ESRD) is a serious chronic disease that resulted from complications of chronic renal failure and a final diagnosis that requires treatment modalities such as dialysis or continuous ambulatory peritoneal dialysis (CAPD). However, CAPD is rarely selected as renal replacement therapy by ESRD patients in Indonesia. Therefore, the phenomenon associated with patients undergoing CAPD is unclear, especially in Indonesia. The purpose of this study was to explore the lived experiences of ESRD patients undergoing CAPD therapy. The research method employed qualitative descriptive phenomenology. The participants in this study were 10 ESRD patients with CAPD. Data collection utilized semi-structured interviewed and data was analyzed using the Colaizzi approach. The result of the study was explained through 6 themes. These are: 1) Condition improved with CAPD, 2) Freedom of activity, 3) Between feeling better and bored 4) Health is increased, 5) It is sustained life, 6) Resignation to accept illness. In conclusion, the patients with CAPD felt significant positive changes in their life and CAPD is considered life-sustaining for the participants, as the majority of the symptoms was decreased significantly. Therefore, the partisipants felt their conditions improved better. The unpleasant sides of CAPD are feeling bored. The support of the family is important as it produced strength and passion for patients in undergoing CAPD.

**Keywords:** Continuous ambulatory peritoneal dialysis, end stage renal disease, lived experience.

## Introduction

End stage renal disease (ESRD) is a serious complication of chronic renal failure and requires renal replacement therapy in the form of hemodialysis (HD), peritoneal dialysis (PD) or transplantation as mainstay treatments (Tannor, Archer, Kapembwa, Van Schalkwyk, & Davids, 2017). ESRD patients condition could be worsening which can lead to an emergency conditions and required prompt treatment (Shari, Suryani, & Emaliyawati, 2014). ESRD has been recognized globally as a complication of disease. In Taiwan, the prevalence of ESRD reached 2,584 per million in 2010, while around 2,260 and 1,870 were reported in Japan and the US (Chao et al., 2018). In Indonesia, the number of newly diagnosed ESRD or the ESRD incidence increased from 9649 in 2010 to 30 831 in 2017 and the prevalence of ESRD sufferers increased from 11484 in 2010 to 77892 in 2017 (Abdurahman, Bandiara, & Supriyadi, 2019). Basic Health Research (Riskesdas, 2013) report has indicated that the prevalence of ESRD in Indonesia is around 0.2%, and this will continue to increase with the increasing number of elderly.

ESRD affects nearly every organ system in the body with a variety of signs and symptoms. The resulting physical and mental disabilities affect the patient in their daily life activities. Hemodialysis, peritoneal dialysis (PD) and kidney transplantation are modalities for renal replacement therapy. Hemodialysis is the most common mode of therapy for ESRD worldwide, in New Zealand and Australia, approximately 17.7 and 9.1% of patients (USRDS, 2012). Based on the Indonesian Renal Registry / IRR (2014), the majority of services provided at dialysis facilities are hemodialysis (82%). The rest were in the form of CAPD services (12.8%), transplantation (2.6%) and CRRT (2.3%).

There are some ESRD patients who died due to queues or long waiting lists for HD even though it was time to do dialysis, while the hospital has added HD machines, but until now there is still a waiting list for ESRD patients to have HD every week. This phenomenon is experienced by dialysis nurses, and the nurse educate HD patients to consider other renal replacement therapies such as CAPD to reduce the waiting list. However, CAPD is still minimally practiced in Indonesia due to several obstacles felt by patients. Nurses with advanced skills are required to be able to educate the patients regarding this intervention (Mulyana, Trisyani, & Emaliyawati, 2020).

Althought, ESRD patients who undergo CAPD therapy may experience many benefits, such as freedom of lifestyle and being able to do activities just like healthy people. Maintaining a lifestyle perspective was previously considered important in maintaining a normal lifestyle. In addition, changing therapy modalities, moving from one modality to another is a common experience. Some patients report a worse experience using HD than PD (Morris, Liles, & Roskell, 2015).

In this context, the results of preliminary studies have indicated that at the beginning of dyalisis therapy the patient, feel fear, shock, and refuse the theraphy. In addition, at the first time the patient did dialysis with CAPD, the patient felt stressed and unable to do anything. The patient feels anxious and worried about CAPD therapy, because he perceived that the CAPD therapy it is only to prolong his life and he perceived that the possibility of survival is about 50% and the possibility of passed away is also about 50% (interview Mr B). The experience of patients undergoing CAPD therapy is a unique experience. This phenomenon related to lived experienced of patients undergoing CAPD therapy cannot be described quantitatively because the meaning, perception, burden, or quality of life possessed by each patient is different and unique.

The research about lived experiences of ESRD patients who use CAPD therapy is still limited both in Indonesia and abroad, so researchers are interested in exploring patient experiences while undergoing CAPD in a hospital in West Java Province. Similar studies have often been carried out in Indonesia with the target or as informant being family members of patients with terminal renal failure who undergo hemodialysis (HD) therapy. Patients with terminal renal failure must perform renal replacement therapy by choosing appropriate therapy and becoming routine so that it affects their quality of life. The hope of recovering their health, only prolonging life or providing a better quality of life is a consideration of the chosen therapy. ESRD patients may need to switch to another kidney replacement therapy (Awuah et al., 2013). The result study of Yalamanchili et al. (2013) have indicated that patients feel that CAPD is beneficial, while others are worried about complications that can have serious consequences for their bodies. So that medical personnel also need to provide promotional steps starting before the patient initiates dialysis. So that the patient knows the context of each dialysis therapy he will choose. Therefore, to explore the values, meanings, burdens, benefits, feelings, and life experiences of these patients, it is through conducting research with qualitative phenomenological methods, to gain a deeper understanding of the lived experiences of people with ESRD who undergo CAPD therapy.

Therefore, one way to explore the values, meanings, burdens, benefits, feelings, and life experiences of patients is to conduct research with qualitative methods to obtain a more in-depth and specific picture of the experiences of individuals with ESRD undergoing kidney replacement therapy using CAPD.

## Method

This study employed a qualitative method with a descriptive phenomenology approach to explore the phenomenon. Descriptive phenomenology is the study of human experience it seeks to gain understanding of the human world as the basis of science which brings justice to the experience of everyday life and goes to the things themselves (Christensen, Welch, & Barr, 2017).

The research participants was selected through purposive sampling technique, based on certain considerations made by the researcher or inclusion criteria as follows: Participants aged ≥18 years, participants who suffer from end stage renal disease, active participants with CAPD therapy ≥1 years, and able to communicate in Indonesian and cooperatively. The participants of this study were accessed through the Hemodialysis Unit of the Hospital in West Java by observing the list of ESRD patients who had CAPD therapy. The list which contained identity data and patient's phone numbers that could be contacted were also provided by the doctor in charge of CAPD theraphy. After finding participants who match the inclusion criteria, the information related to the study was provided to the participants. The inform consent then provided to the participants which consists of the research objectives and asksed the willingness to be a participant in this study. Once, approval has been obtained from participants to contribute in this study, the researcher discussed with the participants regarding willingness to be interviewed, the time and place for the interview to be conducted. In this study, 10 participants of ESRD patients who undergo CAPD were participated.

This research was conducted in February 2020 and Ethic approval for conducting this study was obtained from the Health Research Ethics Committee of the UNPAD Faculty of Medicine no. 216 / UN6.KEP / EC / 2020. Data collection in this study utilized semi-structured in-depth interviews. Data analysis was conducted through the Colaizzi approach for analysis as follows :1) Read all the transcript results repeatedly, 2) Look back at data transcripts and select statements that are significant, 3) Formulate the meaning or meaning of important statements, 4) Categorize these meanings into themes according to participants' expressions, 5) Form a description of the phenomenon, 6) Identifying the fundamental structure, 7) Confirming or re-validating the description of the phenomenon to the participants (Colaizzi, 1978).

## Results

The phenomenon of lived experience of patients undergoing CAPD was described through 6 themes, namely: 1) Condition improved with CAPD, 2) Freedom of activity, 3) Between feeling better and bored 4) Health is increased, 5) It is sustained life, 6) Resignation to accept illness. These themes will be explained in the next section.

### Theme 1: Condition improved with CAPD

This theme was derived from the experiences of participants who revealed changes in the conditions felt by participants during CAPD that made participants felt that their conditions were getting better after switching therapy to CAPD. Participants felt a difference in their conditions, when he underwent HD therapy for more than a year and then Shifted to CAPD. They revealed that CAPD gave more benefits because they felt significant changes and they felt that the CAPD has made their body felt more comfortable, as indicated below:

So the benefits are a lot more, four times a day, this is not a problem, this is a routine, the same way when we pray, since at 5 o'clock in the morning I finished prayer, then I sometimes overslept..then my wife .. will help me to complet the CAPD therapy .. if I overslept.

It was revealed that their condition was getting better and better.

CAPD provides greater flexibility for patients in terms of time management: 1) Patients who are treated with CAPD, should be trained to adapt the CAPD prescription procedure in their daily activities if necessary and; 2) Clinical visits related to the implementation of CAPD are scheduled every 4 -12 weeks, compared to three times a week to HD unit for patients treated with HD.

After the patients shifted to CAPD for more than a year and the patiens felt, that several complaints such as hypertension, nausea, anorexia, all are felt decreasing. The patient feels that CAPD is suitable for renal failure treatment, as it made the patients feel more comfortable and healty. They perceived that it is because they felt several complaints had decreased, and there were even participants who mentioned that they had no more complaints after shifted to CAPD., as indicated above:

### Theme 2: Freedom of Activity

They revealed that they could freely do light activities after undergoing CAPD. All participants have various types of mobility, such as being able to ride their own vehicle, doing small businesses, doing house chores, even light exercise. As Mrs. I below:

CAPD patients are very likely to do their job, so it has no impact on their

income financially and, they could travel more freely than HD patients (Makkar, Kumar, Mahajan, & Khaira, 2015).

In this case, CAPD has increased autonomy and independence for the patients suffering from end-stage renal disease compared to HD facilities, and this is reflected in higher employment rates for patients treated with home CAPD compared to HD facilities (François & Bargman, 2014). A similar experience was also expressed by Mr. G as follows:

Participants felt that after switching to CAPD they became independent and independent of machine. As expressed by Mrs. I below:

### Theme 3: Between feeling better and bored

This theme was taken from participants who said that CAPD was simpler, more practical, the distance and time for dialysis had no obstacles. As stated by Mr. E below:

The majority of patients with renal failure can be treated with PD, an effective dialysis modality with similar overall survival at a lower cost compared to HD (François & Bargman, 2014). A similar experience was also expressed by Mr. A, who stated that during the CAPD there were no perceived obstacles related to the cost.

The ease of information was also revealed by Mrs. I which stated that the information of CAPD was obtained from nurses. However, all participants expressed the ease of CAPD information can be accessed anywhere such as from the internet, books, or people who are undergoing CAPD, so it is easier to get information.

During conducting CAPD there are also some limitations, including preparing CAPD fluids, confusion of CAPD equipment, blockage of the tube, body shivering after changing the fluids, and others. New patients with ESRD may be more eager to change their life habits to meet dialysis care requirements. But over time, patients feel bored and easily frustrated with the need to adhere to a long list of dietary restrictions and CAPD fluid replacement (Chan, Zalilah, & Hii, 2012). The following is an expression from participant no. 1, P2, P3, and P5, which revealed that they were saturated with CAPD fluid replacement routines had to be prepared in advance, as conveyed by Mr.A, below:

### Theme 4: Health is Increases

This experience was expressed by participants when undergoing CAPD felt that their health had improved such as improved blood pressure, condition became more fit, improved physical condition, body became more energetic and so on. Below is an expression from Mrs. I who stated that her physical condition was improving.

They also felt changes in their psychosocial aspects such as a good sleep patterns, opening up to the environment, feeling ashamed was gone, and not experiencing stress. CAPD treatment offers increased autonomy and control, flexibility in daily life and less social restrictions can also be reasons for better psychological health in patients (Makkar et al., 2015). CAPD patients also showed a greater reduction in depressive symptoms and greater patient satisfaction with treatment, because having depressive symptoms had a greater effect on HRQOL than the CAPD modality itself and the prevalence of depressive symptoms remained high despite the tendency to increase over time (Jung et al., 2016). As indicated in the quotation below:

In addition, they felt that their life was back to normal like before suffering from ESRD. Some participants revealed that they seemed to return to their former identity. Most CAPD patients could easily carry out routine activities such as working, walking up the stairs, washing, driving, traveling and also do not have sexual problems. CAPD patients were more energetic, cheerful, and active and have a good level of well-being. They become more flexible, such as returning to themselves before being sick (Paraskevi, 2011), as indicated below:

### Theme 5: CAPD sustained life

Waiting for the end, as part of the experience of going through the day, is a sad approach to life. Trapped in a process without end and life like being robbed because dialysis is only their only hope at this time. Although, dialysis keeps patients alive, and death is inevitable for all humans, CAPD is like the last call of life for them (Lin, Han, & Pan, 2015). The same experience was expressed by Mr. N as seen in the quote below:

Patients perceived that they live one day more anticipating their death and hoping to die with dignity, i.e. death without suffering (Lin et al., 2015). A similar experience was also expressed by Mrs. L who was worried about lifetime dialysis because there are relatives who had the same history and eventually died. Patients experienced uncertainty with a lack of information and unexpected illnesses, between life and death, and difficulty planning their life ahead. They were worried how long they will live with this disease. Patients also fear they will live alone, and believe that it will end in death (Sahaf & Ilali, 2017).

### Theme 6: Resignation to accept the disease

This experience was expressed by several participants who experienced ESRD and inevitably faced therapy that the participants had previously not known about the therapy. As expressed by Mr. T :

Positive meaning of a disease has implications for the emergence of a feeling of resignation to the patients. When sickness is interpreted positively by the patient, such as being patient and optimistic, the immunity in the body can increase. This affects their behavior (actions) both towards themselves and others which are related to health, illness, disease and medication. The pain felt by the patient is considered a disease that has become the destiny of Allah SWT. This statement assumed that pain must be accepted sincerely by the patient. Finally, the patient was resigned and patient with pain. This was because illness is considered as a test from Allah SWT with the aim that the sufferer would be better. On the other hand, illness can lead to an upbeat and optimistic attitude in the sufferer when sick, so that the patient has hope for recovery (Rahmawati & Muljohardjono, 2016). As expressed by Mrs. I, as follows:

When a person is afflicted with illness, spiritual power can aid in healing. The strength of one's spirituality can be an important factor in how to deal with changes caused by chronic disease (Potter & Perry, 2005).

## Discussion

Participants expressed that at the begining of the CAPD therapy, their body needed adaptation about five to six months. They revealed that their initial complaints such as swelling, weakness, anorexia, nausea, shortness of breath etc. gradually decreased. Another experience, there were also some participants who felt afraid because they will feel similar complaints with the previous therapy, before CAPD. Eventually, in a period of about five to six months, such complaints had decreased and even most of the complaints has been felt disappeared by certain participants.

According to Ören and Enç (2013) changes in conditions for the better outcomes are considered an important indicator of the results of treatment provided to participants. With CAPD they felt there was there was changes in their condition and they felt the benefits of CAPD and therefore the participants believed that CAPD is more safe. This was reflected as a feeling of satisfy, comfort, and feeling the benefits of CAPD for their condition because in the previous therapy they did not feel it. They perceived that CAPD is more suitable for them as an ESRD patients as also it less painful compared to the previous therapy which often causes participants to undergo frequent intravenous line insertion. This was explained by (Alharbi, Alraddadi, Alharbi, & Alharbi, 2017) that ESRD patients require dialysis almost every day, which inevitably affects their symptoms and emotions, for example, muscle weakness is the most frequent and, medication-related symptom among patients with ESRD may experience more intense emotional distress due to treatment-related symptoms than patients with other illnesses.

Participants who had undergone CAPD independently for more than a year indicated that they were able to mobilize, to do their homework, and socialize with local community members. CAPD allows individuals to independently adjust their lifestyle (Airheart, 2016). In addition, CAPD therapy achieves and maintains normality by maximizing the flexibility, freedom and mobility that is possible with CAPD. Ekelund and Andersson (2010) expressed their experience that CAPD can be seen as an easier option. Patient experience reveals that CAPD offers positive lifestyle choices, for example the patient is free during the day and the patient does not need to go to a dialysis unit, is a simpler option compared to HD. That is because they can set their own time about their treatment so they are able to schedule their activities without worrying about going to the hospital which takes time and money. They find it simpler and more practical than having to go to a dialysis center every week.

Patients undergoing CAPD fluid replacement have to spend a lot of time each day either outdoors or indoors. It is important for the patient to be able to find a way to spend the time, so that the patient does not get bored easily. According to Charles Corr (2015) CAPD patients experience a feeling of saturation saturation because they have to change fluids up to four times a day, to avoid saturation some patients can watch TV and play video games to avoid boredom, or others prefer to read and chat with other people. Some patients listen to music, sleep while assisted by someone closest to replace fluids. When replacing CAPD fluids, this can be a good opportunity to spend time in a way the patient can enjoy.

Patients who routinely do CAPD feel that their health has improved or improved after undergo CAPD within a period of five to six months as a period of adaptation. After six months, several participants revealed that their physical health were better, which were described by normal blood pressure, no shortness of breath, no swelling, no weakness, ideal body weight, and more powerful body. Research conducted by Ghaffar, Chasani, and Saktini (2017)

also revealed similar results. This can be linked to the elimination of azotemia toxin in ESRD patients through the implementation of CAPD that is conducted continuously every day and every six hours or four times a day of CAPD treatment whereas in HD treatment it is fluctuating because dyalisis procedure only condnucted for two to three times a week in the hospital. Azotemia toxin elimination is closely related to the severity of symptoms experienced by the patient.

The psychosocial factors are also improved in the participants after undergoing CAPD. This shows that improved physical health, psychological well-being and satisfaction with CAPD has led to the improvement treatment adherence and better disease management. This positive result may be directly related to the increase in HRQOL.

The participants expressed that CAPD was only intended to prolong or maintain the condition of their body so that their life would be longer because they were assisted by CAPD. Participants realized that the ESRD disease could not be cured and participants could only survive with CAPD. Lin et al. (2015) revealed that ESRD patients are trapped in an endless process with dialysis. ESRD patients are always exposed to continuous dialysis treatment unless they have a successful kidney transplant. Day after day they live waiting to end and hope to die well.

CAPD is like the last call of life for them. As a result, the participants found that they wanted to value life more by anticipating their own death and making hopes for a meaningful death, that is death without suffering. They did this because they expressed their concern of having dialysis all their life. Many ESRD patients though they were undergoing CAPD had severe symptoms for the participants, indicating that palliative care should be an integral part of nursing services (Hwang, Tsai, & Chen, 2010).

The thing that was most feared by the participants was death, as well as their families who were not ready to lose their loved ones. However, what worries the participants even more was that if the participant falls in a helpless condition, it can be troublesome for their family, but participants can only accept and resign everything to medical personnel no matter what. The commonness of patients often makes communication between medical personnel and patients felt hampered. This could affect the patient's attitude that they felt, they are only able to resign and accept medical intervention based on their illness.

In this study, each participant interpreted ESRD differently, ESRD as a test, as a remedy for sins, as a warning and so on. According to Ulrich (2008), the grieving response has entered a period of acceptance if the person has accepted the conditions and consequences he or she has experienced. The belief in God's power made the participants in this study felt resigned, sincere, and accepted the destiny given by God. Hope has a close relationship with spiritual matters. If there are obstacles in the spiritual, it can cause individuals to have low expectations and lead to despair.

Getting closer to God through self-reflection is what most participants feel is important in their spiritual life. Self reflection has encouraged participants to strengthen their knowledge of religion and improve the quality of prayer in their everyday life.

## Conclusion

The phenomenon of the lived experience of ESRD patients undergoing CAPD therapy is explain through the 6 themes obtained from this study, namely: Condition improved with CAPD, Freedom of activity, Between feeling better and bored, Health is increased, CAPD making life sustained and, Resignation to accept the disease. The researchers concluded that patients receiving CAPD treatment have various kinds of positive sides. Participants experienced significant positive changes in their life. Therefore, CAPD is considered life-sustaining for the participants. After undergoing CAPD participants are able to do several important activities that were not able to do when they were in previous treatment. With CAPD most of participants the symptoms such as swollen feet, shortness of breath, inability to move were decreased. So that the partisipants felt that their conditions improved better, therefore the participants considered to continue the CAPD treatment. The unpleasant sides of CAPD is feeling bored because of frequent practices fluid replacement in a day, yet there are many ways that can be done by participants to avoid boredom. Furthermore, the support provided by the family and the willingness to be healthier, has produced strength and passion for ESRD patients in undergoing CAPD.

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# Perceived Stigma, Psychological Response, and Nurse Coping In The Covid-19 Pandemic In Indonesia

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## Abstract

Nurses are at the forefront of being directly involved in the care of Covid-19 patients. This can put nurses in a difficult position, especially if they had lack support from the surrounding environment. The society's negative stigma towards nurses can trigger psychological problems for them. Good coping is needed to maintain the work performance of nurses. This study aims to identify the perceived stigma, psychological response, and coping of nurses involved in caring for Covid-19 patients in Indonesia. This research was a cross-sectional study based on an electronic survey. The number of respondents was 509 nurses who came from all regions in Indonesia on 11–20 April 2020. Respondents were nurses who handled Covid-19 patients directly. The data were collected using a modified questionnaire the Berger stigma scale, DASS and Brief of Cope with a total of 27 questions. The questionnaires used have been proven valid and reliable after being tested on 30 nurses treating Covid-19 patients with a Cronbach Alpha value as follows: modified Berger Stigma Scale 0.952; modified DASS 0.928; and modified Brief of Cope 0.753. Most respondents were 26-35 years old (52.1%), female (61.5%), and worked in government-owned hospitals (48.3%). 231 respondents were stigmatized (45.4%), 274 respondents were depressed (46.2%) and 209 respondents experienced stress (41.1%). The majority of respondents chose problem focused coping (65.8%). This study shows that some respondents feel they were stigmatized by society, but they have good coping (problem focused coping) to reduce their mental burden. Negative stigma against nurses is often difficult to avoid. Support from family and colleagues was something that can ease the mental burden of nurses. Support from the government was needed to educate the public so that it does not give negative stigma to nurses and other health workers.

**Keywords**: Coping, Covid-19, nurses, stigma.

## Introduction

Since December 2019, the city of Wuhan in China has reported cases of pneumonia caused by a new type of corona virus, namely Covid-19, which has now spread throughout the world (Li et al., 2020). Currently, there are 213 countries and territories affected by Covid-19 with almost 21 million cases, and 768,969 of them died (Worldometers.info, 2020). Per 15 Agustus 2020, the number of cumulative positive cases in Indonesia reached 137,468 with 6,071 fatalities (Satgas Penanganan Covid-19, 2020). In May 2020, there were more than 230,000 medical workers contracted with Covid-19 and more than 600 nurses died from the virus in 79 countries around the world. Whereas in Indonesia, as of August 1, 2020, 153 health workers died from Covid-19 and 55 of them were nurses. This makes Indonesia the country with the second highest death rate for health workers in Southeast Asia.

Coronaviruses are a large family of viruses that cause illness ranging from mild to severe symptoms. The virus that causes Covid-19 is called Sars-CoV-2. Transmission comes from close contact and droplets of the patient. About 44% of infections are thought to occur before symptoms appear (He et al., 2020). It is estimated that about 86% of infections remain undocumented, and about 55% of cases are contagious. This may be due to the period of infection that precedes symptoms, the frequency of asymptomatic cases, and the poor sensitivity of nasopharyngeal RT-PCR (Siordia, 2020).

Facing this pandemic situation, health workers are at the forefront of being directly involved in the diagnosis, treatment and care of Covid-19 patients who are at risk of experiencing psychological distress and other psychological health symptoms (Ornell et al., 2020). The increasing number of confirmed cases, high workload and limited personal protective equipment, and lack of support have made the mental burden of health workers even heavier (Chew et al., 2020). The increase in Covid-19 cases has caused many workers who work in the health sector to be exposed to this virus, one of which is a nurse. It is not uncommon for nurses to experience stigmatization from the community.

Erving Goffman defines stigma as a phenomenon when an individual with certain attributes that is highly discredited by society is rejected or excluded as a result of these attributes (Goffman, 1963). Stigma is a process whereby the reactions of others negatively affect a person's normal identity. The existence of stigma felt by nurses causes various mental health problems including stress, anxiety and even depression which can affect the quality of their work. Quality of work life is a reflection of the satisfaction of the nurse which has implications for several dimensions of life of the nurse, among the lives at home, the work environment, working conditions and the nurses' perception about their work (Somantri & Yudianto, 2018).

Nurses suffer from stigma from society as they work in hospital environments, a high-risk area for SARS-CoV-2 contamination (Koh et al., 2005). Stigma is associated with violence against healthcare workers: more than 200 attacks on healthcare workers and health facilities during the ongoing pandemic had been reported by May 2020 (Bagcchi, 2020). Healthcare workers were denied access to public transport, insulted in the street, evicted from rented apartments, and even physically assaulted. In Indonesia, there was refusal of the bodies of nurses who were confirmed to be Covid-19 and expulsion from their homes due to the fear of local residents (Elvina, 2020; Suyudi, 2020).

During the Covid-19 pandemic, the prevalence of depression and anxiety was high (Zheng et al., 2021). Anxiety is common among health care workers who are directly involved in managing affected patients during pandemics (Spielberger, 2010). Causes of anxiety among nurses include a lack of personal protective equipment and a concern that they can carry infections from the work environment to the family (Shanafelt et al., 2020). High levels of anxiety are related to the stress experienced by nurses during the Covid-19 pandemic (Mo et al., 2020).

Having direct contact with Covid-19 patients, health care workers (HCWs) are more exposed to traumatic events such as patients' suffering and deaths (Pappa et al., 2020), which could further amplify their anxiety, stress, and depression. For this reason, it is important to carry out an investigation about the stigma, psychological response and coping of nurses during Covid-19 pandemic in Indonesia.

## Method

This study was designed as a descriptive quantitative study to describe stigma, depression, anxiety, stress and coping of nurses in Covid-19 pandemic in Indonesia. This research had passed the ethical board of RS. Islam Sultan Agung Semarang with number 180/B1/FIK-SA/IV/2020. The population of this study were all nurses caring for Covid-19 patients in Indonesia. After calculating the sample size using the Slovin formula, the sample size was 509. 509 respondents have provided written informed consent prior to data collection. Data collections were taken from April 11 until April 20, 2020. Respondents filled out a questionnaire using a Google-form sent via WhatsApp application which was distributed randomly throughout Indonesia. Data analysis was implemented using a computer program. Proportion of stigma, depression, anxiety, stress and coping were determined.

For stigma, modification of Berger Stigma Scale was used (Berger et al., 2001). This tool consisted of a total 12 question in personalized stigma factors. A 4-point likert scale was used, ranging from 1 (‘Strongly Disagree’) to 4 (‘Strongly Agree’), which means the higher the score, the greater the stigma.

For depression, anxiety and stress, modifications of DASS-21 questionnaire was used (Osman et al., 2012). This tool consisted of a total 15 question with proportional questions in each depression, anxiety, and stress subscales. A 4-point likert scale was used, ranging from 0 (‘Never’) to 3 (‘Almost Always’), which means the higher the score, the greater depression, anxiety and stress.

For Coping, modification of the Brief Of Cope questionnaire was used (Carver, 1997). This tool consisted of a total 15 questionnaire with proportional question in each subscales (problem focused coping, emotional focused coping, less useful coping). A 4-point likert scale was used, ranging from 1 (‘Never’) to 4 (‘Always’), which means the higher the score, the greater score in each subscales. The questionnaires used in this study have been proven valid and reliable after being tested on 30 nurses treating Covid-19 patients with a Cronbach Alpha value as follows: modified Berger Stigma Scale 0.952; modified DASS 0.928; and modified Brief of Cope 0.753.

## Results

### General Characteristics

General characteristics of respondents in this study can be seen in table 1. Most of the respondents were 26–35 years old (52.1%), female (61.5%), and worked in government-owned hospitals (48.3%).

**Table 1 General Characteristics of Respondents**

| General Characteristics | Frequency (%) |
|---|---|
| Ages | |
| 17 – 25 years | 73 (14.3 %) |
| 26 – 35 years | 265 (52.1 %) |
| 36 – 45 years | 133 (26.1%) |
| 46 – 55 years | 38 (7.5%) |
| Gender | |
| Female | 313 (61.5%) |
| Male | 196 (38.5%) |
| Work Unit | |
| Public health center | 84 (16.5%) |
| Government-owned hospitals | 246 (48.3%) |
| Private hospital | 154 (30.3%) |
| Others | 25 (4.9%) |

**Table 2 Proportion of Stigma, Depression, Anxiety and Stress**

| Variabel | Frequency (%) |
|---|---|
| Stigma | |
| Stigmatized | 231 (45.4%) |
| Not stigmatized | 278 (54.6%) |
| Depression | |
| Depressed | 274 (46.2%) |
| Not depressed | 235 (53.8%) |
| Anxiety | |
| Anxious | 180 (35.4%) |
| Not anxious | 329 (64.6%) |
| Stress | |
| Stressed | 209 (41.1%) |
| Not stressed | 300 (58.9%) |

### Proportion of Stigma, Depression, Anxiety and Stress

Data on stigma, depression, anxiety, and stress were classified into 2 categories based on the median cut-off point value because the data were not normally distributed as can be seen in table 2. As many as 231 respondents (45.4%) felt stigmatized, 274 respondents (46.2%) were depressed, and 209 respondents (41.1%) were stressed.

### Proportion of Coping

The coping variables are classified into 3 categories, namely problem focused coping, emotional focused coping, and avoidance coping according to the question category in the questionnaire. Most of the respondents (65.8%) have practiced problem focused coping.

**Table 3 Proportion of Coping**

| Variabel | Frequency (%) |
|---|---|
| Coping | |
| Problem focused coping | 335 (65.8%) |
| Emotional focused coping | 157 (30.8%) |
| Less Useful coping | 17 (3.3%) |

## Discussion

This research was conducted at the beginning of the Covid-19 pandemic in Indonesia. From 509 respondents, 45.4% (231) of respondents felt stigmatized. When compared with our study, a study in India showed 54.6% of respondents also had a high perceived stigma score (Uvais et al., 2020). Perceived stigma arises when a person is aware of the social stigma against their group, and then internalizes it so that it can result in a loss of self-confidence and self-efficacy (Vogel et al., 2013). The social stigma in the Covid-19 pandemic is caused by unscientific beliefs and a lack of public knowledge (Bagcchi, 2020).

In this study, 46.2% of respondents experienced depression. Nurses have to face enormous workload and high-risk infection, which may lead to mental health problems such as anxiety or depression (Kang et al., 2020). The depression level of health workers (doctors and nurses) is getting higher along with the increasing level of hospitals in the care of Covid-19 patients (Liu et al., 2020a).

35.4% of respondents (180 people) in this study experienced anxiety. Anxiety is defined as a state of anxiousness or worry resulting from the anticipation of a real or perceived threat in a situation (Spielberger, 2010). Anxiety creates psychological problems for nurses, which reduces the quality of service during the pandemic (Wahyuningsih et al., 2020). Anxiety is commonly experienced by health workers who are directly involved in the care of Covid-19 patients and potentially affecting nurses' well-being and work performance (Labrague & Santos, 2020).

The main source of anxiety in nurses during the Covid-19 pandemic was fear of becoming infected or unknowingly infecting others, lack of personal protective equipment (PPE), fear of harbouring the novel coronavirus at work, lack of access to Covid-19 testing, fear of transmitting the virus at work, doubt that their institution would support them if they became infected, lack of access to childcare facilities during lockdown, fear of being deployed in an unfamiliar ward or unit and lack of accurate information on the disease (Mo et al., 2020; Shanafelt et al., 2020).

In this study, 41.1% of respondents (209 people) experienced stress. During pandemic, nurses are faced with a work environment with high job demands, high work pressure and symptoms of physical and psychological stress that can affect their health and well-being (Mo et al., 2020). Previous studies have shown that nurses with high levels of stress can be triggered by frustration, depression and other psychological and emotional disorders (Mo et al., 2020; Teles et al., 2014).

Coping is defined as a person's cognitive and behavioural efforts in response to stressors that determine how those stressors will affect physical and emotional well-being (Lazarus et al., 1984). In this study, 65.8% of respondents (335 people) used adaptive coping, namely problem focused coping. The purpose of problem-focused coping is to solve the problem or take action to change the status quo (Huang et al., 2020). Problem-focused coping was associated with better mental health and emotion-focused coping was associated with reduced mental health (Chang et al., 2007).

## Conclusion

The nurse may face a greater risk of exposure to Covid-19 patients as they spend more time on wards, provide direct care to patients, and are responsible for the collection of sputum for virus detection (Liu et al., 2020b). This condition might provoke stress, anxiety, and depression that can be seen from the results of this study. Social support can be an important factor in reducing psychological responses to nurses. Strengthening social support among nurses can mitigate the impact of work pressure on health (Mo et al., 2020; Ozbay et al., 2007). Nurses also have to maintain relationships with family and colleagues to get spiritual support to alleviate their mental burden. To avoid stigma against health workers, especially nurses, it is necessary to educate the community so that it does not give a bad stigma because it can affect the psychological condition of nurses.

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# Research Priority of Gerontic Nursing in Indonesia: findings from a Delphi Study

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### Abstract

While elderly population in Indonesia continues to increase, research around elderly and health care for elderly is still limited. The purpose of this study was to identify priority of research area on Gerontic Nursing in Indonesia. This was a descriptive study, using Delphi study with 2 survey rounds. Round 1 involved 34 participants purposely selected among nurses who worked in the area of and had a research interest in Gerontic Nursing. Open ended online questionnaire about priority areas was sent to potential participants. Data was analyzed for its similarity, resulted in 36 research areas around Gerontic Nursing. Round 2 involved 204 nurses with the same criteria as in round 1, selected using convenience sampling technique. Close ended questionnaire using Semantic Differential Scale ranged from 1 to 9 was sent online to potential participants. Data was descriptively analyzed for median, interquartile range (IQR), and range. Findings indicated 10 levels of research priority. Level 1 research priority with median of 9, IQR 1, and range 5 were long term care for elderly, family knowledge on caring for elderly, personal hygiene in elderly, competency of Gerontic Nurse, and nutrition in elderly. Nurse academics and researchers are suggested to collaborate with nurse practitioners in various settings to conduct research on these priority areas.

**Keywords:** Delphi study, elderly, gerontic nursing, long-term care.

## Introduction

Elderly population in Indonesia has doubled in the last five decades. By 2019, this specific group of population had reached 25,6 million or 9,6% of Indonesia total population (Biro Pusat Statistik, 2019). With a significant increase of elderly population, nursing as an integral part of national healthcare system should provide high quality health services in order to maintain adequate quality of life among elderly. This becomes more important especially in a specific circumstance such as Covid-19 pandemic, where Indonesia is reported as a country with high death rate among elderly population (United Nations, 2020).

In order to provide a better care for elderly, evidence-based practice resulted from rigorous studies is essential to provide safe and efficient outcomes for patients (Grove & Gray, 2018). Rigorous studies are achieved when researchers follow appropriate guidelines, procedures and design in conducting their research. In addition, it is also essential that researchers provide adequate reasons with clear explanation of why particular studies are important. Evidence from research priority may help researcher to do this.

Some studies involving elderly and healthcare for elderly in Indonesia are already conducted. These studies include research on anxiety to death, that indicates satisfaction in life as the dominant factors associated with death anxiety among specific ethnic group in Indonesia (Lukman et al., 2018). A study in nursing homes on dementia is also conducted in West Java. Findings indicate that low education, cerebrovascular diseases, and diabetes mellitus are predictors of dementia among elderly (Fitriana et al., 2020). A research on family support intervention for elderly with chronic condition has been conducted in Jakarta, resulted in evidence to support policy for family empowerment in caring for older people (Maryam et al., 2018).

The studies above are examples of some studies conducted in Indonesia among elderly that has notably given substantial empirical evidence for the development of nursing knowledge and nursing practices. However, there are no studies identifying which research areas are considered as priority in Gerontic Nursing. By identifying priorities, nurse practitioners, nurse academics, and nurse researchers may refocus their research area for the development of the most needed evidence in caring for the elderly. In addition, research priorities identified by nurses working in the specific area are more relevant to the specialty and minimize the gap between theory and practice (Ramelet et al., 2012). This current study is the very first research aimed at identifying priority of research area on Gerontic Nursing in Indonesia.

There are several methods to priorities research area; including Delphi study, nominal group technique, and consensus development conference. Nominal group technique and consensus development conference require physical meeting to gain group consensus, which would have been difficult to achieve in the current study because of two reasons. First, participants for this study are nurses from all around Indonesia. Secondly, in order to obey health protocols, physical meeting is prohibited due to Covid-19 pandemic. Delphi studies are able to bridge this issue because they allow national participants over a wide geographic area to express their opinions without having to conduct a physical meeting (Keeney et al., 2017).

The term Gerontic Nursing is used and has been agreed by nursing experts in Indonesia. This is because Gerontic Nursing reflects nursing for elderly with its three essential elements of nursing i.e. nurturing, caring and comforting (Meiner & Yeager, 2019). Other countries such as Australia and the US prefer the term Gerontologic Nursing. The term Gerontic Nursing is also used in nursing curriculum in Indonesia.

## Method

This was a descriptive research using Delphi Study. The Delphi technique was developed by Dalkey and associates at the Research and Development (RAND) Corporation. This technique has three distinctive characteristics. First, it has anonymous response where opinions of members of the group are obtained by formal questionnaire. Second, there is an iteration and controlled feedback where interaction among participants is affected by a systematic exercise conducted in several iterations, with carefully controlled feedback between rounds. Third, it has statistical group responses where group opinion is defined as an appropriate aggregate of individual opinions in the final rounds (Diamond et al., 2014).

Delphi study consists of 2–3 surveys involving participants or experts in the related fields. Delphi study as a research design has been utilized in nursing in a wide range of studies such as identifying nurse competencies (Collins et al., 2017), developing a self-care guideline (Suyasa, 2013), identifying priorities for nurse's professional development (Cooper et al., 2017), and analyzing nursing research priorities in critical care (Acosta et al., 2020).

Delphi study in this research was designed as a 2-round survey. Participants in all rounds were considered as experts in this study. They were nurses who were already providing care for elderly in hospitals, community, nursing homes; lecturers in nursing institutions, and researchers who had interest in Gerontic Nursing all around Indonesia.

## Delphi Study Round 1

Round 1 Delphi Study involved 34 participants purposely selected among nurses who were currently providing care for elderly in hospitals, community, nursing homes, lecturers in nursing institutions and researchers who had interest in Gerontic Nursing all around Indonesia with minimum educational background of DIII in nursing. Open ended online questionnaire about research area or specific topic in Gerontic Nursing was sent to potential participants. Information sheet was also sent to potential participants, and they were requested to participate in the study using online system via email and WhatsApp application. They were asked to consent prior to data collection. Data collection for round 1 was conducted in November 2020. As data in round 1 was collected using open ended questionnaire, the data analysis was done following three steps: 1) reading the whole data to see various responses from participants, 2) collapsing the same or similar statements into one statement, and 3) keeping the wording as true as possible to one of the statements provided by the experts (Keeney et al., 2017). This resulted in 36 research areas around Gerontic Nursing. In order to validate the findings in round 1, all 36 research areas were sent back to participants. All agreed that the areas were relevant as item measures for round 2 Delphi Study.

## Delphi Study Round 2

Round 2 involved 204 nurses with the same criteria as in round 1. Participants in round 2 were selected using convenience sampling technique. Questionnaire in round 2 was developed based on responses in round 1. Close ended questionnaire using Semantic Differential Scale ranged from 1 to 9 was sent online to potential participants. The lowest priority represents as 1 and the highest priority represents as 9. Information sheet was sent to potential participants and they were requested to participate in the study using online system via email and WhatsApp application. They were asked to consent prior to data collection. Data collection for round 2 was conducted in November 2020. Prior to data analyses, data was checked for error and missing. In this study, no data error and missing were found. After data checking, descriptive analyses were conducted for median, interquartile range (IQR), and range using SPSS version 20. The IQR is calculated as the difference between the third and the first quartile. The conclusion for research priority was made following rules that the higher the median, the smaller the IQR and range, means the higher the research priority.

This study was approved by Research Ethics Committee of Institute of Technology and Health Bali, reference number 03.006.2/KEPITEKES-BALI/IV/2020.

**Table 1 Summary of Research Method in Round 1 and Round 2**

| Method | Round 1 | Round 2 |
|---|---|---|
| Sampling technique | Purposive | Convenience |
| Sample size | 34 | 204 |
| Questionnaire | Open ended | Close ended (Semantic Differential Scale) |
| Data analyses | Qualitative | Quantitative (Median, IQR, Range) |

## Results

### Demographic characteristic of participants

The majority of participants in round 1 and 2 were females (55.9 and 69.1, respectively), and mostly working as academic/researcher (58.8 and 42.6, respectively). In terms of educational background, 50% of participants in round 1 had master level, and 32.4% of participants in round 2 were graduated from Ners Profession (Details are presented in Table 2). Especially in round 2, participants were a representation from 14 provinces in Indonesia, including Bali, East Nusa, West Nusa, South Sulawesi, South East Sulawesi, Maluku, Banten, Jakarta, East Java, Central Java, West Java, Riau, Papua, and West Papua.

**Table 2 Gender and Educational Background of Participants in Round 1 and Round 2**

| Characteristic | Round 1 (N=34) | | Round 2 (N=204) | |
|---|---|---|---|---|
| | n | % | n | % |
| Gender | | | | |
| Male | 15 | 44.1 | 63 | 30.9 |
| Female | 19 | 55.9 | 141 | 69.1 |
| Education | | | | |
| Diploma III | 5 | 14.7 | 27 | 13.2 |
| Bachelor/Bachelor of Applied Science | 4 | 11.8 | 29 | 14.2 |
| Ners Profession | 1 | 2.9 | 66 | 32.4 |
| Master | 17 | 50.0 | 58 | 28.4 |
| Nursing Specialist | 6 | 17.7 | 12 | 5.9 |
| Doctor | 1 | 2.9 | 12 | 5.9 |

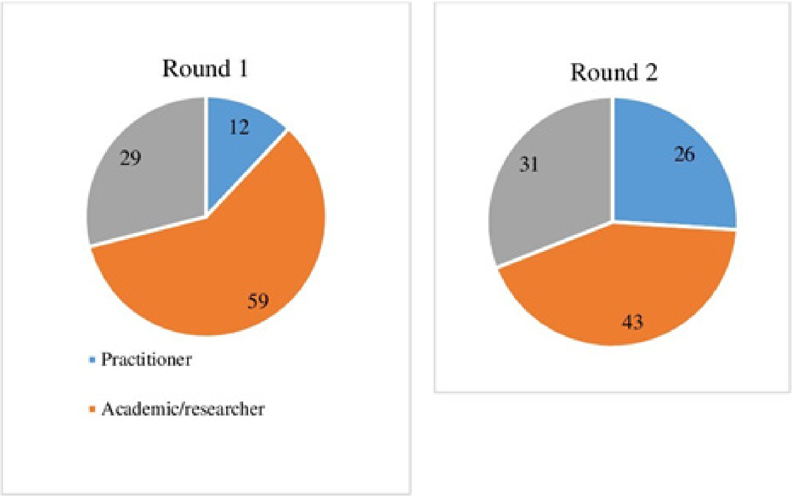

**Figure 1 Roles of Participants in Round 1 and Round 2**

Roles of participants in nursing are an important figure for the study as it reflects the expertise of participants. As illustrated in Figure 1 below, most participants (59% and 43 %, respectively) in Round 1 and 2 had roles as academics/researcher.

### Findings of round 1

Responses from open ended questionnaire in round 1 were analyzed for its similarity resulted in the identification of 36 research areas in Gerontic Nursing (Table 3, column 1). These areas are the source for quantitative, close ended questionnaire in round 2.

### Findings of round 2

Based on statistical analyses of median, IQR and range, there were 10 levels of research priority. Level 1 research priority with median of 9, IQR 1, and range 5 were long term care for elderly, family knowledge on caring for elderly, personal hygiene in elderly, standard competency of Gerontic Nurse, and nutrition in elderly. Level 2 research priority with median of 9, IQR=1, and range 7 were psychological problems and daily living activities in elderly. Meanwhile level 3 research priority with median of 9, IQR=1, and range 8 were psychological problems in elderly and daily living activities. In addition, neglect and aloneness among elderly in Indonesia (median of 8, IQR=2, and range 8) was considered as the lowest level of priority. Details are presented in Table 3.

**Table 3 Priority Level of Research Area in Gerontic Nursing (N=204)**

| Research area identified in Round 1 | Median | IQR | Range (min-max) |
|---|---|---|---|
| **Level 1** | | | |
| Long term care for elderly | 9 | 1 | 5 (4–9) |
| Family knowledge on caring for elderly | 9 | 1 | 5 (4–9) |
| Personal hygiene in elderly | 9 | 1 | 5 (4–9) |
| Standard competency of Gerontic Nurse | 9 | 1 | 5 (4–9) |
| Nutrition in elderly | 9 | 1 | 5 (4–9) |
| **Level 2** | | | |
| Psychological problems in elderly | 9 | 1 | 7 (4–9) |
| Daily living activities of elderly | 9 | 1 | 7 (4–9) |
| **Level 3** | | | |
| Quality of life of elderly | 9 | 1 | 8( 1–9) |
| Fall prevention in elderly | 9 | 1 | 8 (1–9) |
| Immune system in elderly | 9 | 1 | 8 (1–9) |
| **Level 4** | | | |
| Comorbid condition in elderly | 9 | 2 | 5 (4–9) |
| **Level 5** | | | |
| Nursing intervention in elderly | 8 | 1 | 6 (3–9) |
| **Level 6** | | | |
| Family role in caring for elderly | 8 | 1 | 7 (2–9) |
| Non-communicable diseases in elderly | 8 | 1 | 7 (2–9) |
| **Level 7** | | | |
| Preventive health care for elderly | 8 | 2 | 5 (4–9) |
| Degenerative diseases in elderly | 8 | 2 | 5 (4–9) |
| Culture of caring for elderly | 8 | 2 | 5 (4–9) |
| Musculoskeletal problems in elderly | 8 | 2 | 5 (4–9) |
| Readiness for quality Aged Care Facilities | 8 | 2 | 5 (4–9) |

| Research area identified in Round 1 | Median | IQR | Range (min-max) |
|---|---|---|---|
| **Level 8** | | | |
| Technology support in caring for elderly | 8 | 2 | 6 (3–9) |
| Medication management in elderly | 8 | 2 | 6 (3–9) |
| Roles of nurses in caring for elderly at home | 8 | 2 | 6 (3–9) |
| Health promotion in elderly | 8 | 2 | 6 (3–9) |
| Development of tools/equipment for fulfilment in daily needs of elderly | 8 | 2 | 6 (3–9) |
| Socio-cultural aspects of elderly | 8 | 2 | 6 (3–9) |
| **Level 9** | | | |
| Spiritual aspects of elderly | 8 | 2 | 7 (2–9) |
| Assessment tools for elderly | 8 | 2 | 7 (2–9) |
| Fear of loss in elderly | 8 | 2 | 7 (2–9) |
| Anxiety in elderly | 8 | 2 | 7 (2–9) |
| Family relation in caring for elderly | 8 | 2 | 7 (2–9) |
| Incontinence in elderly | 8 | 2 | 7 (2–9) |
| Activities during hospitalization | 8 | 2 | 7 (2–9) |
| **Level 10** | | | |
| Neglect in elderly | 8 | 2 | 8 (1–9) |
| Aloneness in elderly | 8 | 2 | 8 (1–9) |

Min = minimum, Max = maximum, IQR = interquartile range

Besides research priority as presented in Table 4, participants in round 2 also suggested other research areas including behavioral risk factors in elderly, elderly in disaster condition, end of life care, terminal care, hospice care, adverse life events, health literacy, recreational needs in elderly, occupational and modality therapy, caring for elderly in Covid-19, caregiver burden, intergenerational relationship, self-efficacy, and family resilience.

## Discussion

This is the very first study in Indonesia to identify research priority in Gerontic Nursing. Literature search using EBSCOHOST, ProQuest, and Science and Technology Index (SINTA) could not identify similar study in the Indonesian setting. Nurses, not only in Indonesia, but also worldwide, constitute the largest health workforce and play essential roles in health care for the elderly. Therefore, nurse's involvement in research is important to support evidence-based practice in Indonesia.

Indonesia is one of the fastest growing developing countries with advancing population of elderly. The need for long term care for elderly in Indonesia is already discussed in previous studies (Agustin et al., 2019). Another study indicates that long term care for elderly in Indonesia has been established using community empowerment by conducting integrated health post for the elderly (Pratono & Maharani, 2018). In addition, the Ministry of Health also highlights the importance of providing adequate long term care for elderly especially for those with high dependency level (Kementerian Kesehatan RI, 2019). However, the sustainability, equitability, and quality of long-term care for elderly in Indonesia remains a challenge (Schröder-Butterfill, 2020). In line with this, findings of the current study emphasized the need to conduct further research on long term care for elderly in Indonesia as the first level of priority.

It is not surprising that findings of this study indicated family knowledge in caring for elderly also as the first level of priority. It has been argued for decades that family is the main caregiver for older people in Indonesia, and family support is essential for caring of the elderly. Family support not only includes emotional, instrumental, and informational, but also a reciprocal relationship between elderly and their family caregiver (Kamaryati & Malathum, 2020). Therefore, providing support including training for family caregiver is important. Previous studies have identified this issue, for example, the exploration of family experience in caring for elderly with dementia (Ibad et al., 2017) and support for family of self-care ability in community (Suardana et al., 2018). As indicated by findings of this current study, more research is needed on family issues and support for family caregiver in providing adequate care over time to elderly.

A standard competency is important to ensure health care professionals meet expected and required knowledge and skill to provide care. Standard competency in Gerontological Nurse in other countries such as Iran has been discussed in the literature (Purfarzad et al., 2019). Although the need and the roles of nursing in elderly care have been identified in Indonesia for almost two decades, no studies on the development and evaluation of standard competency of Gerontic Nurse are conducted. Findings of our current study support that the development of standard competency of Gerontic Nurse in Indonesia is essential and also becomes the first level priority.

Nutritional status is a person's health condition that may be influenced by the intake and utilization of nutrients. In elderly, nutritional status may involve food intake and body mass index. Nutritional status of elderly is another research area found as the first level of research priority in this study. This supports previous evidence that nutritional status is an important measure for health of elderly as poor nutritional status is considered as a risk factor for frailty (Setiati et al., 2019). Furthermore, malnourished among elderly is also found to be associated with less functional capacity and low independence (Arjuna et al., 2017). However, despite evidence suggesting the relationship between nutritional status and health of elderly, research around this issue is still limited. Some more studies in the Indonesian context focusing on nutritional status are important.

Personal hygiene includes bathing, dressing, toileting, and oral hygiene. Personal hygiene especially in frail older people is another important issue and was identified as another area of the first level of priority in research for Gerontic Nursing. Attending personal hygiene in home setting has been identified as an important role of nursing (Hørdam et al., 2017). Personal hygiene in elderly may influence physical condition. More importantly, it is considered as a symbol of dignity in many societies. A study found that personal hygiene is an indicator for quality of life in globalization era (Hinek et al., 2019).

Psychological problems in elderly including anxiety, depression and loneliness are prevalent both in institutionalized and non-institutionalized elderly (Hassan et al., 2017). More evidence is essential in the Indonesian context especially what is best to handle the psychological problems. This is in line with the finding of this study, as this issue is found as the priority research area level 2.

Similar to psychological problems, research on daily living activities in elderly is also crucial and agreed as the priority research area level 2 in this research. Daily living activities include eating, bathing, dressing, toileting and transferring. As age advancing, together with declining in some functional status of elderly, fulfilment in daily living activities is a challenge especially in frail elderly (Ran et al., 2017).

Quality of life, prevention of fall and increasing immune system in elderly are considered as research area with priority level 3. Quality of life in elderly could be both subjective and objective. Subjective quality life involved with elderly's satisfaction and appreciation with his or her living status. This includes personal income, the degree of feeling safe when elderly travels outside the house, and perceived health status. Meanwhile, objective quality of life involves the observation of living standard including safety of the street and outside living condition and quality of health care (Şahin et al., 2019).

The prevalence of fall among elderly becomes a great concern as it shows alarming number of 29% (Susilowati et al., 2020). When 1 among 3 elderly lives in fear of falling, best measure and strategies to prevent fall are imperative. Fall may impact on physical and psychological well-being of elderly. Physical impact may include wound, fracture, and head trauma. Psychological impact include fear of falling and depression. This may also lead to worsen health status, poor quality of life and higher burden of care for family. Therefore, more research on fall prevention in elderly is also essential.

Immune system in elderly is another important issue to be discussed following two reasons. Firstly, influenza vaccine is not included in the national policy as a mandatory immunization (Susilarini et al., 2020). Secondly, it is acknowledged that infectious diseases such as influenza virus infection among elderly is a concern in Indonesia especially in Pandemic Covid-19 (Azwar et al., 2020). Therefore, conducting research on immune system and intervention on how to increase immune system among elderly is important.

Although caregiving for elderly by family members is pivotal in the Indonesian context due to its cultural background, it is inevitable that providing alternative residential aged care facilities for frail or sick elderly is important. This is probably because of globalization and the need to work outside house for other family members especially younger generation, making alternative aged care facilities becomes more apparent. This was highlighted in this study as research priority area level 7.

It is evident that with the increase number of elderly populations, especially those with chronic diseases and multimorbidity conditions, the use of medication also increases (Lavan et al., 2016). Multimorbidity then leads to polypharmacy (Abdulah et al., 2018). If polypharmacy is not managed well, it may cause medication error, which may further develop new comorbidity or complication or worsen patient existing condition. Therefore, it is essential to find evidence on medication management, on how elderly cope with medications and polypharmacy, as well as evidence on how to reduce medication error among elderly patients.

In this globalization era, research on technology support in caring for elderly is also a priority. It is evident in this study that this issue is agreed by participant as the priority area level 8. Technology support includes not only support for direct care for elderly such as technology for fall detection or equipment for fulfilment of daily living activities, but also support for better care coordination among nurses and interdisciplinary team such as supplementation with information technology for communication and care coordination (Blumenthal et al., 2016).

Interestingly, although neglect and aloneness among elderly in Indonesia are identified by previous studies (Sahar et al., 2018), they were considered as the lowest research priority by participants. This may be due to the fact that the concept of neglect and aloneness are poorly understood in Indonesia.

## Conclusion

One of distinguished advantages from this study related to the use of Delphi study is that the findings of this study have the depth of quality data resulted from round 1. The data from round 1 is validated and agreed by adequate sample size in round 2. Two rounds Delphi study in this research result in thirty-six research areas that are classified into ten levels of research priority in Gerontic Nursing. Among the 36 research areas, 5 of them are considered as level 1 priority. These include long term care for elderly, family knowledge on caring for elderly, personal hygiene in elderly, standard competency of Gerontic Nurse, and nutrition in elderly. All these areas are the essentials roles of nursing and they give significant implications for nursing.

There are three implications for nursing practice and nursing research arising from this study. First, nurse researchers/ nurse academics in Gerontic Nursing may refocus their research to fit with the research priorities resulted from this study. Second, nurse practitioners in various settings should work together in collaboration with nurse researchers/nurse academics as a research team to conduct rigorous research. Third, nurse practitioners should apply findings from research in their practice to support quality elderly care in Indonesia.

However, this study has some limitations. Firstly, although the sample size in this study is considered adequate, the number of nurses with expertise in Gerontic Nursing involved in this study could have been greater. Secondly, it consists of 2 rounds Delphi study. There are several research areas arise from round 2 that have not been examined quantitatively to reach consensus. Future researchers are suggested to re-examined this issue periodically as the health of the elderly is influenced by bio-social-spiritual aspects of individual, family, community, and environment. Similarly, health care for the elderly is also dynamic, influenced by socio-culture and policy changes.

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# The Lived Experiences of Adolescents Living with a Schizophrenic Mother

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## Abstract

The character building and the development of adolescents are greatly influenced by their mothers. Adolescents who have a schizophrenic mother can undergo problems in their development. This study aimed to explore the lived experiences of adolescents who live with a schizophrenic mother in Bandung. This is a qualitative study with a phenomenological approach. In-depth interviews were conducted with six adolescents aged 17–24 who live with a schizophrenic mother in Bandung. Interview transcripts were analyzed using the Colaizzi method. Eight essential themes emerged in this study. The participants were experiencing various negative emotions while living with their mother and lack of mother-child attachment, but they kept on trying to accept the mother's condition. They expected that there will be no stigma toward their mother. They needed supports and a friend who could understand and give advice. Notwithstanding the negative situations, they could find a lesson behind the hardship and the father became the source of inspiration. Getting supports from the father and having good friends are the main keys for them to survive. The implications for nursing practice are the need to provide health education programs to help adolescents manage emotions, the development of family-focused care programs, and peer-support groups. Further research is needed in Indonesia to develop appropriate interventions to address mental health problems for adolescents who have schizophrenic mothers in Indonesia.

**Keywords:** Adolescents, phenomenology, qualitative, schizophrenic mother.

## Introduction

A mother was a highly influenced figure in adolescent development. A mother-child relationship affected the adolescent to build their social relationship. The disturbance in the relationship might cause a tremendous problem in adolescent development (Santrock, 2014). The case study held by Cucu-Ciuhan (2015) declared that a schizophrenic mother had a high risk to experience a relationship disturbance with her children. The relationship disturbance was marked by disorganized attachment so that her children had difficulty trusting others.

Herbert, Manjula, and Philip (2013) stated that the relationship disturbance of the children who live with schizophrenic parents caused them to have emotional, social, and academic difficulty. The emotional difficulties felt by those children were fear, loneliness, and the loss of peace and happiness in the family. They were also afraid to go out with their parents and could not bring their friends' home. The lack of social support and the sorrow from the bad experience later caused difficulty in studying (Herbert et al., 2013).

Jundong et al. (2012) and Ranning et al.(2018) also supported that there was a learning difficulty on children with schizophrenic parents. They declared that children with schizophrenic parents had a worse school performance compared to those with non-schizophrenic parents. Jundong et al. (2012) study showed that the associated factor to the children's bad performance was the genetic factor. While according to Ranning et al. (2018), the environmental factor was the most associated with the children's school performance. The environmental factors were stress in the family and the parents had difficulty in helping with their children's homework.

There are many negative impacts caused by a schizophrenic mother on adolescent life. Hence, it was important to analyze the possibility of adolescent mental disorders and the factors used as an intervention in handling adolescent psychosocial problems. So far, the research on adolescent lived experience with a schizophrenic mother was held mostly in the western country. In Asia, this research was held in Hong Kong, Taiwan, Iran, India, and Korea. There was not any phenomenological research yet on adolescent lived experience with a schizophrenic mother in Indonesia, especially in Bandung.

The preliminary studies by Dinas Kesehatan Kota Bandung recorded that the schizophrenic patients in 2019 increased from 741 to 941 patients. From that number, there were 876 patients in the productive age and about 20% among them were mothers. Therefore, the researcher was interested to conduct profound research about the lived experience of adolescents living with a schizophrenic mother in Bandung. Additionally, to analyze whether the culture in Bandung affected the adolescents' lived experience.

## Method

The descriptive phenomenological method was applied in this study. Six adolescents were selected based on the purposive sampling technique. The inclusion criteria for participants in this study were adolescents aged 10–24 years old who live with a mother diagnosed with schizophrenia for more than two years. The research was conducted in May-August 2020 in the working area of Puskesmas Babakan Sari, which is one of the places in Bandung with the highest number of schizophrenic patients. Data collection was completed through in-depth interviews by asking open-ended questions to explore the lived experiences of adolescents living with a schizophrenic mother. Each interview lasted about 30–90 minutes. The interview procedure was carried out under Covid-19 prevention protocol.

The interviews were transcribed verbatim and then analyzed using the Colaizzi method. The researcher read and re-read the transcript repeatedly to identify significant statements. The significant statements were highlighted and put into the formulated meaning table. Then, the researcher classified the significant statements and formulated meanings into sub-themes. The sub-themes were categorized into eight main themes after being analyzed carefully into each interview transcript, significant statements, formulated meaning, and sub-themes. After that, the researcher developed a comprehensive description of the phenomenon based on the theme that had been composed. The researcher also performed bracketing to avoid mixed meanings with existing theories. Finally, the researcher validated the results to the participants to ensure that the themes obtained were appropriate with the participants' meaning.

The ethic approval of this study was provided by the Research Ethics Committee of Universitas Padjadjaran with the issuance of ethical clearance number 475/UN6.KEP/EC/2020. The participants in this study had signed informed consent. However, informed consent for the participant under 18 years of age was signed by parents. Data confidentiality was guaranteed by the researcher.

## Results

The participants of this study were six adolescents, consisted of three females and three males between 17-24 years old. Those adolescents lived in a house with a nuclear family. However, one of the participants was no longer living with the father because the parents were divorced and the father had remarried. The mothers had been diagnosed with schizophrenia for 10 to 20 years.

Eight essential themes emerged in this research: (1) experiencing various negative emotions while living with their mother, (2) lacking of mother-child attachment, (3) trying to accept the mother's condition even though it is very hard, (4) finding a lesson behind the hardship, (5) getting supports from many people, (6) expecting that there will be no stigma toward the mother, (7) needing a friend who could understand and give advice, (8) making the father as the source of inspiration.

### Experiencing various negative emotions during their stay with their mother

The participants in this study revealed various negative emotions they had during their stay with their mother. The feelings of bewildered, sadness, pity, anger, disappointment, mixed feeling, helplessness, fear, to feeling tired and stressed with their mother's behaviour.

Three of the six participants revealed confusion when they saw their mother's behaviour. One of the participants revealed that he could not understand his mothers' behaviour when she had relapsed:

"Glasses, plates were flying..; broken..; And then she was playing with all of that… until…(huff)I don't know… I can't wrap my mind around it…"(P1)

Four of the six participants revealed that they were sad to see the behavioural changes of their mother and felt pity for her. A boy said that he was sad and sorry for his mother, moreover when he saw his mother was chained. Another participant said that he was sad because his life was not like others who could live quietly with their parents.

Four of the six participants also revealed their guilt to their mother. One boy thought that he caused his mother to stress and to have a mental illness.

"Maybe she was confused because of my sickness… She wanted me to have the surgery so I could get healthy. But it couldn't happen because there wasn't any money. So, maybe it caused her stress…. then she started to act weird"(P4).

Three of the six participants declared that they were angry and disappointed with their mother's behaviour. One boy revealed that he was disappointed, angry and sad when his mother said he was not her son. A girl stated that she felt tired and angry with her mother's behaviour:

"We were very tired, you know. Sometimes I felt so angry…Sometimes I was yelling at her. Even my sister, the oldest one, once hit her hand with a broom because she didn't want to let the knife go.."(P6)

Four of the six participants said that they felt helpless to deal with their mother's condition. Two of the participants said that they just stayed still and cried to see their mother's rage. They could not do anything to calm their mother. Another participant said that she did not want a life like this and there wasn't anybody who understood her.

Three of the six participants revealed that they were ashamed of their mother's condition. They were ashamed to bring their friends home and also when their mother was screaming at home.

Four of the six participants declared that they were afraid and startled to see their mother's behaviour. A boy revealed that he was scared of his mother's emotional changes and his mother would commit a crime. Then, another girl stayed away from her mother because she was afraid that her mother would hurt and harm her physically.

Three of the six participants revealed their tiredness and stress in taking care of their mother. A girl said that she was sick and tired of her mother's endless behaviour. A boy revealed that even though he looked fine on the outside, he felt slump and depressed on the inside because his life was changed.

### The lack of mother-child attachment

This study revealed that since their mother had schizophrenia, they felt forgotten and ignored because their mother's behaviour changed to rude and ignorant. They also didn't trust their mother so it put their relationship away.

Four of the six participants revealed that they felt forgotten and ignored because of their mother's behavioural changes. Their mother became a very different person from before she had schizophrenia. One boy revealed that his mother became rude and treated him like he was not her son. Other participants felt that his mother slept too much, then she became ignorant and forgot her own family.

Two of the six participants said that they did not trust their mother's words. They said that sometimes they doubted their mothers' words and they didn't feel any connection when they talked to their mother. As a girl stated:

"It's been a long time since my mother was like that .... I didn't believe in her. Whatever she taught me, I would think that this person doesn't make sense. I don't want to listen to what she said." (P6)

### Trying to accept the mother's condition even though it is very hard

The participants in this research revealed that even though they had many difficulties while they were living with their mother, they still tried to accept their mother's condition as it was.

Five of the six participants stated that they reminisced about their mothers' unnatural behaviour. They remembered when their mother acted strangely and was in a rage. Their first experience in watching their mothers' unnatural behaviour was an unforgettable bitter memory for them.

Three of the six participants revealed that it was difficult to tell their mother to take the medicine. Besides the medicine, another difficulty they faced was because their mother was childish. They felt like taking care of a child instead of being taken care by a mother. Then, two participants said that they had difficulty in taking care of their mother because their mother was stubborn and didn't want to listen to them.

Five from six participants revealed that their mother relapsed frequently on many things. This made them worried more about their mother's condition. The most frequent thing that made their mother relapsed was dropping out of her medicine. Besides the medicine, one participant said that his mother would relapse on tiredness. Then, another participant said that every time his mother was resentful, she would relapse and raged. Three participants also said that their mother would relapse if she was left alone at home.

The participants did many efforts to take care of their mothers and to keep their mothers calm. One boy said that he prayed for his mother, gave her understanding and motivation, gave presents to his mother (money and food), and he also took his mother to walk to calm her. A girl said that she tried to calm her mother by doing what she wanted and taking her to do her checkup. Their mother could also be calmed by encouraging her and joking with her. However, one of the participants said that she could not calm her mother, so when her mother relapsed she would lock her mother in a room or she would take her mother to be hospitalized in a mental hospital.

Five of the six participants revealed that they used to bury their own emotion and relieved the stress by doing activities outside the house. Most of the participants said that hanging out with their friends could eliminate their sadness, make them laugh and encourage them, as one girl stated:

"I ended up going out, culinary with my friends or watch the cinema. That's it... I merely go to the mall for refreshing...I just want to forget about it for a moment anyway..." (P6)

Other than hanging out with friends, another girl used to soothe her feelings by being alone in her room while listening to music. Then, a boy chose to join a youth organization to relieve his sadness, to get motivated and learn to be mature.

The participants said that the key to surviving their life changes was to be patient and to accept their mothers' condition. Three of the six participants revealed the importance to motivate themselves to become stronger. One of the participants said that he had to be strong to face his life fate because he was the only one who could change himself to be stronger. Another participant said that he tried to calm and to motivate himself to be stronger and living his life as it was. A girl said that she tried to put in herself to live her life as it was and not to feel sad about her family condition.

Three of the six participants revealed that the sources of their biggest strength in facing the life changes were their faith and their good friends. One of the boys said that his biggest strength was his faith. Doing prayer and reading the Quran made him stronger and he could forget about his problems. Besides his faith, having good friends was also a strength for him. A girl added that based on her religion 'heaven lies beneath the mother's feet'. So, the participant still tried to accept no matter how bad her mother condition was and tried to make her mother happy while she was still alive.

**Finding a lesson behind the hardship**

Most of the participants in this study revealed that there was a lesson behind the hardship in their life. The changes in their mother's condition and their family situation made them learn to be an independent and responsible person.

Three of the six participants revealed that they wanted to do well at school. The participants made their mother's situation a motivation to be an achiever. Then, two of the six participants revealed their desire to continue their study to a higher level even with their effort. Their mother's condition and the changes in their family didn't hold their desire to continue their study.

Three of the six participants revealed that they had to become independent since childhood because of their mothers' condition changes. They said they learned to be independent because they didn't want to trouble their parents, as one of the participants said:

”Yes, actually there was a lesson from what happened before. Honestly, since I was little I had to think how to stop bothering my parents anymore.”(P4).

Two of the six participants said that they felt responsible for their parents. They felt that they needed to work and being responsible for the family. Another participant added that she had to take care of herself because it was no longer possible to depend on her mother.

**Getting supports from many people.**

The participants in this study were getting support from many people to endure facing their mother's condition. They got the support from their father, siblings, close friends also from the community health centre. The support that they got encouraged them and made them hopeful in facing their mother's condition. Four participants said that their main support was from their father. While two other participants got their main support from their siblings. Besides that, they also had their grandmothers, uncles and aunts who gave them advice, prayers and care. These were some of the participant statements:

”My father's support was my main support. Then, the relatives who live nearby, like my aunts, my uncles, especially my grandmother… They also prayed for me... They said if I ever needed anything just go and tell them.” (P1)

“…The most important was the support. The support that I get from the family and my siblings… The support encouraged me to accept this...” (P3)

Besides the support from their family, three of the six participants stated that they got advice as support from their close friends. Then, two of the six participants stated that they were glad to have support from the community health centre. They were glad when their mother was involved in the community health centre's activity. A boy stated: ”I was glad when the community health centre had a program to make a slipper with ribbons….My mum was asked to join…. When she got home, there was some reward like a wallet….and she was happy..” (P1).

### Expecting that there will be no stigma toward the mother.

Half of the participants in this research expected that there wasn’t any stigma toward their mother. They received many negative attitudes from their neighbourhood and hoped that their mother could be accepted by the community. Two of the six participants said that their neighbours acted negatively because of their mother’s erratic behaviours. One of the participants said there was a neighbour who looked at her cynically and a neighbour who mocked her mother. Another participant said that he was sad because people around him took his mother for granted and she was considered to have no potential.

Three of the six participants revealed that they wished their mother would be accepted by the community. They hoped people could understand their mother’s condition and didn’t isolate her, as a girl stated:

“What I wanted from my neighbourhood was for them to understand. The neighbours accepted her.”(P3).

Two of the six participants revealed that they were grateful because some of the neighbours accepted their mother’s condition. The participants were glad because the neighbours talked to their mother and understood their mother’s condition. The participants were also grateful because people had begun to accept their mother’s childish behaviours.

### Needing a friend who could understand and give advice.

Living with a schizophrenic mother was a bitter experience for all participants. All the participants in this research revealed that they needed a close friend to understand them and to give them advice. All participants said that they didn’t tell much about their mother’s condition and only confided to their close friends. But there was a girl who revealed that she was confused about whom should she confide to. She wanted to share her story but she felt nobody understand her feeling.

Two of six participants said that they preferred to confide to their friends than to their family. They liked to confide to their friends better because they thought friends were understood them more, as one boy stated:

”Usually, I confide to a friend. As for me, after junior high, I rarely told my matter to my parents. I preferred to tell my friends because to tell them it would be better. They knew me better.” (P4).

One of the six participants revealed that he liked to hang out with older people. His mother’s condition changes made the participant preferred to interact with the older people so he could have some advice and lessons from them.

### Making the father as the source of inspiration

Five of the six participants in this study considered their father as their source of inspiration because their father was the only one who gave them a lot of advice and the role model to accept their mother’s condition. Their father had a double role. He was also being a mother for them. This theme consisted of three sub-themes.

Two of the six participants revealed that they respected and obeyed their father. Since childhood, the participants were afraid of and obeyed their father. Then four of the six participants said that their father educated and gave them the advice. He was also being a mother to participants. As one boy said:

”Well my dad guided me; he was a father and a mother at once… He supported me to finish my study…That was my dad.”(P1)

A girl revealed that now she depended on her father and her father was the only one who taught her and gave her advice. She also revealed that their father was the one who did the house chores instead of their mother.

Three of the six participants stated that they got an example from their father to accept their mother’s condition. One girl said that she respected her father’s patience to deal with her mother’s rude behaviour. Another girl said that she was able to endure living with her mother because she saw her father endured it as well. Her father accepted her mother’s condition as she was and was always patient, she stated:

”I saw my dad. He could endure with my mum’s condition, so I followed him to endure. That’s it…we were together in this.”(P5).

## Discussion

This study revealed that adolescents who lived with a schizophrenic mother felt various negative emotions. Their mother's unnatural behaviour made them bewildered and scared, also ashamed toward their friends. They had sad experiences while living with their mother so they had a mixed feeling in their heart. They were sad and felt sorry for their mother, but they were also angry and disappointed because of their mother's bad behaviours. They felt helpless, yet they have no other choice but to accept their mothers' condition. Eventually, they were tired and stressed to take care of their mother.

In this study, three of six participants revealed that they felt ashamed of their mother's condition toward their friends. They were embarrassed to bring their friends home or to introduce their friends to their mother. This result was supported by the research from Chan and Heidi (2010) who declared that adolescent with schizophrenic mother tend to have low self-esteem. The participants in this research who revealed their shame were all female. It was possible because the female's self-esteem was lower than the male's which was shown in the research of Agam, Tamir, and Golan (2015) and the research of Minev, Petrova, Mineva, Petkova, and Strebkova (2018). According to Minev et al. (2018), male adolescents had higher self-esteem because they tended to be independent and didn't count on others' opinion while females were more vulnerable to conformity.

Besides that, four of six participants felt guilty for their mother. They thought that they had caused their mother stressed and resulted in mental illness. Ferguson (2011) research also showed that some children blamed themselves for causing their mother to have a mental illness. Ferguson (2011) declared that children who blamed themselves for their parents' illness might affect in low self-esteem. Dam and Hall (2016) also revealed that the children of parents with mental illness tend to blame themselves because they could not help healing their parents.

Living with an abnormal mother was hard for them. They were sick and tired of dealing with their mother. One of the participants revealed that she was so tired of dealing with her mother 'like it was endlessly'. The participants who revealed their tiredness and stress in taking care of their mother were the youngest in the family. It proved that the child's age when the mother had schizophrenia for the first time affected their emotion and coping mechanism. This was supported by Foster, O'Brien, and Korhonen (2012) who declared that the older children tended to be tougher than the younger children. Hence, the older children also had more burden than the younger children because they had to take care of the younger children, their sick parents and house chores (Yamamoto & Keogh, 2018).

The participants in this study revealed that since their mother had schizophrenia, their mother became different and their relationships were distant. Perera, Short, and Fernbacher (2014) declared that the mental illness' symptoms affected negatively to mother and child relationship. In this study, the symptoms experienced by their mother made them rude to their child, could not talk properly and often daydreaming. Meanwhile, the effect of the treatment made her sleep more often and forget her children. So the mother and child relationship became distant.

In this study, there was not any specific measurement held about the kind of attachment bond between the adolescents and their mothers. However, most of the participants showed a lack of attachment to their mother. They were faced to a dilemma; on one hand, they wanted to be closer to their mother, on the other hand, they were afraid of their mother's aggressive behaviour. They wanted to confide in their mother but they didn't feel connected while talking to their mother. This made it difficult for them to be close to their mother. Because of this lack of attachment, the participants were sad, upset, and felt forgotten.

According to Power et al. (2016), one of the ways to improve the attachment model in the family was with open communication. The open communication about mental illness made the family enable to have better coping and better attachment relationship in the family. The family member's resilience might be built by joking with each other, doing a family event or family routine (Power et al., 2016). Sutini, Keliat, and Gayatri (2014) stated that generalist therapy for families with ineffective coping suggested by the Community Mental Health Nursing (2006), included building rapport, identifying problems, discussing commonly used coping, discussing alternatives for problems solving and training the family members to use effective coping.

The participants in this study experienced various difficulties while living with their mother. They felt hard to deal with their mothers' unnatural behaviour and had difficulties to take care of their mother. They had difficulties in telling their mother to take her medicine because their mother was being stubborn and childish. Three of the participants felt that taking care of their mother was like taking care of a child. They had to give extra attention to her. This was similar to the research of Petrowski and Stein (2016) revealing that ten female adolescents who were participated in the research switched role with their mother. Sometimes they were the parent to their mother.

The interesting thing in this research was even though taking care of schizophrenic mother was a heavy burden to them; they still tried to endure and continued to take care of their mother. This result was supported by Chan and Heidi (2010) who revealed that although the adolescents with schizophrenic mother had various bitter experiences in their life, they felt responsible in their parents' treatment. They also wanted to keep giving emotional support to their parents. In this study, the participants revealed that they tried various ways to take care of and calm their mother, such as trying to understand her, comforting her, talking to her and joking with her, giving her presents, taking her to walk, and motivating her.

The participants in this research did various ways to cope. The coping they did was to avoid seeing their mothers. One of the participants soothed herself by being alone and listening to the music in her room. But most of the participants relieved their feelings by doing some activities outside their home such as strolling, hanging out with friends and joining a youth organization. This result was also revealed by Van Loon, Van de Ven, Van Doesum, Witteman, and Hosman (2014) who declared that the adolescents living with mental illness parents sometimes purposely spent a long time with their friends outside their home to avoid their parents.

The participants also revealed that they could endure by trying to be patient, strong and accept their mother's condition as their fate. The source of the biggest strength for participants was their faith and good friends. One of the participants stated that by doing worship and reading the Quran, he could forget his problem and the negative things in his mind. This was appropriate with the research of Hernandez and Barrio (2015) who revealed that religion, faith and spiritual practice could reduce the emotional burden and help someone to have a good relationship and be more responsible in taking care of people with mental illness.

The religious value was upheld in the Sundanese community. Religion was taught strictly to the children in every family. Their religion encouraged them to get closer to God and considered that every trial in their life would never exceed their strength. They believed that everything that happened to them was God's fate (Kadiyono & Harding, 2017). This religious value encouraged the participants to accept their mother's condition as their fate.

Most of the participants revealed that they got lessons behind their hardship. The participants said that they learnt to take care of themselves since childhood because they couldn't depend on their mother anymore. Their family changes made them learn to be independent and responsible. They build a responsibility since childhood by working and helping to take care of their parents.

This result was supported by Chan and Heidi (2010) and Foster (2010). Chan and Heidi (2010) revealed that the adolescent got the lessons from their mother's problem. They were stronger, more mature and more considerate to others. They also learnt to see everything from a different point of view. Foster (2010) also revealed that children who had parents with mental illness tended to be responsible and independent since childhood.

However, the result in this study was different from Jundong et al. (2012) and Ranning et al. (2018) who declared that children with schizophrenic parents showed a worse school performance compared to those with normal parents. Three of the six participants in this study said that their mother's condition and their family changes didn't affect their school performance. They were encouraged to do well because they wanted to devote to their parents and make them proud. The parents' happiness was an important thing and an obligation to the participants.

This study also revealed that the adolescents were getting support from many people. They got support from their father and family, close friends and the community health centre. Four participants in this study revealed that their main support was from their father. While two participants revealed that their main support was from their siblings. The difference might be because one of the participants only lived with her mother and her siblings while the father of another participant was rarely home.

Some study promoted the importance of family support for adolescents. Foster et al. (2012) declared that support from siblings could increase the resilience in children with mental illness parents. Perera et al. (2014) revealed that the main support system for children was from the nuclear family. The support from extended family was also important to children. Meanwhile, Grové, Reupert, and Maybery (2016) study explained that adolescence needed social support through groups, peer or anyone, even from someone they didn't know.

The participants revealed that they were also glad to have support from the community health centre. The things that made them glad was to see their mother could involve in the community health centre's activity, like making any kinds of handicrafts. They were also glad to see their mother could interact and mingle with others. By joining the activities, their mother was empowered and had positive changes.

In this research, half of the participants expected that there wasn't any stigma toward their mother. Even though they were grateful because some of the neighbours understood and accepted their mother, there were still some who acted negatively to their mother. They hoped the community could understand and accept their mother's condition.

Suryani (2015) revealed that a stigma could be the source of the family burden. The family would feel ashamed because their surrounding was gossiping about their family member with mental illness. They were isolated from the community because of their relative's bad behaviours or words. They felt that the stigma was one of the reasons for their relative's relapse. Fauziah, Suryani, and Hernawaty (2019) research about the Sundanese family's experience on mental illness stigma indicated that mental illness stigma on the Sundanese community was still strong.

Fauziah et al. (2019) declared that even though the Sundanese community upheld the Egalitarian (human's equal right and level), society still disdained people with mental illness. Society was still labelling people with mental illness as "crazy people" and treated them negatively. This made the family of people with mental illness experienced the feeling of being ashamed, insulted, resentful and sad. According to Fauziah et al. (2019), strong family bonding was one of the keys in enduring the stigma.

Most participants in this study never told much about their mother's condition to their friend and they only confided to their close friend, a very trustworthy friend who could understand them. They felt that their friends knew them and understood their situation better. The study of Grové et al. (2016) also revealed that part of the adolescents in their research tried to get support by confiding about their parents' mental illness to their peer. They did this because they felt that their friend could understand and wouldn't leak their secret to others. Bowden and Greenberg (2010) said that the adolescents didn't want to depend on their parents anymore. That's why they used their friends to receive a response to their ideas or their actions.

Different from other participants, the third participant said that she was confused about whom she should confide to. This was supported by Chan and Heidi (2010) study who revealed that the adolescents couldn't confide about their parents' mental illness to their friend because they felt nobody could help them. Yamamoto and Keogh (2018) also showed that children of parents with mental illness tended to conceal their parents' sickness and their families' problems. Yamamoto and Keogh (2018) added that the children felt more comfortable if they could talk with friends who had similar experiences with them. Therefore, it was important for the mental health nurse to do a home visit or to form a peer-support group for the adolescents. With the peer-support group, those adolescents could share and support each other. They would freely confide in each other because of the same experience they had walked through.

Fortunately, most of the participants in this research had a kind and patient father. They declared that their father was their source of inspiration. They respected their father very much because their father was the only one who advised and educated them. Their father also played the mother's role. Besides, their father gave them a role model to accept their mother's condition. Their father was always patient in dealing with their mother's rude behaviour and endured to live with their mother. Their father was one of the reasons they could endure their mother.

The presence of a loving and dependable father was one of the keys in building trust and confidence for the adolescent (Santrock, 2014). Other than that, a father should be a supportive partner to his wife (Yogman & Garfield, 2016). The supportive partner was a partner who "understand", "care", "emotionally there" and someone who could always be a place to confide. The husband's presence and support were the main support system for a schizophrenic mother (Perera et al., 2014). In this research, the participants' father tried to be a supportive partner for their mother by helping to do the house chores, educating the children, calming their mother when she relapsed, giving a routine medicine and taking their mother to do her check-up.

Various negative emotions that were shown by the participants in this research indicated the importance of teaching them to manage their emotion. The implication for nursing practice was to help the participants manage their emotions, to give health education about the definition, signs and symptoms, also the schizophrenia treatment. The psychiatric nursing needed to conduct a home visit to find out the situations and challenges faced by the family to provide good health education (Suryani, Komariah, & Karlin, 2014). By giving health education, the knowledge about their mother's condition was expected to increase so they could develop their confidence and positive mind in taking care of their mother.

## Conclusion

This study revealed that the adolescents still respected their mother as a parent because in their religion it said that 'heaven lies beneath the mother's feet'. They made their mother's condition and the changes in their life as a motivation to do well in school and they wanted to make their parents proud of them. Hitherto, they could take care of their mother by seeing their father as a role model. The presence of a kind and supportive father and also good friends were the reasons they could endure to live with their mother.

In this deinstitutionalize era, this study also suggested promoting family-focused care in community mental health nursing program in Indonesia. The mental health nurses were expected to do home visit regularly, give counselling or health education with the family of the schizophrenic patients. The mental health nurses could work alongside psychologists or psychiatrists to build family-focused care programs for them. Besides that, the interesting thing in this research was the importance of the community health centre's support to empower people with schizophrenia and to form a peer-support group for adolescence who live with a schizophrenic mother.

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# An Exploration of Nurses' Experience of Family Presence During Resuscitation in Intensive Care Setting

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## Abstract

The family presence during resuscitation (FPDR) has received wide support to be implemented in the ICU.The implementation of FPDR has positive impacts on family satisfaction. However, some of the nurses' opinion still not agree on implementation of FPDR in ICU. This research therefore utilized phenomenological approach to gain descriptive explanation regarding this phenomenon. The purpose of this study is to explore the nurse's experiences in the implementation of FPDR in the ICU. This research was conducted on the year 2020 and qualitative phenomenological approach was utilized for this research. Ten (10) ICU nurses have participated in this study and in-depth interview was employed for data collection. Data analysis is conducted using Colaizzi. Result of this research areexplained in 6 themes which describe the phenomenon of nurses' experience onfamily presence during recusitation, as follows: (1) Decisions on family; (2) From burdened to selfconfident; (3) Families enhancing teamwork; (4) The bereaved family disrupts the CPR process; (5) Feels of ignoring patiets' family and (6) Expectingthe family be accompanied by staff nurse.From a nurse's perspective, the implementation of FDPR has a positive impact on patients, families and on the ICU nurse team. However, this also has an unpleasant impact on ICU nurses, especially if the nurse is not ready for the practice. Therefore, policy support and training for nurses are needed in its implementation.

**Keywords:** Family presence, intensive care, nurse's experience, phenomenology.

## Introduction

The concept of Patient Family Centered Care is to involve families in all aspects of health service delivery including the presence of the family during Cardiac Pulmonary Resuscitation (CPR) (Abdar, Educator, Rafiei, & Tbc, 2016). Family presence during resuscitation (PFDR) is the presence of a patient's family member at the scene where resuscitation is condected, so the family may see the cardiopulmonary resuscitation process(Salmond, Paplanus, & Avadhani, 2014). FPDR is supported by 94% to 100% of patient family members, where patients and family members view FPDR as their right(Powers & Candela, 2016). The Family perspectives on FPDR vary widely. Families feel their presence will provide support, they want to see that everything has been done, families do not want patients to die alone, and they want to participate in deciding when to stop resuscitation and to declare martyrdom at death (Alshaer et al., 2017)

The view of the family who does not want to be present during the CPR process, the reason is because theey feels they may disturb and the family is worried. Their presence interferes the resuscitation process, the family feels afraid and feels unable to help (Alshaer et al., 2017).

FPDR has a positive impact on family members. Research by Pasquale, Pasquale, Baga, Eid, and Leske (2010)shows that anxiety, satisfaction, and well-being of the family are better in the group that witnessed CPR procedure than in the control group who did not witness the CPR process. Research by Jabre and Borron (2014) also shows that Post Traumatic Stress Disorder (PTSD), anxiety,and depression are significantly lower in family members who have the opportunity to be present during the resuscitation process compared to those who are absent.

FPDR has gain support from families and has a positive impact on family members. However, not all critical care nurses who often involved in CPR procedure are supportive and some of the nurses do not support family attendance during CPR. Nurses who support the practice of family attendance, arguing that family presence is the right of the patient and the family (Chapman, Watkins, Bushby, & Combs, 2012;Porter, Grad Cert Ed, Cooper, & Taylor, 2015;Lederman, Baird, Dong, Leong, & Pal, 2017). Another reason is that the presence of the family benefits the family, namely: relieving family worries and calming down, increasing family satisfaction, feeling the family is contributing to the care of their loved ones, being able to understand what is happening to their loved ones, understanding the severity, family presence allows relatives to know the patient's critical condition, helps dispel doubts by recording everything that is possible, relatives feel closeness and help the grieving process (Hassankhani, Zamanzadeh, Rahmani, Haririan, & Porter, 2017; Twibell, Siela, Riwitis, Neal, & Waters, 2017; Barreto, Garcia-Vivar, Mitchell, & Marcon, 2018).

Nurses who do not support family attendance during CPR because: (1) additional pressure would be placed on staff members, feeling pressure to continue resuscitation, staff performance is scrutinized and supervised by families, increased stress and anxiety among CPR team members, impaired team focus resuscitation and staff want to avoid feelings of insecurity in resuscitation practices (Wacht, Dopelt, Snir, & Davidovitch, 2010;Chapman et al., 2012; Porter et al., 2015, Abdar et al., 2016; Hassankhani et al., 2017; Lederman et al., 2017; Barreto et al., 2018); (2) family presence can result in family members interfering during the procedure, prolonging resuscitation efforts and the potential for families to discontinue resuscitation(Bashayreh, Saifan, Batiha, Timmons, & Nairn, 2015; Porter et al., 2015; Twibell et al., 2017; Hassankhani et al., 2017; Zali, Hassankhani, Powers, Dadashzadeh, & Rajaei, 2017;Waldemar & Thylen, 2018; Barreto et al., 2018); (3) concerns regarding verbal and physical attacks if they allow the family to witness resuscitation(Stefan, Kaltwasser, Rothaug, & Albarran, 2010; Wacht et al., 2010; Bashayreh et al., 2015; Lederman et al., 2017); (4) there is insufficient support for family members and limited space in the resuscitation area (Chapman et al., 2012;Hayajneh, 2013; Lederman et al., 2017; Barreto et al., 2018).

The above studieshas been suggested that that research on FPDR has been conducted in many countries, while in Indonesia, FPDR research is still very limited. Due to differences in cultural backgrounds, educational levels, understanding and religion as well as nurses' practices in carrying out family attendance, of course, will provide a different picture in Indonesia. Therefore, this research is important, to be carried out in an Indonesian context. Internationally, FPDR has received recognition that FPDR has a positive impact on family members who are present during CPR and the families has supported FPDR practices. However, the nurse' opinion of FPDR, has indicated that some nurses support the practice and, some are still not supportive. Therefore, research with qualitative phenomenological approach is needed, to gain understanding of the phenomena experienced, felt and seen by nurses' participants regarding the family presence during the CPR process in the ICU.

The purpose of this study was to explore the experiences of nurses on family presence during the CPR process in the Intensive Care Unit (ICU) of the regional hospital, Bali. The result of the study has the potential, to provide better understanding regarding the nurses' perspective on family presence during resuscitation.

The result of this study is also expected to provide data and information for the development of policy and standard operational procedure of the implementation of FPDR in critical care setting.

## Method

The research utilized qualitative approach descriptive phenomenology which aims to describe the nurse's experience of family presence during the CPR process in the ICU Room. Giorgi (2009) and Moustakas (1994) in Creswell (2014) suggest that phenomenological research is a research design that rooted from philosophy and psychology where researchers describe the human experience regarding a certain phenomenon as described by the participants. The study was conducted at the ICU at the District Hospital, Bali. The data collection of this study began, after ethical clearance from the health research ethics committee of the Universitas Padjadjaran number: 219/UN6.KEP/EC/2020 has been obtained. Subsequently, the permission for conducting this research was also obtained from the Director of District Hospital, Bali. Then, the researcher accessed prospective participants through director of nursing and the head of nursing at the critical care setting

Participants of the study were selected using the purposive sampling based on inclusion criteria: (1) Nurses who have conducted CPR in the ICU which attended by the family more than once time; (2) Nurses with at least have 2 years working experience in the ICU; (3) Minimum educational background 3 years nursing diploma. Prospective participants were given information about the study and signed an informed consent if they agreed to participate in this study. Data collection was conducted through in-depth interviewson Mar 5 – April 30, 2020 and it was conducted in the ICU head nurse' office. The interview was audio recorded with the participants permission and the data was then transcribed verbatim. The interviews'duration were about 30 to 60 minutes. The participants in this study were ten (10) ICU nurses who were met the inclusion criteria. Data analysis used the Colaizzi method.

The criteria for maintaining the quality of this study were derived from Lincoln and Guba (1985) regarding the rigor and trustworthiness of the qualitative study through credibility, transferability, dependability, and confirmability.In this study, credibilitywas achieved through member checking where the themes obtained from the participant's interviews are conveyed back to the participants to get feedback regarding the theme formulated by the researcher.In this case, almost all of the participants recognized the theme conveyed by the researcher as significant issues of what they felt. Except for participant 9, who has suggested that she only feels some significat issues, namely in the theme: decision is on the family, feels of ignoring patiets' family, and expecting the family be accompanied by staff nurse. Transferabilitywas achieved through applying the phenomenological method in this study, so that the results could be applied to other situations which have nearly similar context. Dependability was achieved through implementing the descriptive phenomenological method and conducted data analysis with Colaizzi (1978) approach, so that a rich description of the phenomenon under study could be obtained. Confirmabilitywas achieved through the implementation of phenomenology research method, and the achievement of credibility, transferability, and dependability in this study (Lincoln & Guba, 1985).

## Results

The nurses' experiences in implementing family presence during resuscitation in the ICU setting at Hospital in Bali is described in the 6 themes: (1) Decisions is on the family; (2) From burdened to self confident; (3) Families enhancing teamwork; (4) The bereaved family disrupts the CPR process; (5) Feels ignoring patients'family and (6) Expecting the family accompanied by staff nurse.

### Decision on family

The first theme in this study is "Decisions on Family" with the sub-theme of giving choices to families which are obtained from the participants' expressions that when the patient's condition worsens, the participants give the option of offering whether to attend or not to attend CPR. As stated by P1 and P9. "... So far, for me personally ... even if there are patients who get worse ... we keep calling the family ... we educate ... it's up to them to watch our actions or come out ..." (P1.12)

"... the patient is experiencing a deterioration ... we are family KIE ... then if the family wants to wait for the patient to take action ... we will invite ... then if not ... we'll also invite ... (P9.10)

### From burdened to self-confident

This theme was obtained from the experiences of participants who expressed the participants 'feelings at the beginning of doing CPR, attended by their families until the participants' experiences increased.

Participant 1 expressed feelings of nervousness and discomfort, but with increasing experience of doing CPR in the presence of family, participants felt calm and could control their emotions. Here is P1's expression:

"…. Honestly… the first time.. I did that RJPO… .. I continued to have my family…… nervous sometimes… sometimes… when we had done the right thing… looked at it like that… there was still a sense uncomfortable too… "(P1.19)

"... At first, I was nervous ... to face the patient's family ... especially if the patient started to complain ... or did aggressive actions ..." (P1.25)

"…… And… now… because I am used to taking action witnessed by my family… we just do it according to the procedure with a feeling of calm…" (P1.23)

"... but ... over time because we often face ... conflicts like that ... over time I can control ... our emotions ... control emm ... our feelings of empathy ... concentrate on the patient ... as well as ... by concentrating on the patient and still facing… umm… family emotions… family conflicts… "(P1.26)

At the beginning of carrying out CPR in the presence of the family, participant 3 expressed feelings of pressure and felt a psychological burden, but with the increased experience of doing CPR in the presence of the family, P3 felt that they could be trained to provide IEC during the CPR process and felt more motivated and excited about doing CPR. Here's a P3 quote:

".....While doing CPR accompanied by family ... for the first time it was done CPR accompanied by a family ... it felt like I was depressed .. very depressed .. nervous ... (P3.10)

"... When we first did CPR, especially in the ICU ... if we were seen by several families, we felt a psychological burden to do CPR .." (P3.1)

"... At first it was really hard to pay attention to it ... but over time after doing CPR several times accompanied by the family ... we can be trained to do IEC during the CPR process ... so that the psychological burden of the family can be more accepting .." (P3.32)

"... We did CPR in the ICU several times ... we met several patients ... we did CPR with family assistance ... over time it became a motivation ... what is the name ... enthusiasm for the team to save this patient .. Moreover, being accompanied by family .. it becomes a spirit .... "(P3.13)

### Families enhancing teamwork

The next theme in this research is "Families enhancing teamwork" with the sub-theme Cooperation between teams is better. This theme is derived from the experience of participants who feel that the presence of a family during CPR affects team performance. As stated by P5:

"... keep on ...the positive side ... we are as a resuscitation team ... our actions are more organized ... more systematic ... in carrying out resuscitation actions ..." (P5.11)

The same thing was also expressed by participant number 7. The following was the statement of participant 7 below:

"…. Another positive thing… there is family assistance during resuscitation… we work as a team… can be more systematic andorganized according to the existing Standard Operating Procedure .. (P7.5)

### The bereaved family disrupts the CPR process

Another experience expressed by participants in this study was "The bereaved family disrupts the CPR process", where participants see for themselves the emotional response of the family who accompanies the patient when the family witnesses the CPR process, such as the patient's family screaming hysterically, the family hopes the patient must live, the family tends to fainted and family cried. Participants felt that the family response was disturbing the CPR efforts.

"… If the results are not as expected…. the patient's family screams ... the denial stage or does not accept ... it also disturbs us as health workers .. "(P4.27)

The same thing was also expressed by participant number 7 and 8. The following is the statement of participant 7 and 8 below:

"... There were also families screaming ... even fainting ... it really made our concentration break ..." (P7.11)

"... A less cooperative family ... when doing resuscitation ... he cries too hysterically which is also very disturbing when we do resuscitation .... (P8.8)

### Feels of ignoring patients'family

The fifth theme is "Feels of ignoringpatients' family " with the sub theme of neglecting family psychological situation. This theme is derived from the experience of the participants that when doing CPR, the participants ignore the family psychology.

"... While the family ... umm ... I don't know if the family cries .. whether he accepts it ... we ignore it..emm ... you can say we ignore the psychological and emotional impact of the family ... because we focus on saving the patient .." (P5.24)

Participants also shared similar experiences with P6. The following is the statement of participant 6 below:

"... No one accompanies the family ... or calms the family ... we are busy with our respective duties as a CPR team to save patients ... so we focus on patients ..." (P6.17)

### Expecting the family be accompanied by staff nurse

The next theme is "Expecting the family to be accompanied by professional staff " with the sub-theme of requiring other professional staff. This theme is the hope of the participants with the existence of other professional staff who help participants to accompany the family when the participants focus on doing CPR on patients, so that the families present at CPR are there to accompany and calm and provide explanations of every action during the CPR process. The following is the expression of participant 3 below:

"... Indeed in several times we have RJP ... there needs to be something like that ... someone explains what we are doing ... like a professional nurse is also important ... but so far we have also... can handle the psychological burden of the patient's family .. (P3.32)

The same thing was also expressed by participant number 4. The following is the statement of participant 4 below:

"... Also I hope ... besides there are people or teams who prepare and carry out their respective duties ... here also I hope for one more person to help prepare or inform the patient's family from the beginning of the action we take ... until the end ..." (P4. 38)

In this study it was also revealed that 9 participants (P1, P2, P3, P4, P6, P7, P8, P9 and P10) supported family presence during CPR and only 1 participant (P5) did not support family presence during CPR.

"…This means that in essence ... that I support ... the existence of a family ... watched us take action or a family was in the room when the patient was taken ..." (P1.45)

The same is expressed by P7. Here's the P7 expression:

"... In my opinion ... seen from the positive and negative sides that I experienced and I feel ... I feel more on the positive side.... so I support the presence of the family during CPR ... (P7.37)

Different experiences are expressed by P5. Here is P5's expression:

"... If seen from the positive and negative impacts that I have had and I have felt ... I don't really support my family when we do resuscitation ..." (P5.46)

## Discussion

The nurse participants explained that when the patient's condition worsened, the nurse participants would gave the choices to the family, to attend or not attend in the CPR process for the patient. Critical care nurses also advocate for patients and families in making treatment planning decisions including the implementation of palliative care and end of life care(AACN, 2015). The ENA and AACN recommend that health care agencies develop written protocols (policies and procedures) for regulating family attendance practices by including the following components in the protocol: (1) describing the benefits of family attendance from the perspective of patients, family members, and health care providers; (2) establish criteria for assessing family members so that patient care is not interrupted or delayed; (3) screen family members before offering options (for example, excluding those who show emotional distress, anger, drunkenness or altered mental status); (4) offer options and support for family members when they choose not to attend; and (5) assign family facilitators to consult with the health care team to get consensus and an appropriate timing and to support family members before, during and after CPR (Pankop, Chang, Thorlton, & Spitzer, 2013)

According to the IPFCC (2010), the role of nurses in the PFCC concept, namely: (1) Nurses listen to and respect the perspectives and choices of patients and families, (2) Nurses communicate and share complete and unbiased information with patients and families so that families receive information timely, complete and accurate to participate effectively in care and decision-making, (3) Nurses encourage and support patients and families to participate in care and decision-making at their chosen level, and (4) Patients, families, care practitioners health and health care leaders collaborate in the development, implementation and evaluation of policies and programs in research, facility design and in professional education and in care delivery.

Based on the description above, it can be concluded that the participants have implemented the components of the FPDR Standard Operating Procedure recommended by ENA and AACN, although currently there is no FPDR Standard Operating Procedure in the hospital. Participants have also performed their role as educators or communicators by communicating and sharing complete and unbiased information with patients and families so that families receive timely, complete and accurate information

At the beginning of the participants doing CPR, attended by their families, the participants felt that there was a feeling of pressure, a feeling of discomfort and a feeling of burden. The results of this study are in accordance with the results of research by Wacht et al. (2010) showing that most staff members oppose FPDR on the grounds of concerns about family criticism, additional pressure to be exerted on staff members, fear of lawsuits and fear of hurting family feelings. This study is in line with the research of Porter et al. (2015) which involved 347 respondents who found that 17% of staff did not support FPDR because they felt uncomfortable with family presence or felt monitored, there was fear of litigation or concerns about violating patient confidentiality and prolonging resuscitation efforts. Research by Chapman et al. (2012) revealed that the reasons for staff not supporting family attendance include (1) disrupting the resuscitation process, (2) feeling pressure to continue resuscitation because performance is being monitored, (3) limited space in the resuscitation area, (4) no adequate support for family members of specialized professional staff.

The increasing experience of doing CPR in the presence of the family, caused the participants' feelings to change from feeling overwhelmed to feeling confident in doing CPR. Five participants, namely P2, P3, P6, P7 and P8 expressed feelings of comfort from the increasing experience of doing CPR in the presence of their families. Participant 1 revealed that they feel calmer now even though they are supervised by their family. P2 said he felt more comfortable working. Participants also felt that the increased experience of doing CPR in the presence of the family was also felt by the participants to increase the ability to think critically and be more systematic, more responsible, better trained to giveinformation during the CPR process, feel motivated to correct the shortcomings of the first experiences that were carried out, be able to control emotions and feelings of empathy.

Self-confidence is an attitude or belief in one's own abilities, so that you are not too anxious about taking action, feel free to do things according to your wishes and responsibilities for your actions, are polite in interacting with others, have a boost in achievement and can get to know own strengths and weaknesses. The formation of self-confidence is a process of learning how to respond to various stimuli from outside of itself through interactions with the environment (Lauster, 2012). Self-confidence is influenced by several factors, namely self-concept, self-esteem, education and experience (Ghufron & Risnawati, 2010). Experience plays an important role in increasing emotional care for critical nursing and only nurses who have knowledge and high confidence about the CPR process can provide emotional care to the family (Connell & Landers, 2008).

Based on the description above, the researcher can conclude that the emergence of participants' self-confidence is due to an adaptive process with increasing experience of doing CPR in the presence of the family. To increase self-confidence, participants should do CPR more frequently attended by their families.

The theme "Families enhance teamwork" was lifted from the experiences of participants who revealed the impact of having a family on teamwork. P1 and P4 revealed that teamwork would be better with the presence of family. Participants 1, P5, P7, P8 and P10 revealed that the presence of a family during resuscitation causes teamwork to be better, more systematic and organized in accordance with the existing SPO and is more coordinated. The results of this study are in line with the research of Gomes, Dowd, and Sethares (2019), which identified that most nurses (92%) had experienced resuscitation witnessed by their families and most of them had positive attitudes about the benefits and results of resuscitation witnessed by families. The results showed that nurses did not believe that family attendance was too distressing for the family or that the resuscitation team's performance would be negatively affected.

Based on the description above, it can be concluded that family presence can also have a positive impact on teamwork. Teamwork becomes better, more systematic, coordinated and orderly by implementing CPR procedures in accordance with the existing Standard Operating Procedure.

Another experience expressed by participants in this study was "The bereaved family disrupts the CPR process", where participants see for themselves the emotional response of the family who accompanies the patient when the family witnesses the CPR process, and participants felt that the family response was disturbing the CPR efforts. The results of this study are in accordance with the research of Bashayreh et al. (2015)who conducted an exploratory qualitative study of 31 health professionals in 11 critical areas in 6 Jordanian hospitals, indicating that there may be a traumatic psychological effect on families due to witnessing traumatic resuscitation on their loved ones. Research by Hassankhani et al. (2017), Zali et al. (2017), Twibell et al. (2017), Waldemara and Thylen (2018),and Barreto et al. (2018) revealed that family presence will be painful for them and families feel depressed. Another study revealed that nurses did not agree with the implementation of FPDR in adults and nurses because they thought FPDR had many weaknesses where family members became depressed (Zali et al., 2017). WaldemaraandThylen (2018) expressed concern that families intervene during resuscitation, it is too painful for them that there is a strong consensus that there should always be a dedicated healthcare professional to care for the family.

Chapman et al. (2012) conducted a cross-sectional study of 221 doctors and emergency room nurses to investigate the perceptions of emergency department staff about family-witnessed resuscitation, it was found that staff did not support family presence, one of which was family presence which resulted in disruption of the resuscitation process. This study is supported by Leung and Chow (2012) that the presence of a family during CPR results in chaotic resuscitation. This is in line with the results of Hayajneh(2013) study which showed 75% (n = 102) agreed that family members are very likely to interfere with the resuscitation process. Research with similar results, namely research by Bashayreh et al. (2015), Porter et al. (2015), Twibell et al. (2017), Hassankhani et al. (2017), Zali et al. (2017), WaldemaraandThylen (2018), and Barreto et al. (2018) who showed that family presence could result in family members interfering during the procedure, prolonging resuscitation efforts and the potential for families to discontinue resuscitation.

Based on the description above, it can be concluded that the bereaved family needs information about the actions taken to the patient, the actual condition of the patient and the progress of the patient’s condition, so that it requires health workers who have special skills to become effective communicators.

Another experience revealed was the negative attitude of the participants, namely ignoring the psychological impact of the family accompanying the patient. All participants revealed that so far the participants did not pay attention to family feelings, both emotionally and psychologically, no one accompanied the family or calmed the family and no one gave explanations about the actions that were being carried out during CPR. Participants can only provide information before and after carrying out CPR actions. This is because the participants are more focused on saving patients and the limited number of team members who already have their respective roles.

A study conducted by Jabre et al. (2013 )of 570 family members, in which the intervention group received emotional and psychological support from experienced staff who were not part of the resuscitation team. The results showed that PTSD and anxiety disorders were lower in the group supported by experienced staff than in the group that did not receive emotional and psychological support during resuscitation. This study is supported by Soleimanpour, Tabrizi, Rouhi, Golzari, and Mahmoodpoor (2017) a study was conducted in Iran on 133 family members of patients, the intervention group (n = 74) and the control group (n = 59). In the intervention group, a nurse who did not participate in the resuscitation was responsible for supporting the patient’s family psychologically based on the developed protocol. The results showed that depression, anxiety and PTSD were significantly lower in the nurse-accompanied group.

Based on the description above, it can be concluded that the participants experienced a dilemma between making efforts to save patients or providing psychological support to their families. While family support is also important for preventing depression, anxiety and PTSD. Other professional staff are needed to assist the family or there is a division of tasks in the resuscitation team, some of which are assigned to assist the family.

All participants hope that there will be other professional staff who help participants to accompany the family when the participants focus on doing CPR on the patient, so that the families who are present at CPR are there to accompany and calm and provide explanations of every action during the CPR process. Powers and Candela (2017) in this study emphasizes the need for dedicated people serving as Family Support Person (FSP) to meet family needs so as to allow the team to focus on patient care. Family support person (FSP) is a role assigned to certain health care providers who do not have responsibility for direct patient care during resuscitation and are specifically assigned to initiate interventions to help families, provide emotional and psychosocial support (Abdar et al., 2016). This research is supported by research by Barreto et al. (2018) which suggests having people who qualify as facilitators. The role of a facilitator was identified as a strategy to prepare the family at the bedside of the patient and support the family before, during and after resuscitation.

Based on the concepts and descriptions above, the researchers concluded that one of the strategies for the successful implementation of FPDR practice is a dedicated person serving as a Family Support Person (FSP) to meet family needs by providing emotional and psychosocial support, thus enabling the team to focus on patient care. The FSP is a role assigned to a specific healthcare provider who has no responsibility for direct patient care during resuscitation.

The limitation of this study is that this studywas conducted during the COVID-19 pandemic. It had an impact that interviews were conducted with participants and researchers both used masks and kept their distance, so that researchers had a little difficulty observing the facial expressions of the participants. However, this can be overcome by focusing more on voice recordings which are employed as the main data source for this research.

## Conclusion

The phenomenon of the livedexperience of nurses onthe implementation of FPDR were described in the six (6) themes: the decision is in the family; the nurse feels burdened initially but felt confidentwith increasing experience; the family presence has enhanced the teamwork; the presence of grieved and angry family often disrupted the nursing work; the nurse felt ignoring the patient's family; and expectedthe family be accompanied by a staff nurse.

From the ICU nurse's perspective, the implementation of FDPR has a positive impact on patients, families and on the ICU nurses' team. However, this experience also has created an unpleasant impact on ICU nurses, especially if the nurse was not ready for the practice. Therefore, policy support and training for the ICU nurses are needed in its implementation.

Conflict of Interests

The author states there is no conflict of interest in this study

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# Correlation between Spiritual Well-Being and Level of Fatigue among Patients Suffering from Breast Cancer

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## Abstract

Cancer-related fatigue has been shown to be a significant side effect that influences a person's wellbeing, during treatment, and after treatment. It is recorded that cancer patients have also been shown experiencing spiritual distress. The study aims to determine the connection between spiritual well-being and cancer-related fatigue among patients suffering from breast cancer during chemotherapy treatment. 112 patients who were undergoing chemotherapy treatment were recruited in this study using a correlational design. The instruments used in assessing spiritual well-being and fatigue are Functional Assessment of Chronic Illness Therapy - Spirituality (FACIT-Sp) and FACIT-Fatigue Scales. Data were analyzed using the Spearman Correlation analysis. Mean spiritual well-being score was 35.91 (SD = 6.89), and the mean fatigue score was 33.04 (SD = 9.58). There were a moderate and significant correlation between fatigue scores and spiritual well-being ($r = .364$, $p < 0.001$). Breast cancer patients who had higher spiritual well-being that means they would alleviate fatigue symptoms. Therefore, nurses should consider that increasing spiritual well-being would reduce fatigue and vice versa.

**Keywords**: Breast cancer, chemotherapy, fatigue, spiritual well-being, treatment.

## Introduction

Breast cancer patients with a complicated stage suffer from the threat of death, uncertainty, and various symptoms because of the disease and its treatment (fatigue, pain, weakness, dry mouth, constipation, decreased energy, taste change, and depression) (Sari, 2019). All these symptoms are reported to impact on a cancer patient's functional status and wellbeing status (Dodd, Cho, Cooper, & Miaskowski, 2010). Spiritual distress can occur due to suffering of being terminally ill (Lestari, Nuraeni, & Setyorini, 2018; Loh, 2004; Villagomeza, 2005). Patients with spiritual distress have stated that they see the meaning of their life, their illness, death and suffering as a punishment. Such patients may well be unstable emotionally, sad, withdrawn, apathetic, and in denial (Komariah, Adriani, Indrayani, & Gartika, 2020; Loh, 2004). Having a complicated breast cancer diagnosis, or other life-threatening conditions, could change a person's perception about life (Komariah, Adriani, et al., 2020; Manning-Walsh, 2005), and put such an individual in danger for altered spiritual well-being that changes within the person's wellness, symptoms of their disease and treatment.

Moreover, many studies have reported that the impact of advanced breast cancer patients enduring cancer-related-fatigue (CRF) is extensive (Hsieh et al., 2019; Kinkead et al., 2018; Zimmaro et al., 2019)). Most cancer patients reside with CRF because of their cancer treatment and diagnosis. A number of advanced breast cancer patients might have physical and psychological comorbidities that may augment fatigue and complicate its management (Bower, 2008; Loh, 2004). Fatigue symptoms are also the common side effect of patients who are admitted to the chemotherapy unit in Indonesian hospitals (Nurhasanah, 2014). According to the National Comprehensive Cancer Network (2009), fatigue experienced by cancer patients is a state of persisting weakness, where the sensations felt are very personal, as well as the type of fatigue that is not relieved by rest. Fatigue can affect patients in an immensely negative way. It impacts on the spiritual well-being due to feelings of uncertainty, helplessness and fears about death. Thus, it results in patients experiencing set-backs in a chemotherapy treatment schedule (Borneman, Irish, Sidhu, Koczywas, & Cristea, 2014).

Fatigue is a general term used to describe the different feelings with a diversity of terminologies indicating alleviated either physical, mental, emotional, or social capacity, and it is also indicate distress (Lewis, Salins, Rao, & Kadam, 2014). Fatigue is the paramount prevailing symptom among cancer patients receiving radiation therapy and cytotoxic chemotherapy. CRF is an experience subjective to the individual cancer patient, and it is affected by various determinants, such as physical, psychological, and spiritual factors. Physically, fatigue can result from the direct effects of cancer, cancer-related symptoms, and therapy effects; psychologically, fatigue can result from the emotional distress stimulated by cancer and its effects; and spiritually, fatigue can result from the spiritual dryness due to cancer. Not only a few cancer patients feel like religion or spirituality becomes their comfort, which in several occasions, it is associated to positive psychological result and depletion in distressful symptoms (Lewis et al., 2014). Spirituality is said to higher quality of life because it provides social support, enhances the connection with the spouse, and provides interpretation, and decreases self-focus and anxiety (Garssen, Uwland-Sikkema, & Visser, 2015). Studies also showed that, in contrast to those who only involved less in spiritual activities, patients with certain illness but holding a great principle to spirituality seem to have a finer adaptation, undergo the higher level of well-being and quality of life, and encounter lower degree of distress (Garssen et al., 2015). This study examines spiritual well-being and fatigue in patients suffering from breast cancer who undergo chemotherapy and determines presence of interconnection between fatigue and spiritual well-being in breast cancer stage III.

Concept of spiritual well-being is defined as an expression (Wilding, Muir-Cochrane, & May, 2006), a person's mental spiritual measure, which is built by two domains, namely religion and spirituality. Clay, Talley, and Young (2010) defined spiritual well-being as the capability to foster expectation and take interpretation from life experiences and feel the life force in dealing with self, God, family, and life elements that help empower themselves. Spiritual well-being is instrumental in health and healing process. According to Ellison (2006), the spiritual well-being is defined as the process of elaborating the nature of the dynamic bond between the person and the Creator, whose harmonious relationship is dependent on the deliberate self-development, usually on the basis of the appropriateness between experiencing a meaningful life, the goals and values of personal life. This self-development is also made as a personal challenge, done by meditation or contemplation leading to an inner state of happiness.

Gomez and Fisher (2003) explain spiritual well-being as a concept describing the innate state, with an element of motivation or inner drive to find the purpose of life, which is naturally dynamic and subjective. Further, it is focused on something distinctive, which then is believed to be the truth. Spiritual well-being contains a real act of dealing with the essence of existence, certain inner experience and belief. All of them provide a goal, meaning and values for a quality of life, e.g., by giving thanks to God, loving others, and learning from previous life experiences (Gomez & Fisher, 2003). Spiritual well-being has some components, such as, feelings of harmony, peace, the meaning and purpose of life, and the power of faith (Bredle, Salsman, Debb, Arnold, & Cella, 2011). Faith is an important aspect that contributes to the spiritual well-being of the person. Various studies have pointed out that faith, especially faith in God, helps the cancer patient to live well amidst the pain and suffering from cancer. There are many ways in which the persons with advanced breast cancer express their faith in God and how belief in God helps them to cope with cancer. Some of them express faith in God through prayers asking for strength and spiritual well-being (Komariah, Hatthakit, & Boonyoung, 2020).

Regarding sense of spiritual well-being, in a Muslim country, Ahmad, binti Muhammad, and Abdullah (2011) used a qualitative study to explore religious practice and spirituality and coping among three Malay Muslim females with advanced breast cancer. They figured that life-threatening diseases, for instance breast cancer, can be a spiritual encounter and a deeply emotional experience as they cope and find the way toward healing. Therefore, it can be concluded that spiritual well-being in this study reflects the extent to which patients live in harmony with regard to the meaning, purpose, and values of life amidst suffering from cancer (Komariah, Hatthakit, et al., 2020) This component is important in the treatment process of cancer to increase hopeful health results. In Indonesia, two studies tested about the level of spiritual well-being among breast cancer patients, they stated that moderate level of spiritual well-being among all cancer survivors (Suara, Mardiyono, & Anggorowati, 2017) but poor level of spiritual well-being among breast cancer patients undergoing chemotherapy (Wahyuningsih, Sofro, & Dwidiyanti, 2019).

Additionally, several studies have shown that 80% to 90% of patients suffering from breast cancer experiencing fatigues during undergoing chemotherapy (Schmidt et al., 2015). Fatigue symptoms were consistently documented for above 50% of various types of cancer therapy (Naraphong, Lane, Schafer, Whitmer, & Wilson, 2015). Research study regarding fatigue among breast cancer in Indonesia reported that majority of the breast cancer patients developed fatigue in moderate level (50%) and , severed level 61 (42.4%) whereas only few (7.6%) of them had mild level of fatigue (Dahlia, Karim, & Damanik, 2019).

The chemotherapy regimen can cause fatigue; for instant, breast cancer patients who received 5Fluoroacil, Doxorubicin and Cyclophosphamide chemotherapy had muscle weakness caused by stimulation cell oxidative reactions from peroxidation lipids and protein carbonyl. They are released from doxorubicin and delivered to C2C12 myotubes which will activate caspases enzymes and proteolysis and which result in muscle cell apoptosis. It causes reduced muscle mass and contraction ability as the originator of the complaint of fatigue (Gilliam & St. Clair, 2011). When cancer threatens the meaning of an individual life, religion and spirituality are often important coping strategies (Lewis et al., 2014). Fatigue can impact all dimensions of a person's life including physical, psychological, social and spiritual well-being. This study assesses the correlation between spiritual well-being and level of fatigue among patients suffering from breast cancer undergoing chemotherapy treatment.

## Method

This is a cross sectional study appraising fatigue and spiritual well-being in breast cancer patients undergoing chemotherapy. A total of 112 breast cancer selected using consecutive sampling who receiving chemotherapy between January and June 2018 at Chemotherapy unit in a teaching hospital, if they satisfied the selection criteria and gave consent to participate. Inclusion criteria consisted of aged more than 18 years old, have a diagnosis of stage III newly or recurrently, cognitively intact without mental illness. The participants who satisfying the selection criteria and willingness to participate in this study imparted the following self-report questionnaires to examine fatigue and spiritual well-being. Fatigue and spiritual well being were assessed using the functional assessment of chronic illness therapy (FACIT) measurement system, which is a collection of QOL questionnaires aimed to the management of chronic illness such as cancer. The tools are validated and permission for use wasobtained following registration (www.facit.org). It is a cross sectional study where the patients were screened at a certain point of time during their active cancer chemotherapy medicaments. The researcher did the screening after obtaining patients informed consent for the same. The study was authorized by Intuitional review board of the Faculty of Nursng, Prince of Songkla University, Thailand, number 2017 NSt-Qn 054.

The Functional Assessment of Chronic Illness Therapy (Fatigue) (FACIT-F) was utilized to estimate the level of fatigue. The questionnaire consists of 13 items in the form of statements. The total score of FACIT-F should be in the range of 0-52. If the score was < 30, this indicates that the patient is having severe fatigue. The higher score of FACIT-F demonstrates a low-stage of fatigue, whereas a lower outcome of FACIT-F indicates a high level of fatigue. The original instrument showed reliability of alpha Cronbach 0.95 and the validity test 0.88 (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997) while the Indonesian version reported 0.88 for reliability test and alpha Cronbach .95 (Aisyah, 2017).

The Functional Assessment of Chronic Illness Therapy (Spiritual) (FACIT-Sp). The measurement of spiritual well-being was assessed by the FACIT–Sp which was established by Cella et al. (1993). The FACIT-Sp is a 12-item scale with 2 subscales (meaning/peace and faith); 8 items of meaning/peace (items 1, 2, 3, 4, 5, 6, 7, 8), and 4 items of faith (items 9, 10, 11, 12). Using Likert-type scales (absolutely not = 0, a bit = 1, slightly = 2, quite a lot = 3, very much = 4). A higher score indicates a higher stage of spiritual well-being. Reliability was announced for the total FACIT-Sp and subscales. The internal consistency varied from 0.81 to 0.88. The possible scores of the FACIT-Sp stretched from 0 – 48. The instrument had a Cronbach's alpha coefficient of .87.

Data was registered in Microsoft excel and evaluated using statistical package for social science version 16 (IBM corporation). A Bivariate Spearman's correlation analysis was carried out between independent and dependent variables.

## Results

A total of 112 breast cancer patients undergoing chemotherapy were included in the study. Average age of patients who participated in the study was 47.2 ± 8.2 years. Among the patients studied 32.1% had stage IIIa, 60.7% had stage IIIb, and 7.2% had stage IIIc illness (Table 1). Based on the demographic data crosstab analysis, the study resulted that only the education had a significant relationship with spiritual well-being. While the occupation and family income had significant relationship with fatigue (Table 2).

Bivariate relationships were chosen between dependent and independent variables using Spearman's correlation analysis. There was a notable connection between fatigue scores with spiritual well being ($P < 0.001$), (Table 3).

**Table 1 General Data on the Breast Cancer Patients Undergoing Chemotherapy**

| General Data | Categories | Frequency | Percentage (%) |
|---|---|---|---|
| Age (Year) | Mean : 47.2 | - | - |
| | SD : 8.2 | - | - |
| | Range : 27 – 64 | - | - |
| Education | Primary | 63 | 56.3 |
| | High School | 41 | 36.6 |
| | University | 8 | 7.1 |
| Marital Status | Single | 4 | 3.8 |
| | Married | 89 | 79.2 |
| | Widow | 19 | 17 |
| Breast Cancer Staging | IIIa | 36 | 32.1 |
| | IIIb | 68 | 60.7 |
| | IIIc | 8 | 7.2 |
| Chemotherapy treatment | FAC | 90 | 80.4 |
| | TAC | 13 | 11.6 |
| | AC+paclitaxel | 9 | 8.0 |
| Chemotherapy/cycle | 1 | 42 | 37.5 |
| | 2 | 35 | 31.3 |
| | 3 | 16 | 14.3 |
| | 4 | 19 | 16.9 |

**Tabel 2 Crosstab of Demografic Data, Spiritual Well-Being, and Fatigue**

| Demographic data | Spiritual well-being | Fatigue |
|---|---|---|
| Education | 0.023* | 0.087 |
| Occupation | 0.322 | 0.009* |
| Family income | 0.335 | 0.014* |

Chi Square, $*p < 0.05$

**Table 3 Means, Standard Deviation and Correlations of Spiritual Well-Being and Fatigue**

| Variables | N | Mean Value | SD | Correlation | p |
|---|---|---|---|---|---|
| Spiritual well-being | 112 | 35.91 | 6.9 | . | |
| Fatigue | 112 | 33.04 | 9.6 | .364 | 0.000* |

## Discussion

The study reported that there is a positive association between spiritual well-being and fatigue; it means that higher spiritual well-being would alleviate the fatigue symptoms. In other words, the nurses should consider that by increasing spiritual well-being, it would potentially reduce fatigue and vice versa.

These associations could also mean that spiritual well-being would suggest more connectedness in life that would aid them endear to positive health behaviors such as being physically and socially active, going for walks in nature etc., This could give them a purpose and meaning in life and reduce distressful symptoms. Indian study on spiritual well-being in advanced lung cancer showed that there was statistically notable association between spiritual well-being and depression, anxiety, five domains of QOL (fatigue, distress and sadness, mood, work, relationship with others) and enjoyment of life (Kandasamy, Chaturvedi, & Desai, 2011). Spiritual wellbeing is a complex dynamic state which has a significant impact on clinical outcomes (Komariah & Ibrahim, 2019; Nuraeni, Nurhidayah, Hidayati, Sari, & Mirwanti, 2015).

Cancer related fatigue is an immense perception of exhaustion physically, mentally, emotionally which occurs secondary to the disease or due to disease related treatment. It can persevere over time and interferes with daily routines and varies from the tiredness of everyday life, which is normally nonpermanent and diminished by rest. Cancer treatment-related fatigue usually enhances following therapy is done; nevertheless several levels of fatigue may continue for months or years after the treatment. Research specifies that for at least a subset of patients, fatigue may be a conspicuous matter long into survivorship.

According to Lewis et al. (2014), fatigue is a general term used to describe the different feelings with a diversity of terminologies indicating alleviated either physical, mental, emotional, or social capacity, and it is also indicate distress. Fatigue is the most prevailing symptom among cancer patients receiving radiation therapy and cytotoxic chemotherapy. Fatigue symptoms were consistently documented for more than 50% of various types of cancer therapy (Naraphong et al., 2015).

Health related QOL is the degree to which average or predicted physical, emotional and social wellbeing are influenced by a medical condition or its treatment. Its evaluation demands for attention to several measurements, which include physical concerns (e.g. symptoms), functional ability, family well-being, emotional well-being, spiritual well-being, sexuality and social functioning. Hence in cancer treatment multidimensional, multifaceted approach is quintessential for successful treatment outcomes. In cancer patients, the focal point is usually aimed at treatment and treatment related matters, regulating physical symptoms and comorbidities. Psychological, interpersonal and spiritual well-being matters are seldom evaluated and addressed (Nuraeni, Ibrahim, & Rizmadewi, 2013; Nuraeni et al., 2015). This study brings out the importance of spiritual well-being in cancer patients and its impact and correlation on fatigue which is one of the most distressing and difficult to treat symptom.

According to Bredle et al. (2011), spiritual well-being has some components, such as, feelings of harmony, peace, the meaning and purpose of life, and the power of faith. Faith is an important aspect that contributes to the spiritual well-being of the person. Various studies have pointed out that faith, especially faith in God, helps the cancer patient to live well amidst the pain and suffering from cancer. There are many ways in which the persons with advanced breast cancer express their faith in God and how belief in God helps them to cope with cancer. Some of them express faith in God through prayers asking for strength and spiritual well-being (Komariah, Hatthakit, et al., 2020).

A study done by Taylor in patients with recurrent cancer with various clinical subtypes showed that the symptom distress was inversely related to spiritual well-being (Taylor, 1993). A similar kind of study done in breast cancer patients showed that lower amount of symptom burden and distress was associated with a better spiritual well-being (Manning-Walsh, 2005). Likewise, demoghraphic data, namely education was significantly related to spiritual well-being, it was inconsistent with previous study indicated that education unrelated to spiritual well-being (Suara et al., 2017). In the present study, occupation and family income were significantly unrelated to spiritual well-being, however they have a significantly related to fatigue.

The findings of this present study support that the nursing interventions to increase the patients' spiritual well-being can reduce their fatigue. So, this research can be used as an evaluation and input to enhance the quality services, particularly the provision of holistic nursing care among patients with breast cancer undergoing chemotherapy.

## Conclusion

To sum up, based on the findings of this study concluded that spiritual well-being has significant relationship with fatigue among persons suffering from breast cancer undergoing chemotherapy. In addition, the education level has significant relationship with spiritual well-being, whereas the occupation and family income have significant relationship with fatigue.

Furthermore, since this study applied convenience sampling and the population included only the Indonesian women with breast cancer undergoing chemotherapy, conducting similar studies using random sampling in other wards and other chronic disease centers is recommended.

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# The Effect of Brain Game on Cognitive Function in Stroke Patients

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## Abstract

The decline in cognitive function has been a disorder frequently experienced by stroke patients. The present study aimed to determine the effect of android-based brain games on cognitive function in stroke patients. Brain games in this study are designed using an exploratory approach to various cognitive function domains that are damaged. The quasi experiment using two groups pretest and posttest design involved 15 individuals for each group recruited from a hospital in West Java through purposive sampling with a sample calculation formula using a paired numerical analytical research formula. The intervention group received an android-based brain games three times a week for one month, the control group received placebo intervention (mentioning colors of different words) three times a week for one month. The FACT-Cog Version 3 questionnaire utilized as the measuring instrument. Measurements were taken every week after the intervention for one month. The results indicated that there was a significant change in cognitive function scores before and after the intervention in the intervention group ($p = 0.000$). Meanwhile, in the control group there is no significant change ($p = 0.164$). Moreover, the results of cognitive function score analysis after intervention between the intervention and control group exhibit a significant difference ($p = 0.000$). The brain game intervention has a significant effect on cognitive function after the third treatment in the first week ($p < 0.05$). Also, the results exhibit the potential effect of brain games on the cognitive function level of stroke patients. Some of the things that make the intervention in this study effective in improving cognitive function are that the respondents included in this study are only those who have a score greater than or equal to 46, which may be different when applied to patients with lower scores. In addition, the intervention was carried out on respondents who had experienced a stroke for the first time and may be different if applied to people who have had several strokes. Therefore, it is important to expand the criteria for respondents in further research. Furthermore, this can be used as an option of the nursing intervention to manage cognitive problems among stroke patients.

**Keywords:** Brain game, cognitive function, stroke.

## Introduction

Stroke is classically characterized as a neurological deficit attributed to an acute focal injury of the central nervous system (CNS) by a vascular cause, including cerebral infarction, intracerebral haemorrhage (ICH), and subarachnoid haemorrhage (SAH), and is a major cause of disability and death worldwide. (Sacco et al., 2013). Weinstein et al., (2014) mention that individuals with strokes experience weak cognitive function in the immediate recall of logical and visual memory, verbal, language, executive function, and visuospatial and motor skills.

Cognitive function is defined as the ability to understand daily events, make decisions and adapt to the environment (Yoo et al., 2015). The decline in cognitive function resulted from a lack of blood flow to the brain, leading to the hypoxemia to regional area of the brain and causing chain reactions that resulted in the death of brain cells and their constituents. Unfortunately, it is common among stroke patients. Studies found that the incidence of cognitive decline among stroke patients were 20-80% (Sun et al., 2014). Middleton et al., (2014) reported that cognitive impairment was more common in acute strokes (76.3%) compared with chronic stroke (67.3%) ($p = 0.09$).

The cognitive impairment experienced by stroke patients is identified as lowering the patient's ability to live independently. Early assessment of cognitive impairment is particularly important at the early diagnostic stage (Wulandari & Ismail, 2019). Study reported that cognitive impairment does not only affect individual coping abilities and daily activities, but also negatively impacts on patients' work and social relationships (O'Connor et al., 2010). World Health Organization (2017) explains that cognitive impairment is a strong predictor of functional ability and the need for care in older people. The annual conversion rate from mild cognitive impairment to Alzheimer's disease or non-specific dementia ranges between 12% and 15%. Furthermore, Fitriana et al., (2020) in her research found that stroke has a significant relation with the incidence of dementia in adults. This is inseparable from the decline in cognitive function experienced by stroke patients. The complexity of the negative impacts brought about by cognitive impairment causes patients to experience obstacles in carrying out daily activities and results in decreased quality of life (Cheung et al., 2012).

Several domains of cognitive impairment that occurred due to stroke include attention and concentration, memory, executive function and speed of processing (Reid-Arndt et al., 2010). Harvey (2019) described strategies for assessing the cognitive function domain through tests that could be carried out on each sub-domain of cognitive function. This cognitive assessment can provide clues about the extent of functional deficits and their potential for treatment.

Furthermore, Harvey (2019) explains that the attention domain could be stimulated by visual processing, using the similarity theory approach. Selective attention tasks often provide distraction information and ask the patient to guess expected information. Distractors can be presented in sound forms for auditory tasks and alternatively colors, texts, sizes for visual tasks. The other domain in cognitive function is memory functioning. Manipulation of working memory refers to the process of operating on information stored in working memory storage. The prototypical manipulation of working memory task is digit span backwards, where the participant is asked to recall information in reversed order compared with presentation ("258"→"852").

The other domain of cognitive function is the visuospatial domain and executive function. The visuospatial domain is a constructional ability such as drawing or imitating various kinds of images and composing blocks (Sun et al., 2014). The application of this domain stimulation is by arranging a row of blocks bearing numbers. Meanwhile, the executive function is also commonly referred to as reasoning and problem solving. Thus, tasks of problem solving, planning, manipulating mazes, and other complex tasks where management of multiple cognitive abilities are required, fall under the domain of executive functioning (Harvey, 2019). Applications in the executive function tasks are simple logic games such as 1.....3 = 4, and respondent must choose one of the signs (+, -,: or x) to be filled at that blank space.

Interventions applied to the stroke patients should be fun, light, and not energy-draining since a study reports a strong correlation between decreased cognitive function and stress, anxiety, and fatigue (Cheung et al., 2012). Therefore, the intervention given is expected to reduce stress, improve mood, not be tiring, and reduce anxiety. Cognitive training is one of the non-pharmacological interventions reported to have a good success rate in improving cognitive function both subjectively and objectively after chemotherapy for breast cancer (Chan et al., 2015).

Kesler et al., (2013) studied internet and computer-based cognitive training interventions with a focus on improving the executive function of breast cancer survivors and reported that they significantly improve executive and motor function ($p = 0.008$), verbal function and language skills ($p = 0.003$), orientation and attention ($p = 0.009$), and self-report improvement ($p = 0.02$). Other study on cognitive training interventions was conducted by Chen et al., (2015) in the form of visual training consisting of four modes for stroke patients who had a decreased cognitive function and impaired eye movement for 30 minutes once a day, five times a week, for four weeks. This training proved to be significant in improving attention and concentration, executive function, memory, visual skills, abstract thinking, calculation, and directional force, as well as its total standard score ($p < 0.01$).

From those two studies, cognitive training effectively improve cognitive function, but in both training patient should have and be able to operate a computer and internet properly. In Indonesia, not everyone has a computer connected to the internet. In addition, visual training requires a therapist to determine which mode is suitable for the patient according to the patient's vision condition.

This becomes the basis for developing intervention media that can be used independently by the patients' families to improve patients' cognitive function. The researchers attempted to develop the android-based cognitive training which is expected to improve the cognitive function of stroke patients as indicated by improvements in the cognitive domains (attention and concentration, memory, executive function, and speed of processing) (Harvey, 2019). The objective of this study is to determine the effect of Android-based brain games on cognitive function in stroke patients.

## Method

Quasi experiment with two group pre-test and post-test design was used in the present study. The treatment group was given intervention in the form of playing the android-based brain games for 30 minutes once a day, three times a week for one month. The intervention was carried out under the supervision of the researcher while in the hospital and continued with a home visit to the respondent's house for respondents who had been discharged from the hospital. Respondents played brain games independently and the researcher monitored the duration of the game. This game consisted of four games, all of which aim to improve cognitive function by adopting the cognitive domain assessment approach (Harvey, 2019).

The first game was "Attention Game" which was designed based on the visual processing, using the similarity theory approach. The second was "Memory Game", designed using a serial recall task approach. The third was "Visual Game", using constructional theory. In the fourth game, a simple logic game approach called "Executive Functions Game" was applied. These four games were implemented to improve cognitive function, covering several domains i.e. attention, memory, visuo-spatial, and executive functions. The control group received the provision of a placebo in the form of another type of brain game three times a week for one month (placebo) by watching the Android-based video media, the respondents were asked to read and verbally mentioned a word "written" in different colour. Technically the researcher made a schedule for implementing the intervention to the respondents and the family. Furthermore, the intervention was carried out according to schedule starting from the time the patient underwent treatment at the hospital and continued at home. During the intervention at home, the researcher conducted a home visit according to the intervention schedule for each respondent. During the implementation of the intervention, the family also accompanied the respondent to provide motivation and see the respondent's progress during the intervention. Measurement of cognitive function was carried out by the researcher directly every weekend after the intervention for 1 month.

The population of this study included the ischemic stroke patients at one of the hospital in West Java. The purposive sampling was used as the sampling technique with inclusion criteria: 1) Aged ≥ 18 years, 2) first episode of stroke, 3) have a cognitive dysfunction indicated by score greater or equal to 46 of the FACT-Cog Version 3, 4) Voluntarily join this study.

The determination of the number of samples uses a paired numerical analytical research formula. That formula is n_1=n_2= (((Z_α+Z_β ) S)/(X_1-X_2 ))^2 , where n is the number of research respondents in each group, Z_α is standard deviation α (type I error is set at 5% with a two-tail hypothesis), Z_β is standard deviation β (type II error is set at 5%), X_1- X_2 is the minimum difference between the mean which is considered significant, and S is the standard deviation of the difference in value between groups (Dahlan, 2013). Based on this formula, the minimum sample size is 13 people for each group. Anticipation of dropout, loss to follow-up and non-compliance of respondents in the process of this research was carried out by correcting the sample size using the formula n'= □(n/(1-f)) , where n' is the number of research samples, n is sample size calculated, and f is estimated proportion of drop out (15%). A total of 30 individuals were selected as the sample (15 for each group: intervention and control). Sample group allocation is carried out by utilizing a simple random allocation techniques using a computer random number generator (random.org).

The demographic questionnaire containing gender, date of birth (age), marital status, occupation, religion, latest education, and history of disease as well as the FACT-Cog Version 3 questionnaire were used to collect the data. The researchers have obtained permission to use the FACT-Cog Version 3 questionnaire from the FACIT. This instrument has validity, reliability, and equivalence in good clinical and research studies with a cronbach α value of 0.707–0.929. The validity value is 0.725 (Cheung et al., 2013).

The researchers have met the required language translation requirements required by FACIT.org such as translating using two independent translators who are tasked with translating from English to Indonesian, sending the translation results to the third translator who is in charge of reviewing English and the two translations directly, choosing one of the three translation results and sending only the results of the translation to the fourth translator to translate back from Indonesian to English (Tyupa, 2011), sending the results of the back-translation step document for review and testing the questionnaire to 10 stroke patients who had cognitive function problems to find out whether the grammar in the translated questionnaire can be understood by the research respondents. The result of this questionnaire test is that all patients can understand the grammar and meaning of the questions in the questionnaire.

The data analysis was conducted using the descriptive and inferential analysis. The paired t-test was carried out to determine the difference in mean scores of pre- and posttest in the intervention and control group. The independent t-test was employed to determine the difference in cognitive function mean scores in the pretest and posttest of intervention and control group as well as to determine the difference between the pretest and posttest cognitive function scores. To determine the effect pattern of Android-based brain games on cognitive function in the intervention group, the repeated ANOVA and post hoc tests were utilized. This test can reveal a pattern of the effect of intervention given (Dahlan, 2014). The significance level used was $p < 0.05$, with a confidence level of 95%. This study was approved by the ethics committee of Jenderal Achmad Yani Institute of Health Science with a letter number : 003/KPEK/I/2020.

## Results

**Table 1 Table of Frequency Distribution, Percentage, and Homogeneity Test of Respondent Characteristics of Intervention- and Control Group (N=30)**

| Characteristic | Intervention (n = 15) | | Control (n = 15) | | p Value |
|---|---|---|---|---|---|
| | f | (%) | f | (%) | |
| Age (Years Old) | | | | | |
| 36–45 (late adult) | 1 | 6.67 | 3 | 20 | 0.625[a] |
| 46–55 (early elderly) | 10 | 66.67 | 8 | 53.34 | |
| 56–65 (late elderly) | 3 | 20 | 2 | 13.33 | |
| >65 (senior) | 1 | 6.66 | 2 | 13.33 | |
| Sex | | | | | |
| Male | 7 | 46.67 | 8 | 53.33 | 0.716[a] |
| Female | 8 | 53.33 | 7 | 46.67 | |
| Working Status | | | | | |
| Working | 8 | 53.33 | 9 | 60 | 0.625[a] |
| Not Working | 7 | 46.67 | 6 | 40 | |
| Marital Status | | | | | |
| Married | 12 | 80 | 12 | 80 | 1.00[a] |
| Not Married | 3 | 20 | 3 | 20 | |
| Level of Education | | | | | |
| Elementary | 1 | 6.66 | 0 | 0 | 1.00[b] |
| Junior High school | 4 | 26.67 | 5 | 33.33 | |
| Senior High school | 9 | 60 | 9 | 60 | |
| Diploma/Bachelor Degree | 1 | 6.67 | 1 | 6.67 | |
| Comorbidity | | | | | |
| Yes | 11 | 73.33 | 11 | 73.33 | 1.00[a] |
| No | 4 | 26.67 | 4 | 26.67 | |

**a : Chi-Square*
**b : Fisher's Exact Test*

**Table 2 Table of Difference in Mean Score of Cognitive Function of Pretest and Posttest within and Between Intervention and Control Groups (N =30)**

| Variable | Mean | SD | T | P |
|---|---|---|---|---|
| Cognitive Function Score within group: Intervention group | | | | |
| Pretest | 69.67 | 12.915 | -24.231 | 0.000[a] |
| Posttest | 90.80 | 13.385 | | |
| Control group | | | | |
| Pretest | 68.73 | 13.689 | -1.468 | 0.164[a] |
| Posttest | 69.00 | 14.338 | | |

| Variable | Mean | SD | T | P |
|---|---|---|---|---|
| Cognitive Function Scores Between Groups;<br>Pretest | | | | |
| Intervention | 69.67 | 12.915 | 0.191 | 0.850[b] |
| Control | 68.73 | 13.869 | | |
| Post-Test | | | | |
| Intervention | 90.80 | 13.385 | 4.303 | 0.000[b] |
| Control | 69.00 | 14.338 | | |

*Note: a = Paired t-test, b = Independent t-test*

**Table 3 Table of Results of Repeated ANOVA Test On Posttest Cognitive Function Scores of Android-Based Brain Games Treatment in The Intervention Group from The First to The Fourth Week**

| Intervention Treatment (Week-) | Mean | SD | P |
|---|---|---|---|
| 1 | 70.867 | 3.514 | 0.000 |
| 2 | 74.60 | 3.344 | |
| 3 | 85.60 | 3.319 | |
| 4 | 90.80 | 3.456 | |

**Table 4 Table of Results of The Paired Wise Comparison Test of Android-Based Brain Game Posttest in The Intervention Group from The First Week to The Fourth Week**

| Comparison of Intervention Treatment Time of Brain Games (Week-) | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| 1 | | -3.733* | -14.733* | -19.933* |
| 2 | 3.733* | | -11.000* | -16.200* |
| 3 | 14.733* | 11.000* | | -5.200* |
| 4 | 19.933* | 16.200* | 5.200* | |

*) The mean difference is significant ($p < 0.05$)

All of the respondents were able to follow the research process for 1 month without any dropout, most of them belonged to the early elderly age (60%), had a working status (56%) and had comorbidities (73%). 80% of respondents were married with the highest level of education from Senior High (60%). The percentage of sex between men and women was balanced in the two groups, as was the status of marriage. The whole data on homogeneous characteristics were seen from the results of the chi-square and fisher's exact homogeneity test ($p > 0.05$).

The baseline (pre-test) of cognitive function scores in both groups refered to the same condition (homogeneous) as indicated by the results of Levene's homogeneity test ($p > 0.05$). The highest mean score of cognitive function in the intervention group was derived from the measurement of cognitive function in the fourth week after treatment, which is 90.80.

The results of Independent t-test on the pretest cognitive function scores represent no difference in cognitive function scores before the intervention between the intervention and the control group ($p = 0.850$). Therefore, this filtered out any bias from the differences in baseline cognitive function scores between the two groups.

There was a significant change in cognitive function scores between before and after the intervention in the intervention group (p = 0.000). While in the control group, there was no significant change in cognitive function scores between before and after the intervention (p = 0.164). Morevore, the results of cognitive function score analysis after the intervention between the intervention- and control group exhibited a significant difference (p = 0.000).

The difference in the mean cognitive function of both groups was negative, meaning that there was an increase in cognitive function scores after the intervention, whereas in the intervention group the cognitive function score was higher ($\Delta$ = 21.13). The score was merely 0.27. Statistically, there was a significant difference in cognitive function scores between the intervention and control group (p = 0.000).

The results of repeated ANOVA tests showed a change in the mean scores of cognitive function in the intervention group after being given brain games intervention 3 times a week for 1 month (p=0.000). Furthermore, the results of the post hoc test showed that the brain game intervention could have a significant effect on cognitive function after the third treatment in the first week ($p<0.05$). Each measurement revealed a significant difference in cognitive function ($p<0.05$).

## Discussion

The results of the study proved that Android-based brain games have a positive effect on cognitive function. This was supported by the cognitive function scores of the post-test intervention group and the difference in the mean post-test between the intervention group and control groups. Furthermore, the result of ANOVA and post hoc test in this study revealed a pattern of cognitive function improvement over time.The brain games applied in the study were designed with an exploratory approach in various domains including training for the brain which in the previous study was found to be effective in improving the attention and concentration, executive function, working memory, and processing speed (Reid-Arndt et al., 2010). The significant change in cognitive function scores after brain games intervention is in line with the results of research conducted by Al-Thaqib et al., (2018) which stated that computerized cognitive training games improved the domain of cognitive function, including attention and motor speed in normal healthy subject. This study has similarities with research conducted by researchers in using a cognitive training game approach. However, it differs in terms of research subjects that focus on healthy people and the cognitive training games used are computer-based. So it can be concluded that both Android-based and computer-based brain games are proven to have an effect on improving cognitive function both in stroke patients and in healthy people.

Also, this is in line with research conducted by Strobach & Huestegge (2017) which applies commercial computer-based cognitive training tasks by targeting working memory. The study results showed that the number of respondents with cognitive failures was reduced in the intervention group in contrast to the control group at the posttest. Performance improvements are more noticeable for high performing participants (i.e., magnification effects). The difference between the intervention in this study and the research conducted by the researcher lies in the target focus of the cognitive function domain, which only focuses on working memory. Meanwhile, the intervention in this study involved stimulation in the attention, memory, visuo-spatial, and executive functions domains. Cognitive training can be designed according to the focus of the intervention objectives by using a work approach in the domain to be stimulated. So that it is very possible to develop cognitive games in accordance with the direction of intervention goals.

Based on the results of mean difference in cognitive function scores in the intervention and control groups, there is a significant difference between these scores with p = 0.000. The results of repeated ANOVA and post hoc tests showed that the brain game intervention have a significant effect on cognitive function after the third treatment in the first week ($p<0.05$). It is recommended that routine brain game treatment be conducted more than three times, given the results of the study showing that changes in cognitive function scores in the intervention group are seen in the third intervention. This is supported by Kesler et al., (2013) which stated that the increase in cognitive function is seen in the first, second, third, fourth, fifth, and sixth months. The key to successful implementation of brain games lies in its routine of three times a week for one month, regular and continuous implementation so that it can help improve the domain of cognitive function, including increasing attention and concentration, executive function, working memory, and processing speed.

The development of dendrite connections in the brain depends on the activity of the individual in getting impulses from the environment. Dendrites become functional when there is an increase in synaptic strength due to a pair of electrical signals along two different neural pathways. This pair of signals increases the rate of neurotransmitters release in the synaptic cleft and facilitates the transmission of active signals from one neuron to the next. This explains that neurons that initially do not function optimally can be maximized by facilitating the rate of neurotransmitter release, so that signals can propagate easily through active neurons and affect inactive neurons (Lawson, 2013). A person's cognitive function is influenced by the number of active brain cells and how many connections there can be between brain cells. This connection can be enhanced if we practice often to be able to "create meaning" or understand what is being learned. In addition, the brain will receive stimulation well if the source of the stimulation is obtained in many ways, for example through hearing and vision as applied to the brain games in this study.

The effectiveness of Android-based brain games intervention in this study lies in the cognitive function improvement strategy by mixing and matching several techniques used to provide active stimuli in the cognitive domain. In addition to the combination of techniques, visual stimuli are also provided that increase memory use, attention and concentration, speed of processing, and executive function. By improving these domains, especially executive function, there will be improvements in overall cognitive function. Brain neurons will be increasingly stimulated by complex impulses from the stimulation of the cognitive domain at the same time, the work of the brain will be more optimal so that it can improve cognitive function (Lawson, 2013).

Stimulation strengthening is done through an interesting, colorful, and graphic form of game as a strategy to strengthen the stimulus. High patient motivation to continue to participate in the program is one of the keys to the success of the therapy and rehabilitation programs, especially for stroke patients. Burgers et al., (2015) stated that games are important vehicles for learning and behavior change as long as players are motivated to continue playing. Therefore, choosing a game-based intervention that is easy to use and attractive is an important point. This is in line with what Hung et al., (2016) explained that selecting games for rehabilitation based on designed-for-fun video games would be a more economical, more feasible, and much more measured way to provide strong and personal motivation for various stroke patients, especially those who have video gaming experience before.

The results of this study indicate the influence of brain games on the cognitive function level of stroke patients so that they can be used as an independent nursing intervention options in managing stroke patients' cognitive function.

### Limitation

The limitation of this study is that the respondents included in the study were only those who had a score greater than or equal to 46, possibly different when applied to patients with lower scores. In addition, the intervention was carried out on respondents who had experienced a stroke for the first time and may be different if it was applied to people who have had several strokes. Therefore, it is important to expand the criteria for respondents in further research.

## Conclusion

The findings indicate that brain games have a positive effect on cognitive function. The application of brain games as part of nursing care interventions in patients with cognitive dysfunction is a strategy that involves the stimulation of various stimuli from the domains of cognitive function. Additionally, to increase the effectiveness of brain games, it is important to establish a routine play schedule for patients 30 minutes once a day, three times a week so that the simulation of the cognitive function domain takes place simultaneously. The implementation of brain games can be conducted either with a nurse's direction or independently by the patient, considering that the digital brain game application is designed to make it easier for patients to obtain independent training so that it can improve patient self-management as well.

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# The Structure, Process, and Outcome of Mentorship on Survivor with Schizophrenia: A Case Study

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## Abstract

The personal recovery paradigm in schizophrenia patients require a change of service. One of the changes that can be made to support the schizophrenia recovery process is a change in the concept of the relationship between patients and nurses. Nurse mentorship for schizophrenia patients is a new terminology of innovation in a supportive relationship between health workers and patients. At present, it is not known how the structure, process, and outcome of mentorship to schizophrenia survivors. This study aimed to explain how the structure, process, and outcome of mentoring nurses to schizophrenia survivors. This research is qualitative research using the case study method involving three cases of mentorship conducted in Banyumas Regional Hospital. A total of nine participants were involved in this study which consisted of three nurses as mentors, three schizophrenia survivors, and three caregivers. Data were collected by semi-structured interview techniques, observation, and document review. After in-depth analysis seven research themes were found. Participants' perception about the structure of mentorship include the theme mentorship requires a variety of abilities of nurses and conditions of survivors who can participate in mentorship. While the mentorship process includes the theme requires patience in mentorship, giving guidance for the recovery of survivors, and facing the recurrence of survivors due to treatment factors. Participants revealed the outcome of mentorship in the theme mentors feel inner satisfaction, and survivors feel more enthusiastic about life. The results of this study provide the view that mentorship has the potential to be developed into quality nursing interventions to support the recovery process of schizophrenia survivors.

**Keywords**: Case study, mentorship, schizophrenia recovery.

## Introduction

Schizophrenia is a serious mental disorder that is most often found in society. According to WHO, as many as 21 million people in the world suffer from schizophrenia (WHO, 2016). In Indonesia, based on the results of the 2018 Riskesdas the proportion of households with severe mental disorders (schizophrenia or psychosis) nationally is 7 per 1,000 households (Ministry of Health, 2018). Globally there has been a change in the concept of healing in mental patients (Korsbek, 2016). Whereas in the past the view of healing schizophrenia patients rests more on the view of "clinical recovery" which emphasizes symptom relief and a reduction in the recurrence rate, in recent years this concept has been replaced by the concept of "personal recovery". Personal recovery in mental health refers to the process of changing attitudes, values, feelings, goals, and skills and rebuilding one's integrity to live a satisfying life within the limitations caused by illness (Anthony, 1993; Deegan, 2003; Suryani, 2018). Changing the view from the concept of clinical recovery to personal recovery demands changes in inpatient care. Recovery-oriented services are a paradigm shift from clinical-oriented services that emphasize more on stabilization and reduction of clinical symptoms to value-oriented services and principles of patient-centered service (person center care) and involve individuals in the service process (personal involvement) (Waldemar, Arnfred, Petersen, & Korsbek, 2015). The concept of personal recovery schizophrenia in Indonesia has not been widely applied in services. Based on the results of Nurhayati's research, Kusumah and Murwasuminar (2019) revealed that currently, the Community Mental Health Nursing (CMHN) program is a program that helps recover schizophrenia survivors by making home visits as one of its activities. The CMHN program in Indonesia is currently not fully implemented due to several reasons, namely incomplete mental health policies and lack of research or the lack of use of evidence-based practice in the application of mental health services (Nurhayati, Kusumah, & Murwasuminar, 2019). In Indonesian culture, especially Sundanese culture there is a philosophy of life that is in accordance with the concept of mentoring, namely "Silih Asih", "Silih Asah", and "Silih Asuh". "Silih asih" has the meaning loving each other and "silih asah" has the meaning of wanting to give knowledge. Then the "silih asuh" that has the meaning of guiding each other. The culture has become a philosophy that will be very meaningful when developed to help schizophrenia recovery process.

The coaching or mentoring approach is a form of relationship between patients and professionals who can facilitate the recovery process (Borg & Kristiansen, 2004; Suryani, 2018). Mentorship is a concept that has long been known as an effort to increase one's capacity. Mentorship is hidden assistance (offline help) from mentors to mentees (mentoring participants) in making significant changes in knowledge, work or ways of thinking (Clutterbuck & Megginson, 1999). There are several studies that prove the effectiveness of mentorship-based interventions from nurses to patients in improving the health conditions and quality of life of patients. Some of these studies include COPD patients (Cameron-Tucker et al., 2016), recovery patients with myocardial infarction (Terence John Frohmader, Lin, & Chaboyer., 2016) and breast cancer metastatic patients (Ye et al., 2017). Based on a preliminary study conducted at the Integrated Mental Health Installation at Banyumas Hospital in December 2019, data were obtained that there was a mentorship-based activity with activities to provide guidance from nurses to post-hospitalized schizophrenia patients. The guidance program uses a mentorship approach as a new innovation for recovery-oriented schizophrenia. As an intervention innovation, nurse mentorship to schizophrenia survivors has never been evaluated for its quality. According to Donabedian (1988), to evaluate the quality of a health service one must pay attention to structure, processes and outcomes. This research article aims to determine the structure, process, and outcome of mentorship of nurses to survivors of schizophrenia.

## Method

The research method used in this research is an explanatory case study. This method was chosen because the researcher wanted to emphasize the explanation and understanding of the structure, process and outcome (Donabedian, 1988) of the nurse's mentorship program for schizophrenia survivors in the real-life context (Polit & Beck, 2004; Robson & McCartan, 2016; Yin, 2017).

### Participants and Research Settings

The unit of analysis in this study was a case of nurse mentorship to schizophrenia survivors in the Puntadewa community at Banyumas Hospital. Participants in this study included nurses as mentors, schizophrenia survivors as mentee in mentorship and caregivers. The sampling technique used in this study was purposive sampling. This research has received approval from the UNPAD research ethics committee with Ethics Approval Letter Number: 381 / UN6. KEP / EC / 2020. and from the Health Research Ethics Committee of Banyumas Hospital with a certificate of ethics worthy number: 085 / KEPK-RSUDBMS / III / 2020 dated March 26, 2020.

### Mentorship Process

Nurses who become mentors have attended training and workshops on recovery, therapeutic communication techniques, coaching techniques, and mentoring for schizophrenia patients. Schizophrenia survivors in this study were schizophrenia patients who were undergoing an outpatient process at Banyumas General Hospital. Schizophrenia survivors who take part in the mentorship process are determined based on several considerations from the mentor, including the closeness of the relationship that has been previously established.

The mentorship process at the Puntadewa community begins by making an agreement between the mentor and the caregiver and schizophrenia survivor to undergo a mentorship program. The next step is that the nurse, together with the survivor and caregiver, is to explore the living conditions experienced by the survivors. The exploration includes conditions of family relationships, friendship, work, daily activities, spirituality, and education. After exploration, the mentor and the survivor discuss the goals and plans for achieving these goals.

The goals and achievement plans that have been prepared are mutually agreed upon between the survivor and the mentor. Survivor is committed to carrying out the plan that has been prepared. Caregivers are asked to assist and support the implementation of the agreed activities. At the next meeting, the mentor evaluated the implementation of the activities. The mentor and the survivor discussed the achievements and obstacles in carrying out the activities that have been determined. At this stage, the mentor provides support to the survivor, has a positive attitude, and acts constructively to help the survivor achieve the goal of recovery. If the previously set goals have been achieved, the mentor encourages the survivor to create new additional goals for his recovery. The termination of the mentorship process will be carried out when the stated goals have been achieved and both parties mutually agree to stop the mentorship process.

### Data analysis

According to Miles and Huberman (2002), there are several stages of data analysis that are commonly used in case study research. The data analysis stage was preceded by data collection. At the data collection stage, researchers obtained information collected through interviews, observations, and document reviews. The three pieces of information are transcribed into sentences.

Data reduction is the first analysis step after data collection. This process includes data selection, focusing, simplifying, and abstraction of data that appear in observation notes, document review, and data transcription. At this stage, the researcher tried to appreciate the data by listening to the recorded conversations over and over again. Then, the researcher read the textual data that has been obtained repeatedly. Researchers classify data into patterns by emphasizing, shortening, focusing, and selecting and paraphrasing the data transcript into a code/

coding. Researchers conclude and combine codes that have the same pattern or have a relationship into a category. Then, from several categories that have been formed, the researcher analyzes and combines the same categories into a larger pattern, namely themes. Data collection and data reduction interact with each other by making conclusions and presenting data, there is reciprocal interaction and the development is sequential and interactive. This stage continues until the end of the analysis process.

The next stage is data presentation (data display). The data presentation stage is carried out after a number of data obtained are performed data reduction. This stage is done by arranging the information into an orderly arranged table of information. The purpose of presenting this data is done so that researchers get well-organized information in a form that is easily accessible and concise so that researchers can see what is happening and or make data conclusions. The last stage is to describe the conclusion and verification (conclusion drawing and verification). At this stage, the researcher makes conclusions and verification based on the data obtained. Researchers conducted a deductive analysis of the themes that had been formed using a framework of structure, processes and outcomes according to Donabedian (1988) to find out how these themes described the quality of health service interventions.

## Results

Overall, there were nine participants involved in this study which included nurses as mentors, schizophrenia survivors, and caregivers of schizophrenia survivors. After conducting an in-depth analysis process, themes related to the structure, process and results of nurse's mentorship to schizophrenia survivors were obtained as follows:

### Structure of Mentorship for Schizophrenia Survivors

According to Donabedian (1988), "structure" can be defined as the qualifications of service providers required, the equipment and equipment required and the resources required to carry out an intervention. The results of the analysis of this study found that structural elements including the theme of mentorship require a variety of abilities of nurses and conditions of survivors who can participate in mentorship. The following is a discussion of this theme.

1) Mentorship Requires a Variety of Nursing Abilities

This research reveals that mentorship requires a variety of abilities of nurses. Conceptually, mentorship is a relationship that involves two parties, namely someone who is considered more experienced / expert (mentor) and someone who is considered less experienced / beginner (mentee) to develop personal and professional abilities (Dancer, 2003).

The nurses who participated in this study had more than ten years of experience working in the area of mental nursing. This opinion was also conveyed by the nurse that one of the important things to become a mentor for survivors of schizophrenia is experience.

"And for sure we have to have the experience, we have long an experience in mental health, they really believe," (M03)

In this study, the participants believed that to become a mentor they needed to master mental nursing, psychology and apply therapeutic communication and update science.

"Indeed, the first is like in psychology which has been famous for so far, namely building trust relationship, yes ... the term is how we build trust first with patients or their families..." (M02)

Based on the observations, the mentor applies several therapeutic communication techniques during mentorship activities. This can be seen in the following observational data;

"The mentor and survivor seemed to laugh with humor conveyed by the mentor in between their conversation" (Obs_02)

"The mentor uses open-ended questions when asking about the condition of the survivor". (Obs03)

According to participants, one of the skills a mentor considers necessary is the ability to analyze the problems at hand.

"... we explore the potential things that could cause that problem which may be needed here. So it is not just an asset to talk, but also to be able to analyze the facts. "(M02)

Participants also highlighted the mentor's ability to establish relationships with doctors in charge of patients, rehabilitation institutions and parties who can provide capital for survivors to work. According to the mentor, this ability is needed to help overcome the various challenges faced during the recovery process for schizophrenia survivors.

"We also have to have a relationship with related links related to rich mental nursing, like we have to have a relationship with people in the orphanage so that we can quickly access it when those we mentor need rich rehab" (M01)

2) Conditions for Survivors Who Can Join Mentorship

The results of this study found several conditions for survivors who could join the mentorship program. This research reveals that mentorship will be easier to do for survivors with good insight.

This opinion was expressed by the following participants;

"So if he is aware that" oh I have a psychotic disorder, "he realizes that the symptoms can appear without him knowing it ... he is aware of that, if he is aware, of course it's different when we give advice, if someone has a negative insight…huh ... doesn't feel sick anymore, continues to feel good, we just give advice, he can fight like that. " (M01)

This opinion is supported by the results of a document review, which shows that based on the mentorship document notes, the mentor's description explains the condition of the survivor's insight:

"Description of the condition of the mentee: communicative, good insight, lack of activity, feeling lazy to do activities" (Dok_01)

The next condition is schizophrenia survivors who often recur. According to participants, there are several factors that cause survivors to recur frequently, namely environmental conditions that are not supportive for survivor recovery, caregivers who do not know how to care for survivors of schizophrenia or economic factors that cause survivors to be at risk of withdrawal from drugs.

"It's time for the patient to be treated like that ... so in a condition where patients who often relapse usually need a mentorship approach." (M02).

## Process of Mentorship for Schizophrenia Survivors

According to the Donabedian framework (1988), "process" is how the intervention is carried out in providing services. The process includes how to build relationship skills, use skills and knowledge in service delivery. The results of this study reveal that the mentorship process includes the following themes;

1) Requires Diligence in Conducting Mentorship

The results of this study reveal that doing mentorship requires patience. Participant data shows that the mentorship process takes a long time and requires patience. This patience is especially true when facing changes in the condition of the survivors and the nature of schizophrenia recovery which requires a long period of time. As the participant's expression follows:

"At the time ... first, the initial guidance was still lacking ... the mental condition was still sometimes invited to my house. I was still "ndleming" (talking to myself. Ed), talking to myself, the view was still there ... well then after being diligent , yes ... for up to 2 years it's been very good, the communication is continuous. " (M01)

This study revealed that the mentor and survivor agreed on a mentorship meeting schedule. In this study, it was found that the mentorship meeting was held once a month at the same time as taking medication from the survivor. Meanwhile, according to survivors, they can meet with a mentor outside the agreed schedule if they feel there is a problem that needs to be conveyed to the mentor.

"Yes, when you meet every month you take the medicine. Then, for example, there is such a condition ... a problem that feels heavy or a problem with drugs that don't match, so I usually ask the sir ... (name of mentor). " (S01)

The results of the analysis also indicated that the mentor had a close relationship with the survivor. A close relationship can mean that both parties feel emotional and comfortable to live the relationship. This opinion is supported by the following observational data:

"Survivors and caregivers show not awkward behavior when talking with mentors // Survivors and caregivers use the language used in everyday life" (Obs_01)

Apart from building close relationships, the mentor also maintains the boundaries of the relationship with the survivor.

"But don't tell the dark side too much for example; (Saying) "I was also a drinker" for example. So you really have to be careful to know the limits where what should we tell and which ones we should keep first." (M03)

2) Providing Guidance for Survivor Recovery

Research participants highlighted that mentorship is an activity to provide guidance for survivor recovery. Some data support the theme of providing guidance for survivor recovery, namely mentors teaching survivors how to deal with schizophrenia symptoms. This can be seen from the following participant expressions;

"When the condition is good, the insight is good, I realize the communication is continuous, I will tell you about hallucinations ... yes, if here, the hallucination management is ..." (M01)

The findings of the data analysis indicated that the mentor used potential sources of support for recovery survivors. Support in the form of commitment from the family is needed during the mentorship process as revealed by the following mentor

"But when the family decided and say ; "okay sir, that I ask my son to be visited every month by Pak Dwi then what the doctor instructs us to try." (M02)

In addition to family support, the mentor also uses the potential that exists in the survivor and the conditions in the surrounding environment.

"What are you managing...the fish pond he said at home ... yes yes because in his environment he is a rice field ..." (M01)

The findings in this theme are mentors discussing the future of survivors to build survivor optimism. The following is the mentor's statement about discussing the future of the survivor;

"I convey for the enthusiasm ... for the future what you want, for example work ... especially work, you have to work, have a job or have activities later to get money then be happy." (M03)

3) Confronting a Survivor Recurrence Due to Treatment Factors

The results of this study identified that in conducting mentorship, mentors often face recurrence of survivors due to medical factors.

"So the point is stable, the drug is stable, it continues to stop ... because it feels stable, it stops and keeps relapses,". (M01)

The mentor revealed that during the mentorship process, the mentor provided psycho-educational interventions to increase medication adherence to reduce recurrence of schizophrenia survivors. This opinion is supported by the results of observational data showing that the mentor discussed the benefits of survivor treatment for recovery.

"Survivor asks the mentor about the drugs that are obtained, sometimes changing drugs // The mentor explains the treatment process and the drugs he is taking." (Obs_03)

## Outcome Mentorship for Schizophrenia Survivors

The concept of "outcome" referred to by Donabedian (1988) is how the effect of the health services provided has an impact on the patient's health status.

The following is a discussion of this theme.

1) The mentor feels an inner satisfaction

The results of this study reveal the benefits of mentorship felt by nurses as mentors. Analysis of the results of interviews with the three mentors showed that they felt inner satisfaction after doing mentorship. A mentor said that there is a sense of satisfaction in being able to provide something useful for others even though it is only in the form of advice. The same thing was conveyed by other mentors that the mentor felt invaluable inner satisfaction when the survivor made progress in recovery. This opinion is as expressed by the following mentor;

"We have a sense of satisfaction, because we can provide something useful for others even though it's just advice. But when the advice is carried out and it gives a positive result, we feel that there is a separate inner satisfaction ... thank God, our knowledge is very beneficial, there is a sense of inner satisfaction. " (M01)

In addition, another form of satisfaction felt by the mentor is increasing brotherly friendship and adding to the experience of the mentor. This opinion was supported by the survivor's statement which stated that the mentor stayed in touch with the survivor's place during Eid.

"He (mentor) when Eid comes here, bro, get along with him" (S02)

"It adds to our experience in handling patients because when we finish this case, there will definitely be other cases that we will have to solve that can eventually add insight, okay?" (M02)

2) Survivor Feeling Increased Spirit of Life

This research shows that mentorship has a positive impact on the recovery process for schizophrenia survivors. Researchers obtained subjective data about the benefits of mentorship based on the changes felt by survivors of schizophrenia. The results of the study revealed that survivors felt an increased enthusiasm for life during the mentorship process from the nurses. Participants stated that they were becoming more optimistic, able to control their emotions and felt excited to do positive activities.

"Sometimes there are problems with the family. For example, if I have a problem with my brother, it is not suitable or what about it, I sometimes confide in sir (name of mentor). " (S02)

This opinion was supported by the caregiver who saw the change in the survivor to become more able to control his emotions.

"Previously, sometimes sometimes when you say this loudly you can plaque you (playing hit) first .... if so, it's the same as Mbakyu. If it's not now ... it's weak isn't it. Now if I tell "diem", "(K03)

## Discussion

### Structure of Mentorship for Schizophrenia Survivors

1) Mentorship Requires a Variety of Nursing Abilities

Experienced nurses have better work abilities because they have learned from the actions and problems they have faced. The work experience that nurses have in a particular field will shape the expertise in that field. A study on the work experience of nurses revealed that the work experience of nurses has a significant effect on nurses' performance. (Khandra, 2019). As identified by other studies, mentor friendliness, knowledge and ability in conveying information, open communication skills, active listening, and providing constructive feedback are needed to be a good mentor (Terence J Frohmader, Lin, & Chaboyer, 2017; LaFleur & White, 2010). In addition, establishing a therapeutic relationship is very important in supporting recovery to increase survivor cooperation and hope (Roberts & Boardman, 2014).

McKimm, Jollie, and Hatter (2007) state that one of the values and principles in mentorship is the ability to reflect on past experiences. Mentors and mentees are expected to be able to identify and analyze previous experiences for future improvement (Dancer, 2003). Mentorship is not only seen as a problem-solving process, it is also a problem management process. The mentorship requires imagination and innovation to identify missed opportunities or potential that is not used by individuals so that these individuals can be more constructive in life, able to develop themselves and increase self-motivation (Dancer, 2003). Dancer (2003) states that the role of a mentor may change as the mentoring relationship develops and may include roles as a "networker" and a "connector". In this study, the mentor is expected to have a network and be able to become a liaison between the needs of recovery survivors and other appropriate parties. A study revealed the perspective of schizophrenia survivors that therapy must meet their needs for recovery in social functioning and personal growth contexts (Dilks, Tasker, & Wren, 2010). This opinion is in accordance with the principle of holistic recovery, that is, apart from physical and psychological conditions. The recovery process must also pay attention to recovery supporting factors such as housing, employment, education and family (Bellack, 2006). Occupational problems in survivors of schizophrenia are very common (Darsana & Suariyani, 2020). According to McGurk, Mueser, DeRosa, and Wolfe, (2009) "working" for survivors of schizophrenia is closely related to the recovery process.

2) Conditions for Survivors Who Can Join Mentorship

The dimension of insight is one of the important factors affecting recovery parameters in schizophrenia patients (Mashiach-Eizenberg, Hasson-Ohayon, Yanos, Lysaker, & Roe, 2013; Yanos, Roe, Markus, & Lysaker, 2008). Poor insight is a very common phenomenon in schizophrenia where about 97% of patients with a first episode of the disease do not admit that their symptoms are related to the disease process (Soroka, Dziwota, Pawęzka, & Olajossy, 2017). Improved insight can make patients realize the need to adhere to the principles of care, able to build and maintain long-term interpersonal relationships. This opinion is in accordance with a review which states that good insights are associated with positive outcomes, such as treatment adherence and better recovery (Cavelti, Kvrgic, Beck, Kossowsky, & Vauth, 2012).

Schizophrenia survivors who often recur, according to the mentor, needs to be overcome by doing mentorship. Recurrence of schizophrenia has a negative impact and puts a burden on the patient, and affects the family directly or indirectly (Nurmaela, Suryani, & RAfiyah, 2018). A qualitative study involving schizophrenia patients revealed that participants suggested strengthening psychoeducation sessions, home visits and strengthening nurse-patient therapeutic relationships in providing care to help reduce recurrence of schizophrenia patients (Sariah, Outwater, & Malima, 2014). This is in line with the opinion of Suryani (2018) who said that a supportive environment is needed for survivors to undergo the recovery process. Support from health workers, families and communities and the government can encourage survivors to find their strength based so that schizophrenia survivors can undergo a good recovery (Suryani, 2018).

## Proccess of Mentorship for Schizophrenia Survivors

1) Requires Diligence in Conducting Mentorship

A mentorship relationship is a special relationship where two people make a real connection with each other. In other words, they form bonds that are built on mutual trust and respect, openness and honesty in which each party can still be themselves (Dancer, 2003). A study revealed that a mentor must have a level of patience and understanding in guiding them to achieve their goals (Henry-Noel, Bishop, Gwede, Petkova, & Szumacher, 2019). Meanwhile, according to McKimm, Jollie, and Hatter (2007) mentorship is a long-term relationship process to achieve a goal that requires the patience of both parties. According to Bellack (2006), the recovery process is a non-linear process, meaning that recovery is not a series of sequential steps. One time the individual can experience progress in the recovery process, but at another time the individual experiences a recurrence or setback. Mentors who understand the principles of schizophrenia survivor recovery will understand that patience is needed in conducting mentorship because they will face various conditions for schizophrenia survivors.

According to McKimm, Jollie, and Hatter (2007) state that one of the qualities of a mentor is that the mentee must be easily accessible. Mentees can easily meet with mentors if at any time the mentee needs a mentor. The quality of the mentor-mentee relationship is very important to achieve mentorship goals, if the relationship does not occur and one or both parties feel uncomfortable in the relationship, the mentorship process will not be sustainable (McKimm, Jollie, & Hatter, 2007). According to Roberts and Boardman (2014), one of the important domains to support recovery-based practice for schizophrenia patients is to support individuals and their families to fulfill their potential and shape their own future by establishing therapeutic relationships and increasing their involvement and increasing hope.

According to participants, this was done so that the advice or guidance given by the mentor could be accepted by the survivor as professional advice. Openess is one of the dimensions of action required in a therapeutic relationship. This opinion is in accordance with the opinion of Stuart (2014) which states that nurses' self-disclosure must be done carefully and have a therapeutic purpose. The benefits of nurses' openness can be used to increase cooperation, learning, catharsis and support (Stuart, 2014). The openness of the nurse that is not in accordance with the conditions currently being experienced by the client and the number of statements of openness that is too much from the nurse can make the client not have time to openly convey the problem he is experiencing (Stuart, 2014).

2) Providing Guidance for Survivor Recovery

According to Suryani (2018), schizophrenia patients who undergo recovery need to receive guidance from a mentor so that survivors are enthusiastic and committed to carrying out the recovery process. This opinion is in line with Vance (1995) in Schaffer, M. A., and Mbibi, N. (2014) which states that a mentor has a role to maintain, encourage, guide, and act as a role model for mentees to behave healthily. Survivors who recover from schizophrenia often report that they are greatly helped by someone who believes in them in a mentorship relationship (Kelly & Gamble, 2005). These results are in accordance with the results of research that the mentorship program was successfully used to guide patients with myocardial infarction recovery programs in improving health, patient welfare (Terence J Frohmader et al., 2017) and improving quality of life and medication adherence in the recovery process for patients with eating disorders (eating disorders) (Perez, Van Diest, & Cutts, 2014).

According to Suryani (2018), a health worker must be able to see the potential that exists in society. Community empowerment can be done to develop potential in the community, develop community contributions in helping the recovery process for schizophrenia survivors. The recovery process requires support from various factors such as treatment, society, government and religious factors (Hamaideh, Al-Magaireh, Abu-Farsakh, & Al-Omari, 2014). Research in Jordan reveals that social support such as support from friends or trusted people is the most influential domain for the quality of life for survivors of schizophrenia (Hamaideh et al., 2014).

Building survivor optimism in the recovery process in accordance with the framework in the mental disorder recovery process which includes aspects of Connectedness, Hope & Optimism, Identity, Meaning in Life and Empowerment (CHIME) (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). This opinion is also consistent with the results of research by Borg and Kristiansen (2004) which states that a relationship that fosters hope can help the recovery process for schizophenic patients. Hope in the characteristics of recovery means self-confidence to get a better future by overcoming problems and obstacles that occur. Hope is a key component in the recovery process for schizophrenia survivors. (Frese III, Knight, & Saks, 2009).

3) Confronting a Survivor Recurrence Due to Treatment Factors

Non-adherence to taking medication is a problem that often occurs in schizophrenia patients (Barkhof, Meijer, de Sonneville, Linszen, & de Haan, 2012). A study revealed that 62.1% of the 95 schizophrenia patients relapsed due to treatment non-adherence (Singh, Karmacharya, & Khadka, 2019). According to qualitative research involving schizophrenia patients, it was found that one of the causes of recurrence in schizophrenia patients was due to non-compliance with treatment (Amelia & Anwar, 2013). A study states that doing psychoeducation accompanied by a combination of work alliances such as improving the relationship between service providers and patients is proven to be more effective in increasing patient medication adherence (Phan, 2016). Another study involving 72 schizophrenia patients revealed that the therapeutic relationship between health care providers and schizophrenia patients is a strong predictor of treatment adherence in schizophrenia patients (Tessier et al., 2017).

## Outcome Mentorship for Schizophrenia Survivors

1) The mentor feels an inner satisfaction

Mentorship relationships that have been established for a long time can add to a wider friendship. Unlike other relationships, mentorship usually deals with problems that may overlap with personal and professional boundaries (Dancer, 2003) so that mentors and mentees feel the closeness of their relationship. Wolak et al. (2009) who examined mentorship in the area of nurse education reported that most of the mentors in the mentorship program they studied expressed feelings of happiness seeing their mentee develop as a nurse. The findings of this study support mentorship research for patients with myocardial infarction rehabilitation (Terence J Frohmader et al., 2017) and patients with chronic obstructive pulmonary disease (Wood-Baker, Reid, Robinson, & Walters, 2012), where the nurse as a mentor expresses satisfaction when the client able to make lifestyle changes that are healthier for the disease. A systematic review also reveals the positive impact mentorship has on mentors personally and practically, personal satisfaction, professional success, and contributions to the organization and the profession (LaFleur & White, 2010).

2) Survivor feeling the increased spirit of life

These results are in line with several studies which reveal that mentorship programs for patients can have a positive impact on the patient's recovery process. The results of a case study in Australia regarding nurse mentorship to patients with myocardial infarction showed an increase in quality of life, decreased anxiety and increased physical activity ability of patients (Terence John Frohmader et al., 2016). Research conducted on women with metastatic breast cancer in China found that mentorship-based programs can significantly reduce emotional distress (anxiety, depression, etc.), improve quality of life and patient resilience (Ye et al., 2017). In addition, participants in the study also revealed that feelings of empowerment emerged, especially in increasing self-confidence and hope (Ye et al., 2017).

Some of the participants felt happy because they had a place to address their problems during the recovery process and got solutions from mentors. According to Fertman and Allensworth (2016) mentorship is a health promotion by engaging in interpersonal relationships using social support theory. Social support is all forms of assistance or things given by people in their social environment that can provide emotional benefits or influence the behavior of the recipient (Fertman & Allensworth, 2016). In this mentorship process, the mentor shows a sense of empathy, care and positive appreciation and encouragement for schizophrenia survivors, which is a form of emotional support from the mentor. Someone who gets emotional support will create a sense of comfort, togetherness, a feeling of belonging and being loved when facing stressful situations (Sarafino & Smith, 2014).

## Conclusion

Research in Indonesia has not explored the mentorship of nurses to schizophrenia survivors. The lack of information regarding mentorship for schizophrenia survivors makes the results of this study provide important information for nursing science. The nursing implication of the results of this study is that nurses are expected to increase experience in managing schizophrenia patients and increase knowledge and skills of evidence-based schizophrenia patient care. In carrying out mentorship for schizophrenia survivors, nurses must be patient in conducting mentorship for schizophrenia survivors. Nurses' skills in using various abilities are needed to help schizophrenia survivors in overcoming the challenges of schizophrenia recovery. In addition to providing benefits to the schizophrenia survivor recovery process, mentorship can also provide a feeling of inner satisfaction for nurses as mentors.

Nurse mentorship approach to schizophrenic patients is in accordance with the service principle of "patient centered care" in a mental hospital. In summary, nurse mentorship for schizophrenia survivors can be developed in a mental hospital as a clinical care practice as well as a home care service.

The mentorship approach is a new

innovation that has the potential to be developed into an inpatient nursing practice in mental hospital and later integrated in Community Mental Health Nursing (CMHN) to help the recovery process for schizophrenia survivors. The development of mentorship interventions for schizophrenia survivors in the community needs support from policy makers so that nurses can provide patient centered care and ensure continuity of care for schizophrenia survivors.

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# Prone Position Improve Physiological Parameters of Preterm Infants Weaning from CPAP: A Randomized Control Trial

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## Abstract

The need for continuous positive airway pressure (CPAP) was vital for preterm infant with respiratory distress, but the impact of long-term use was very harmful. The effort to do weaning must be done and facilitate the infant to adapt wean off CPAP. The effect of positioning on stabilized physiological parameters may help preterm infant to adapt under gradual weaning from CPAP. Aim in this study to determine the effect of prone positioning on physiological parameters in preterm infants under gradual weaning CPAP. From Mei to September 2020 total sample 60 preterm infants on non-invasive ventilation or CPAP were randomized into prone position (intervention group, n = 30) and supine position (control group, n = 30). Oxygen saturation, respiratory and heart rate between groups were compared. In the prone position was significant higher than supine position at 30th minute. The mean oxygen saturation in the prone position (99.87±0.35) was higher than in the supine position (97.63±1.45; p=0.001), the mean respiratory rate in the prone position (42.10±8.59 breaths/min) was lower than in the supine position (53.20±6.24 breaths/min; p=0.001), and the mean heart rate in the prone position (144.63±13.07/ beats/min) was lower than in the supine position (153.53±10.02/beats/min; p=0.001), so that the prone position can be applied to increase oxygen saturation and to maintain the stability of respiratory rate in preterm infants during gradual weaning. The failure to wean off CPAP (re-CPAP) in the prone group was less frequent which is 3 respondents (5% versus 10%). However, there is no relation between positioning and re-CPAP (p=0.472).

**Keywords:** Preterm infant, prone position, weaning CPAP.

## Introduction

Generally, premature infants have respiratory distress syndrome (RDS). This occurs in newborns less than 28 weeks' gestation and is very rare in full-term babies (Torabian, Alinejad, Bayati, Rafiei, & Khosravi, 2019). RDS was more common in premature babies because the lungs of premature babies were not able to produce sufficient surfactant, making it difficult for the lungs to expand, and requiring more energy to breathe (Montgomery, Choy, Steele, & Hough, 2014). Clinical manifestations that arise from respiratory distress syndrome, namely increased respiratory rate, decreased saturation, cyanosis, and decreased pulmonary sound (Emaliyawati, Fatimah, & Lidya, 2018). Newborns with prematurity, difficulty breathing or respiratory distress must admitted immediately in the neonatal intensive care unit (NICU) (Hendrawati et al., 2017).

Respiratory distress syndrome in preterm infants can be treated with non-invasive ventilator such as continuous positive airway pressure (CPAP) (Ho, Subramaniam, & Davis, 2020). CPAP is widely used in NICU in some major hospitals in Indonesia. Based on the medical record data of the Perinatology Unit of the Department of Pediatrics, Cipto Mangunkusumo Hospital (IKA RSCM), 180 (24%) babies receive CPAP. In addition, the medical record data of Fatmawati Central General Hospital, from January to June 2020, found that 187 babies received intensive care and 54 (28.9%) babies received CPAP therapy. Meanwhile, the number of babies who received intensive care at the Gatot Subroto Army Hospital, from January to June 2020, 66 (18.6%) babies received CPAP therapy.

Currently, the early initial use of continuous positive airway pressure give potential benefits rather than mechanical ventilation (Dunn et al., 2011). This has led practice guidelines and recommendation by the American Academy of Pediatrics (AAP) to utilize CPAP as the primary mode of respiratory support even the most premature infants (Committee on Fetus and Newborn, 2014). There were several adverse side effect in long-term useing CPAP, namely nose damage, delay in oral feeding, prolonged hospitalization, decreased parental ties, and developmental therapy (Lam et al., 2019). The CPAP weaning process must be done when the respiratory stability criteria are met (Abdel-Hady, Shouman, & Nasef, 2015). The criteria for readiness for weaning from nasal CPAP for 24–48 hour before weaning were the pressure at FiO2 of 0.21, normal work of breathing with no persistent tachypnea (60 breaths for >2h), Oxygen saturation >93%, no apnea associated with bradycardia (heart rate <100 beats/minute) (Amatya et al., 2014; Chawla et al., 2017).

The success of wean off CPAP is based on the individual's ability to adapt to spontaneous breathing and maintain adequate gas exchange (Lam et al., 2019). The proper weaning process in premature babies from wean off CPAP in a stable condition was very useful for reducing complications (Maffei, Gorgoglione, & Vento, 2017). The weaning process was too fast reported, it would increase the frequency of apnea, air leakage syndrome, abdominal distension, increasing work of breathing, and oxygen demand which results in babies returning to use mechanical ventilation (Abdel-Hady et al., 2015).

The positioning in premature infants was the basic standard of neonatal nursing. A prior study (Malagoli et al., 2012) found that prone position was associated with decreased inspiratory pressure and increased oxygen saturation compared to the supine position in preterm infants during the weaning process from mechanical ventilation. Few studies about the impacts of positioning preterm infant on their adaptation to spontaneous respiration after weaning from mechanical ventilation (Güler & Çalışır, 2020). Moreover, various studies have pointed to the effects of prone positioning while they under continuous positive airway pressure (CPAP) were oxygen saturation more stable, lower respiration rate, heart rate more stable, also improving ventilation and optimizing gas exchange (Babaei et al., 2019; Ghorbani, Asadollahi, & Valizadeh, 2013). However, the author was not found the study about the effect of body positioning during weaned off CPAP and lack of trial evaluating position to prevent CPAP failure. The critical conditions that need to continue is observed when premature babies under weaning of the CPAP.

The evaluation was related to the impact of body positioning on oxygenation status namely oxygen saturation, heart rate, and respiratory rate. The purpose of this study was to identify the impact of the prone and supine position on oxygen saturation, heart rate, and respiratory rate in preterm infants undergoing the CPAP weaning process.

## Method

This study used a parallel-group study design with a randomized controlled trial (RCT). This study follows the guidelines of the Consolidated Standards of Reporting Trials (CONSORT). The intervention group was the prone position setting intervention group and the control group was the supine position. The sample in this study were all preterm infants with respiratory distress who underwent gradual weaning with a decrease in oxygen fraction <25% (Dargaville et al., 2013). The study was conducted from May to September 2020 in the Neonatal Intensive Care Unit (NICU), Fatmawati Hospital and Gatot Subroto Army Hospital, Jakarta. Block randomization technique using computerized was used. After obtaining consent from infants' parents, the author provide initial randomization results on in envelopes. Then the nurse took the envelope according to the order of the baby, the mother of the premature infant had no knowledge of which treatment was given in the room.

Premature infants receiving care in the NICU were recruited if they met the following criteria: 1) aged <37 weeks based on the Ballard score; 2) diagnosed with RDS and

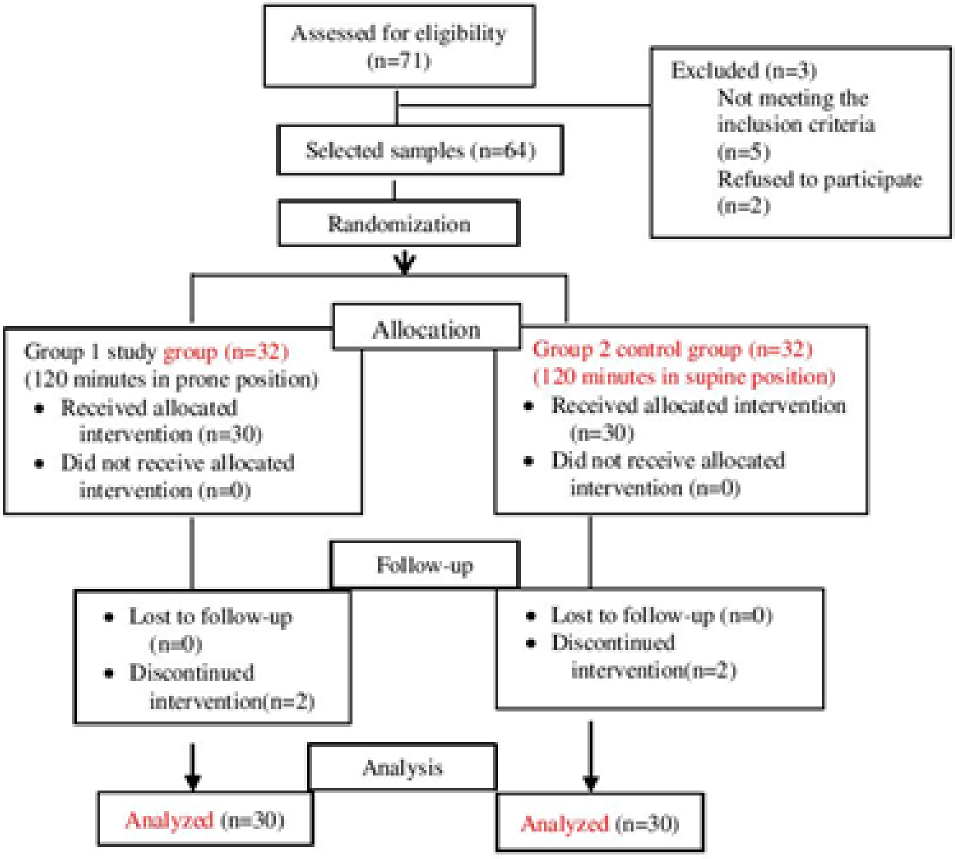


**Figure 1 CONSORT flow diagram of participant recruitment process**

currently on CPAP; 3) currently undergoing CPAP weaning with gradual decreased oxygen fraction automatically (FiO2 <25%); 4) had no contraindication for prone and supine position (e.g., post-abdominal surgery, congenital heart disease). The exclusion criteria included infants who had severe congenital diseases Tetralogy of Fallot (ToF) and diaphragmatic hernia), worsening oxygenation status or hemodynamically unstable, had a history of air leak syndrome and lung collapse, and infants with mottle. Based on the study by Antunes et al. (2003) obtained the proportion of failure incidence in P1 (failure wean in prone position) of 4% and 33% of success in P2 (success wean in supine position), so the number of respondents per group was 30 respondents. The sample size calculation was based on the hypothesis test formula with different proportions of the independent group (Dahlan, 2016).

$Z\alpha=1.96$; $\alpha= 0.05$, $B= 0.20$; $P1= 0.04$; $P2=0.33$; $P1-P2= 0.29$ (effect size); $P =(1/2(P1+P2))$

$$n = \frac{\left\{ z_{1-\alpha/2}\sqrt{2\bar{P}(1-\bar{P})} + z_{1-\beta}\sqrt{P_1(1-P_1)+P_2(1-P_2)} \right\}^2}{\left(P_1-P_2\right)^2}$$

The Health Research Ethics Committee at the National Hospital Cipto Mangunkusumo approved this study with a requirement to obtain written consent from the participants at Rumah Sakit Umum Pusat Fatmawati and Rumah Sakit Pusat Angkatan Darat Gatot Subroto (Reff: 279/UN2.F1/ETIK/PPM.00.02/2020).

Intervention

Each infant have different time for readiness weaning from CPAP. The study process takes place from 08.00 a.m.- 04.00 p.m. For each study group, the intervention was conducted twice a day one infant in control group and one infant in study group which lasted for 150 minute. The authors have previously shared the aim and explained the procedures of the study to the NICU nurses who cared for the infants recruited for the study. The procedures of the study were based on a previous study by Babaei, Mohammadi, and Soleimani (2019), the authors made observations every 15 minute for 120 minute. Due to the possibility of the instability of the physiological conditions, in the first 15 minutes of placing the infant in any of the two positions, no data was recorded; then, after the infant was in constant conditions, every 15 minutes, heart rate, SpO2, and respiratory rate were recorded.

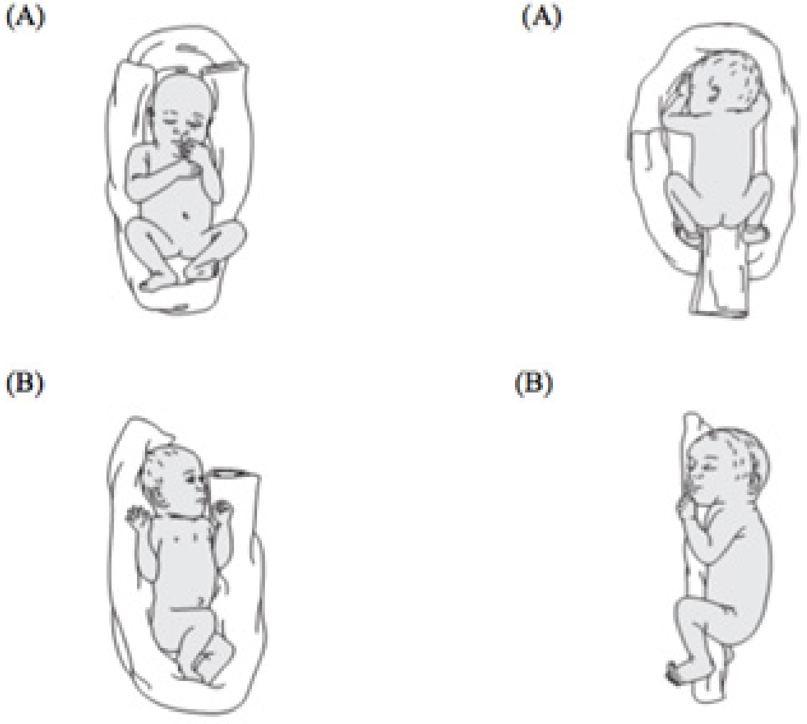
a. Prone position

The infant in study group were turned to a prone position for 120 minute, and level of heart rate, respiratory rate, oxygen saturation were recorded every 15 minute. The intervention procedure followed a protocol developed based on Efendi, Sari, Riyantini, Anggur, and Lestari (2019) which was follows: a) The author prepared a tool, a swaddling cloth to support the baby's body when giving position, b) Preparing assessment and observation sheets, and ensuring the readiness of the monitor to function properly, c) Ensuring that the positioning was done after 60 minutes feeding competed d) Nurses washed their hands according to WHO guidelines, e) Nurses provide prone positions with several stages, namely: 1) Maintaining the baby's head in the midline or midline position and not turning to one side, and providing soft pads on the baby's neck to support the head, 2 ) Give the head a slightly flexed position with the chin close to the chest, 3) Give the baby a soft cloth until the shoulders are slightly flexed towards the chest, 4) The position of the baby's hands is abducted so that the ends of the hands are near the baby's mouth, 5) Then give the position of the hips and knees flexion, 6) The baby's knees are in the midline of body growth and the position of the knees is not wide open, 7) Provide a nest position to be able to support the legs in a flexed and crossed position, 8) tighten the nest on the outermost part of the baby's body so that it looks like the baby is confined in a cage and attaches the fixation to the nesting see Fig 2.

b. Supine position

The infant in control group were placed to a supine position for 120 minute, and level of heart rate, respiratory rate, oxygen saturation were recorded every 15 minute. Whereas the supine position is given through several stages, namely: 1) Maintaining the baby's head in the midline or midline position and not turning to one side, and providing soft pads on the baby's neck to support the head, 2) Providing a slightly flexed head position with the chin close to the chest, 3) Give a soft cloth to the baby until the shoulders are slightly flexed towards the chest, 4) The position of the baby's hands is abducted so that the ends of the hands are near the baby's mouth, 5) Then give the position of the hips and knees flexed, 6) The baby's knees are in the middle line of growth body and knee positions are not wide open, 7) Provide a nest position to support the legs to form a flexed and crossed position, 8) Tighten the nest on the outer part of the baby's body so that it looks like the baby is confined in a cage and attaches the fixation to nesting see Fig. 2.

The measurements in this study were parameters of oxygenation status were namely oxygen saturation, respiratory rate, and heart rate. As references, normal values of vital signs for preterm infants are follows: heart rate of 121 – 179 beats per minute; respiratory rate of 21 – 59 breaths per minute; and oxygen saturation (SpO2) of ≥93% (Baker, 2015). The data collection tools used were the observation sheet to obtain primary data directly from the respondent's parents and medical records. Measurement of oxygenation status using a cardiorespiratory



Supine position A and B

Prone position A and B

**Figure 2 The illustration of giving body position for preterrm infants (Source: Boxwel (2010): Neonatal Intensive Care Nursing. 2nd Edition)**

monitor, pulse oximetry to assess oxygen saturation that has been calibrated at the hospital's electromedical technician, and to support the positioning of the baby's body using a soft swaddle.

Data collection

The measurement is divided into 3 parts, namely; 1) baseline data for 10 seconds, the author recorded the oxygenation status before giving the position (T0); 2) the resting phase, namely the author and NICU nurses provides a prone/supine body position for 15 minutes to prevent the effects of previous activities or positioning; 3) the intervention phase of the baby in the prone/supine position for 120 minutes (T1-T7), see Fig.1 (Babaei, Mohammadi, & Soleimani, 2019).

Infants who experienced an increase in respiratory rate of >75 times/minute, desaturation of <88%, and bradycardia (<100 beats/min)for less than 6 hours were considered CPAP failure, and thus, needed to be back on CPAP (re-CPAP) (Wright, Sherlock, Sahni, & Polin, 2018).

Demographics and clinical history were collected from the patient's medical records, including the use of surfactants, antenatal steroids, intrauterine growth restriction (IUGR), patent ductus arteriosus (PDA), bronchopulmonary dysplasia (BPD), and gastroesophageal reflux. The duration of use of CPAP has been recorded from the time the infant received various forms of the noninvasive ventilator (Bubble Continuous Positive Airway Pressure (BCPAP) or non invasive ventilator (NIV).

Data analysis

Normality test on data oxygen saturation, respiratory rate, and heart rate at start intervention 30 minutes (T1) and end of intervention at 120 minutes (T7) with the Shapiro Wilk test. While the homogeneity test on demographic data used the Independent T-test. Bivariate analysis between physiological parameter and body position was applied by used the Independent t-test. In addition, the corellation between re-CPAP and body position were used Chi-square (α=0.05).

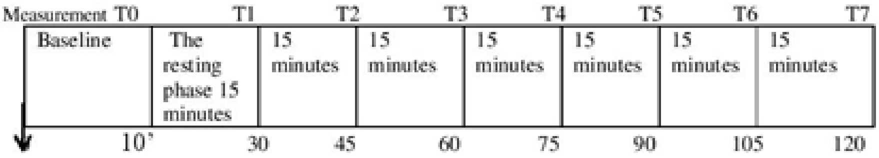


**Figure 3 The sequence of study procedure**

## Results

### Subjects' Demography

The characteristics of the infants who participated in this study were the mean gestational age of premature babies in the prone position with RDS 32.87 weeks, while the mean age of correction was 33.90 weeks. The average length of time using CPAP in the prone position was faster than the supine position, which was 6.3 days. Based on the results of the homogeneity test, it can be seen that there is no difference in the characteristics of the intervention group and the control group (p value> 0.05) (Table 1). The proportion of males was 66.7%, and preterm infants who failed weaning were 9 respondents (15%) (Table 1). However, the bivariate analysis were used chi-square results between body position against reCPAP were not significant. See table 2. Based on table 3 preterm infants who failed to wean off CPAP, the mean age of gestation was 30 weeks, birth weight was 1440 grams, and the duration of using CPAP was 12.3 days. Based on table 4, the preterm infants who failed to wean off CPAP (reCPAP) did not get antenatal steroids 8 infants, not getting surfactant 7 infants, and experiencing sepsis/NEC 7 infants.

Oxygen saturation

The intervention was conducted in 120

minute, from the baseline (T0) until end of intervention (T7) the mean of oxygen saturation of prone position more higher than supine position (see table 5). Independent T-test showed that there was a difference in the percentage oxygen saturation between the prone and supine groups at 30 minutes (T1) and 120 minutes (T7). At 30 minutes (T1), the mean percentage oxygen saturation was significantly higher in infants with prone position (99.87 ± 0.35) compared with that in infants with supine position (97.63 ± 1.45; p = 0.001). Similarly, the mean percentage oxygen saturation was also higher in infants with prone position compared with that in infants with supine position at 120 minutes (100 ± 0.00 vs 97 ± 0.87; p = 0.001), see table 5.

### Respiration rates

The mean of preterm infant's respiration rate in the prone group was lower than in the supine group, and more stable at T5 (see table 5). Further analysis with the Independent

**Table 1 Demographic Characteristics of Preterm Infants May – September 2020 (n=60)**

| Characteristic | Prone | | | | Supine | | | | P |
|---|---|---|---|---|---|---|---|---|---|
| | (n,%) | Mean | SD | Min-Max | (n,%) | Mean | SD | Min-Max | |
| Gestational age (week)* | | 32.87 | 2.57 | 28-36 | | 32.07 | 3.34 | 26-36 | 0.303 |
| Correctional age (week)* | | 33.90 | 2.52 | 29-38 | | 32.43 | 3.42 | 26-36 | 0.064 |
| Actual body weight (gram)* | | 1873 | 439.05 | 1165-2670 | | 1657.33 | 566.27 | 800-3200 | 0.309 |
| Prolong of using CPAP (day)* | | 6.30 | 2.63 | 2-14 | | 9.33 | 3.42 | 3-15 | 0.062 |
| Sex** | | | | | | | | | |
| Male | 21 (52.5) | | | | 19 (47.5) | | | | 0.784 |
| Female | 9 (45) | | | | 11(55) | | | | |
| Antenatal steroids** | 9(15) | | | | 11(18.3) | | | | 0.791 |
| Surfactant** | 2(3.3) | | | | 3(5) | | | | 0.647 |
| Sepsis/NEC** | 9(15) | | | | 11(18.3) | | | | 0.584 |
| PDA** | 13(21.7) | | | | 16(26.5) | | | | 0.438 |
| IUGR** | 9(15) | | | | 15(25) | | | | 0.114 |
| Re-CPAP** | | | | | | | | | |
| Yes | 3 (5) | | | | 6 (10) | | | | |
| No | 27 (45) | | | | 24 (40) | | | | |

*Independent t-test,
**Chi-square; Abbreviations: NEC: enterocolitis necroticans,
**PDA: patent ductus arteriosus, IUGR: intrauterine growth restriction.

**Table 2 The Relation Between Recpap with Prone and Supine Position (N=60)**

| Intervention groups | reCPAP |  |  |  |  |  | Correlation | p-value* |
|---|---|---|---|---|---|---|---|---|
|  | no |  | yes |  | Total |  |  |  |
|  | n | % | n | % | n | % |  |  |
| Prone | 27 | 90 | 3 | 10 | 30 | 100 | 0.140 | 0.472 |
| Supine | 24 | 80 | 6 | 20 | 30 | 100 |  |  |
| Total | 51 | 85 | 9 | 15 | 60 | 100 |  |  |

*Chi square

**Table 3 Demographic Characteristics of The Preterm Infant with Recpap (Gestational Age, Birth Weight, Duration of Using Cpap) (N= 9)**

| Characteristic | Mean | Min-Max |
|---|---|---|
| Gestational age (weeks) | 30 | 27–32 |
| Birth weight (grams) | 1440.3 | 800–2100 |
| Duration of using CPAP (days) | 12.3 | 7–15 |

**Table 4 Demographic Characteristics of The Preterm Infant with Recpap (Antenatal Steroids, Surfactant, Sepsis/Nec, Pda, Iugr) (N= 9)**

| Characteristic | Yes | No |
|---|---|---|
| Antenatal steroids | 1 | 8 |
| Surfactant | 2 | 7 |
| Sepsis/NEC | 7 | 2 |
| PDA | 3 | 6 |
| IUGR | 4 | 5 |

**Table 5 The Mean of Oxygen Saturation, Respiration Rate and Heart Rate In Prone and Supine Position During Intervention**

| Category | Time | Prone |  | Supine |  |
|---|---|---|---|---|---|
|  |  | mean | SD | mean | SD |
| Oxygen Saturation | T0 | 97.87 | 1.19 | 97.00 | 1.43 |
|  | T1 | 99.87 | 0.35 | 97.63 | 1.45 |
|  | T2 | 99.23 | 1.00 | 97.50 | 1.50 |
|  | T3 | 99.60 | 0.62 | 97.47 | 1.50 |

| Category | Time | Prone | | Supine | |
|---|---|---|---|---|---|
| | | mean | SD | mean | SD |
| Oxygen Saturation | T4 | 99.97 | 0.18 | 97.13 | 1.38 |
| | T5 | 100 | 0 | 97.23 | 1.50 |
| | T6 | 100 | 0 | 97.13 | 1.22 |
| | T7 | 100 | 0 | 97.00 | 0.87 |
| Respiration Rate | T0 | 49.03 | 6.32 | 53.30 | 7.16 |
| | T1 | 42.10 | 8.59 | 53.20 | 6.24 |
| | T2 | 41.73 | 5.06 | 52.53 | 7.50 |
| | T3 | 38.57 | 6.17 | 54.17 | 7.00 |
| | T4 | 37.83 | 5.66 | 52.70 | 6.96 |
| | T5 | 36.27 | 5.77 | 53.63 | 6.87 |
| | T6 | 36.13 | 4.66 | 54.47 | 6.65 |
| | T7 | 34.37 | 4.66 | 56.47 | 4.49 |
| Heart Rate | T0 | 155.83 | 7.28 | 154.80 | 9.03 |
| | T1 | 144.63 | 13.07 | 153.53 | 10.02 |
| | T2 | 143.30 | 10.36 | 153.40 | 8.73 |
| | T3 | 141.57 | 8.06 | 153.77 | 8.46 |
| | T4 | 138.93 | 6.51 | 153.90 | 7.84 |
| | T5 | 138.57 | 6.71 | 153.00 | 8.69 |
| | T6 | 137.07 | 5.61 | 155.53 | 8.38 |
| | T7 | 135.73 | 4.14 | 158.30 | 8.50 |

**Table 6 Differences In Oxygen Saturation, Respiratory Rate, and Heart Rate Between Two Groups (N=6)**

| Physiological Parameters | Intervention groups | | T Independent | |
|---|---|---|---|---|
| | Prone | Supine | T value | P-value |
| Oxygen saturation | | | | |
| Baseline 0 minute (T0) | 97.87 + 1.19 | 97.00 + 1.43 | 2.488 | 0.628 |
| 30 minutes (T1) | 99.87 + 0.35 | 97.63 + 1.45 | 8.206 | 0.001 |
| 120 minutes (T7) | 100 + 0.00 | 97 + 0.87 | 18.866 | 0.001 |

| **Physiological Parameters** | **Intervention groups** | | **T Independent** | |
|---|---|---|---|---|
| | **Prone** | **Supine** | **T value** | **P-value** |
| Respiratory rate | | | | |
| Baseline 0 menit (T0) | 49.03 + 6.32 | 53.30 + 7.16 | 2.538 | 0.318 |
| 30 minutes (T1) | 42.10 + 8.59 | 53.20 + 6.24 | 5.726 | 0.001 |
| 120 minutes (T7) | 34.37 + 4.66 | 56.47 + 4.49 | 18.705 | 0.001 |
| Heart rate | | | | |
| Baseline 0 menit (T0) | 155.83 + 7.28 | 154,80 + 9.03 | 2.446 | 0.471 |
| 30 minutes (T1) | 144.63 + 13.07 | 153,53 + 10.02 | 2.959 | 0.004 |
| 120 minutes (T7) | 135.73 + 4.13 | 158,30 + 8.50 | 13.074 | 0.001 |

α=0.05

T-test showed that the respiratory rate of the groups in the prone and supine positions at 30 minutes (T1) and at 120 minutes (T7) obtained p-value = 0.001 <α (0.05), it can be explained that there was a difference. significantly the respiratory rate at 30 minutes (T1) and 120 minutes (T7) between the prone and supine position groups (see table 5).

Heart rates

The mean of heart rate in the prone group was lower than that in the supine group (see table 5). The results of further analysis with the Independent T-test showed that the heart rate of the group prone and supine positions at 30 minutes (T1) obtained p-value = 0.004 <α (0.05) and at 120 minutes (T7) obtained p-value = 0.001 <α (0.05) it can be explained that there was a significant difference in heart rate at 30 minutes (T1) and 120 minutes (T7) between the prone and supine position groups (see table 5).

## Discussion

The results showed that changes in oxygenation status were seen in the first 30 minutes. The change in oxygenation status started from 30 minutes and stable at 120 minutes (100%), post-administration and the mean oxygen saturation at the prone position tended to be stable and save while compared to the supine position. Abdeyazdan, Nematollahi, Ghazavi, and Mohhamadizadeh (2010) stated preterm infant with undergoing from mechanical ventilation the change in oxygen saturation was significant after the first 15 minutes to 120 minutes after administration (p = 0.01). The main results of this study indicated that there was a significant difference between the position of the prone and supine bodies on oxygen saturation, respiratory rate, and heart rate (p = 0.001) (Table 5).

The prone position has a positive impact on oxygen saturation, namely reaching the normal range (>93%-100%) after 90 minutes post positioning. The results showed that there was a significant difference after giving the prone position for 120 minutes undergoing CPAP weaning (p = 0.001). In the study by Babaei et al. (2019) giving the prone position for 180 minutes to 62 infants with NCPAP, the mean oxygen saturation in the prone position was higher and stable than the supine position (p = <0.001). This is because the prone position provides better synchronization between the thorax and abdomen, resulting in increased tidal volume and a better oxygen saturation impact (Malagoli et al., 2012).

During the observation of 120 minutes, the mean heart rate was stable at T4 and T5, namely 75-90 minutes after giving the position. Ghorbani, Asadollahi, and Valizadeh (2013) identified that giving the prone and supine positions to 2 groups for 120 minutes in preterm infants with NCPAP-attached respiratory distress showed a change in heart rate in the first group of prone positions, namely 135 ± 15.04 beats per minute and the supine group 144.27 ± 130.9 beats per minute (p = 0.002). In the supine position, the heart rate during observation tended to be tachycardia with the average heart rate in 120 minutes, namely 158.30 + 8.50. The results of a study by Hough et al. (2016) involving 60 preterm infants identified the impact of giving a prone position in premature infants with CPAP, there was an increase in lung muscle in the first 2 hours (0.02) and stable for the first 4 hours (p = 0.03), the heart rate was more stable in the prone position. This could be due to the prone position providing better synchronization between the thorax and abdomen, thus making the diaphragm muscle shorten better (Malagoli et al., 2012). Good coordination between the thorax and abdomen helps premature babies to adapt better in improving the muscle for breathing.

The results of the observation of the respiratory rate showed that the prone position group experienced changes in the normal range for each time change (p = 0.001). This is supported by the study of Ghorbani et al. (2013) who stated that there was a change in the mean respiratory rate in preterm infants with respiratory distress attached to NCPAP during the 120-minute prone position, where the tachypnea was initially more stable (p = 0.002). In line with the study of Babaei et al. (2019) giving the prone position for 180 minutes to 62 infants with NCPAP, the mean respiratory rate was better at 55.61 ± 6.4 (p = <0.001).

The weaning success of CPAP at the prone position compared to the supine position is not significant. Respondents who experienced re-CPAP in the supine group were 6 respondents. The results of the further analysis showed no relationship between assignment and reCPAP. The author has not found any literature on assigning a position to prevent reCPAP. However, giving prone body position from several study results can provide a positive impact for premature babies with respiratory distress, namely better stability of oxygen saturation, respiratory rate, and heart rate.

Several factors that influence the success of weaning CPAP are gestational age, age of correction, and birth weight (Abdel-Hady et al., 2015). Meanwhile, factors that can delay the wean off CPAP are maternal chorioamnionitis, anemia, infants experiencing gastroesophageal reflux which can prolong the duration of CPAP used (Rastogi et al., 2012). In this study, infants who experienced reCPAP were 27–32 weeks' gestation, birth weight. 800-2100 grams and experiencing sepsis / NEC. Preterm infants experienced failed to wean off CPAP with the length of CPAP used were 7–15 days. According to a study by Rastogi et al. (2012), birth weight, chorioamnionitis, anemia, and GER played a significant role in weaned off CPAP and the length of CPAP use. Wright, Sherlock, Sahni, and Polin, (2018) babies with a gestation age of 25–28 weeks tend to fail to wean off CPAP (45%), among them have low birth weight and born with cesarean section. So that action was needed to prevent dependence on a long breathing device and the occurrence of bronchopulmonary dysplasia (BPD). Dargaville et al. (2013) stated that antenatal use of corticosteroids in mothers who are threatened with giving birth at 24–33 weeks' gestation can reduce re-CPAP (> 90%).

Limitation

The limitation of the study was the author did not investigate any differences in the use of the CPAP setting in the two hospitals, namely the use of BCPAP and CPAP that use ventilator mode (NIV). Furthermore, the study should use the position of quarter prone or semi-prone. Addittion, the author was not compare the demographics with physiological parameters between 2 groups that might be effect of weaning process.

## Conclusion

Oxygen saturation in infants in prone position tends to be more stable than infants in the supine position. The respiratory rate and heart rate were also more stable in the prone than in the supine position group. There were significant differences in oxygen saturation, respiratory rate, and heart rate at 30 minutes (T1) and 120 minutes (T7) between the prone and supine position groups. Infants from the supine group had more reCPAP were 6 infants. There is no relationship between assignment and reCPAP. Positioning is a strategy for treating premature infants and has a positive impact on both neuromotor, musculoskeletal and physiological functions. So that the nurse can give positioning especially prone position saved about 120 minute. In addition, It is very important to created stability of the infant's oxygenation status during the CPAP weaning process. Nurses can better apply and documented monitor the positioning of preterm infants undergoing the CPAP weaning process.

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