

Comparison of Central Venous Pressure (Cvp) Score Among Patients on Mechanical Ventilator With Head of Bed (Hob) Elevation 30O; Neutral, Right, and Left Side Positions

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Abstract

Early mobilization is important for critical patients to improve cough reflex, relieve bronchial secretions, facilitate the work of mucociliary drainage muscles, and to prevent ventilator-associated pneumonia and pressure sores. However, at the same time patients often experience changes in vital signs due to fluctuating conditions. Central Venous Pressure (CVP) measurement is often necessary to monitor the central circulatory system. Unfortunately, in a clinical setting, the patient's position must be changed first to a 30o neutral head of bed (HoB) position rather than the left or right side HoB position. This study aims to determine differences in CVP scores among patients in mechanical ventilation at 30o HoB position elevation in a neutral, right, and left. This quantitative comparative study involved 24 subjects who were recruited sequentially. Data were analyzed using ANOVA. The results showed that the mean CVP value at the elevation of the neutral HoB position elevation was 13.5 ± 3.96 , the HoB elevation on the right side was 12.8 ± 4.16 , and the HoB elevation on the left side was 14.4 ± 4.17 . There is a significant difference ($p < 0.05$) among the three positions. The post hoc analysis test found that the HoB 30o neutral position vs the left side position was higher and significantly different from the HoB 30o elevation in the neutral vs right side position ($p < 0.05$). This study suggests that nurses need to consider changes in CVP values while changing the position of the patients with a HoB elevation of 30o in a neutral position, right side, and left side. Although statistically there is a difference among the three positions, in fact the difference in value is less than 1 cmH₂O which is not clinically evident.

Keywords: Central venous pressure, HoB elevation, Mechanical ventilation

Introduction

Intensive care is one of the nursing services for patients with acute or chronic illnesses in emergency situations, critical who require monitoring of vital functions, more specifically intensive therapy and immediate action that cannot be given in the general care room (Linda, Kathleen & Mary, 2010). Hemodynamic disorders are one reason patients need intensive care unit (ICU). One of the hemodynamic assessments that are often carried out in the ICU is the measurement of right atrial pressure or central venous pressure/ CVP.

Right atrial pressure data helps support the diagnosis, knows the patient's condition and provides appropriate therapy. The current CVP is an indicator that is still reliable in terms of estimating the intravascular volume adequacy (Izzakovic, 2008). The CVP measurement results in interpreting the pressure of the right atrium which shows blood volume status, heart effectiveness as a pump, and vascular tone which indirectly describes the initial right heart load or right ventricular pressure at the end of the diastole from the venous return. CVP measurement is carried out if the patient has hypotension that does not respond to basic clinical management, ongoing hypovolemia and / or the patient needs an inotropic infusion that can be measured at any time or incidentally (Cole, 2007; Scales & Fernandes, 2010). Normal CVP values using a manometer system are 5–10 cmH₂O (Cole, 2007).

The recommended position for CVP measurement is the position of head of bed (HoB) elevation 30°. At the HoB elevation 30° position, the blood flow pressure gradient from the inferior vena cava leading to the right atrium is able to deal with vascular resistance and right atrial pressure, thereby increasing venous return and increasing right ventricular filling (preload), leading to increased stroke volume and cardiac output. The gravitational force of the patient's position significantly affects venous return, cardiac output, and venous pressure (Kim & Sohng, 2006). However, changes in right or left side position in critical patients with mechanical ventilation are important as early mobilization to prevent secondary complications such as nosocomial

pneumonia infections, thrombophlebitis, muscle atrophy, accumulation of respiratory tract secretions, reducing pain on the paralyzed side, facilitating circulation blood, contractures, joint stiffness and pressure sores (Yemima, 2007)

Positioning side to side can prevent pressure sores is also very effective in increasing the process of removing bronchial secretions on the basis of gravitational effects. This stimulates the secretion to move from one or more lung segments to the airway where the secretions can come out by mouth by coughing reflex or by mechanical aspiration and can increase the strength of the diaphragmatic breathing muscles so that breathing can be adequate and the process of weaning off the ventilator can be faster and the risk of pneumonia can be minimized (Kathleen, 2010).

However, changes in position can cause some negative potential effect for critical patients. When the patient is in the right side position, the return of blood from the inferior part through the inferior vena cava (IVC) experiences kinking because the close IVC to the right facilitates suppression by the kidney, and anatomically located the heart in the left hemithorax, when tilted to the right, the left side of the heart slightly pushes to the right which causes a decrease in the diameter of the right atrial space, so that the blood volume / venous return decreases resulting in a greater decrease in blood pressure compared to the lateral left position (Hazebroek & Bonjer, 2011) This has the potential to affect the value of the CVP.

Apart from the above, the change in position is not too much a concern for nurses in treating CVC-installed patients and mechanical ventilation to evaluate the difference in CVP values. Observations of researchers during intensive clinical learning, all critically ill patients with hemodynamics were stable either installed with mechanical ventilation and CVC or not, in their care they were transferred to the position every 2 hours as a form of early mobilization. During the transfer of position, patients often experience changes or decrease in vital signs because of their fluctuating conditions and immediate monitoring of CVP values to monitor intravascular volume adequacy, so

that the fluid challenge test in determining the appropriate action is aggressive and rapid resuscitation or requires additional drugs. However, so far the patient's position to obtain a CVP value must be changed first in a neutral HoB elevation position 30o. This allows that the measurement of CVP values must be immediately carried out by health workers, especially nurses at that time without having to change their position first so that the CVP value can be known and analyzed to determine the action or therapy more quickly and precisely so that the impact of changes and vital signs and deterioration of the patient's condition can be minimized and even prevented.

Quick, short and sudden changes in position can increase oxygen consumption, cause changes in the hemodynamic status of patients who are unstable and time-consuming and health workers in treating critical patients, especially patients with myocardial infarction who are given supination, pronation, right lateral, and left lateral positions (Siepe, et. al. 2005). According to Kozier & Erb, (2009), a change in position that is too fast causes a decrease in venous return, a decrease in the mean arterial pressure (MAP) and central venous pressure which results in a decrease in cardiac output. The purpose of this study was to examine the differences of CVP scores among patients with HoB elevation 30o in a neutral, right side, and left side position.

Table 1 Characteristics of the Subjects (n= 24)

	Characteristics	Frequency (f)	Percentage (%)
Age (years)	18-40	10	41.7
	41-60	11	45.8
	> 60	3	12.5
Gender	Male	13	54.2
	Female	11	45.8
Disease group	Internal disease	3	12.5
	Digestive Surgery	5	20.8
	Neurosurgery	3	12.5
	Neurology	5	20.8
	Obstetrics	5	20.8
	Cardiology	2	8.3
	Surgical Oncology	1	4.2

Method

This is a quantitative comparative study. The population of the study was all patients admitted in the General Intensive Care Unit (GICU) in a teaching hospital of West Java Province. Twenty-four patients were recruited consecutively with the inclusion criteria; having stable hemodynamic conditions and their aged between 18 to 65 years. Ethical approval was obtained from the Health Research Ethic Committee Faculty of Medicine Universitas Padjadjaran with the number 194/UN6.C1.3.2/KEPK/PN/2015. The researcher measured the CVP values, then validated by a senior nurse who incharge in the shift time as data taken. CVP measurements were started at the neutral HoB elevation 30o position for ten minutes, then continued at the right and left side positions. CVP was measured using a manometer and recorded on the measurement sheet. Data were checked for normally by using Shapiro Wilk test. Data were normally distributed (p = 0.785). Anova test was performed to examine the differences among three data means.

Result

The characteristics of the subjects included age, gender, and disease group were presented in the table 1 below.

Based on the mechanical ventilation mode used, almost half of the subjects used either CPAP or SIMV mode. More than half of the subjects used PEEP of 5 CmH2O. All subjects' heart rate within a normal range of 60-100 times / minute. Half of the subjects had MAP between 70-90 mmHg as presented in the table 2.

The subjects' CVP value measured in the position of a neutral HoB elevation 30o, right side, and left side HoB 30o positions. Most of the subjects showed their CVP values > 10 CmH2O in all three positions (Table 3).

Mean score of CVP values at HoB elevation 30o left side position was consider a the highest (14.4 ± 4.17) compare to the HoB

Table 2 Mode of Mechanical Ventilation, PEEP, and Hemodynamic Status of the Subjects (n= 24)

Use of Mechanical Ventilation		Frequency	(%)
Mode Ventilator	VC	1	4.2
	SIMV	10	41.7
	CPAP	11	45.8
	PS	2	8.3
PEEP (cmH2O)	5	15	62.5
	6-10	9	37.5
	11-15	0	0
Hemodynamic Status			
Heart Rate	< 60	0	0
	60-100	24	100
	> 100	0	0
Sistolik	< 100	0	0
	100-140	21	87.5
	> 140	3	12.5
Diastolik	< 70	11	45.8
	70-90	13	54.2
	90-110	0	0
MAP	< 70	2	8.3
	70-90	13	54.2
	> 90	9	37.5

Table 3 CVP Values at 30o Head of Bed (HoB) Elevation Neutral, Right Side, and Left Side Positions (n=24)

Measurement Position	CVP Value (CmH2O)						Σ
	< 5		5-10		> 10		f
	f	%	f	%	f	%	%
HoB elevation 30° neutral	0	0	6	25	18	75	24(100)
HoB elevation 30° right side position	0	0	9	37.5	15	62.5	24(100)
HoB elevation 30° left side position	0	0	3	12.5	21	87.5	24(100)

Table 4 Mean Score of CVP Values among Head of Bed (HoB) Elevation 30° Neutral Right, and Left Side Positions

Measurement Position	Mean ± SD (CmH2O)	p
HoB elevation 30° neutral	13.5 ± 3.96	0.000
HoB elevation 30° right side	12.8 ± 4.16	
HoB elevation 30° left side	14.4 ± 4.17	

Table 5 Post Hoc Paired Wise Comparisons CVP Value between Head of Bed (HoB) Elevation 30° Neutral vs Right Positions and Neutral vs Left Side Positions

Measurement Position	CVP Value	
	Mean difference (cmH2O); IK 95%	p
HoB elevation 30°: Neutral vs Right Side	0.69 (0.248-1.127)	0.004
HoB elevation 30°: Neutral vs Left Side	0.85 (0.374-1.334)	

elevation 30° neutral and right side positions. ANOVA test showed there was significant difference among means score of HoB elevation 30° neutral, right side, and left side position ($p < 0.05$) (Table 4). A post hoc analysis of Paired Wise Comparisons was carried out to compare two mean difference, and the results showed there was significant difference between CVP values at positions of HoB elevation 30° (neutral vs right side) and HoB elevation 30° (neutral vs left side) ($p < 0.05$) (Table 5).

Discussion

The condition of critical patients in intensive care requires strict and accurate hemodynamic monitoring, such as the rise and fall of blood pressure that can change at any time which greatly affects or causes the shutdown of the functions of other body organs, and even patients who are treated intensively in a short time can be experiencing multiorgan dysfunction syndrome (MODS). The most common cause of MODS is a decrease in perfusion (Marik & Cavallazzi, 2013). Decreased perfusion is caused by a decrease in hemodynamics, one of which can be caused by a decrease in CVP values (Mulyati, Fatimah & Susilaningih, 2012). CVP values can be decreased, one of which is caused by a hypovolemic fluid status disorder.

In table 3, it can be seen that the CVP value of the HoB elevation 30° position is neutral or before a change in position is mostly above the value of 10 cmH2O. The value of CVP

in critically ill patients tends to increase, this is one form of therapy in meeting the fluid needs of critical patients with the aim of maintaining intravascular fluid in preventing the occurrence of hypovolemia, shock and tissue hypoperfusion and worsening tissue damage (Marik & Cavallazzi, 2013). Patients with certain conditions to meet and maintain positive airway pressure need high PEEP and in this study, there were 9 respondents with the use of a 6-10 mmHg PEEP setting. CVP values measured in the HoB elevation 30° neutral position tend to increase can also be caused by the use of PEEP between 6-10 mmHg, because an increase in PEEP significantly increases CVP values (Cao, Liu & Chen, 2008; Mulyati, Fatimah & Susilaningih, 2012). Furthermore, Mulyati, et al., (2012) found that the mean difference in CVP value of PEEP 5 cmH2O to 10 cmH2O PEEP was 2 mmHg.

Theoretically, at the HoB elevation position 30° the return flow of blood from the inferior part to the right atrium is very good. This is because vascular resistance and right atrial pressure are not too high, so venous return to the right atrium is quite good and right ventricular filling pressure (preload) increases, which ultimately increases stroke volume and cardiac output (Kim & Sohng, 2006) Changes in the position of neutral HoB elevation 30° laterally or tilted affect the backflow of blood leading to the heart. Cicolini et al. (2010) stated that the head up or HoB position had an effect on changes in blood pressure and central venous pressure. Different positions affect hemodynamics

including the venous system.

Changing the angled position to the right can result in changes in the shape of the chest, abdomen and decreased intrathoracic pressure which can reduce venous return, cardiac output, and MAP. In this study there was a decrease in CVP value when the HoB elevation 30o position was tilted right. In the study of Lan et al. (2010) and Thomas et al. (2007), the hemodynamic effect is more common in the lateral position than the supine position as a result of decreased venous return because the inferior vena cava is bent. The position of the inferior vena cava adjacent to the right side facilitates suppression by the kidneys. Decreasing almost 10% of the volume at the end of the right ventricular diastolic at right lateral position, the condition is associated with a decrease in the amount of blood volume leading to the atrium even though the cardiac index tends not to change.

According to Lorenzo et al. (2012), the size of the inferior vena cava (IVC) is closely related to the results of the CVP assessment. The study states that measuring IVC diameter through ultrasonography can be used as determination of CVP values in indicating fluid volume status (Citilcioglu, 2014; Wiwatworapan, Ratanajaratroj & Sookananchai, 2012). In the right side HoB 30o position, IVC has kinking because the close IVC to the right facilitates suppression by the kidneys, and anatomically the location of the heart in the left hemithorax, when tilted to the right, the left side of the heart pushes to the right which causes the diameter of the right atrial space decreased, so that the volume of blood / venous return has decreased so that the impact on the decrease in blood pressure is greater when compared with the left lateral position (Hazebroek & Bonjer, 2011). The results of a study conducted by Yoon et al (2006) that the CVP value at right-angled position shows a lower result than the head up or supine position and it is recommended that the level of the transducer should be placed higher. According to Daihua et al., (2012) there is significant influence between changes in position on stroke volume in septic patients with mechanical ventilation. Furthermore, it was stated that head up 30o increases stroke volume and MAP, at right side HoB 30o position, MAP results are $81 \pm$

12.3 while HoB 30o is left side 83.8 ± 11.6 . Stroke volume is often used to predict fluid responsiveness based on the results of CVP assessment, so that in this case stroke volume is indirectly the result of a CVP value (Marik & Cavallazzi, 2013).

Based on this explanation, the results of this study corroborate the statement of research that has been carried out by Daihua et al., (2012) and Marik & Cavallazzi, (2013). right side due to an increase in the diastolic end diameter of the right ventricle and the right atrium in the left position, allowing the high return to the right atrium (Sen, Aydin & Discigil, 2007; Aries et al., 2011). Evaluation of inferior vena cava from echocardiography in subcostal display showed that the IVC diameter decreased which was observed at the end of inspiration when intrathoracic pressure was negative and caused an increase in the ventricular right (RV) in filling from systemic veins. IVC size was significantly affected by the position of the patient, the smallest in the right lateral position, the middle in the supine position, and the largest in the left lateral position which correlated with the right atrial pressure (Ginghina et al. 2009).

Referring to a study conducted by Maas, Grerts & Jansen (2011), this study found the same finding trend. Gravitational changes due to changes in position affect numerous cardiovascular (CV) and neurohumoral adjustments of gradient friction calculations on MAP and CVP values, where changes in position towards the left lateral increase in the diameter of the inferior vena cava which results in increased right atrial pressure of 1 mmHg and finally increase CVP. Changes in the left side position have an impact on increasing preload as a result of accumulated blood volume (300-800 ml) in the upper arm and backflow from the lower vein which is then detected by atrial baroreceptors activity and stimulates the sympathetic system and heart rate and contractility which can increase preload and cardiac output which correlates with right atrial pressure. This mechanism ends with an increase in CVP. However, this does not benefit patients with heart failure or after infarction without bradycardia because the heart has decreased function (Maas, Grerts & Jansen, 2011).

Based on statistical value using anova test and the post-hoc paired wise comparisons test, there were significant differences in CVP values in patients with mechanical ventilation between the position of HoB elevation 30o in a neutral position, right side and left side. The average CVP difference is 0.69 and 0.85 cmH₂O (less than 1 cmH₂O). In clinical judgment, these differences do not show significant differences, because it will not lead to differences in clinical interpretations and therefore these differences will not affect the determination of diagnosis and selection of therapy, noting that the respondents in this study were 25% in normal CVP values, but if the patient is at a low or high CVP value, it could be a clinical consideration in determining the intervention (Mulyati, Fatimah & Susilaningsih, 2012). Another implication of the results of this study, CVP can be measured in the position of the right side or left side HoB elevation 30o without having to change the position of the HoB elevation 30o to a neutral position.

Conclusion

Based on the results of the study it can be concluded that there was a significant difference in CVP values of patients with mechanical ventilation among HoB elevation 30o neutral, right side, and left side positions. Mean score of HoB elevation 30o left side position was the highest. The mean difference between HoB elevation 30o neutral and left side position was higher than neutral and right side position. There was significant difference between mean score difference of HoB elevation 30o neutral-left side and neutral-right side positions. Although it was statistically difference, in fact, the values less than 1 CmH₂O which perhaps clinically did not have significant meaning.

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Setiyawan: Comparison of Central Venous Pressure (CPV) Score among Patients on Mechanical Ventilator

Yemima. (2007). *Pengaruh Mobilisasi Pada Klien Stroke yang Mengalami Gangguan Fungsi Motorik Dengan Kejadian Dekubitus di Rumah Sakit Mardi Rahayu Kudus. (The Effect of Mobilization on Stroke Clients with Motor Function Disorders with Decubitus Incidents at Mardi Rahayu Kudus Hospital). Tesis. Tidak dipublikasikan. Semarang: PSIK FK UNDIP.*

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Mucositis Effect on Quality of Life of Hospitalized Children with Cancer Who Received Chemotherapy

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Abstract

Mucositis is very common in children with cancer who received chemotherapy. Mucositis in children renders other health problems such as pain, eating problems, insomnia, and emotional problems that directly determine children's quality of life. The purpose of this research was to identify how the effects of mucositis on quality of life in children with cancer who received chemotherapy. The method used in this research is correlative descriptive analytic with cross-sectional design. Samples taken in this research utilized consecutive sampling technique. The children with cancer who met the inclusion criteria were approached to participate in this research. Sixty children with cancer hospitalized in Dr. Hasan Sadikin Hospital Bandung recruited in this research. Mucositis identification utilized Oral Assessment Guide (OAG). Data quality of life (QoL) would be assessed with PedsQoL Cancer Module 3.0. Data were analyzed by Chi-square correlation test. There are 53 children (88.3%) who experienced mucositis. In contrast, there are only 7 children who didn't experience mucositis (11.7%). Based on this survey, there are 37 children (61.7%) have bad quality of life. Otherwise, 23 children (38.3%) have good quality of life. This research found that there is a significant relationship between mucositis and QoL of children with cancer. Accordingly, the relationship between mucositis cases and QoL of children with cancer valued at 0.006 ($p < 0.05$). Mucositis cause low QoL in children with cancer compared to them without mucositis. Nurse should increase nursing care for children with mucositis as the side effect of chemotherapy. Suggested efforts are to prevent mucositis complication that will impact QoL, such as giving oral care with honey, keeping humid oral mucosa, and preventing infection.

Keywords: Chemotherapy, children with cancer, mucositis, quality of life.

Introduction

Cancer is a group of abnormal cells formed by growing, unlimited and uncoordinated cells unrelated to surrounding cells and physiologically malfunctioned (Price & Wilson, 2013). This abnormal group of cells is produced by factors; genetic and surroundings (Baggot et al., 2002). It changes cell metabolism and destructs body's physiological functions (Price & Wilson, 2013).

Nowadays, cancer is a serious and threatening disease for children around the world. The threat is immense according to recent numbers of new cancer sufferers. National Cancer Institute or NCI (2009) stated that there are more than six millions new cancer sufferers every year. Additionally, NCI (2009) assumed four percent cancer were in children.

Children with cancer is a growing problem in Indonesia (Sujudi, 2002). According to Gatot (2008), the prevalence of cancer in children in Indonesia hits four percent and it means four percents of birth rate in Indonesia will suffer cancer. Nowadays, cancer is included into the top ten of lethal cause of children mortality in Indonesia (Kemenkes RI, 2017). This fact is supported by the data from National Hospital (RSUPN) Dr. Cipto Mangunkusumo Jakarta which also showed that cancer is included into the top ten of lethal cause of children mortality in Indonesia. The data from Dr. Hasan Sadikin Bandung Hospital in 2010 showed similar fact; that cancer is the first cause for children mortality in this hospital and chemotherapy in children with cancer is the most common case (Departemen Ilmu Kesehatan Anak RSUP Dr. Hasan Sadikin Bandung, 2016).

Cancer in children should be treated adequately. NCI (2009) stated that cancer treatment in children includes chemotherapy, bio-therapy, radiological therapy, cyrotherapy and spinal cord transplant peripheral blood stem cell. The most applied therapy in cancer for children is chemotherapy. Chemotherapy does not only provides a good impact, but also provides adverse side effects for children, both physically and psychologically. Side effects that occur depend on the type and dose of chemotherapy

drugs used. Chemotherapy causes children to be susceptible to mucositis, infections, bleeding, fatigue, lethargy, hair loss, nausea, vomiting, diarrhea, constipation, decreased appetite, neuropathy, haemorrhagic cystitis, urinary retention, moonface, sleep disorders, and an effect on fertility adult (National Cancer Institute, 2010; Hockenberry et al., 2010). The most common side effect experienced by children is mucositis. This often interferes with the daily activities of the child, including school (van Vliet, Harmsen, de Bont, & Tissing, 2010). Mucositis is an oral mucosa membrane inflammatory and ulceration. Oral Mucosa consists of mucosa cells that incessantly and promptly divided. Chemotherapy disturbs mucosa cell division and it leads to mucositis. Mucositis has negative effects for children (Cancer Care Nova Stovia (CCNS), 2008).

According to a study by United Kingdom Children's Cancer Study Group and Pediatric Oncology Nurses Forum or UKCCSG-PONF in 2006, the mucositis prevalence among children is around 30–40%. Another study by Cancer Care Nova Stovia (CCNS) in 2008, stated that mucositis prevalence was even bigger, it was 45–80%. In Indonesia, studies on mucositis prevalence are yet unpopular. Despite, Nurhidayah, Sholehati, and Nuraeni (2013) from Dr. Hasan Sadikin Hospital Bandung, revealed that most respondents suffered from mucositis (67.9%).

Mucositis in children renders other health problems; pain, insomnia, eating problems and emotional problems that directly determine children's quality of life. A study by Cheng et al. (2012) on mucositis effects to children's quality of life comprised 140 children of 6–18 years old in China disclosed decrease of quality of life based on problems of eating, gulping, drinking, sleeping and talking. In Indonesia, studies on quality of life of children with cancer are yet unpopular. Despite, Irmawati, Irwanto, and Cahyadi (2013) from hospital in Surabaya identified the quality of life in children with cancer using PedQoL 3.0, this studies revealed that the scores from children for treatment anxiety, cognitive problem and total scale was high. The subscale procedure anxiety, worry, and pain-hurt had low-scores for both children, and the overall scores was

61–81. Another study by Cheng (2008) in Hong Kong, revealed 80% oral mucositis by cancer therapy in adults resulted disturbance to patients' daily activities and psycho-social functions. The study utilized Chinese Version Functional Assessment of Cancer Therapy General Questionnaires (Ch-FACT-G). The result illustrated correlation between mucositis effects to children's quality of life; social, emotional, and physical life. Quality of life should be considered as a significant consideration for cancer treatment in children. Dr. Hasan Sadikin Hospital Bandung is the reference hospital for children cancer case in West Java. A study on children cancer case in this hospital disclosed that most children were suffering from pain caused by mucositis. This pain leads children to experience gulping, drinking, sleeping and speaking problems. Pre-study showed similar result, most parents claimed their children suffered from emotional (easily disturbed) and physical problems as well as eating and speaking problems (articulation).

It's very important for nurse to understand effects of mucositis to the quality of life of children with cancer. This understanding helps nurses to decide properly nursing interventions for children regarding their condition. Consequently, mucositis effects on quality of life of children with cancer is essential to be studied. The objective of this study is to identify mucositis effect on quality of life of children with cancer.

Method

This study design used correlative descriptive analytic with cross sectional design (Polit & Beck, 2008). This method aimed to recognize how mucositis determines the quality of life of children with cancer. Hypotheses formulated in this research are mucositis effect to quality of life of children with cancer is exist. The object of this research is children with cancer in children care centre in Dr. Hasan Sadikin Hospital Bandung which has average attendance of 30 children each month. Samples were obtained in this research using a consecutive sampling method. The inclusive criteria were: 1) the object of this research is children with cancer aged 2-18

years, 2) children were in ongoing treatment in Dr. Hasan Sadikin Hospital Bandung, and 3) children were in stable hemodynamic conditions. While the exclusive criteria is children with nasofaring cancer stage 3-4; the children in this stage are obstructed to open their mouth, therefore it's almost impossible to assess their mucositis. The time range of this research is 3 months from July 2015 to September 2015 with 60 samples of children with cancer hospitalized in Kenanga I and II Children Care Center in Dr. Hasan Sadikin Hospital Bandung.

Mucositis identification in children utilized Oral Assessment Guide (OAG). This instrument was designed by Eilers, Berger, and Petersen (1988); Dodd (2004); and Eilers (2004). This assessment is considered as affable for nurses to assess mucositis in children. OAG consists of eight assessment parameters, namely objective assessment to see the status of mucous membranes, lip, tongue, gingival, and tooth conditions; as well as functional and subjective studies to assess sound; salivary gland function, and swallowing ability. The assessment is described in score 1 to 3 for each parameter. Score one (1) if normal, score two (2) if there is a moderate change, and score three (3) if there are severe changes. The method of OAG assessment is done by observation, visual examination, palpation, and auditory. The lowest mucositis score is 8 and the highest score is 24.

Data of children quality of life would be assessed with PedsQoL (Pediatric's Quality of Life) Cancer Module 3.0 designed by Varni, Burwinkle, dan Seid (2005). This instrument is proven for its reliability and validity and had been translated into 69 languages. The PedQoL Cancer Module 3.0 instrument is specifically used to assess the quality of life of children with cancer. The PedQoL Cancer Module 3.0 includes eight domains, namely pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication. Assessment is given with a score of 0 to 4 on each item in question. Each answer to the question is converted to a scale of 0 to 100 for standard interpretation, namely the score 0 = 100, score 1 = 75, score 2 = 50, score 3 = 25, and score 4 = 0. The total

score is calculated by adding the score of the question answers divided by the number of questions answered on all domains.

Research of nursing must be tied to these codes of conduct; self determination, anonymity and confidentiality, protection from discomfort, beneficence and justice (Polit & Beck, 2008). This study has received ethical approval from the Health Research Ethics Committee Dr. Hasan Sadikin Hospital Bandung with a number of ethical clearance LB.04.01/A05/EC/154/V/2015. The researcher would take sample of data in accordance with procedures for administrative and research permission.

Samples of data would be processed with statistical analysis on result of study. Data analysis will use univariat dan bivariat analysis. Univariat analysis aimed to analyze research variables descriptively. Descriptive analysis describes mucositis cases and quality of life of children with cancer using mean value, standard deviation, and frequency distribution. Univariat result data

showed here as frequency and percentage. Bivariat analysis was completed to examine hypothesis with proportion differentiation test using correlative statistical test (Chi-square correlation test). Moreover, the latter employed to determine relation between independent and dependent variables. This analysis employs meaning degree α 5% ($p < 0.05$). If only $p < \alpha$, therefore hypothesis is rejected.

Result

This research was completed in Kenanga Room I and II Children Care Center in Dr. Hasan Sadikin Hospital Bandung in 3 months since July to September 2015. There were 60 hospitalized children with cancer and earned chemotherapy in both rooms.

Mucositis case of hospitalized children with cancer in Children Care Center Kenanga Room I and II Dr. Hasan Sadikin Hospital Bandung is drawn in table below.

Table 1 Mucositis Case of Hospitalized Children with Cancer in Children Care Center (n = 60)

Mucositis Case	Frequency (n)	Percentage (%)
Non-Mucositis	7	11.7
Mucositis	53	88.3

Table 2 Quality of Life of Hospitalized Children with Cancer in Children Care Center (n = 60) according to PedQoL Cancer Module 3.0

Quality of Life	Value Mean	Deviation Standard	Minimum Score – Maximum Score
Total Score	49.23	21.73	11.54 – 94,44
Pain and Hurt	48.75	35.26	0.00 – 100.00
Nausea	39.50	33.59	0.00 – 100.00
Procedural Anxiety	48.61	39.78	0.00 – 100.00
Treatment Anxiety	71.39	33.63	0.00 – 100.00
Worry	33.75	38.92	0.00 – 100.00
Cognitive Function	50.23	25.49	0.00 – 100.00
Physical Function	58.33	36.47	0.00 – 100.00
Communication Function	54.44	33.52	0.00 – 100.00

Table 3 Quality of Life of Hospitalized Children with Cancer in Children Care Center (n = 60) according to PedQoL Cancer Module 3.0

Quality of Life	Frequency (n)	Percentage (%)
Good Quality of Life	23	38.3
Bad Quality of Life	37	61.7

Tabel 4 Mucositis Correlation with Quality of Life of Hospitalized Children with Cancer in Children Care Center (n = 60)

Variables	Quality of Life PedQoL Cancer Module 3.0
Mucositis Case	p = 0.006

Table 1 showed that most children with cancer who received chemotherapy experience mucositis as many as 53 people (88.3%). As a fraction as many as 7 people (11.7%) had no mucositis.

Quality of life (QoL) of hospitalized children with cancer in Children Care Center Kenanga Room I and II Dr. Hasan Sadikin Hospital Bandung is drawn in table below.

Based on table 2, questionnaire PedQoL Cancer Module 3.0 expose quality of life based on treatment anxiety experienced by children with cancer attain highest value mean (71.39). Quality of life with high mean value in addition to aspects of treatment anxiety also followed by aspects of perceived physical appearance (58.33), communication (54.44), and cognitive problems (50.23). Otherwise, quality of life based on children's worry to face their illness and their medication has lowest value mean of 33.75, followed by aspects of nausea (39.50), procedural anxiety (48.61), and pain and hurt (48.75).

Based on table 3, there are 37 children (61.7%) have bad quality of life. Otherwise, 23 children (38.3%) have good quality of life. Mucositis correlation with quality of life of hospitalized children with cancer in Children Care Center Kenanga Room I and II Dr. Hasan Sadikin Hospital Bandung drawn in table below.

Based on table 4, there's such a significant relationship between mucositis and quality of life of children with cancer. Accordingly, the relationship between mucositis cases and quality of life of children with value p of 0.006 ($p < 0.05$) based on quality of life PedQoL Cancer Module 3.0.

Discussion

Mucositis Cases in Children with Cancer

Patients who earned chemotherapy were risked 20%-40% to experience of mucositis. Oral mucositis symptoms consist of objective symptom (erythema, lesions, and edema), subjective changes (pain, sensitivity and dry

feeling) and functional adjustment (changes of voice, gnawing and swallowing) (Potting et al., 2005). Mucositis caused by injured cells. Injured cells ensued by drugs; chemotherapy side effects, chemicals, infections, traumas or irritated lattice caused by mechanic stuffs (for example, contact between mucosa and stuffs as tooth brush).

This result shows that almost all children with cancer who earned chemotherapy experienced mucositis. There are 53 children out of 60 (88.3%) who experienced mucositis. In contrast, there are only 7 children who didn't experience mucositis (11.7%). This research synchronizes former research by Nurhidayah, Sholehati, and Nuraeni (2013) who showed that most children with cancer (67.9%) who earned chemotherapy experienced mucositis. According to a study by United Kingdom Children's Cancer Study Group and Pediatric Oncology Nurses Forum or UKCCSG-PONF in 2006, mucositis prevalence in children with cancer reach 30-40%. Another study by Cancer Care Nova Stovia (CCNS) in 2008, revealed bigger probability of mucositis prevalence (45-80%).

Mucositis in children with cancer could be categorized as severe. According to Eilers (2004), mucositis renders various disorders; physiologically and functionally. Physiological disorders caused by mucositis are lesions, ulceration, extra inflammation, pain and infection. Lesions and ulceration caused by mucositis predispose bacterial infection, fungi and virus. This will threat children for its systemic infection risk. In addition, functional disorder caused by mucositis are gnawing, swallowing and speaking obstruction.

This research reveals 88.3% of children with cancer who earned chemotherapy experienced mucositis. Based on claims by children with cancer who experienced mucositis, there are several disorders entailing. They are soreness, insomnia, eating and emotional problem and activity obstruction. These disorders disturb directly the quality of life of children with cancer.

Quality of Life of Children with Cancer

Severe illnesses emerged in childhood; cancer is one of them, could bring down children's growth and future prospects. Cancer is a severe disease with double effects; the troubling illness itself and side effects of its treatments. Cancers need continuing medication and treatment, one of them is chemotherapy. Severe condition experienced by children costs their physical, psychological and social condition (Bulan, 2009). This cost due to children's maturation process and children growth in each level. Disturbed growth relates children's quality of life.

Continuing chemotherapy for children with cancer will cost physically (easily infected, bleeding, fatigue, lackluster, falling hair, mucositis, sick, constipation, low appetite, neuropathy, hemorrhagic cystitis, urinate retention, moonface, insomnia and fertility for adults). Psychosocial effect is another side effect of continuing chemotherapy. Among them are mood disorder, anxiety, lost confidence, low self esteem, depression and behavioral changes lead to school refusal (Hockenberry et al., 2010). All these are immense for children with cancer. Moreover, their quality of life will decrease to the lowest level.

Based on questionnaire PedQoL Cancer Module 3.0 children with cancer who hospitalized and experienced treatment have low quality of life. Based on this survey, there are 37 children (61.7%) have bad quality of life. Otherwise, 23 children (38.3%) have good quality of life. This number reveals most children with cancer are in no good quality of life.

Questionnaire PedQoL Cancer Module 3.0 expose quality of life based on treatment anxiety experienced by children with cancer attain highest value mean (71.39). Result of this questionnaire displays anxiety treatment for children with cancer resulted better quality of life compared to other aspects. This aspect comprises treatment for children's anxiety emerged throughout their medication at hospital. Regularity of medication leads to low anxiety throughout their medication at hospital. A similar study conducted by Bariah et al. (2011) in Malaysia also shows that the quality of life aspect in terms of treatment of

anxiety has the highest mean value of 81.94. The research of Ji et al. (2011) also shows that quality of life viewed from procedural anxiety has a mean value of 68.02. This indicates that children are experiencing fears about the procedural treatment that undergoes, resulting in decreased quality of life. Quality of life with high mean value in addition to aspects of treatment anxiety also followed by aspects of perceived physical appearance (58.33), communication (54.44), and cognitive problems (50.23).

Otherwise, quality of life based on children's worry to face their illness and their medication has lowest value mean of 33.75. The latter contradicts the previous; in case of facing illness and medication, the children attained lowest score. The children are vulnerable to anxiety of side effects, or their probability of thriving medication. Moreover, the anxiety of recurrence of cancer is also excess their feeling. These factors contribute to lower children's quality of life. In this study, the quality of life with the lowest mean value in addition to the aspects of worry or fear, followed by aspects of nausea (39.50), procedural anxiety (48.61), and pain and hurt (48.75) that show has a worse quality of life when compared with other aspects.

This study is in line with the results of research Fawzy et al. (2013) that conducted in Egypt using the PedQoL Cancer Module 3.0 questionnaire. Research of Fawzy et al. (2013) showed that children with cancer had a poor quality of life with a mean value of 62.29. When viewed from various aspects that shape the quality of life, the research of Fawzy et al. (2013) have similar results with the results of this study where the lowest mean value of quality of life score is in the aspects of worry (44.11), perceived physical appearance (50.6), and procedural anxiety (55.34). While the highest mean value on quality of life score is in communication (75.98) and cognitive problems (72.63).

The similar studies in Brazil also used the PedQoL Cancer Module 3.0 questionnaire (Scarpelli et al., 2008). This study shows that children with cancer have poor quality of life with a mean of 76.41. But in a study in Brazil it shows that the aspect of pain and hurt has a higher value than other aspects with a mean value of 86.47. This shows that

the children are able to adapt to the pain and hurt that felt. The study was supported by research conducted by Tsuji et al. (2011) in Tokyo, Japan, which also showed poor quality of life in children with cancer with a mean of 77.89. In the study of Tsuji et al. (2011), communication aspect has the lowest value when compared with other aspect with mean value equal to 67.03. Based on this it can be concluded that children with cancer may have obstacles in communication, for example because it is difficult to tell doctors and nurses what is felt, answer questions from doctors and nurses, and difficult to explain the disease to others.

If the value of quality of life in these countries is compared between the mean values of this study conducted in Indonesia, especially in Dr. Hasan Sadikin Hospital Bandung with some studies conducted abroad, including in Thailand, China, Brazil, Japan, Malaysia, and Egypt, the value of total quality of life of children with cancer in Indonesia is much lower when compared with the score of quality of life values in the countries outside. This shows that the quality of life of cancer children in Indonesia is worse when compared with other countries. Thus it is necessary efforts of health workers, especially nurses to be able to improve the quality of life of cancer children in Indonesia in particular. Nurses should be able to provide support to children and families in identifying effective coping strategies so that children and families feel comfortable in chronic conditions experienced by children and can adapt positively to have a better quality of life.

Mucositis Relationship with Children with Cancer Quality of Life

This study found that there's such a significant relationship between mucositis and quality of life of children with cancer. Accordingly, the relationship between mucositis cases and quality of life of children with value p of 0.006 ($p < 0.05$) based on quality of life PedQoL Cancer Module 3.0. Mucositis is able to worsen quality of life of children with cancer in comparison with non mucositis case in children with cancer.

This study confirms previous study by Cheng et al. (2012) on mucositis effects on

quality of life of children and teenager as it taken from 140 samples with age range of 6–18 in China. Cheng's study found that there's generic decrease of quality of life among children and teenagers with cancer. Common symptoms emerged as eating, swallowing, drinking, sleeping, oral problem. Another study by Cheng (2008) in Hong Kong revealed oral mucositis, caused by cancer therapy, among 80 adult patients had disturbed their daily activities and social life. The result confirmed positive line of mucositis effects on social life, emotional life and physical fitness among children. The conclusion is, the children who experience mucositis were disturbed physically, emotionally and socially. The disturbs lead to a worsened quality of life.

In this matter, nurses should actively foster children with cancer to minimize the occurrence possibility of mucositis caused by chemotherapy. Possible treatments are oral cares; oral cleanliness to protect oral cavity, to prevent plaque emergence on teeth, to keep mucosa humid, to keep mucosa integrated, to keep away infection, to prevent oral ulceration and to maintain other oral functions. Oral mucosa damage is unavoidable, but it could be minimized by preventing infection.

Moreover, the children with heavy side effects should experience good quality of life. They should be physically, emotionally good and excel their social and academic life. One of prime efforts, to boost their quality of life, is children ought to learn their course at the hospital as well as to interact and earn their emotional therapy to help them to cope with the side effects.

Conclusion

This research found that there is a significant relationship between mucositis case in children with cancer with their quality of life explained by p value = 0.006 ($p < 0.05$) based on quality of life PedQoL Cancer Module 3.0. Therefore, significant relationship between mucositis with quality of life in children with cancer is confirmed. Mucositis cause low quality of life in children with cancer compared to them without mucositis.

Nurse, in this matter, should increase

cares for children with cancer to minimize mucositis probability as side effect of chemotherapy. Suggested efforts are cares for oral cleanliness to maintain healthiness of oral cavity, preventing surface plaques on children teeth to ward off dental caries, keeping humid oral mucosa, maintaining mucosa integrity, preventing infection, preventing oral ulceration and maintaining oral function. Oral mucosa damage is unavoidable. However, prevention steps to ward off infection could minimize damage to oral functions. Additionally, profound side effect of medication shouldn't prevent children to gain good life; physical, emotional, social and academic. To provide them opportunities to learn and to interact while they are hospitalized and to give them extra sessions of psycho-therapy would help them to cope with medication's side effects.

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Nursing Students' Roles and Experiences of Disasters in A Nursing School

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Abstract

Due to its location on the 'Pacific Ring of Fire', Indonesia is often prone to natural disasters. Therefore, Indonesian nurses need to have the ability to assist in disaster situations because they are considered one of the important elements of the workforce in disaster preparedness and response. However, the current nursing curriculum in Indonesia does not adequately prepare nurses to respond to this situation. The main objective of this study is to understand the role experiences of Masters of Nursing students and experiences in disaster settings in a nursing school in East Java, Indonesia. A single case study design has been used. Data collection was carried out through semi-structured interviews. The participants are registered in the Master of Nursing program in the School of Nursing at a University in East Java. The data for research were analysed thematically. Four main themes were identified: 'personal feelings', 'working outside their scope of practice', 'lack of disaster preparedness', and 'lack of mental health care and knowledge'. This study found that students of a Masters in Nursing at a nursing school in East Java, Indonesia were not adequately prepared to face disaster situations. This study found that working outside the scope of practice and lack of mental health knowledge were the main problems for these Master of Nursing students. Apart from starting disaster training early in their education, it is recommended to provide training in the psychological context of disaster preparedness.

Keywords: Disaster, Indonesia, nursing, nursing students, nursing roles.

Introduction

The United Nations International Strategy for Disaster Reduction (UNISDR) defined a disaster as:

“A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts. (UNISDR, 2017, terminology on disaster risk reduction section).”

In 2015, 998 million people were affected by disasters, with 22,773 losing their lives. In total, 345 disasters were recorded with the majority of these happening in the Asia-Pacific region, and a total of 11 occurring in Indonesia (UNISDR, 2014). Disasters in Indonesia are predominantly geophysical or hydrological in nature. The Indonesian National Disaster Management Authority (2015) reported that, in 2014, 425 disasters struck Indonesia causing 206 deaths and 1,505 injuries, with 41 people missing. In 2015, there were 1,116 disasters with 186 deaths, and affecting a further 636,205 people, with 9,557 survivors being evacuated (The Indonesian National Disaster Management Authority, 2015).

These ongoing situations have heightened recognition of the role of nurses in disaster management and response (Veenema, 2018). As an important part of the health disciplines, nurses are on the frontline of responding to disasters (Cusack, Arbon & Ranse, 2010). However, Chapman and Arbon (2008) have asserted that it is not only nurses who need

to respond to disasters, but also nursing students. In western countries, nursing students have been involved in responding to emergency situations, including disasters such as that which occurred in Haiti, and the cases of Tropical Cyclones Debbie and Irene (American Red Cross, 2012). Therefore, providing nursing students with disaster preparedness training is crucial to ensuring that they are well-prepared for disaster situations (Chapman & Arbon, 2008).

Disaster preparation education has been established in several schools of nursing in the United States of America (USA) by developing a variety of programs ranging from certificates to master’s degrees (Veenema, 2018) (see Table 1). These schools include, but are not limited to, Adelphi University (a Graduate Certificate in Emergency Management), Johns Hopkins University (Master of Science in Nursing Health Systems Management: Emergency Preparedness/Disaster Response), St. Louis University (online certificate program of Disaster Preparedness for Nurses), Grand Valley State University (a series of lectures for senior nursing students on the threats of bioterrorism agents and re-emerging infections), and University of Texas at Austin (Initiatives for Mass Casualty Education course) (Veenema, 2018).

These programs provide opportunities for practicing nurses to prepare appropriate responses to catastrophic, mass casualty events and public health emergencies (Veenema, 2018). Moreover, these educational programs support a wider strategy of preparing nursing students for disaster events (Hutchinson, et al., 2011). Moreover,

Table 1 Universities Providing Disaster Nursing Courses in United States (Veenema 2018)

Universities	Course
Adelphi University	Graduate certificate of Emergency Management),
Hopkins University	Master of Science in Nursing Health Systems Management: Emergency Preparedness/ Disaster Response
St. Louis University	Online certificate program of Disaster Preparedness for Nurses),
Grand Valley State University	A series of lectures for senior nursing students on the threats of bio-terroristic agents and reemerging infections),
University of Texas at Austin	Initiatives for Mass Casualty Education course)

Olivia, Claudia and Yuen (2009) argued that disaster preparedness content delivered within a school of nursing will develop and enhance nurses' preparedness for emergency cases in the future.

International Council of Nurses (ICN) has established the minimum standard of nursing disaster curricula to be applied in nursing schools. This curricula covers the basic standard of nursing competencies in order to be ready to participate in disaster situations, including mitigation, preparedness, response, and recovery programs (World Health Organisation 2009).

In 2015 the The Association of Indonesian Nurse Education Center (AINEC) established a curriculum for Bachelor of nursing program. This curriculum contained a disaster nursing subject (AINEC 2015; Hermawati, Hatthakit, & Chaowalit 2010). Indonesian nursing students in East Java receive two units of disaster nursing content in their seventh semester of undergraduate nursing program. This module covers the International Council of Nursing (ICN) disaster nursing competencies (AINEC 2015). This unit, however, is not enough to adequately prepare nursing students to be fully ready to assist in a disaster area (Hermawati, Hatthakit, & Chaowalit 2010). Generally, disaster nursing content is not available in Master's curriculum in Indonesia. However, Master's of Nursing in limited universities provide elective program such as seminars, training and disaster drills. One of these universities is a university in East Java. Therefore, the Kelud Eruption occurred in East Java in 2014, many Master students from the school were involved in assisting during this situation. However, even with the current training, the experience of these students providing care in disasters is unknown. In addition, the experience of nursing students in lower middle income countries, such as Indonesia are under represented in the disaster literature. Therefore, this study will focus on exploring the experience of Master's of nursing students in responding to a disaster in East Java, Indonesia.

Method

While the focus of this study lends itself to the potential use of one of several qualitative traditions or methodologies, the case study method was chosen. Case study is an approach summarised in-depth investigation of experience in the diversity of the social environment under study (Hentz, 2007). It was envisaged that the complexity of the student experience of working in a disaster would be described holistically through the case study method. Purposive sampling was employed in this study. It was possible that some of the participants might experience anxiety or have an emotional reaction when discussing their experiences in disaster setting. Therefore, enabling participants to come forward and identify themselves voluntarily was important.

Data collection was conducted through semi-structured interviews. The researcher interviewed seven participants until data saturation had been reached. Data saturation is the point in the research process when no new information is discovered in data analysis, this point was reached after seven interviews (Fusch and Lawrence, 2015).

All participants provided care after the Kelud volcanic eruption, while one participant also experienced providing care during a flood. Of the seven participants, five had responded to a disaster once, one had responded twice, and another four times. These students were enrolled in a general Master of Nursing course concerned with specialty areas of practice, including critical care nursing, and mental and community health.

The setting for the study is a university in East Java, Indonesia. The location was chosen specifically because there was a disaster (Kelud Eruption) in February 2014. This research was conducted a year after the catastrophic event. Moreover, this nursing school provides disaster seminar and drills in the second semester of its Master's program. Further recruitment criteria included being over 18 years of age, and participating in disaster settings from 2012 to 2014. The data collection was conducted in 2015

through semi-structured interviews as the data collection method. As part of this, the researcher provided a set of questions as a guide for the interviews. All interviews were conducted in a private secure room at the university. Each interview took between 60 to 90 minutes for each participant, and all participants gave informed consent. The interviews were audio recorded. Ethics approval was sought and gained for this study at Flinders University (SBREC6336) as well as the Ethics Committee of the Cendekia Utama Kudus Health Collage in Indonesia (380/EC/KEPK-S2/06/2014).

A thematic analysis was used to generate the initial findings from the data resulting in four main themes being used to present the overall findings of the study. Thematic analysis was used to analyse the data. An inductive, semantic approach to thematic analysis was selected, as this method supported the exploratory nature of the study and ensured that the themes identified were strongly linked to the collected data (Braun & Clarke, 2013).

Following Braun and Clarke's (2013) process, the data was analysed using six steps. Firstly, the researcher familiarised herself with the data through the transcription process. In this step, the researcher transcribed the interview data into written form. Transcribing the data into text enables the researchers to deeply understand the data and check its rigour and accuracy. The second step is to generate initial codes, and then to collate data. This is followed by the third step, which involves the researcher looking for the broader meaning of the data through generating codes to develop main themes and sub-themes. Step four involves two phases consisting of reviewing the themes that have emerged during step three (reviewing the level of the coded data and refining the entire data set). Step five consists of defining and naming the themes, and identifying the essence of each theme. The final step consists of the researchers writing up a final report of the themes (Braun & Clarke, 2013).

To gain trustworthiness within a qualitative study the data must ensure faithful descriptions of the subjective interpretations

of participants (Munhall, 2012). In this study each transcript was taken back to each participant for verification. In addition, through using the six steps of data analysis by Braun and Clarke (2013) a decision trail was created that can then be replicated by other researchers, thus enhancing trustworthiness of the data (Munhall, 2012).

How the researcher(s) maintain the Trustworthiness? Otherwise we cannot believe the results.

Result

This study found that the majority of Master of Nursing students believed that participating in disaster settings created a challenging work environment for them, due to their limited ability to cope with personal feelings, working outside their scope of practice, lack of disaster preparedness, and a lack of mental health knowledge and care.

Personal feelings

In this study, common feelings experienced by the participants were identified as worry, anxiety, and confusion in the pre-disaster response.

I felt anxious, yes ... I was also anxious when I was going to the disaster area ... Was it going to be okay or worse? You know, it (the volcano) was erupting. Eruption of Kelud was not only once. There were sudden tremors and smoke (Participant 1).

Anxiety was experienced when the participants thought about the potential chaotic situation of the disaster setting. Additionally, six of the seven participants felt worried and anxious about whether or not they could be of any help during the disaster. I was afraid, worried, and confused before going there [to the disaster setting]. "Can I help them? [the disaster survivors]" (Participant 2).

... before knowing the situation in the disaster setting ... there were two possibilities ... "Is it okay to be there? ... am I safe there? Or maybe will be like a victim as well?" ... I felt anxious (Participant 4).

Before going there ... I was so worried ...

I was worried if I could not do anything there (Participant 5).

However, once they were in the disaster area, they felt relieved and eager to be participating. Yes... and after I arrived there [in the disaster area], I enjoyed it... not worried anymore... we worked in a team.. so ..it was memorable time, we can help others (the victims) (Participant 1).

I was worried at first .. again. However, when we arrived there.. I was so relieved... it was different from what I thought beforehand. (Participant 5).

All the participants stated that they were able to manage their personal feelings during disaster response. In the post-disaster phase, most participants also experienced positive personal feelings. Participants felt relieved and happy as they had gained more experience compare to their friends who had not volunteered. They thought that they not only attained disaster concept through their education, but were also able to practice it in a real situation. This was a positive overall aspect for them.

...yes... hmmm... ah, after volunteering and we were home, for sure we felt so relieved ... we had finished ..//.. finally, finished. By the way, I have an additional positive aspect. For most of my classmates, participation in a disaster setting was only as concept in a class, but for us... for those who participated in the Kelud eruption, they experienced the real situation. Lucky me! I had been involved directly. It was a positive point for me. Well, it was my feeling when arrived home. (Participant 1)

...yes. In post-disaster ... I think ... there is such a personal satisfaction ... so proud of myself ... first, because we have the real experience, second because we helped to save the patients and their families. I think I did not have any traumatic feelings although it was my first time there ... but, I was motivated enough ... full of spirit. If there is another disaster, I will participate ... if possible. We can save other people, can't we? (Participant 4).

Students were worried, anxious and confused before taking part in the disaster event. However, once they were at the affected

area, they were able to participate and could manage their own feelings. During the post-disaster phase, all participants experienced positive feelings such as happiness, interest, and motivation. Consequently, with the positive outcomes of their experiences, they wanted to participate in disaster responses in the future.

Working outside the normal scope of practice

A major concern for the nursing students interviewed was the expectation that in disaster work, they were expected to work outside their scope of practice. Students mentioned that in the disaster situation, they needed to help other volunteer health professionals. For example, they were asked to stitch wounds and give prescriptions to patients, duties that are normally a medical officer's responsibility. This concern is illustrated by Participant 6,

The number of doctors was very limited ... nurses were also taking part in some medical activities ... although maybe it was not our responsibility. The situation required us to ... when there were some patients with wounds ... we did wound care ... stitched the wound ... and also giving prescriptions to the patients ... So [whether] we wanted it or not, we had to do it. It was an unpredictable situation ... an emergency situation (Participant 6).

As the disaster setting was an emergency situation, the participants felt that they should take action as soon as possible and fill in any gaps as needed. Five participants mentioned that in order to support each other in the disaster setting, doing the jobs of other professionals was a must. We helped doctors in giving medications and we infused patients as well ... (Participant 5).

We collaborated with doctors in handling the patients and treating the wounds (Participant 2).

Due to the limited number of people volunteering, most of the participants mentioned that their jobs needed to be flexible while in the disaster area. Furthermore, unclear job descriptions and expectations within the disaster setting challenged them. Yes, it was not clear ... our job description was not clear. For example, there was a case, when there was an emergency call, and we had no job description beforehand, we were

confused about it, who should be in triage, who should be here ... who should be there. So, everyone was asked to be there randomly to an emergency call. There was no clear job description (Participant 3).

Due to the limited numbers of people volunteering, most of the participants mentioned that their jobs needed to be flexible while in the disaster area. On occasions, other volunteers would ask them to take over their jobs; for example, nursing students were asked to handle and distribute the logistics of food delivery and distribution to the evacuation area. I was also asked to assist in handling many jobs..such as... helping army in providing food to the victims of disaster... (Participant 1)

At that time, food was abundant, but it was not distributed well ... only in one area.. So, we helped to bring the food to other evacuation area. (Participant 3)

In relation to providing appropriate services to the community during the disaster response, there were unclear job descriptions for the participants in this study. This was further exacerbated by a shortage of health professionals working in the affected area, meaning that nursing students were often left to do the tasks of other professions. To summarise this theme, nursing students experienced a challenging work situation due to often undertaking work which was outside of their normal scope of practice.

Lack of disaster preparedness.

The participants in this study talked about the lack of disaster preparedness. Due to the large number of disasters in Indonesia, all the participants thought that becoming competent in disaster nursing was crucial in order to support their disaster preparedness. The participants claimed that their knowledge of disasters was deficient in terms of disaster concepts, including simulations, and research about disasters.

In my undergraduate program, it [the curriculum] was so general... (Participant 4).

Five participants agreed that it would be beneficial if disaster content was taught earlier in their overall education.

Honestly, we needed to learn disaster theory in our bachelor's degree or the diploma. So far, in the master's program, the theory was

very general. Not enough [about disasters] ... it was limited ... yes (Participant 7).

We did not need only theory, but also simulations and trainings as well ..., more practical skills are needed. Not only the theory ... in both of them [undergraduate and postgraduate programs] (Participant 2).

The participants were interested in learning about disaster preparedness in the Master of Nursing program and how to respond to chaotic situations. Three of the participants stated that receiving disaster education from an early age was very important. Participants believed that children, for example, should receive a basic disaster education when they are in elementary school. Learning about disaster theory in their Master of Nursing program was beneficial, but the participants stated that they would have preferred to have learned this earlier in their academic career.

We have learned more in the master's program ... I have learned more ... the theory of the pre-and in-hospital program, how to evacuate patients as well. Therefore, when we were in the disaster program, we could help more. Maybe because we learn new competencies based on the American Nurses Association (Participant 6).

Overarching concepts of what happens in a disaster was described as being ineffective and needing improvement. Moreover, they also believed that both undergraduate and postgraduate nursing students needed more disaster training. The participants recommended that the availability of a disaster research laboratory on the university campus would enable students to conduct research on disasters. Furthermore, the participants mentioned that such research could provide recommendations in relation to what volunteers should do when taking part in a disaster situation.

Research can give a recommendation in specific disaster situations. I think there is still no research in disaster settings in Indonesia, especially in our campus (Participant 6).

Overall, the participants stated that disaster concepts, training, and research taught by Indonesian schools of nursing, as well as that learned outside of these schools, was insufficient. The participants identified this as the major factor that had an impact on their ability to participate successfully in

disaster responses.

Lack of mental health knowledge and care during the disaster response, students encountered patients with mental health-related issues. The participants stated that they tried to provide holistic care to the patients through therapeutic communication. However, they believed that they had little knowledge of how to care for these patients' mental healthcare needs. An example given by Participant 4 stated that, as part of their duties, they needed to persuade people to evacuate from their homes and leave their properties unoccupied. This process was not easy because most of the victims did not want to leave, as they wanted to keep their belongings safe. For some people, this was all they owned. Therefore, the participants believed that they needed to be taught how to care for distressed people during their nursing studies.

A sensitive approach was needed to persuade people to evacuate ... because they thought that their property like house, land ... or their pets were more important, so they tended to stay there than evacuate to the evacuation area. In this case, we had to persuade them to follow our instructions in the evacuation process (Participant 4).

... when we evacuated them ... some of them did not want to be evacuated ... so ... yes, so we forced them, but not arrogantly, softly, this is what we call ... caring ... yes ... caring ... they did not want to leave their belongings ... and we had to understand that (Participant 7).

Additionally, the participants stated that they needed to be silent and listen to the concerns of the people affected by the disaster. They also stated that it was primarily the female students who communicated with the affected people, as they were considered to be calmer, and could control their emotions. Thus, the participants in this study proposed that learning about theory and taking part in simulations focusing on the mental health aspects of patient care were needed. Participant 6 stated that there was a patient with a mental health problem and his team was not able to provide effective therapy or holistic care. As a result, his senior colleague, a nurse who worked in a psychiatric hospital, handled the case.

We could not do anything to the patient, it was done by Mr. A. He just finished his master's study in our nursing school. He did the therapy of the patient until her condition was getting better. So calm ... not hysterical ... no panic anymore. Yes, lucky us, there was Mr. A at that time. Finally, she was able to walk back home ... we should not let patients like her feel so sad with her own feelings for such a long time. I highlighted that it was important to focus on mental problems as well. We have to learn holistic care ... psychological, physical, social aspects as well. If we do not know all these aspects, we will have difficulties in the real situation, especially in disaster settings (Participant 6).

The importance of studying mental health was also mentioned by Participant 2 who stated that in the recovery phase, nurses should be able to assess patients' mental health.

It [the mental health program] was outside the subject, outside the curriculum. As we did not learn it at our campus, we did not practice it in the disaster situation. We did not explore the condition of those patients with non-physical trauma. Honestly, it was very much needed in the disaster ... it was very important (Participant 2).

The small cohort in this study felt that specific education in mental health and mental illness would be beneficial for them when responding to disaster situations.

Discussion

The Master of Nursing students involved in this study were worried and anxious before taking part in the disaster event. However, once they were in the disaster area, they were able to participate and could manage their own feelings well and focus on the job at hand. Fothergill, Palumbo, Rambur, Reinier and McIntosh (2005) stated that personal feelings, worry, and anxiety prior to participation in a disaster setting is experienced by nurses before taking part in any disaster response. Hammad, Arbon, Gebbie and Hutton (2012) added that personal emotions such as fear and anxiety affected nurses prior to their participation in disaster response. Several authors have found that these feelings can

decrease the willingness to respond to disasters (Considine et al., 2011).

However, in the study reported here, these thoughts and emotions were managed by all the participants due to the willingness to help others. Once the Master of Nursing students were in the disaster location, their negative feelings turned to constructive thoughts and they became excited and interested in the job at hand. Fothergill et al. (2005) supported this finding and argued that a commitment to helping other people supports nurses' willingness to volunteer in disaster settings. In addition, responding to a disaster allows nurses to have positive personal feelings about being part of the disaster response which then supports their willingness to participate in future disaster responses (Fitzgerald et al., 2010; Hammad et al., 2012).

As part of their role in the disaster area, the students were asked to perform unfamiliar procedures that they did not do in their usual practice. They performed these tasks because of the emergency situation and the limited number of health workers in the field. Working outside the normal scope of practice is not new and is part of the work required in most disaster settings (Baack & Alfred 2013). Arbon et al. (2006) and Chapman and Arbon (2008) found that in these situations, nurses are frequently asked to do jobs outside their scope of practice, regardless of whether they are qualified or not. Gallardo et al. (2015) found that nursing students with more experience in disaster settings performed medical treatments outside of their scope of practice. It is not clear if the Master of Nursing students in this study were legally covered to work outside their scope of practice, or whether or not Indonesia has a modified practice authority for student nurses in disaster settings (Association of State and Territorial Health Officials 2012).

The students in this study not only worked outside of their scope of practice, they also performed other tasks unrelated to nursing such as handling the logistics of food. Gebbie and Qureshi (2002) found that this is another common occurrence with nurses often assisting operations officers in logistics, planning, finance, and administration. The participants believed that disaster content should be learned by nursing students as early

as possible in undergraduate studies. They suggested that the undergraduate program of nursing would be the best educational level to introduce them to disaster content. This is not a new finding and many studies have argued for undergraduate programs to include disaster nursing (Usher & Mayner, 2011; Oztekin, Larson, Ugras & Yuksel, 2013; Peoples, Gebbie & Hutton, 2015). The participants in this study stated that they had received specific disaster content in their master's programs. However, they felt that this education did not meet all their needs in the disaster setting. They wanted to understand the role of government, undertake disaster training drills, and learn about disaster preparedness. Ireland, Emerson, Kontzamanis and Michel (2006) found that incorporating disaster training in the undergraduate program of nursing is helpful for enhancing nursing students' knowledge of disaster environments.

Disaster education and training are considered as effective ways to improve nursing students' knowledge of disasters (Kaplan, Connor, Ferranti, Holmes & Spencer, 2012). Disasters are chaotic situations which can contribute to the mental illness of survivors (Ranse, Hutton, Wilson & Usher, 2015), which is not uncommon in these circumstances. Warsini, West, Mills and Usher (2014) found that patients not only suffered from mental illness, but also identified as being anxious, depressed, having post-traumatic stress disorder, and having a heightened suicide risk (Warsini et al., 2014). Consequently, affected people need comprehensive psychiatric nursing care (Montazeri & Baradaran, 2005). However, all the participants lacked mental health knowledge and felt that they were unable to cope with this situation. Ranse, Hutton, Jeeawody and Wilson (2014) found that nurses identified the psychosocial aspects of disaster nursing as an important area for further research, as was improvement to clinical practice including training and curriculum development.

In order to be able to take care of patients with mental illness in the post-disaster phase, Nasrabadi, Naji, Mirzabeigi and Dadbakhs (2007) recommended that nurses be trained in mental health care prior to disaster response.

Although undergraduate and postgraduate nursing schools have established disaster curricula, mental health disaster content is still lacking (Ranse et al., 2015). Therefore, providing training in the psychological context of disaster preparedness in schools of nursing is a recommendation of the participants in this study in order to prepare them for dealing with the mental health problems that arise during disasters. Ranse et al. (2015) recommended that the availability of psychological disaster programs in nursing education is necessary to enhance nurses' and nursing students' preparedness to assist during disaster response.

Nursing students believed that disaster nursing preparedness would impact positively on their knowledge and roles in disaster responses. However, this is an area of research yet to be explored in this setting. In addition, exploring nurses' perspectives in providing mental health support to the patients in the disaster setting may uncover the need of specific psychological contents suitable to be established in nursing curricula of nursing schools in Indonesia. Further research is needed to understand more of these issues.

Qualitative studies elicit data from a small sample size; thus, the findings of this research may not be representative of the greater population of nursing students. Another limitation is that all the participants were Master of Nursing students. Despite these identified limitations, this research contributes to knowledge of nursing students' experiences in the disaster setting. As such, it provides an initial starting point for further research.

Conclusion

This research provides an insight into nursing students' experience of Master's of Nursing students in responding to a disaster settings in Indonesia. To capture the entire picture of Indonesian Master of Nursing students' participation in the disaster setting, and understand the perspective of nurses in lower middle income countries, further investigation should be undertaken. This study has found that student concerns, a challenging work

environment, different roles, and the lack of disaster preparedness all contribute to the nursing students' experience of disaster response in Indonesia. This study has found that these factors need to be improved and has made recommendations to commence training earlier in nursing education and to include training in mental health nursing in Indonesia's nursing schools.

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The Effect of the E-Patuh Application on HIV/Aids Patients' Adherence in Consuming Antiretroviral

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Abstract

Adherence to medication is a behavior that refers to the client's obedience to following treatment, and making lifestyle changes in accordance with the recommendations from health care providers. Antiretroviral adherence is of utmost importance for HIV / AIDS patients. Its effects are often a problem in antiretroviral treatment and toxicity and are often a reason for switching or stopping antiretroviral treatment. This study aims to determine the effect of the 'E-Patuh' application on antiretroviral adherence in HIV / AIDS patients in West Java. The research design was quasi-experimental with a nonequivalent control group design. The locations of this research were in RSUD Kota Bandung and in RSUD Kota Banjar. Respondents were selected without randomization and used a purposive sampling technique. Respondents in this study were 30 people. The data were obtained using self-report questionnaires. The intervention group was monitored for 30 days with the android-based 'E-Patuh' application and monitored on the 'E-Patuh' website and then measured the value of adherence with self-reports. Data were analyzed using SPSS 22 with chi-square test. The results showed that there was a significant difference between the value of adherence before and after the application of 'E-Patuh' in the intervention group ($p < 0.05$) with a value of $p = 0.006$. The results of this study prove that the use of the 'E-Patuh' application has a positive effect on adherence to ARV medication in the intervention group with the 'E-Patuh' application support system. The use of 'E-Patuh' is very helpful in improving ARV adherence in HIV / AIDS patients. The features contained in 'E-Patuh' are directly reminiscent of the time to take medication for PWLH. 'E-Patuh' should be a consideration for PLHIV and health care providers in hospitals to improve ARV adherence to reduce mortality in people living with HIV.

Keywords: Adherence, Antiretroviral, E-Patuh Applications.

Introduction

Human Immunodeficiency Virus (HIV) is a virus that attacks leukocyte (lymphocytes) in human body and causing acquired immune deficiency syndrome (AIDS) (Kemenkes, 2014). HIV/AIDS is a complex chronic disease. The number of HIV in Indonesia in the fourth quarter of 2017 was 14,640 and AIDS was 4,725 people. The highest AIDS percentage at 30–39 years (35.2%), followed by 20–29 years your (29.5%) and 40–49 years (17.7%). West Java is the third highest number of HIV infections in Indonesia in the period of March 2016 amounted to 28,964 people and the number of AIDS in West Java was ranked sixth in Indonesia with 6,502 people.

The development of using antiretroviral therapy as a treatment of choice in HIV/AIDS has significantly improved the health condition of HIV people. Palella et al. (1998) explains that ARVs have illustrated that HIV/AIDS patients can be treated, to reduce the morbidity, mortality and improve quality of life. Hypersensitivity reactions to antiretroviral drugs are more common in HIV patients than in other general disease populations. The reasons why people with HIV experience hypersensitivity reactions to antiretroviral medications are more often multi-factor, such as immune hyperactivity factors, changes in medication metabolism, profilesocytes, oxidative stress, and genetic predisposition (Nursalam, 2007).

The medication effects should not be an obstacle to starting antiretroviral therapy. Not all patients have effects of arising from the ARV treatment. ARV treatment is beneficial when compared to the risk of morbidity and death that would occur if the patient did not get ARV therapy (Kemenkes, 2011).

The level of antiretroviral adherence in Indonesia is low, with a range of 40–70% still below the national target of adherence > 95% (Latif, Maria, & Syafar, 2014). Kemenkes (2017) showed the number of people living with HIV who were getting ARVs in the fourth quarter of 2017 was 91,369 people. The total of 88,386 people used first-line regimens, 2,983 people receiving second line and 2,983 people was drop out of medication.

Cohen et al. (2011) said Disobedience in

the treatment of antiretroviral medication has a significant impact on patients who live it, such as the onset of symptoms that aggravate the state of the patient. Technology developments on ARV adherence interventions have been used in PLHIV including of pager, smartphone, SMS, video, computer-based programs and the development of behavioral intervention technology intervention technology (BITs) to improve ARV compliance (Pellowski & Kalichman 2012). Along with the development of existing interventions, nurses should play a role to increase ARVs adherence. Dayer et al. (2013) and Whellan et al. (2013) explained that their study focus on improving to ARVs adherence, providing educational information on ARV medication treatment and HIV/AIDS information based on electronic monitoring system.

In this study The E-Patuh application is developed from the existing electronic monitoring system applications based on Android and website system with Google servers to store patient's data. The features are improving of medication adherence and document medical history, CD4 history, and symptoms experienced by PLWHA during medication treatment. The forms of the report are immediately sent and documented in the "E-Patuh" website application system. E-Patuh Supported with reminders and notifications to remind people living with HIV to take medication on time.

Method

This study used quasi experimental with nonequivalent control group design approach with experimental group (A) and control group (B). The value of ARV medication adherence was measured in pretest and posttest. The experimental group was given intervention by using E-Patuh android application as user and then readied for respondent's smartphone. The Experimental group was conducted in Ujung Berung Hospital. For the control group were not given intervention in the form of E-Patuh android application and was conducted in Banjar Hospital. This study would evaluate the treatment of E-Patuh in a month.

The sample technique in this research used nonprobability sampling with purposive sampling. The numbers of experimental group were 15 respondents and 15 respondents for control group without any randomization in each group. The data were tested statistically to determine the difference of scores in the intervention group and control group on pre-test and post-test using chi square test of SPSS program to measure the pairs of nominal data or dichotomy (Dahlan, 2015).

This study used indirect measurement methods in the form of self-report using the Morisky Medication Adherence Scale (MMAS) questionnaire. Measurement of ARV medication adherence used the self-report questionnaire was developed with a four-item scale of questions and supplemented

with additional items that discussed the circumstances surrounding compliance behavior. The questions were measured by 4 items, namely 1. Are you sometimes having difficulty remembering the time to take medicine?, 2. When you feel good, do you sometimes stop taking medicine?, 3. Think four days back, have you missed it Taking medicine?, 4. At times when your condition feels worse, do you stop taking medicine?. The question category was responded to yes/no for each item with a response dichotomy (Morisky, Ang, Krousel-Wood, & Ward, 2008).

Result

Table 1 The Respondent’s Characteristics

Characteristic	Group				p
	Intervention		Control		
	f	%	f	%	
Age (Old):					0.247
17–20 years	6	40	3	20	
21–40 years	5	33.3	8	53.3	
40–60 years	4	26.7	4	26.7	
Gender:					0.000
Male	14	93.3	7	46.7	
Female	1	6.7	8	53.3	
Married Status:					0.161
Married	3	20	6	40	
Single	10	66.7	7	46.7	
Divorce	2	13.3	2	13.3	
Education:					0.638
Elementary	1	6.7	-	-	
Middle	3	20	3	20	
High	9	60	6	40	
University	2	13.3	6	40	
Work:					0.593
Private employees	7	46.7	9	60	
Entrepreneurship	3	20	1	6.7	
Unemployment	3	20	1	6.7	
Laborer	1	6.7	1	6.7	
IRT	1	6.7	3	20	
Duration of ARVs:					0.091
15 years	10	66.7	3	20	

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6 – 12 months	5	33.3	6	40	
5 – 10 years	-	-	6	40	
Type of ARV					0.036
3FDC	10	66.7	11	73.3	
Lamipudin, Tenopovir, Evafiren			1	6.7	
Duviral dan evafiren			2	13.3	
Lamifudin, neviral, TDF			1	6.7	
Duviral dan neviral	5	33.3			
Side Effects of Treatment:					0.521
No complaints	7	46.7	1	6.7	
Nausea	2	13.3	8	53.3	
Dizziness, nausea	-	-	6	40	
Rash	1	6.7	-	-	
Dizzy and limp	5	33.3	-	-	

$p < 0.005$ (homogeneity test)

Table 2 Pretest Score the ARV adherence in Intervention and Control Group

Group	Adherence Level			x^2	p
	High	Medium	Low		
	f (%)	f (%)	f (%)		
Pre- test intervention group	6 (40.0)	5 (33.5)	4 (26.5)	2.812	0.245*
Pre-test control group	12 (80.0)	3 (20.0)	-		

*chi square test $p < 0.05$

Table 3 Posttest Score the ARV adherence in Intervention and Control Group (n = 30)

Group	Adherence Level			x^2	p
	High	Medium	Low		
	f (%)	f (%)	f (%)		
Pre- test intervention group	8 (53.3)	7 (46.7)	-	6.234	0.013*
Pre-test control group	11 (73.3)	4 (26.7)	-		

*chi square test $p < 0.05$

Table 4 Pretest and Posttest Score an ARV Adherence in Intervention Group (n = 15)

Group	Adherence Level			x^2	p
	High	Medium	Low		
	f (%)	f (%)	f (%)		
Pre- test intervention group	6 (40.0)	5 (33.5)	4 (26.5)	10.179	0.006
Pre-test control group	8 (53.3)	7 (46.7)	-		

*chi square test $p < 0.05$

Table 5 Pretest and Posttest Score an ARV adherence in Control Group (n = 15)

Group	Adherence Level			x^2	p
	High	Medium	Low		
	f (%)	f (%)	f (%)		
Pre- test intervention group	12 (80.0)	3 (20)	-	3.068	0.080
Pre-test control group	11 (73.3)	4 (26.7)	-		

*chi square test $p < 0.05$

The table 1 describes the characteristics of respondents between the intervention and control groups. The study showed the most respondents were range of aged 21–40 years (53.3%) and almost all respondents in the intervention group were male (93.3%). The marital status data most of the respondents were single on intervention group 66.7% and 46.7% for control group. Most of the respondent was senior high school with 9 people (60%), private employment amounted to 9 people (60%). Most of the respondents suffered from HIV-positive people and underwent ARVs within 1–5 years at 10 (60.7%) in the intervention group. Most of the 3FDC ARVs consumed by all respondents were 21 respondents. 1 person (6.7%) of the control group did not have antiretroviral side effects but in the intervention group, a small percentage of 1 (6.7%) of the respondents had side-effect rash on the skin.

Pretest intervention and control group using chi square test showed on the table 3 and the result obtained p value = 0.245. Since p value 0.05 hence statistically there is no significant difference of pretest score of ARV adherence medication level between group intervention and control groups. Pre-test adherence levels in the control arm were almost 12 (80%) in high adherence. Meanwhile, in the intervention group there are still respondents with compliance of less 4 (26.5%) of respondents.

Posttest in intervention and control group using chi square test on table 3 obtained p value = 0.013, because p value <0.05 then statistically there was significant difference in post test score of adherence medication intervention group antiretroviral drug and control groups. The post-test adherence level in the control group of 11 (73.3%) was in high adherence level and the intervention group had respondents with high adherence of 8 (53.3%) respondents.

In the test to know the difference of pretest and posttest in intervention and control group using categorical comparative analysis not paired by using chi square. Differences of ARV preoperative and posttest test compliance scores in the intervention group will be presented in table and the control group will be presented in table below:

Between pre-test in intervention group got small part of adherence value 4 (26%) of respondent with low compliance category at pre-test and at post-test there is no value of compliance of respondent in low adherence category. The result of statistic test with chi square test in table was obtained p value = 0.006, because p value <0.05 then statistically there is a significant difference between antiretroviral drug adherence level score before and after giving of E-Patuh application in intervention group.

In the test of difference between pretest and posttest in control group using chi square test in table 5 obtained p value = 0.080, because p value <0.05 hence statistically there is no significant difference between antiretroviral medication adherence level scores in group control before and after application of E-Patuh to the intervention group.

Discussion

This study prove a positive effect of E-Patuh applications against ARV medication adherence on the intervention group. The features provide reminder of taking the medicine for respondents in real time, enlarge the knowledge's, to guide the patient for health care provider in West Java and changes the patient behavior in ARV medication.

Several methods have been developed to improve ARV adherence by building up the android and website monitoring system. Study of Dayer's et al. (2013) shows the methods of changing patient behavior using reminders, counseling, strengthening, education, simplifying the dosage, or combining those methods. In general, the compliance interventions are categorized as behavioral, educational, or organizational based on modifying the environment or patient, delivering information, or reducing the risks that impede treatment and establish communication with health care providers.

A similar study Zia's (2014) on the implementation of ARV antiretroviral monitoring system by smartphone-based client server method shows three respondents stated strongly agree that the reminder helps to remind ARV medication. The respondent agree that the message feature can facilitate

for communicating with the clinic staff while on ARV therapy, to help the officer in the process of collecting the results of CD4 examination, determines the consumption schedule and facilitates communication between the officer and the patient during the ARV therapy. Dayer's et al. (2013) again illustrates the potential benefits of smartphone technology to increase effectiveness in compliance programs, refine financing, as a real-time tool for evaluating medication adherence.

The study of electronic monitoring system became good opportunity in the modernizing of information and telecommunication tools in health community. The expansion of information and technology should be in line with utilization in the field of health specially in monitoring the system for ARV medication adherence to patients who living with HIV.

After giving for a month of E-Patuh application to the intervention group on 15 respondents and remain active using E-Patuh application the respondent still get the medication adherence intervention in the form of reminder with alarm and notification time of taking the medicine on time. While using the E-Patuh application researchers have submitted articles on HIV/AIDS to be able to provide information and education about the importance of medication adherence and educate the respondents' understanding of HIV/AIDS.

After using E-Patuh during the treatment package program, it was found that 5 respondents still had difficulty remembering the time to take medication but on the other hand there were increasing of adherence to 6 respondents who before using E-Patuh had trouble often skipping medication within four days. This compliance improvement is evidenced by no respondents claiming to have a problem with taking time to take medication time during the use of E-Patuh.

The E-Patuh application is an android-based smartphone app and website that is connected with internet network that can access communication, information and as remainder. This technology provides the principle of benefit to PLWHA to improve the behavior of obedient to ARV. The features contained in the E-Patuh application can enhance compliance by providing remainder

or alarm to take medication so that they can directly change their behavior by providing health promotion through APP, providing information on medication schedule, education delivery, and health service information. All information and education provided can be known by the notification that goes into android system of PLWHA.

The descriptive result indicates the level of adherence to taking antiretroviral drugs before and after the administration of the E-Patuh Application in the control group. From the table shows almost all the respondents have high adherence with the amount of 12 (80%) in the control group pre-test. After the provision of E-Patuh application in the intervention group showed that there was a decrease in compliance rate of PLHIV as evidenced by the compliance level in the control group with the high adherence category amounted to 11 (73.4%). The level of education in the control group was partially educated at university level with 6 (40%) respondents and SMA 6 (40%) respondents. The level of education in the control group tends to be better so it has better pre-test and post-test compliance percentage.

The effects of antiretroviral treatment in the control group were mostly 8 (53.3%) respondents felt nauseated. As a result of side effects of ARV treatment one of the factors that inhibited adherence to the control group said 2 respondents discontinued treatment when physically felt better. This research is supported by research of Sugiharti, Yuniar, and Lestary (2014) which get nausea, fever, rash made ODHA cannot stand side effect so decided to stop treatment.

Marital status in the control group married one of the social support factors to the support system of respondents in ARV adherence with 6 (40%) of respondents. In line with Galistiani and Lia (2013) say social support especially in the context of intimate relationships or the quality of marriage and family relationships is the most important source of social support. Social support from people around the patient can be a boost to HIV treatment adherence.

In this study, the extent of ARV adherence in general is quieted <95% below the national target. It will have an impact on the spread or suppression of HIV virus to PLHIV. With the

issue, WHO and the Ministry of Health through a system of curing with this prevention, care and treatment program emphasize that ongoing care and with attention to ARV adherence can suppress the virus in the body, reduce the risk of transmission to others, help people living with HIV and help keep long life (Kemenkes, 2017).

Given that antiretroviral therapy is a lifelong therapy, then the problem of treatment adherence was a common problem. Various studies show obstacles to obstacles such as fear of side effects, forgetfulness, unhealthy lifestyles, poor health conditions, missing medicine boxes, lack of personal awareness, opportunistic infections, daily activities, economic problems insufficient income for ARV treatment, unemployment, and fear of stigma. While adherence supporters, among others, have a regular schedule of taking medication, understanding the importance of adherence, getting good treatment results and confidence in the treatment process (Yuniar, Handayani, & Arsyastami, 2012).

Technological developments cannot be denied so quickly and rapidly in all aspects of human life. This becomes an opportunity and a challenge for us especially in the field of health. The demand of technological development with the internet network in the health world leads the health service system in paying attention to the compliance of antiretroviral programs for PLHIV. Utilization of technology in the field of health services in hospitals or in the community, especially for PLWHA will assist PLWHA in undergoing a life-long antiretroviral regimen program, facilitate access to health services, delivery of information and education, time efficient and financing in various aspects of service. Acceptance of technology based on android and website in it the use of E-Patuh application to PLWHA will guide some aspects of knowledge, attitude of PLWHA in antiretroviral treatment program so that ODHA become know, understand and able to change behavior in taking decision during undergoing ARV treatment program.

Taiwo and Downe (2013) said that in Technology Acceptance Models And Theories argue that interaction between humans and technology will affect the social and psychological factors of individuals

and even individual characteristics. A similar opinion is supported by the theory of Acceptance Technology Model (TAM) by Davis (1989) is a model for predicting individual acceptance of a new technology. TAM is actually adopted from the theory of reasoned action model (TRA) by Ajzen and Fishbein (1975), the theory of action with one premise that reactions and perceptions of a person to something that will determine the attitude and behavior of the person.

Differences in adherence levels of PLHIV pretest and posttest in both groups tended to better control group. This can be influenced by some external and internal support factors in the patient so as to perceive and behave toward something that can improve compliance. External support factors are employment, most respondents work as private employees in the control group of 9 (60%) of respondents and intervention groups 7 (46.7%) with varying salary. A minority of 3 (20%) of the respondents in the intervention group were unemployed so that the work factor could be a factor in the intervention group had less compliance than the control group because the work would affect income to meet the needs of antiretroviral treatment. Although ARV programs are free but access to ARVs requires financing. This study was supported by Wulandari (2015) study which stated that insufficient income made respondents did not routinely come to take the medicine, and vice versa respondents with middle to high income and work become private employees tend to always actively come to take antiretroviral drugs.

Conclusion

The growth of technology becomes good change for people living with HIV to be more effective in ARV medication program. PWLH needs the program for monitoring their ARV medication. The implementation E-Patuh based android and website system had positive outcome for increasing ARVs medication adherence.

After using E-Patuh during the treatment package program, it was found that 5 respondents still had difficulty remembering the time to take medication but on the other

hand there were increasing of adherence to 6 respondents who before using E-Patuh had trouble often skipping medication within four days. This compliance improvement is evidenced by no respondents claiming to have a problem with taking time to take medication time during the use of E-Patuh. . The ARVs adherence medication score in control group were relatively better at the beginning. Although in the control group there were no less adherence categories for the respondents, but the control group experienced a decrease in adherence after posttest. There were 2 respondents who expressed difficulties remembering the time of taking the medicine and 1 respondent said sometimes stop treatment if feeling better. Patient compliance issues in this control group tend to be time-dependent and the prevalence is low in pre-test. Different when done post-test after obtained 2 respondents expressed difficulties remembering taking medicine and 2 respondents stated stop treatment if feeling better.

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Factors that Correlate with The Health Services Seeking on Breast Cancer Patients

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Abstract

Most cases of breast cancer are found to be in an advanced stage. This is because of the patient delay in coming to health service after the emergence of early symptoms of breast cancer. It is necessary to identify factors that allegedly prevent patients from seeking health services as early as possible. The purpose of this study was to analyze factors related to the search for health services. This research used cross-sectional method. The population of this study was breast cancer patients where the sampling technique using consecutive sampling with the number of samples researched as many as 100 people. Data were obtained through a reliable questionnaire to use (Alpha Cronbach's questionnaire = 0.92, Alpha Cronbach's health questionnaire = 0.85). Analysis of this research data using univariate (frequency distribution), bivariate (Chi-Square) and multivariate (logistic regression). The result of bivariate analysis showed that the variables related to health seeking behavior are education (p value = 0.02; $r = 0.3$) and health belief (p value = 0.01; $r = 0.24$). While the variables that most related to health service seeking behavior was health belief (p value = 0.02) and OR value 3.46. This could be caused by patient's health belief in which the patient assumes that the symptoms were not dangerous and the choice of alternative medicine as the first choice and the patient's fear of treatment due to lack of information that obtained by the patient. It can be concluded that health beliefs are the most correlated factor with health-seeking behavior so it is necessary to consider the prevention efforts of breast cancer especially related to health belief. Community beliefs about routine health checks should be key interventions such as counseling and discussions with the community regarding the importance of routine health screening as part of early detection of disease.

Keywords: Breast Cancer, factors, health beliefs, health seeking behavior.

Introduction

Breast cancer is one of the health problems that cause a high number of morbidity and death in women. This is reinforced by data shown by Yang Liu, Jian Zhang, Rong Huang, We-Liang Feng, Ya-Nan Kong et al. (2017), where it is estimated that about 15% of deaths in women in the world are caused by breast cancer. Not only in the world level, Indonesia also has a high incidence of breast cancer (Yang Liu et al., 2017).

Based on the data from Infodatin Kemenkes RI (2015), breast cancer, especially in Indonesia is cancer with the highest percentage of new cases that reached 43.3% with the percentage of death reached 12.9%. Based on the data obtained from Bandung Health Department, the incidence of breast cancer in the city of Bandung is still high. The number of breast cancer patients from year 2014 to 2015 has increased from 239 cases to 523 cases. Despite the decline in the number of breast cancer cases from 2015 to 2016, the incidence of breast cancer cases is still high in 459 cases (Infodatin Kemenkes RI, 2015, Bandung Health Department, 2016).

The earlier treatment of breast cancer might be beneficial to reduce morbidity and mortality rate. Not only is needed treatment done as soon as possible, prevention is needed to reduce the rate of breast cancer in the late stages. The results of the research conducted by Unger-Saldana et al. (2015) showed that most of the respondents in their study (45%) were diagnosed as having advanced stage III and stage 4. This could be caused by various factors such as the delay of the patient themselves to seek treatment and delay in diagnosis of the system health services (Unger-Saldana et al., 2015)

Some actions can be done in preventing the occurrence of breast cancer such as implementing a healthy lifestyle and breast self-examination regularly, especially for women aged over 50 years. Unfortunately, prevention behavior like breast self-examination has not become something that is needed and important to be done by women. It can be seen from a research conducted by Kusumawati and Miasari (2014) which shown that someone who does not have a family history with breast cancer, 55% among them

do not do breast self-examination as a form of early detection of breast cancer (Putri, 2015; Kusuwamati & Miasari, 2014).

The high number of women who did not make early breast cancer detection efforts had an influence on the discovery of breast cancer cases diagnosed in an advanced stage (Wang, 2017). Mirfarhadi et al. (2017) in his study explains that there is one predictive factor that is significantly related to the delay of diagnosis and treatment in breast cancer patients one of which is not doing breast self-examination (SADARI) (Mirfarhadi et al., 2017).

Symptomatic patients who do not receive immediate medical help may be diagnosed with cancer in an advanced stage. Advanced stages of breast cancer will affect the quality of life and the prognosis of the patients. In stage I, the patient has a 70% chance of recovery so that the quality of life is not too disturbed. In stage II the possibility of recovery is 30-40%, which causes the quality of life at this stage began to be disturbed, especially physical and psychological problems. In stage III, the likelihood of life is low so the quality of life decreases. In stage IV, therapy is not very meaningful, causing the quality of life to be very bad. This indicates that the impact of the more late a person is diagnosed with cancer will affect the poor quality of life of the person (Moatter et al., 2015).

The lower mortality rates of breast cancer compare to the morbidity rates indicates the possibility of cancer recovering if it detected and handled earlier. About 30-50% of cases of cancer recently can be prevented (WHO, 2017). This can be achieved through behaviors that stay away from risk factors and the implementation of prevention strategies from existing research evidence. The burden of cancer can be decreased through early detection and good management to prevent further progressing of cancer that have a high chance of being cured if diagnosed early and treated adequately (WHO, 2017).

The results of a study by Wang (2017) showed a similar data which that early cancer detection will reduce the number of further pain and mortality caused by breast cancer significantly. The most important point for a good prognosis in cases of breast cancer is to identify the presence of cancer cells in the

early stages. There are now many approaches or actions to diagnose breast cancer as early as possible. Unfortunately, at this time almost 80% of cases of breast cancer in Indonesia diagnosed or known by health workers when it entered the advanced stage. This can be due to one of them by the expensive diagnostic checks that need to be done, takes a long time and is considered unsuitable for young women (Wang, 2017).

The number of cases of breast cancer found in advanced stages is caused by the delay in making decisions when they should go to health services (Glenz et al., 2002). Decision making of a person to visit or utilize existing health services is influenced by several factors that are important to be known, especially by health provider. There are many health models applied in the nursing practice such as Behavioral Model of Health Service Utilization to understand the attitudes and values of clients on health and disease, and to provide effective health services (Glenz et al., 2002; Notoatmodjo, 2012).

Theoretical approach of the Behavioral Model of Health Service Utilization allows to assist health professionals, especially nurses, where the use of this theory allows for an illustration of the relationships between the determinant factors of the use of health services, alleviating the forecasting of future needs on health services, determine the presence or absence of services from the use of health services that are one-sided, suggest ways of manipulating policies related to variables in order to provide better health services especially for breast cancer patients (Glenz et al., 2002; Notoatmodjo, 2012). This theory explains that there are three main factors that influence health service utilization behavior including predisposing, enabling, and need factor. Predisposing factors are factors inherent in the individual itself (such as age, sex, marital status, race, education, family type, occupation, health knowledge and beliefs). The enabling factors explain the individual's capabilities and the means by which the individual may utilize health care facilities (such as family income, health insurance ownership, access to health services and available health services). As for the need factor is a factor where a new person utilizes health services when individuals feel

disturbed by his health condition (Glenz et al., 2002; Notoatmodjo, 2012).

Health workers, especially nurses, need to analyze the process from the beginning of the onset of symptoms until the patients get treatment for breast cancer so the nurses know the factors that affect the patient's delay in obtaining medical help. There are two main factors that affect the delay of breast cancer patients to come to the health service including internal factors derived from within the individual itself and external factors originating from outside the breast cancer patients (eg. family) and health organizations that can facilitate early detection of cancer (Brousselle et al., 2017).

Factors included in the internal factors include the knowledge factor of the patient where the average patient does not know that a lump that appears is something that must be checked immediately so that when the symptoms appear most of patients do not take care it seriously. In addition, the presence of excessive fear and anxiety also became one of the obstacles of breast cancer patients to immediately check the situation when first appeared symptoms such as a lump in the breast (Anggraeni, Ngatimin, & Arsin, 2012). While that includes into external factors such as inequity access to the diagnosis that affects the early detection of cancer and family factors that also have an important role in decision making patients to come to health services. Families are the main drivers for their self-examination but breast cancer patients tend to ignore the invitations of their families. The suggestion from the study says that there needs to be a deeper involvement of health workers, especially in the field of better health promotion so that knowledge does not cause anxiety or excessive acknowledgment in patients (Brousselle et al., 2017, Anggraeni et al., 2012) .

In contrast to previous research results, Hikmanti et al. (2007) in his study said that there is no significant relationship of knowledge, work, fear, family support, health insurance, medical treatment costs, medical treatment other than hospital, family history and education of respondents to delayed treatment of breast cancer. This is made possible by other factors such as factors from local community leaders or factors of

health workers who have an influence on the immediate medical search behavior of breast cancer patients (Hikmanti et al., 2007).

West Java is the third highest province for most cases of breast cancer in Indonesia after Central Java and East Java. Therefore, it needs special attention by health workers, especially regarding the delay in breast cancer patients to be diagnosed in the early stages so as to facilitate treatment and increase the likelihood of recovery. According Pahria (2017) West Java is the province with the largest population in Indonesia where approximately 49.3% of its citizens are female. About 0.5% of women in West Java have breast cancer and predicted about 9.6% of young women in West Java are at risk of developing breast cancer. This needs to be an important concern for nurses in order not to increase the incidence rate of breast cancer in West Java (Pahria, 2017).

Nurses can play an active role in decreasing the incidence of late diagnosis in breast cancer patients. Nurses can play an active role in preventing late diagnosis in breast cancer patients especially in the prevention phase that focuses on groups at risk of developing breast cancer. Nurses can screen women who have a history of breast cancer and behaviors that are at risk for breast cancer (eg. smoking) where the nurse reviews risk group knowledge about signs and symptoms that need to be alerted towards breast cancer and invites the risk group to routinely perform breast self-examination behavior (check breast itself) and within a certain timeframe perform a radiological examination that can detect early breast cancer (Melo et al., 2017).

Based on some data from the results of research conducted by Brousselle (2017), Wang (2017), and Hikmanti (2007) where there are still some differences related factors that affect the decision making of breast cancer patients (especially factors knowledge, fear and support family) to visit health care facilities as early as possible and in West Java itself is not known for sure the underlying factors of decision making treatment of cancer patients, especially for patients in the city of Bandung.

Researchers are interested to know what factors and what the main factors behind a person late diagnosed breast cancer,

especially in the area of West Java. Through this research is expected to get a picture of the constraints of patients come to health services when the initial symptoms of breast cancer appear. By knowing it is expected to be done in the future secondary preventive efforts where health workers try to prevent cancer develop and cause complications or cause severity that will affect the quality of life of patients with breast cancer that will also affect the possibility of patients getting closer to the death as well it is expected that in the future patients who have symptoms of breast cancer in the early stages can be known as soon as possible so that healing efforts can be done more leverage.

This study aims to examine factors related to the search for health services in breast cancer patients with the specific aim of analyzing the relationship between predisposing factors: age, marital status, history of breast cancer, education, occupation, health knowledge and beliefs with health seeking behavior behavior as soon as possible in breast cancer patients; analyze the relationship between supporting factors: income, access to health services and ownership of health insurance with health seeking behavior as soon as possible in breast cancer patients; and analyze the factors most closely related to the search for health services as soon as possible by breast cancer patients.

Method

This study a cross-sectional study design with a total sample of 100 breast cancer patients that obtained from the cross sectional study sample calculation formula. The location of this study was in the working area of Bandung City Health Office and Cancer Stop Home in Sukajadi District. The data had collected from March to June 2018. Data collection techniques were conducted by distributing questionnaires to respondents to find out factors related to health service search behavior in breast cancer patients.

Data Analysis

Univariate analysis was done to describe the frequency distribution of several variables by calculating the median value of the total score of the respondents of each

variable. Bivariate analysis was done to see the relationship between two variables (independent and dependent variables) using Chi-Square test. Multivariate analysis was done using logistic regression test. The data

was analyzed using a statistical software.

Result
Predisposing Factors with Health Service

Table 1 Cross-Tabulation Between Predisposing Factors and Health-Seeking Behavior (N = 100)

Variables	Health service seeking behavior				p value	X ²
	≥ 3 months		< 3 months			
	(f)	(%)	(f)	(%)		
Age						
> 40 years	60	60.00	22	22.00	0.30	1.04
≤ 40 years	11	11.00	7	7.00		
Marital status						
Married	70	70.00	29	29.00	1.00	0.00
Single	1	1.00	0	0.00		
Education						
≤ High school	69	69.00	24	24.00	0.02*	4.55
> High school	2	2.00	5	5.00		
Occupation						
Working	26	26.00	16	16.00	0.08	2.90
Not working	45	45.00	13	13.00		
Family history						
No	70	70.00	26	26.00	0.07	2.27
Yes	1	1.00	3	3.00		
Knowledge						
Less knowledge	28	28.00	11	11.00	0.89	0.02
Good knowledge	43	43.00	18	18.00		
Health belief						
Negative	39	39.00	8	8.00	0.01*	6.18
Positive	32	32.00	21	21.00		

Table 2 Cross Tabulation Between Enabling Factors and Search Behavior Health Services (N = 100)

Variables	Health service seeking behavior				p value	X ²
	≥ 3 months		< 3 months			
	(f)	(%)	(f)	(%)		
Income						
< Regional Minimum Wage	66	66.00	23	23.00	0.07	2.64
≥ Regional Minimum Wage	5	5.00	6	6.00		
Health insurance						
No	1	1.00	0	0.00	1.00	0.00
Yes	70	70.00	29	29.00		

Access to health service						
Unaffordable	14	14.00	4	4.00	0.48	0.49
Affordable	57	57.00	25	25.00		

Table 3 Multivariat Analysis of Health Service Seeking Behavior

Variable	Coefficient	P	OR (CI 95%)
Education	1.27	0.19	3.56 (0.53-23.81)
Occupation	-0.60	0.23	1.83 (0.20-1.48)
Family history	-1.82	0.17	0.16 (0.01-2.22)
Health belief	1.24	0.02	3.46 (1.24-9.62)
Income	0.57	0.44	1.77 (0.41-7.65)
Constant	-0.33	0.06	0.72

Search Behavior

Table 1 above showed some variables that influence the delay in the seeking for health services (≥ 3 months). The delay in the seeking for health services is mostly found in respondents aged > 40 years (60.00%). Among marital marriage status, those status with married status (70.00%) showed a higher percentage on health service seeking behavior. Among occupation group, respondents who were not working showed a higher percentage on health service seeking behavior (45.00%). Among family history group, respondents that had no history of breast cancer in the family showed a higher percentage on health service seeking behavior (70.00%). Among knowledge group, respondents that had a good knowledge of breast cancer showed a higher percentage on health service seeking behavior (43.00%), and had negative health confidence showed higher percentage on health service seeking behavior (39.00%). While the results of Chi Square test showed that predisposing factors that have relationship with health service search behavior is the variable of education and health belief. While the variable age, marital status, occupation, history of breast cancer and knowledge there is no relationship with health seeking behavior in breast cancer patients

Enabling Factors with Health Service Search Behavior

From table 2 above shows that the delay in the search for health services (≥ 3 months) mostly occurred in respondents with income

$<$ regional minimum wage (66.00%), health insurance (70.00%) and access to affordable health services (57.00%). While the results of Chi Square test show that of the three supporting factors of income, ownership of Askes and Askes to health services all three have no relationship with health service search behavior.

Variable that have significant correlation with health service seeking

Of the five influential variables, health confidence was the only variable that significantly correlated with the health service seeking with the odd-ratio of 3.46. This means that breast cancer patients who have positive health beliefs will conduct health service search as soon as possible 3 times higher than patients who have negative health belief, after controlled variable education, occupation, income and history of breast cancer in the family.

Discussion

Predisposing Factors with Health Service Search Behavior

Based on education, respondents who experienced the most delay in the search for health services were respondents with low education level (\leq high school). In this study, there was a relationship between education and health seeking behavior in breast cancer patients. This means that the higher the level of a person's education, the higher possibility not to be late in searching for health services. Yang Liu et al. (2017) in his research that

women who have lower levels of education were likely to have poorer quality of life. People with low education usually live in areas far from urban and technological advancements in which one is difficult to be exposed to the possibility of early breast cancer screening so that the risk of delay in the search for health services and the diagnosis of breast cancer is higher in women with lower levels of education.

Based on the health beliefs, respondents experiencing delays in the search for health services were those who have negative health beliefs (39.00%). In this study, there was a relationship between health beliefs and delay in the search for health services. This may be due to several factors such as the patient presuming that the symptoms were not dangerous, the selection of traditional medicine as the first treatment, and the fear of breast cancer examination and treatment (Brousselle et al., 2017). Symptoms that appear were often regarded as something that was not dangerous because in general, the initial symptoms were felt like a lump does not cause pain so that they regarded it as something that was not harmful. Selection of treatment were the most of the respondents said they had undergone traditional treatment first before finally choosing medical treatment. As Rahayuwati's et al. study (2016) stated that the selection of therapies for breast cancer patients was influenced by the families and the environment. This was a lot happening in the community where people were more confident in what was widely spread in the community through word of mouth including traditional medicine that grows around the community. Fear of treatment also became one of the factors that influence the respondent's belief in health. Like chemotherapy treatment, many patients got information from the neighborhood around the dwelling that chemotherapy was a terrible treatment when it is well prepared then the side effects can be minimized.

Enabling Factors with Health Service Search Behavior

Based on the income, respondents who experienced the most delay were respondents with income < regional minimum wage (66.00%). In this study there is no relationship

between income and health seeking behavior in breast cancer patients. This means both women who have enough or insufficient income allow for late in searching for health services after the initial symptoms of breast cancer appear. Women who have enough income allow higher rates for early detection of breast cancer. But the economic status of a good economy is usually associated with a good job that allows to have a busy enough and not too concerned with health problems themselves. Women who have less income are more likely to be late in searching for health services because they do not have the cost to come to health services (Arndt et al., 2002).

Based on the ownership of the health insurance, respondents who experienced the most delay in the search for health services were the respondents who had health insurance (70.00%). In this study there is no relationship between the ownership of the health insurance and the delay in conducting health service search. This can be interpreted that people who have health insurance is not necessarily searching for health services as soon as possible. Rossalia and Wibawa (2016) in his research mentioned that patients who do not have Askes tend to be late in searching for health services because of the limitations in terms of the cost of treatment for breast cancer costs considerable. While in this study, most of the respondents who experienced delays precisely the patients who have health insurance. This is because the fear of treatment is greater, they tend to choose an alternative treatment that usually the side effects of treatment is very minimal. Most respondents also feel that the symptoms of the illness are not so dangerous that when the respondent feels no pain, the health costs borne by the government will not guarantee the patient to come to the health service as soon as possible.

Based on access to health services, respondents who experienced the most delay in the search for health services were those who said access to health services was still affordable (57.00%). In this study there is no relationship between access to health services and health service search behavior. This can mean that the patient whose residence is close to the health service is not necessarily go to

health services as soon as possible. Brousselle et al. (2017) in his research stated that so far the closest health facilities to the community residence usually have poor infrastructure facilities and less complete so that patients need time to come to health services that can diagnose diseases such as breast cancer.

Variable that have significant correlation with health service seeking

Health confidence is the most influential variable among other variables because in this health belief includes several factors that affect the behavior of a person such as the perception of the disease and the fear of an examination. So when a person feels that he is healthy when in fact there is a health problem and not immediately done the examination then this is the cause of a late person in searching for health services. The results of this study also indicate that breast cancer patients who have negative health beliefs will not conduct health service search as soon as possible 3.46 times higher than patients who have positive health beliefs.

The role of health workers is considered very important because when the patient considers the initial symptoms that appear is not a dangerous thing is required suatu prevention efforts to the wider community so that people assume that the symptoms that appear is not a thing that is not dangerous but is something that should be suspected and conducted examination as a state probably by health personnel.

Conclusion

Based on the results of research conducted can be drawn conclusion as follows:

1. Predisposing factors that have relationship to health seeking behavior are health education and belief. The age variable, marital status, occupation, history of breast cancer and knowledge have no relation to health seeking behavior in breast cancer patients.
2. The three variables in the supporting factors of income, ownership of access to health care and access to health services have nothing to do with health seeking behavior.
3. Based on the relationship between the overall variables obtained using logistic

regression analysis, the variables most closely related to health service search behavior are health confidence variables.

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Effect of Nei Guan Acupressure Point as Adjuvant Therapy on Highly Emetogenic Chemotherapy-Induced Nausea-Vomiting in School-Age Children with Cancer

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Abstract

Chemotherapy as a pediatric cancer treatment has nausea and vomiting side effects. Nausea and vomiting in school-age children with cancer can lead to nutritional, emotional, playing, and school function disorders, decreasing the quality of life in children. An adjuvant therapy that can decrease chemotherapy-induced nausea and vomiting is acupressure which is non-invasive and safe. Nei Guan acupressure point uses pressure technique on the wrist. This study was conducted to determine effects of Nei Guan acupressure on nausea and vomiting due to highly emetogenic chemotherapy in school-age children with cancer. The study design was quasi-experimental through a pre-post test design study approach, with single-blind control. Thirty respondents obtained from the average calculation of two population hypothesis test, were divided into a control and intervention group comprising 15 people respectively. Both groups got the same antiemetic. Measurement of nausea was performed three times during the study using the Pediatric Nausea Assessment Tools (PeNAT), while vomiting intervals were documented for every vomiting and retching. Data analysis used the Mann Whitney and independent t-test. The analysis result in the control group showed that the average nausea value tended to increase and the vomiting interval was faster than in the intervention group. In conclusion, Nei Guan acupressure affects nausea and vomiting due to highly emetogenic chemotherapy in school-aged children with cancer although it is not statistically significant ($p\text{-value} > 0.05$). Nurses are expected to monitor ongoing nausea and vomiting, and consider acupressure as adjuvant therapy, besides providing pharmacological treatment to reduce nausea and vomiting.

Keywords: Acupressure, chemotherapy, nausea, school-age children, vomiting.

Introduction

The Ministry of Health of the Republic of Indonesia (2015) explains that cancer is included in non-communicable diseases and is the cause of around 8.2 million deaths in the world in 2012. WHO data (2016) revealed the prevalence of pediatric cancer is approximately 4% of all cancer cases, and child mortality in the world due to cancer is estimated at 90,000 children each year. The Indonesian Hospital Association Data and Information Center (PERSI) (2014) reports that 2–4% of cancer incidence in Indonesia occur in pediatric patients. It estimates that every year there are approximately 11,000 cases of childhood cancer, and about 10% of child mortality is caused by cancer.

Childhood cancer management includes surgery, chemotherapy, and radiotherapy. The therapy can be single or combined. Providing treatment through radiotherapy and surgery is a local therapy while giving treatment through chemo is a systemic therapy (Balduci, 2008). The primary goal of chemotherapy is to cure, control or reduce the growth of cancer cells (Price & Wilson, 2009).

The incidence of side effects in pediatric patients is bone marrow depression, diarrhea, stomatitis, hair loss, skin disorders, and vomiting and nausea (Apriany, 2010). Chemotherapy-induced nausea and vomiting are the most common side effect in children. The study of Millennials, Baraz, Baraz, Nourt, and Baeis (2015) explained that the prevalence of chemotherapy-induced nausea and vomiting in pediatric patients is 54%–96%. The most feared experience by patients is nausea, while in the third place is vomiting. The response of vomiting to chemotherapy can occur after emetogenic agents have chemically stimulated the vomiting center. Emetogenic agents directly stimulate the release of serotonin (5 HT₃) from intestinal enterochromaffin cells to the Chemoreceptor Trigger Zone (CTZ) in the area postrema of the cortex and arouse the vomiting center, resulting in nausea and vomiting reactions (Rhodes & Mc Daniels, 2001). Related to this, chemotherapy drugs are classified into 4 emetogenic levels, which are high (>90%), medium (30% – <90%), low (10% – <30%) and minimal (<10%) (Children's Oncology

Group, 2015).

School-age children are the group at risk of experiencing nausea and vomiting. Batson et al. (2016) reveal that school-age children with cancer, who experienced nausea and vomiting after three months of chemotherapy show 24% increase in anxiety level and 28% in depression rate which results in emotional behavior changes, and nutritional disorders. This condition can interfere with the primary task of school children, namely fulfilling adequate nutritional needs, carrying out school functions and playing (Wong, Hockenberry, & David, 2011).

Nutrition is a top priority in the growth period of school-age children as at this age children need sufficient energy to think and move according to their developmental tasks (Ball, Bindler, & Cowen, 2012). Also, a study conducted by Nurhidayah, Hendrawati, Mediani, and Adistie (2016) found that 53.3% of school-age cancer patients had a poor quality of life with the lowest score on school functions due to chemotherapy-induced nausea and vomiting. The impact of nausea and vomiting on school function results in children often skip school, get quickly tired when attending lessons and have difficulty to concentrate while studying. The playing function impairment in school children may be caused by fatigue due to chemotherapy-induced nausea and vomiting.

The management of nausea can be performed by pharmacological and non-pharmacological therapy while the non-pharmacological management can be performed on pediatric patients as adjuvant therapy both in hospitals and at home as palliative care to improve quality of life. According to Suardi (2011), the use of complementary therapy can divert a person's uncomfortable perception so that a balance between body, mind, and spirit is expected to reduce the stress he/she faces. Nurses, as health workers can perform complementary traditional health services which are empirically beneficial and safe, as is stated in the Government Regulation of the Republic of Indonesia No. 103 the Year 2014, article 30 paragraph 2.

Some types of complementary therapy that can be executed in pediatric cancer patients are music therapy, food supplements

(herbal), aromatherapy, imaginary guidance and massage therapy (Ball et al., 2012). Massage therapy in the form of applying pressure to specific points has advantages over other treatments in reducing chemotherapy-induced nausea and vomiting in children can be performed in a caring room, is non-toxic, free of charge, harmless and does not use any media.

Acupressure uses fingertip pressure. The pressure is applied using the fingertips, beginning with mild stress then gradually the pressure is increased until a gentle but painless sensation is felt (Rusdiatin & Maulana, 2007). This therapy is derived from an acupuncture therapy based on the concept of ancient China that uses special needles to acupuncture points (Xie Wei) (Jie, 2008). The central principle in acupressure is to balance between yin and yang. In the human body, there is a meridian line (Jing Luo) which is a channel for flowing vital energy (Qi) and blood (Xue) and serves to connect Zhang Fu organs that are associated with four limbs (Sukanta, 2008). The choice of acupressure as a complementary therapy is safe and effective which can minimize the side effects of nausea and vomit with the pharmacological treatment provided (Hosseini, Tirgari, Forouzi, & Jahani, 2016). One of the acupressure points to reduce chemotherapy-induced nausea and vomiting is the Nei Guan point. A study conducted by Shen & Yang (2016) state that Nei Guan acupressure therapy can significantly increase energy on the meridian line by reducing severe vomiting nausea in cancer patients receiving chemotherapy. This acupressure point is easier to use in pediatric patients than other positions because the location of the pressure point is accessible, easy to learn, non-invasive and recommended for the recovery of the digestive tract (Miao et al., 2017).

Based on the previous explanation, the inference is that Nei Guan point acupressure can be performed quickly, effectively, and is well tolerated in pediatric cancer patients as adjuvant therapy. Acupressure is non-invasive, so it is not painful and is a touch therapy. The difference with the above research is that the study would be carried out by considering highly emetogenic chemotherapy and specific nausea and vomiting instruments to pediatric

patients. This study aimed to determine the effect of Nei Guan acupressure point as adjuvant therapy for highly emetogenic chemotherapy-induced nausea and vomiting in school-age children with cancer.

Method

This research was a quantitative study with a quasi-experimental research design using a single-blind approach to pre-post test design study. The study was conducted at the Kenanga 2 Room, Dr. Hasan Sadikin Hospital Bandung in August-September 2017. This study obtained approval from the Health Research Ethics Committee of Universitas Padjadjaran with number LB.04.01/A05/EC/204/VII/2017.

The study subjects were obtained in parallel based on a randomized allocation list (randomization table) that was made without the knowledge of the researcher and was only known by the coordinator rater as the study was single blind. The selection of study subjects was through consecutive sampling technique based on specific criteria until the minimum number of study subjects was fulfilled. Inclusion criteria for the study subjects used in this study included obtaining highly emetogenic pharmacology, platelets $> 50,000 / \text{mm}^3$, obtaining intra-vena or intrathecal chemotherapy.

The number of the study sample was 30 people obtained from the results of calculation of the average hypothesis test of two populations. The study sample was school-age children (6–12 years) who received highly emetogenic chemotherapy. The sample was divided into two groups, namely the control and intervention group as many as 15 people respectively. The control group received standard pharmacological therapy in the form of anti-emetic administration, while the intervention group received standard pharmacological treatment in the form of anti-emetic and intervention of Nei Guan acupressure as adjuvant therapy. Nei Guan acupressure is performed for two days and given three times a day, 30 minutes before chemotherapy, before breakfast and before dinner. Five raters (research assistants) who were previously trained, assisted in the

acupressure treatment and data collection.

The measuring instrument used in this study is the Pediatric Nausea Assessment Tools (PeNAT) made by L. Lee Dupuis, M.Sc., Phm., FCSHP. The researcher has received permission to use the instrument and change the language, so the researcher conducted a back translation, content validity and reliability test with the Interclass Correlation Coefficient (ICC) test to 5 raters using media hand out and video. The content validity test was carried out by two experts, namely child nursing and palliative care experts. The result of the test obtained a value of 0.75 after using the Gregory formula, so it indicated that the instrument had a high validity value. The reliability test was carried out on ten pediatric patients with cancer whose results were obtained with a kappa value of 0.866 which indicated that the degree of conformity among the five raters had high stability.

Measurement of nausea value was carried out three times, namely 1 hour after chemotherapy (P1), after waking up the second day (P2) and before going to bed the second day (P3). Measurement of vomiting interval in both groups was carried out on the first day of chemotherapy until the second day. After the respondent parents' submitted the

informed consent, the researcher explained about recording the time of vomiting/nearly vomiting for two days. Vomiting intervals were recorded in the sheet provided by the researcher. Parents wrote down the time each child experienced vomiting or almost vomited.

The numerical comparative hypothesis test in pairs for the measurement of nausea values P1, P2 and P3 in each group used the Friedman test because measurements were performed more than twice and were not normally distributed. The numerical comparative hypothesis test between the control and intervention group in the nausea scale measurement P1, P2 and P3 used the Mann Whitney test because it was not normally distributed. The analysis was also used to determine the difference in mean of vomiting interval between the control and intervention group calculated in minutes. The measurement of an unpaired numerical comparative hypothesis test for the difference in vomiting interval used unpaired t-test because it was normally distributed.

Result

Table 1 Frequency Distribution Based on Characteristics of Respondents in Control and Intervention Group (n = 30) at Dr. Hasan Sadikin Hospital Bandung

Variable	Total	%	Group	
			Control (n=15)	Intervention (n=15)
Sex				
Man	17	56.67	9 (60,0)	8 (53,3)
Woman	13	43.33	6 (40,0)	7 (46,7)
Age (years)				
6–8 years	19	63.34		
9–10 years	4	13.33		
11–12 years	7	23.33		
Average				
± SB			8 ± 3	8 ± 2
Range			6–12	6–12
Type of Cancer				
Systemic	11	36.67	4 (26,7)	7 (46,7)
Solid	19	63.33	11(73.3)	7 (46,7)
Experience of Vomiting				

Yes	25	83.33	11(73.3)	14(93.3)
No	5	16.67	4(26.7)	1(6.7)

Table 2 Nausea Value Differences on First (P1), Second (P2) and Third (P3) Measurement in Control Group

Control Group (n=15)	Nausea Value			p ^a -Value
	First Measurement (P1)	Second Measurement (P2)	Third Measurement (P3)	
Median	1,00	1,00	2,00	0,001*
Min.-max. Range	1,00 – 2,00	1,00 – 3,00	1,00 – 4,00	

* Analysis using the Friedman test, significant $p \leq 0.05$

Table 3 Nausea Value Differences on First (P1), Second (P2) and Third (P3) Measurement in Intervention Group

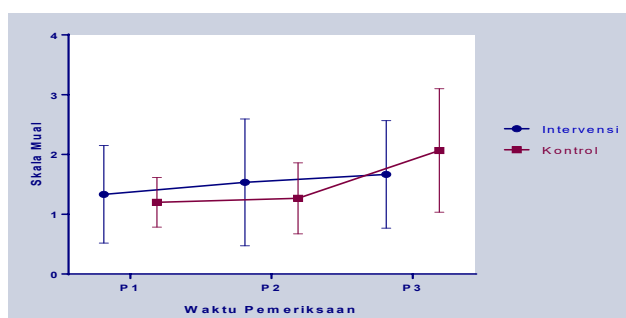
Intervention Group (n=15)	Nausea Value			p ^a -Value
	First Measurement (P1)	Second Measurement (P2)	Third Measurement (P3)	
Median	1.00	1.00	2.00	0.244
Min.-max. Range	1.00 – 4.00	1.00 – 4.00	1.00 – 4.00	

Note: Analysis using the Friedman test, significant $p \leq 0.05$

Table 4 Nausea Value Differences among P1, P2, and P3 in Control and Intervention Group

Measurement	Control Group (n=15)		Intervention Group (n=15)		p-Value
	Median	Min-Max	Median	Min-Max	
First (P1)	1.00	1.00–2.00	1.00	1.00–4.00	0.967
Second (P2)	1.00	1.00–3.00	1.00	1.00–4.00	0.713
Third (P3)	2.00	1.00–4.00	1.00	1.00–4.00	0.305

Note: Analysis using the Mann Whitney test, significant $p \leq 0.05$



Graph 1 Differences in mean values of nausea in the control and intervention group

Table 5 Differences in Vomiting Intervals between Control and Intervention Group

Vomiting Interval (Minute)	Group		p-Value
	Control n=11	Intervention n=9	
Median ± SD	289,4 ± 148,4	313,6±187,0	0,751
Range	82,5 – 513,3	84,6 – 724,5	

Note: Analysis using an unpaired t-test, significant $p \leq 0.05$

The characteristics of the respondents indicated sex was dominated by male (56.67%). The highest age in the two groups was 6–8 years on average (63.34%) (Table 1). Most cancers were solid tumors (63.33%) with the most diagnosed disease, Rhabdomyosarcoma. Most respondents in both groups had previous experiences of nausea and vomiting (83.33%).

The mean of nausea value in the first measurement and the second measurement had the same value (median = 1). The mean value of nausea in the third measurement tended to increase (median = 2). Results of the Friedman test obtained a p-value of 0.001 ($p\text{-value} \leq 0.05$) so it can be inferred that in the control group there was a significant difference in the mean value of nausea between P1, P2, and P3 (Table 2).

There was no difference in the mean value of nausea for the three measurements because they had the same value (Median = 1.00). Statistical tests using the Friedman test obtained a p-value of 0.244 ($p\text{ value} > 0.05$), so the result showed that in the intervention group there was no significant difference in the mean of nausea value between P1, P2, and P3 in the intervention group (Table 3).

Statistical test results on measurements between the control and intervention group using the Mann Whitney test showed that the first measurement (P1) was 0.967, the second measurement (P2) was 0.713, and the third measurement (P3) was 0.305. The three measurements showed that there were no significant differences marked with a p-value > 0.05 (Table 4).

Furthermore, there was a tendency of rising nausea values in the control group compared to the intervention group (Graph 1). The study results explained it as clinically significant, but statistically insignificant (Dahlan, 2010).

Also, the mean vomiting interval showed that the vomiting interval in the control

group was faster (289.4 minutes) compared to the intervention group (313.6 minutes). The results of unpaired t-test showed that the use of acupressure affected vomiting/ almost vomiting after chemotherapy even though it was not statistically significant ($p\text{-value} > 0.05$) (Table 5).

Discussion

Nausea and vomiting are side effects of chemotherapy which are most often felt by pediatric cancer patients. The response of vomiting to chemotherapy can occur after the vomiting center receives chemical stimulation from the emetogenic level. The acute phase of nausea vomiting occurs when chemotherapy and radiation drugs cause serotonin release from enterochromaffin cells in the intestine. Increased serotonin receptors or 5-Hydroxytryptamine type 3 (5HT3) in the central nervous system area, especially in the CTZ area, will cause nausea and vomiting. Vomiting occurs when the CTZ stimulates the vomiting center, and efferent impulses are sent through cranial nerves V, VII, IX, X, XII and spinal nerves to the central area of salivation, abdominal muscles, respiratory center, and nerve center (Rhodes & Mc Daniels, 2001).

Some of the effects of nausea complained by several study subjects were reduced appetite and sleep disorders. Decreased appetite can lead to a risk of nutritional deficiencies. Owen, Hanson, Mc Arthur and Mikhailov (2013) explain, approximately 46% of children and adolescents with cancer are malnourished or at risk of malnutrition. Many of those who lose appetite do not even want to eat at all. Hence, it is often found that hospital food is still left or not touched at all. Besides a decreasing appetite is the impact of chemotherapy side effects, it can also be due to the type of food that is not generally served

like at home, while school-age children need adequate nutritional intake in increasing growth and development according to their age level.

Rahmayanti and Agustin (2015) explain school-age children with cancer who get chemotherapy have poor sleep quality. Nausea can cause sleep disorders which causes discomfort. Discomfort due to nausea from chemotherapy effects can decrease the quality of life of children with cancer as nausea causes fatigue (Sefrina, Nurhaeni, & Hayati, 2014). Fatigue can interfere with the developing tasks of school children whether playing or studying.

Several study subjects felt nauseous complaints a few hours after undergoing highly emetogenic chemotherapy. This is in line with several studies explaining that the peak of nausea and vomiting can occur after 1–2 hours after chemotherapy, but other studies reveal that the height of acute vomiting will reach a maximum of 5–6 hours in the first 24 hours after administration of chemotherapy (Enikmawati, 2016; Rithirangsrirroj et al., 2014).

The administration of antiemetic drugs before chemotherapy aims to prevent nausea and vomiting as a result of the highly emetogenic level. Gilmore et al. (2013) explain that without prophylactic antiemetic drugs, the incidence of chemotherapy vomiting is between 30% and <90% in chemotherapy drugs with moderate and high emetogenic levels, so administration of antiemetics should be before chemotherapy. Prevention of nausea and vomiting with antiemetic administration will successfully control nausea and vomiting in the acute phase, namely 0–24 hours after the chemotherapy administration.

The administration of antiemetic therapy in both groups was in the form of ondansetron via intravenous. Ondansetron is one of the types of antiemetic which is antagonistic for serotonin receptors. Katzung, Master, and Trevor (2013) describe serotonin receptor antagonists as potent antiemetics with the mechanism of action of blocking serotonin receptors in the vomiting center and Chemoreceptor Trigger Zone mainly through peripheral serotonin receptor blockade in spinal afferent nerves.

The statistical test results between the two groups showed that the test results were not significant but from the mean values between groups explained that acupressure had the effect of suppressing chemotherapy-related nausea. The results of the mean nausea value showed that the control group tended to increase the mean value of nausea, while the intervention group did not experience an increase (Graph 1).

Acupressure is one of the adjuvant therapies by applying pressure to the skin on the acupoints. The pathological state of nausea and vomiting can occur due to a chronic disease which causes weakness in the stomach (Wei). Applying acupressure can accelerate the circulation of energy (Qi) and blood (Xue) through the flow of meridian lines (Jing Luo), after performing massage stimulations to the appropriate points (Jie, 2008). The acupoint for nausea and vomiting is the Nei Guan point. This point will stimulate the release of alpha beta ($\alpha\beta$) and alpha (α) fibers through sensory receptors. These fibers will interact with the central nervous system which results in endorphogenic cells removing endorphins from the hypothalamus. The increased levels of endorphins in the blood and cerebrospinal fluid will cause a sense of comfort and decrease the impulse of nausea and vomiting in the area of Chemoreceptor Trigger Zone (CTZ) and vomiting center (Dastgir, 1988; Syarif et al., 2011).

Nausea and vomiting felt by people with cancer who get chemotherapy are acute and slow nausea and vomiting. Syarif et al. (2011) explain that patients who receive chemotherapy will experience mild nausea and vomiting on the first day and will increase on the second day. This study contrasted with the explanation because the intervention group which received acupressure in this study did not increase the mean value of nausea on the second day. This result is in line with the study result by Eunice (2012), explaining that the effect of Nei Guan acupressure is noticeable on the second day to the fifth day.

The administration of acupressure and antiemetics has a similar goal, which is to provide comfort by decreasing the value of nausea and vomiting. The mechanism

of decreasing nausea and vomiting in both is different; acupressure is by increasing endorphins and antiemetics by blocking serotonin receptors. The effect of acupressure administration was illustrated in the intervention group with the value of nausea in the first to third measurements did not increase, and the vomiting interval was longer. This showed that the administration of adjuvant therapy along with pharmacological treatment was more influential in decreasing the value of nausea compared to merely pharmacological administration. The inference was that giving acupressure affected suppressing nausea and vomiting due to chemotherapy.

Conclusion

Based on the study results, the majority is male respondents; they have a solid tumor type, and previous nausea and vomiting experiences. Also, the study results show that the control group tends to increase in the mean of nausea and vomiting, and vomiting intervals are faster. The conclusion is, the effect of applying acupressure to emetogenic chemotherapy-induced nausea and vomiting in school-age children with cancer is clinically significant, even though statistically not significant.

There are limitations in this study, namely taking too many raters can affect the depth of acupressure suppression, and the intervention was carried out for two days to obtain data on the trend of nausea due to the administration of highly emetogenic chemotherapy and applying pressure on other acupressure points given singly or combined.

For health services: it expects that the study results may be input for the hospital as a service standard in handling chemotherapy-induced nausea and vomiting, and coordinating with the health promotion section to facilitate the creation of leaflets and videos on Nei Guan acupressure. Giving acupressure can be considered as an option for nurses and patient's parents as adjuvant therapy which is carried out simultaneously with the provision of pharmacological treatment.

For researchers: it expects that the study

results can be used as input to carry out further research related to the use of acupressure to reduce chemotherapy-induced nausea and vomiting by considering the homogeneity of cancer types, other age of children, and cycle of chemotherapy. Besides Nei Guan point, further research can be carried out to other points, both singly and in combination.

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Food and Activities Taboos among Sundanese Pregnant Women

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Abstract

Taboos are found everywhere including Indonesia. There are different types of taboos in Indonesia especially during pregnancy. This study aimed to identify the practice of taboos related to food and activities among Sundanese pregnant women in West Java, a province with the largest population. A cross-sectional study was conducted with 312 pregnant women, who come to antenatal care at maternal and child health clinics of hospital, health care center and private midwifery clinics at four districts area in West Java province (Cianjur, Bandung, Sumedang and Garut) from October–December 2014. The data were selected purposively used the questionnaires included important demographic characteristics and questions regarding food and activities taboos during pregnancy. SPSS Win.12.0 were used for data analysis. The practice of food and activities taboo among pregnant women showed were about 29.4% very often, 42.1% often, 22.4% rarely, and 6.1% never in avoid to eat certain foods and to do particular activities during pregnancy. No statistically significant association was found between food and activities taboo during pregnancy and data demographics of respondents ($p>.05$). Still often done by pregnant women in avoid to eat certain foods and restriction to do particular activities. To assess the true picture we need to conduct larger studies in the community with interview method. These findings would be an important information for nurses in developing health education in maternal periods, and considering women's culture and beliefs in nursing care plan.

Keywords: Activities, foods, taboos, pregnant women.

Introduction

The traditional background sometimes influences of the woman's behavior during pregnancy. Maintaining a healthy pregnancy is very important to the general health of the pregnant mother and her fetus. According to World health organization (2016), Indonesia is one of the country has the biggest maternal mortality ratio (MMR) in South East Asia and the larger number of mortality contribution. The most frequently of the causes of maternal (pregnancy-related) deaths still dominate by haemorrhage 30.3%, hypertension 27.1%, and 7.3% infection (Soedarmono, 2017). There are several factors that explain why maternal mortality is still high, it can be attributed to antenatal care, nutritional status of pregnant women, success rates of maternal and infant health services, family planning programs, environmental conditions, and socio-economic conditions (WHO, 2016).

The ignorance about nutritional needs and do any activities during pregnancy worsens the outcomes of pregnancy. Commonly, maternal mortality are often rationalized through assumption that mother may have done wrong during pregnancy such as unattended prenatal care or belief in certain activity (eg, taboos).

In order to get wellness throughout the pregnancy and into early parenthood, pregnant woman and her family should have a proper planning and preparation for the pregnancy. Unfortunately, in Indonesia, it's a common phenomenon that pregnancies happen expectantly. Many married women did not want to be pregnant after having two or three children, but they were not using contraceptives, or they were using methods with relatively high failure rates.

In exploring the food and activities taboos during pregnancy, for example Ali (2004) found that pregnant mothers believing if their restricting all foods during the first 6 months that would be easy to labor a small baby. Similarly, there is considerable evidence of women's beliefs and practices regarding food restriction during pregnancy and lactation in Korea, that women self-food restriction as Asian women are advised to avoid cold foods because they are not good for the mother and baby. Thus, this self-restriction eating certain

food differs from because food unavailable or poverty. However, the cultural tradition also effects as a cause of dietary behavior. Even though, without a scientific basis, popular myths about the mother's diet during pregnancy and breastfeeding can become barriers to maternal health and lead to unnecessary dietary restrictions in pregnancy (Goun, 2017).

Pregnancy and childbirth have universally been accepted as a natural means of continuing human's life, although in Indonesia, the cultural variation in beliefs about pregnancy and childbirth are considered more important and also the specific social aspects by many ethnic groups. Therefore, many beliefs and practices relating to childbearing process must be observed by the woman and her family to ensure the health and well-being of herself and her newborn baby (Liamputtong Rice, 2000).

Considering the importance of daily activities including meeting nutritional needs and carrying out appropriate activities during pregnancy and the direct impact of pregnancy outcomes, this study will identify pregnant women who practice food and activities according to general characteristics.

Method

A cross-sectional study was conducted with 300 pregnant women who attended to antenatal care at maternal and child health clinics of hospital, health care center (Puskesmas) and private midwifery clinics at four districts area in West Java province (Cianjur, Bandung, Sumedang and Garut) from October–December 2014. A minimum sample of 300 pregnant women was required using 5 percent level of significance, a bound error of 5% and an anticipated prevalence of 50 percent. The researcher had discuss with the head of maternal and child health clinic, and division of education hospital to explain the purpose of study, procedure and conduction of the data collection and how to respond any questions. This study was conducted in accordance and approval of the nursing faculty of Universitas Padjadjaran. The permission obtained from the directors of those hospitals and facilitate to processing

data collection. A cover letter form give to the participants explained about the purpose of the study and instructions how to complete the questionnaire. The form asks for decision to participants if they would to participate in this research or not. In addition, this cover letter specified that the participant is completely voluntary with no risk or benefits. Confidentially were maintained by the list of names or any identifying personal information on questionnaires. These questionnaires kept for five years

The questionnaires included important demographic characteristics and questionnaires related with food and activities taboos during pregnancy. Hypothesize measurement models based on the questionnaires were tested through confirmatory factor analysis (number of cases =30). Using correlation technique score items with total score through coefficient correlation product-moment was computed and alpha Cronbach's. Internal Consistency Reliability was estimated using Cronbach's

coefficient alpha. The validity and reliability coefficients for the subscale of taboos instruments was Cronbach's $\alpha = .86$

Appropriate statistical analyses were performed with the software SPSS 1Win. 12.0 For Windows. Frequencies and percentages were calculated for demographic profile like women ages, gestational age, have been pregnant, education background, occupation, and monthly family income. Mean and standard deviation are reported for analysis result questionnaires. Statistical analysis included summation of scores of each participant (n=300) and measures of variability (range, mean and standard deviation). Furthermore, this study are for expanded of statistical analysis and it used by t-tests. The level of statistical significant was set on .05 to see if there was a significant finding between practical of food and activities taboos across to demographic data.

Result

Table 1 Distribution Frequency of Demography Characteristics of the Pregnant Women

Characteristic	Category	F	%
Age	Less than 20	30	10
	20–29	169	56
	30–39	77	26
	40 or greater	24	8
Gestational Age	Trimester I	59	20
	Trimester II	102	34
	Trimester III	139	46
Parity	Primi gravida	128	43
	Multigravida	142	47
	Grande multigravida	30	10
Education	Low education	242	81
	Middle education	31	10
	Higher education	27	9
Employment Status	Employed	79	26
	Not employed	221	74
Monthly Family Income	Less than IDR 1,000,000	141	47
	IDR 1,000,000 to IDR 2,000,000	101	34
	IDR 2,000,000 or more	58	19

Table 2 Percentage Distribution of Various Food and Activities Taboos during Pregnancy by Frequency Level

Question Items	Very Often n (%)	Often n (%)	Rarely n (%)	Never n (%)	M ± SD
Avoid too much sleeping	8(12.7)	127(42.3)	115(38.3)	20(6.7)	2.61± .79
Avoid eating a fatty food	64(21.3)	131(47.3)	93(31.0)	12(4.0)	2.82± .81
Avoid eating seafood like eel, shrimp, octopus, crab, squid, ray fish, other fish	10(3.3)	111(37.0)	125(42)	54(18.0)	2.26±.79
Husband avoid to kill the animal	85(28.3)	144(48.0)	68(22.7)	3(1.0)	3.04±.74
Avoid to see the wild and frighten animal	45(15.0)	134(44.7)	85(28.3)	36(12.0)	2.63±.88
Avoid to hate someone	197(65.7)	79(26.3)	16(5.3)	8(2.7)	3.55±.72
Avoid to rude behave to others	208(69.3)	71(23.7)	13(4.3)	8(2.7)	3.60±.70
Avoid to going out in the evening	97(32.3)	161(53.7)	32(10.7)	10(3.3)	3.15±.74
Avoid to watching criminal's television program	58(19.3)	174(58.0)	64(21.3)	4(1.3)	2.95±.68
Avoid to hearing the bad news	88(29.3)	185(62.0)	27(9.0)	0	3.20±.59
Restriction to eat some kind of fruits and vegetable like pineapple, avocado, pomegranate, guava, orange squash, durian, jack-fruit, papayas, sugar cane, and eggplant	55(18.3)	55(18.3)	113(37.7)	77(25.7)	2.29±.04
Avoid to see a moon eclipse	251(83.7)	48(16.0)	1(0.3)	0	3.83±.38
Avoid to drink a cold water	61(20.3)	145(48.3)	78(26.0)	16(5.3)	2.84±.81
Avoid to eat in big plate during pregnancy	61(20.3)	145(48.3)	78(26.0)	16(5.3)	2.84±.81
Avoid to cut hair	61(20.3)	145(48.3)	78(26.0)	16(5.3)	2.84±.81
Avoid to fishing	61(20.3)	145(48.3)	78(26.0)	16(5.3)	2.84±.81
Avoid to preparing the baby's needs during pregnant	61(20.3)	145(48.3)	78(26.0)	16(5.3)	2.84±.81
Total	88(29.4)	126(42.1)	67(22.4)	18(6.1)	2.95±.33

Table 3 The Correlation between Demographic Characteristics Data and Taboos

Demographic Data	Food taboos		Activities taboos		Total Score	
	Mean±SD	F or t (p)	Mean±SD	F or t (p)	Mean±SD	F or t (p)
Age						
<20	2.90±.41	5.15(.12)	2.58±.35	2.67(.05)	2.91±.41	.16(.93)
20–29	3.20±.50		2.77±.40		2.96±.32	
30–39	3.06±.49		2.69±.39		2.94±.33	
>40	3.33±.48		2.82±.41		2.95±.34	
Gestational Age						
Trimester I	3.29±.46	3.00(.06)	2.85±.41	3.41(.06)	2.96±.37	.18(.83)
Trimester II	3.13±.53		2.67±.40		2.96±.30	
Trimester III	3.10±.48		.72±.39		2.94±.33	
Parity						

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Primigravida	3.15±.49	03(.97)	2.71±.42	.26(.77)	2.95±.36	.49(.61)
Multigravida	3.14±.51		2.74±.38		2.94±.29	
Grande multigravida	3.16±.48		2.76±.41		3.00±.35	
Education background						
Low education	3.19±.49	1.45(.23)	2.77±.42	1.83(.12)	2.94±.34	1.75(.14)
Middle education	3.03±.51		2.60±.38		2.86±.31	
Higher education	3.05±.48		2.70±.41		3.08±.27	
Employment status						
Employment	3.13±.49	.35(.55)	2.73±.38	2.76(.39)	2.95±.32	0.34(.56)
Not employment	.16±.50		2.73±.41		2.95±.33	
Monthly family income						
< IDR 1,000,000	3.22±.48	2.97(.05)	2.79±.41	3.02(.05)	2.93±.35	.35(.71)
IDR 1,000,000–2,000,000	3.12±.52		2.71±.40		2.96±.32	
> IDR 2,000,000	3.03±.49		2.64±.37		2.97±.29	

This research findings divide into demographics characteristic data, practically of food and taboos activities and correlation between demographics data with food and activities taboos. The demographic profiles of the samples are presented in Table 1. Pregnant women in all of period of pregnancies whose came to obstetric clinic without high-risk condition. All the participants dominated by maternal age 20 and 29 years (56.3%). The gestational age in trimester III (46%) which week's gestation was set based on the subjects self-report of their due date and the medical record. Most of women in multigravida (43%), and (80.7%) of participants were low-education category, which they education level were elementary school and junior secondary school. Also the pregnant women mostly as a housewife (73.7%) and their monthly incomes about IDR 1,000,000 (\$100 USD) or less.

The table 2 showed about practically of food and activities taboos among pregnant women during pregnancy. The higher

responses from participants answered is “often” (42.1%). Which the highest mean for question “avoid to seeing a moon eclipse” (3.83±.38), it is describes that some pregnant women forbidden to see moon eclipse (83.7%). The higher mean in taboos activity was (3.60±.70) for a question “avoid to rude behave to others”, indicating that some of pregnant women (69.3%) keep away from unpleasant behavior during pregnancy. Other responses very often frequently by women pregnant was “avoid to hate someone” (65.7%) with mean (3.55±.72). Furthermore the others higher mean score findings according to taboos activity for questions: “avoid to hear the bad news during pregnancy” (3.20±.59), “avoid going out in the evening” (3.15±.74), and question for “husband avoid to kill the animal” (3.04±.74), and the lowest score is the question by “avoid to eat some seafood like eel, shrimp, octopus, crab, squid, ray fish, other fish” (2.26±.79). Other responses from participant as food taboos was “restriction to eat some kind of fruits and vegetable like pineapple, avocado,

pomegranate, guava, orange squash, durian, jack-fruit, papayas, sugar cane, and eggplant" (2.29±.04), although most participant answered in "rarely" (37.7%).

Discussion

Our study show a high percentage of respondents' taboos in belief to avoid some activities during pregnancy. If we compare all activities of Sundanese pregnant women, they are prefer to do a good things than negative activities, such as avoid to kill the animal, avoid to rude behave to others, and avoid to hearing the bad news. Although there are some activities that are avoided by pregnant women which have nothing relevance with a good or bad behave, including avoid too much sleeping, avoid to see the wild and frighten animal, avoid to going out in the evening, avoid to watching criminal's television program, avoid to see a moon eclipse, avoid to cut hair, avoid to fishing, and avoid to preparing the baby's needs during pregnant.

The reason for these high numbers could be, because the respondents were more health conscious and belief that activities during pregnancy have contribution to their pregnancy outcomes. Drawing from this result that the majority of women avoid eating certain foods such as sea foods, fruits and vegetables. The most common reason women said the reason for avoiding eating certain fruits or vegetables is fear of having an abortion. Other reasons avoiding for such activities related to the taboos' during pregnancy had about labor curse. Many mothers are told to avoid eating in a big plate because it thought to cause large placenta and labor obstruction. Similarly, there is considerable evidence of women's beliefs and practices regarding food restriction during pregnancy and lactation in Pakistan, reported that pregnant mothers believing if their restricting all foods during the first 6 months that would be easy to labour a small baby (Ali 2004). Also, the study from Schlenker (2015) identified a number of factors that are likely to influence personal perception of foods. How people perceive themselves in relation to food and food patterns plays a role in their attitudes toward food and personal eating

behaviour.

This study in line with previous studies in Bangladesh showed that, most of the pregnant mother had a tendency of not to eat certain foods such as meat, they believed that it would lead to the birth of a large baby, which would hamper the smooth delivery and they have beliefs if they eat 'duck meat' might cause of asthma, cold and cough, allergy, pressure, digestion problem and afraid the baby will be voice like a duck. Also 'goat meat' might cause asthma, hot temper of child, bad smell of child's body and diabetes (Bhuiyan, 1988). Our study also showed that pregnant women avoid to eat seafood like eel, shrimp, octopus, crab, squid, ray fish, and others fish, even though they do not give any reason. However, this finding supported by study from Bhuiyan (2001) in Bangladesh and India, which they study found that women do not eat fish during pregnancy, because they beliefs eat a kind of fish could be increased movement of fetus and may cause child's Hysteria. Other reason explain by the women that "Boal fish" may cause big mouth, cold and cough disease of child. Whereas a study in India also have misbelieves about fish, their pregnant mother thinks that fish is 'hot food' and it might increase the temperature of their child. Regarding superstition about some fruits and vegetables, previous study in Bangladesh showed that, fruits like pineapple might cause miscarriage (Valenski, 2017). The study in Nigeria, also showed that most of the women believes that pineapple might cause abortion; child's skin might have eye spot like pineapple. Some women believes that black berry may cause black skin like black berry, others believe that, if they drink coconut water, their child's eyes might be white. There have also some misbelieves about tea, coffee, particularly at in local government area, in Nwangele showed that, tea, coffee might causes excessive bleeding during labor and delivery (Maduforo, 2016). Not only in Indonesia, Nigeria, and Bangladesh but also other country have the nutritional beliefs or taboos among the pregnant women. According to study in Pakistan about nutritional beliefs and practices among diabetic pregnant mothers, the finding showed that women said tea and coffee might cause child's dark skin. While,

most of their pregnant women did not eat cauliflower, turnip and potato, as they thought that it might cause loose motion of the child. Besides, in India it was showed that their pregnant mothers did not eat milk, egg, fish, meat, onion, garlic etc. “hot food” as they think it might increase the temperature of the child (Salma, 2017).

The develops ways of eating based on ethnic or cultural background, religious beliefs, family habits, socio economic status, health status, geographic location, and personal likes and dislikes. However, the growing ethnic and cultural diversity has been acculturated individual to view food, and think about particular food is safe or unsafe to eat, good or bad will usually have a pronounced effect on that's food's acceptability to them.

Therefore, the respect of taboos is one of the things common to all humans. Taboos are found everywhere, and are always aimed at preventing some form of perceived danger or misfortune. However, various types of taboos in some countries are clear to describe the majority of pregnant women still have a big misunderstanding during pregnancy that affects their practice.

Conclusion

The findings from this study supported the practically maternal health care activity at four districts of West Java province, Indonesia have strongly influenced by taboos behavior including taboos activity and taboos food than encouraging behaviors. According to the result of this study, most of beliefs of pregnant women during pregnancy taboos activities potential give a high influence to pregnancy outcomes, particularly in restriction consume a certain foods. Our main concerning issues is that we feel these dietary restrictions leads to pregnancy complication such as anemia, malnutrition and low birth weight. Which the nutritional factors play an important role in pregnancy periods to ensure optimal birth outcomes, maternal health and determine the quality of human resources in future. Through taboos behavior, health promotion about maternal health care can accommodate with information dissemination among pregnant

women.

Currently other cultural practice, pattern experiences, behaviors, opinions, beliefs, feelings, and knowledge of a community still need to be explored. Therefore, we recommend further larger studies should be conducted in the community setting in this regard to know more about the factors influence to their cultural beliefs. These studies added to nursing's knowledge based, and encourage client education. Through taboos behavior, nurse providers must provide health education for pregnant women on practically maternal health care activity.

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The Experience of Symptom Cluster and Symptom Alleviation Self-Care in Patients with Head and Neck Cancer: A Qualitative Study

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Abstract

Patients with head and neck cancer usually experience physical and psychological changes and adjustments related to the disease and management of therapy. The patients will experience symptom cluster and will use effective symptom alleviation self-care to relieve the symptoms. The proper identification of symptom cluster and the effectiveness of using symptom alleviation self-care will be the basis for the success of disease management. This study aimed to investigate the symptom cluster and symptom alleviation self-care in patients with head and neck cancer, and which has an impact on the quality of life. This research was a pilot study using a qualitative design and involved five patients at the public hospital in Semarang, Indonesia. The qualitative design has been chosen to explore the varied of symptom experienced by the patients about the nature, number, location, duration and intensity of experiences, which may different experiences of symptom cluster and symptom alleviation self-care for each patient with Head and Neck Cancer. Data were collected through semi-structured interviews and analyzed used the qualitative content analysis process. Three themes were identified in this study, including: the patients' experience of symptom cluster, the patients' experience of symptom alleviation self-care, and the impaired quality of life domain. The results of this study showed that the patients' experience sickness and gastrointestinal symptom cluster during illness and undergoing therapy, as well as variations in the symptom alleviation self-care, including: diet/ nutrition/ lifestyle changes, mind/ body/ spiritual control, biological treatment, herbal treatment, and prescribed medicine. The symptom cluster and symptom alleviation self-care has an impact on the patients' outcome that is the quality of life. This study showed that the experience of symptom cluster and symptom alleviation self-care varied and highly individualized, which has an impact on the quality of life. The importance of proper identification about symptom cluster and the effectiveness of using symptom alleviation self-care by the nurses will be the basis for the success of disease management to improve the patients' quality of life. Therefore, optimizing the nurses' role is needed as the basis for the development of symptom management nursing programs.

Keywords: Head and neck cancer, symptom alleviation self-care, symptom cluster, quality of life.

Introduction

Head and neck cancer included in the top six incidences of cancer in the world (Jemal et al., 2011). This disease can cause death and suffering caused by experiences of physical and psychological changes and adjustments related to the disease and management of therapy (Cheng & Lee, 2011; Caldeira, Carvalho, & Vieira, 2014). During this time, patients experience many individual symptoms associated with physical and psychological changes. The physical changes experienced by head and neck cancer patients include pain, fatigue, drowsiness, nausea, vomiting, sleep disturbance, lack of appetite, and other symptoms (Cheng & Lee, 2011). Psychological changes due to depression, anxiety, and distress can also occur (Haisfield-Wolfe, McGuire, & Krumm, 2012). Sometimes, multiple symptoms will appear simultaneously.

The phenomenon associated with the emergence of symptom cluster needs to be investigated because cancer patients have multiple symptoms that can cause suffering (Marylin J. Dodd, Miaskowski, & Lee, 2004). Some studies support this statement (Barsevick, 2016; Kirkova, Aktas, Walsh, & Davis, 2011). Symptom cluster will affect outcomes, which will subsequently affect survival, ultimately decrease functional status over time, and decrease adherence to therapy, even death (M. Dodd & Faan, 2001; Kurniawati, Kuhuwael, & Punagi, 2013). Furthermore, symptoms in symptom cluster experienced by patients are subjective phenomena that must be assessed by patients who report or experience them. An example is research on nausea which states that the nature, number, location, duration and intensity of experiences described as nausea varied. Some patients identified symptoms as part of the experience of nausea, and others described symptoms associated with nausea but separate from it (Olver & Elliott & Koczwar, 2014). Therefore, a qualitative study is needed when they report nausea or other symptoms, which are designed to explore the possibility that patients use the term to describe a cluster of symptoms, rather than just regarding them as separate associated symptoms. Nevertheless, the

symptom cluster related investigation deals not only with how the symptom cluster is formed, but also the symptom management strategies used.

Self-care management is one of the useful strategies to control and manage symptoms complained by patients. S (M.J. Dodd, Miaskowski, & Paul, 2001; Richard & Shea, 2011; Temtap & Nilmanat, 2011). The use of self care methods to treat symptoms is commonly called symptom alleviation self care. Several studies have suggested that cancer patients perform various symptom alleviation self cares to relieve and manage multiple symptoms (Williams et al., 2010; Williams, Lantican, Bader, & Lerma, 2014). Therefore, an effective self care method is required as a condition in the symptom management. With data of an effective self care strategy, patients' quality of life may increase (M.J. Dodd et al., 2001).

Based on the research background, the head and neck cancer patients' experiences of symptom cluster and symptom alleviation self care and the impact on the quality of life need to be explored. This research could become a basis for improvement of symptoms and disease management so that the distress can be reduced and the occurrence of the symptoms can be prevented.

Method

The study used qualitative method. The participants consisted of 5 head and neck cancer patients at the public hospital in Semarang, Indonesia. The inclusion criteria are adult patients aged 18–70 years old, able to communicate well and cooperatively, have been diagnosed as having head and neck cancer without metastasis to the brain that proven by diagnostic tests and signs of accompanying symptoms, and not experiencing mental disorders.

Data collection was done using semi-structured interviews. An interview guide with 3 open-ended questions was prepared by the researcher. The question of the interview guide about the patients' experience of symptom cluster, the patients' experience of symptom alleviation self care, and the impaired quality of life domain. The

questions focus on how the patients perceive symptoms and how to manage symptoms called symptom alleviation self care.

Total of 5 cancer patients being semi-structured interviews about symptom cluster. Interview results were analyzed using content analysis. It consists of transcribing (making transcripts of the patients' conversations), determining the meaning unit for searching relationships between words, sentences or paragraphs and finally, abstracting data to form several themes (Elo & Kyngäs, 2008).

Result

Participants who participated in this study were 5 patients with head and neck cancer; 2 patients were male and 3 patients were female. The participants' age ranges from 40 to 60 years. Three themes were identified in the study. The themes indicate the interrelations and describe the symptom cluster and symptom alleviation self care among head and neck cancer patients. The study conducted by Kim mentions that a symptom cluster is a stable group of two or more concurrent symptoms and is related to each other and independent of other symptom clusters (M.J. Dodd et al., 2001; Kim, McGuire, Tulman, & Barsevick, 2005). The explanation of each of the themes is as follows:

Theme 1: The patients' experience of symptom cluster

The patients mentioned that they experienced sickness and gastrointestinal symptom cluster. They experienced multiple symptoms simultaneously, which are independent of symptoms or other symptom groups.

Subtheme 1: Sickness symptom cluster

Sickness symptom cluster is a physical disorder caused by disease and therapy management. This symptom consists of a collection of symptoms of pain, fatigue, sleep disturbance and decreased appetite. The following statements describes the occurrence of cluster symptoms because of cancer experienced by the participants:

"When I feel tired or too much activity, the cancer will be painful. When the pain appears, I will not be able to sleep. So, my

activities must be reduced and I must take some rest. "(P 1)

"The pain that I feel heavy in the area of cancer. it is so painful, every day I cried. The medicine from the doctor is not very helpful, I cannot sleep. Sometimes I sleep only in a chair and very short "(P 2)

In addition, sickness symptom cluster can also occur due to chemotherapy process. One of the participants stated:

"Ever since I had this chemotherapy, I felt a growing pain in the area of cancer and the whole body. Therefore, I finally decreased my appetite, I just spent ¼ portion than usual, and I substitute with lontong (rice cake). Since I have decreased my appetite, I also feel tired and weak when doing daily activities. That may be due to reduced food intake "(P 3)

Subtheme 2: Gastrointestinal symptom cluster

This cluster symptom consists of a groups of symptoms of nausea and vomiting. It can be caused by chemotherapy. The following statement is related to this:

"After chemotherapy I experienced nausea and wanted to vomit. For 2 weeks, I felt the effects of chemotherapy, every day I feel both. I still feel nauseated even though I have taken medicine from the doctor and sometimes vomited "(P 3)

Theme 2: The patients' experience of symptom alleviation self care

Symptom alleviation self care is done to overcome the patients' symptoms. The symptom alleviation self care performed by the 5 participants varied, including 5 complementary therapy, as follows:

Subtheme 1: Diet/ nutrition/ lifestyle changes

A total of 4 participants used diet/ nutrition/ lifestyle changes as a self care method to solve the symptoms. This method was done by avoiding sweet foods, animal protein, and fried foods, eating fruits and vegetables, replacing white rice with brown rice, eating little but often, eating ice cream, avoiding scent/ smell.

"What is my taste or what I want then will eat and I drink, so it can overcome the nausea.

For example I want to eat ice cream then I will eat it, sometimes I also avoid the smell that can make me nauseous. “(P 1)

“When I feel nauseated, I will stop eating and when I do not feel vomit, then I start to eat again, spend a portion of it long. Then, for example I am not appetizing rice then I will replace with other foods, such as eating fruit or before eating I drink juice first, eat other foods so my stomach is not empty. “(P 2)

“I eat brown rice and vegetables to reduce nausea and vomiting. I keep my food for example, avoiding sweet foods, animal protein, and fried foods. I replace it by drinking fruit juice every day, but using fruit that is not sweet too. “(P 5)

Subtheme 2: Mind/ body/ spiritual control Symptom alleviation self care was done by praying, distraction, activity. Two participants performed this method to treat nausea, pain, and other symptoms that appeared. This was expressed by the participants, as follows:

“Our minds are also transferred to others to cope with nausea. We also created activities to reduce the pain. “(P 1)

“In addition, I read the istiqfar to relieve the pain, read the prayer I do every time when the pain appears, so I do not feel it” (P 2)

Subtheme 3: Biological treatment (vitamin)

This method was done by taking vitamins. Symptom alleviation self care was done by 2 participants, as indicated by the following statement:

“I consumed vitamins, wine extract which is a sackly product to accelerate the growth of dead cells.” (P 5)

Subtheme 4: Herbal treatment

A total of 4 participants used herbal treatment to solve the symptoms that appear. This method was done by consuming mangosteen peel, garlic, and Chinese herbs. This is supported by the following statement:

“I just take herbal medicine to overcome the nausea, mangosteen skin consumption that has been sold in the form of packing and biocipres, and the consumption of onion

(bawang lanang) to boost immunity.” (P 1)

“I bought Chinese herbs at Pharmacies to relieve my pain. Because I have taken medicine from a doctor but it cannot overcome it. “(P 2)

“I have a habit of chemotherapy, I bring dates, every time I feel nauseated I take one, so I do not vomit.” (P 3)

“At first, I was told my friend to consume malikus leaves or his name is African leaf. When consuming it, the pain as sliced can disappear and stop, so the pain is not the terrace. “(P 5)

Subtheme 5: Treatment prescribed Consuming oral medicine and using patch from doctors were done by two participants to relieve pain. This is expressed in the following statement:

“I was given medicine by a doctor in the form of plastic outboard. The medicine was only used for 3 days only. Although the drug can not reduce pain too much but I can still sleep about 5 minutes compared to previous types of drugs given by doctors. “(Ps 2)

“I take pain medication from a doctor to reduce pain in the area of cancer.” (P 5)

Theme 3: The impaired quality of life domain

All participants expressed that there was life quality decrease during illness. All patients experienced disturbance in the domain of functional scale, scale of symptoms (fatigue, pain), global QOL, and single item (financial difficulties). This is reflected by the following statements as follows:

“I have not been able to work to make a living, even just for my daily activities I still can not be maximized. This is because I still have to undergo routine checks to the hospital “(P 1)

“When I get sick and feel severe pain, my family forbids me to do daily activities. Food and drink had been prepared by my family and placed on the table above my bed. I feel the pain every day and it does not decrease. So, I can only cry even I cannot sleep and do other activities. “(P 2)

“I feel fear and anxiety, when the verdict suffered from cancer. I feel this life will end, until I do not want to do anything and just cry in my room. “(P 3)

“Now, when walking can not run quickly, should slowly because if the road is too fast I easily tired, tired and the body feels pain. I realize it is not as strong as it used to be. “(P 5)

Discussion

In this study, the patient experienced many individual symptoms that form the symptom cluster, namely: the experience of sickness and gastrointestinal symptom cluster. The patients experienced two or more symptoms that occur together; they are interconnected and independent of other symptoms or groups of symptoms (M.J. Dodd et al., 2001; Kim, McGuire, Tulman, & Barsevick, 2005). Several studies have shown a correlation between two or more symptoms that make up the sickness of the cluster. These results are supported by two studies, indicating that head and neck cancer patients can experience sickness symptom cluster, consisting of a group of symptoms of pain, fatigue, sleep disturbance and decreased appetite (Chen & Lin, 2007; Kirkova et al., 2011). In addition to the sickness symptom of the cluster, the patients also experience nausea and vomiting, forming a gastrointestinal symptom cluster. Several studies have shown that these two symptoms are consistently present in the same clusters (Barsevick, 2016; Chen & Lin, 2007; Jiménez et al., 2011; Kirkova et al., 2011). It can be concluded that the experience of nausea included unique symptoms that occurred among cancer patients. It was identified that there were concurrent symptoms, which were considered separate but related to nausea, such as vomiting. And they called symptom cluster because they are a stable group of two or more concurrent symptoms and is related to each other and independent of other symptom clusters.

In addition, this study also explore the self care methods used by the patients. The patients used several variations of symptom alleviation self care to treat symptoms, such

as: pain, fatigue, sleep disturbance, decreased appetite, nausea and vomiting. They can be classified into 5 categorical complementary therapies, including: diet/ nutrition/ lifestyle changes, mind/ body/ spiritual control, prescribed treatment, herbal treatment, and biological treatment (vitamins). Self care is a method that benefits cancer patients (Williams et al., 2010). Self care interventions will reduce the side effects of treatment and may affect adherence to treatment regimens, thereby enhancing quality of life (Williams et al., 2014).

Diet/ nutrition/ lifestyle changes and herbal treatments are mostly used by the participants in this study than other self care methods. Similar results were also obtained among cancer patients in the southwestern United States where diet/ nutrition/ lifestyle change had high numbers of self-care responses. Self-care methods used are reported over 90% can be helpful (Williams et al., 2014). The interventions in this method, such as changing eating habits or food modifications, consuming vegetables and fruits, and using nutritional supplements. Another method of self care mostly used is herbal plants. This method has been used as a medicine since ancient times by all cultures. Herbal medicine is made from leaves, branches/ branches, roots, seeds, or even flowers. This medicine may consist of a single herb or combination of herbs, such as traditional Chinese herbs and Ayurvedic from India (Wesa, Gubili, & Cassileth, 2008). Several studies have revealed that herbal treatments are obtained from local herbs. Both methods of self care are used to overcome the pain, fatigue, sleep disorders, lack of appetite, depression, sadness, nausea, vomiting, and anxiety (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014). The used of herbal plant can give the advantages to relieve the symptoms.

Two participants chose to use mind/ body/ spiritual control, biological treatments (vitamins), and prescribed medications. This method was chosen to relieve symptoms of pain, fatigue, sleep disturbances, lack of appetite, nausea, vomiting, and mood disorders (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014). Body/ mind/ spiritual control methods are increasing in popularity and available as part of major medical care (Wesa

et al., 2008). The mind, body, and spiritual modality focus on the interaction between brain, mind, body, spiritual and behavior with the aim of reducing symptoms and improving health. Similar to this study, several other studies have indicated that praying, distraction, and other activities are effective (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014). Mind-body-spiritual therapies are generally safe (Deng & Cassileth, 2013; Mujar et al., 2017; Pinzon-Perez & Pérez, 2016). Biological treatment is an option that patients also use as a self-care method. In this method, the biological treatment that patients often use is the use of vitamins (Christanti & Prasetyo, 2012). Some vitamins and minerals are essential for life and health. In just a few milligrams, the amount of each vitamin is needed by the human body. However, a small amount is very important for all body's biochemical processes. It is used to convert food into energy and to help the body produce hormones, blood cells, and nervous system chemicals (Cassileth, 2011). In addition, prescribed medicines by doctors are still used by patients. Medically determined treatment measures are incorporated into self care to help patients control the symptoms of pain, nausea/ vomiting, sleep disorders and anxiety in cancer patients (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014).so what? In discussion you as author need to explain your opinion for future implication

This study also shows that head and neck cancer patients experience various life quality disorders in the form of weaknesses both physical, psychological, and social. This is supported by a study reporting that patients with nasopharyngeal cancer experienced all the disturbances on the 15 scale of quality of life, including: 5 functional scale, 3 symptoms scale, global QoL and six single items (Kurniawati et al., 2013). Other studies on head and neck cancer patients also showed results similar to previous studies (Leung et al., 2011).

The effects of disease and therapy on the patients' quality of life are illustrated in this study. Proper quality of life assessment will affect the patients' overall sustainability, adherence to therapy and even death (M. Dodd & Faan, 2001; Kurniawati et al., 2013). The assessment of quality of life also needs to pay

attention to the use of symptom management strategies embodied with the symptom alleviation self care and the emergence of symptom experience (M. Dodd & Faan, 2001). Therefore, symptom management for head and neck cancer patients should focus on these three things. This can be an indicator of the successful action of health care providers and the patients' satisfaction to the achievement of their health.

Conclusion

The experiences of symptom cluster and symptom alleviation self care vary and are highly individualized, depending on how individuals respond to the disease and management therapy. The existence of the impact caused by the disease and the management therapy will affect the condition of the patients, that is the disruption of quality of life. The importance of proper identification of symptom cluster and the effectiveness of using symptom alleviation self-care by nurses will be the basis for the success of disease management to improve the patients' quality of life. Therefore, optimizing the role of nurses in the case of symptom cluster assessment, symptom alleviation self care, and quality of life monitoring is needed as a basis for the development of symptom management nursing programs.

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The Mental Burden of Parents of Children with Thalassemia

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Abstract

Thalassemia is an inherited blood disorder in which there is a chronic abnormality of red blood cells. When a child suffers from a severe illness, the family usually acts as caregivers, which put them at risk of experiencing a burden of care. This study aims to identify the level of charge perceived by parents caregivers of children with thalassemia. A quantitative approach was used in this research to obtain data by using a continuous sampling. The samples in this research consisted of 71 parents of children with thalassemia, who are either their biological father or mother who attended thalassemia center on August 30, 2017 - September 13, 2017. The instrument was used in this research was modified from a Caregiver Burden Scale instrument (developed by Elmstahl). The data obtained were analyzed using a descriptive statistical technique in which parents burden is categorized into three levels: mild, moderate, and severe levels of burden, and they are measured in percentage. The result showed that 36 respondents (50.7%) perceived a mild level of burden, 31 respondents (43.7%) perceived moderate level of burden, and four respondents (5.6%) saw the severe level of burden. This study concludes that most respondents perceived a mild and moderate level of burden, but in terms of responsibility, economy, expectation, and anxiety, they showed a severe degree of burden. Nurses are suggested to maintain or alleviate the burden by providing education, counseling, emotional support and adaptive coping mechanisms for parents of children with thalassemia.

Keywords: Burden, parents, thalassemia.

Introduction

Thalassemia is one of hereditary and the most common chronic diseases. Thalassemia is a heterogeneous group of the hemoglobin disorders in which the production of normal hemoglobin is partly or completely suppressed as a result of the defective synthesis of one or more globin chains the most common types of clinical importance being α , β , and δ thalassemia (Cappellini, Cohen, Eleftheriou, Piga, Porter, Taher, 2008)

Thalassemia incidence in Indonesia is relatively high, and the country is included in high-risk countries, 3,000 babies born to have thalassemia every year (Mulyani, 2011). Twenty percent of babies born in West Java carry the traits of thalassemia. Yayasan Thalassemia Indonesia-Perhimpunan Orangtua Penderita Thalassemia (YTI-POPTI) recorded 7,238 thalassemia major sufferers in 2016, and 3,200 (45%) of them were residents of West Java. West Java is the area with the largest number of thalassemia patients in Indonesia (Widiyatno, 2016).

Clinical symptoms of β thalassemia include anemia, jaundice, growth retardation, facial bone deformities, enlarged spleen, and susceptibility to infection (James, 2007). Besides, thalassemia might result in psychological and social disorders such as anxiety, depression and social withdrawal (Cakaloz, 2009). Children with symptoms of thalassemia, especially those who have experienced complications, require more excellent care and attention from their family.

Furthermore, the fact that thalassemia cannot be cured permanently requires children with thalassemia to perform regular blood transfusion to live. The transfusion is presented every two to four weeks (Mulyani, 2011). However, routine blood transfusion therapy will cause iron overload in the body, which in turn will require chelation therapy. This lifetime therapy requires constant care and attention from the family.

A person who provides care to a patient is called caregiver (Sukmarini, 2009). Family can provide caring support in different ways, such as emotional, physical, and financial support as well as coordinating with health care and social services, routine health care (getting medicines), personal care such

as eating, bathing, and dressing, assisting homework and financial arrangements (Toesland, 2001).

Providing care and attention to children with thalassemia in the long term will impose a burden on the family. Caregiver burden is a multidimensional response with negative perception and stress resulting from caring for a sick individual (Zarit, 1980). According to Solve Elmstahl (1996), caregiver burden comprises five factors: general strain, isolation, disappointment, emotional involvement, and environment.

The burden might impact the caregivers both physically and psychologically. A research conducted by Sivansh Inamdar in 2008 revealed that 60% of parents of children with thalassemia are burdened and stressed due to the chronic nature of the disease. Furthermore, research by Pouraboli (2017) also mentioned that families whose children suffer from thalassemia in Iran felt psychological, financial, and isolation burdens, not to mention suffering from social stigma in the care situation.

Physical and psychological health of caregivers is negatively affected as a result of the burden imposed on them in the care situation. Parents of thalassemic children showed severe stress in parenting, and it was reported that 67.5% of parents experienced psychological distress (Ali, Sabih, Jehan, Anwar, & Javed, S. 2012). Besides, psychosocial problems are also experienced by parents in caring for children with thalassemia. The difficulties encountered by parents of children with thalassemia, among others, are that they concern about the child's physical weakness (caused by anemia), about financial difficulties, and the child's future (Prasomsuk, Jetsrisuparp, Ratanasiri, & Ratanasiri, 2007).

Influenced by either cultural and religious beliefs that view the course of life as predetermined and set in destiny, many people in Indonesia maintain the attitude of acceptance. (Koentjaraningrat, 2000). This attitude of acceptance is also reflected in coping with the fact that their children suffer from a chronic illness. Indonesian people, especially Sundanese ethnic group, has very close kinship ties (Sudiharto, 2007) and preserve a cooperation culture. When

a family member is down with the illness, the rest of the family will join together in caring for the ill by providing either physical, material, or emotional support. (Suprajitno, 2004). These traits are likely to have an impact on caregiver’s burden in caring for children with thalassemia in Indonesia, which distinguishes them from caregiver burden in other countries.

According to our interview with the parent’s thalassemic children, most of them revealed that they felt exhausted because they had to take their children for blood transfusion therapy every month. Some of them even had to skip work to be able to do that. They also felt exhausted because they were always so worried about the condition of their children that they did not have time to think about their own. Based on this phenomenon, this research focuses on the parents burden as caregivers of children with thalassemia.

Method

This research is quantitative and descriptive. This research was conducted at Sumedang Regional General Hospital (RSUD henceforth), West Java, Indonesia. The variable in this research is a single variable, which is a family burden as caregivers in thalassemic children with sub-variables of general strain, isolation, disappointment, emotional involvement, and environment. The population in this research is families who act as caregivers of thalassemic children at RSUD Sumedang. Using consecutive sampling technique with the criterion of biological mother or father from children six months old Thalassemia up to 12 years old who come to the hospital. On this research,

71 respondents participated in the period of 2 weeks (31 August–13 September 2017).

The instrument used in this research was the Caregiver Burden Scale developed by Elmstahl in 1996. The tool comprises 22 questions covering 5 sub-variables of caregiver burden: general strain (8 questions), isolation (3 questions), disappointment (5 questions), emotional involvement (3 questions), and environment (3 questions). In doing so, a Likert scale of was used to determine the answers: “never”, “seldom”, “sometimes”, and “often.”

The instrument is a standard instrument with a validity value of 0.70. The instrument was back-translated. This instrument is already done back translate by Jasmia (2016) where the translation is done by linguists of the language centre, Faculty Culture of Padjadjaran University that translates from English to English by Tisna Prabasmoro, Ph.D and translated back into English by Rasmus Budhoyono, M.Hum.

It using face validity, validated by 10 people with the same characteristics as the samples. Words that are not understood by the respondents were simplified so it would be easier to understand and answer the questions. Data analysis was conducted using descriptive statistical analysis in which parents burden was categorized into 3 proportions: mild average score 1.00–1.99, moderate average score of 2.00–2.99, and severe levels score 3.00–4.00. Further analysis of the burden of parents use in percentage.

Result

The table above shows that 48 respondents (67.6%) age between 18-40 (early adult), 60 respondents are female (84.5%) and

Table 1 Traits of Parent of Children with Thalassemia (n = 71)

	Category	f	%
Age	18–40 years old (early adult)	48	67.6
	41–60 years (middle age)	22	31
	> 60 year old (elderly)	1	1.4
Gender	Female	60	84.5
	Male	11	15.5
Family Relationship	Mother	60	84.5
	Father	11	15.5

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Education Level	Primary School	23	32.4
	Junior High School	24	33.8
	High School	19	26.8
	Vocational	1	1.4
	Bachelor's Degree	4	5.6
Employment Status	Employment	16	22.5
	Unemployment	55	77.5
Income	Under minimum wage	49	69.0
	Above minimum wage	22	31.0
Duration of Treatment	1–11 months	3	4.2
	1–5 years	16	22.5
	6–12 years	52	73.2
Number of children with thalasemia	1 child	61	85.9
	2 children	9	12.7
	> 2 children	1	1.4
Other support	Family	53	74.6
	Professional support	1	1.4
	None	17	23.9
BPJS/Other insurance beneficiaries	Yes	71	100
	No	0	0

Table 2 Parent Burden as Caregivers of Children with Thalassemia (n = 71)

Burden	f	%
Mild	36	50.7
Moderate	31	43.7
Severe	4	5.6

Table 3 Burden Level in Terms of Sub-Variables of Parents of Children Thalassemia (n = 71)

Sub-variables	f	%
General strain		
Mild	28	39.4
Moderate	33	46.5
Severe	10	14.1
Isolation		
Mild	54	76.1
Moderate	16	22.5
Severe	1	1.4
Disappointment		
Mild	19	26.8
Moderate	34	47.9
Severe	18	25.4
Emotional involvement		

Mild	51	71.8
Moderate	13	18.3
Severe	7	9.9
Environment		
Mild	17	23.9
Moderate	45	63.4
Severe	9	12.7

60 respondents (84.5%) are mothers of thalassemic children. 24 respondents (33.8%) are junior high school graduates, 55 respondents (77.5%) are unemployed, 49 respondents (69%) have income below minimum wage. 73.2% respondents have cared for their thalassemic children for 6–12 years. 61 respondents (85.9%) have 1 thalassemic child, 53 respondents (74.6%) have other family members helped caring for their thalassemic children, and 71 respondents (100%) are BPJS/other insurance beneficiaries.

The table above shows that 36 respondents (50.7%) participated in this research perceived mild level of burden. 31 respondents (43.7%) perceived moderate level of burden, while only 4 respondents (5.6%) who perceived severe level of burden.

The table above shows that, in sub-variable of general strain, 33 respondents (46.5%) perceived moderate level of burden as caregivers. In sub-variable of isolation, 54 respondents (76.1%) perceive mild level of burden. In sub-variable of disappointment, 34 respondents (47.9%) perceive moderate level of burden. In sub-variable of emotional involvement, 51 respondents (71.8%) perceive mild level of burden. In sub-variable of environment, 45 respondents (63.4%) perceive moderate level of burden.

Discussion

Based on the result, it was found that the level of caregiver burden among parents of children with thalassemia are generally mild (50.7%), while 43.7% of the respondents perceived moderate level of burden, and only 5.6% of the respondents that perceived severe level of burden. The burden of the elderly as a caregiver is the mental pressures or loads that

appear on the parents who care for individuals with chronic disease. Caregiver tends to lack of rest, less intake of food, and when the pain usually does not come to health services, it would have an effect on daily activities and care given to the children of thalassemia. (Barbara, 2015).

The burden of the elderly at mild levels indicate parents are having a little trouble on a general strain for responsible care, a little experience feelings of isolation or feeling disappointed, and a little experience difficulties in the environment. The perceived lightness of burden likely will not interfere with the activities of daily caregiver.

Parents believe that the child is a mandate from God that must be preserved. Although the child's condition however and though treatment costs a pricey parents will strive to take care of children (Ambarsari, 2012).

Based on the sub-variable of the general strain, the question item with the highest level of burden is concerning responsibility for the welfare of the child. This is possibly because, according to Friedman (2010), one of the primary functions of family is to provide the essentials to keep the family healthy. The health care function of this family member is a function to carry out health care practice, which is to prevent disease and to care for sick family members. Therefore, families tend to feel responsible in caring for sick their members and responsible for their well-being.

The fact that most of the respondents were mothers of children with thalassemia is most likely the contributing factor to the high level of burden. In Indonesia, many people believe that it is almost exclusively a mother's role to take care of children (Hanifah, Mediani & Nurhidayah, 2018). This is in accordance with Begum (2016) in Jasmia (2017) who stated that women are assigned with domestic

responsibilities, including taking care of family members. Therefore, the burden perceived by female caregivers is higher than their male counterparts. In the current study parents, mostly mothers (84.5%) takes his son for medical treatment undergoes mental burden is light (50.7%).

The next question item with the second highest level of burden is concerning insoluble problems during treatment. One of the tough problems that caregivers encounter during blood transfusion therapy is a shortage of blood supply from the Indonesia Red Cross Society. This condition forces them to be able to find blood donors for their children. This problem is in accordance with the research conducted by Prasomsuk, Jetsrisuparp, Ratanasiri, & Ratanasiri, (2007) which revealed that one of the problems experienced by parents of children with thalassemia is getting further treatment for their children, such as splenectomy and blood transfusion therapy.

In the sub-variable of isolation, most of the caregiver perceived mild level of burden (76.1%). Most of the respondents did not experience deteriorating relationships with friends and relatives. Family and friends play an important role in sharing information and experiences about home care and treatment (Prasomsuk, Jetsrisuparp, Ratanasiri, & Ratanasiri, 2007). A good relationship with friends contribute positively to caregiver burden, especially in terms of isolation. Sudiharto (2007) said that the people of Indonesia especially the Sundanese people have very close kinship ties, when there are family members who are sick then the rest of the family will alleviate the burden of isolation.

Burden on caregiver on sub-variables disappointment, a small portion of respondents experienced high disappointment (25.4%). Parents of children with Thalassemia wish all their family members to be in good health and without any abnormalities. The family realizes that thalassemia is an incurable disease, but they expect their child's health to improve so that they can live with them as long as possible, get an education as high as possible and have a good future (Prasomsuk, Jetsrisuparp, Ratanasiri, & Ratanasiri, 2007). High expectations led to disappointment and

burden on caregivers. Besides that, parents thalassemic children were disappointed with the present health services, the amount of information provided to them, the means of transport and their financial conditions (Pruthi & Singh, 2010).

It was also revealed that most of the respondents complained about the high cost of taking their children to the hospital. Moreover, 69% of the respondents participated in this research have monthly income below minimum wage. The high cost of thalassemia treatment financially burdens them as caregivers.

In the sub-variable of emotional involvement, 71.8% of the caregivers perceived mild level of burden. Emotional involvement perceived negative feelings parents caregiver when interacting with children suffering from Thalassemia. Research by Ambarsari (2012) mentions that in taking care of sick children, more patient and caregiver rests in God. The existence of a patient and a feeling of confidence to God that all that happened as a test and need patiently provide strength in dealing with issues related to child condition.

In this sub-variable, the question item with the highest level of burden perceived by caregivers is about being offended by and upset about their thalassemic children. According to Darwis (2006), everybody feels emotion. Caregivers of children with thalassemia are also human beings with emotion. When being confronted with their thalassemic children who (like any other children) sometimes could be disobedient, they might be upset and angry at them.

In the sub-variable of environment, 63.4% of the respondents perceived moderate level of burden. In the sub-variable of environment, the burden is caused by "anxiety of not being able to properly take care their children." Anxiety is unrealistic fear (Gunarsa, 2008). Anxiety is a subjective feeling of disturbing mental tension as a general reaction to the inability to cope with a problem or lack of security (Rochman, 2010). Thoughts about the future, stressful situations, fear of losing or fear of being left alone with great responsibility of caring for other family members experienced by the family are the cause of high anxiety (Duci, 2012).

Some of the effects of anxiety are sleep deprivation that might lead to irritability, inability to pay attention to the real problems, which in turn, will prevent an individual from functioning effectively (Cohen, 2002). Caregivers with excessive anxiety will undertake ineffective care that will result in a deterioration in the patient's condition.

Thalassaemia has an impact on children and families. Thus the family needs further information about thalassaemia and its treatment, emotional support, social support, professional support and financial support (Mediani, Nurhidayah, Mardhiyah, & Panigoro, 2017).

Conclusion

It can be concluded that most respondents participated in this research showed mild and moderate level of burden in caring for children with thalassemia. This means that parents can still overcome feelings or pressures felt both feelings of responsibility, feelings of disappointment, isolation, emotional and feelings of the influence of the environment of children with thalassemia, so it does not interfere with the activities and care of their children. Only few respondents perceived severe level of burden. This is probably influenced by Indonesian cultural background of the caregivers that views the course of life as predetermined and set in destiny, which help them in coping with the situation.

In addition, the kinship of the people of Indonesia, especially Sundanese ethnic group, is very close. They value the tradition of mutual cooperation in which the entire family help each other in taking care of a sick family member, either in the form of physical, material, or psychological support to lighten the burden. Based on the question items in the sub-variables of burden, there are some aspects that highly perceived by the caregivers participated in this research, such as question items related to great responsibility for the thalassaemic children welfare, about the hope for a different life, financial cost, and about anxiety.

It is necessary for nurses to relieve caregivers burden through education,

counseling, social support, improving the ability of coping mechanisms so that it will not affect the physical and psychological health of caregivers.

Based on the results of this study is expected clinical nurses and the community can provide nursing care to families of children thalassaemia both to educate about the disease and knowledge about the treatment. Clinical nurses should make time for counseling with caregivers when they take their children for blood transfusion therapy. By doing so, the real problems can be identified and nurses will be able to design family care nursing plan that suit both the needs of the patient and the caregivers.

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