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REVIEW ARTICLE

EFFECT OF PROGRESSIVE MUSCLE RELAXATION ON SLEEP QUALITY AMONG PATIENTS WITH CHRONIC DISEASES: A LITERATURE REVIEW

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Abstract

Background: Sleep disturbance is prevalent among patients with chronic diseases. Thus, the use of non-pharmacological interventions is needed. Progressive muscle relaxation is considered effective to improve sleep quality, but its discussion is still limited.

Objective: To investigate the effect of progressive muscle relaxation on sleep quality among chronic disease patients.

Design: Literature review.

Data Sources: Search was performed through the CINAHL, Science Direct, and ProQuest database from 2014 to 2019 for English-based, full-text research articles.

Review Methods: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methods was used to select articles. Critical Appraisal Skills Programme was used for quality assessment.

Results: From the 644 articles yielded, six articles were included. Progressive muscle relaxation could be given alone or in combination with cognitive behavioural therapy. It also has been proven to improve sleep quality among patients with chronic diseases regardless their ages. Procedures in progressive muscle relaxation vary, but all studies reported significant improvements on sleep quality. Most of studies used audio as a medium for progressive muscle relaxation training.

Conclusion: Progressive muscle relaxation significantly improves the sleep quality among patients with chronic diseases. It is recommended for future studies to compare the effectivity between 4 or 7 muscle groups and 16 muscle groups on sleep quality.

KEYWORDS

progressive muscle relaxation; chronic disease; sleep; outcome assessment; health care

BACKGROUND

The prevalence of sleep disturbance among patients with chronic diseases remains high, which ranged from 2.8% to 17% according to a study in nine countries (Koyanagi et al., 2014). Sleep disturbance or poor sleep quality is higher in patients with chronic conditions than those with non-chronic conditions. Patients with chronic conditions with more than four diseases have a risk of sleep disturbance increased to 7.62-fold (5.88-9.87) than those with non-chronic disease. This condition is likely associated with disruption of breathing during sleep, night time awakening caused by a specific symptom of disease (nocturia in diabetes), pain, and anxiety (Koyanagi et al., 2014).

There are many bad impacts of sleep disturbance for patients with chronic diseases. In patients with haemodialysis, sleep impairment would decrease the quality of life and increase medication use and mortality rate (Elder et al., 2008). A recent study reported that poor sleep quality is associated with lower vitamin D levels (Han et al., 2017). Disturbed sleep also causes increased mortality rates, exacerbations and use of emergency department for chronic obstructive

pulmonary disease (Omachi et al., 2012). In diabetes, sleep impairment is associated with higher levels of HbA1c (Ohkuma et al., 2013) and increases fatigue (Zhu et al., 2018).

To treat sleep disturbance, medications have been used. However, the long-term use of sleep medication or pharmacological intervention may have side effects, and its effectiveness and safety in improving sleep quality among older people still need to be proven (Burke et al., 2018). Therefore, a non-pharmacological intervention should be provided as an alternative method of improving sleep quality among patients with chronic diseases. There are many types of non-pharmacological interventions such as physical activity, light therapy, mind-body intervention (progressive muscle relaxation, yoga), acupressure, back massage, and chamomile extract beverage for improving sleep quality (Shang et al., 2019). According to a qualitative study, progressive muscle relaxation has become the second most favourite method in improving sleep quality (Hyland et al., 2016). A previous review has also explained the effectivity of progressive muscle relaxation in the

improvement of sleep quality in menopause women (Amanda, 2019). In addition, other reviews have discussed the use of mind body interventions (meditation, mind-body movement and relaxation) on sleep quality (Neuendorf et al., 2015), and the use of the progressive muscle relaxation among cancer patients (Pelekasis et al., 2017). A review that proves the benefit of progressive muscle relaxation for patients of other chronic diseases is needed. Our review would summarize the findings of recent studies in regard to the effectivity of progressive muscle relaxation on sleep quality among patients with chronic diseases.

METHODS

Design and Search Methods

Searching procedure was conducted through CINAHL, ScienceDirect, and ProQuest databases from 2014 to 2019 for English-based full-text research articles using specific keywords including “progressive muscle relaxation”, and “sleep”. We used Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methods for article selection (Pati & Lorusso, 2018).

Inclusion and Exclusion Criteria

The inclusion criteria were based on PICO (Population = patients with chronic diseases, Intervention = progressive muscle relaxation, Comparison = between progressive muscle relaxation and other complementary techniques, and Outcome = sleep quality). The exclusion criteria were observational studies, study protocols and review articles.

Screening

The first author did the first screening, and the other authors did the screening for content analysis.

Data Extraction

Data were extracted in the table which contains authors, participants, design, intervention, and outcome.

Quality Appraisal

We used the Critical Appraisal Skills Programme to assess the quality of research articles (Critical Appraisal Skills & Programme, 2018).

Data Analysis

A thematic analysis was used to analyse the data, with the following steps: 1) understanding data, 2) identifying codes, 3) identifying themes from the codes, 4) refinement of the themes, and 5) defining themes (Braun & Clarke, 2006).

RESULTS

Search Outcome

We yielded 520 articles from Science Direct, 25 from CINAHL, and 102 from ProQuest. Title and abstract screening were firstly done, 60 articles were excluded. There were 24 articles for full-text review, 18 of which were excluded. Finally, six articles were included (See Figure 1). Of the six articles, five studies investigated the progressive muscle relaxation alone to improve sleep quality, and one study gave

progressive muscle relaxation as a part of cognitive behavioural therapy (CBT). The summary of the studies or data extraction is in Table 1.

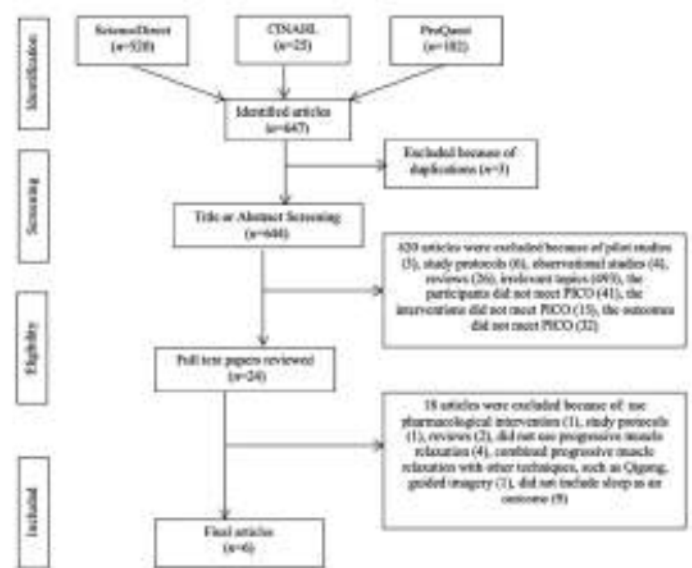


Figure 1 Flow chart of article selection

Quality Assessment Results

Of six articles, two articles have strong validity results, two articles have moderate validity because no blinding was performed, and the others have low validity because of the absence of randomisation and blinding. There are no studies excluded based on the quality assessment (See Table 2).

Analytical Findings

Total participants in this review are 648 patients. Not all of the participants were elderly. The mean age of the participants is 55.41 years. Most of them aged more than 40 years, and majority are Asians (90.89%). The studies were conducted in Turkey (60.95%), China (15.89%), Iran (14.04%), and Spain (8.9%). Five studies were conducted in community and the other was in a hospital setting. The average of the study period is 7.6 weeks ranged from 4 to 12 weeks. But, the studies in hospital settings have shortest duration, 7 days.

Progressive muscle relaxation procedures

There were similarity and differentiation of progressive muscle relaxation procedures among all studies. The similarity lied in the duration of progressive muscle relaxation. All studies did progressive muscle relaxation for 30 minutes, but varied in terms of frequency per day and muscle groups. Progressive muscle relaxation could be done twice a day or once. For once a day, the intervention was done in the evening before sleep (Akgün Şahin & Dayapoğlu, 2015; Alparslan et al., 2016). For twice a day, it was done in the morning and before sleep (Chegeni et al., 2018; Hou et al., 2014; Yilmaz & Kapucu, 2017).

Various muscle groups involved in the intervention were identified. It could be 16, 7, or 4 muscle groups. Two articles applied progressive muscle relaxation using 16 muscle groups (Alparslan et al., 2016; Chegeni et al., 2018), one article using 7 muscle groups (Yilmaz & Kapucu, 2017), one article using 4 muscle groups (Akgün Şahin & Dayapoğlu, 2015), and one article combined the 16, 7, and 4 muscle groups (Mateu et al., 2018).

Table 1 Summary of Included Studies

Authors	Design	Participant	N	Media	Intervention	Duration	Control group	Tool	Outcome
(Alparslan et al., 2016)	Interventional Investigation	Internal ward patient (n=235)	282	Booklet	Progressive muscle relaxation	7 days	Standard care (n=47)	PSQI	Significant sleep quality in experiment group ($p=.001$), but no differences between two group at the end of research ($p=.891$)
(Hou et al., 2014)	RCT	Maintenance haemodialysis (n=52)	103		CBT	12 weeks	Standard care (n=51)	PSQI	Significant improvement of sleep quality ($p=.001$)
(Mateu et al., 2018)	RCT crossover	Non-oncology Low back pain (n=28)	58	CD Audio	Jacobson progressive muscle relaxation	8 weeks	Music (n=30)	MOSS	Significant improvement in sleep adequacy and sleep time and decrease in sleep disturbance ($p<.05$)
(Akgün Şahin & Dayapoğlu, 2015)	Pre-experiment	COPD (n=45)	45	Handbook & CD audio	Progressive muscle relaxation, deep breathing	6 weeks	-	PSQI	Significant improvement of sleep quality ($p<.01$)
(Chegeni et al., 2018)	RCT	COPD (n=45)	91	Booklet, CD audio	Progressive muscle relaxation	8 weeks	Routine care (n=46)	PSQI	Significant improvement in PSQI sub-categories: sleep quality, sleep latency, sleep duration and sleep efficiency ($p<.05$)
(Yilmaz & Kapucu, 2017)	RCT	COPD (n=34)	68	Booklet, CD audio	Progressive muscle relaxation	4 weeks	No intervention (n=34)	CASIS	Significant improvement of sleep quality ($p<.01$)

Note: RCT: Randomized Controlled Trial, CD: Compact Disk, CBT: Cognitive Behavioural Therapy, COPD: Chronic Obstructive Pulmonary Disease, PSQI: Pittsburgh Sleep Quality Index, MOSS: Medical Outcome Study-Sleep, CASIS: COPD and Asthma Sleep Impact Scale

Progressive muscle relaxation media

Various media were identified in the progressive muscle relaxation. Most of the articles used CD audio as their medium (Akgün Şahin & Dayapoğlu, 2015; Chegeni et al., 2018; Mateu et al., 2018; Yilmaz & Kapucu, 2017). Two of them used CD from the Turkish Psychologist Association, one study used CD from the Student Research Committee

of Khoramabad School of Nursing and Midwifery, and the others did not clearly explain what media they used. Mp3 player was used to deliver the audio. Booklets and handbooks were still used in four studies (Akgün Şahin & Dayapoğlu, 2015; Alparslan et al., 2016; Chegeni et al., 2018; Yilmaz & Kapucu, 2017).

Table 2 CASP analysis

Authors	Clear focused issue	Randomised allocation	Properly analysed	Blinding	Similar start	Treated equally	Treatment effect	Confidence limits	Applicability
(Alparslan et al., 2016)	√		√			√	√	√	√
(Hou et al., 2014)	√	√	√		√	√	√	√	√
(Mateu et al., 2018)	√	√	√	√	√	√	√	√	√
(Akgün Şahin & Dayapoğlu, 2015)	√		√		√	√	√	√	√
(Chegeni et al., 2018)	√	√	√	√	√	√	√	√	√
(Yilmaz & Kapucu, 2017)	√	√	√		√	√	√	√	√

DISCUSSION

Progressive muscle relaxation was first developed by Jacobson in 1934 as tension and relaxation of 16 muscle groups. Bernstein et al. (2000) modified progressive muscle relaxation for 7 and 4 muscle groups via counting and recall. There are three techniques of progressive muscle relaxation including Jacobson's progressive muscle relaxation, overt progressive and covert progressive muscle relaxation. The Jacobson's progressive muscle relaxation uses less tension of muscle then relaxation. Overt progressive muscle relaxation uses strong tension of

muscle then releases it. Meanwhile, covert progressive muscle relaxation lets the tension of muscle away (Smith, 2005).

Progressive muscle relaxation procedures

Despite the variation of the procedures, there was improvement of sleep quality in most studies at the end of the studies ($p<.05$). One study reported no difference between control and experiment group, which was likely due to the age of the participants. In that study, most participants in the control group aged less than 50 years and those in the experiment group aged more than 50 years (Alparslan et al., 2016). Sleep impairment is probably more prevalent among older adults. The

underlying reasons are cognitive problems, pain, and chronic disease (Lewis et al., 2014). In this review, not all of the participants were elderly. Progressive muscle relaxation is effective for all chronic disease patients regardless their age.

A multi-country study found that some chronic diseases had significant association with sleep problems. There were asthma, chronic obstructive pulmonary disease (COPD), diabetes, and stroke (Koyanagi et al., 2014). In our review, of all six articles, three articles discussed the effectivity of progressive muscle relaxation in COPD patients, one article in haemodialysis patients, one in low back pain patients, and the remaining articles in internal ward patients. Most of the participants suffered from COPD. There are several factors causing sleep disturbance among COPD patients, including cough, dyspnea, pleghm, wheeze, and use of corticosteroid inhaler (Chang et al., 2016; Omachi et al., 2012). In haemodialysis patients, sleep disturbance is associated with duration of the disease and pain (Pan et al., 2019). Pain intensity has dependent association with sleep disturbance although the correlation is weak (Alsaadi et al., 2011).

The effectivity of progressive muscle relaxation in improving sleep quality is explained in several mechanisms. Progressive muscle relaxation could give a relaxation effect through distraction of attention and sensation of systemic tension and relaxation of the muscle (Bernstein et al., 2000). It also induces deep relaxation by reducing the electrical activity in the inferior frontal gyrus (IFG), superior frontal gyrus (SFG) and posterior cingulate cortex (PCC) (Kobayashi & Koitabashi, 2016). This relaxation would decrease anxiety and depression as well as relieving insomnia symptom (Wolkove et al., 2007).

Progressive muscle relaxation media

Progressive muscle relaxation is one of the effective and safe methods for improving sleep quality among patients with chronic diseases either in a community setting or in an hospital setting. The positive effect of progressive muscle relaxation in sleep can be seen in 7 days. There is no adverse effect reported by all studies. Nurses could give progressive muscle relaxation for helping patients to manage their sleep impairment. Training of progressive muscle relaxation could be given as a part of discharge planning to enhance self-management at home, which could improve quality of life (Zeng et al., 2014).

Progressive muscle relaxation is very applicable in clinical settings. CD audio is most likely used as a medium. However, the use of CD audio in Indonesia would give more challenge because of technology barrier. Many of the hospitalized patients do not have device to use CD audio. Some studies used mp3 player for the patients. The cost needed to buy an mp3 player for each patient would increase the hospital burden. We need more advanced technology to solve this problem such as smartphone apps. This technology is more applicable due to the growing number of mobile owners in Indonesia. Recently, Indonesia becomes the fourth largest marketplace for mobile phone worldwide (Statista Research Department, 2020).

Limitations of the study

This review has several limitations including the narrow range of the study years and the use of English-based articles, which might exclude other important articles that use other languages.

CONCLUSION

Progressive muscle relaxation could improve sleep quality among patients with chronic diseases. There were variations in progressive muscle relaxation techniques, including variations in frequency in each day, muscle groups involved, and media. Despite the variance in progressive muscle relaxation methods, all studies reported significant results of progressive muscle relaxation in enhancing sleep quality among chronic disease patients.

DECLARATION OF CONFLICTING INTEREST

There is no conflict of interest to disclosure.

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AUTHORS CONTRIBUTION

SM: Done literature review, and drafted the manuscript.

SY: Contributed to design, methodology, discussion, and final proof of the manuscript.

DD: Analysed the manuscript.

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ORIGINAL RESEARCH

WHAT ROLES DO INDONESIAN NURSES PLAY IN THE EARLY IDENTIFICATION AND INTERVENTION OF CHILDREN WITH DEVELOPMENTAL DISABILITIES? A QUALITATIVE STUDY

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Abstract

Background: Developmental delays can be a basis for identifying children who may experience a disability. Accordingly, developmental screenings and monitoring are implemented to facilitate early identification of developmental disabilities

Objective: To explore Indonesian's community nurses' perceptions regarding their roles in the early identification and intervention of developmental disabilities

Method: This was a descriptive phenomenological study. Eleven community health nurses participated in a multiple semi-structured interview. Thematic analysis was used to analyse data.

Findings: Four themes of nursing roles emerged, these include parents' expression of need, a focus on curative management, provision of nursing care and being alert to discuss a possible developmental delay. Indonesian nurses describe their roles as focusing on curative management and include monitoring child growth and nutritional status because they perceive these roles as the main program of the centres and as to fulfilling parents' expressions of needs, however they will raise concern when it is suspected or observed, that the child has delayed development.

Conclusion: Child's developmental surveillance has been implemented in developed countries as the basis to identify developmental disabilities earlier in children, however Indonesian nurses focus more on nutrition and eradicating communicable diseases rather than child's developmental monitoring. More investigation is needed to find barriers of implementation of developmental screenings.

KEYWORDS

child; developmental disabilities; nurses; Indonesia

BACKGROUND

Developmental disabilities refers to a group of chronic, lifelong disability characterised by physical and/or mental impairment which manifested before the individual attains age 22 and result in substantial functional limitations in day to day activities such as self-care, communication, learning, mobility, independent living and self-direction ([American Association on Intellectual and Developmental Disabilities, 2020](#)). Some common type of developmental disabilities are Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorders (ASDs), learning disabilities, behavioural and emotional disorders, communication disorders, cerebral palsy and Down syndrome ([Patel et al., 2010](#)).

According to [WHO \(2012\)](#) developmental delays can be a basis for identifying children who may experience a developmental disability ([Batshaw et al., 2013](#); [Patel et al., 2010](#)). Current practice of early identification of developmental delays has been addressed through developmental surveillance (known as developmental monitoring) and developmental screening programs targeting young children between

birth and preschool age ([Hamilton, 2006](#); [Pizur-Barnekow et al., 2010](#); [Rydz et al., 2005](#); [Squires et al., 2002](#)). The programs are usually delivered by general practitioners (in European countries) or paediatricians (in United States) through well-child check-ups or health supervisions ([Guevara et al., 2013](#); [King et al., 2010](#)). Other groups delivering the program are public health, community health nurses ([Armstrong & Goldfeld, 2008](#); [Barbaro et al., 2011](#); [Fraser et al., 2016](#)), general practice nurses ([Walsh & Mitchell, 2013](#)), child educators and other professionals in child care or early intervention ([Pizur-Barnekow et al., 2010](#)). Moreover, child development monitoring and screenings have been mandated as a national service in the majority of developed countries (e.g. Child Find and Oregon Healthy Start in the US; Universal Child and Family Health Service (UCFHS) in Australia) ([Australian Health Ministers' Advisory Council, 2011](#); [Macy et al., 2014](#)). Therefore, a nationwide initiative of child development monitoring and screenings is critical to support the implementation of early identification of developmental disabilities.

However, this mandate for early identification of developmental delay may not be the case in developing countries where poverty, poorly sustained health and education systems and lack of expertise remain high (Charema, 2012). Moreover, developing countries like Indonesia still have a high number of health problems in terms of infectious diseases, maternal and neonatal mortality rate, under-five mortality rate, malnutrition including iron and iodine deficiency and severe growth stunting (Ministry of Health, 2015, 2019). As a result, early intervention for children with disabilities may not be a major concern and readily available.

The aim of this study was to explore Indonesian nurses' perception regarding their roles in the early identification of developmental disability and their intervention. By investigating their perceptions, the roles of the nurses and how they perform their roles would be revealed.

METHODS

Study Design

A descriptive phenomenology approach with semi-structured interviews have been employed to collect data. Phenomenology is "an approach to exploring and understanding people's everyday life experiences through hearing, seeing, believing, feeling, remembering, deciding and evaluating" (Polit & Beck, 2010). Through in-depth interviews, the informants are helped to describe their working experiences without leading the discussion.

Participants

Eleven participants were recruited from four community health centres in Banten Province Indonesia. According to Polit and Beck (2010) a phenomenological study involve a small number of study participants-often 10 or fewer. However, this study recruited eleven participants as an effort to experience the phenomenon in the same way. The inclusion criteria included nurses who worked in the community health centres and who had work experience in the centres for a minimum of 12 months. The exclusion criteria were to exclude those nurses who had not had any experience in child health service.

The participants were recruited after receiving approval from the Health Department of the City (*Dinas Kesehatan*) and after receiving ethics permission (Project number 6460) from Flinders University Social and Behavioural Research Ethics Committee. The researcher met the managers of the centres to introduce the study and hand out the research package (letter of introduction, informed consent form and information sheet). The managers then introduce the head of child health services and asked her to introduce the researcher to the nurses who met the criteria of the study. During introduction of the study, researcher met the nurses in the health centres and took part in friendly conversation to build rapport with them prior the scheduling of interviews. Semi-structured interviews were conducted in an informal conversation which often started with an idea in mind, open-ended questions were put to the informants, and the conversation followed these to gain greater understanding.

Data Collection

Data collection were gathered from field notes and in-depth interview with 11 nurses and five of them were followed into second interview. The interviews were conducted in a quiet room in the centres that the

informants chose. All of the interviews were conducted in working hours when the informants available. The main researcher of this study did all the interviews which mostly run for approximately an hour. All of the interviews were audio-recorded and transcribed by the researcher. In the first interview, the researcher asked questions guided by the interview protocol to remain focused but without a rigid structure. After the first interview, the researcher added some notes to explain the situation and highlighted important issues or unclear statements that needed a clarification in the next interview. The second interview was focused on the main issues that emerged in the first interview and also to ask if there were any additional responses from the first interview the participant wish to provide. Due to time limitations, the second interview was not successfully conducted with all participants. Only five out of eleven participants participated in the second interview. The remainder of the participants reported they were too busy.

Data Analysis

Thematic analysis was used to analyse data. Thematic analysis refers to "a method of identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006). Thematic analysis is applied by reading the interview transcripts line by line, underlying the key words, creating codes (sub-themes) and then themes or categories (thematic structures) to see patterns (Munhall, 2007; Taylor et al., 2006). Refinements of the codes and themes requires the researcher to read the text several times before then being able to see what the participants actually felt was important to highlight. The data were translated from Bahasa Indonesia into English version by the main researcher as she originally come from Indonesia. An Australian editor also helped the main researcher to proof-read the research report.

Trustworthiness

To gain the rigor for this study the researcher established trustworthiness by reading and reflecting on materials of the study and ensuring the research credibility, fittingness, auditability and confirmability had been achieved (Taylor et al., 2006; Tobin & Begley, 2004). Credibility addresses an issue of "fit" between respondents' view and the researcher interpretation (Tobin & Begley, 2004). Credibility in this study was achieved through member checking and prolonged engagement with the respondents through multiple semi-structured interviews. Fittingness or transferability refers to the extent to which the findings fit with other contexts outside the study setting or the ability for generalizability ((Taylor et al., 2006; Tobin & Begley, 2004). Fittingness or transferability in this study was achieved through the fact that similar findings had been found from other studies and judgment of different findings is shown in the discussion chapter. Auditability or dependability refers to the effort that shows the research process is logical and consistent (Taylor et al., 2006; Tobin & Begley, 2004). In this study, auditability can be found in documentation of data, methods, decisions and the end product that is consistent with the process. Confirmability is achieved if the credibility, fittingness and auditability can be demonstrated in the study (Taylor et al., 2006).

Trustworthiness may also be maintained by being reflexive with the study. Being reflexive means being aware of the researcher's own biases and pre-conceptions and taking steps to avoid influencing the results (Munhall, 2007). This includes making the biases explicit, not asking leading questions, and checking out with the participants that the records of interviews accurately reflect their opinions and

viewpoints (Munhall, 2007). The researchers maintained the trustworthiness through member checking as the participants were asked to check and validate the results they provided during interviews. The participants were approached with a written summary of the interview, to be read and they were asked to add notes of clarification or addition. All of those written documents were returned and were signed by the participants to show their agreement with the content of the interview.

Ethical Considerations

Ethical approval was gained from the ethics committee at Flinders University. In this study, participation was voluntary and required an informed consent before any interview took place. An information sheet about the study, the purpose, procedures, confidentiality for participants, benefits of research to participants, related to risks and participants' rights were provided together with the informed consent. In terms of storing data, the researcher maintained the anonymity of participants by masking their names in the data (used pseudonyms). Permission for audio recording was requested prior to interviews.

FINDINGS

The majority of the participants were female and have graduated from a Nursing Diploma program, which is a three-year nursing education program at a vocational level equivalent. There was only one male participant who has already retired but was still needed by Centre 1 due to shortage of nursing staff (Robert, 2014). He was also the only one who had graduated from SPK level (Sekolah Pendidikan keperawatan), the High School Certificate in Health Care (three-year nursing education post completing Primary School). Centre 1 only has three nurses whereas the other three centres have seven nurses.

All of the female participants have worked in the centres for one to four years whereas the male participant has the longest experience (34 years). In addition, all of the participants had experience working either in hospitals or clinics before they worked in the centre. Generally, the main responsibilities of the participants were those of an area manager providing nursing health care through home/school visiting or a centre-based service. Other responsibilities included school health checks; the eradication of Tuberculosis, eye health, child immunization, Integrated Management of Childhood Illnesses (IMCI) and health monitoring.

Nurses' perception of their roles in early identification and intervention

The perception of nurses' roles in early identification and intervention of developmental delay has been analysed based on the nurses' experience and beliefs about child development. The majority of the participants regarded their roles in child development as based on parental requests. Therefore, if the parents did not express a concern about their child's development, the participants perceived their roles as a focus on curative management. Even if the parents did not raise a concern about their child's development but the child was suspected with delays or having a possible developmental disability, the participants described their roles as provision only in terms of nursing care rather than a child developmental assessment. These include providing motivation and reassurance, providing parent education and information and feeding support. The participants also illustrated their

roles as being alert to discussing a possible developmental delay when they were managing the presenting/primary issue of the children.

a. Parents' expression of need

Five participants mentioned that their roles were influenced by the parents' expression of their child's needs. Most of the participants illustrate that parents seek community health nurses due to an illness rather than developmental problems.

"Basically, we work based on what parents express, for example, if the parents express the child has cough, so we focus on respiratory assessment" (Clara, centre 1)

"If the parents of the child did not express about their child's development, we not really concern with that" (Susanne, Centre 3)

This appeared to be the case even if the child had previously been diagnosed with a developmental disability.

"If the parents express that, we give intervention as much as we can do, otherwise refer" (Ruth, Centre 4)

"Parent of children with Down syndrome, they only come for treatment of cough or cold" (Anne, Centre 2)

b. A focus on curative management

Eight out of the eleven participants frequently described the focus of their roles as curative, often through assessing and monitoring the child's physical growth and nutritional status. One participant perceived curative management as what the centre was for. When they were asked about developmental assessment, they looked unsure, and explained again that they were only focused on monitoring child's growth and nutrition status.

"Usually we only monitor their growth development, check their nutrition status..." (Clara, Centre 1)

"Regarding the child growth and development, we more focused on the child nutrition" (Anne, Centre 2)

In addition, they argued that the focus should be on curative management because this was part of the centre's program and the government program, believing this to be the more important aspect.

"Because the main child program in the centre is nutrition and immunization, maybe there is child development monitoring here, but I usually do not do that (laugh)" (Ruth, Centre 4)

"The most government concern is about malnutrition, they not really concern with child developmental problem, centre will be considered negative if there any malnutrition case in our area, therefore we also focus on child nutrition" (Gayle, Centre 4)

c. Provision of nursing care

All participants illustrated aspects of their nursing care experience when they meet children suspected of having a developmental delay or disability in the centres. The most frequent nursing care term they mentioned was "referral" with NVivo calculating a word frequency of "refer" or "referral" of 60 times. Referral was shown as a significant aspect as all participants mentioned this.

"Developmental problems are referred to the specialist" (Barbara, Centre 1)

"Refer to Tangerang Selatan hospital, because we only have general practices here, we don't have paediatricians" (Fiona, Centre 4)

They also explained other aspects of nursing care that they were able to provide, which included: conducting assessments through family interviews (2 participants); collaboration with community health workers, doctors, physiotherapists and nutritionists (3 participants), feeding support (3 participants), providing motivation and reassurance (6 participants), providing parental education (5 participants) and information (4 participants). The following quotes from the participants illustrate these aspects of nursing care.

"Collaboration with physiotherapy in the centre" (Susanne, Centre 3)

"We provide motivation because typically the family has low confident, isolate, the child does not go to school. The point is motivation, to make them socialise with society" (Michelle, Centre 2)

"One day there was a child with language delay, I taught the mother to stimulate the child by keep talking and asking questions more frequent" (Clara, Centre 1)

d. Being alert to discuss a possible developmental delay

Seven participants described that when they meet the parents, they are alert to a developmental delay while they manage the main issue as raised by the parents. This may be even if the parent does not raise any concern with the child's development. If the child had not presented with an illness, the developmental delay may have been missed.

"I have an experience with a child with Down syndrome. Firstly, she comes because of having cough and cold, and because I knew from the child appearance, I validated with the mum, what developmental achievement the child has and how the child feeding" (Kelly, Centre 2)

"Children with developmental problems mostly come with comorbid illnesses such as cough, cold, fever, diarrhoea, malnutrition, they frequently come, thus we can analyse why their weight is not increasing, is there any contact with TB? is there any seizures? We investigating by asking the parents" (Robert, Centre 1)

DISCUSSION

Participants identified four aspects that they perceive as nursing roles in the early identification and intervention of developmental delays and disabilities. These include fulfilling parents' expression of needs, being alert to discuss a possible developmental delay, providing nursing care for children with developmental disabilities and curative health management. The description of their roles reflects the current practice of Indonesian nurses in the Community Health Centres (CHCs). This practice differs from community health nurses' practice in other countries who describe their roles to include conducting child developmental screenings (Caley et al., 2006; Fraser et al., 2016), monitoring early signs of Autism (Barbaro et al., 2011; Pinto-Martin et al., 2005) and supporting parental roles including enhancing mother-child interactions (Armstrong et al., 1999; Barnes et al., 2003; Fraser et al., 2016) (which are the core of early intervention programs for children with disabilities (Guralnick, 2005).

Fulfilling parents' expressions of needs is regarded as a component of the nursing role. When parents show concern with their child's development, the nurses provide support including motivation and reassurance; they offer parental education and further assessment, but were often limited with insufficient guidelines and facilities. Unfortunately, if the parents do not express concerns regarding their child's development, the nurses acknowledge that they do not really address child development care and focus on the program that has been

set up by the manager of the centre. This perception may hamper early detection of developmental delays and intervention, even though they believe that child developmental monitoring is part of their nursing role. In cases where parents have initiated concern for their child's developmental needs, the AAP algorithm for developmental-behavioural surveillance and screenings is put in place to elicit and attend to parents' or care givers' concerns (Marks et al., 2011). The algorithm suggests primary care professionals should consistently ask parents questions about their child's development using open-ended questions (Marks et al., 2011). Parents may not disclose information if the clinicians do not ask (Glascoe, 2005). Moreover, parents from low income status may be unlikely to raise developmental concerns (Glascoe & Dworkin, 1995). Importantly, parental concerns are indicators of their child's general development including speech and language (Marks et al., 2011). Reasons why parents may hesitate to raise developmental concerns vary. It may be due to the social myths surrounding motherhood, childhood and medicine (Williams, 2007). A qualitative study exploring mothers' beliefs around the detection of subtle developmental problems in young children found that mothers were hesitant in seeking advice from others including health professionals due to a mythical notion of a "good" mother, and their perceptions of childhood and medicine (Williams, 2007). The study concluded that mothers view good child developmental and behaviour as being the result of good motherhood and vice versa, leading to self-blame if the child is having developmental problems.

Participants described their role as one of being ready to discuss a possible delay even when the child has been brought to the centre by the parents because of acute illness. Furthermore, when it is suspected or observed, that the child has delayed development or has developmental disabilities, they will raise concern with either parents or their colleagues (doctors and midwives). The findings are similar to a Randomised Controlled Trial (RCT) study in 2008 which was concerned with signs of developmental delays and mother-infant relationship problems (Skovgaard et al., 2008). Skovgaard et al. (2008) revealed that community health nurses are regarded as being able to identify young children with mental disorders when they raise concerns of child development problems and mother-child relationship problems during general health surveillance (Skovgaard et al., 2008). Moreover, the study highlights that even nurses who have no formal training in infant mental health assessment, and rely only on their empirical knowledge about developmental milestones, can relate their concerns to a potential diagnosis of mental disorders. This study emphasizes the importance of being alert and to raise a concern when a developmental problem (e.g. red-flag in developmental milestones) or mother-infant relationship problems (e.g. emotional, behavioural, sleeping and eating disorders) is suspected. Being alert, however, should be followed by careful and close monitoring of the child's development, and recommendation for further assessment and evaluation (Marks et al., 2011) as well as referral to an early intervention program (Giordano, 2008) such as through an intensive home visiting program (Squires et al., 2002) which forms part of a community health nurse's role (Armstrong et al., 1999) or Child and Family Health Nurses roles (Fraser et al., 2016).

Participants describe various approaches to nursing care based on their experiences in dealing with children with developmental delays or neurodevelopmental disabilities (e.g. Down syndrome, Autism, and Attention Deficit Hyperactivity Disorders). In general, providing

referrals is the most frequent of their roles. This action may reflect the fact that they do not want to lose the child from the centre's service but it also indicates they are unable to conduct developmental assessments, identified as one of their barriers. Therefore, they refer the child to the doctors in the centres in the first instance, then to the Tangerang Public Hospital as the main referral. Participants further explain that referral is instigated by providing a letter of referral to be used at either the Tangerang Public Hospital or other private child developmental clinics. However, referrals may prove ineffective as the nurses rely on parental motivation to initiate the process. According to King et al. (2010) there should be a system of referral-tracking as many families do not follow through with referrals and often do not understand why they are being referred.

Indonesian nurses describe their roles as focusing on curative management and include monitoring child growth and nutritional status. The nurses believe that frequent illness, delays in child growth and malnutrition influence child development. Two studies on child development in developing countries support the argument that poverty, malnutrition and infectious disease are factors that put a child at high risk of having poor cognitive development (Grantham-Mcgregor et al., 2007; Walker et al., 2007). Poverty leads to inadequate provision of nutritious food to protect brain development during pregnancy and infancy, whereas infectious disease may affect the process of organ development, reducing the child's physical activity and play (Grantham-Mcgregor et al., 2007; Walker et al., 2007). Walker et al. (2007) argue that stunting as a result of malnutrition; inadequate cognitive stimulation; iron and iodine deficiencies are risks factors that need urgent intervention in developing countries. These two articles support the findings of the current study in the Indonesian context, as most of the participants perceive their roles to focus on curative management through monitoring nutrition status as well as infectious diseases.

It can be concluded that Indonesian nurses' perception of their roles in early identification and intervention of developmental delays may differ from other nurses in particular, those from developed countries. For example, Walsh and Mitchell (2013) explain that Australian general practice nurses' roles include immunisations, child health checks, general child health and development, asthma, feeding, fever and settling or sleeping management. Interestingly, Australian nurses also raise the need for professional development in childhood growth and development (Walsh & Mitchell, 2013). They describe that child health checks which include areas addressing parental concerns about development, child head circumference and height (Walsh & Mitchell, 2013) are similar to this study. In addition, nurses in Australia are developing more contemporary services including provision of home visits, individual consultations, drop-in clinics, parental management clinics and Positive Parenting Program (Triple P program) (Barnes et al., 2003) which cover concepts of an early intervention service (Guralnick, 2005). According to Guralnick (2005) early intervention aims to improve parent-child interaction; influencing parents to provide home and community experiences that can substantially influence a child's development; ensuring that the home environment contains appropriate toys and materials; engaging with social activity that is stimulating and interactive; and ensuring child health and safety through providing proper nutrition and maintaining a preventive healthcare regime (immunization and well-baby care).

CONCLUSION

Early identification of developmental delays and disabilities is critical to support the optimal development of children. One of the main aims of an early identification program is to ensure that children in need receive appropriate and timely intervention. Although early identification of developmental delays (DD) and intervention for children with developmental delays and disabilities exist in most developed countries, this may not happen in developing countries, particularly in Indonesia.

In regard to early intervention for children with developmental delays and disability, the nurses perform their role through the provision of nursing care. Nursing care includes providing the motivation and encouragement to support the inclusion of the children with developmental delays and disabilities, a principle of disability delivery service which is similar to delivery in developed countries. In addition, the nurses believe that children with disabilities should not be kept at home or become a source of shame for the parents. Thus, intervention in the form of inclusion and participation is predominant in the perception and beliefs of the nurses, although not enough to support the full inclusion and participation of children with developmental delays or disabilities.

DECLARATION OF CONFLICTING INTEREST

There is no conflict of interest to be declared.

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AUTHOR CONTRIBUTION

Concept generation, data collection, writing and editing of the manuscript (M), Concept generation, critically reviewed, writing and revision of the thesis (LC and PJ).

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ORIGINAL RESEARCH

NURSING RESEARCH PRIORITIES IN INDONESIA AS PERCEIVED BY NURSES

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Abstract

Background: To promote excellence in nursing research, setting research priorities is needed to meet the need of community aligned with the national context. Unfortunately, limited number of studies has examined nursing research priorities in Indonesia.

Objective: To identify nursing research priorities in Indonesia from the perspectives of nursing experts.

Methods: This was a descriptive qualitative study. Focus group discussion was conducted among participants who were purposively selected ($n = 13$). Data were analyzed using a consensus-based method.

Results: The top ten research priority lists were identified. The priorities were nurse competence, quality of nursing care in nursing services, nursing policy, nurse work environment, nurse mobility, interprofessional education and collaboration, teaching learning evaluation, nursing career, complementary therapy in nursing, and technology and informatics in nursing.

Conclusion: Findings of this study could be used as the basis of direction for development of future research in Indonesia.

KEYWORDS

nursing research; qualitative research; focus groups; nursing process; nursing services

BACKGROUND

Setting nursing research priorities is becoming popular today to guide researchers to conduct future studies and advance research collaboration ([Aungsuroch et al., 2019](#)). But, although setting a research priority or research agenda is considered as the main strategy to bridge the gap between nursing science and practice ([Aungsuroch et al., 2019](#)), there is a limited number of studies related to the identification of research priorities in nursing in Indonesia, which is just limited to only two studies ([Utomo et al., 2011](#); [World Health Organization, 2017](#)), which focus on the national strategies for operational research to support prevention and control of malaria, tuberculosis and neglected tropical diseases, and focus on health care system addressing rich-poor gaps in health care access and outcomes. Thus, it is difficult to conclude that these research priorities represent health care in Indonesia, especially priorities in nursing discipline.

Determining nursing research priorities is very important because research is an essential component of the nursing educational process, and it has a tremendous influence on current and future professional nursing practice ([Tingen et al., 2009](#)). In addition, although the nursing roles vary in a variety of settings, but their primary goal remains the same: to provide optimal care using evidence-based practice, and the source of evidence is based on nursing research. In other words, nursing research is vital to the professional nursing practice ([Tingen et al., 2009](#)).

Nowadays, nursing research has been developed in Indonesia, especially in nursing education, which students in undergraduate and graduate programs are required to conduct research for conferring degree. However, the question is whether the number of researches that have been conducted is aligned with the national context, or based on the needs in nursing services and education. As a nurse, we need to answer the demand of Indonesian community through research in response to the stage of nursing development ([Thompson, 2017](#)). Thus, this study aimed to identify nursing research priorities as perceived by Indonesian nurses in Indonesia, which specifically focus on nursing education and services.

Funding of Nursing Research Projects

Typically research funding for major nursing projects has come from Ministry of Research, Technology and Higher Education of the Republic of Indonesia (RISTEK-DIKTI) and LPDP (Indonesia Endowment Fund for Education) as the best regional fund management institutions to prepare future leaders and foster innovation for a prosperous, democratic and justice; and to focus on developing the quality of human resources in various fields that support the acceleration of Indonesia's development ([Simlitabmas, 2018](#)). Research and community service become one of the things that are being emphasized by the government in universities in Indonesia. The success indicators are intellectual property patents improvement, upgrading of downstream products, especially research leading to community

service, and enhancement of industrial prototype products. There are many funding schemes are designed to help universities in Indonesia to strengthen international collaborative research, such as funding for research and community research grant, international research collaboration and international publication grant, national innovation system research incentives, enhancing international publication (EIP), and research pro (non-degree) ([Simlitabmas, 2018](#)).

METHODS

Study Design and Participants

This was a descriptive qualitative study. Participants were purposively selected to explore more information regarding nursing research priorities in Indonesia. The inclusion criteria of participants were: directors of nursing, nurse managers (all grades), clinical nurse specialists, and clinical nurse facilitators, who are closely involved in all levels of health services. In this study, there were 13 participants were selected, which consisted of: 9 nurses' educators, 1 hospital nurse manager, 2 clinical nurses in hospital, and 1 member from Association of Indonesian Nurse Education, as they would be able to provide relevant information in regards to nursing research priorities in different settings. The participants were contacted through short message service (SMS) and phone call.

Procedure

Data were collected on September 2017 in the Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada. Once the participants accepted the invitation, an appointment was scheduled for focus group discussion (FGD). FGD was conducted using bilingual languages, Indonesian and English language by principle investigators approximately for 120 minutes. There were two steps of procedures in this study: i) all participants were given a blank of paper and asked to

write the nursing research priorities based on their expertise, observation and clinical practice in the nursing field, ii) the principle investigators collected all the information and wrote all the priorities items in front of all of participants in the white board, iii) each participant was asked to discuss each item by comparing the items and emerged if there were same contents. In the end, consensus was reached among all participants and agreed with the priorities.

Data Analysis

In this study, a consensus-based approach was chosen to determine nursing research priorities as perceived by Indonesian nurses. Consensus tends to improve the acceptability of the exercise; individual ranking prevents dominance of a few participants ([Viergever et al., 2010](#)).

Ethical Consideration

The ethical approval of this study has been secured by the Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia. We confirmed that each respondent has obtained an appropriate informed consent. All participants were informed about the objective of the study and assured that participation in the study was voluntary. Moreover, they were able to withdraw from the study at any time. The researchers guaranteed the confidentiality of their data and also ensured them that their information would be published anonymously.

RESULTS

This study aimed to determine nursing research priorities in Indonesia. The first step to do was to invite all participants to list priorities using a written method. From this method, there were 51 items identified as shown in **Table 1**.

Table 1 List of Research Priorities in A Written Method

Nursing Education		
1. Learning media	4. Optimizing the role of nursing profession in developing health policy	
2. Learning method – curricula	5. Awareness of nurses towards nursing profession	
3. Learning evaluation	Nursing Service	
4. Research development	1. Elderly health management	
5. Learning (labs and clinics) supervision	2. Non communicable disease control	
6. Internship program	3. Environment and disaster risk reduction	
7. Interprofessional education	4. Dementia	
8. Application of OSCE as national exam	5. Vulnerable family and intervention	
9. Patients education for community	6. Assessment methods	
10. Personal behavior of students, lecture and staff	7. Expanding and enhancing disaster preparedness and mitigation	
11. Curriculum development	8. Health promotion and prevention for chronic diseases	
12. Student center learning	9. Behavior modification for patients with CVDs	
13. Teaching methods	10. Palliative care and end of life	
14. Feasibility of practice setting and curriculum demand	11. HIV and infection promotion and prevention	
15. Qualification of teachers	12. Pain management	
16. Evaluation of competencies (cognitive, affective, psychomotor)	13. Nursing informatics	
17. Curriculum evaluation	14. Early detection for emergency	
18. The role of teacher as students’ advisor	15. Universal coverage	
Nursing Organization		16. Efficiency of nursing care
1. Nurse competence		17. Humanistic nursing care
2. Human resources management		18. Patient safety
3. Career ladder		19. Quality of nursing care

Nursing Service (Cont.)

20. Standard of nursing language	25. Complementary therapy in independent nursing practice
21. Nursing delivery	26. Independent nursing practice
22. Infection prevention and control	27. Nursing technologies
23. Effectiveness of nursing intervention	28. Independent nursing practice
24. Nurses role in the program of family health	

The next step was that the principle investigators invited all participants to discuss one by one of the topics to understand why they chose the topic by providing the reasons, and then comparing each item to find similarities and differences. In this step, all items were grouped into 10 research priorities (see **Table 2**), and agreed by all participants. And the further step was that the principle investigators analyzed the contents and developed area for possible investigation in each priority. Member check was done to confirm that the findings were agreed by participants (see **Table 3**).

Table 2 Top 10 Nursing Research Priorities

1. Nurse competence
2. Quality of nursing care in nursing services
3. Nursing policy
4. Nurse work environment
5. Nurse mobility
6. Interprofessional education and collaboration
7. Teaching learning evaluation
8. Nursing career
9. Complementary therapy in nursing
10. Technology and informatics in nursing

Table 3 Nursing Research Priorities and Areas for Possible Investigation

Priorities	Possible Investigations
Nurse competence	<ul style="list-style-type: none"> To develop strategies to improve nurse competence To identify factors related to nurse competence and performance To develop instrument to measure nurse competence To evaluate nurse competence
Quality of nursing care in nursing services	<ul style="list-style-type: none"> To develop strategies to improve nursing care quality To develop standard for nursing practice/guideline in each setting To develop nursing outcome or sensitive indicators To develop instrument to measure nursing care quality, nurse satisfaction, and nursing outcomes
Nursing policy	<ul style="list-style-type: none"> To explore the policy on nursing workforce (supply and demand) To explore the sources of health policy that influence nursing practice To better understand policy/advocacy concepts and methodology utilized in all levels of nursing education and services
Nurse work environment	<ul style="list-style-type: none"> To examine the impact of nursing work environment on patient outcomes To improve positive practice environment
Nurse mobility	<ul style="list-style-type: none"> To identify internal nurse mobility (rural to urban area or urban to rural area) and their related factors To identify factors influencing nurse turnover
Interprofessional education and collaboration	<ul style="list-style-type: none"> To develop framework for interprofessional education (IPE) and interprofessional collaboration (IPC) in hospital setting To measure the effectiveness of interprofessional education and collaboration
Teaching learning evaluation	<ul style="list-style-type: none"> To examine the effectiveness of teaching learning To measure learning outcome To evaluate curriculum models To measure nurse educators' competence
Nursing career	<ul style="list-style-type: none"> To develop the framework of nursing career development To identify career needs from the perspectives of staff nurses To explore perspectives of students on nursing career as a choice
Complementary therapy in nursing	<ul style="list-style-type: none"> To examine the effect of complementary nursing therapies on patient outcomes To explore the attitudes of nurses toward the use of complementary nursing therapies
Technology and informatics in nursing	<ul style="list-style-type: none"> To explore the attitudes, knowledge, awareness, and readiness of nurses towards use of technology and informatics To identify nurses' technology and informatics competencies To examine the effect of technology and informatics on nursing and patient outcomes

DISCUSSION

Our findings reveal nursing research priorities in Indonesia, which were

grouped into ten themes, namely: nurse competence, quality of nursing care in nursing services, nursing policy, nurse work environment, nurse mobility, interprofessional education and collaboration, teaching

learning evaluation, nursing career, complementary therapy in nursing, and technology and informatics in nursing. We discuss the research priorities in each theme as the following:

Theme 1. Nurse Competence

All participants agreed that nurse competence should be the first priority in Indonesia. Competence is the basis of the frameworks of professional practice ([Cashin et al., 2017](#)), which refers to the total of observable behaviors that occur in professional practice, categorized and specified in relation to measurable standards. Competence also refers to unobservable attributes, capacities, dispositions, attitudes, and values that the professional should have, which are inferred by detectable behaviors ([Campion et al., 2011](#); [Gunawan, Aunguroch, & Fisher, 2018](#); [Rass, 2008](#)). The need for development and evaluation of competence is subjected to nurses. Competence assessment is a paradigm that is common in the healthcare environment and this being particularly true within the nursing profession ([Franklin & Melville, 2015](#)). In this study, our research priorities include developing strategies to improve nurse competence based on the level of nurses, as there are many nurses background in Indonesia ([Gunawan & Aunguroch, 2015](#)). In addition, we need to measure nurse competence and identify factors influencing their competence.

Theme 2. Quality of Nursing Care in Nursing Services

Quality of nursing care is the important indicator of best practices in the hospital, which also reflects on nursing image. This priority is likely to focus on studies regarding the improvement of strategies to increase care quality, development of standard of nursing practice, nursing outcomes and sensitive indicators and their measures. Nursing-sensitive outcome indicators are valid and reliable measures that reflect the structure, processes and outcomes of nursing care and clinical practice in the hospital unit setting ([Doran, 2010](#); [Heslop & Lu, 2014](#))

Theme 3. Nursing Policy

This priority is likely to focus on studies to explore the health policy regarding the supply and demand of nurses in Indonesia, and identify the sources, concept and methods influencing nursing practice in all levels of education and practices. As a nurse, we need to be more prepared in the role of advocacy and policy development ([Staebler et al., 2017](#)). Through policy work, nurses can and should influence practice standards and processes to assure quality of care.

Theme 4. Nurse Work Environment

This priority is likely to identify the impact of nurse work environment on patient outcomes and to improve positive practice environment. Research suggests that administrative interventions aimed at improving the quality of the practice environment, have more effect on staff retention and maintenance of adequate staffing levels than increasing recruitment or salaries ([Twigg & McCullough, 2014](#)). Positive Practice Environments (PPE) are settings that support the excellence and the effectiveness of work, particularly to support nurse performance, improve quality patient care and to ensure the health, safety and personal well-being ([IChRN, 2018](#)).

Theme 5. Nurse Mobility

To know the trend of internal nurse mobility is needed, as we found unequal distribution of nurses in Indonesia. Most of nurses tend to move to urban areas, especially in big cities in DKI Jakarta, West Java, Central Java, East Java, and North Sumatera ([Gunawan, 2016](#)). However, some participants said that nurses nowadays are moving to

rural areas because high competition in urban areas. That is why we need to know the updated information and its related factors. In this priority, the participants are not likely to focus on international mobility because some barriers for international migration, especially for language. In addition, we also focus on nurse turnover and its affecting factors.

Theme 6. Interprofessional Education and Collaboration

Interprofessional education is an important step to provide patient care in a collaborative team environment among health professions students. Once health care professionals begin to work together in a collaborative manner, patient care will improve ([Buring et al., 2009](#)). Interprofessional teams enhance the quality of patient care, lower costs, decrease patients' length of stay, and reduce medical errors ([Institute of Medicine Committee on the Health Professions Education, 2003](#)). This priority is likely to focus on studies related to development of framework for interprofessional education and collaborative practice, measurement of its effectiveness.

Theme 7. Teaching Learning Evaluation

The purpose of nursing education is to transfer nursing knowledge and assist nursing students to acquire the necessary skills and attitudes associated with nursing practice ([Salsali, 2005](#)). This priority focuses on the effectiveness of teaching learning and to measure the learning outcomes and curriculum models. In addition, we seek to measure the nurse educator's competence. Teaching learning is a dynamic process, which includes active engagement of both the student and faculty ([Johnson-Farmer & Frenn, 2009](#)). Thus, the teacher is responsible to create an environment that improves students' focus ([Horsfall et al., 2012](#)).

Theme 8. Nursing Career

A career plan refers to a process of becoming aware of self, opportunities, constraints, choice, and consequences; identifying career-related goals, timing, and sequence of steps to attain the goals ([Gunawan, Aunguroch, Sukarna, et al., 2018](#)). This priority is likely to focus on studies related to the identification of career needs of nurses at different career stages, as well as to explore the hospital frameworks or programs whether it meets and satisfy nurses needs or not. As literature said that it is crucial to assess nurses' career needs and its development program from hospital ([CHANG et al., 2007](#)). In addition, it focuses on the exploration of students' perspective in choosing nursing as career.

Theme 9. Complementary Therapy in Nursing

The use of complementary/alternative therapies has increased exponentially during the past quarter century ([Lindquist et al., 2013](#)), including in Indonesia. Complementary is preferred by some as it conveys the idea that a therapy is used as an adjunct to Western therapies whereas alternative indicates a therapy that is used in place of a Western medicine approach ([Lindquist et al., 2013](#)). This priority focuses on the exploration of Indonesian nurses toward complementary therapies and examination of their effects on patient outcomes.

Theme 10. Technology and Informatics in Nursing

The need for research on technology has arisen over the past 20 years and it has been used to support the daily living activities, help interaction, educate patients, and enable the use of healthcare services ([Korhonen et al., 2015](#)). Nurses need to anticipate the impact of technology on care to move beyond a reactive approach to

technological advances (Archibald & Barnard, 2018). Information communication technology (ICT) and its applications are seen as tools to engage patients in self-care (While & Dewsbury, 2011). This priority is likely to focus on research related to the attitudes, knowledge, awareness, and readiness of nurses towards the use of technology and informatics, nurses' competencies on technology and informatics, and identification of the effect of technology and informatics on nursing and patient outcomes.

Limitation of the Study

In this study, although we think that the research topics identified could represent the research priorities in Indonesia, however, it is possible that some important topics were missed because the participants were limited to some parts of the regions, particularly only in Yogyakarta Indonesia. Further study is needed to validate the items with bigger sample size in Indonesia.

CONCLUSION

This study provided the top ten nursing research priorities and areas of possible investigation. These priorities could be considered as the basic of future direction of nursing research in Indonesia and funding should be coherent with these priorities as acknowledged by nurse experts. This study is a positive step towards the future of professional nursing development.

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DECLARATION OF CONFLICT OF INTEREST

None declared.

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AUTHORSHIP CONTRIBUTION

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	LL, YA, WW, SS, JG, MP
Involved in drafting the manuscript or revising it critically for important intellectual content;	LL, YA, WW, SS, JG, MP
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	LL, YA, WW, SS, JG, MP
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	LL, YA, WW, SS, JG, MP

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ORIGINAL RESEARCH

LIVED EXPERIENCE OF NURSES IN CARING FOR PERSONS WITH OUT-OF-HOSPITAL CARDIAC ARREST IN RURAL AREAS OF EAST JAVA INDONESIA: A PHENOMENOLOGICAL STUDY

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Abstract

Background: Out-of-hospital cardiac arrest can occur anywhere, including in rural areas. Nurses are demanded to have skills for critical care to save lives.

Objective: This study aimed to explore lived experience of nurses in caring for persons with out-of-hospital cardiac arrest in the rural areas of East Java, Indonesia.

Methods: This study employed a phenomenological research design. Five nurses were selected from five village health posts using a purposive sampling. A semi-structure interview was used to collect data. Colaizzi's method was used for data analysis.

Results: Four themes emerged, including (1) being fast and responsive, (2) needing a family trust, (3) feeling worried, and (4) lacking personnel and infrastructure.

Conclusion: The role of nurses in saving lives of persons with out-of-hospital cardiac arrest is very important. It is suggested for the nurses to always improve the quality of knowledge management of persons with critical conditions, provide understanding of basic life support in community, increase the trust of family in nurses, and improve the collaboration between nurses and community. The government also need to provide better emergency equipment and add health personnel in community.

KEYWORDS

out-of-hospital cardiac arrest; Indonesia; ethics; nursing; health services

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BACKGROUND

Pondok Kesehatan Desa (PONKESDES) is a health facility located in the village that aims to improve the health welfare of rural communities, especially in East Java Province, Indonesia. PONKESDES held in East Java is to improve the health status of the community by being a primary service provider to increase the awareness of the community about healthy environment, improve clean and healthy behavior, and improve easy access to people in rural areas ([Department of Health Service, 2011](#); [East Java Governor Regulation, 2010](#)). The role of nurses in PONKESDES is very important, including the authority in emergency condition to save lives ([East Java Governor Regulation, 2010](#)).

The rural areas located in East Java Province of Indonesia have only one nurse in each village, which is quite challenging because the distance to from the rural area to the hospital takes about one hour with poor road conditions. In addition, each village has no ambulance available to provide services. However, nurses are still demanded to provide the best care in every condition. Nurses are required to be

sensitive to the environment, culture, and legal ethics, as well as being sensitive to emergency conditions that threaten the lives such as Out-of-Hospital cardiac arrest (OHCA) ([Jainurakhma et al., 2017](#); [Mumpuni et al., 2017](#); [A. A.-I. Siregar, 2017](#); [Winarni, 2017](#)).

In critical or emergency conditions, nurses hold the principle of caring as the core of professionalism, which nurses treat clients and families as a whole as a human being, respecting the trust of clients and families and all the differences exist while still upholding the similarities in nursing care ([Izzah et al., 2018](#); [Jainurakhma et al., 2017](#); [Mailani & Fitri, 2017](#)), thus creating a harmonious relationship between client-family and nurse, and creating satisfaction with the high quality of emergency services ([Mailani & Fitri, 2017](#)).

However, as there is lack of information regarding the caring experience of nurses in PONKESDES, the aim of this study was to explore the caring experience of PONKESDES nurses when dealing with clients with OHCA in rural areas of East Java, Indonesia.

METHODS

Study Design

A phenomenological study was used in this study.

Participants

Five nurses were selected from five PONKESDES using a purposive sampling. The inclusion criteria of the sample were nurses who worked at the PONKESDES for at least three years, and had experience in caring for clients with out-of-hospital cardiac arrest conditions.

Data Collection

Data collection in this study was carried out for six months from August 2018 to January 2019 in five areas, including: Ngranggon Anyar, Cengkir, Brangkal, Mojosari, and Krangkong. A semi-structure interview was conducted to explore lived experience of nurses when dealing with clients with OHCA. The interviews were done by the researchers for 30-60 minutes and all processes were recorded using a voice recorder. The interview was conducted in the workplace of each participant.

Data Analysis

Data were analyzed using the Colaizzi's methods (Polit & Beck, 2010), with the following stages: 1) listening to the participant's verbal interview results from the recording, 2) making transcripts and collecting all transcripts, 3) reading the entire transcripts of all participants repeatedly to determine and underline the essence of

significant statements, 4) clustering theme, 5) validating the description with participants, 6) putting together new data in the final description, 7) integrating the theme in the narrative description.

Trustworthiness

The credibility of the study was examined by extending the observations in the work environment of nurses, and triangulation (source and time). The entire research process was audited by senior nurses in the village environment as a dependability testing stage.

Ethical consideration

The study was approved by the Institutional Research Institute of Kepanjen STIKes, Number: 2017.4 / ST / LPPM / STIKes-KPJ / XII / 2017. The study permission was also obtained from the Head of Research Institute and Community Service at Kepanjen College of Health Sciences. Informed consent was obtained from the participants as a manifestation of their voluntary involvement in the research. Full disclosure of the study was given and the participants were assured of their confidentiality and anonymity.

RESULTS

Participants involved in this study were five nurses, three men and two women. They are all Muslim and having Javanese ethnic background. Majority has 5 years of experience and hold bachelor degree in nursing. All of them have emergency trainings.

Table 1 Participants' Demographic Data

Participants	Education	Experience as a nurse in PONKESDES	Emergency Training
1 (P1)	Bachelor of Nursing and Ners	5 years	Basic life support (2005), First aid training in the emergency department (2015)
2 (P2)	Diploma III in Nursing	5 years	Basic trauma life support (2012)
3 (P3)	Bachelor of Nursing and Ners	5 years	First aid training in the emergency department (2017)
4 (P4)	Diploma III in Nursing	7 years	First aid training in the emergency department (2007)
5 (P5)	Bachelor of Nursing and Ners	8.5 years	First aid training in the emergency department, Basic cardiac life support (2005)

The results of the study showed that five themes emerged from data, including: 1) being fast and responsive; 2) needing a family trust; 3) feeling worried; 4) lacking personnel and infrastructure.

Theme 1: Being fast and responsive

This theme was raised by the nurses when dealing with clients' critical conditions when conducting initial assessments, providing first aid with airway-breathing-circulation (ABC) stability, and referring clients to more complete facilities. This requires fast and responsive behavior to save lives. This is explained in the following statements:

"The main determinant of success is our speed in dealing with emergency condition and referring the clients to the nearest hospital. So, the problem will be resolved" (P4 & P1)

"Airway-breathing-circulation should be prioritized, so the client's life can go on" (P2)

"The factor of success is timing. Our speed in providing help, or referring to a better place. A client with a cardiac arrest can immediately have his/her heart stop" (P2)

"If there is a person with cardiac arrest, we immediately resuscitate the heart. This is our alertness in critical care"(P2)

Theme 2: Needing a family trust

Nurses need family trust in caring for the client. One of which is by making good communication with families who are experiencing anxiety, especially when facing clients with critical conditions. If trust does not exist from the family, nurses do not get the authority to conduct first aid to save the clients. It is explained in the following:

"The family should trust the nurse to provide first-aid to clients. That's the key" (P1)

"We understand that family is anxious in the critical condition, they just need to trust us" (P3)

"If the family refuses, cardiac massage will not be done" (P1)

To maintain the trust, calming the family is also needed in order to reduce the tense in critical condition. The participants explain this in the following:

"We explain to family what happened and what must be done. This is to calm the family" (P4 & P2)

"I immediately gave help to the client, and explained the condition to the family" (P1)

Theme 3: Feeling worried

The theme shows that the nurses often feel worried when caring for clients with cardiac arrest in the community. This is due to the cardiac arrest events rarely occurred in their work environment. This is explained in the following:

"I feel worried when facing an emergency condition" (P4)

"Worried in facing emergencies. How to immediately help and send clients to the hospital?" (P3)

"I dealt with emergency condition, I was still nervous and worried" (P2)

"I feel worried if the lives of our patients would not be helped. The distance to hospital was far enough, the rescue staff was only one person, and no transportation to immediately help" (P1)

Theme 4: Lacking personnel and infrastructure

This theme explains that there was lack of facilities in providing emergency services, including lack of health personnel, special emergency transportation, emergency equipment, and emergency response system. This is expressed by the following participants:

"When there was a person with cardiac arrest at his home, I was alone, with the interval of 3 minutes of the incident" (P1)

"There was no pre-hospital assistance, no infrastructure facilities, no call center facility to assist, no transportation available, facilities, and no village assistance" (P1)

"We use manual tools in helping a person with cardiac arrest. The existing equipment did not meet the standards for emergency" (P3)

"There was only oxygen and nasal cannula, no bag valve mask, long spinal board, or cervical collar, and no automatic defibrillator (AED). If there is a cardiac arrest patient, yes, we do cardiopulmonary resuscitation, and if there was a vehicle, immediately we took the client to the closest hospital in 30 minutes, the fastest trip" (P1)

DISCUSSION

Nurses in carrying out their duties are required to always prioritize the holistic needs of the clients. Although the emergency conditions in their working area are very rare, but this does not close the possibility of the critical events in the community. Therefore, nurses need to gain authority in conducting health services outside of the authority as stipulated by professional organizations to save lives. This is in line with the policy of [East Java Governor Regulation \(2010\)](#) states that, the formation of a prosperous, moral, fair, independent, and competitive community should be formed by providing easy access to affordable, quality and quality rural communities.

Four themes emerged in this study. The theme "being fast and responsive" is one of the caring values raised by nurses in dealing with clients with critical conditions in the community, fast and responsive in identifying client's emergencies by reviewing the client's airway-breathing and circulation (ABC), helping or providing action to meet ABC's needs client, responsive in solving emergency problems that occur to the client, inform the client's condition to the family, and immediately take a referral action to the nearest health facility (hospital) that can be taken the most quickly is 30 minutes by using a

vehicle. The ability of nurses in conducting primary surveys must be fast and precise, so as to be able to determine the gravity that occurs, and immediately take a decision on the situation, and how to stabilize the airway-breathing and circulation conditions that occur ([Hidayah & Amin, 2017](#); [Kaban & Rani, 2018](#); [Prawesti et al., 2018](#)). The speed and responsiveness of nurses in dealing with emergency conditions often have problems, which the level of community or family knowledge and responsiveness in reporting emergency conditions is still felt to be very lacking, so this also influences the success of emergency cases that occur in rural communities. However, the time of help in patients with emergency conditions greatly determines the survival (golden hour) and the phase of victim care ([De Gruyter et al., 2019](#); [Winarni, 2017](#)), and increases client-family client satisfaction when critical conditions ([Mailani & Fitri, 2017](#); [Nastiti, 2017](#)). The speed in which AEDs are given by people who find cardiac arrest victims are also very influential in increasing OHCA life expectancy and neurological conditions ([Auricchio et al., 2019](#); [Karlsson et al., 2019](#); [Leung et al., 2000](#)), but unfortunately in the PONKESDES work area there are no AED facilities available, as well as the ability of officers when providing quality CPR will determine the success of rescuing clients with cardiac arrest at home, whether done on the floor or above the place sleep against chest recoil accuracy ([Ahn et al., 2019](#)). The provision of cardiac pulmonary resuscitation (CPR) with two rescuers is more effective, where the first helper performs CPR and provides oxygenation through BVM (bag-valve-mask) and the second helper opens the airway with both hands ([Shim et al., 2015](#)), but the phenomenon in our study that nurses often work alone when doing their jobs, including CPR.

The second theme "needing a family trust" indicates that a nurse's caring relationship will form properly if interpersonal relationships are created with a bond of trust ([Jainurakhma et al., 2017](#)). An important key in providing emergency nursing care when in rural areas is family trust. If this trust is not obtained, emergency response licensing is not granted by family members as well, so that the nurses are not able to assist quickly and precisely. Families trust will have an impact on demands on nurses, and this is what is not desired by the nurses. Emergency conditions are often constrained when requiring patient and / or family trust to be immediately referred to the hospital, this is not only detrimental to the client physically but also financially, the longer the waiting time referring to the hospital will further aggravate the condition and treatment while at home sick ([De Gruyter et al., 2019](#); [Sulistio et al., 2015](#)). Therefore, nurses' communication about client emergency information is urgently needed to increase family trust. Good and directed communication (focus) on conditions experienced by clients when emergencies have a major impact on patients and families ([Firstiana et al., 2017](#); [Jainurakhma et al., 2017](#); [Ocak & Avsarogullari, 2019](#)).

That communication is also meant to calm the family who experience confusion when they find family members lying unconscious, and fears that occur in the family's mind about the death of the client ([Nugroho, 2017](#)), and the family's ignorance in providing first aid during emergency events such as cardiac pulmonary resuscitation ([Nugroho, 2017](#); [Rosyid et al., 2018](#); [Winarni, 2017](#)). They need to be given information about the emergency conditions experienced by clients ([Herawati & Faradilla, 2017](#); [Paputungan et al., 2018](#)), and what efforts can be done to help clients, both personally, conditions physical, and requires emotional reinforcement when dealing with the condition of

one of their family members who are threatened with death, as well as how the life expectancy of this critical client (Ocak & Avsarogullari, 2019; H. R. Siregar & Antoni, 2017).

The third theme “feeling worried” indicated that the nurses have mental discomfort due to emergency equipment is very rare in rural areas. This is a dilemma for nurses who really want to help the clients, but the condition does not support them. We understand that the presence of equipment such as AEDs (automatic external defibrillators) greatly contributes to the rescue of victims with cardiac arrest before getting further help in hospital, this is evident victims with cardiac arrest who received AED facilities life expectancy increased threefold compared with the help of victims of OHCA without AED (Karlsson et al., 2019). However, defibrillation was only available at the nearest hospital which was 30 minutes away from the village. Thus, this needs high attention.

The last theme “lacking personnel and infrastructure” indicates that the environment that nurses work has no stand-by village transportation facility, no emergency response system, BVM (bag-valve-mask), long spinal boards, AEDs (automatic external defibrillator), and cervical collar. This is a nightmare for nurses who want to help or refer clients to emergency conditions, which should ideally have referral facilities such as an adequate supply of oxygen, portable monitors, suction devices, emergency medicine, and other devices (needles) (Dawes et al., 2014), AED (Karlsson et al., 2019).

Finding of this study highlight the phenomena of caring practice of nurses in emergency conditions, which require a solution that can improve welfare in the health sector for rural communities, including the need to increase the empowerment of resources available in rural communities, such as the need for basic life support training for the community (Hidayah & Amin, 2017; Nugroho, 2017; Rosyid et al., 2018; Winarni, 2017), so they will be more sensitive to any emergency conditions and be able to synergize with the nurses in providing client-first aid with emergency airway-breathing-circulation. The existence of an integrated emergency response service system is also needed in the village area (Mumpuni et al., 2017; Winarni, 2017) to provide services for 24 hours emergency medical service (Dawes et al., 2014), as well as the completeness of emergency equipment to reduce the death rate due to cardiac arrest (Mumpuni et al., 2017; Prawesti et al., 2018; Winarni, 2017). And integrated emergency training every year for community and health workers in the PONKESDES work area is necessary to do to facilitate community skills and responsiveness in dealing with emergency cases in the community area (Kaban & Rani, 2018; Mumpuni et al., 2017; Prawesti et al., 2018; Rosyid et al., 2018; Winarni, 2017).

CONCLUSION

Nurses are very meaningful to improve the quality of life of people in community, specifically in rural areas in the Province of East Java. With their caring nursing practice, nurses are quickly and responsively saved lives of people with cardiac arrest. However, their works require the family and community trusts, as well as supported by complete infrastructures. Findings of this study revealed the nursing practice and its limitation, and therefore, it is suggested for the nurses to always improve the quality of knowledge management of persons with critical conditions, provide understanding of basic life support in community,

increase the trust of family in nurses, and improve the collaboration between nurses and community. The government also need to provide complete emergency equipment and to add health personnel in community.

DECLARATION OF CONFLICTING INTEREST

None.

AUTHORS CONTRIBUTION

All authors have contributed from conception to the finalization of this study. Most of the significant intellectual content of this publishable copy of the article was done by the corresponding author.

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ORIGINAL RESEARCH

QUALITY OF LIFE OF FAMILY CAREGIVERS OF CHILDREN WITH LEUKEMIA: A DESCRIPTIVE QUANTITATIVE STUDY

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Abstract

Background: Treatment of children with cancer can affect daily lives of family caregivers. This can disrupt roles in social life, limit daily activities, disrupt health and physical and emotional balance as well as causing economic problems and creating poor quality of life.

Objective: To describe the quality of life of family caregivers of children with leukemia based on characteristics of parents and children.

Methods: This was a descriptive quantitative study. The population was all parents as the primary caregivers who had children aged 0-15 years diagnosed with leukemia in pediatric wards of Provincial General Hospital of Dr. Hasan Sadikin Bandung, Indonesia. Thirty-four respondents participated in this study selected using a total sampling. The quality of life of family caregivers was measured using the quality of life family version standard questionnaire, and the children's severity of leukemia was identified by the severity of illness scale standard questionnaire. Data were analyzed using frequency distribution, mean, and standard deviation.

Results: The study results showed that family caregivers had poor quality of life (58.8%), with the worst sub-dimension including physical and psychological health conditions (55.9%), followed by social conditions (52.9%), and spiritual health conditions (50.0%). The majority of family caregivers who had the poorer quality of life were at the older age, male, having a primary education level, caring for their children for less than 12 months with severe leukemia, and having an average monthly income of fewer than 1.5 million rupiahs.

Conclusion: Poor quality of life was identified among family caregivers of children with leukemia. Therefore, it is suggested for nurses to provide nursing care holistically not only for the children but also the families to increase their quality of life.

KEYWORDS

caregivers; quality of life; parents; leukemia; child; Indonesia

BACKGROUND

Cancer is a term for disease in which cells divide abnormally without control and can attack the surrounding tissue ([National Cancer Institute, 2009](#)). Cancer can strike all ages, including children, and it is considered the second leading cause of death in children aged five to 14 years ([Ministry of Health of the Republic of Indonesia, 2015](#)). The Indonesian Child Cancer Foundation also said that the prevalence of cancer in children increases by 7% each year ([Yayasan Onkologi Anak Indonesia, 2017](#)). The incidence of childhood cancer in Indonesia is around 2-4%. Every year, there are 11,000 cases of cancer in children and 10% of them cause death ([Widodo & Amanda, 2018](#)). Based on data from [Provincial General Hospital of Dr. Hasan Sadikin Bandung \(2017\)](#), chemotherapy in cancer patients was the most frequent case in the Department of Pediatrics and Child Health, as many as 1,412 patients. While in January to October 2017, there were 952 cases of cancer in children aged 0-18 years in Provincial General Hospital Dr. Hasan Sadikin Bandung.

[The Indonesian Pediatric Association \(2017\)](#) revealed that 3/4 of cases of malignancy in children in Indonesia occurred due to leukemia. In addition, global data showed that nearly 300,000 cases of childhood cancer from 2001-2010 showed that leukemia was the most experienced type of childhood cancer ([Saputra, 2017](#)). According to data from [Provincial General Hospital of Dr. Hasan Sadikin Bandung \(2017\)](#), there was 328 children who had leukemia in the last ten months of 2017.

Cancer diagnosis and treatment have a big impact not only for patients but also for families, and they affect every aspect of family life ([Duci & Tahsini, 2012](#)). Complex treatment protocols, including chemotherapy, intra-spinal drug injection, radiotherapy, and surgery lead to anxiety in the children and parents. The emotional reactions of parents to chronic illnesses experienced by their children have the potential to cause symptoms of post-traumatic stress and affect their

quality of life (Tsai et al., 2013). Caring for cancer patients can interfere with the quality of life of parents as informal primary caregivers.

Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL Group, 1995). Quality of life consists of four sub-dimensions, specifically physical health conditions, psychological health, social health, and spiritual health conditions (Kudubes, Bektas, & Ugur, 2014). Quality of life in older people can be influenced by several factors, such as characteristics of parents including age, gender, level of education, culture, length of care given to the child, amount of income, and as characteristics of children including severity of disease (Song, Nam, Park, Shin, & Ku, 2017; Turkoglu & Kilic, 2012).

A research conducted in Sri Lanka showed that nearly 50% of parents of children with leukemia had a low quality of life (Pathirana, Goonawardena, & Wijesiriwardane, 2015). According to Mancini et al. (2011), parents experienced various kinds of physical problems as a consequence of their roles in caring for children with cancer. The physical health problems frequently complained by parents were very severe fatigue, lack of time to rest, weight loss, and loss of appetite, which could be influenced by parental characteristics such as age, gender, education level, culture, income, and length of care to the children (Hacioglu, Özer, Erdem, & Erci, 2010; Kim & Spillers, 2010; Lim et al., 2017; Song et al., 2017).

A previous research conducted in China showed that parents of cancer patients experienced high emotional stress, with 54% of moderate to severe anxiety and 21% of depression. Parents of cancer patients also experienced fatigue, fear, feelings guilty, anxiety, depression, despair, regret, sleep problems, and high social isolation (Song et al., 2017). In addition, parents felt their social relationships were disrupted because they only focused on patients so that their own needs were neglected (Stenberg, Ruland, & Miaskowski, 2010). They most likely focused all their attention on maintaining patient care, managing pain, helping patient mobilization, meeting the patient's daily needs, contacting health workers, and delivering patients to get treatment (Kudubes et al., 2014; Turkoglu & Kilic, 2012). Additionally, they felt guilty about the fact that they were genetically responsible for the disease, and were worried and doubt about the future of their children (Mancini et al., 2011).

However, psychological and social problems in the parents can be influenced by the characteristics of parents and children (Hacioglu et al., 2010; Kim & Given, 2008; Kong, 2007; Lim et al., 2017; Litzelman, Catrine, Gangnon, & Witt, 2011; Song et al., 2017). Besides, negative experience can be dangerous because it can cause stress and physical health to be deteriorated, disrupted financial problems, sleep disorders, and other psychological problems for the parents of cancer children. These negative experiences can also affect the ability of parents to care for children with cancer (Song et al., 2017). According to Weaver and Flannelly (2004), those who have adequate spiritual conditions can accept the disease that occurs, and try to overcome it in a positive and directed manner.

Parents are the main source of emotional and social support for children with cancer, and they are responsible for how well patients carry out their disease. The level of difficulty experienced by parents when

knowing their child is diagnosed with cancer has an important effect on the child's psychological adjustment (Stenberg et al., 2010). The parents' declining quality of life can influence the quality of care and the quality of life of the patient (Turkoglu & Kilic, 2012). The involvement of parents is very important in the optimal management of cancer patients to ensure treatment compliance and continuity of care. If parents experience sustained fatigue and a decrease in quality of life, this can result in delays in the care that the child must undergo and this can drop the child's health condition off. Therefore, the quality of life of parents must be considered for the good of the parents themselves as an informal primary caregiver as well as patients' health (Mancini et al., 2011).

Research in Indonesia related the quality of life in 33 family members who treated children with leukemia who underwent chemotherapy at Provincial General Hospital of Hasan Sadikin Bandung showed that 54.5% of family members had a good quality of life. It could happen since the family had adapted to the responsibility of care since the child got the disease (Gamayanti, Rakhmawati, Mardhiyah, & Yuyun, 2012). However, the study only examined the quality of life in each dimension without analyzing it based on the characteristics of parents and children although the characteristics of parents and children such as parents' age, sex, education level, income, duration of care given to children, culture, and the severity of illness suffered by children are the factors that can influence quality of life.

The aim of our present study was to identify the quality of life of family caregivers in children with leukemia based on the characteristics of parents and children.

METHODS

Study Design

This study used a descriptive quantitative design.

Participants

The participants in this study were all parents as the primary caregivers and having children aged 0-15 years who were diagnosed with leukemia in inpatient rooms of Kenanga I and II at Provincial General Hospital of Hasan Sadikin Bandung, East Java, Indonesia. Thirty-four participants were selected using a total sampling technique.

Instrument

There were two instruments in this study: 1) The standard questionnaire of quality of life family version developed by Ferrell and Grant (2005) was used to identify the quality of life of parents (Ferrell & Grant, 2005). The questionnaire consists of 37 questions categorized into four sub-dimensions, especially physical health conditions (5 items), psychological health (16 items), social (9 items), and spiritual health conditions (7 items). All questions are measured using an ordinal differential semantic scale, with negative and positive statements with the lowest score of 0 and the highest score of 10. A good quality of life is indicated if the score \geq means value.

The scale has been translated into Indonesian language by a linguist at the Language Center of the Faculty of Cultural Sciences, Universitas Padjadjaran, and back-translated into English by another linguist at the Language Center, Faculty of Cultural Sciences, Universitas

Padjadjaran. The accuracy of the translation results was carried out by the other linguists as a translator at the English Language Education Institute (Think English) Bandung. After the translation process, validity content testing was carried out by a lecturer at the Faculty of Nursing at the Universitas Padjadjaran, followed by face validity with ten parents who asked for family caregivers for children with leukemia at Provincial General Hospital of Hasan Sadikin Bandung, Indonesia. The scale had an item content validity index of 0.790, and reliability value using Cronbach Alpha of 0.923.

2) The severity of illness scale questionnaire was used to see the severity of leukemia in children that was developed by [Young-Saleme and Prevatt \(2001\)](#). The scale has an item content validity index of 0.790 and a reliability value using Cronbach Alpha of 0.800. The scale is available in Indonesian language. This questionnaire has been translated into Indonesian by [Nursyamsyah \(2018\)](#). The questionnaire consisted of 6 questions related to the seriousness of the disease using the Likert scale with a value of 1 to 7.

Data Collection

The study was carried out in the inpatient room of Kenanga I and II at Provincial General Hospital of Dr. Hasan Sadikin Bandung. The study was conducted from April to May, 2018. Data were collected by distributing the questionnaires after the respondents have agreed to participate in this study and have signed informed consents. The data collection was done by the researchers and one research assistant, a nurse in the inpatient room of Kenanga I and II at Provincial General Hospital of Dr. Hasan Sadikin Bandung. Briefing prior to data collection was done to ensure that the perception of the researcher and research assistant was the same.

Data Analysis

Data were analyzed using descriptive statistics. As the data were normally distributed, mean and standard deviation were used. The higher the mean value, the higher the quality of life and the severity of leukemia suffered.

Ethical Consideration

The study was ethically approved by the Health Research Ethics Committee of Provincial General Hospital of Dr. Hasan Sadikin Bandung with number LB.4.01/A05/EC/035/11/2018. The study permission was also obtained from the Department of Research and Education of Provincial General Hospital of Dr. Hasan Sadikin Bandung with number LB.02.01/X.2.2.1/6125/2018. Prior to data collection, informed consents were made to all respondents. The objectives and the procedures of the study had been explained, and confidentiality of each respondent was ensured.

RESULTS

Quality of Life of Family Caregiver of Children with Leukemia

Table 1 showed that the average of the quality of life of family caregivers of children with leukemia was 198.12 with a standard deviation of 43.580. The minimum value of quality of life was 116 and the maximum value was 296. Table 2 revealed that overall quality of life of family caregiver of children with leukemia was poor (58.8%).

Table 1 Quality of Life of Family Caregivers of Children with Leukemia (N=34)

	Mean	Standard Deviation	Minimum-Maximum Value
Quality of Life	198.12	43.580	116-296

Table 2 Category of Quality of Life of Family Caregivers of Children with Leukemia (N=34)

Quality of Life Category	f	%
Good	14	41.2
Poor	20	58.8

Table 3 Subdimension of Quality of Life of Family Caregivers of Children with Leukemia (N=34)

Sub-Dimensions of Quality of Life	Mean	Standard Deviation	Minimum-Maximum Value
Physical Health Conditions	28.79	8.559	15-46
Psychological Health Conditions	68.62	21.617	36-108
Social Conditions	48.24	19.311	9-84
Spiritual Health Conditions	52.47	9.699	24-70

Table 3 showed that the sub-dimension of psychological health conditions had the highest mean value of 68.62 while the sub-dimension which had the lowest mean value was the physical health conditions (28.79). And Table 4 showed that the majority of respondents (55.9%) had the poor quality of life in the sub-dimension of psychological health conditions and physical health conditions. Meanwhile 50.0% of respondents had a good quality of life in the spiritual health conditions sub-dimension. However, the frequency distribution in each sub-dimension of the quality of life had no significant difference.

Table 4 Category of Sub-Dimensions of Quality of Life of Family Caregivers of Children with Leukemia (N=34)

Sub-Dimensions of Quality of Life	Quality of Life			
	Good		Poor	
	f	%	f	%
Physical Health Conditions	15	44.1	19	55.9
Psychological Health Conditions	15	44.1	19	55.9
Social Conditions	16	47.1	18	52.9
Spiritual Health Conditions	17	50.0	17	50.0

Table 5 showed that younger parents tended to have a better quality of life compared to older parents. In addition, the percentage of male parents (63.6%) who experienced a decreasing quality of life were more than female parents (56.5%). In addition, parents who had a higher level of education and total income tended to have a better quality of life compared to the parents who had a lower education level and amount of income. Also, parents from Java, Sunda, and Sumatera inclined to have poor quality of life. Parents who have cared for their sick children for less than 12 months (59.3%) and their children with more severe disease (66.7%) had a high percentage in the poor quality of life category.

Table 5 Quality of Life of Family Caregivers of Children with Leukemia According to Characteristics of Respondents (N=34)

Characteristics of Respondents	Quality of Life			
	Good		Poor	
	f	%	f	%
Parent's Age				
Late Youth (17-25 years)	1	50.0	1	50.0
Early Adult (26-35 years)	6	46.2	7	53.8
Late Adult (36-45 years)	4	33.3	8	66.7
Early Elderly (46-55 years)	3	50.0	3	50.0
Late Elderly (56-65 years)	0	0.0	1	100.0
Parent's Gender				
Male	4	36.4	7	63.6
Female	10	43.5	13	56.5
Parent's Education Level				
Primary School	2	18.2	9	81.8
Junior high school	4	33.3	8	66.7
Senior high school	6	75.0	2	25.0
College	2	66.7	1	33.3
The Duration of Giving Care to Children				
<12 months	11	40.7	16	59.3
>12 months	3	42.9	4	57.1
Severity of Leukemia Suffered by Children				
Mild	8	50.0	8	50.0
Severe	6	33.3	12	66.7
Total Parent Income per Month				
<1.5 million	6	28.6	15	71.4
1.5-2.5 million	2	66.7	1	33.3
2.5-3.5 million	3	50.0	3	50.0
>3.5 million	3	75.0	1	25.0
Parent's Culture				
Java	2	25.0	6	75.0
Sunda	11	47.8	12	52.2
Sumatera	0	0.0	2	100.0
Betawi	1	100.0	0	0.0

DISCUSSION

The quality of life of family caregivers of children with leukemia at the Provincial General Hospital of Dr. Hasan Sadikin Bandung was poor which against the results of a previous study conducted by [Gamayanti et al. \(2012\)](#) at the same hospital, which revealed that there was a good quality of life of family caregivers of children with leukemia. This distinct result might be due to the use of different questionnaires. The previous questionnaire on the physical dimension only examined one facet and rest, while in the spiritual dimension only examined the relationship with God. In our study, the questionnaires are more comprehensive covering all facets of each dimension, thus describing the results more thoroughly as well. Although the results of this study are different from the research conducted by [Gamayanti et al. \(2012\)](#), the results of this study are in line with the research by [Lim et al. \(2017\)](#) and [Song et al. \(2017\)](#) which revealed that parents who took care for children with cancer are likely having poor quality of life.

Good or poor quality of life of the parents however can be influenced by the characteristics of the children and the parents themselves. The results of our study showed that older people tended to have poor quality of life. These results are consistent with a study conducted by [Song et al. \(2017\)](#), mentioned that older caregivers experienced higher emotional stress and a lower quality of life. According to [Rohmah and](#)

[Bariyah \(2015\)](#), this can occur because, at a later age, a person will experience changes in physical, cognitive, or social life, so that it can worsen their quality of life, which in turn affects the quality of care for their children. The results of our study also showed that the majority of older people experienced poor quality of life in the sub-dimension of physical health conditions. The results of this study somehow are consistent with the research conducted by [Kim and Spillers \(2010\)](#) found that younger caregivers had better physical health compared to the older ones. This may be related to the ageing process that occurs in each individual.

[Pangkahila \(2007\)](#) revealed that each individual has three stages of the ageing process. The first stage is called the subclinical stage when a person is in the age range of 25-35 years. At this stage, most of the hormones in the body begin to decline, besides that the formation of free radicals can damage body cells, but at this stage, the decrease in hormones and body cells damage is not too visible. The second one is the transition stage when individuals are in the age range of 35-45 years. The hormone levels decrease to 25% and free radicals begin to damage the genetics so that it can lead to several diseases, such as arthritis, reduced memory, infectious diseases, and various other diseases. The last stage is the clinical stage when individuals reach the age of 45 years and above. At this stage, the decrease in hormone levels continues.

There is also an alleviation in body function and the immune system so that individuals are more susceptible to disease.

Furthermore, the results showed that 50% of parents, in the range of 17-25 years old (late adolescents), experienced psychological health conditions have poor quality of life. According to the social role theory, younger parents may experience greater pressure because they should adjust to their new roles as parents. Also, more than 50% of parents, aged 36-65 years, experienced the psychological health conditions have poor quality of life. [Rohmah and Bariyah \(2015\)](#) stated that at a later age, individuals might experience psychosocial changes. The results of this study also revealed that most parents, in the late adult age category (36-45 years), experienced the social conditions have poor quality of life. According to [Santrock \(2013\)](#), at this time individuals usually experience an increase in social activity. However, parents who take care for children with leukemia would feel their social relationships are disrupted because they only focus on the needs of patients, so they have poor quality of life ([Stenberg et al., 2010](#)).

Based on the gender, male and older people (63.6%), especially in the social and spiritual sub-dimensions, have poor quality of life. According to [Lim et al. \(2017\)](#), this can happen because men have a role as the backbone of the family, so they find it difficult to divide their time between working and taking care of their sick children. It is not easy for a father to play a dual role as a breadwinner and helping his wife in caring for a sick child ([Khouri, Huijter, & Doumit, 2013](#)). As a result, many patriarchs often cannot participate in social activities, eventually, have to stop working as a consequence of caring for their sick children, and this can increase emotional stress ([Wadhwa et al., 2013](#)). [Pathirana et al. \(2015\)](#) and [Lau et al. \(2014\)](#) also mentioned that many parents have to stop working because they have to take care of their children and continue to meet the cost of care, which could increase the burden and reduce the quality of life.

Based on the results of this study, we also found that the parents who had a good quality of life in the sub-dimension of spiritual health conditions mostly female as much as 52.2%. It is in line with a statement of [Kim and Spillers \(2010\)](#), women have greater spiritual values. In this case, what is meant by spirituality is not only a relationship with God, but also a relationship with themselves, others, and also nature. [Alvin Rich \(2012\)](#) revealed that the differences in the level of spirituality in women and men could due to factors such as emotional, psychological, and judgment of the surrounding environment. Men and women have different ways of expressing their spirituality. Women tend to be more sensitive to emotional relationships, more involved in feelings, and more understanding of others. Whereas men further limit their personal feelings. [Durik et al. \(2006\)](#) mentioned that women and men could feel the same emotions but women tend to be more able to express their feelings such as shame, happiness, sadness, affection, guilt, and sympathy compared to men. [Stark \(2002\)](#) also stated that the difference in spirituality levels might also be related to physiological factors, while men tend to be more impatient than women because men have more testosterone than women. In addition, [Stark \(2002\)](#) also revealed that the judgment in the society could affect one's spirituality. People see the perpetrators of violence and crime tend to be men, so society considers women have a higher level of spirituality and religiosity than men. This assumption made women meet the society's assumption to be more religious.

Most female parents who experienced the sub-dimension of physical health conditions had a have poor quality of life (65.2%). According to [Hagedoorn, Sanderman, Bolks, Tuinstra, and Coyne \(2008\)](#), it could happen because women have the main role as administrators of children, households, and husbands. When one family member is sick, women usually become the main nurse in taking care of the sick family member, so that the burden borne by women can increase and this may have a negative impact on their physical health. In addition, female parents also tend to have poor psychological conditions (56.5%). According to [Hagedoorn et al. \(2008\)](#), women experience higher psychological pressure because, in addition to being in charge of caring for their children, they also have to take care of their households and husbands. Furthermore, women are also more sensitive to emotional relationships, more involved in feelings, and more understanding of others. So that it tends to make women dissolved in sadness related to the conditions experienced by their children at this time, and that can reduce their psychological well-being ([Alvin Rich, 2012](#)).

Based on the level of education, the results revealed that parents who had the poor quality of life were mostly primary school graduates (81.8%). These results are different from the previous study conducted by [Song et al. \(2017\)](#) and [Litzelman et al. \(2011\)](#) stated that parents with higher education had poorer quality of life because they were actively involved in the medical decision-making process so that it could increase stress and reduce their quality of life. However, these results related the quality of family caregiver's quality of life of children with leukemia carried out in the Provincial General Hospital of Dr. Hasan Sadikin Bandung are in line with the results of research conducted in the Netherlands by [Van den Tweel et al. \(2008\)](#). The results of their research showed that low levels of education in children's caregiver with anemia are associated with high pain scores and low motor function experienced by the caregivers. It happened because parents with low education had a perception of poor health so that it could lower the quality of life.

The results of this study also showed that family caregivers who had the poor quality of life mostly got low income, the average monthly income was less than 1.5 million rupiahs (71.4%). This is consistent with a statement from [Dumont et al. \(2006\)](#), parents with economic difficulties experience increased parenting burdens and decreased quality of life. The financial burden can cause parents to experience stress so that it can reduce their quality of life ([Santo, Gaiva, Espinosa, Barbosa, & Belasco, 2011](#)). Moreover, the treatment cost for leukemia is quite expensive so that it can increase the family's financial burden ([Klassen et al., 2011](#); [Song et al., 2017](#)). [Haciolioglu et al. \(2010\)](#) also stated that low income might cause poor quality of care, while high income might significantly affect life satisfaction.

The findings also showed that parents who had cared for their children affected by leukemia for less than 12 months had the majority of poor quality of life (59.3%) compared to parents who had cared for their children for more than 12 months (57.1%). These results are in line with the research conducted by [Klassen et al. \(2011\)](#), which showed that parents who cared for their children less than 12 months experienced a worse quality of life because in the first 12 months children still needed a higher intensity of care. Besides, [Lim et al. \(2017\)](#) also mentioned that caregivers had a higher burden of care at the time of the initial diagnosis. [Lau et al. \(2014\)](#) in his research on family life experiences in the first year of caring for a child with ALL found that 46% of parents

stopped working thereby reducing their income and creating a family financial burden. Moreover, the difference in the quality of life between parents who cared for their children for less than 12 months and those who care for their children more than 12 months can also occur because of parents' psychosocial health increases over time. In the early stages of diagnosis, parents experience shock, rejection, disappointment, depression, and anxiety about the diagnosis of leukemia that occurs in their child. In the early stages of diagnosis, parents also cannot adjust to the conditions experienced by their children (Pai et al., 2007). Previous research has also shown that considerable stress is experienced by parents and children in the first year of children diagnosed with leukemia (Hedström, Ljungman, & von Essen, 2005). Tsai et al. (2013) also found that stress levels experienced by parents and children began to decline after undergoing treatment in the first six months. Increasing psychosocial conditions in parents can also occur because of parents' experience and confidence in caring for their children is also increasing over time (Leow, Chan, & Chan, 2014).

In our study, the parents also tended to have poor quality of life in caring for children with severe leukemia. These results are consistent with the research conducted by Kim and Spillers (2010), which stated that caregivers who treated cancer patients with more advanced stages had a heavier burden and lower quality of life compared to those who treated early-stage cancer patients. According to Lim et al. (2017), it can occur because in cancer patients with a more advanced stage, caregivers experience more pressure due to having to prepare themselves to face patient deaths and provide palliative care, where palliative care planning and issues to deal with death are one sensitive issue which can increase stress. This study also found that mostly parents who cared for their children with severe leukemia had poor physical conditions (61.1%). The poor physical conditions experienced occur due to the increasing burden of the treatment. In worse conditions, patients need more intensive care, so that the time needed to treat patients every day becomes longer so that the fatigue felt by parents increases (Leow et al., 2014).

CONCLUSION

It is concluded that the family caregivers in children with leukemia had poor quality of life including in all sub-dimensions of quality of life. Therefore, it is suggested for nurses to provide nursing care holistically not only for the children but also the families. Health care institutions also should make a family support group, specifically for family caregivers to support each other and share their experience in treating leukemia.

DECLARATION OF CONFLICTING INTEREST

The authors declare no conflicts of interest.

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AUTHORS CONTRIBUTION

IN conceptualized and designed the study. SH conducted the literature search and reviewed data. DPH performed the data collection. IN, SH, DPH drafted the manuscript. All authors conceived of the presented idea, provided critical

feedback, and analyzed the research as well as discussed, the results and contributed to the final manuscript. All authors contributed to the writing of the manuscript. All authors read, edited, and approved the final manuscript.

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PERSPECTIVE

NURSING THE NURSED: ADDRESSING COVID-19 PANDEMIC CRISIS IN THE CUEN THEORY PERSPECTIVE

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Abstract

Caring as an unending expression of nursing holds true this very time of trials. Humanity is faced with a crisis in the COVID-19 however healthcare professionals are standing still to save the world. This document illustrates how CUEN theory is applied in the care of patients undergoing emerging infectious diseases and stipulates its contribution to the care of patients having infected with the disease.

KEYWORDS

nursing; covid-19; CUEN theory; caring

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The concern of COVID-19 places the entire humanity to test. Both advanced and developing countries experience the phenomenon as evidenced by integrating practices and forging collaboration with the hope of saving humanity. Various approaches intend to shed gleam in the circumstance; however, the number of cases unceasingly elevate. Such condition demands unifying effort across stakeholders. Like any other forms of ordinary flu, the virus is transmitted during close unprotected contact. Airborne spread has not been reported and it is not believed to be a major driver of transmission. Based on the documented trend (Tsai & Wilson, 2020), those of highest risk include people more than 60 years and with underlying conditions such as but not limited to chronic respiratory disease, cancer, hypertension and diabetes among others.

With the Proclamation No. 922 declaring State of Public Health Emergency throughout the entire Philippines by its Executive Officer due to recognition of COVID-19 a threat to national security (National Government of the Republic of the Philippines, 2020). Different stakeholders took their share of that pie in addressing the outbreak. Inter-agency task force was created in the management of this emerging infectious disease including that of local government units, the transportation group, labor and employment sectors since the economy is also affected.

The Ministry of Health of the Philippines which prime mandate is anchored on the welfare of human health and well-being exhibited supervision in the surveillance and detection of those possibly invaded by the virus. Amidst vigilance, still the figure persists. Class suspension in all levels declared openly, with intentions of stopping the spread. Crowded places such as schools, offices, social gatherings and the like were discouraged. In other words, social distancing aimed to maintain virus-free environment are stringently implemented.

The illustration speaks the exact opposite in health care environment. Hospitals are still open, nurses still touch patients to check their temperature, pulse and assess. Nurses do not hesitate and move nearer even if the *nursed* have colds, cough and fever. Though protective equipment is all over, yet the *human* touch assures the *nursed* everything will find order in them in the midst of chaos. Caring as unending expression of nursing manifests the place (Acob, 2018).

CUEN theory as anchored in Boykin and Schoenhofer (2001) theory of nursing as caring describes nursing profession dedicated to working with care, and compassion committed to helping the *nursed* and significant others in the spirit of caring. The theory highlighted the crucial role of nurses along the attentive moment of showing empathy, which in turn makes caring a central concept in the expression of unending care. Nurses are to begin with competence in the delivery of professional nursing as well as genuine interest, honesty and zeal to adjoin with others. Further, the nurse starts to explore the real and deeper meaning of caring as the unending expression of nursing practice and better distinguish that of the usual manner of intentional caring.

However, the essential structure of the uncaring is experienced when the *nursed* failed to discern his fullness of well-being and healing. This will result in a sense of mistrust and disconnection to the health care provider. The sense of damage and grief among patients, limits this caring theory.

From this caring standpoint, the core of nursing is articulated as nurturing persons living and growing in the caring environment. Living and caring of personhood centers on the individual living the essence of his own life. Nursing's ultimate goal is knowing person as holistic entity maintained by the support system as they live within the context of a caring environment.

Caring is an unending language of nursing is a deliberate and genuine presence of a nurse with the nursed who is identified to grow and live in a caring relationship (Acob, 2018). The perceptiveness and agility in creating effective ways of communication with ethical caring are developed gradually through the intention to care. CUEN theory believes a person is a dignified being that lives and grows in a caring environment. He/she has no impartiality- therefore complete and integrated. In the light of COVID-19 crisis, may the healthcare workers recognize *people, not as an object of care*, but co-equal participants in the delivery of efficient service. They should be appreciated as a whole, complete beings with no infirmity living in a caring environment from moment-to-moment as a language of nursing. Moreover, the theory suggests that care should be rendered as an unending expression in the practice of nursing that distinctively focuses on persons through the healing use of self in a compassionate way central to the day-to-day experience of the nurse-nursed relationship (Acob, 2018).



Figure 1 The dynamics of Caring as Unending Expression in Nursing theory (Acob, 2018)

The four smaller circles are slightly overlapping in the bigger circle at the middle. The framework can be interpreted as the four phases of interaction that exist only when the nurse and the nursed are interacting. No one can create the nursing situation except when the nurse and the patient intermingle with each other. The four phases of caring are irremovable and ineradicable. The nursing situation can only happen when both stakeholders (patient- nurse) congregate; in like manner which sustains the movement, being invigorated by the interaction of caring (Acob, 2018).

The bigger circle (**Figure1**) speaks that the focus of every caring opportunity is an interaction between the nurse and the nursed. This interaction enhances the knowledge in particular and the development of a patient-nurse relationship. The experience developed during the interaction generates meaning for one's existence in a caring environment beyond and within their present situation of interaction. This is pivotal to the development of their relationship in the transforming community health care (Acob, 2018).

The practice of nursing within this structure firstly requires appreciation and/or acknowledgment that patients are humans needing care, especially in these critical times. The nurse becomes an instrument

and as a means to an end which in turn depersonalized the support system of the practice environment. In this phase, the nurse assesses the patient of the pre-identified indicators of COVID-19. The caring nurse comes into avenues of knowing more, establishing a connection through appreciative inquiry with active listening skills at the moment.

After the nurse completely realizes the existence of self as a person who cannot fulfill complete caring, communication through proper channel should took into place. In these junctures of trials, patients may need not a nurse to nurse them in their activities of daily living; rather just yearned for a compatriot to talk to. To this end, communication evolves and is necessary. What is learned is essential at this moment of caring that allows the nurse to bring substance and element to care and create designs as evidence of caring attribute that is both influential in that caring environment. Communicating patient's concerns and listening to their stories of survival, new possibilities arise from nursing in practice as a caring profession. Informing the patient faithfully and objectively affirms valuing and honor. Respecting their convictions reaffirms the core of nursing and refreshes the caring intention of the nurse.

With a number of cases swell, the government offers identified possibilities ethical and applicable so that patients make informed choices. The nurse warrants the nursed to be enlightened on the options to address their concerns in accordance with their beliefs (Jepson et al., 2005). Family members being part of the patient's support network must also be nurtured on the issues encompassing the patient's decision.

As the nurse constantly interacts with the nursed and his/her support system structure, caring takes place in the nursing situation. The nurse-nursed shares lived experience in which caring between enhanced personhood (Boykin & Schoenhofer, 1993). When the nurse is ready to care for the sick patient affected by COVID-19, the nursing situation comes into life. Offering options as the patient creates informed intentions involve the expression of respecting the integrity and actions that further strengthen the bond of nursing, hence the lived relationship of a nurse and the patient are created and understood.

Lastly, the nurse-nursed conjointly advance to emerge the identified option made. Its complete undertaking of interventions will come into play, signaling the last phase of the CUEN theory. This calls for the dual implementation of specified answers-to-their-problem which later impacts to quality and improvement. The hospital industry gradually transforms to alleviate human condition which underscores redesigning effective, safe care that further justifies the very reason for the presence of nursing practice and the need for nurses.

The idea further expresses the underlying belief that continuous learning and conduct of the investigation will produce desired health outcomes and that a given technique and theory are effective. The alignment of professional knowledge through evidence-based practice is a means to acquire the goal of excellence and is the success pointer for the entire phase of the interaction. However, if the identified solutions did not show any signs of a positive outcome, then the process repeats itself paving to a cyclical and never-ending.

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There is no conflict of interest to be declared.

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LETTER TO EDITORS

‘WASH YOUR HAND!’: THE OLD MESSAGE FROM FLORENCE NIGHTINGALE TO BATTLE COVID-19

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It is undeniable that coronavirus disease 2019 (COVID-19) has become a new global problem today. Its outbreak started in Wuhan China in late 2019 and by March 2020 it has spread around the world. We still keep counting the confirmed cases, deaths, and recoveries in all affected countries. COVID-19 - ‘CO’ stands for corona, ‘VI’ for virus, and ‘D’ for disease - is a new virus linked to the same family of viruses as Severe Acute Respiratory Syndrome (SARS) with several symptoms including fever, cough, and shortness of breath, as well as pneumonia in severe cases (Unicef, 2020). The virus is transmitted through direct contact with respiratory droplets of an infected person (generated through coughing and sneezing), and touching surfaces contaminated with the virus. The COVID-19 virus may survive on surfaces for several hours, but simple disinfectant can kill it.

In response to the today’s situation, many people are busy and may be panic to buy face masks, soaps, alcohol-based hand sanitizer to wash their hands in order to prevent the virus. However, if we would just remember the same old message from Florence Nightingale “wash your hand”, it will be fine. Florence Nightingale, The Lady with the Lamp, is the nursing pioneer who told use to wash hands. If she was here today, she would be quite disappointed over lack of hand hygiene around the globe. In her career, she focuses on infection control, good hygiene, clean water, clean sheets, fresh air exercise, good food, and all factors to place us in the best position.

As I am a nursing lecturer in one of universities in Thailand. I always act like Florence Nightingale and bring her principles to all nursing students, and I ask them to spread and apply the information to the

world. Like she said, “Every nurse ought to be careful to wash her hands very frequently during the day. If her face too, so much the better” (Nightingale, 1860, p. 53). It is understandable that breaking the habit is difficult, but it does not mean it is too late to change. Many people may understand the benefits of hand washing, but they are too lazy. Some also know about hand washing, but they may not clearly understand, or they do not have good facilities.

Therefore, this letter is however to invite all nurses, specifically in Thailand, to remember what Florence told us, specifically to emphasize the importance of hand washing for themselves and the people around them. Showing them how to do correct-hand hygiene and prevent infection. Washing our hands often, especially before eating; after blowing our nose, coughing, or sneezing; and going to the bathroom. We should find the ways to change and enforce preventive behaviors based on the recommendations from World Health Organization. In addition, all nursing organizations and institutions also should keep promoting good hygiene to the community in the public arena. Hopefully we can combat the virus together.

DECLARATION OF CONFLICTING INTEREST

There is no conflict of interest to be declared.

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