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FACTORS RELATED TO THE SUCCESSFUL
TREATMENT OF TUBERCULOSIS: A
LITERATURE REVIEW

Kusuma Wijaya Ridi Putra*,

Chanandchidadussadee Toonsiri

DOI : <https://doi.org/10.33546/bnj.749>

136-146

SOCIAL SUPPORT OF PARENTS OF
CHILDREN WITH LEUKEMIA

Nursyamsiyah*

DOI : <https://doi.org/10.33546/bnj.792>

155-161

PERCEPTION OF NURSES IN DECISION-
MAKING PROCESS IN PALLIATIVE CARE FOR
PATIENTS WITH CANCER IN PUBLIC HEALTH
CENTERS

Atsarina Fauzan*, Sri Setiyarini, Christantie

Effendy, Martina Sinta Kristanti

DOI : <https://doi.org/10.33546/bnj.815>

169-175

FACTORS ASSOCIATED WITH HEPATITIS B AND C
CO-INFECTION AMONG PEOPLE LIVING WITH
HUMAN IMMUNODEFICIENCY VIRUS IN VIETNAM

Le Hieu Thuy Anh*, Suchada Thaweesit

DOI : <https://doi.org/10.33546/bnj.813>

147-154

KNOWLEDGE, PERCEPTION, AND BURDEN OF
FAMILY IN TREATING PATIENTS WITH
SCHIZOPHRENIA WHO EXPERIENCE RELAPSE

Suryani*, Eka Wahyu Ningsih, Aan Nur'aeni

DOI : <https://doi.org/10.33546/bnj.683>

162-168



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TABLE OF CONTENTS

DOI: <https://doi.org/10.33546/bnj.v5i4>

REVIEW ARTICLE

- FACTORS RELATED TO THE SUCCESSFUL TREATMENT OF TUBERCULOSIS: A LITERATURE REVIEW PDF
136-146
Kusuma Wijaya Ridi Putra, Chanandchidadussadee Toonsiri
DOI : <http://dx.doi.org/10.33546/bnj.749>

ORIGINAL RESEARCH ARTICLE

- FACTORS ASSOCIATED WITH HEPATITIS B AND C CO-INFECTION AMONG PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS IN VIETNAM PDF
147-154
Le Hieu Thuy Anh, Suchada Thaweessit
DOI : <http://dx.doi.org/10.33546/bnj.813>
- SOCIAL SUPPORT OF PARENTS OF CHILDREN WITH LEUKEMIA PDF
155-161
Nursyamsiyah Nursyamsiyah
DOI : <http://dx.doi.org/10.33546/bnj.792>
- KNOWLEDGE, PERCEPTION, AND BURDEN OF FAMILY IN TREATING PATIENTS WITH SCHIZOPHRENIA WHO EXPERIENCE RELAPSE PDF
162-168
Suryani Suryani, Eka Wahyu Ningsih, Aan Nuraeni
DOI : <http://dx.doi.org/10.33546/bnj.683>
- PERCEPTION OF NURSES IN DECISION-MAKING PROCESS IN PALLIATIVE CARE FOR PATIENTS WITH CANCER IN PUBLIC HEALTH CENTERS PDF
169-175
Atsarina Fauzan, Sri Setiyarini, Christantie Effendy, Martina Sinta Kristanti
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REVIEW ARTICLE

FACTORS RELATED TO THE SUCCESSFUL TREATMENT OF TUBERCULOSIS: A LITERATURE REVIEW

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Abstract

Background: Many tuberculosis sufferers experience recurrent events due to incomplete treatment processes. It is often found that tuberculosis sufferers re-enter the hospital because the condition is getting worse. Thus, factors related to the successfulness of the treatment of tuberculosis warrant identification.

Objectives: This review was to summarize and identify the current literature related to the successful treatment of tuberculosis and its factors.

Design: A Whittemore and Knafl's integrative review was used.

Data Sources: Data sources included four electronic databases: EBSCO, PubMed, Science Direct and Google Scholar to search literature published between 2002 and 2017.

Review methods: A systematic process was carried out to extract and analyze the data of all included studies.

Results: A total of 146 articles were deemed appropriate for the topic, but only 28 articles were included based on inclusion criteria. It was found that a wide range of factors related to the successful treatment of tuberculosis, including predisposing factors (socioeconomic, knowledge, psychological stress, and availability to access health service), reinforcing factor (family support and social stigma), and enabling factor (physician and nurse support).

Conclusion: Family support, socioeconomic, physician and nurse support, availability to access health services, social stigma, psychological stress, and knowledge were significant factors of the successful treatment of tuberculosis. For future research, the interventions to promote the program for decreasing the occurrence of the recurrent tuberculosis in the community need to consider these factors for the successful treatment of tuberculosis and collaborates with tuberculosis patients, family and health service for development of appropriate intervention.

KEYWORDS

tuberculosis; successful treatment; precede-proceed model; literature review

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INTRODUCTION

Tuberculosis is one of the most perceived health problems in the global community, despite the implementation of DOTS treatment strategies in many countries since 1995 ([Perhimpunan Dokter Paru Indonesia, 2006](#)). The incidence rate in Indonesia in accordance with national strategies for tuberculosis treatment 2010-2014 is expected to decrease from 235 per 100,000 population to 224 per 100,000 population ([Indonesian Ministry of Health, 2014](#)). Government of the Republic of Indonesia has a prime target for tuberculosis control in 2015-2019, which is a reduction in the incidence of tuberculosis faster than just about 1-

2% per year to 3-4% per year and reducing the mortality rate of 4-5% per year. It is expected that by 2020 Indonesia could reach the target of a 20% reduction in the incidence and mortality rate of 25% of the incidence rate in 2015 ([Indonesian Ministry of Health, 2014](#)).

Many tuberculosis sufferers experience recurrent events due to incomplete treatment processes. It is often found that tuberculosis sufferers reenter the hospital because the condition is getting worse. Tuberculosis sufferers who experienced this recurring

incident argued that fear of being excluded from neighbors caused by stigma from neighbors for their illnesses and also related to their economy (when they did treatment, their income would be reduced). For this reason, the authors want to find information regarding factors that can influence the success of tuberculosis treatment. The authors use the Precede-Proceed model to identify the initial factors. There are many factors that can be related to the successful treatment of tuberculosis, among other predisposing factors (socioeconomic, knowledge, psychological stress, belief, lifestyle, intelligence, perception, attitudes, and availability to access health service), reinforcing factor (family support, culture, and social stigma), and enabling factor (policies, programs of health, physician and nurse support). The aim of the review was to summarize and identify the current literature related to the successful treatment of tuberculosis and its factors.

Conceptual Framework

In educational and ecological assessment phase of Precede-Proceed Model addressed by [Green and Kreuter \(2005\)](#) had three

factors, among other predisposing factors, reinforcing factors, and enabling factors. Predisposing factors are characteristics of a person or community that can manipulate the behavior of that person or community. Predisposing factors that will be included in this literature review, namely socioeconomic, availability to access health service, knowledge, and psychological stress. Reinforcing factors are consequence of the behavior carried out, either in the form of rewards or punishments, which in turn will strengthen the motivation for behavior change. Reinforcing factors are family support and social stigma. Enabling factors are factors possessed by the environment that can be used to facilitate behavior change. The enabling factors include physician and nurse support. The selection of Precede-Proceed Model as a conceptual framework for this review because it is considered appropriate to determine the factors that can influence the success of tuberculosis treatment, both from individuals, social, environmental, to health services (see **Figure 1**).

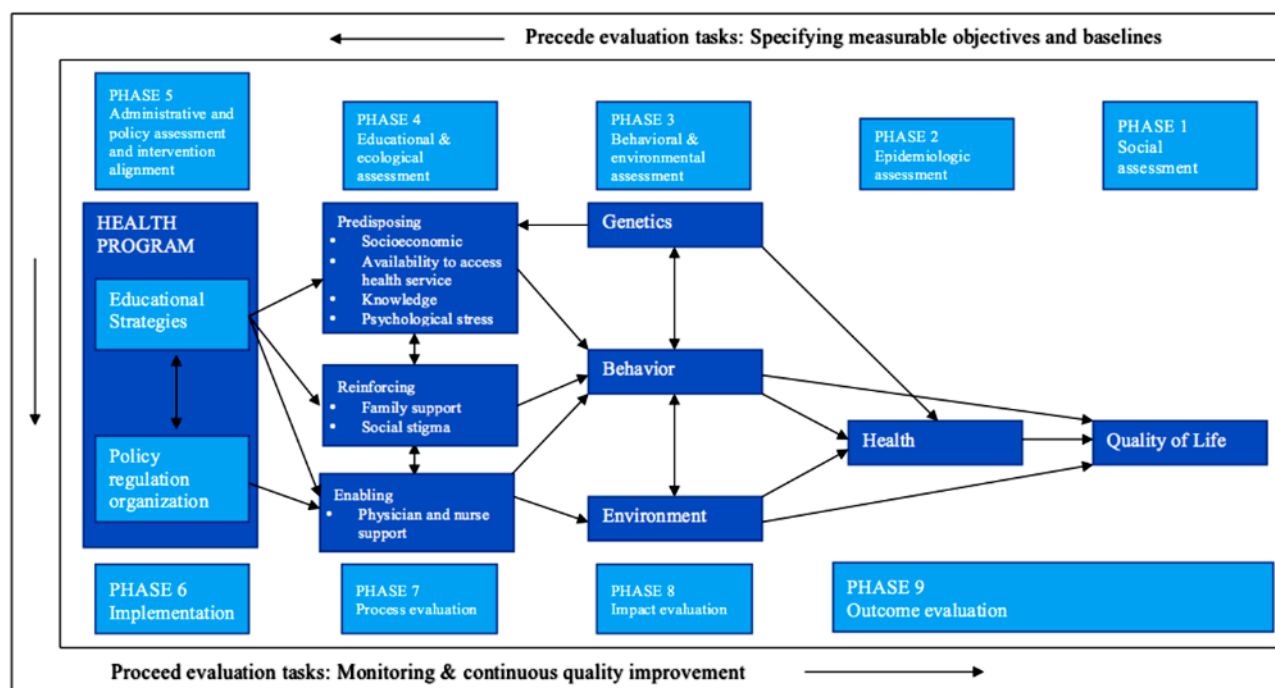


Figure 1 Conceptual framework of integrative review of the factors related to the successful treatment of tuberculosis

METHODS

Design

Our review used a guideline of the integrative review created by [Whittemore and Knafl \(2005\)](#) to identify literature relating to phenomenon analysis and health problems. It allows the inclusion of both experimental and non-experimental research. Studies indicate that well-done literature review can present state of science and potential to play the significant role in evidence-based practice to nursing science and practice, and to contribute theory development ([Whittemore & Knafl, 2005](#)). The literature

review has been identified as a robust tool for synthesizing available literature on a given topic. This approach combines data from theoretical and empirical literature and allows for a full understanding of the topic under investigation ([Souza et al., 2010](#)).

Search methods

The following electronic databases were searched for relevant research articles: EBSCO, PubMed, Science Direct and Google Scholar. The literature search used keywords "tuberculosis" and

the “successful treatment of tuberculosis”, and “factors related to the successful treatment of tuberculosis”.

The authors used four steps in the process of selecting literature originating from electronic databases before getting the articles as the final sample of this review. First step, we generally did a search and found 362,124 articles. From these articles we did a screening to find articles that were very relevant and could be used as material for the review. The screening results obtained 1,569 articles that were considered relevant for use. The third stage was re-screening all articles with inclusion and exclusion criteria, as well as avoiding duplication of the same title. One hundred forty-six articles obtained from this screening. The final step, of 146 articles, 28 articles were considered best fit for further review (Figure 2).

To explore factors that related to the successful treatment of tuberculosis, we collected data from the published literature through electronic databases. The information derived from the literature that includes opinions, theoretical, research-qualitative and quantitative research, in addition to integrative and systematic reviews. For identifying and selecting from a variety of literature that was used as a review, we broadened the search to include factors related to the successful treatment of tuberculosis, including the aspect of the patient, family, community and other factors originating the service system.

In the literature review, we set inclusion and exclusion criteria in the search of electronic databases. The inclusion criteria included, among others, (1) published in English and Indonesian language, (2) published between 2002 and 2017, and (3) focused on factors and the successful treatment of tuberculosis. Exclusion criteria were studies that did not focus on the factors that related to the successful treatment of tuberculosis, research design that had poor quality, and unclear arguments in the literatures.

The literature included in this review had no limitations that must be the same as the conceptual framework we wanted to find information regarding factors that could influence the success of tuberculosis treatment and supported the model that was used as the conceptual framework. In the search method, the authors were only guided by the inclusion criteria and exclusion criteria specified above.

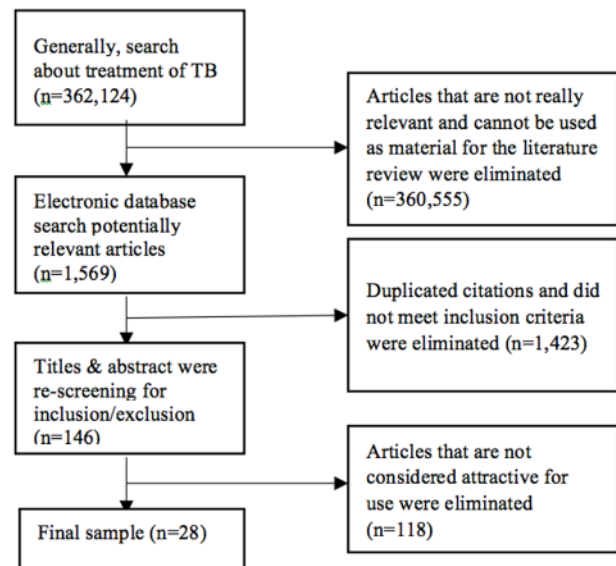


Figure 2 Flowchart of literature search

Data analysis

The data analysis in the research review requires that the data from the primary source be ordered, encoded, categorized, and summarized into an integrated conclusion explaining the research problem (Cooper, 1998). In this case, the authenticity of information and methodological quality in search of data originating from primary sources should be considered and discussed in the final report (Kirkevold, 1997). However, in order to reach the aim of this study, to determine the state of knowledge gaps related to the successful treatment of tuberculosis on tuberculosis patients, the authors used framework developed by Green and Kreuter (2005) as guide. The articles were read several times to determine the patterns, directions, similarities, and differences to produce a quality final report. Using a constant comparison method of grouping similar comparable data, making the analysis and synthesis process even further to achieve the objective of this review leads to a better understanding of the issues raised, particularly the successful treatment of tuberculosis among tuberculosis patients.

RESULTS

Based on the search results, there were some articles that match the criteria that had been set. Summary of included literature could be seen in Table 1 and Table 2.

Table 1 Summary of included literature

Author (year), country	Design	Purpose	Results
Bani et al. (2015), Indonesia	Descriptive correlational study (Cross-sectional)	To find out correlation between knowledge, attitude, and the prevention of pulmonary tuberculosis in Dayu district	A part of more humanity had good knowledge (92.5%), negative attitude (50.5%), and positive attitude (54.5%). Chi square obtained p-value of .508 on knowledge, p-value of .747 on attitude, indicated no correlation between knowledge, attitude, and the prevention of pulmonary tuberculosis.

Author (year), country	Design	Purpose	Results
Bothamley et al. (2011) , United Kingdom	Cohort	To identify workload and effectiveness of tuberculosis control programs in UK cities	Data retrieval was done varies, namely from 0 to 22 months. The results showed that national achievements had a good correlation with changes in workload for commissioning organizations ($r = 0.8$; $p < .01$), but this factor was inversely proportional to the number of clinics. There were 4 cities that had not reached the target, including Birmingham, Bradford, Manchester and Sheffield ($C2 = 4.2$; $p < .05$).
Dimas et al. (2016) , Indonesia	Descriptive correlative (Cross-sectional study)	To provide information about the correlation of drug supervisor activeness with motivation and medication compliance	There was a relationship between the activeness of supervisors taking medication with motivation and medication adherence in tuberculosis patients ($p = .000$; $p = .001$, respectively). The existence of good motivation was also correlated with the level of adherence to taking medication also good ($p = .011$).
Dobler et al. (2015) , Mongolia (Western Pacific region)	Retrospective cohort study	To determine the effectiveness of community-based DOT compared to traditional clinic-based DOT in Ulaanbaatar, the capital of Mongolia	The success of TB treatment with positive smear reached 85.1%. The cure rate and treatment success were quite high in patients who received DOT treatment in the community than those who received treatment at the DOT clinic (aOR 2.66, 95% CI 1.81–3.90; aOR 2.95, 95% CI 1.85–4.71, $p = .001$, respectively).
Gao et al. (2015) , Canada	Cross-sectional study	To identify knowledge levels of patients in a TB clinic, identify Chinese immigrants' knowledge and perceptions of Latent TB Infection (LTBI), specify messages that would be most appropriate for LTBI education in this population, and identify the most appropriate format of health promotional materials to address the specifics needs of this population	The level of knowledge of respondents was very low about LTBI (95% CI: 38.3%, 41.7%) due to their difficulties in accessing the health system so that they experienced confusion and caused stigma among them related to LTBI. In addition, the health promotion method suitable for Chinese immigrants was online video.
Gupta et al. (2004) , India	Case-control study	To look into the socio-economic and demographic characteristics of patients of tuberculosis (TB)	There was a correlation between the increase in TB incidence and socio-economic and demographic factors, including age, education level, income level, home environment conditions, water availability, and density living in the same house.
Herrero et al. (2015) , Argentina	Cross-sectional study	To identify the association between non-adherence to tuberculosis treatment and access to treatment	Men were more likely to experience non-compliance in undergoing treatment (OR = 2.8; 95% CI 1.2 - 6.7). In addition, TB patients who underwent hospital health checks (OR = 3.4; 95% CI 1.1 - 10.0) and those who experienced difficulties in transportation costs (OR = 2.5; 95% CI 1.1 - 5.9) also experienced non-compliance in undergoing treatment.
Ibrahim et al. (2014) , Nigeria	Cross-sectional study	To determine the proportion of TB patients with interrupted treatment, and to identify the factors associated with interruption of TB treatment	There were 378 TB sufferers and 71 (19%) of whom had experienced a treatment breakup. There were several factors that prevent a TB sufferer from undergoing treatment, including distance to a place to stay for TB treatment related to travel costs (AOR: 11.3; 95% CI: 5.7-22.2), ignorance of the duration of treatment and when it feels the condition is better (AOR : 6.1; 95% CI: 2.8-13.2), and smoking behavior (AOR: 3.4; 95% CI: 1.5-8.0). In addition, TB sufferers also said there was an unfriendliness of health workers when providing services.
Irnawati et al. (2016) , Indonesia	Cross-sectional study	To determine the effect on the family support medication adherence of tuberculosis patients in Puskesmas Motoboi Kecil	There was an influence of family support for medication compliance in TB patients ($p = .001$).

Author (year), country	Design	Purpose	Results
Karyadi et al. (2002) , Indonesia	Cross-sectional study	To determine the social conditions endured by patients with pulmonary TB and to consider the consequences of the disease	The results showed that TB patients experienced poor nutritional status, negative attitudes from the surrounding community so that some of them were expelled from work and experienced fear that conditions could interfere with their marriage. However, TB sufferers get support from their families, both financially and socially.
Kirana et al. (2016) , Indonesia	Descriptive survey (Cross-sectional study)	To evaluate the compliance of patient with tuberculosis in BKPM Magelang	There were 63% of respondents who adhered to the treatment of tuberculosis. The result of the study showed high rate of medications compliances in patients with tuberculosis. The factors that cause the disobediences were effects of the medicine, other diseases, perception of distance and transportation. The study showed high compliances of tuberculosis patient as the result of the respondent's knowledge that were good.
Kondoy et al. (2014) , Indonesia	Cross-sectional study	To know risk of factors (age, gender, education, employment, level of income, knowledge and the side effects of anti-tuberculosis drugs related with obedience of treatment patients with pulmonary tuberculosis in five health centers in the city of Manado	The result of research indicates that the variables, which were related with treatment compliance of TB patient, were education ($p=.000$) and knowledge ($p=.000$). Variable that were not related to obedience of treatment TB patients were age, gender, education, occupation, level of income, and side effect OAT ($p>.05$).
Kurniati (2015) , Indonesia	Cross-sectional study	To identify any obstacles in the implementation of tuberculosis therapy and how to overcome them in Balai Pengobatan Penyakit Paru-paru (BP4) Unit Minggiran, Yogyakarta	The psychological response to the respondents was the highest category at 82.5% (33 respondents), family support for the most respondents was in the good category that was equal to 75% (30 respondents). The family support variable was not significant at the probability of .584 greater than the constant value of .024, which indicated that there was no influence on the implementation of TB therapy. The psychological response variable was significant at the probability of .008 smaller than .024 which indicated that there was an influence on the implementation of tuberculosis therapy. The efforts of officers according to the DOTS Corner procedure are in the good category of 100%.
Loriana et al. (2014) , Indonesia	Quasy-Experiment (Non-Randomized Control Group Pretest and Posttest Design)	To determine the effects of counseling on knowledge, attitudes, and adherence to treatment of pulmonary TB patients in the region of Samarinda City Health Department	There was an influence of counseling on increasing knowledge, attitudes, and adherence to patients with pulmonary TB treatment. This can be seen from the results of the Wilcoxon test carried out before and after the counseling ($p=.000$).
Smit et al. (2011) , Ghana	Descriptive study	To determine personal, health service, community and treatment factors contributing to the high default rate of DOTS implementation in Kwaebibirim district of Ghana	TB patients who experienced treatment breakdown due to several factors, including interactions between individuals, social, and health status (duration of treatment and side effects that occur).
Nugroho et al. (2016) , Indonesia	Descriptive correlative (Cross-sectional study)	To determine the relationship between knowledge of tuberculosis patients and family support with medication adherence tuberculosis in public health service of Jekulo Kudus	The results showed that the better the level of knowledge and family support for TB patients, the better the level of adherence to treatment ($p=.003$; $p=.039$, respectively).
Pongoh et al. (2015) , Indonesia	Descriptive study	To determine the behavior of particular knowledge attitude and practice of health workers in health centers Manado	The majority of respondents had ages 26-35 years as many as 39 respondents (52.0%), most of them were female with 65 respondents (86.7%). Respondents had good knowledge, attitude, and practice.

Author (year), country	Design	Purpose	Results
Retni and Sugiyanto (2010) , Indonesia	Cohort (Retrospective)	To determine the relationship of social support families with a cure rate of pulmonary tuberculosis patients at the health center Umbulharjo, Yogyakarta	Family support of pulmonary tuberculosis patients mostly was in the high category at 83.8% of all respondents. Cure rate of pulmonary tuberculosis patients was mostly in the fast category of 90.3% of all respondents. There was association between family social support and recovery rates of pulmonary TB patients ($p = .047$).
Rohmana and Suhartini (2014) , Indonesia	Case-control study	To discover the correlation between the factors which are exist in taking medicine observer (Pengawas Minum Obat/ PMO) towards medication compliance of pulmonary tuberculosis patients. And also, dominant variables that influence medication compliance of pulmonary tuberculosis patients	The result of research shows that variable of PMO's knowledge level ($p = .013$, $\alpha = .05$), and health education ($p = .000$, $\alpha = .05$) correlated with medication compliance of pulmonary tuberculosis patients. Health education was a dominant variable that 6.018 times on medication compliance of pulmonary tuberculosis patients.
Sari et al. (2016) , Indonesia	Cross-sectional study	To determine the relationship between knowledge, attitudes and compliance outpatient pulmonary tuberculosis in 5 regional public hospitals in Jakarta	There was no significant relationship between knowledge, attitudes and compliance of outpatients with pulmonary TB patients.
Setiawan (2013) , Indonesia	Cross-sectional study	To analyze the influence of the side effect of anti-tuberculosis treatment adherence in BBKPM Surakarta	There was an influence of the side effects of anti-tuberculosis treatment with TB patient adherence in undergoing treatment in BBKPM Surakarta ($p = .04$)
Tang et al. (2015) , China	Cross-sectional study	To assess non-adherence to anti-TB treatment among internal migrants with pulmonary TB living in Shenzhen, China, and examine risk factors for non-adherence in order to identify targets for intervention	Around 33.74% of respondents experienced non-compliance in undergoing treatment. This was caused by several factors, including lack of information regarding the treatment process that must be undertaken, and travel time to the nearest health service.
Tsefahuneygn et al. (2015) , Ethiopia	Cross-sectional study	To assess the level of adherence to anti-TB treatment among patients taking anti-TB drug treatment and to identify factors associated with non-adherence, and to assess treatment outcomes and factors associated with poor treatment outcomes among TB patients previously treated at the health institutions of Alamata District, northeast Ethiopia	The level of adherence and the success rate in anti-tuberculosis treatment was quite high. Respondents who were unsuccessful in treatment due to economic problems, died, and experienced treatment failure related to Human Immunodeficiency Virus (HIV) infection [aOR = 2.1, 95% CI 1.5–3.0]; SPPTB case (aOR = 3.4, 95% CI 2.4–4.8); SNPTB case (aOR = 2.0, 95% CI 1.5–2.8); and cases of bone care (aOR = 2.6, 95% CI 1.5–3.7).
Theron et al. (2015) , Multi Centre Study (South Africa, Zimbabwe, Zambia, & Tanzania)	Cohort	To explore the association between psychological distress, clinical characteristics (such as TB-related morbidity), socio economic characteristics (such as income, educational level, health literacy, and unemployment), and healthcare seeking behaviour, such as the duration of symptoms that passed before patients sought care	The results showed that respondents experienced psychological distress. Respondents who experienced psychological distress were associated with heavy consumption of alcohol, female gender, increased morbidity, and previous TB. All of these affect the level of adherence to the treatment process.
Tolossa et al. (2014) , Ethiopia	Community-based cross-sectional survey	To identify community knowledge, attitude, and practices towards tuberculosis	Most respondents had sufficient knowledge about TB and knew that TB transmission could be prevented. Respondents would seek the closest health care when experiencing symptoms of TB and prefer to take medication in modern medicine
Tupasi et al. (2016) , Philippines	Case-control study	To identify factors associated with loss to follow-up during treatment for multidrug-resistant (MDR) tuberculosis (TB) in the Philippines	Factors that led to treatment discontinuation in multidrug-resistant TB (MDR-TB) cases included treatment side effects (vomiting severity) and alcohol consumption. However, several other factors that could reduce the incidence of discontinuation include good levels of knowledge, assistance in the treatment process, support, and a high level of trust from health workers.

Author (year), country	Design	Purpose	Results
Wijayanti and Khusnal (2010) , Indonesia	Descriptive correlative (Cross-sectional study)	To identify the correlation between the parents' healthy attitudes and the life quality of children with tuberculosis	All of respondents had good quality of life. However, only 46% of parents had high healthy attitude. The results of the statistical examination by Spearman Rank Correlation showed that the correlation value was .551 for TACQOL questionnaires for the parents and the correlation value was .316 for TACQOL questionnaires for the children with the significance level of $p < .05$
World Health Organization (2013) , Switzerland and USA	Guidelines	To develop the evidence-informed recommendations using procedures outlined in the WHO handbook for guideline development	Guidance from the World Health Organization (WHO) on nutritional care and support for patients with TB, in support of their efforts to achieve the Millennium Development Goals

Table 2 Factors related to the successful treatment of tuberculosis

Author	Predisposing Factors				Reinforcing Factors		Enabling Factor
	Socio-economic	Availability to access health service	Knowledge	Psychological stress	Family support	Social stigma	Physician and nurse support
Bani et al. (2015)			✓				
Bothamley et al. (2011)							✓
Dimas et al. (2016)							✓
Dobler et al. (2015)		✓					
Gao et al. (2015)			✓			✓	
Gupta et al. (2004)	✓						
Herrero et al. (2015)	✓	✓					
Ibrahim et al. (2014)		✓					✓
Imawati et al. (2016)					✓		
Karyadi et al. (2002)	✓						
Kirana et al. (2016)		✓					
Kondoy et al. (2014)			✓				
Kurniati (2015)				✓			
Loriana et al. (2014)			✓				
Smit et al. (2011)						✓	
Nugroho et al. (2016)					✓		
Pongoh et al. (2015)			✓				✓
Retni and Sugiyanto (2010)					✓		
Rohmana and Suhartini (2014)			✓				
Sari et al. (2016)			✓				
Setiawan (2013)			✓				
Tang et al. (2015)			✓				
Teshfahunevgn et al. (2015)		✓					✓
Theron et al. (2015)				✓			
Tolossa et al. (2014)			✓				
Tupasi et al. (2016)							✓
Wijayanti and Khusnal (2010)					✓		
World Health Organization (2013)					✓		

The factors related to the successful treatment of tuberculosis include predisposing factors (socioeconomic, availability to access health service, knowledge, and psychological stress), reinforcing factors (family support and social stigma), and enabling factors (physician and nurse support). **Figure 1** illustrates a diagram of the model adaptation to identify factors related to the successful treatment of tuberculosis among tuberculosis patients.

Predisposing Factors

Socioeconomic

Many tuberculosis patients in the community who recognize that tuberculosis treatment is sometimes constrained by socioeconomic factors. They reasoned that if they took treatment for tuberculosis it would take up their work time, so they get sanctions related to the overly licensing process or lack of opinion on the day they take control/ treatment for their tuberculosis

(Gupta et al., 2004). It is also supported by the results of research conducted by Karyadi et al. (2002) who said that socioeconomic can become an obstacle to tuberculosis treatment because people with tuberculosis will have difficulty in changing their living conditions. Herrero et al. (2015) also said that socioeconomic has a negative effect on the treatment of tuberculosis. The negative effects are related to transportation costs and costs associated with additional drugs. Transportation costs are linked to the long distance between home and health care where they control tuberculosis.

Availability to access health service

In addition to socioeconomic, another factor that may affect tuberculosis treatment process is the availability of access to health services. The availability of access to health services is usually related to the distance between houses with health care facilities and the convenience of transportation to health services (Herrero et al., 2015; Ibrahim et al., 2014; Kirana et al., 2016; Tesfahuneygn et al., 2015). Herrero et al. (2015) said that with the problems associated with the distance and ease of transportation, the need for decentralization of health services tuberculosis, making it more affordable and more accessible to people with tuberculosis. Decentralization of tuberculosis health services will have a better impact on adherence and high success in treatment of tuberculosis (Dobler et al., 2015; Herrero et al., 2015). Based on the results of research from Dobler et al. (2015), it can be seen that the presence of health services in the form of DOTS services closer to people with tuberculosis in the community will have a positive impact of high compliance rate and success of tuberculosis treatment in the community.

Knowledge

Knowledge is one of the domains of behavior formation in the treatment of tuberculosis, so it can improve the success of tuberculosis treatment and prevent the occurrence of recurrent tuberculosis (Bani et al., 2015; Kondoy et al., 2014; Tang et al., 2015). In addition to the knowledge of tuberculosis sufferers themselves, the knowledge of drug controllers can also influence the success rate of treatment in tuberculosis patients, especially adherence in DOTS treatment (Rohmana & Suhartini, 2014). Increasing the knowledge of tuberculosis patients can be through the provision of counseling and counseling with the ultimate goal is to improve the success of treatment of tuberculosis patients (Loriana et al., 2014; Pongoh et al., 2015; Tang et al., 2015). Community knowledge of tuberculosis also affects the success of tuberculosis treatment in the community because it can reduce the stigma that arises in the community and prevent the spread of tuberculosis in the community (Gao et al., 2015; Tolossa et al., 2014). However, there is also a study says that knowledge has nothing to do with the success of tuberculosis treatment, especially tuberculosis treatment adherence (Sari et al., 2016). Sari et al. (2016) argue that there may be other factors that may influence the success of tuberculosis treatment that is not present in the study, such as the role of the drug supervisor, family support, and the disturbing side effects of poor drug combinations. Knowledge of drug side effects also needs to be noted in the success of tuberculosis treatment. When side effects of DOTS are given to tuberculosis sufferers with unsupported good knowledge of the side effects of consuming DOTS may

cause concerns of tuberculosis patients in undergoing treatment so that it can lead to the breaking of treatment and the occurrence of recurrent tuberculosis (Setiawan, 2013).

Psychological stress

One of the internal factors that must be considered is the management of psychological stress. Management of good psychological stress will make a tuberculosis patient more likely to undergo treatment. This is supported by the results of research from (Kurniati, 2015) who said that a good psychological response influences the implementation of tuberculosis therapy. The same is expressed by Theron et al. (2015) who said that with the existence of severe psychological distress will lead to increased adherence to tuberculosis treatment so that the need for management of psychological stress to overcome it. Theron et al. (2015) also explained that this psychological distress relates to knowledge of medical and socioeconomic procedures.

Reinforcing Factors

Family support

Family support is one of the factors that can influence adherence of tuberculosis patients in undergoing the treatment process and result in recurrent tuberculosis. Family support can include motivation for tuberculosis patients to undergo treatment, become drug supervisors in providing support in accessing health services to get anti-tuberculosis drugs (Irnawati et al., 2016; Nugroho et al., 2016; Retni & Sugiyanto, 2010; World Health Organization, 2013). If poor family support can lead to failure in treatment and recurrent tuberculosis, it can lead to an increasing severe prognosis of the disease. However, different things are expressed by Wijayanti and Khusnal (2010) that family support in the form of parental behavior has no significant relationship with the quality of life of children suffering from tuberculosis. This is because of the child's perception of the disease he/she suffered.

Social stigma

One of the factors that can affect the process of tuberculosis treatment and lead to recurrent tuberculosis is social stigma. Gao et al. (2015) revealed that most tuberculosis patients will hide their illness and refuse to take regular medication according to their concerns about their neighbors who will isolate and stay away from them when they know they have tuberculosis. Smit et al. (2011) revealed that the stigma in society will arise when knowing someone undergoing tuberculosis treatment and most people will avoid the tuberculosis patients because it is considered an infectious disease. The stigma that arises in the community is often related to a person's level of knowledge related to tuberculosis and its treatment Gao et al. (2015).

Enabling Factor

Physician and nurse support

Patients with tuberculosis who experience withdrawal treatment that is sometimes caused by lack of support from physicians, nursing staff, and other caregivers in the treatment facilities (Tupasi et al., 2016). Lack of support from physicians and nurses is due to the lack of numbers of tuberculosis nurses who really understand the tuberculosis treatment process (Bothamley et al., 2011). Physician and nurse support can be manifested in good attitude and action when providing information / counseling

about treatment and side effects caused by treatment to be served as well as in providing DOTS services (Pongoh et al., 2015; Tupasi et al., 2016). Attitudes of physician and nursing staff who are less friendly cause patients with tuberculosis to be disobedient in undergoing treatment (Ibrahim et al., 2014). Most tuberculosis nurses are also drug supervisors who provide motivation to patients with tuberculosis during treatment. Their activity is closely related to the level of adherence of tuberculosis patients in receiving tuberculosis treatment (Dimas et al., 2016). The success of the treatment of tuberculosis and the occurrence of recurrent tuberculosis rate reduction can be achieved when there is a positive response from the public health service for the handling of tuberculosis in the community (Teshahuneygn et al., 2015).

DISCUSSION

This integrative review indicates major factors which related to the successful treatment of tuberculosis and the incident of recurrent tuberculosis among tuberculosis patients of a socioeconomic, availability to access health services, knowledge, psychological stress, family support, social stigma, and physician and nurse support. From the results of the review of the above article it can be concluded that factors that are closely related to the success of tuberculosis treatment and the occurrence of recurrent tuberculosis are socioeconomic, knowledge, family support, and physician and nurse support. From a socioeconomic perspective, many people with tuberculosis argue that if they are taking treatment for tuberculosis, they will take up their work time, so they get sanctions related to the overly licensing process or lack of opinion on the day they are in control of their tuberculosis (Herrero et al., 2015; Karyadi et al., 2002). In addition, socioeconomic is also closely related to availability to access health service, where the availability of access to closer health services and affordability can save their expenses and facilitate them to access health services, especially tuberculosis treatment services (Herrero et al., 2015; Ibrahim et al., 2014; Kirana et al., 2016; Teshahuneygn et al., 2015). Herrero et al. (2015) suggest that with the problems associated with the distance and ease of transport, hence the need for decentralization of tuberculosis health services, making it more affordable and more accessible to people with tuberculosis.

One other dominant factor is knowledge as one of the domains forming one's behavior. This knowledge is not only the knowledge of tuberculosis sufferers but also the family's knowledge of tuberculosis and its treatment process. With good knowledge of the tuberculosis treatment process, the family can provide good family support, perform the duties as the supervisor of taking medicine, and reduce the stigma that arise within the family (Imawati et al., 2016; Nugroho et al., 2016; Retni & Sugiyanto, 2010; World Health Organization, 2013). In addition, knowledge of tuberculosis and its treatment process is also important to the community with the goal of an active role in preventing the spread of tuberculosis and providing support for tuberculosis treatment in its environment (Gao et al., 2015).

Physician and nurse support are also an important factor in the success of tuberculosis treatment. This is because their activity in providing information/ counseling associated with tuberculosis and treatment process, especially in terms of side effects DOTS, is needed by patients with tuberculosis so they can undergo treatment without worrying about side effects and know how to deal with side effects of DOTS consumed (Pongoh et al., 2015; Tupasi et al., 2016). The less friendly attitude of physician and nursing staff causes patients with tuberculosis not to continue the treatment process that they are undergoing (Ibrahim et al., 2014). In addition, the lack of physician and nursing staff support is also due to a lack of physicians and nursing staff who understand tuberculosis and its treatment process (Bothamley et al., 2011).

Limitations of this study are the words used in searching and clarifying the existing literature. The research literature is limited to journal articles obtained from four search engines, EBSCO, PubMed, Direct Sciences and Google Scholar, which results in insufficient sampling probability. This study also was limited only to seven factors that can influence the success of tuberculosis treatment, so that it does not rule out the possibility of other factors that can also influence the success of tuberculosis treatment.

CONCLUSION

The most important factor that must be considered to provide health promotion action among tuberculosis patients doing tuberculosis treatment were socioeconomic factors and knowledge of tuberculosis disease and treatment. With this literature review, it is expected that every health worker will pay attention to the factors that can influence the success of tuberculosis treatment.

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Declaration of Conflicting Interest

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Authors Contribution

KWRP: The main compiler of the literature review and looking for sources used for article writing. CT: Searching for sources used for writing and checking for English writing.

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References

- Bani, S. F., Rosid, F. N., & Jadmiko, N. A. W. (2015). *Relationship between knowledge level and public attitudes against prevention of pulmonary tuberculosis*

- in Dayu Village area. (Dissertation). Surakarta: Universitas Muhammadiyah Surakarta.
- Bothamley, G. H., Kruijsaar, M. E., Kunst, H., Woltmann, G., Cotton, M., Saralaya, D., . . . Chapman, A. L. (2011). Tuberculosis in UK cities: workload and effectiveness of tuberculosis control programmes. *BMC Public Health*, 11(1), 896. <https://doi.org/10.1186/1471-2458-11-896>
- Cooper, H. M. (1998). *Synthesing research: A guide for literature reviews* Thousand Oaks, California: Sage.
- Dimas, S. B., Sukartini, T., & Hidayati, L. (2016). *Drugs supervisor activeness correlated with motivation and tuberculosis medication adherence*. Paper presented at the The 7th International Nursing Conference, Surabaya.
- Dobler, C. C., Korver, S., Batbayar, O., Oyuntsetseg, S., Tsolmon, B., Wright, C., . . . Marais, B. J. (2015). Success of community-based directly observed anti-tuberculosis treatment in Mongolia. *The International Journal of Tuberculosis and Lung Disease*, 19(6), 657-662. <https://doi.org/10.5588/ijtld.14.0927>
- Gao, J., Berry, N. S., Taylor, D., Venners, S. A., Cook, V. J., & Mayhew, M. (2015). Knowledge and perceptions of latent tuberculosis infection among Chinese immigrants in a Canadian urban centre. *International Journal of Family Medicine*, 2015. <https://doi.org/10.1155/2015/546042>
- Green, L. W., & Kreuter, M. N. (2005). *Health planning: An educational and ecological approach*. New York: McGraw-Hill.
- Gupta, D., Das, K., Balamughesh, T., Aggarwal, N., & Jindal, S. K. (2004). Role of socio-economic factors in tuberculosis prevalence. *Indian Journal of Tuberculosis*, 51(1), 27-32.
- Herrero, M. B., Ramos, S., & Arrossi, S. (2015). Determinants of non adherence to tuberculosis treatment in Argentina: barriers related to access to treatment. *Revista Brasileira de Epidemiologia*, 18, 287-298. <https://doi.org/10.1590/1980-5497201500020001>
- Ibrahim, L. M., Hadejia, I. S., Nguku, P., Dankoli, R., Waziri, N. E., Akhimien, M. O., . . . Nwanyanwu, O. (2014). Factors associated with interruption of treatment among pulmonary tuberculosis patients in Plateau State, Nigeria. 2011. *Pan African Medical Journal*, 17(1). <https://doi.org/10.11604/pamj.2014.17.78.3464>
- Indonesian Ministry of Health. (2014). *Indonesian health profile 2013*. Jakarta: Ministry of Health of the Republic of Indonesia.
- Irnanawati, N. M., Siagian, I. E., & Ottay, R. I. (2016). The effect of family support on drug compliance on tuberculosis patients at public health center of Motoboi Kecil, Kotamobagu City. *Jurnal Kedokteran Komunitas dan Tropik*, 4(1), 59-64.
- Karyadi, E., West, C., Nelwan, R., Dolmans, W., Schultink, J., & Van der Meer, J. (2002). Social aspects of patients with pulmonary tuberculosis in Indonesia. *Southeast Asian Journal of Tropical Medicine and Public Health*, 33(2), 338-345.
- Kirana, R. C., Lutfiyati, H., & I., W. H. (2016). The description of compliance level of patients in BKPM Magelang in the periode of February – March 2015. *Jurnal Farmasi Sains dan Praktis*, 1(2), 36-42.
- Kirkevold, M. (1997). Integrative nursing research—an important strategy to further the development of nursing science and nursing practice. *Journal of Advanced Nursing*, 25(5), 977-984. <https://doi.org/10.1046/j.1365-2648.1997.1997025977.x>
- Kondoy, P. P. H., Rombot, D. V., Palandeng, H. M. F., & Pakasi, T. A. (2014). Factors related to compliance of tuberculosis lung patients in five public health centers in Manado City. *Jurnal Kedokteran Komunitas dan Tropik*, 2(1), 1-8.
- Kurniati, A. (2015). Barriers to tuberculosis treatment and how to handle it in Balai Pengobatan Penyakit Paru-paru (BP4) Unit Minggir, Yogyakarta. *Journal of Holistic Nursing Science*, 2(1), 19-27.
- Loriana, R., Thaha, M. R., & Ramdan, I. M. (2014). *Effect of counseling on knowledge, attitude and compliance with pulmonary tuberculosis patients in the working area of the City Health Department of Samarinda*. Retrieved from <http://pasca.unhas.ac.id/jurnal/files/1445b949d295c9486aeb541ca379aefb.pdf>
- Nugroho, A. S., Muhlisin, H. A., & Yulian, V. (2016). *The relationship between patient knowledge of tuberculosis and family support with medication adherence in the working area of Public Health Center of Jekulo, Kudus District* (Doctoral dissertation). Indonesia: Universitas Muhammadiyah Surakarta.
- Perhimpunan Dokter Paru Indonesia. (2006). *Tuberculosis: Guidelines for diagnosis and management of treatment in Indonesia*. Jakarta: Perhimpunan Dokter Paru Indonesia.
- Pongoh, M. E., Palandeng, H. M., & Rombot, D. V. (2015). Description of health personnel behavior on pulmonary tuberculosis treatment at Public Health Center of Manado City. *Jurnal Kedokteran Komunitas dan Tropik*, 3(2), 108-117.
- Retni, A., & Sugiyanto, S. (2010). *Relationship of family social support with healing level of pulmonary tuberculosis patients at Umbulharjo II Public Health Center Yogyakarta*. (Doctoral Dissertation). Indonesia: STIKES 'Aisyiyah Yogyakarta.
- Rohmana, O., & Suhartini, A. S. (2014). Factors on the drug controller related to the compliance of treatment of pulmonary tuberculosis patients in Cirebon City. *Jurnal Kesehatan Komunitas Indonesia*, 10(1).
- Sari, I. D., Mubasyiroh, R., & Supardi, S. (2016). Relationship between knowledge and attitude and patient compliance among outpatient tuberculosis in Jakarta Province 2014. *Media Penelitian dan Pengembangan Kesehatan*, 26(4), 243-248.
- Setiawan, M. R. D. (2013). Effect of anti-tuberculosis drug side effects on pulmonary tuberculosis treatment at BBKPM Surakarta. *Nexus Kedokteran Komunitas*, 2(1).
- Smit, J., Norgbe, G., & Du Toit, H. (2011). Factors influencing default rates of tuberculosis patients in Ghana. *Africa*

- Journal of Nursing and Midwifery*, 13(2), 67-76. <https://doi.org/10.1016/j.ijtb.2017.03.010>
- Souza, M. T. d., Silva, M. D. d., & Carvalho, R. d. (2010). Integrative review: what is it? How to do it? *Einstein (São Paulo)*, 8(1), 102-106. <https://doi.org/10.1590/s1679-45082010rw1134>
- Tang, Y., Zhao, M., Wang, Y., Gong, Y., Yin, X., Zhao, A., . . . Wang, W. (2015). Non-adherence to anti-tuberculosis treatment among internal migrants with pulmonary tuberculosis in Shenzhen, China: a cross-sectional study. *BMC Public Health*, 15(1), 474. <https://doi.org/10.1186/s12889-015-1789-z>
- Tesfahuneygn, G., Medhin, G., & Legesse, M. (2015). Adherence to Anti-tuberculosis treatment and treatment outcomes among tuberculosis patients in Alamata District, northeast Ethiopia. *BMC Research Notes*, 8(1), 503. <https://doi.org/10.1186/s13104-015-1452-x>
- Theron, G., Peter, J., Zijenah, L., Chanda, D., Mangu, C., Clowes, P., . . . Pym, A. (2015). Psychological distress and its relationship with non-adherence to TB treatment: a multicentre study. *BMC Infectious Diseases*, 15(1), 253. <https://doi.org/10.1186/s12879-015-0964-2>
- Tolossa, D., Medhin, G., & Legesse, M. (2014). Community knowledge, attitude, and practices towards tuberculosis in Shinile town, Somali regional state, eastern Ethiopia: a cross-sectional study. *BMC Public Health*, 14(1), 804. <https://doi.org/10.1186/1471-2458-14-804>
- Tupasi, T. E., Garfin, A. M. C. G., Kurbatova, E. V., Mangan, J. M., Orillaza-Chi, R., Naval, L. C., . . . Joson, E. S. (2016). Factors associated with loss to follow-up during treatment for multidrug-resistant tuberculosis, the Philippines, 2012–2014. *Emerging Infectious Diseases*, 22(3), 491. <https://doi.org/10.3201/eid2203.151788>
- Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Wijayanti, A., & Khusnal, E. (2010). *Relationship of healthy behavior of parents with quality of life of tuberculosis patients' children at lung disease treatment center (BP4) Province of Yogyakarta Special Region Year 2010* (Doctoral Dissertation). Indonesia: STIKES 'Aisyiyah Yogyakarta.
- World Health Organization. (2013). *Guideline: Nutritional care and support for patients with tuberculosis*. Geneva: World Health Organization.

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ORIGINAL RESEARCH

FACTORS ASSOCIATED WITH HEPATITIS B AND C CO-INFECTION AMONG PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS IN VIETNAM

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Abstract

Background: Human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV) are the leading causes of death from infectious diseases. Because of sharing same transmission routes, the co-infection of HIV with HBV or HCV is common. And the co-infections make HIV infected persons have higher morbidity and mortality than those who infected only with HIV. This study aims to investigate factors that may have influence on the co-infections of HBV or HCV among HIV positive individuals.

Objective: The goals of this study were to identify factors associated with the co-infection of HBV or HCV among people living with HIV.

Methods: Quantitative research method was applied in this study to examine factors associated with HBV or HCV co-infection among HIV infected people. A total of 250 HIV infected individuals in Khanh Hoa province, Vietnam were the sample of this study. It employed the Social Ecological Model (SEM) as a theoretical perspective that focused on multiple levels of factors. Descriptive statistic was used to describe the general characteristics of the respondents. And Binary logistic regression was carried out to measure the influence of factors on the co-infection.

Results: The multivariate analysis of this study showed that HIV-HBV co-infection was associated significantly with residents of Nha Trang ($OR= 7.179$). Regarding HIV-HCV co-infection, being men ($OR= 7.617$), unemployed ($OR= 4.013$), a resident of Nha Trang ($OR=10.894$) and an injecting drug user ($OR= 16.688$) were risk factors of the co-infection.

Conclusions: This study recommended that intervention strategies to prevent HIV-positive individuals from co-infection with either HBV or HCV should focus on altering individuals' risk behaviors and their socio-economic environments. Also, specific preventing programs should be implemented and focus on unemployed populations, injecting drug users, men in general, as well as people living in particular areas, especially cities having a large number of people living with HIV.

KEYWORDS

HIV; HCV; HBV; co-infection; Vietnam

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INTRODUCTION

Human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV) are blood-borne viruses, which are one of the top causes leading deaths by infectious disease worldwide ([Alter, 2006](#); [Centers for Disease Control and Prevention, 2018](#)). These three viruses can be transmitted in similar ways such as exchange of blood, or other body fluids,

during injecting drug use (IDU), sexual contact or mother-to-child transmission during the perinatal period ([Centers for Disease Control and Prevention, 2018](#); [Petty et al., 2014](#); [World Health Organization, 2017a, 2017b](#)). Therefore, HIV-positive individuals are more likely to have a risk of co-infection with HBV or HCV ([Kamenya et al., 2017](#); [Mohammadi et al., 2009](#)).

HBV and HCV were as major contributors of liver cirrhosis, liver cancer and liver-related deaths, have become one of the important causes of illness and reduce life expectancy among people living with HIV (Bhaumik et al., 2015; Kim et al., 2017).

In Vietnam, HIV, HBV, HCV, as well as their co-infections remain a major public health issue. Some studies were conducted in Vietnam (Hanoi, and Ho Chi Minh City) to investigate co-infections prevalence. These studies revealed that the overall prevalence of HBV co-infection were 5 - 12.9%; and about 21.2 - 36% experienced HCV co-infection (Huy et al., 2014; Mohan et al., 2017; Quang et al., 2015). Understanding about the situation of HIV co-infection with HBV or HCV among HIV positive people in Vietnam, especially about which factors associated with these co-infection is important for HIV health workers and nurses in developing more effective intervention strategies to prevent HBV and HCV. However, limited studies were conducted in Vietnam to investigate factors associated with these co-infections. Therefore, this study aimed to identify risk factors associated with HBV or HCV co-infection among HIV-positive individuals in Vietnam.

METHODS

Study design

This study was quantitative research to examine factors associated with hepatitis B or hepatitis C co-infection among people living with HIV. It relied on secondary data of the survey from 2016 to 2017 on "HIV, HBV and HCV co-infection of patients receiving ARV and methadone treatment in Khanh Hoa Province", conducted by the Preventing HIV/AIDS Center of Khanh Hoa. The secondary data used in the study was collected in Khanh Hoa Province, situated in the south central coast of Vietnam.

Sample

The study population of this study comprised HIV-positive people receiving ARV treatment in Khanh Hoa Province. These HIV-positive people received a diagnosis of HBV or HCV co-infection. The sample size of this study totaled 250 respondents, which was calculated by the original survey using the Taro Yamane Formula (Yamane, 1973). The study applied all inclusion and exclusion criteria of the sampling method according to the original survey. All HIV positive persons receiving treatment of ARV in Khanh Hoa province before 31 December 2016 were included in this study. However, the sample recruited had some exceptions: people who refused to participate in the survey, and those who died, moved to other provinces or withdrew from treatment.

Instrument

The subjects of this study were drawn from secondary data of the original survey mentioned previously. The original interviews were conducted face-to-face using questionnaires. Trained interviewers collected data from medical reports first, then made appointments with the HIV people for structured interview, using

a paper-based questionnaire and took samples for blood testing (confirmed test for HIV, HBV and HCV). The questionnaires included patient's general information, risk factors of HIV, HBV and HCV infection and patient's medical information.

Ethical approval

This study received approval for the secondary use of "HIV, HBV and HCV co-infection data on patients receiving treatment ARV and methadone in Khanh Hoa Province, Vietnam" from Khanh Hoa HIV/AIDS Center, that conducted and managed the original data set. The ethics approval for this present study was granted by the IPSR-Institutional Review Board (IPSR-IRB) of the Institute for Population and Social Research, Mahidol University (COE. No. 2018/05-160).

Data analysis

This study employed the Social Ecological Model (SEM) as a theoretical perspective that focused on multiple levels (personal and environmental) of factors and their complex interplay that influence specific behavior. Total of 12 variables was analyzed in this study, which was categorized into four levels, including intrapersonal levels (age, sex, education, marital status, employment status, sexual orientation, experience of injecting drug use and duration of ARV treatment); interpersonal levels (practicing unsafe sex and partner's history of injecting drugs); organizational level (place of residence); and community level (tattooing). Descriptive statistic was used to describe the general characteristics of the respondents (frequencies and percentages). Multivariate analysis (Binary logistic regression) was carried out to identify the risk factors for the co-infections (HIV co-infection with HBV or HCV). There are 2 models, each model is appropriate with each dependent variable (HIV and HBV co-infection, HIV and HCV co-infection). STATA software version 14 was used for all statistical analyses.

RESULTS

Characteristics of HIV Positive People Co-infected with HBV or HCV

Of 250 HIV infected individuals, over one half of respondents were men (59.6%). The age-range of respondents was from 20 - 70 years with a mean of 38.2. The prevalence of HIV-HBV and HIV-HCV co-infection was 20.8% and 37.6%, respectively. Individual 30-39 years old were at a higher risk of HBV or HCV co-infection compare to those in age group less than 30. Male respondents had a higher rate of HIV co-infection with HBV or HCV than HIV infected female (Table 1). Respondents residing in Nha Trang were co-infected with HBV or HCV at a higher frequency compare to those who resided outside Nha Trang. Marital status, education, employment status, history of injecting drug use and tattooing had a relationship with HIV-HCV co-infection ($p < .05$); however, the same did not hold for HIV-HBV co-infection. Meanwhile, sexual orientation had a correlation with co-infection of HBV ($p < .05$), but not with HCV co-infection.

Table 1 Characteristics of HBV and HCV infection in 250 HIV infected people in Vietnam

All factors		Overall sample N (%)	HIV-HBV co-infection Number of possibility(%)	HIV-HCV co-infection N Number of possibility(%)
Intrapersonal Levels				
Age	≤ 29	24 (9.6)	9 (37.5)	9 (37.5)
	30-39	137 (54.8)	26 (19)	56 (40.9)
	≥ 40	89 (35.6)	17 (19.1)	29 (32.6)
	Total	250	52 (20.8)	94 (37.6)
	Mean = 38.2, SD = 8.3, Min = 20, Max = 70			
χ^2			4.495	1.581
p			0.106	0.454
Sex	Female	101 (40.4)	21 (20.7)	15 (14.8)
	Male	149 (59.6)	31 (20.8)	79 (53)
	Total	250	52	94
	χ^2			
	0.000			
p			0.998	0.000*
Marital status	Never married	60 (24)	13 (21.7)	29 (48.3)
	Ever married	190 (76)	39 (30.5)	65 (34.2)
	Total	250	52	94
	χ^2			
	0.036			
p			0.850	0.049*
Education	Primary school or lower	41 (16.4)	8 (19.5)	17 (41.5)
	Secondary school	101 (40.4)	21 (20.8)	46 (45.5)
	High school or higher	108 (43.2)	23 (21.3)	31 (28.7)
	Total	250	250	94
	χ^2			
	0.057			
p			0.972	0.036*
Employment status	Employed	192 (76.8)	36 (18.7)	61 (31.8)
	Unemployed	58 (23.2)	16 (27.6)	33 (56.9)
	Total	250	52	94
	χ^2			
	2.111			
p			0.146	0.001*
Sexual orientation	Heterosexual	234 (93.6)	46 (19.7)	86 (36.8)
	Homosexual	10 (4)	6 (60)	3 (30)
	Total	250	52	89
	χ^2			
	9.307			
p			0.002**	0.664
Duration of ARV treatment	No	194 (77.6)	39 (20.1)	69 (35.6)
	Yes	56 (22.4)	13 (23.2)	25 (44.6)
	Total	250	52	94
	Mean= 4.8, SD= 2.7, Min= 1, Max= 12			
	χ^2			
	0.255			
p			0.613	0.217
History of Injecting drug use	No	156 (62.4)	31 (19.9)	23 (14.7)
	Yes	94 (37.6)	21 (22.3)	71 (75.5)
	Total	250	52	94
	χ^2			
	0.217			
p			0.641	0.000*
Interpersonal Level				
Practicing unsafe sex	No	76 (31.1)	17 (22.4)	34 (44.7)
	Yes	168 (68.9)	35 (20.8)	55 (32.7)
	Total	244	52	89

All factors		Overall sample N (%)	HIV-HBV co-infection Number of possibility(%)	HIV-HCV co-infection N Number of possibility(%)
χ^2			0.074	3.251
p			0.786	0.071
Partner's history of injecting drug	No	187 (85.8)	39 (20.3)	72 (38.5)
	Yes	31 (14.2)	8 (25.8)	11 (35.5)
	Total	218	46	83
χ^2			0.481	0.103
p			0.488	0.749
Organizational Level				
Place of residence	Others	74 (29.6)	6 (8.11)	15 (20.3)
	NhaTrang	176 (70.4)	46 (26.1)	79 (44.9)
	Total	250	52	94
χ^2			10.278	13.455
p			0.001*	0.000*
Community Level				
Tattooing	No	182 (72.8)	33 (18.1)	47 (25.8)
	Yes	68 (27.2)	19 (27.9)	47 (69.1)
	Total	250	52	94
χ^2			2.892	39.547
p			0.089	0.000*

* $p < .05$ is considered as significant

Risk factors associated with the co-infection of HIV with HBV or HCV

The Multivariate analysis in Model 1 (Table 2) showed place of residence associated strongly with HIV-HBV co-infection. The risk of HBV co-infection was significantly higher among HIV-positive individuals residing in Nha Trang ($OR = 7.179$, 95% $CI = 1.982 - 26.009$) than among those residing in other areas.

In Model 2 (Table 3), of twelve variables, four variables which were categorized as intrapersonal factors (sex, employment status and history of injecting drug use) and organizational factor (place of residence) were significantly associated with HIV and HCV co-infection. Regarding sex, the risk of HCV co-infection was

significantly higher among HIV-positive males ($OR = 7.617$, 95% $CI = 2.345 - 24.742$) than females. In terms of employment status, being unemployed was significantly associated with a higher risk of HCV co-infection among HIV-positive individuals ($OR = 4.013$, 95% $CI = 1.228 - 13.109$) compared with being employed. Additionally, HIV-positive individuals residing in Nha Trang had a higher risk of HCV co-infection ($OR = 10.894$, 95% $CI = 3.577 - 33.186$) than those who lived in other areas. Regarding the history of injecting drugs, having injected drugs was significantly associated with increased HCV co-infection among HIV-positive individuals ($OR = 16.688$, 95% $CI = 5.848 - 46.624$) compared with those never having injected drugs.

Table 2 Model 1 - Binary logistic regression analysis of HIV co-infection with HBV (n=218)

Factors		HIV co-infection with HBV		
		OR	95% CI Lower	Upper
Intrapersonal Levels				
Age	≤ 29			
	30-39	0.596	0.172	2.06
	≥ 40	0.67	0.170	2.631
Sex	Female			
	Male	0.657	0.257	1.678
Marital status	Never married			
	Ever married	1.503	0.485	4.651
Education	Primary school or lower			
	Secondary school	0.849	0.285	2.532
	High school or higher	0.99	0.329	2.972
Employment status	Employed			
	Unemployed	1.971	0.763	5.095

Factors		HIV co-infection with HBV		
		OR	95% CI	
			Lower	Upper
Sexual orientation	Heterosexual			
	Homosexual	3.971	0.409	38.584
History of Injecting drug use	No			
	Yes	0.813	0.279	2.373
Duration of ARV treatment	≤ 6			
	> 6	1.109	0.015	0.687
Interpersonal Levels				
Practicing unsafe sex	No			
	Yes	1.019	0.409	2.539
Partner's history of injecting drug	No			
	Yes	0.813	0.279	2.373
Organizational Level				
Place of resident	Other			
	NhaTrang	3.139*	1.185	8.316
Community Level				
Tattooing	No			
	Yes	2.157	0.794	5.860
LR chi-square= 16.97		Pseudo R square= 0.0755		
Note: * <i>p</i> <0.05; ** <i>p</i> <0.01; *** <i>p</i> <0.001		Degree of freedom= 14		

Table 3 Model 2-Binary logistic regression analysis of HIV co-infection with HCV (n=218)

Factors		HIV co-infection with HCV		
		OR	95% CI	
			Lower	Upper
Intrapersonal Levels				
Age	≤ 29			
	30-39	0.604	0.128	2.838
	≥ 40	0.365	0.068	1.96
Sex	Female			
	Male	7.617**	2.345	24.742
Marital status	Never married			
	Ever married	1.85	0.555	6.169
Education	Primary school or lower			
	Secondary school	0.758	0.22	2.61
	High school or higher	0.374	0.106	1.322
Employment status	Employed			
	Unemployed	4.013*	1.228	13.109
Sexual orientation	Heterosexual			
	Homosexual	0.541	0.037	7.933
History of Injecting drug use	No			
	Yes	16.688***	5.848	46.624
Duration of ARV treatment	≤ 6			
	> 6	1.048	0.401	2.736
Interpersonal Levels				
Practicing unsafe sex	No			
	Yes	1.039	0.353	3.057
Partner's history of injecting drug	No			
	Yes	0.841	0.217	3.261
Organizational Level				
Place of residence	Other			
	NhaTrang	10.894***	3.577	33.186

Factors		HIV co-infection with HCV		
		OR	95% CI	
			Lower	Upper
Community Level				
Tattooing	No			
	Yes	0.411	0.134	1.257
LR chi-square= 120.27***		Pseudo R square= 0.4152		
Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$		Degree of freedom= 14		

DISCUSSION

This study found that some intrapersonal and organizational factors had strong associations with the co-infections. Particularly, in Model 1, about HIV and HBV co-infection, place of residence was found to be strongly associated with co-infection. Concerning the co-infection of HIV and HCV in Model 2, four variables were strongly associated with co-infection including employment status, residency, sex and history of injecting drugs.

Regarding place of residence, which was grouped in organizational level, the findings from multivariate analysis showed a statistically significant association in both two models, with HIV-HBV and HIV-HCV co-infections. It might have been because of the sample size, among 250 respondents, 176 lived in Nha Trang, accounting for 70.4% of the sample size (Table 1). As such, this made the prevalence of co-infection in Nha Trang higher than in other areas.

In Model 2, in terms of the co-infection of HIV and HCV, sex was one of the risk factors strongly associated with co-infection. Specifically, males were more likely to face a higher risk of HIV and HCV co-infection than females. This result was concordant with another related studies conducted in northern Vietnam, China, the US and Africa (Huy et al., 2014; Kim et al., 2008; Umutesi et al., 2017; Wu et al., 2017). This might be because women are less likely than men to adopt health risk behaviors such as consuming alcohol, injecting drugs, engaging in practicing unsafe sex or having multiple sexual partners. Furthermore, due to norms regarding masculinity, men are socially and culturally expected to be strong. Therefore, they rarely perceive themselves as being at risk of health problem. Also, many refuse to admit that they lack sufficient knowledge and information regarding health (Budesu et al., 2008; Courtenay, 2000; Gupta, 2000; Kaplan & Marks, 1995).

Moreover, employment status was strongly associated in Model 2 regarding HIV-HCV co-infection. In particular, unemployed individuals were significantly more likely to have HIV-HCV co-infection than those who were employed. This might be because unemployed individuals usually have lower knowledge levels about disease prevention than those who were employed, and those with higher incomes (Pharr et al., 2012; Sun et al., 2013). In addition, associations were identified between unemployment and risky health behaviors such as consuming alcohol, smoking and risky sexual practices (unprotected sex) (Hammarström & Janlert, 1997; Pharr et al., 2012). Individuals practicing risky behaviors may have an increased risk of contracting diseases like

HBV and HCV etc. This result was similar with related studies in other countries like China and Iran (Mohammadi et al., 2009; Zhang et al., 2017).

History of injecting drug was found to be a strong determinant of HIV-HCV co-infection among HIV-positive individuals as illustrated in Models 2 (Table 3). This was because, injecting drug was one of risk factors of transmitting diseases like HCV or HIV, in that injecting drug users may share or re-use needles, syringes. Therefore, they can be transmitted diseases through direct contact with the blood of an infected person (Centers for Disease Control and Prevention, 2018; World Health Organization, 2017b). And the results of the present study were similar with related studies in Brazil, Vietnam, China and Thailand (Huy et al., 2014; Kuehlkamp et al., 2014; Sungkanupaprh et al., 2004; Zhang et al., 2017).

CONCLUSION

Multivariate analysis revealed specific intrapersonal factors (including sex, employment status and history of injecting drug use), and organizational factor (residency) had a strong relationship with HBV or HCV co-infections among HIV-positive individuals. These findings could help healthcare providers, nurses and policy makers to direct their interventions to focus more on particular risk groups and to alert HIV-positive patients to their potential risks factors. The local government needs to provide preventive education program and campaigns in public to educate those people who are at high risks of the co-infections to become aware of their risks and health outcomes of the co-infections. Also, preventive education programs should emphasize behavioral changes among HIV-positive individuals, especially those who are males, unemployed, injecting drug users. In addition, intervention strategies should focus on particular geographical areas, especially areas with a large number of HIV-positive individuals. Furthermore, the local government should have HBV and HCV screening policy in place. Health care institutions should conduct routine surveillance regarding the rate and prevalence of these three types of co-infections in the HIV epidemic context. Especially for the nurses providing cares for HIV positive patients, knowing about the HIV and hepatitis virus co-infection, as well as the factors associated with these co-infection will help developing a proper care plan for each individual HIV patient. For example, encouraging HIV positive patients to undergo HBV or HCV screening, and providing them safety precautions about what things to do or not in order to do to prevent HBV or HCV transmission.

Declaration of Conflicting Interest

Authors have no conflict of interest to declare.

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Authors Contribution

AHTL: Performed analysis on all samples, interpreted data, wrote manuscript and acted as corresponding author.

ST: Supervised development of work, helped in data interpretation and manuscript evaluation.

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References

- Alter, M. J. (2006). Epidemiology of viral hepatitis and HIV co-infection. *Journal of Hepatology*, 44, S6-S9. <https://doi.org/10.1016/j.jhep.2005.11.004>
- Bhaumik, P., Bhattacharjee, P., & Sil, S. K. (2015). Hepatitis B and hepatitis C virus co-infection among human immunodeficiency virus infected patients of Tripura. *International Journal of Scientific Study*, 3(6), 77-80. <https://doi.org/10.17354/ijss/2015/397>
- Budesa, T., Egnor, E., & Howell, L. (2008). Gender influence on perceptions of healthy and unhealthy lifestyles. *All Volumes (2001-2008)*, 3.
- Centers for Disease Control and Prevention. (2018). HIV/AIDS and viral hepatitis. Retrieved from <https://www.cdc.gov/hepatitis/populations/hiv.htm>
- Courtenay, W. H. (2000). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine*, 50(10), 1385-1401. [https://doi.org/10.1016/S0277-9536\(99\)00390-1](https://doi.org/10.1016/S0277-9536(99)00390-1)
- Gupta, G. R. (2000). Gender, sexuality, and HIV/AIDS: The what, the why, and the how. *Canadian HIV/AIDS Policy and Law Review*, 5(4), 86-93.
- Hammarström, A., & Janlert, U. (1997). Unemployment and sexual risk-taking among adolescents. *Scandinavian Journal of Social Medicine*, 25(4), 266-270. <https://doi.org/10.1177/140349489702500409>
- Huy, B. V., Vernavong, K., & Kính, N. V. (2014). HBV and HCV coinfection among HIV/AIDS patients in the National Hospital of Tropical Diseases, Vietnam. *AIDS Research and Treatment*, 2014. <https://doi.org/10.1155/2014/581021>
- Kamenya, T., Damian, D. J., Ngocho, J. S., Philemon, R. N., Mahande, M. J., & Msuya, S. E. (2017). The prevalence of hepatitis B virus among HIV-positive patients at Kilimanjaro Christian Medical Centre Referral Hospital, Northern Tanzania. *The Pan African Medical Journal*, 28. <https://doi.org/10.11604/pamj.2017.28.275.11926>
- Kaplan, M. S., & Marks, G. (1995). Appraisal of health risks: The roles of masculinity, femininity, and sex. *Sociology of Health & Illness*, 17(2), 206-221. <https://doi.org/10.1111/1467-9566.ep10933391>
- Kim, J. H., Psevdos Jr, G., Suh, J., & Sharp, V. L. (2008). Co-infection of hepatitis B and hepatitis C virus in human immunodeficiency virus-infected patients in New York City, United States. *World Journal of Gastroenterology: WJG*, 14(43), 6689. <https://doi.org/10.3748/wjg.14.6689>
- Kim, Y. C., Ahn, J. Y., Kim, J. M., Kim, Y. J., Park, D. W., Yoon, Y. K., . . . Choi, B. Y. (2017). Human immunodeficiency virus (HIV) and hepatitis virus coinfection among HIV-infected Korean patients: the Korea HIV/AIDS Cohort Study. *Infection & Chemotherapy*, 49(4), 268-274. <https://doi.org/10.3947/ic.2017.49.4.268>
- Kuehlkamp, V. M., Schneider, I. J., Biudes, M. F., Galato, D., Silva, J. d., Maurici, R., . . . Schuelter-Trevisol, F. (2014). Factors associated with hepatitis C seropositivity in people living with HIV. *Revista Panamericana de Salud Pública*, 35, 53-59.
- Mohammadi, M., Talei, G., Sheikhan, A., Ebrahimzade, F., Pournia, Y., Ghasemi, E., & Boroun, H. (2009). Survey of both hepatitis B virus (HBsAg) and hepatitis C virus (HCV-Ab) coinfection among HIV positive patients. *Virology Journal*, 6(1), 202. <https://doi.org/10.1186/1743-422x-6-202>
- Mohan, C., Ha, T. V., Hoffman, I., Eron, J., & Go, V. (2017). Viral Hepatitis among HIV+ Patients in Northern Vietnam. *Open Forum Infectious Diseases*, 4(Suppl 1), S661-S661. <https://doi.org/10.1093/ofid/ofx163.1763>
- Petty, L. A., Steinbeck, J. L., Pursell, K., & Jensen, D. M. (2014). Human immunodeficiency virus and coinfection with hepatitis B and C. *Infectious Disease Clinics*, 28(3), 477-499. <https://doi.org/10.1016/j.idc.2014.05.005>
- Pharr, J. R., Moonie, S., & Bungum, T. J. (2012). The impact of unemployment on mental and physical health, access to health care and health risk behaviors. *ISRN Public Health*, 2012. <https://doi.org/10.5402/2012/483432>
- Quang, V., Chau, N., Dung, N., & Tam, D. (2015). HBV and HCV coinfection in patients with HIV/AIDS in Ho Chi Minh City, Vietnam. *Journal of Clinical Virology*, 69, 226. <https://doi.org/10.1016/j.jcv.2015.06.016>
- Sun, X., Shi, Y., Zeng, Q., Wang, Y., Du, W., Wei, N., . . . Chang, C. (2013). Determinants of health literacy and health behavior regarding infectious respiratory diseases: a pathway model. *BMC Public Health*, 13(1), 261. <https://doi.org/10.1186/1471-2458-13-261>
- Sungkanuparph, S., Vibhagool, A., Manosuthi, W., Kiartiburanakul, S., Atamasirikul, K., Aumkhyan, A., & Thakkinstian, A. (2004). Prevalence of hepatitis B virus and hepatitis C virus co-infection with human immunodeficiency virus in Thai patients: a tertiary-care-based study. *Journal of the Medical Association of Thailand*, 87(11), 1349-1354.
- Umutesi, J., Simmons, B., Makuza, J. D., Dushimiyimana, D., Mbituyumuremyi, A., Uwimana, J. M., . . . Nsanzimana, S. (2017). Prevalence of hepatitis B and C infection in

- persons living with HIV enrolled in care in Rwanda. *BMC Infectious Diseases*, 17(1), 315. <https://doi.org/10.1186/s12879-017-2422-9>
- World Health Organization. (2017a). Fact sheet-Hepatitis C. Retrieved from <http://www.who.int/mediacentre/factsheets/fs164/en/>
- World Health Organization. (2017b). Fact sheet-HIV/AIDS. Retrieved from <http://www.who.int/mediacentre/factsheets/fs360/en/>
- Wu, S., Yan, P., Yang, T., Wang, Z., & Yan, Y. (2017). Epidemiological profile and risk factors of HIV and HBV/HCV co-infection in Fujian Province, southeastern China. *Journal of Medical Virology*, 89(3), 443-449. <https://doi.org/10.1002/jmv.24666>
- Yamane, T. (1973). *Statistics: An introductory analysis* (3rd ed.). New York: Harper and Row.
- Zhang, C., Li, X., Liu, Y., Qiao, S., Chen, Y., Zhou, Y., & Shen, Z. (2017). Co-infections of tuberculosis, hepatitis B or C viruses in a cohort of people living with HIV/AIDS in China: predictors and sequelae. *AIDS Care*, 29(8), 974-977. <https://doi.org/10.1080/09540121.2016.1271388>

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ORIGINAL RESEARCH

SOCIAL SUPPORT OF PARENTS OF CHILDREN WITH LEUKEMIA

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Abstract

Background: Leukemia in children is not only a stressor for children but also all family members, especially for parents. Caring for children with leukemia relies on the importance of social support to overcome various crises caused by the disease and its treatment. However, parents' perceptions of social support can be affected by several factors. Thus, assessment of factors that impact social support of parents of children with leukemia is needed.

Objective: This study aimed to analyze the social support perceived by parents of children with leukemia and examine the relationship between perceived social support and characteristics of parents and children.

Methods: A quantitative study with cross-sectional approach in 104 parents of children with leukemia aged 3-18 years. Social support was measured using Multidimensional Scale of Perceived Social Support (MSPSS) questionnaire. Data were analyzed using univariate analysis, Mann-Whitney U, Kruskal-Wallis, and Spearman Test.

Results: Total scale score of the Multidimensional Scale of Perceived Social Support (MSPSS) of parents of children with leukemia was 5.74 ± 0.48 . The highest subscale score was on family support (6.06 ± 0.46). There were statistically significant differences in MSPSS total scores based on parental education and family income ($p < 0.05$).

Conclusion: Nurses play an important role to provide support for parents who have children with leukemia, especially in risky families. Support that nurses can provide among parents of children with leukemia is by giving information about disease and care, empowering the family, and finding support outside the family, such as the source of financial support related to treatment, utilization of cancer foundations, and supporting group and others.

KEYWORDS

children with leukemia; parent; social support

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INTRODUCTION

Leukemia is the most common form of childhood cancer. It is more common in boys and white, with a peak incidence between 2-5 years of age ([Hockenberry & Wilson, 2013](#)). Leukemia accounts for 29% of all childhood cancers ([Siegel et al., 2017](#)). In general, leukemia is classified based on how quickly the diseases progresses; acute leukemia, and chronic leukemia. Acute Lymphoblastic Leukemia (ALL) is the most common type of leukemia found in children ([American Cancer Society, 2016](#)).

In Indonesia, it is estimated that there are 4,100 new cases of cancer in children every year. Based on the Child Cancer Register Data, Department of Childhood Cancer, Dharmas Hospital Cancer Indonesia, cases of child cancer tend to increase from 2006 to 2014. Over the past 9 years, leukemia is the most common

type of child cancer ([Ministry of Health of the Republic of Indonesia, 2015](#)). West Java is one of the provinces in Indonesia with the largest population. The incidence of childhood cancer in West Java is classified as high. In 2017, according to data from the Referral Hospital in West Java, there were 2.102 children hospitalized in that hospital ([Hastuti, 2019](#)).

Meanwhile, based on the preliminary research results done by the researcher in 2 hospitals in Bandung, which is the capital city of West Java Province, the number of incidence of children with leukemia in Bandung increases every year. There were 291 children with leukemia who had to undergo treatment in both hospitals in 2017.

Leukemia is one of chronic diseases that require long treatment. For parents of children with chronic diseases, the presence of disease itself can be a greater stressor in care when compared to healthy children. Parents are required to manage disease and care of their children. They also need to continue doing the household chores, balancing work activities, and meeting the physical, social, and emotional needs of other family members. Caring for children with chronic conditions has more energy, time and financial demands (Cousino & Hazen, 2013; Kaakinen et al., 2010). Caring for children with chronic diseases relies on the importance of social support. Social support is one of the effected factors in a family coping in the management of cancer children (Fletcher et al., 2010). Social support is reported to have a statistically significant relationship with hopelessness and depression in parents of children with cancer. The more social support, the less hopelessness, and depression suffered by the parents (Bayat et al., 2008).

Social support has been defined as a resource provided by other persons (Altay et al., 2014). Social support is described as a "meta-construct" consisting of several sub-constructs. In some studies, social support includes two constructs, namely received social support and perceived social support (Haber et al., 2007). Measurements of received social support are designed to assess supportive behaviors that are provided to the recipients by their support networks. While measurements of perceived social support are designed to assess recipient's perceptions concerning the general availability of support and/or global satisfaction with support provided (Haber et al., 2007). Social support proposed in this study is perceived social support based on considerations that not all resources given to someone are perceived as social support by that person.

Parents whose children suffer from cancer describe the importance of support to ease their burden at the beginning of the diagnosis, during treatment, end of treatment, even after completing treatment. Adequate support can help families cope with various crises caused by the disease and its treatment (Björk et al., 2011; Björk et al., 2009; Earle et al., 2007; Sundler et al., 2013). Family, friends and significant others are the sources of support perceived by parents who have children with cancer (Altay et al., 2014). The kind of support chosen by parents of children with cancer was emotional support provided by partners and other family members, good communication with doctors, psychologists, nurses, other parents with similar situation, and other support groups. Parents also state the need to contact friends, relatives and other closest people (Kisić et al., 2012).

The Multidimensional Scale of Perceived Social Support (MSPSS) was designed to measure the adequacy of support from three resources: family, friends and significant others (Zimet et al., 1988). The MSPSS questionnaire was widely used in several studies to examine how families who care for sick family members perceive the social support from their family, friends and closest people (Altay et al., 2014; Bayat et al., 2008; Larsen et al., 2013; Winahyu et al., 2015). Furthermore, the questionnaire was used to assess social support perceived by parents of the three sources.

Parents' perceptions of social support can be affected by several factors. The most important factors are family income and education level (Larsen et al., 2013). A study conducted by Altay et al. (2014) showed that the shorter the duration of the disease, the higher the total social support scores of parents who had cancer children. The study results also showed that a lower mean total scale score was found in parents who stated that their expenditure was higher than their income. Another study conducted by Rosenberg-Yunger et al. (2013) stated that single parents need social-emotional, practical and financial support to assist them in taking care their children.

Nurses are health care provider who has the longest interaction with children and families. Nurses can be a consultant on the difficulties of social support of the parents of children with leukemia. It is important for nurses to identify the social support perceived by parents to support children's and family health. Nurses also need to examine the factors at risk in parents who have low social support so that interventions can be carried out to provide adequate social support to parents. This study aims to examine the perceptions of social support perceived by parents of children with leukemia using the MSPSS. This study also focuses on examining the relationship between the total scale scores of perceived social support and the characteristics of parents and children.

METHODS

Study design

This was a quantitative study with cross-sectional design approach.

Setting

This study was conducted in the nursing children ward and polyclinic of two general hospitals in Bandung from 18 April 2018 to 1 June 2018. The hospital is a referral hospital which has sufficient resources to provide treatment for children with cancer.

Sample

The number of samples were calculated using a cross-sectional study sample calculation formula $n = \frac{N \times Z\alpha^2 p q}{d^2 \times (N-1) Z\alpha^2 p q}$ (Nursalam, 2013) with $p=50\%$ (unknown), $q=1-p$ (100 %-p), $Z\alpha 0.05 = 1.96$, $d = 0.1$, $N = 291$. Based on the calculation, the minimum samples were 100 respondents. One hundred and four parents joining this research were chosen by purposive sampling technique. The inclusion criteria of this study were: mother or father of more than 18 years old, having leukemia children 3-18 years aged, the main caregivers in the family, living with their children, and was able to read and write. The exclusion criteria were: mother or father having more than one child with chronic disease, and having children with leukemia accompanied by developmental delay.

Instrument

This study used two instruments, namely demographic questionnaire and the Multidimensional Scale of Perceived Social Support (MSPSS). Questions about demographic characteristics included characteristics of children (age, sex, length of time

diagnosed) and characteristics of parents (age, sex, education level, parents' employment status, family income, and marital status).

The MSPSS consisted of 12 items assessing perceived social support of the parents from significant others (items 1, 2, 5, and 10), family (items 3, 4, 8, and 11) and friends (items 6, 7, 9, and 12) (Zimet et al., 1988). Each item was graded from 1 to 7. The participant could give a minimum of 1 point which means he/she does not agree, and a maximum of 7 points which means he/she agrees. To calculate mean scores, significant other subscale: sum across items 1, 2, 5, & 10, then divided by 4; family subscale: sum across items 3, 4, 8, & 11, then divided by 4; friend subscale: sum across items 6, 7, 9, & 12, then divided by 4. Total Scale: sum across all 12 items, then divided by 12. The range of scores based on the questionnaires was 1-7. A high score means a high level of perceived social support (Zimet).

The use of the MSPSS instrument in this study was an adaptation of the Indonesian version from the research of Winahyu et al. (2015) with permission. The Cronbach's alpha reliability coefficient was 0.903 and the correlation coefficient (*r*) was 0.489-0.781. Validity and reliability tests were conducted on 30 respondents before data collection.

Ethical consideration

Before collecting data, the researcher conducted ethical clearance from the Research Ethics Committee of Padjadjaran University Bandung on 29 March 2018 number: 253 / UN6.KEP / EC / 2018. The respondents who met the inclusion criteria were offered to be the participants of the study. The participation was voluntary. The respondents were asked to fill out a questionnaire provided by the researcher. For the confidentiality purpose, the researcher did not display information about identity, both name and address of the respondent in the questionnaire. The researchers used initials or identification numbers as a substitute for the identity of the respondents. The study was conducted after obtaining permission

from the head of two general hospitals. The author confirmed that all respondents have been well informed regarding the procedure of the study and have provided consent to participate in this study.

Data analysis

Descriptive analysis was carried out to the mean and standard deviation for continuous variables, and frequency and percentage for categorical variables. Normality test used was Kolmogorov-Smirnov. The results of the normality test showed that the dependent variable (social support) is not normally distributed. The bivariate analysis used were Mann-Whitney U, Kruskal-Wallis and Spearman test. Mann-Whitney U is used to compare scores of dependent variables that are not normally distributed with ordinal 2 groups independent variables. Meanwhile, Kruskal-Wallis is used if there were 3 groups. Spearman Test was used to examine correlation between dependent variables that were not normally distributed with independent variables.

RESULTS

Table 1 showed the characteristics of children and parents. The age of the children in this study ranged from 3 to 16.4 years, with the mean of age of 8 years. There were slightly more boys (51%) than girls (49%). The length of time after diagnosis ranged from 3 to 60 months, with the mean time of 15.5 months. The age of parents ranged from 21 to 58 years, with the mean age of 37.9. The majority of respondents were women (83.7%) or mothers of the children. Nevertheless, there were also some males or fathers acted as the primary caregivers of children (16.3%). Most parents did not work (64.4%) as they were housewives. The majority of parents had primary education level (60.6%) with income less than Rp. 1,500,000 every month. The majority of parents are married (86.5%), and only a small percentage of parents were single parents (13.5%).

Table 1 Descriptive Characteristic of Children and Parents (n=104)

Characteristics	n(%)	M±SD (Min-Max)
Child's Age (year)		8±4.2 (3 – 16.4)
Parent's Age (year)		37.9±7.4(21-58)
Length of time diagnosis (month)		15.5±13.2 (3 – 60)
Child's Sex		
Male	53(51)	
Female	51(49)	
Parents' Sex		
Male	17(16.3%)	
Female	87(83.7%)	
Parents Education		
Primary Education	63(60.6)	
Secondary Education	33(31.7)	
High Education	8(7.7)	
Parent's Employment Status		
Unemployed	67(64.4)	
Employed	37(35.6)	

Characteristics	n(%)	M±SD (Min-Max)
Family Income		
< Rp 1.500.000	48(46.2)	
Rp 1.500.000 – 2.500.000	15(14.4)	
Rp 2.500.000 – 3.500.000	21(20.2)	
> Rp 3.500.000	20(19.2)	
Parent's Marital Status		
Divorced/Single Parent	14 (13.5)	
Married	90(86.5)	

Description: n = number, % = percentage, M = mean, SD = standard deviation

Table 2 Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents (n= 104)

Variable	Mean	SD	Range ^a	Range ^b
Subscales:				
Significant Others	5.96	0.45	4.50-7	1-7
Family	6.06	0.46	5.00-7	1-7
Friend	5.20	1.02	2.00-7	1-7
Total Scale	5.74	0.48	4.33-7	1-7

Range ^a= Range of score based on sample's responses | Range ^b= Range of score based on the questionnaires

The total scale score as shown in **Table 2** is 5.74 ± 0.48 (min 4.33 – max 7). The family sub-scale score is the highest in comparison to the scores of sub-scale significant other and friends. While **Table 3** showed the MSPSS total scale scores based on the child's

age, the parent's age, and length of time of diagnosis of leukemia. There was no statistically significant correlation between the MSPSS total scale scores with child's and parent's age and the length time of diagnosis ($p > 0.05$).

Table 3 Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents and Child's Age, Parent's Age and Length of Time of Diagnosis (n= 104)

Characteristics	Perceived Social Support	
	<i>r</i>	<i>p value</i>
Child's Age	-0.050	0.611
Length of Time of Diagnosis	0.080	0.417
Parent's Age	0.017	0.862

Note: analysis using Spearman test

Table 4 Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents and Child's Sex, Parent's Sex, Parent's Employment, and Parent's Marital Status (n= 104)

Characteristics	Perceived Social Support			
	<i>n</i>	<i>M±SD</i>	<i>U</i>	<i>p value</i>
Child's Sex			1245.000	0.486
Male	53	5.80±0.49		
Female	51	5.67±0.46		
Parent's Sex			564.000	0.120
Male	17	5.55±0.57		
Female	87	5.78±0.45		
Parent's Employment Status			1048.500	0.192
Employed	37	5.67±0.41		
Unemployed	67	5.67±0.50		
Parent's Marital Status			438.500	0.066
Married	90	5.77±0.49		
Divorced/Single Parents	14	5.57±0.38		

Note: analysis using Mann-Whitney U

Based on **Table 4** above, there were no statistically significant differences in MSPSS total scale scores of parents based on child's and parent's sex, parent's employment status, and parent's marital status ($p > 0.05$). And **Table 5** shows that there were

significant differences in MSPSS total scale scores of parent based on parent's education and family income ($p < 0.05$). The higher education and income of parents, the higher social support perceived by the parents.

Table 5 Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents and Parent's Education and Family Income (n= 104)

Characteristics	Perceived Social Support			
	<i>n</i>	<i>M±SD</i>	<i>K-W</i>	<i>p value</i>
Parents Education				
Primary Education	63	5.68±0.42	9.539	0.008
Secondary Education	33	5.73±.054		
High Education	8	6.23±.043		
Family Income				
< Rp 1.500.000	48	5.66 ±0.45	11.175	0.011
Rp 1.500.000 – 2.500.000	15	5.85±0.40		
Rp 2.500.000 – 3.500.000	21	5.63±0.59		
>Rp 3.500.000	20	5.97±0.42		

Note: analysis using Kruskal-Wallis

DISCUSSION

This study showed the total scale score of social support of parents of children with leukemia measured by the Multidimensional Scale of Perceived Social Support (MSPSS) 5.74 ± 0.48 (min 1, max7). Zimet classified the mean scores of 5.1 to 7 as high support. The highest subscale score was on family support (6.06 ± 0.46). The results in the study were different from previous studies conducted by Altay et al. (2014) in Turkey which showed that the score of parents of children with cancer was 51.18 ± 25.30 (min. 12, max. 84) and the highest subscale score was significant other support (19.97 ± 10.56) (min. 4, max. 28). The perceived social support of parents classified moderate support.

The high social support perceived by parents in this study is probably related to the socio-cultural conditions. Glazer (2006) showed that perceptions of social support can differ from one culture to another. There is indeed a different culture between Bandung and another region in West Country. Based on the characteristics of Indonesian culture in general, communities in Indonesia have high cooperation and family culture, which resulted on high support perceived by parents.

Parent's education and family income were other factors affecting parents' perceptions of social support in this study. The total subscale score of perceived social support in parents with a low educational level was lower in comparison to parents who were middle and high educated. Statistically, this study found the value was significant ($p < 0.05$). Most of the respondents in this study had completed formal education up to elementary and junior high school (60.6%). Parental education influences in health-seeking behavior (Rabbani & Alexander, 2009). Health professionals can be a source of social support needed by parents. One of supports needed by parents of children with cancer was emotional support provided by health professionals such as doctors, psychologists,

nurses and support groups from the parent with the same experience (Kisić et al., 2012).

There was a statistically significant difference between the total scale score of perceived social support of parents with low income (<Rp.1.500.000) and the level of income above it ($p < 0.05$). The higher family income, the more social supports perceived by parents. The results of this study were supported by previous studies conducted by Altay et al. (2014) that the family income was a risk factor of parent social support. The total score of social support perceived by parents was lower in parents who reported more expenses than income. Low family income levels, receiving support, and educational level were risk factors affecting access to care (Larsen et al., 2013).

Child's and parent's age in this study were not statistically significant to the total scale of perceived social support of parents with leukemia ($p > 0.05$). These results were supported by the research conducted by Altay et al. (2014) showed there was no significant difference between social support and age. The length of diagnosis in this study was not statistically significant to the perceived social support of parents with leukemia ($p > 0.05$). The results of these studies were not supported by the research conducted by Altay et al. (2014) which showed that perceived social support was negatively correlated with the duration of illness and statistically significant correlation ($r = -0.272$, $p = 0.01$). The total scale score increased as the duration of the disease got shorter (Altay et al., 2014).

The child's and parent's sex, parent's employment, and parent's marital status were not statistically significant to the total scale scores of parent's perceived social support ($p > 0.05$). This was supported by the research conducted by Altay et al. (2014) that showed that there was no difference in social support scores based on sex. Although there were differences in scores between perceived social support of single parents and married parents,

but it was not statistically significant ($p=0.06$). Previous research showed that single parents had difficulty in managing their child's disease. It was caused by a lack of emotional and financial support as they are looking after their ill children (Crosier et al., 2007; Mullins et al., 2010; Wiener et al., 2013).

There is surely a limitation in conducting this study. As it was conducted at two hospitals in Bandung, the result of this study could not be generalized. Meanwhile, the strongest aspect of this study is that it is the first study in Indonesia, especially in Bandung that identifies perceived social support from family, friends and significant other parents of children with leukemia. This study shows that support from family was the most perceived by parents. Culturally, the family system in Indonesia is very close. If a child gets sick, all of the family will take care of the child. Grandmothers, grandfathers, uncles, aunts, and other siblings help parents taking care their sick children. Future studies are recommended to add larger samples and are conducted in different cultures.

CONCLUSION

This study has shown that support from the family is the greatest support perceived by parents. The family has an important role in helping parents dealing with their child's illness. Nurses need to emphasize the role of the family in providing support for the parent by utilizing family support in dealing with childhood leukemia. Parent's education and income are factors that affected perceived social support. Nurses play an important role in risky groups by providing information for the family, empowering families to take advantage of the support they have and look for support outside the family such as sources of family financial support related to treatment, utilization of cancer foundations, support groups and others.

Declaration of Conflicting Interest

The author declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

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References

- Altay, N., Kilicarslan, E., Sari, Ç., & Kisecek, Z. (2014). Determination of social support needs and expectations of mothers of children with cancer. *Journal of Pediatric Oncology Nursing*, 31(3), 147-153. <https://doi.org/10.1177/1043454213520471>
- American Cancer Society. (2016). Leukemia in children. Retrieved from <https://www.cancer.org/cancer/leukemia-in-children.html>.
- Bayat, M., Erdem, E., & Gül Kuzucu, E. (2008). Depression, anxiety, hopelessness, and social support levels of the parents of children with cancer. *Journal of Pediatric Oncology Nursing*, 25(5), 247-253. <https://doi.org/10.1177/1043454208321139>
- Björk, M., Nordström, B., Wiebe, T., & Hallström, I. (2011). Returning to a changed ordinary life—families' lived experience after completing a child's cancer treatment. *European Journal of Cancer Care*, 20(2), 163-169. <https://doi.org/10.1111/j.1365-2354.2009.01159.x>
- Björk, M., Wiebe, T., & Hallström, I. (2009). An everyday struggle—Swedish families' lived experiences during a child's cancer treatment. *Journal of Pediatric Nursing*, 24(5), 423-432. <https://doi.org/10.1016/j.pedn.2008.01.082>
- Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, 38(8), 809-828. <https://doi.org/10.1093/jpepsy/jst049>
- Crosier, T., Butterworth, P., & Rodgers, B. (2007). Mental health problems among single and partnered mothers. *Social Psychiatry and Psychiatric Epidemiology*, 42(1), 6-13. <https://doi.org/10.1007/s00127-006-0125-4>
- Earle, E., Clarke, S., Eiser, C., & Sheppard, L. (2007). 'Building a new normality': mothers' experiences of caring for a child with acute lymphoblastic leukaemia. *Child: Care, Health and Development*, 33(2), 155-160. <https://doi.org/10.1111/j.1365-2214.2006.00638.x>
- Fletcher, P. C., Schneider, M. A., & Harry, R. J. (2010). How do I cope? Factors affecting mothers' abilities to cope with pediatric cancer. *Journal of Pediatric Oncology Nursing*, 27(5), 285-298. <https://doi.org/10.1177/1043454209360839>
- Glazer, S. (2006). Social support across cultures. *International Journal of Intercultural Relations*, 30(5), 605-622.
- Haber, M. G., Cohen, J. L., Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology*, 39(1-2), 133-144. <https://doi.org/10.1007/s10464-007-9100-9>
- Hastuti, A. (2019). Jumlah pasien kanker yang dirawat inap di RSHS Bandung meningkat tajam [The number of cancer patients hospitalized in RSHS Bandung has increased sharply]. Retrieved from http://rri.co.id/bandung/post/berita/629058/seputar_jabar/jumlah_pasien_kanker_yang_dirawat_inap_di_rshs_bandung_meningkat_tajam.html
- Hockenberry, M. J., & Wilson, D. (2013). *Essential of Pediatric Nursing* (9th ed.). St. Louise Missouri: Elsevier.
- Kaakinen, J. W., Duff, V. G., Coehlo, D. P., & Hanson, S. M. H. (2010). *Family health nursing* (4th ed.). Philadelphia: F. A. Davis Company.
- Kisić, T., Konstantinidis, N., Kolarović, J., & Kačanski, N. (2012). Importance of psychological support for families of children with cancer. *Medicinski Pregled*, 65(5-6), 223-227. <https://doi.org/10.2298/mpns1206223k>
- Larsen, H. B., Heilmann, C., Johansen, C., & Adamsen, L. (2013). Socially disadvantaged parents of children treated with allogeneic haematopoietic stem cell transplantation (HSCT): Report from a supportive intervention study, Denmark. *European Journal of Oncology Nursing*, 17(3), 302-310. <https://doi.org/10.1016/j.ejon.2012.08.003>
- Ministry of Health of the Republic of Indonesia. (2015). *Cancer situation*. Jakarta: Data Center and Information, Ministry of Health of the Republic of Indonesia.
- Mullins, L. L., Wolfe-Christensen, C., Chaney, J. M., Elkin, T. D., Wiener, L., Hullmann, S. E., . . . Junghans, A. (2010). The relationship between single-parent status and parenting capacities in mothers of youth with chronic health conditions: The mediating role of income. *Journal*

- of *Pediatric Psychology*, 36(3), 249-257. <https://doi.org/10.1093/jpepsy/jsq080>
- Nursalam. (2013). *Metodologi penelitian ilmu keperawatan [Nursing research methodology]*. Jakarta: Salemba Medika.
- Rabbani, A., & Alexander, G. C. (2009). The association between family structure, reports of illness and health care demand for children: evidence from rural Bangladesh. *Journal of Biosocial Science*, 41(5), 645-659. <https://doi.org/10.1017/s0021932009990058>
- Rosenberg-Yunger, Z. R., Granek, L., Sung, L., Klaassen, R., Dix, D., Cairney, J., & Klassen, A. F. (2013). Single-parent caregivers of children with cancer: factors assisting with caregiving strains. *Journal of Pediatric Oncology Nursing*, 30(1), 45-55. <https://doi.org/10.1177/1043454212471727>
- Siegel, R. L., Miller, K. D., and Jemal, A. (2017). "Cancer Statistics, 2017". *CA: A Cancer Journal For Clinicians*, 67(1), 7-30. <https://doi.org/10.3322/caac.21387>
- Sundler, A. J., Hallström, I., Hammarlund, K., & Björk, M. (2013). Living an everyday life through a child's cancer trajectory: families' lived experiences 7 years after diagnosis. *Journal of Pediatric Oncology Nursing*, 30(6), 293-300. <https://doi.org/10.1177/1043454213513837>
- Wiener, L., Pao, M., Battles, H., Zadeh, S., Patenaude, A. F., Madan-Swain, A., . . . Group, L.-P. S. (2013). Socio-environmental factors associated with lone parenting chronically ill children. *Children's Health Care*, 42(3), 264-280.
- Winahyu, K. M., Hemchayat, M., & Charoensuk, S. (2015). Factors affecting quality of life among family caregivers of patients with schizophrenia in Indonesia. *Journal of Health Research*, 29(1), 77-82. <https://doi.org/10.14456/jhr.2015.52>
- Zimet, G. D. Multidimensional scale of perceived social support (MSPSS). Retrieved from https://docs.wixstatic.com/ugd/5119f9_2f88fadcd382463daf5821e8af94a865.pdf
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30-41.

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ORIGINAL RESEARCH

KNOWLEDGE, PERCEPTION, AND BURDEN OF FAMILY IN TREATING PATIENTS WITH SCHIZOPHRENIA WHO EXPERIENCE RELAPSE

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Abstract

Background: Schizophrenia is a mental disorder with a high incidence and relapse due to a lack of family support. Families do not understand how to treat patients with schizophrenia. There are several factors related to the family's abilities in treating patients with schizophrenia, there are the level of family's knowledge, perception, and burden.

Objective: This study aimed to describe the knowledge, perception and burden of family in treating patients with schizophrenia who experience a relapse.

Methods: The research used descriptive quantitative method. Samples were selected by consecutive sampling technique and obtained 100 respondents. Data were collected by a questionnaire consisting of family knowledge and perception developed by the researcher, and Zarit Burden Interview scale was used to measure the family burden. Data were analyzed using percentages, score T, and the Zarit Burden Interview analysis.

Results: Findings showed that 31 respondents (31%) had good knowledge, 42 respondents (42%) had sufficient knowledge, and 27 respondents (27%) had insufficient knowledge. In terms of perception, 66 respondents (66%) had a positive perception and 33% had a negative perception. In addition, 42 respondents (42%) had moderate to heavy burden levels, 23 respondents (23%) had a very heavy level of heavy burden, and 3 respondents (3%) with very heavy levels of burden.

Conclusions: Based on the results, it is necessary to increase the frequency of health education for the families. In addition, it is also important to hold a sharing program between families to reduce family burden.

KEYWORDS

family's burden; knowledge; perception; schizophrenia

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INTRODUCTION

Schizophrenia has been known as a severe and chronic mental disorder that affects all aspects of the life of the sufferer ([Suryani et al., 2013](#)), because there was a group of psychotic symptoms that affected various areas of individual functioning, including thinking, communicating, receiving and interpreting reality, feeling and showing emotions, and behaving socially acceptable ([Stuart, 2009](#)). Data from the World Health Organization (WHO) showed that people with mental disorders diagnosed with schizophrenia were around 24 million worldwide ([Who, 2014](#)). While the prevalence of schizophrenia in Indonesia showed an increase from 1.7 to 7 per mile ([Riskseddas, 2018](#)). Furthermore, data in Indonesia had been a shifted, schizophrenia usually

occurred in the age of around 18-45 years changed to a younger age of 11-12 years ([Arif, 2006](#)).

Schizophrenia is a disease that needs serious attention from the government because of its impact on the state's burden, as a result of the patient's unproductivity and ongoing medical costs ([Suryani, 2015](#)). Based on a recent study, the prevalence of relapse in people with schizophrenia was in the range of 50-92% globally ([Weret & Mukherjee, 2014](#)). [Keliat \(2011\)](#) explained several factors affected patient relapse, they were patients, doctors, nurses, and families. Families had a very important role in caring for family members with mental illness and providing support during the recovery period ([Sadock & Sadock, 2010](#)).

[Berglund et al. \(2003\)](#) stated that the family's ability in caring for patients with schizophrenia might reduce the percentage of relapse within a year. The ability of the family in caring for patients with schizophrenia is strongly influenced by several factors. These factors were family's knowledge, perception, and burden ([Chien & Lee, 2002](#); [Knock et al., 2011](#)). It was important for families to have knowledge related to the concept of schizophrenia, appropriate treatment methods, and treatment that should be done ([Suryani, 2015](#)). Perception was the identification and interpretation of stimulus based on information received ([Stuart, 2009](#)). Perception in the family was useful to determine the care to the patient ([Dalky, 2012](#)). The level of family burden also greatly influences the family's role in caring for patients with schizophrenia. According to [Adeosun \(2013\)](#), it was known that a high family burden cause the family cannot performed their role properly.

Based on an interview conducted on January 2014 at the X Mental Hospital to the nurses in the outpatient unit, it was revealed that the high rate relapse of patients with schizophrenia could be caused by a lack of family's ability in caring for their family members. The family assumes that patients who have been allowed to go home after hospitalization means that they have been fully recovered and no longer need to take medicine. This assumption might derive from the lack of family's knowledge and perception. Whereas according to [Motlova et al. \(2006\)](#) the key in preventing relapse in patients with schizophrenia was adherence to long-term treatment and it is influenced by knowledge and perception about the treatment.

In addition, researchers interviewed 3 families of patients with schizophrenia who took their family members for treatment due to relapse. Based on the interview it was found that the family had been felt tired and angry because the patient had relapsed several times. Further the family added, that the family did not understand how to treat patients with schizophrenia properly to prevent relapse. The family explained that sometimes families feel burdened with the responsibility of caring for patients, because family activities were disrupted. Besides being burdened in activities, the family was also burdened in economic because they have to spend large amounts of money for treatment. Therefore, families felt depressed and lack of motivation in caring for the patients. Further based on observations in the outpatient unit, it was identified that most families only waited outside the examination room when the patient was being examined, so the families could not take the opportunity to discuss with the doctor about the patient's progress. This might influences the family's knowledge and perception regarding caring to the patients. Therefore, it is important to find out the knowledge, perception and also family's burden in caring for patients with schizophrenia who experience relapse as the consideration for future appropriate interventions.

METHODS

Study Design and Sample

The research design was quantitative-descriptive design. The variables of this study were the level of family knowledge, family

perceptions, and the level of family burden. The samples in this study were taken by consecutive sampling technique. The respondents were the families of patients with schizophrenia who took patients to the outpatient unit at Hospital X, with the inclusion criteria of the respondents were 1) families who live with the patients; 2) respondent is patient's family; and 3) one of the respondent's family is patient with schizophrenia who experience relapse. Data collection was carried out within one month, and was obtained 100 respondents. This study was conducted in July 2014.

Instrument

The data were collected using questionnaires. The questionnaire was made into three parts, including instruments that measure family knowledge, perceptions and burdens. The family knowledge and perception questionnaire was compiled by researchers based on various relevant sources of theory. The knowledge questionnaire measured about the concept of schizophrenia and how to treat patients with schizophrenia, while the instrument for measuring the level of family burden using a Zarit Burden Interview which was used to measure the family burden in caring for the elderly ([Bédard et al., 2001](#)). This instrument was translated through back translation and modified by researchers so that it was in accordance with the research. The results of the validity test for knowledge instruments were 0.313 - 0.904 and perceptions were 0.672 - 0.765 while the reliability for knowledge, perception and zarit burden interview were 0.781, 0.765, and 0.830 ([Yap, 2010](#)) consecutively.

Data Analysis

Data were analyzed using descriptive quantitative method with distribution frequencies. Data analysis to measure perception factors using T scores, because the number of items from each aspect is different. The perceptions using T score categorized as: 1) T scores > 31.2, it means respondents had positive perception and 2) T scores ≤ 31.2, it means respondents had negative perception. While family burden was analyzed used the standard instrument of Zarit Burden Interview which categorized as: 1) scores 0 – 19 as no/minimal burden; 2) scores 20 – 38 as moderate to severe burden; 3) scores 39 – 57 as severe to very severe burden; scores 58 – 84 as extremely severe burden and knowledge were calculated using the percentage categorized into good (percentage of correct answers 76 – 100%); moderate (percentage of correct answers 56 – 75%); and low (percentage of correct answers less than 55%).

Ethical Consideration

All respondents involved in the study were given information about research and has agreed to participate in research voluntarily. In addition, the research process has obtained research approval and permission from the West Java Provincial Mental Hospital by letter No. 423.4 / 8920 / Pendik / 2013.

RESULTS

Table 1 shows more than a half of respondents are males; most of them are in early and late adult development. Nearly two fifths of the respondents are parents with the primary level of education,

and three fifths of the respondents are working. The duration of illness is 1 to 5 years for just under a half of patients' and all of the patients had experienced relapse between 1 to 5 times.

Table 1 Respondents' Characteristics (n=100)

Characteristics	Frequency	Percentage (%)
Gender		
Male	58	58
Female	42	42
Age (years old)		
18-25	5	5
26-40	36	36
41-60	52	52
> 60	7	7
Family Relationship with Patients		
Parents	39	39
Husband/Wife	24	24
Brother/sister	29	29
Child	8	8
Education Level		
Primary Education (SD/SLTP)	44	44
Secondary Education (SLTA/SMA)	43	43
Higher Education	13	13
Working Status		
Working	64	64
Not working	36	36
Duration of Illness (Years)		
1-5	47	47
6-10	35	35
>10	18	18
Frequency of Hospitalization		
Never	25	25
1-5 times	64	64
6-10 times	7	7
>10 times	4	4

Table 2 Frequency Distribution of Families Knowledge to Caring for Patients with Schizophrenia (n=100)

Characteristics	Frequency (f)	Percentage (%)
Good	31	31
Moderate	42	42
Low	27	27
Total	100	100

Table 2 shows that a significant proportion of family has moderate to good knowledge to caring for patients while those who lack knowledge in treating patients are only less than one third. While **Table 3** shows that more than two-thirds of families have a positive perception of schizophrenia and only less than one-third of respondents have negative perceptions.

Table 3 Frequency Distribution of Families Perception about Schizophrenia (n=100)

Characteristics	Frequency (f)	Percentage (%)
Positive	66	66.00
Negative	34	34.00
Total	100	100.00

Table 4 Frequency Distribution of Family Burden in Caring for Patients with schizophrenia (n=100)

Characteristics	Frequency (f)	Percentage (%)
No/minimal burden	32	32
Moderate to severe burden	42	42
Severe to very severe burden	23	23
Extremely severe burden	3	3
Total	100	100.00

Based on **Table 4**, almost one third of families have a minimum burden and more than two thirds have moderate burden to extremely severe burden.

DISCUSSION

There were several factors that influence the family's ability in caring for family member who suffer from schizophrenia. The first factor is the knowledge of the family about the illness. In this study it was found that there were 31 respondents (31%) who had good knowledge, 42 respondents (42%) who had moderate knowledge, and 27 (27%) respondents had low knowledge. Having good knowledge is very important for family in determining how to care for patients. As revealed by [Li et al. \(2007\)](#) that providing knowledge to families about schizophrenia was important, especially for families with low levels of education. There were several reasons why many respondents has moderate and low level of knowledge. According to [Li et al. \(2007\)](#) one of the factors that influenced a person's level of knowledge was the level of education. Nearly half of the respondents had primary education levels (44%), and as many as 43% respondents had secondary education levels, while only a small proportion of respondents who has high level of education (13%). Based on these data it can be seen that the education level of most respondents was still low. [Yusuf et al. \(2009\)](#) explained that the level of education determines how families care for the patients and to prevent patients from relapse. Low education level of respondents in this study may lead to the lack of initiative of the respondents in seeking information relating to the diagnosis and treatment of the patients, this statement was supported by the research results of [Adeosun \(2013\)](#).

In general, the level of families education determine the families response in receiving information related to the recovery of patients, and will influence their ability in caring for the patients ([Suryani et al., 2016](#)). Knowledge about diagnoses, treatment, and

patient care are very important for the family ([Li et al., 2007](#)). This knowledge is not only important for the preventing patient relapse, but also important for the families who care for them. Good knowledge reduced the families level of stress when treating for the patients and will further improve the quality of care ([Chien & Lee, 2002](#)).

On the other hand, most of the age of the respondents was in the late adult range of 41 to 60 years (52%). [Chien et al. \(2004\)](#) explained that at this age a person has experienced physical and psychological deterioration, so that respondents became more passive in seeking information about patient's illness. Furthermore, this age is also called transitional age, at this age a person is more concerned with his own health status so there is not enough time to find information about schizophrenia. According to [Kate et al. \(2013\)](#), family caregiver with productive age had better experiences in treating patients with schizophrenia compare to nonproductive ones.

The Mental Hospital where this study was conducted, has been had a counseling program for families and patients about mental illness, but counseling about schizophrenia itself was very rare. Health education was always given to the families of patients by nurses when doing assessment. However there were some families who did not accompany patients when the health education was given. When the doctor provides consultation to patients and families, information about the diagnosis and treatment for the patients were provided. However, it was difficult to understand by the patients and families. So, it is necessary to provide a planned psycho education for the families of patients to overcome various psychosocial problems due to their lack of knowledge about schizophrenia ([Suryani et al., 2016](#)).

Based on analyzing the incorrect answer by most respondents, it was found that the concept of relapse; and what the family must do if the patient has a relapse was the most wrong answered by the respondent. The steps that must be carried out by the families when the patient have relapse are: first, bring the patient to a calm place and make him relaxed, second, assessing what is experienced by the patient, third, giving pharmacological therapy according to his schedule, and fourth bring the patient to treatment immediately ([Stuart, 2009](#)). However, the answer of most respondents was directly gave the drug to patients, even if it was not a medication schedule. That means the respondent's knowledge regarding the actions that must be taken when the patient deterioration was very lacking, this could be caused by a less of counseling about relapse. This condition can strengthen the reason for the frequent of patients experiencing relapse in the past year. Based on the data there were 86 respondents (86%) who often experienced relapse. In addition, from the study, it can be seen that the education background of the respondents was low and most of them were elderly and had experienced physical deterioration, thus the method of health education that had been carried out by the hospital was less effective for respondents with these characteristics.

Beside knowledge, family's perception also has important aspect in caring for family's member with schizophrenia. Based on the results of the study, 66 respondents (66%) had a positive

perception and 34 respondents (34%) had a negative perception. Positive perceptions of the respondents can be influenced by several factors such as acceptance to the patient's condition. This was indicated by the sincere love of the family while caring for the patient. This sincerity arises because most of the respondents are parents of the patients. This is related to affective function in the family, which is the basis of family strength. Affective functions in the family include nurturing, fostering, a balance of mutual respect, transition and identification, separation and coherence ([Friedman et al., 2010](#)). From the demographic data, it was found that the relationship between respondents and patients as parents was 39 respondents (39%). Sincere attention and affection from the family and the people closest to the patient will greatly help the healing process of the patients ([Sulistiyorini et al., 2013](#)). In addition to the acceptance of the patient's condition, perception is also influenced by the culture that develops in the community about schizophrenia. Culture in the community will shape the family mindset of caring for patients with schizophrenia. As there are some cultures that assume that the patient's illness is a cause by magical things or something, so it will not be recovered if taken to the doctor or to the hospital, except to the dukun (traditional healer) ([Suryani et al., 2013](#)). Such perceptions will cause the families provides inappropriate care to the patient. So that the patient difficult to recover and often experiences relapse ([Papastavrou et al., 2009](#)). According to [Dalky \(2012\)](#), there were several ways to improve families' perceptions in caring for patients with schizophrenia including sharing between family members, having faith in religion, praying, accepting the patient's condition, and having support from other families.

Although most respondents showed positive perceptions, there were still 21 respondents (21%) who had negative perceptions. Negative perceptions can occur due to a lack of information about schizophrenia. It could be cause by having wrong information about schizophrenia and its treatment. The level of education can affect people's perception. The education level of the respondents in this study was mostly low. [Srinivasan and Thara \(2001\)](#) found that people with a low level of education more often stated that the causes of schizophrenia were supernatural, while people with a high level of education could better understand about the causes of schizophrenia because they were able to access and receive information correctly.

Most families of people with schizophrenia have experienced burden in caring for the family's member with schizophrenia ([Suryani, 2015](#)). From the results of this study it was found that the level of burden with the highest percentage was moderate to severe burden. Some respondents even have severe burden. This level of severe burden can be related to the duration of illness, frequency of relapse, family relationships with the patient, and the occupational status of the respondent.

According to [Gutiérrez-Maldonado and Caqueo-Urizar \(2007\)](#), family burden was divided into 2 types, namely subjective and objective burden. Subjective burdens were feelings of stress, anxiety, confusion and loss. Whereas objective burden included economic burdens, family boundaries for socializing and activities, and a setback in inter-family relations ([Knock et al.,](#)

2011). Based on the research of Adeosun (2013), it was found that factors that might affect the level of family burden were the work status of a person, the age of the family caregiver, and the duration of patients' illness. Schulze and Angermeyer (2003) added that the developing of stigma in society also greatly affects the level of burden.

Based on the result of this study about the occupational status of the respondents, most of respondents (64%) had jobs and only a small portion of respondents (36%) who did not work. This means that the families had income to pay for the patient's treatment. In addition, most respondents were not burdened with costs, because there is health insurance namely Kartu Indonesia Sehat (Indonesia Health Card) for treatment in mental health hospital. However, families felt burden for having difficulty in managing time between working and caring for the patients. Adeosun (2013) stated that higher levels of burden were seen in family caregiver who works, because they had to divide the time between caring for patients and work. Because the family's obligation to care for the patient, many families felt that they were losing their normal lives, feeling that their own time was diminishing or not even there (Knock et al., 2011).

The duration of the illness can also increase the burden on respondents. Demographic data showed 47 patients (47%) had schizophrenia for 1-5 years, 35 patients (35%) for 6-10 years and 18 patients (18%) for > 10 years. Adeosun (2013) revealed that families became more afraid of their future lives due to chronic diseases of the patients because they took up most of their time to care for patients over a long period of time. Families must spend a lot of energy and set-aside time to treat patients for years. The age of most respondents in this study was in the old age range; this age is an age where there have been some physical and psychological deterioration. Respondents might have health problems, so they have limitations and feel heavy burdens in caring for the patients. Study by Chien et al. (2004) which aimed to measure the level of families' burden in caring for patients with schizophrenia showed that the level of burden was higher in families that have health problems, weak functions, and low social support from other family members is needed to participate in caring for patients, so the family burden is reduced and patient care becomes more optimal.

The families have been faced the burden on their own, because of the lack of support provided by the health care center or related hospital. Kertchok et al. (2011) explained that there was a need for programs from health workers, especially nurses, regarding intervention to families who care for patients with schizophrenia so that families would have a normal life. In addition, patients who often relapse also add to the burden of the family in caring for the patient (Farkhah et al., 2017). The results of the study showed that 86 patients often experienced relapse. Frequent relapse would make the families felt anxious, worried and depressed about the future of themselves and the patient (Chien et al., 2004).

Stigma from the community can also added burden to the family (Suryani, 2015). There were various stigmas arose from the public about schizophrenia (Suryani et al., 2016). Angermeyer

and Matschinger (2003) explained that there are 4 types of stigma namely interpersonal interaction, structural discrimination, a developing image of mental disorders, and social access. Stigma could interfere family's relationships with local communities so that families feel isolated (Suryani, 2015). The families considered that the patient was the cause of various problems. These condition made families felt anxious and worried about their own lives (Suryani, 2015). This was also supported by Christopher (2012) which stated that the majority of respondents in their study felt fear and anxiety about their health and their lives in the future. The conditions described above reinforce the results of this research in which the level of respondents' burden were at moderate to severe levels, and even very heavy burden. This was in accordance with the research conducted by Papastavrou et al. (2009) that found that 43% of respondents in his study had a high level of burden with a score of 24/42 using the Family Burden Scale (FBS).

Based on the results of the study, it can be seen that the factors of low knowledge and high family burden in treating patients were the most experienced factors in families of patients with schizophrenia. This showed that both of these factors could be the cause of relapse in patients with schizophrenia, so these need to be considered by nurses. Nurses need to assess family knowledge about patient care and provide education if family knowledge is low. As well as the burden of the family, assessment of the family burden needs to be done. Furthermore, the factors that influence the family burden are also important to be studied and examined through further research.

CONCLUSION

All patients with schizophrenia in this study experienced a relapse, and based on the research it was seen that family knowledge was inadequate in treating patients with schizophrenia, as well as family burden, most of which were at moderate and high levels, while the family's perception of schizophrenia is good.

Mental Hospital in the setting of study was expected to develop a mental health program to increase the optimal families' role in the family's daily life of patients with schizophrenia in the term of increasing knowledge and family's perception, by increasing regular counseling regarding patient diagnosis, treatment, the cause of relapse, and how to care for the patients at home, thus the family would have a good knowledge and a positive perception about schizophrenia. Moreover, the factors that influence the family burden are also important to be studied in further research.

Declaration of Conflict of Interest

The authors declare that there is no conflict of interest.

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Authors Contributions

All authors have contributed in the preparation of the manuscript. SS: Managing the research process, developing the idea for research proposal,

checking and finalizing manuscript before submitting it. EWN: Writing for research proposal, collecting and analyzing data. AN: collecting and analyzing data, and drafting manuscript.

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References

- Adeosun, I. I. (2013). Correlates of caregiver burden among family members of patients with schizophrenia in Lagos, Nigeria. *Schizophrenia Research and Treatment*, 2013. <https://doi.org/10.1155/2013/353809>
- Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, 108(4), 304-309. <https://doi.org/10.1034/j.1600-0447.2003.00150.x>
- Arif. (2006). *Skizofrenia memahami dinamika keluarga pasien [Schizophrenia understanding the dynamic of patient's family]*. Bandung: Refika Aditama.
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist*, 41(5), 652-657.
- Berglund, N., Vahlne, J. O., & Edman, Å. (2003). Family intervention in schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 38(3), 116-121. <https://doi.org/10.1007/s00127-003-0615-6>
- Chien, W.-T., & Lee, I. (2002). Educational needs of families caring for patients with schizophrenia. *Journal of Clinical Nursing*, 11(5), 695. <https://doi.org/10.1046/j.1365-2702.2002.00649.x>
- Chien, W.-T., Norman, I., & Thompson, D. R. (2004). A randomized controlled trial of a mutual support group for family caregivers of patients with schizophrenia. *International Journal of Nursing Studies*, 41(6), 637-649. <https://doi.org/10.1016/j.ijnurstu.2004.01.010>
- Christopher, J. H. (2012). *A psychosocial study of persons with chronic mental illness and family caregivers burden*. Retrieved from https://shodhganga.inflibnet.ac.in/bitstream/10603/8757/20/20_appendices.pdf
- Dalky, H. F. (2012). Perception and coping with stigma of mental illness: Arab families' perspectives. *Issues in Mental Health Nursing*, 33(7), 486-491. <https://doi.org/10.3109/01612840.2012.676720>
- Farkhah, L., Suryani, S., & Hernawaty, T. (2017). Faktor caregiver dan kekambuhan klien skizofrenia [Caregiver factors and schizophrenic clients recurrence]. *Jurnal Keperawatan Padjadjaran*, 5(1).
- Friedman, M. M., Bowden, V. R., & Jones, E. G. (2010). *Buku ajar keperawatan keluarga: Riset, teori, dan praktek [Family nursing teaching book: Research, theory, and practice]*. Jakarta: EGC.
- Gutiérrez-Maldonado, J., & Caqueo-Urizar, A. (2007). Effectiveness of a psycho-educational intervention for reducing burden in Latin American families of patients with schizophrenia. *Quality of Life Research*, 16(5), 739-747. <https://doi.org/10.1007/s11136-007-9173-9>
- Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Positive aspects of caregiving and its correlates in caregivers of schizophrenia: a study from north India. *East Asian Archives of Psychiatry*, 23(2), 45.
- Keliat, B. (2011). *Manajemen Kasus Gangguan Jiwa: CMHN Intermediate course [Case management of mental disorder]*. Jakarta: EGC.
- Kertchok, R., Yunibhand, J., & Chaiyawat, W. (2011). Creating a new whole: Helping families of people with schizophrenia. *International Journal of Mental Health Nursing*, 20(1), 38-46. <https://doi.org/10.1111/j.1447-0349.2010.00706.x>
- Knock, J., Kline, E., Schiffman, J., Maynard, A., & Reeves, G. (2011). Burdens and difficulties experienced by caregivers of children and adolescents with schizophrenia-spectrum disorders: A qualitative study. *Early Intervention in Psychiatry*, 5(4), 349-354. <https://doi.org/10.1111/j.1751-7893.2011.00305.x>
- Li, J., Lambert, C. E., & Lambert, V. A. (2007). Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. *Nursing & Health Sciences*, 9(3), 192-198. <https://doi.org/10.1111/j.1442-2018.2007.00327.x>
- Motlova, L., Dragomirecka, E., Spaniel, F., Goppoldova, E., Zalesky, R., Seleпова, P., ... Höschl, C. (2006). Relapse prevention in schizophrenia: Does group family psychoeducation matter? One-year prospective follow-up field study. *International Journal of Psychiatry in Clinical Practice*, 10(1), 38-44. <https://doi.org/10.1080/13651500500305424>
- Papastavrou, E., Charalambous, A., & Tsangari, H. (2009). Exploring the other side of cancer care: the informal caregiver. *European Journal of Oncology Nursing*, 13(2), 128-136. <https://doi.org/10.1016/j.ejon.2009.02.003>
- Riskesdas. (2018). *Hasil riset kesehatan dasar [Basic health research results]*. Retrieved from <http://labdata.litbang.depkes.go.id/menu-progress-puldata/progress-puldata-rkd-2018>
- Sadock, B., & Sadock, V. (2010). *Kaplan & Sadock buku ajar psikiatri klinik [Kaplan & Sadock clinical psychiatry teaching book]*. Jakarta: EGC.
- Schulze, B., & Angermeyer, M. C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine*, 56(2), 299-312. [https://doi.org/10.1016/s0277-9536\(02\)00028-x](https://doi.org/10.1016/s0277-9536(02)00028-x)
- Srinivasan, T., & Thara, R. (2001). Beliefs about causation of schizophrenia: Do Indian families believe in supernatural causes? *Social Psychiatry and Psychiatric Epidemiology*, 36(3), 134-140. <https://doi.org/10.1007/s001270050302>
- Stuart. (2009). *Principles and practice of psychiatric nursing* (10th ed.). Missouri: Elsevier.
- Sulistiyorini, N., Widodo, A., & Zulaicha, E. (2013). *Hubungan pengetahuan tentang gangguan jiwa terhadap sikap masyarakat kepada penderita gangguan jiwa di Wilayah Kerja Puskesmas Colomadu 1 [Relationship of knowledge about mental disorders and people's attitudes towards people with mental disorders in the working area]*

- of Public Health Center of Colomadu 1]. Surakarta: Universitas Muhammadiyah Surakarta.
- Suryani, S. (2015). Caring for a family member with schizophrenia: The experience of family carers in Indonesia. *Malaysian Journal of Psychiatry*, 24(1).
- Suryani, S., Welch, A., & Cox, L. (2013). The phenomena of auditory hallucination as described by Indonesian people living with Schizophrenia. *Archives of Psychiatric Nursing*, 27(6), 312-318. <https://doi.org/10.1016/j.apnu.2013.08.001>
- Suryani, S., Widiyanti, E., Hernawati, T., & Sriati, A. (2016). Psikoedukasi menurunkan tingkat depresi, stres dan kecemasan pada pasien tuberkulosis paru [Psychoeducation reduces depression, stress and anxiety in pulmonary tuberculosis patients]. *Jurnal Ners*, 11(1), 128-133.
- Weret, Z. S., & Mukherjee, R. (2014). Prevalence of relapse and associated factors in patient with schizophrenia at Amanuel Mental Specialized Hospital, Addis Ababa, Ethiopia: institution based cross sectional study. *International Journal of Interdisciplinary and Multidisciplinary Studies (IJIMS)*, 2(1), 184-192.
- WHO. (2014). Schizophrenia. Retrieved from <http://www.who.int/mediacentre/factsheet/fs397/en/>
- Yap, P. (2010). Validity and reliability of the Zarit Burden Interview in assessing caregiving burden. *Annals Academy of Medicine Singapore*, 39, 758-763.
- Yusuf, A. J., Nuhu, F. T., & Akinbiyi, A. (2009). Caregiver burden among relatives of patients with schizophrenia in Katsina, Nigeria. *South African Journal of Psychiatry*, 15(2). <https://doi.org/10.4102/sajpschiatry.v15i2.187>

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ORIGINAL RESEARCH

PERCEPTION OF NURSES IN DECISION-MAKING PROCESS IN PALLIATIVE CARE FOR PATIENTS WITH CANCER IN PUBLIC HEALTH CENTERS

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Abstract

Background: Nurses have a key role in promoting patients' involvement in decision-making process of palliative care to improve their dignity and satisfaction. However, there is a dearth of studies exploring this involvement, especially in public health centers in Indonesia.

Objective: This study aimed to explore the perception of nurses in decision-making process and to understand what type of decision-making made by health care providers in palliative care.

Methods: This was a descriptive explorative study with qualitative approach. Participants were selected using purposive and snowball sampling. Data were collected using Focus Group Discussion (FGD) and in-depth interview. Content analysis method by inductive approach was used for data analysis. Consolidated criteria for reporting qualitative research (COREQ) was also used.

Results: Eight themes emerged in this study, namely: (1) Collecting information about patients' current physiological condition, (2) Creating alternative strategies according to the patients' current physiological condition, (3) Establishing implementation type to be performed, (4) Providing information to the patients, (5) Discussing decision-making between patients and family, (6) Choosing/rejecting an action by patients, (7) Performing selected actions, and (8) Evaluating action. Three points that are different from the existing theory were: (i) there was a discussion between patients and family, (ii) the absence of the process of collecting information after a patient rejects to act, and (iii) there were three types of decision-making: paternalistic, shared, and informed decision-making.

Conclusion: This study serves as an input for nurses to pay more attention in decision-making process in palliative care in patients with cancer, and to encourage patients to give contribution in decision-making as part of shared decision-making.

KEYWORDS

decision-making; palliative care; public health center; cancer

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INTRODUCTION

Palliative care is an approach aimed at improving the quality of life on patients and families in dealing with problems related to threatening diseases, which include prevention and relief from suffering through identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems ([World Health Organization, 2017](https://www.who.int/news-room/fact-sheets/detail/palliative-care)). In recent years, palliative care has been increasingly recognized not only for cancer patients

but also for those with advanced diseases ([Sigurdardottir et al., 2014](https://doi.org/10.1186/s12913-014-0014-1)).

Based on the report of Basic Health Research in 2013, the prevalence of cancer in Indonesia was 1.4 per 1000 population ([Research and Health Development Board, 2013](https://www.bkph.go.id/publications)). The highest prevalence of cancer was in the Special Region of Yogyakarta

(DIY) amounted to 4.1 per 1000 population. There are four districts and one municipality in Yogyakarta ([Research and Health Development Board, 2013](#)), which the prevalence of cancer in Sleman District amounted to 6.1 per 1000 population that needs further attention.

Patients with cancer in need of palliative care are strongly encouraged to be involved in decision-making to improve their dignity and satisfaction ([Bélanger et al., 2014](#)). The individual right in decision-making is an integral part in treatment of cancer patients. Otherwise, making a decision with consideration from the family only or without patients' consent is a violation of the patient's right ([Chusairi, 2004](#)). Therefore, nurses become the key role in promoting an effective communication to increase patient's involvement in decision-making ([European Oncology Nursing Society, 2006](#)). As there is a dearth of knowledge exploring this issue especially in Indonesia, thus this study aimed to explore the perception of nurses in decision-making process and to understand what type of decision-making provided by health care professionals in palliative care in public health centers.

METHODS

Study Design

This was a descriptive explorative study with qualitative approach, which was conducted in Sleman District, Yogyakarta Indonesia between January and February 2015.

Participants

The target population of this study was nurses at public health centers in Sleman District, Yogyakarta. There were 25 public health centers with a total of 382 nurses. Samples were selected using purposive and snowball sampling, which consisted of 26 nurses. Inclusion criteria of the sample were: 1) nurses who did palliative care to patients with cancer, 2) nurses who had experiences in caring patients with cancer at least for two years, and 3) willing to participate in this study. Participants were selected purposively, striving for a mixture of gender, age, educational level, length of work, and specialty. At this stage, the head of administration of public health centers introduced the study to potential participants, which followed by the first author to check their eligibility. The process of selecting participants were: 1) The authors gathered information about public health centers from Department of Health in Sleman District, which had the highest patients with cancer, such as Public Health Center of Depok 1, Gamping 2, Seyegan, Godean 2, and Godean 1. However, those five public health centers were not all given palliative care due to referral condition and therefore they were excluded, 2) The authors selected the other public health centers that provide palliative care for patients with cancer, with a total of eight public health centers.

Data Collection

Focus group discussion (FGD) and in-depth interview were used for data collection. Participants of FGD were invited via letters and short message services to come to the Faculty of Medicine,

Public Health, and Nursing, Universitas Gadjah Mada in January 2015 in 11 participants, and participants of in-depth interviews were met at their workplace by an appointment between January and February 2015 in 15 participants. FGD and in-depth interviews were conducted by the first author (AF) who had no contact or no relationship with the participants prior to the interviews. FGD was done in 75 minutes, while in-depth interviews lasted between 20 and 60 minutes each. All interviews were audio-recorded to ensure that all communication was gathered. An interview guideline was made by the first author (AF), then developed and reviewed by nursing lecturer and a PhD student trained as a qualitative researcher (MSK). The interview guideline consisted of eleven questions regarding the decision-making process and the types of decision-making. Field notes were also made during and after the interviews. Data collection was completed after 15 interviews, which no new codes were found.

Data Analysis

Data were analyzed using a content analysis method with an inductive approach ([Elo & Kyngäs, 2008](#)). The audio-recorded interviews were transcribed verbatim in the Indonesian language by the first author (AF). The transcripts were then read line-by-line by the first author (AF) to check their accuracy. In addition, audit trail by an independent rater (NR) was performed by reading all transcripts. After reading line-by-line for coding development, meaningful sentences were marked for subsequent coding. All collected coding was grouped into several categories to form a theme. All codes were discussed with two authors (AF and MSK) and also an independent rater (NR). Session for categorization development was also held with two authors. Next, themes were developed from the categories. Finally, decision-making theory from [Mccullough et al. \(2010\)](#) and [Hancock and Easen \(2006\)](#) was used to interpret the data. Consolidated criteria for reporting a qualitative research (COREQ) was used to report the results of the study ([Tong et al., 2007](#)).

Ethical Consideration

This study has been approved by the Medical and Health Research Ethics Committee (MHREC), the Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, Indonesia (KE/FK/432/EC 2 May 2014), and the study permission was obtained from all public health centers. Prior to data collection, the participants received comprehensive information about the study procedures and protocols. They were also informed that they could withdraw at any time during or after the interview without any consequences. Once they agreed to be a part of the study, they signed an informed consent form.

RESULTS

Characteristics of Participants

As shown in the **Table 1**, the majority of participants in FGD were females (72.7%) with the average of age of 37.6 years. The majority of participants had educational background of Diploma degree (81.8%) with the average of working experience for 15.5 years.

Table 1 Characteristics of Participant for Focus Group Discussion

Participant Code	Gender	Age (Year)	Educational level	Length of work (Year)
F1	F	33	Diploma	10
F2	F	27	Diploma	4
F3	F	51	Bachelor	30
F4	F	33	Diploma	10
F5	F	32	Diploma	5
F6	F	38	Diploma	17
F7	F	39	Diploma	17
F8	M	46	Diploma	26
F9	M	39	Diploma	18
F10	M	30	Diploma	9
F11	F	46	Bachelor	25
F=72.7%, M=27.3%		Mean±SD (37.6±7.5)	Diploma=81.8%, Bachelor=18.2%	Mean±SD (15.5±8.7)

Table 2 Characteristics of Participants for In-Depth Interviews

Participant Code	Gender	Age (Year)	Educational level	Length of work (Year)
I1	F	29	Diploma	4
I2	F	29	Bachelor	4
I3	M	43	Assistant nurse	20
I4	F	33	Diploma	10
I5	F	45	Diploma	26
I6	F	25	Diploma	4
I7	F	52	Diploma	30
I8	F	45	Diploma	23
I9	F	39	Diploma	16
I10	F	46	Bachelor	25
I11	F	38	Diploma	17
I12	M	47	Diploma	24
I13	M	46	Diploma	26
I14	F	32	Diploma	10
I15	F	27	Diploma	3
F=80%, M=20%		Mean±SD (38.4±8.6)	Diploma=80%, Bachelor=13.3%, Assistant nurse= 6.7%	Mean±SD (16.1±9.6)

As shown in the **Table 2**, the majority of participants in in-depth interviews were females (80%) than males (20%). The average of age of all participants was 38.4%. There were three types of educational background of participants, including diploma, bachelor, and assistant nurses. The average of working experience was 16.1 years.

Analytical Findings

The themes emerged from analysis, namely: (1) collecting information about patient's current physiological condition, (2) creating alternative strategies according to the patient's current physiological condition, (3) establishing the types of implementation that should be performed, (4) providing information to patients, (5) discussing decision-making between patients and family; (6) choosing/rejecting action by patients, (7) performing selected actions, and (8) evaluating actions (see **Figure 1**). Those themes are illustrated below with exemplars from the informants' stories using pseudonyms for the informants.

Theme 1: Collecting information about patient's current physiological condition

Majority of participants agreed that they collected information about patients' conditions during assessment of patients who come to public health centers with their families. Participants expressed this in the following statements:

...Usually when patients had some problems with their physical conditions, they came to the physician for a consultation... (F3)

...Families came to public health center with patients and gave some information about patient's condition. As a nurse, we did assessment and checked vital signs of the patient... (I1)

Theme 2: Creating alternative strategies according to the patient's current physiological condition

Participants were most likely to agree that they had alternative strategies to deal with patients' condition based on the needs. This is explained in the following statements:

...As a nurse, we had to give some alternative medications... (I6)

...We gave some optional treatments without forcing the patients. We chose the best treatment to the patients after we understood patient's prognosis... (I9)

Theme 3: Establishing the types of implementation that should be performed

Majority of participants agreed that health care providers, after having some alternatives, chose the best treatment or option before explaining to the patients. This is explained in the following statements:

- ...Patients did a routine therapy that advised by a physician... (I1)
- ...The physician also gave an advice to patients for hospitalization... (I2)
- ...If there was a bad condition from the patients, the physician referred them to the hospital... (I3)
- ...If there was a bleeding condition, the physician gave a pharmacology therapy to stop the bleeding... (I6)

Theme 4: Providing information to patients

The majority of participants agreed that before decision-making the nurses had a role to provide information to the patients. This can be seen from the following statements:

- ...We provided the information to the patients. They had to know about their disease, what treatment would have to do, and the effect if they rejected the treatment... (F2)
- ...Of course we gave the information about the disease, and the patients had to be hospitalized... (F6)
- ...We gave the information as much as possible... everything about treatment... (I3)
- ...We invited the patients and their family to give insight what they had to do with the disease... (I5)

Theme 5: Discussing decision-making between patients and family

Participants agreed that patients needed to discuss with their family before choosing the treatment. This is explained in the following statements:

- ...Usually, patients were not brave enough to decide, so they asked the family to decide for their treatment... (F3)
- ...Patients could not decide about their treatment, therefore they need family involvement to discuss... (I5)

Theme 6: Choosing/rejecting action by patients

Majority of participants agreed that patients could chose/reject the treatment provided by health care provider. This can be seen from the following statements:

- ...When the patients got an advice from a physician in the public health center, they obeyed to come to do treatment... (I3)
- ...However, the patients did a decision-making because they understood about their disease and treatment... (I4)

Theme 7: Performing selected actions

Participants agreed that nurses did wound care management for the patients in palliative care. This is explained in the following statements:

- ...As a nurse, we did wound care to the patients, and the physician gave pharmacological therapy... (I6)

...We did wound care every day for palliative care... (I8)

...In this public health center, we did wound care for the patients... (I9)

...Patients came to the nursing unit, then we saw their wound and we did wound care if there was no bleeding... (I13)

Theme 8: Evaluating actions

Majority of participants agreed that health care providers evaluated the treatment in patients. If the conditions were getting worst, they referred to the hospital. This is explained in the following statements:

- ...We also had communication with the hospital about the treatment using referral system to evaluate the treatment.... (I3)
- ...If patients were getting worst after the routine treatment in the public health center, the patients had to refer to the hospital for better treatment... (I14)

In this study, we also compared our research results with the Theory of [McCullough et al. \(2010\)](#) and [Hancock and Easen \(2006\)](#). As a result, we found three differences from the theory (see [Figure 1](#)), including:

1) Patients and their families discuss and take a decision

After interviews with 15 participants, nurses obtained additional stages in the process of decision-making process, namely the stage of the discussion process between patients and families in making decisions on the action to be done. According to Theory of [McCullough et al. \(2010\)](#) and [Hancock and Easen \(2006\)](#), there was only patient who did decision-making process for palliative care without their family contribution in decision-making process.

2) There is no process of collecting information after patients reject to act

Based on FGD and interviews, nurses did not reveal any repetitions in gathering information that offer other measures to patients in accordance with the existing theory. According to theory of [McCullough et al. \(2010\)](#) and [Hancock and Easen \(2006\)](#), the health care providers back to first step again (*the process of collecting information after a patient rejects to act*), but in our study the nurse did not do it.

3) Type of decision-making

According to Theory of [McCullough et al. \(2010\)](#) and [Hancock and Easen \(2006\)](#) health care provider did shared decision-making process, but in our study we found that there were three types of decision-making : 1) paternalistic decision making, which family is a major influence in decision-making of patients, 2) shared decision making, which doctors, nurses, and patients discuss to each other regarding the best option for the treatment, 3) and informed decision-making based on fact.

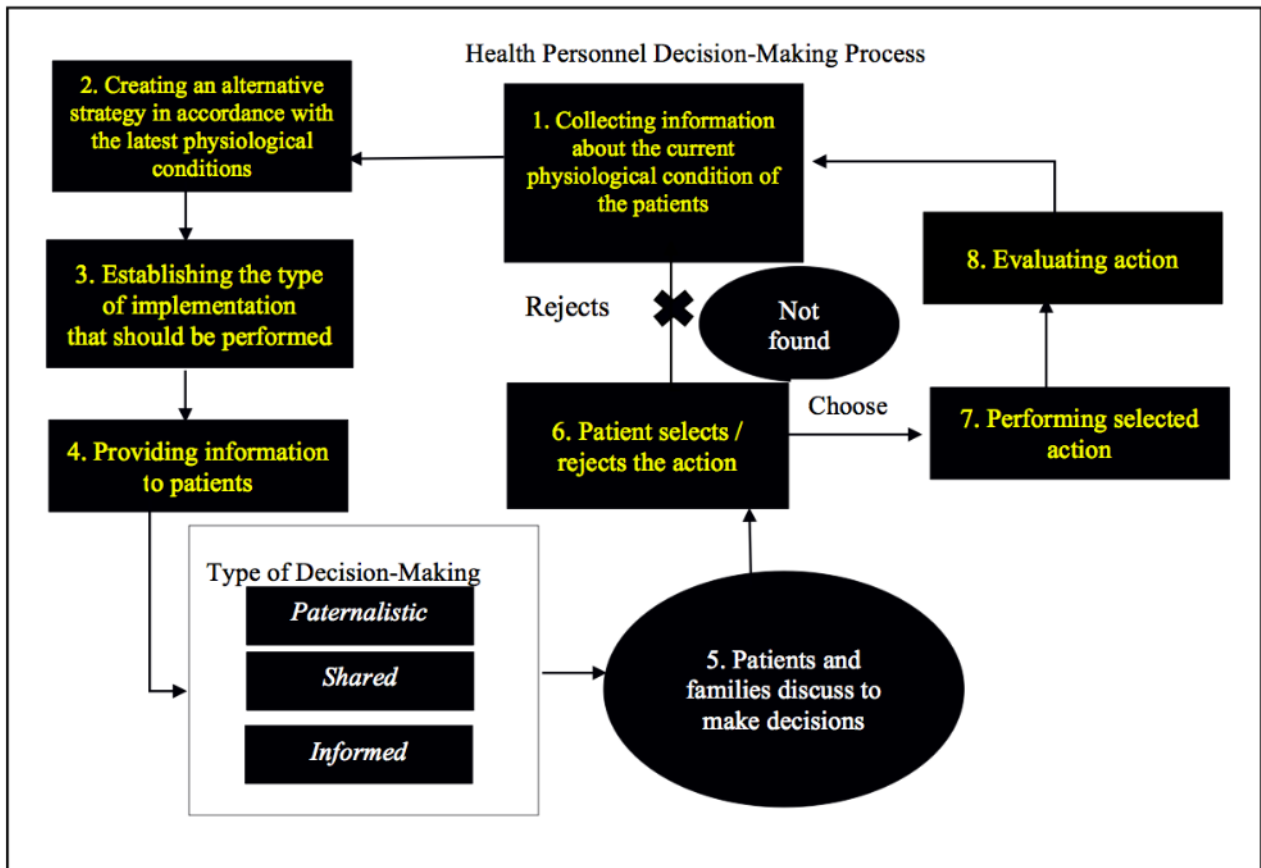


Figure 1 Scheme of Research Results

Remarks:

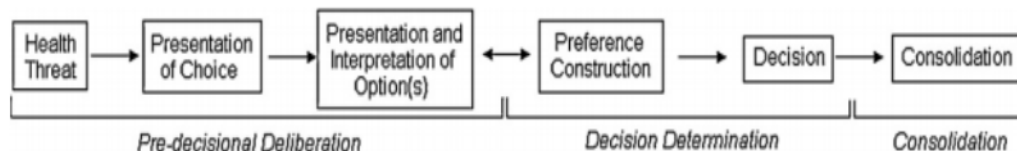
□ : According to Theory of [Mccullough et al. \(2010\)](#) and [Hancock and Easen \(2006\)](#)

○ : The additional step from this study

DISCUSSIONS

The study aimed to determine the perception of nurses in a decision-making process in palliative care and to explore the types of decision-making in palliative care. The results showed that there are similarity with the general process in health care

decision-making in the study of [Witt et al. \(2012\)](#). The existing decision-making process in health care requires the input from the patients. In many cases, the decision-making process consists of several stages: pre-decisional deliberation, decision determination, and consolidation (**Figure 2**).

Figure 2 Decision-Making Process in Health Services ([Witt et al., 2012](#))

The health treatment process is a form of diagnosis, test result, or risk assessment. These results will be followed by the presentation of several options for further actions interpreted by the patients. In this condition, the patients can decide or delegate decision-making. After the decision is made, then consolidation is performed ([Witt et al., 2012](#)). This is in accordance with the results of this study, which there was an exposure to the palliative

care options, which would then be selected through the decision-making process.

A study of [Pratiwi \(2008\)](#) in determining the factors that influence the family decision-making in utilizing health services revealed that there was a high level of utilization of health services, but the perception of health and sick was poor. However, this result was

in line with our study, which the patients were happy to check-up in the public health centers, but they were still looking for other alternative therapies because they assumed that to be healthy is not necessarily from the treatment in the public health center.

According to literature, there are three types of decision-makings: paternalistic, informed decision-making, and shared decision-making, which were also identified in our study. However, the World Health Organization (WHO) prefers shared decision-making to be emphasized, which all health professionals, such as doctors, nurses, and pharmacists, with trained communication skills play a role in encouraging patients to be actively involved in decision-making, or put the patients at the center of decisions of their own treatment and care. The active involvement of patients is expected to increase the knowledge, and thus reduce anxiety and fear (Coulter et al., 2008). Based on the results of this study, the nurses as part of health personnel were less likely to implement shared decision-making.

Additionally, technical guidelines for palliative cancer services published by the Ministry of Health of Indonesia (2013) provides an explanation that decision-making needs to take into account the culture of the patients. However, the results of this study might not be in line with that guideline, which six participants make decisions with paternalistic type. A factor that might influence decision-making process was the resignation of patients to the action that affect the communication between patients and health personnel. Claramita et al. (2010) stated that the patients were less likely to contribute in decision making and lack in verbal communication. So, to avoid paternalistic, the patients need to be supported to communicate verbally with health personnel.

The strength of this study is in the richness of contextual data, especially for the Indonesian context. However, further research is needed to confirm our findings and to identify other possible factors related to patient's rejection in medical intervention.

CONCLUSION

This study explored the perceptions of nurses in decision-making process in palliative care for patients with cancer. Eight themes emerged from this study included collecting information, creating alternative strategies, establishing the types of implementation, providing information, discussing decision-making between patients and family, choosing/rejecting action by patients, performing selected actions, and evaluating actions. Three points that are different from the existing theory were 1) there was a discussion between patients and family, 2) the absence of the process of collecting information after a patient rejects to act, and 3) there were three types of decision-making: paternalistic, shared, and informed decision-making. It is suggested that nurses as a part of health care providers could give more attention during decision-making in palliative care in patients with cancer, especially to encourage patients to give a contribution in decision-making as a part of shared decision-making.

Declaration of Conflicting Interest

The authors declared no conflict of interest.

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Authors Contributions

Each author made substantial contributions to conception or design of the work. AF and MSK contributed in selecting and identifying the participants, conducting the interviews, data analysis, and drafting the manuscript. SS and CE analyzed the data and checked the manuscript.

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References

- Bélanger, E., Rodríguez, C., Groleau, D., Légaré, F., Macdonald, M. E., & Marchand, R. (2014). Initiating decision-making conversations in palliative care: an ethnographic discourse analysis. *BMC Palliative Care*, 13(1), 63. <https://doi.org/10.1186/1472-684x-13-63>
- Chusairi, A. (2004). *Health seeking behavior para pasien poli perawatan paliatif: Studi eksploratif terhadap lima pasien Poli Perawatan Paliatif RSUD dr. Soetomo Surabaya* [Health seeking behavior of patients in polyclinic of palliative care: An explorative study in five patients in Polyclinic of Palliative Care of RSUD dr. Soetomo Surabaya]. Retrieved from http://www.jurnal.unair.ac.id/filerPDF/01_Achmad_Health Seeking Behavior.pdf
- Claramita, M., Prabandari, Y. S., & Van der Vleuten, C. (2010). Developing and validating a guideline on doctor-patient communication for Southeast Asian context. *South-East Asian Journal of Medical Education*, 4, 23-30.
- Coulter, A., Parsons, S., Askham, J., & Organization, W. H. (2008). *Where are the patients in decision-making about their own care?* Copenhagen: WHO Regional Office for Europe.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- European Oncology Nursing Society. (2006). *EONS curriculum cancer in older people*. Retrieved from https://www.kok-krebsgesellschaft.de/wp-content/uploads/2015/07/eons_curriculum_ealderly.pdf
- Hancock, H. C., & Easen, P. R. (2006). The decision-making processes of nurses when extubating patients following cardiac surgery: an ethnographic study. *International Journal of Nursing Studies*, 43(6), 693-705. <https://doi.org/10.1016/j.ijnurstu.2005.09.003>
- McCullough, L., McKinlay, E., Barthow, C., Moss, C., & Wise, D. (2010). A model of treatment decision making when patients have advanced cancer: how do cancer treatment doctors and nurses contribute to the process? *European Journal of Cancer Care*, 19(4), 482-491. <https://doi.org/10.1111/j.1365-2354.2009.01074.x>

- Ministry of Health of Indonesia. (2013). *Pedoman teknis pelayanan paliatif kanker [Technical guidelines for cancer palliative care]*. Retrieved from <http://p2ptm.kemkes.go.id/uploads/2016/10/Pedoman-Teknis-Pelayanan-Paliatif-Kanker.pdf>
- Pratiwi, G. D. (2008). *Faktor-faktor yang mempengaruhi keluarga dalam pengambilan keputusan memanfaatkan layanan pengobatan di Kabupaten Sleman Yogyakarta [Factors that influence family decision-making in the use of treatment services in Sleman Regency, Yogyakarta]*. Yogyakarta: Universitas Gadjah Mada.
- Research and Health Development Board. (2013). *Riset kesehatan dasar [Basic health research]*. Jakarta: Research and Health Development Board, Ministry of Health of Indonesia.
- Sigurdardottir, K. R., Oldervoll, L., Hjermsstad, M. J., Kaasa, S., Knudsen, A. K., Lohre, E. T., . . . Haugen, D. F. (2014). How are palliative care cancer populations characterized in randomized controlled trials? A literature review. *Journal of Pain and Symptom Management*, 47(5), 906-914. e917. <https://doi.org/10.1016/j.jpainsymman.2013.06.005>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. <https://doi.org/10.1093/intqhc/mzm042>
- Witt, J., Elwyn, G., Wood, F., & Brain, K. (2012). Decision making and coping in healthcare: The Coping in Deliberation (CODE) framework. *Patient Education and Counseling*, 88(2), 256-261. <https://doi.org/10.1016/j.pec.2012.03.002>
- World Health Organization. (2017). *Cancer control: Knowledge into action: WHO guide for effective programmes: Module 5: Palliative care*. Geneva: World Health Organization.

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