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Nurses' Perspectives and Experiences in Giving Palliative
Homecare to Paediatric Patients from Marginalized
Communities in Jakarta, Indonesia

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Abstract

The development of palliative care in Indonesia has been slow due to the absence of palliative care guide lines and standards. This results in the limited provision of palliative care where it can only be found available in 14 hospitals in the whole country with a population over 260 million, and the palliative care is basically directed to adult patients. In the paediatric medicine field, the palliative care services in Indonesia is still in its infancy and currently palliative care is served by only one non-profit organization in Jakarta. With around 1,5 million people in Jakarta associated with living in poverty, this organization is focusing on providing free palliative care to children from marginalized communities. The questions that are raised out of these circumstances are how paediatric palliative care is practiced in Jakarta and what the rewarding and challenging parts of the job are. The aim of the study is to describe nurses' perspectives and experiences in giving home-based palliative care to children living with cancer and HIV from marginalized communities in Jakarta. A qualitative study design with content analysis was considered to be the method that fitted the goal of the study best. Semi structured interview was used as data collection method and there were seven nurses who participated in the interviews. The result is described by two main categories; the first category contains different topics that functioned as encouragements to the nurses, and the second category consists of various subjects that contribute to challenges that nurses encounter in their work. Lack of palliative education that lead to certain attitudes in the referral process, misperceptions about pain management and nurses' stress management are discussed as some challenges encountered in the implementation of palliative care.

Keywords: palliative care, paediatric, nurses' experiences, qualitative content analysis, home-based care, Indonesia, Minor Field Study.

TABLE OF CONTENTS

INTRODUCTION	1
BACKGROUND	1
Indonesia	1
Geography	1
Climate	2
Demography	2
Culture	2
Economy	3
Health situation	3
Health care in Indonesia	3
Palliative care	5
Nurses' education and role in health care	5
FORMULATION OF THE ISSUE	6
AIM	7
METHOD	7
Study design	7
Participants	7
Data collection	8
Data analysis	9
Ethical aspects	11
RESULT	11
Encouragements	12
Sense of security in the teamwork	12
Meaningfulness	12
Meeting with patients and their family	13
Personal growth	14
Challenges	14
Lack of knowledge about palliative care amongst health care professionals	14
Patients' and their family's life issues	15
Stigma faced by patients and their families	16
Stress	17
DISCUSSION	18
Result summary	18
Method discussion	18
Data collection	18
Data analysis	19
Result discussion	19
CONCLUSIONS	21
REFERENCES	23

<i>APPENDIX</i> _____	26
Appendix 1 - Interview questions _____	26
Appendix 2 – Information letter _____	27

INTRODUCTION

One of the United Nations' seventeen goals for sustainable development is to ensure healthy lives and promote well-being for all at all ages. The particular goal has a few targets such as to reduce death of new-borns and children under 5 years of age, reduce premature mortality from non-communicable diseases through treatment, promote mental health and well-being, and to achieve universal health coverage including access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all (United Nation 2015).

Palliative care as an approach to improve quality of life in confronting issues related to life-threatening illness is part of health service which endorse the UN's sustainable development goal to promote well-being for patients and their families. The significance of children palliative care service implied, inter alia, in The International Children's Palliative Care Network's charter of rights that presents an international standard of support for all children with life-threatening illness and their families (ICPCN 2011).

However, the existing phenomenon of lack of paediatric palliative care that encountered in many developing countries has become a global problem which needs special attention and effort from many different sectors to deal with (Downing et al. 2012). Indonesia as one of the developing countries in the world is also facing the circumstance where the existence and provision of paediatric palliative care is very limited. As a nursing student who previously worked with children as a teacher, and as a mother of two, I find the matter close to my heart. Being born and raised in Jakarta, the capital city of Indonesia, I always have a special bond to the country thus my concern and interest in the country's development generally and Jakarta in particular. Considering my ability to speak the national language, it is a great advantage to do a research in Indonesia since it benefits the communication and can be a great support to facilitate most of the research process.

Furthermore, finding a strong correlation with the essence of the particular goal and targets for sustainable development stated above has enhanced my motivation to write about children palliative care in my thesis. I believe that everyone can contribute with something and to write about this subject out of nurses' perspectives can be one of the ways to promote the awareness about the need and importance of paediatric palliative care in developing countries.

BACKGROUND

Indonesia

Geography

Indonesia is world largest archipelago nation located between the Indian Ocean and the Pacific Ocean. According to Indonesia's National Coordinating Agency for Survey and Mapping, the country consists of more than 13 000 islands of which over 900 of them are permanently inhabited. Indonesia comprises five main islands which are Sumatra, Java, Borneo (known as Kalimantan in Indonesia), Sulawesi and West Papua (known as

Irian Jaya in Indonesia). Some of the islands have land borders with three other countries: Malaysia, East Timor and Papua New Guinea. Other nearby countries are Australia, India, Singapore, Philippines, Brunei, Vietnam and Thailand.

The total territory of Indonesia is about 7,9 million km² and about ¾ of it consist of sea area since the government claims an exclusive economic zone. The terrain of Indonesia is mostly coastal lowlands, with big part of forests, and interior mountains on the larger islands. Indonesian archipelago lies along the ring of fire, the line where world's most active volcanoes exist. This means that Indonesia has relatively high tectonic and volcanic activities which impact the country with frequent earthquakes and tsunami (Wikipedia 2019).

Climate

Indonesia's climate is relatively even all year round because of its geographical position along the equator. There are two seasons in Indonesia, a dry season that falls between May and October, and a wet season that falls between November and April. The country has rather high humidity ranged between 70 to 90%. Indonesia's climate is almost entirely tropical across the country; however, cooler climate does exist on the higher land around 1500 meters above sea level. Even tundra climate can be found on the mountains above 3500 meters high, including the permanently snow-capped peaks in Papua (ibid.).

Demography

According to Central Intelligence Agency (2019), Indonesia is the fourth most populous country in the world. Almost 60% of Indonesia's 260 million population live in urban area and concentrated on Java, the most populous island. Indonesia has more than 300 ethnic groups which is dominated by Javanese with its proportion of 40% of the population. Following large ethnic groups are, among many others, Sundanese, Malay, Batak, Madurese, Balinese, Acehnese and Chinese.

The ethnic diversity generates a variety of languages in Indonesia. There are more than 700 languages and dialects spoken in Indonesia, and the national language, *Bahasa Indonesia*, is mostly used in education, media, commerce and administration to bridge and unify the language diversity.

On the 2010 census there were more than 87% Indonesian declared Muslim, which makes Indonesia the most populous Muslim-majority country in the world. Other religions which are officially recognised by the government are Christianity where Catholicism is the biggest denomination, Buddhism, Hinduism and Confucianism.

Culture

The culture of Indonesia has been formed by a long interplay between indigenous customs and foreign influences. Indonesia's location along the ancient trading routes between the Far East, South Asia and Middle East also stimulated cultural influences from several religions which are strong in the main trading cities. Some examples of the influenced culture in Indonesia are *kroncong*, a musical genre that has roots in Portugal

and introduced by the Portuguese trader; Balinese dances which tells stories about ancient Buddhist and Hindu kingdoms; Indonesian architecture which was influenced by India; and the Borobudur temple from 8th-century which is the largest Buddhist temple in the world. However, despite the religious and foreign influences, some ethnic groups in Indonesia still practice their original traditional rituals, like the Toraja people who are still practicing their unique burial ceremony (Wikipedia 2018).

Economy

Indonesia is one of the fastest developing countries in south-east Asia with an impressive economic growth since Asian financial crisis of the late 1990s. Asian Venture Philanthropy Network (AVPN u.å.) mentioned that the increase of Indonesia's Gross National Income (GNI) and the growth of Gross Domestic Product (GDP) has contributed to reduction of poverty from 24% in 1999 to 11,4% in 2013. In 2017 Indonesia became a country with trillion-dollar economy and is now the 16th largest economy in the world (Hananto 2018). Social economy in Indonesia is growing fast with sponsorship from both international and local investors.

Nevertheless, the country is still facing many challenges in other sectors such as the wide gap between rich and poor and various health problems (The World Bank 2018). According to the Indonesian Central Bureau of Statistics (Statistics Indonesia u.å.), the proportion of urban slum household in Jakarta is a bit more than 11% in 2016. That means somewhere between 1 to 1.5 million people in Jakarta live in a slum district which is commonly associated with living in poverty.

Health situation

Life expectancy of the population is averagely 73 years. The degree of risk for major infectious diseases such as bacterial diarrhoea, hepatitis A, typhoid fever, dengue fever and malaria were rated as very high according to the 2016 data. There were about 630 000 people estimated living with HIV/AIDS in 2017. However, the accuracy of this data should be treated with extreme caution due to unmeasurable or hidden variables related to stigma and systematic testing amongst vulnerable populations in society. The last data measured in 2012 showed that physician density in Indonesia was 0,2 physicians/1000 population and hospital beds density in 2015 was 1,2 beds/1000 population (Central Intelligence Agency 2019).

Health care in Indonesia

Modern public health care in Indonesia was started by the Dutch under the colonial time, mainly to protect and secure their plantation workers. As time goes by, the health care facilities then expanded to more modern hospitals and midwifery clinics in town and some rural area. Alongside the modern health care and medication, practice of traditional medicine has been existing until present time. Various kinds of traditional healings associated with physical, emotional or spiritual problems usually performs through herbal and magic means by dukun, a Javanese healer, shamans or mediums (Lark & Cunningham u.å.). A mixture of traditional cultural methods, point of views and lack of information and education, may lead to various obstacles and complicated

problems in health care development such as the existence of stigma toward certain diseases in society.

Health status in Indonesia has shown significant improvement in the last two and half decades with some indicators like infant mortality falling and raising of life expectancy. However, the progress in some area such as maternal mortality, high incidents of communicable diseases and increasing of risk factors for non-communicable diseases are still very slow. Even though Indonesia has some breakthrough in its leadership in global health, the country is continuing to be the one of nine other countries in the world that have not signed the WHO Framework Convention on Tobacco Control (Mahendradhata et al. 2017).

Since 1999, due to a decentralization reform in Indonesia, health services have decentralized the responsibility in planning and service delivery management from the Ministry of Health (MoH) to provincial and district governments which run by Provincial Health Offices (PHOs) and District/municipality Health Offices (DHOs). The central MoH maintained to operate some tertiary and specialist hospitals, while PHOs and DHOs each own and operate the provincial and district/municipality hospitals. Some primary health care services provided through primary health centres (*puskesmas*) are also operated by DHOs. The relationship between MoH, PHOs and DHOs is not the hierarchical one as each level has their own directives and area of authority.

The health system in Indonesia has a mixture of public and private providers and financing. Besides the public health services provider mentioned earlier, there are also a range of private providers like networks of clinics and hospitals operated by non-profit organizations, for-profit providers and individual doctors or midwives who run their private practice or clinic. Although Indonesia is facing a challenge of increasing health expenditure, the government's share of total health expenditure is remaining low. The private sector covers about 60 % of the expenses, mostly in form of out-of-pocket (OOP) expenditure. OOP expenditure is direct payment of money from the patient or the family to the health care provider, that may or may not be later reimbursed from the third party such as insurer or state. The high level of OOP expenditure give impact on access to health services for the poor, and in response to this the government of Indonesia has launched various social insurance programmes for health care. However, the continuing high level of OOP expenditure, the complicated payment system and the equality of services throughout all regions in Indonesia still remain to be the challenges in implementing the social insurance programmes (ibid.).

Big differences in population's economy and the absence of a well-established national insurance system was likely to be the explanation to the financial problem for Indonesian patients as presented in a cross-sectional study comparing problems and unmet needs of cancer patients in Indonesia and the Netherlands. The study finds economy problem as the most common problem for Indonesian patients among other problems like physical, psychological and social problems (Effendy et al. 2015b).

Palliative care

When the Indonesian government launched the National Health Insurance (Jaminan Kesehatan Nasional, JKN) as a system to implement universal health care in 2014, the need of palliative care in Indonesia started to get more attention along with the revelation of number of cancer patients. The JKN intended to cover the total population in Indonesia, regardless of their economy status, in 2019. However, at the moment there are only 14 hospitals in the whole country with a population over 260 million which provide palliative care that basically is directed for adults (Ministry of Health Republic of Indonesia (Kemenkes) 2018 see Marketeers 2018). Besides the care provided by those hospitals, palliative care that exists in Indonesia is offered by private sectors, Non-Governmental Organizations (NGO) or Non-profit Organizations (NPO) and located only in a few big cities.

In paediatric medicine field, the global need of palliative care is estimated up to 21.6 million children but the access to palliative care service is lacking in many parts of the world, particularly in resource-poor settings (Downing, Boucher, Daniels & Nkosi 2018). Effendy, Agustina, Kristanti and Engels (2015a) claimed that palliative care services in Indonesia is still in their infancy. The undeveloped referral systems between hospitals and primary care centres hinders continuity of care between care providers. Besides mentioning that palliative care services in Indonesia are only available in seven cities on three major islands, Effendy et al. (2015a) also described that palliative care provided by hospitals and NGOs/NPOs are given to palliative patients generally, with one particular NGO/NPO in Jakarta that is focusing on provision of paediatric palliative care services.

Nurses' education and role in health care

According to the Indonesian National Nurses Association of Central Java, *Persatuan Perawat Nasional Indonesia* (PPNI) Jawa Tengah (2014), the nursing education in Indonesia includes three types:

- Vocational education, which focus mainly to master certain nursing clinical skills and to apply it in nursing care, is a diploma programme.
- Academic education, namely education which is directed primarily at mastering and developing nursing disciplines that cover bachelor, master and doctoral programs.
- Professional education, which is higher education after a degree program that prepares students to have jobs with special skills requirements such as specialist programs and doctoral nursing.

In 1983, PPNI declared in their national congress that Indonesian nursing education is a professional education, hence it must be in the high-level education. With support from the Ministry of National Education and the Ministry of Health, and facilitated by the Health Sciences Education Consortium, a standard form of Indonesian nursing education started to be studied and designed. The nursing education system started to develop along with various dynamics of the development of education in Indonesia.

Unfortunately, the development of the nursing education system in Indonesia has not been optimally implemented. Due to the Indonesian government bureaucratic system,

the education regulations are handled by two ministries, the Ministry of Health and the Ministry of Education and Culture. This condition gives effect to dual policy in the regulation of nursing education which leads to an uncontrolled number and kind of educational institutions, differences in standard and quality of management, and quality of graduates that impact on the performance of nurses in providing nursing services (Lestari 2014).

Furthermore, Lestari (2014) stated that nurses have a special authority as an independent profession in the medical profession, namely to carry out nursing care. Nursing care is an effort to help sick and healthy people, from birth to death, in the form of increasing their knowledge, willingness and ability, so that they can optimally carry out activities to meet their basic daily needs independently without needing assistance and/or depending on others. Nurses play a major role in health services and for that reason it is necessary to conduct standardization of the policy on nursing education in order to provide maximum health services supported by health science, especially nursing science.

Nursing education is frequently emphasizing the meaning and importance of quality and equality in healthcare and treatment. The theory of caritative care which is based on an understanding of humanistic concepts and ethical values such as humanity, dignity and alleviated suffering describes the caring approach in healthcare (Arman 2015a, p.22). The approach to always highlight and respect patients' need, perspective and dignity in all caring activity should be applied throughout the whole health-care process. This means the whole process from the first time we meet the patient until the last time when we have contact with them regardless the reason. This approach is especially crucial in palliative care where patients get treatment and support to have as active, meaningful and good life as possible, despite of a life-threatening illness. Unfortunately, the majority of people who live in developing countries and who are in need of palliative care don't even receive palliative care because it is not firmly integrated in their healthcare systems (Ford 2014). In addition to that, a research (Tarihoran, Sembel & Gunawan 2013) showed a low level of nurses' knowledge related to palliative care in Indonesia due to several factors such as limited provision of palliative care and the circumstances where palliative care has not been specifically included in nursing education curriculum.

FORMULATION OF THE ISSUE

The definition of palliative care by World Health Organisation (WHO) indicate that the approach to improve quality of life of patients and their families is part of human rights. Every person who suffer from a life limited disease should receive treatment and care to relief the physical and non-physical suffering. WHO also points out that palliative care for children represents a special, albeit closely related field to adult palliative care (WHO u.å.).

Palliative care in Indonesia is developing, even though in slow pace, with many NGOs and NPOs who show interest and support to promote the need of palliative care. There are an estimated 700,000 children in Indonesia who are in need of palliative care

services but less than 1% currently have access to paediatric palliative care (Rachel House u.å.). There are also some obstacles such as lack of governments support, differences in cultural values and socioeconomic status which are challenging the development progress. Lack of standardized formal education and public information make understanding of palliative care still very limited, both for public and among health workers.

By highlighting WHO's perspective about palliative care for children and considering circumstances in Indonesia, there are some questions lifted regarding the provision and implementation of paediatric palliative care in the particular country. Examples of thoughts that are raised 1) how to provide the needs for paediatric palliative care in the best way considering the circumstances, 2) the availability and accessibility of palliative care for children from the marginalised community and 3) about the rewarding and challenging sides of giving palliative care for these children. Nurses have a major role as paediatric palliative caregiver and for that reason it is interesting to learn more about their perspectives in order to deepen the knowledge and raise awareness of meaning, importance and necessity of paediatric palliative care.

AIM

The aim of the study is to describe nurses' perspectives and experiences of giving home-based palliative care to children living with cancer and HIV from marginalized communities in Jakarta.

METHOD

Study design

According to Olsson & Sörensen (2011, p. 106) qualitative method is a research procedure with the purpose of getting a person's own written or speaking words and observable behaviours as a descriptive data. Since the aim of this research is to study nurses' perspectives and experiences, the qualitative study design is considered to be the best method that fits the purpose. The motivation to use a qualitative study design is also strengthened by Segesten's (2017, p. 107) statement which says that the understanding of a selected phenomenon or problems is deepened with support from qualitative study design as it aims to create an understanding of a person's life situation.

Participants

The participants in this study are registered nurses employed by Rachel House Foundation which is an NGO/NPO that pioneered the provision of free home-based palliative care to paediatric patients and their families in Jakarta. The palliative care is given by Rachel House's team of nurses and community health workers, working in conjunction with care providers such as hospitals, primary care centres and volunteers from communities. Besides paediatric palliative care service, Rachel House also conducts education programmes and clinical trainings for volunteers, medical

professionals and allied health workers as one of their efforts to help build a palliative care system in Indonesia.

The process to recruit the nurses to participate in this study was mediated by a contact person who works in the organization. An information letter was sent beforehand to the nurses in order to let them know about the aim, method and process of the study. They were also informed that the participation is voluntary. To be included in the study the participant had to be an Indonesian citizen, had to have an Indonesia nursing education, had been working with palliative care for the last six months and understand English. There were seven nurses who agreed to participate in the study, six women and one man, with ages that ranged between 26 and 43 years. Two nurses had a diploma in vocational education, five nurses had a bachelor degree in academic education and two of them continued their education to a master degree. The average length of their working experience as a nurse within various fields was approximately nine years. All of them encountered palliative care as a specific field of work for the first time when they joined Rachel House Foundation, and their working experiences in the foundation ranged between six months and 11 years.

Data collection

Knowledge about a person's world can be gained through an interview which usually consists of three kinds of conversation: logical conceptual conversation, emotional personal conversation and empirical conversation about the everyday world (Olsson & Sørensen 2011, p. 132). This study used semi-structured interview as the data collection method where all participants got the same entry questions regarding a few different fields that were already prepared (appendix 1). Additional questions were asked spontaneously as a follow-up of what emerged as essential for the interviewee. Wihlborg (2017, p. 112) points out that in this way, the individual's unique experiences and understanding of what the interview is about could be explored. All participants were allowed to answer and talk freely with their own thoughts and opinions in order to encourage the delivery of more adequate and sufficient data.

The participants were offered to choose a place where she/he could feel comfortable and they were interviewed individually in order to secure privacy and anonymity. The interviews were carried out mostly in *Bahasa Indonesia*, but some English was also used occasionally in order to clarify some concepts or to get a more precise comprehension between the interviewer and the interviewee. Every interview was recorded with a dictaphone and with a mobile phone as a technical back-up device. Each interview was then transcribed verbatim immediately later the same day.

Opportunities for observation were obtained by taking part in multiple activities. The activities joined were nurses' briefing and training, education programmes for volunteers from communities and for personal from primary health care centres, and home visit to a patient. Fangen (2013, p.32) suggests that experiences gotten from observation can improve understanding and interpretation of the field. Observation and participation in these activities gave a more complete picture of the context and contributed to a better understanding of the nurses' line of work.

Data analysis

The data analysis method used in this study was qualitative content analysis as it is applicable to different kinds of texts. The abstraction and interpretation of this method can be done at different levels, which makes it useful in different research areas. In health and nursing research, qualitative content analysis has been used to review and interpret texts, such as transcription of recorded interviews (Lundman & Hällgren Graneheim 2017, p. 219).

After all the interviews transcribed immediately after each interview, the data analysis process started by reading through the transcription several times to get the sense of the main content. Focus was directed to find sentences with similarities in order to assemble them into different groups that go along with the aim of the study. These sentences units were identified and marked using different colours of a highlighting pen. The sentence units were then translated into English and condensed into shorter texts, while still keeping its central meaning, in order to get more clarity. The next step was to extract the compressed sentence units into descriptive codes which later on were combined into several subcategories and a couple categories. Continuous reflection and consideration to the sentence's whole context while having the aim of the study as a guideline were applied throughout the whole analysing process to make sure that the core of the data collected was intact. Example of data analysis are shown in table 1 below.

Table 1: example of data analysis

Sentence unit	Compressed sentence unit	Code	Subcategory	Category
<i>“When (in the beginning) I did not know about palliative care... they (colleagues) did not question this... they did not look down on me.”</i>	When I was new at my job, my colleagues neither question my limitation of knowledge nor look down on me.	My colleagues treat me well.	Sense of security in the teamwork.	
<i>“A few months ago, I had a close friend here (at work) ... so I got much supports from my colleague, from her. After she resigned, she reminded the other colleagues that I might need some support once in a while. So in the end they also sometimes ask about how am I doing.”</i>	I had a close friend at work who gave me much support. After she resigned, I get my support from the other colleagues.	Feel taken care by colleagues.		
<i>“...because we mostly are helping families from marginalized communities... so they feel</i>	The families from marginalized community feel that the help we	Be useful to other people.	Meaningfulness	

<i>like we are.... a light in their life. It's like...the little things we give means so much."</i>	give means so much to them.			Encouragements
<i>"Maybe I cannot much, but when they need help and I can give it to them.... It is a precious thing."</i>	It is valuable to be able to help them when they need it.	Able to help those in needs.		
<i>"All this time I felt ups and downs because I was troubled by management work or burned out because of job, I usually went to the patients. Because when I met patient's parents...and had conversation with them... or played with the patient... to me it became a good self-care..."</i>	When I was troubled by my duties at work or felt burned out, I would feel better when I had a conversation with the patient's parents or played with the patient.	A good relationship with patients and their family.	Meeting with patients and their family.	
<i>"So, when I met the patients, played with them, they were happy... when I left, I just felt so relieved... All things that troubled me before just gone when I met the patients... When I came to visit, saw their smile and heard that they enthusiastically said 'the nurse is coming...!' ...it filled my soul."</i>	I felt relieved and all my troubles were gone when I met the patients, played with them and saw them happy.	Feel good to see the patient happiness.		
<i>"I learned that I'm not a wonder woman. We're not heroes who can do everything, and not everything can be fixed. Even though...undeniably I kept thinking, thinking and thinking... My way was to remind myself that I have my limitation... and I kept doing the best I could."</i>	I learned that I am a person with limitation who cannot do everything and not everything can be fixed... therefore I just kept doing my best.	To know oneself.	Personal growth	
<i>"I learn to practice my critical thinking... and I also get to practice some clinical skills... but I also have time to speak with the family... to develop my communication skills..."</i>	I get to learn and practice many different things.	New skills and knowledges.		

Ethical aspects

Research ethical considerations are generally about finding the sensible balance between different interests such as interest of knowledge and interest in protecting privacy (Vetenskapsrådet 2018). Along with the study's interest to deepen the knowledge of nurses' experiences in giving palliative care in Indonesia, some privacy protection measurements were taken to ensure the confidentiality and privacy of the persons involved in the data collection.

The contact person helped to look for and ask the participants beforehand for their participation in the study. An information letter about the goal and the method of the study along with an assurance of privacy and confidentiality was then sent to them (appendix 2). The participants were also informed about the voluntariness in the study which meant that they could cancel their participation at any time without any consequences. Before the interview started, the same information was repeated verbally in *Bahasa Indonesia* and every participant could personally give their consent to participate in the study. All recorded data was then treated with strict confidentiality and kept so that unauthorized persons would not have any access to it. The recordings in the mobile phone were erased immediately after the particular interview was transcribed. All other information collected such as data recorded in the dictaphone and all field notes will be destroyed once the thesis is approved.

RESULT

Nurses' perspectives and experiences in giving palliative care to paediatric patients from marginalised communities are covered by two main categories. The first category contains different topics that functioned as encouragements to the nurses, and the second category consists of various subjects that contribute to challenges that the nurses encounter in their work. The categories and sub-categories can be seen in table 2 below.

Table 2: categories and sub-categories

Category	Sub-categories
Encouragements	Sense of security in the teamwork
	Meaningfulness
	Meeting with patients and their family
	Personal growth
Challenges	Lack of knowledge about palliative care amongst health care professionals
	Patients' and their family's life issues

	Stigma faced by patients and their families
	Stress

Encouragements

The nurses deal with many cases and occurrences in their work that affect them in different ways. This category covers circumstances that contribute positive emotions and feedbacks which reinforce their motivation in doing their job.

Sense of security in the teamwork

All nurses experienced their job in giving palliative care to children from marginalized communities as tough, despite the rewarding parts they get from it. When they faced a difficult situation, support from colleagues meant a lot in helping them to cope with the troubles. The death of a patient was a big part of various incidents that the nurses needed to process. Some of the nurses had their own way to deal with their hardship at work for example through self-reflection, meditation, prayer or by listening to religious songs. In spite of that, all nurses found the importance of having colleagues at work to talk to because they were in the same boat and would understand each other.

“ but what I need is for them to listen to me. Eventually I choose the people I feel I can talk to... there is nurse A... or nurse B... in the workplace... they know... more understanding... and I feel that they got my back.” (Nurse 4)

The feeling of insecurity about one’s competence and knowledge in palliative care was one of the things nurses had to deal with in the beginning because nurses in Indonesia do not receive any training or education in palliative care. Acceptance and respect shown by colleagues helped to boost the nurses’ self-confidence and to motivate them in learning and mastering their job. A solid teamwork served as a place to lean on and to gather strength from when the nurses got frustrated over some obstacles that they encountered.

“In that kind of situations, the team was my best solution. Like during a briefing.... I could share how upsetting a certain doctor was or how a patient was challenging. It made me feel so relieved... that they listened to my challenges. It helped so much...” (Nurse 6)

Meaningfulness

The nurses described a feeling of satisfaction when they felt that they were useful to other people and were able to help those in need. To be able to give the best care a child needed in their end of life was a story often brought up in the interviews. Opportunities to fulfil patients’ needs so they could die in peace, without pain and surrounded by their loved ones were part of experiences that lead to meaningfulness for the nurses. Even in the situations where the nurses were not with the patients in their

end of life, they could support and facilitate the family or caregiver so the process went in the best possible way for everyone involved.

“This child had no more unfinished business... There were times when he/she wanted something and we have tried to fulfil it... And when everything’s done, all were fulfilled, he continued in dying condition. The next day I went there, I sat with him for five minutes... then he passed away. It... it made me feel relieved and grateful that I could be useful to him...” (Nurse 1)

Sometimes the nurses felt that they did not or could not do so much to help besides to accompany and be a support to the patients’ family, and to give analgesic drugs to the patients. However, the family’s expression of thankfulness and appreciations, along with stories about what the nurses meant to them and the child, strengthened the sense of meaningful to the nurses.

“One interesting moment was when the mother said: Nurse C, yesterday my daughter fell and bumped her head. Then she directly called out your name ‘Nurse Ccccccc....!!!’ [laugh] That kid was only two years old, but she knew who could help her when she’s in pain.” (Nurse 7)

Besides having an educator role for the patients and their families in caring activities, the nurses are also involved in various education programmes arranged by the foundation such as activating volunteers from the communities to assist and support the patients and their families. The nurses mentioned in interviews how much it meant to them to be able to motivate and involve other people to help a fellow human being, and also to spread the education and see it applied in caregiving activities. Another thing that lead to feeling of meaningfulness and encouragement in giving palliative care was that the nurses could relate to the foundation’s vision and mission because they have the same point of view and goal in that matter.

Meeting with patients and their family

Home visits were one of the activities where the nurses interact in direct meeting with the patients and their family. Many things occur in these meeting and the interaction contributes to feelings of joy, gratefulness, worthiness and encouragement. The nurses illustrated how playing with the children, seeing their smile and having conversation with the parents or other caregivers in the family added to their own happiness and help to relieve their burdens. One of the nurses told me about a relationship with an adolescent patient where they built up trust and developed a special bond. When the patient had difficulties to speak due to her sickness, they continued to communicate with each other through a diary. In the end, even though the patient passed away, the meetings with her had always been a valuable moment that meant a lot to the nurse. Witnessing about the relationships with the patients’ family was also one of many important things that the nurses mentioned in the interviews. A nurse spoke about a HIV patient who was orphaned and only had her aged grandmother as caregiver.

“The thing that made everything so precious was the role of the caregiver, her grandmother. There were other cases where even the parents didn’t care at all, but this girl’s grandmother really took a good care of her. I saw how valuable this was.... It turned out that true love does exist...” (Nurse 2)

Personal growth

Rachel House Foundation provides internal educations for all nurses on a regular basis. Two nurses had a chance to travel to Kerala, India, in order to join a fellowship programme in collaboration with the Institute of Palliative Medicine. In the interviews nurses expressed their appreciation of the educations provided and emphasized the significance of training and education for their personal development.

“At Rachel House we are required to take a role like a doctor. Our critical thinking in discussing a patient’s condition are really taught here. Other nurses out there still feel uncomfortable about it because I experienced this when I worked at a hospital. If something happened at that time, we just thought that there were doctors around (who could look into the matter) ...” (Nurse 6)

“I am glad that there are many training occasions at Rachel House that I could join. I learned to understand that.... the family’s response was normal...so I didn’t have the need to correct them. Instead I could show empathy and assisted them to reflect over the circumstance together.” (Nurse 7)

Besides the formal educations and trainings, the nurses also indicated how they learned from all experiences they’d been through. The combination of education and experiences was beneficial for them to develop compassionate, considerative and sympathetic characters; and to grow into a stronger and wiser person throughout the time.

Challenges

This category describes several obstacles that the nurses encountered when giving palliative care to children with cancer and HIV. The areas which nurses found challenging in caregiving were viewed from different perspectives such as an unstructured health care system, a social setting and a feeling of inadequacy.

Lack of knowledge about palliative care amongst health care professionals

Ignorance and immaturity of the health care system have been issues that the nurses struggle with in order to give the best possible care to palliative patients. Palliative nurses from Rachel House could face rejection from paediatric patients’ families due to lack of information during the referral process or misperception about palliative care such as dropping all treatments which means giving up. Ignorance also contributed to situations where personnel from multiple disciplines involved in the care of a patient

had different points of view and were only focused on their own goals. This issue has become an inconvenience for the nurses and of course a disadvantage for the patient. Certain regulations in the health care system and different points of view about pain management were also a source of challenges for the nurses.

“Patient’s severe pain is really a challenge... not an obstacle, but it is a challenge for us to manage it. Well... the challenge is actually because some medical staff (doctors) at hospital aren’t so aware about palliative care... pain is maybe a symptom that is annoying... for them who haven’t really get it yet. So, the way they assess and manage the pain is different than ours. It is still so difficult (for them) to prescribe opioids. Here in Indonesia, we need them to write the prescription... We are insisting (to get it) not for our sake but it is all for the patient who is suffering with pain and other distress at home. According to the regulations in Indonesia the patient has to be present at the hospital... so the doctor can examine...errr determine that the pain is indeed exist... There is no regulation that allows me as a nurse to bring the opioid with me and deliver it from hospital to the patient’s home.” (Nurse 5)

Patients’ and their family’s life issues

The patients’ wide range of age, between 1-18 years old, made communication and the need to manage different stages in child development challenging issues to some nurses. Sometimes the patients had very few family members who could take care of them. The caregivers were often an aged grandparent who neither had adequate education or spoke proper *Bahasa Indonesia*. This had effects on medication adherence since it was not always easy to pass the information over to the caregiver about the seriousness of the illness or the importance of taking the medicine regularly. It is essential especially for HIV patients because they need to take the ARV (Antiretroviral) therapy, a treatment to reduce the amount of HIV in the body and to boost the immune system, continuously. Children aged between 7-11 years were usually extra challenging because they started to be more aware of their illness and had strong opinions about the medication without the ability to fully understand the significance of the treatment. These patients often claimed that they were tired of taking medicine.

“Sometimes the medicines were not taken regularly at home. That’s a challenge for me, but I could not blame him/her (the patient). Sometimes the obligation to take medication, especially when you have to do it for the rest of your life, is difficult.... It really is difficult.” (Nurse 2)

Patients’ social and economic situation was another issue that correlated with how well the medication and the routines for control visit in the hospital applied. The nurses found that the patients’ and their family’s limited sources in economy reduced the effectivity of the palliative care provided.

“There are many psychosocial and economic factor that influenced the patients’ possibility to go to the hospital because they don’t have (cannot afford) the means of transportation.... Or the only caregiver is the grandmother who doesn’t own a mobile phone... and lack all kind of (economic) support. They need more than medical care... All parts in their life affect the patient...In my opinion economy is the main key. When the patients have nothing to eat, they (the family) will prioritize to provide food first... no matter how bad the state of the disease is. So, their priority will be different than ours since we can afford to eat three times a day.” (Nurse 3)

Stigma faced by patients and their families

The result showed that the nurses had similar impressions and points of view regarding stigma. They had all seen, heard and experienced the existence of stigma in their line of work which was mostly directed toward patients with HIV. The common belief was that this was a ‘dirty’ disease which was related to drug addiction or prostitution. The patients’ family usually asked the nurses to keep the diagnose as a secret to the neighbours, the child’s teacher and friends, and even other family members because they were worried about being treated differently. It is still very common in Indonesian culture that families live together under the same roof, even after the children in the family have grown up and have their own family. There were cases where other adult family members immediately separated their foods and laundries, and were afraid to allow their children to play with a cousin who got a HIV diagnosis. There were also prejudices in the society towards certain kinds of cancer.

“There’s even stigma toward a child who suffered with retinoblastoma. People who did not understand believed it was contagious and they were so afraid to get infected. Some believed the disease was a curse, so if they get to close, they can also get cursed... The patient’s mother cried... didn’t want to bring her child out from the room. It raised such a deep concern... The prognosis was not good, the disease was clearly visible, they had it (economic) tough... and now the family get excluded from social life. It was so heart-breaking.” (Nurse 5)

Stigma has become a concern for nurses as it could limit them in practicing the care, for instance they couldn’t talk freely about the patient’s current issues when the other family members were around. It could also place the nurses in an ethical dilemma between protecting the patients’ status and protecting other people from being infected because of ignorance. Lack of knowledge played an important role as many people assumed that HIV is contagious just by a touch. Furthermore, the nurses said that stigma also still existed amongst health care personal despite the knowledge they were expected to have.

“Yes... stigma came from the medical staff at the hospital. Even not all staff were like that...there were a few... when they see a patient with HIV or AIDS. There was one case where the doctor only weighed the patient and then wrote a prescription. Just like that, that’s it, no physical examination... The patient’s grandmother told me that she was glad when they were visited by Rachel House’s nurse because the patient gets to be examined thoroughly. At the hospital he never been touched (for examination) by the doctor. It was so sad to hear that. Why did a health care personnel act in that way...?” (Nurse 3)

Stress

Stress is the last sub-category that contribute to challenges in giving palliative homecare. In the interviews the nurses talked about how stress has a tendency to be a risk factor for nurses to become burned out. Referrals given by hospitals/local health clinics can cause a patient come too late under Rachel House’s care and to pass away not long after they were referred. Nurses did not have enough time to give the care planned for the patient and they could regret and have feelings of guilt over it. Stress caused by Jakarta’s traffic, weather exposure and the distance to patients’ homes are challenges that the nurses struggle with every day. When the nurses used public transportation to travel, they might have to spend two hours to get to one patient’s home. However, they have now transitioned to a new system enabling them to travel via online taxi or motorcycle taxi for most journeys.

“The negative side of it (home visit) is without doubt tiredness. That’s because we have to work outdoor... exposed by sun, the weather...” (Nurse 2)

“...with the distance and Jakarta’s traffic jam... and I have to travel so far away... If we refused (to provide care to) the patient, who else besides us will give this patient the palliative care...?” (Nurse 6)

In theory the nurses have certain working hours on the day time. However, in fact there is no clear time limit for them in doing their job. Phone calls or messages from patients’ family outside the office hours due to the absence of an on-call system can make the nurses working day very long, as can Rachel House’s thorough medical reporting system. Dealing with the job outside their working hours generates stress that might result in burnout symptoms.

“The patients’ and their family’s problems are to great sometimes... so there’s no working balance... no limit in working time. Or maybe it’s just me who has too much load of work. That is one of the challenges. Sometimes I don’t have limit for it...working until late at night...patient report has to be submitted...different kind of reviews.... Sometimes I wanted to set a limit by turning off my mobile phone. The families have been informed if something happen (trouble) they can

just send a message and I will reply them the day after. But still... I would just keep thinking about it... because I think of how if things like that happened to me and it's my own child who's sick. So, my sense of humanity just kicked back in..." (Nurse 1)

DISCUSSION

Result summary

The result showed that in general the nurses viewed the task to give palliative care to children with cancer and HIV from marginalized communities in Jakarta as both fulfilling and frustrating at times. Experiences that give them positive feelings of encouragement and challenging events that generate feelings of inadequacies merge as a dynamic content in their line of work. The importance to continue and develop paediatric palliative care to marginalised communities in Jakarta was highlighted throughout the entire process of this study.

Method discussion

Conducting this study has not only allowed me to have a deeper comprehension of nurses' experiences of paediatric palliative care in Jakarta, but it has also increased my knowledge in how to perform an empirical qualitative research using interview as data collection method.

Data collection

The study's goal targets the combination of several specific fields which cover nurses' experiences, home-based care, the paediatric patient, palliative care and different levels of social environment. The use of all these terms has resulted in limited data sources considering the number of actors who provide this particular care in Jakarta. It resulted in a limitation of the participant assortment since they are all working under the same foundation. However, the participants are assessed as suitable and representative because of the variation in gender, age, education background and working experience.

Despite my Indonesian heritage and ability in speaking *Bahasa Indonesia*, concerns about the language and culture barriers during the data collection and analysis process appeared in the beginning. It was more than 17 years ago since I lived in Indonesia. Hence concerns about not to be able to keep up with the language's dynamic changes and the culture's progress emerged. But on the contrary, those qualifications played a significant role as beneficial factors in running the study. The possibility to conduct the interviews in the participants' mother tongue reduced the steps in interpretation of data and the risk of losing the essence of information in the translations process. Along with each interview's sequences, a self-reflection was carried out and the questions were evaluated. If necessary, adjustments were made in how a question was asked, along with relevant supplementary questions, performed in order to make sure that the data that was collected suited the aim of the study.

Opportunities to join the nurses' internal training and be a part of the Rachel House team in various community education events during my first week in Jakarta was highly appreciated as it allowed me to establish contacts and relationships with the nurses. This in turn affected the ambience during the interviews positively and added up to possibilities of getting accurate and sufficient information.

Data analysis

Using content analysis as the most suitable data analysis method for this study came out to be both educational and challenging. Transcription was done immediately on the same day after the interviews to ensure that the data collected was correctly represented. Analysing the transcribed data was a time-consuming process since it was required to take a broad view of the context and a careful consideration in every single step of the process. The situation was particularly challenging when the need to discuss a particular thought with someone emerged. Those kinds of circumstances were managed by simultaneously practicing self-reflection and re-evaluating the material over and over again.

Another thing to be aware of during the data analysis process was how one's pre-understanding could influence the result of the study. An example of pre-understanding was the idea that provision of opioids as a pain killer was an indubitable form of care in order to relieve patients' severe pain. However, this has not been a black-and-white issue in some circumstances like the situation in Indonesia. As a result, an understanding about embracing that pre-understanding as a tool to open up a possibility to discover new knowledge and gaining a deeper understanding (Lundman & Hällgren Graneheim 2017, p. 230) was raised. The analysis was carried on by combining my pre-understanding with self-reflections and by taking distance from the data to guarantee that it was the interviewee's voice that was reported. Observation moments through a home visit to a patient have also contributed to a deeper understanding of the context which is necessary during the analysis process in order to increase the accuracy of the result.

Result discussion

The findings in this study basically deal with topics about barriers and facilitating factors in giving paediatric palliative care to marginalized communities with regard to nurses' perspectives. Topics about barriers that the nurses experienced consist of different factors that contribute to ineffectiveness and challenges in their work situation. The facilitating factors consist of various aspects that influenced the nurses' motivation and resulted in encouragement. All the nurses said in the interviews that they took pride in their work, especially in what they do to the patients and their families. However, the risk of discouragement was also implied when issues about obstacles and challenges were mentioned.

A low level of knowledge about the importance and implementation of palliative care amongst the wider medical profession and the general public was one key finding in this study. All nurses mentioned this issue and they also expressed how it affected the provision of palliative care in many different ways. Concerns about the referral system

in Indonesia was raised in the interviews where nurses gave a few examples of the struggle to be able to provide palliative care on time to the patients related to the under developed system. Sometimes the patient was finally referred to Rachel House Foundation when he/she has reached the final stage of the disease and it was almost too late to be able to improve the patient's quality of life, and sometimes the nurses encountered uninterested and nonchalant doctors who rejected palliative care service because they refused to refer their patients to a nurse. Hannon et al. (2016) mentioned in their article that access to palliative care in low- and middle-income countries is dependent of a) its integration into national health policy and b) on general support of the health care delivery system. In Indonesia, palliative care has been established for about two and a half decades and a palliative care policy launched by Indonesian Ministry of Health has existed since 2007 (Putranto, Mudjaddid, Shatri, Adli & Martina 2017). Unfortunately, the development in spreading and implementing the policy has been extremely slow. Palliative care is still an unfamiliar field to most people, even health care personnel. This was also reported by the nurses who were interviewed as most of them got in touch with palliative care for the first time when they started to work at Rachel House Foundation. It is crucial to work for a raising awareness about palliative care in Indonesia since insufficient education and training of health care workers is a main obstacle to the expanded provision of palliative care in low- and middle-income countries (Hannon et al. 2016). Hence the foundation's ongoing work in education and training addressed to nurses and other internal staff, and to other people like volunteers or health care personal at hospitals and primary health centres is extremely important.

The lack of knowledge among health care professionals who were not aware of the meaning of palliative care has an impact to the perception about pain and pain management. One of the nurses told about the existence of reluctance from doctors in using opioids against pain for palliative patients. Morphine was ordinarily practiced at hospitals used only for sedating purpose in some certain level of pain, which was unclear since absence of a clear guideline. There was even perception about sufficiency by just using paracetamol in pain management. This phenomenon is strengthened by the result in a study by (Mediani, Duggan, Chapman, Hutton & Shields 2017) describing how nurses working with children feel powerless in performing pain management because of, among other things, lack of organizational support and professional autonomy. Hannon et al. (2016) wrote that the WHO has encouraged the appropriate use of morphine for cancer pain since 1986 by publishing the analgesic ladder. Nevertheless, the combined consumption of morphine in low- and middle-income countries was less than 10% of global consumption, even though those countries consist of more than 80% of the world's population.

Arman (2015b, pp. 41-45) mentions pain as one of various causes of suffering. Suffering is a phenomenon that brings people together and contributes to feeling of responsibility to take care of each other. To evolve as a health care professional involves many meetings with people's suffering and along with it the presence of humanity. Arman (ibid.) also described that alleviated suffering is a strong motivation for all care. Lack of care where patients' caring measures are denied is a form of uncaring or de-humanizing care. The nurses' difficulties in getting access to opioids in handling patients' pain increased their feeling of frustration since they felt that they

could not reduce the suffering of their seriously ill patients. Wiklund (2003, pp. 79-80) describes health as a complex phenomenon with many dimensions. The sense of well-being as a subjective experience that is based on the individual's lifeworld is one of the dimensions that defines health. Failing in pain management affects patient's experience of health and well-being. This led to increased stress since the nurses felt unable to provide an adequate care to their patients.

The circumstances mentioned above leads to another key finding in this study which was nurses' thoughts about stress and how to cope with this problem. The nurses meant that their experiences in giving palliative care to the children and their families from marginalized communities has enriched them in many ways. To be part of the work in fulfilling others needs and improve their quality of life has contributed to a sense of meaningfulness, along with an increased sense of responsibility in doing their tasks in a proper way. However, the patients' life situation with its complex issues required a great deal of engagement from the nurses which resulted in physical and mental overwork. The high sense of involvement and responsibility combined with other challenging factors in the working environment led to more pressure in performing the work. McCloskey and Taggart (2010) stated in their study that the job to provide palliative care to young people and their families was associated with stress across all form of care and the nurses reported how stress gave negative impact in their professional and private live.

One way to deal with stress is through self-care. In the interview the nurses expressed that they knew the importance of maintaining good health and to take care of themselves. Attention and support from the colleagues and employer played a big role in facilitating the nurses to gather strength in carrying out their work. The nurses' self-care was promoted by doing wellness activities together during working hours like for instance practice meditation, take a massage, have lunch at a restaurant or go to the cinema. The nurses also described a particular activity that was held periodically in order to remember and cherish the patients who recently passed away. The memorial service, called "time to remember", offered a platform for the nurses to process grief and tough situations by sharing all thoughts and feelings related to the care of the particular patient. Nurses play an important role now and in the future in healthcare. In order to be able to continue providing excellent care, it is essential for palliative care nurses to practice self-care. Not only for their own sake, nurses' self-care will also benefit their families, colleagues and patients. "There will be no better time for nurses to understand the importance of self-care so they are able to promote and prepare for the future of nursing practice" (Malloy et al. 2013).

CONCLUSIONS

This study gives a glimpse of the implementation of home-based paediatric palliative care provided to patients from marginalized communities in Jakarta, presented through nurses' perspectives and experiences. The particular category of work contributed to a variety of rewarding and challenging sides of the experiences. The result shows that nurses are dedicated to their patients and involved in many aspects of their life due to the holistic approach. The nurses have an important role in improving patients' and their

families' quality of life. However, there are various barriers they have to face in facilitating patients' needs such as stigma, regulations, drug availability and ignorance. Rachel House Foundation and the nurses work in promoting the importance of palliative care highlight how much more efforts in education, clinical practice and funding needed to be devoted to ensure appropriate and effective palliative care provision to the children and their families.

The outcome of this study can hopefully be used as a means to recognize benefits and difficulties for nurses' current work providing palliative care to children. A continued attention and collaboration from different partners such as government, institutions and communities are necessary in improving paediatric palliative care provision and development in Indonesia. It is crucial to raise awareness about the significance of the work in providing palliative care so that we can increase understanding and support the progress of paediatric palliative care in countries like Indonesia.

More studies are needed in the near future in order to provide knowledge and a better view about the progress of paediatric palliative care in Indonesia and other countries as well. The studies that cover both the global and the national fields will enhance the possibility to facilitate the improvement of particular health care provision with the ultimate goal to support a sustainable development in the long run.

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APPENDIX

Appendix 1 - Interview questions

1. Can you tell me a little about yourself?
2. Can you describe a typical working day for you?
3. You are a nurse who gives palliative care to children from marginalised community. What do you think about that?
4. Please tell me about things that motivate you in this job.
5. From your experiences, what do you think is the challenging part/common obstacle of giving palliative care to the children?
6. Tell me about some times when you felt really satisfied in giving care to the patients and their families.
7. Tell me about some times when you felt really dissatisfied in giving care to the patients and their families.
8. When you experience difficult situations, how do you process the tough circumstance?
9. Do you experience that you get enough moral support in doing your job to give palliative care to children?
10. Tell me about what you are really proud of about your job.
11. Tell me about the most memorable moment/patient for you.
12. Is there something else/more you would like to tell/add?

Appendix 2 – Information letter

Information regarding a thesis about "Nurses' Perspectives About Giving Palliative Homecare to Paediatric Patients from Marginalized Communities in Jakarta, Indonesia".

I am a nursing student at University of Borås, Sweden and as part of the education we are doing a thesis to fulfill the requirement for graduation. I shall be most grateful if you would participate in my thesis research.

What is the research about?

Lack of paediatric palliative care that encountered in many developing countries has become a global problem which needs special attention and effort from many different sectors to deal with. Being born and raised in Indonesia, as a nursing student who previously worked with children as a teacher, and as a mother of two, I find the matter close to my heart. I believe that everyone can contribute with something and by writing about this subject out of nurses' perspectives can hopefully be one of the ways to promote the awareness about the need and importance of paediatric palliative care in developing countries, particularly in Indonesia.

The aim of the research is to describe nurses' perspective and experience of giving home-based palliative care to children from marginalized community living with cancer and HIV in Jakarta.

This research is funded by Swedish International Development Cooperation Agency (SIDA) in form of scholarship. The organisation which responsible for this study is University of Borås.

How does the study go?

This is a qualitative research and the data will be collected by interviewing one participant at a time. The interview will take about 60 minutes. I will use a voice recorder to capture all information. The interview will conduct as a semi structured interview where participants can talk freely about their perspectives, experiences or thoughts.

How do I get information about the results of the study?

When the thesis is approved, it will be published according to customary routines for thesis work at the University of Borås and is available in the database DIVA. Since the research funded by SIDA, the thesis will also be published at SIDA's Minor Field Study (MFS) intranet. If you wish, I can provide you with a copy of the thesis once it has been approved.

Participation is voluntary

Your participation is voluntary and you can choose to cancel your participation at any time. If you choose not to participate or want to cancel your participation, you do not need to state why, and it will also not affect your work. To participate, you need to leave your verbal consent.

If you want to cancel your participation, you should contact the author or the supervisor [contact details see below].

What will happen to the information I give?

In the thesis work I will collect information from you. No names, information or results that can be led to you, or to the object of your information (e.g. patients and their families), as a person, will be reported in the thesis. All material will be treated so that unauthorized persons will not be able to access it.

All data/information will be handled with strict confidentiality. The data material collected (background information and interviews, field notes or other) will be destroyed when the thesis is examined and approved.

Contact details

Please feel free to contact me or my supervisor should you have any question or want to know more about the research.

Kind regards,

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