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Knowledge and healthcare-seeking behavior of family caregivers of children with pneumonia: A qualitative study in an urban community in Indonesia

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Abstract

Background: Childhood pneumonia is the leading cause of death. Family caregivers may have a poor understanding of pneumonia, especially related to prevention and treatment. It is crucial to understand country-specific knowledge and healthcare-seeking behaviors of caregivers of children with pneumonia before planning programmatic responses, particularly in an urban community where the culture-social economic status is diverse.

Objective: This study aimed to describe the knowledge and healthcare-seeking behavior of family caregivers of children with pneumonia in Indonesia's urban community.

Methods: A descriptive qualitative study was conducted at a public hospital in Jakarta, Indonesia, from 10 December 2019 to 28 January 2020. Ten family caregivers of children with pneumonia were included, and a semi-structured interview was conducted for data collection. The audio recording was transcribed verbatim, and the data were analyzed using content analysis.

Results: The emerged data indicated low knowledge of the family caregivers, especially mothers, which considered pneumonia a common cold only, and they failed to understand the risk of its transmission. Using traditional medicines was the first stage of healthcare-seeking behavior. If the symptoms worsened, the caregivers brought their children to the nearest health center. If there was no change in the symptoms, they headed to the hospital. The health center's location, condition, services, and staff attitude were considered factors to choose the services.

Conclusion: Living in an urban area does not guarantee the family caregivers have better knowledge and good healthcare-seeking behavior. Therefore, nurses should provide comprehensive education about pneumonia, its symptoms, and treatment management to improve family care and prevent pneumonia-related deaths. Integrated management of children with illness is recommended to help the family caregivers of children with pneumonia receive treatment as quickly as possible.

Keywords

caregivers; healthcare-seeking behavior; mothers; knowledge; common cold; pneumonia; nursing; Indonesia

Pneumonia is the leading infectious cause of death among children under five; about 2,400 children die every day (UNICEF, 2016). In 2016, Indonesia ranked as the sixth-highest number of pneumonia in the world (Ministry of

Health, 2017). Unlike in other countries in Southeast Asia, the number of under-five deaths caused by pneumonia increases about 0.12% from 2016 to 2017 (Ministry of Health, 2017). High mortality due to pneumonia is

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associated with malnutrition, poor sanitation, air pollution, and lack of access to health care facilities (UNICEF, 2016). The Indonesian government provides integrated childhood illness management but only 60% of children receiving appropriate care from the public health centers (Ministry of Health, 2015).

Family is critical in treating pneumonia in children, as they cannot take care of themselves. Their main problems were high levels of stress, anxiety, adverse family environment, and financial hardship (Pahlavanzadeh, Mousavi, & Maghsoudi, 2018). Also, poor coping skills and a lack of social support have contributed to the child's health issues (Le Roux & Zar, 2017). A previous systematic review has shown a significant association between the role of the family caregiver and the readmittance (McLeod-Sordjan, Krajewski, Jean-Baptiste, Barone, & Worral, 2011). Therefore, ensuring family caregivers' knowledge and behavior in health care is very important in providing appropriate care for children.

Previous studies reported that family caregivers, particularly mothers, have inadequate knowledge about the etiology and symptoms of pneumonia, and many of them treat their children with pneumonia as a common cold and provide the children with traditional medicine to solve one of the symptoms, such as cough or fever that could be a reason for delay treatment (Abbey, Chinbuah, Gyapong, Bartholomew, & van den Borne, 2016; Ndu et al., 2015). A study conducted in six sub-Saharan African Countries reported that only 30% of caregivers were aware of at least one of the two pneumonia symptoms (i.e., fast or difficulty breathing) (Noordam, Carvajal-Velez, Sharkey, Young, & Cals, 2015). Additionally, household wealth-status, maternal and paternal education, and religion were associated with the inequality in the use of child health services (Ayalneh, Fetene, & Lee, 2017; Noordam et al., 2015).

Pneumonia in An Urban Community in Indonesia

In Indonesia, pneumonia, together with diarrhea, is the leading cause of death for children under five. Based on the diagnosis, the prevalence of pneumonia in 2018 was 2%, while in 2013, it was 1.8%. From 2015-2018 confirmed pneumonia cases in children under five years increased by about 500,000 per year. In Jakarta in 2018, 42,305 children under five were found and treated with a diagnosis of pneumonia, approximately 95.53 percent of the 44,285 children under five who are estimated to be sufferers spread across six districts/cities (Ministry of Health, 2018).

Jakarta is included in the metropolitan city, or urban area, which is also the capital of Indonesia. Jakarta is the second-most populous urban area globally, after Tokyo, and covers 6,392 square kilometers. It has a population of around 35,934 million by 2020 (it occupies 6,392 kilometers square (2,468 sq mi). Pneumonia is a lung infection caused by bacteria, fungi, and viruses. The disease is often called a multifactorial disease. Apart from the condition, cleanliness and population density in residence also affect the proliferation of the disease (Ministry of Health, 2015).

While population density is very crowded, that potential to be one of the significant risks for the rising factors of pneumonia. Jakarta has many of the best public and private health facilities (National Statistics Center, 2020). However, people living in Jakarta are diverse. They came from around the province in Indonesia with different socio-economic statuses. Therefore, it is crucial to understand country-specific understanding and health care-seeking behaviors for children with pneumonia before planning programmatic responses, particularly in an urban community where the culture-social economic status is diverse. Also, the family caregiver may have a poor understanding of pneumonia, especially related to prevention and treatment. This study was conducted to explore the knowledge and healthcare-seeking behaviors of family caregivers of children with pneumonia in Indonesia's urban community.

Methods

Study Design and Participants

This descriptive qualitative study involved family caregivers of children with pneumonia referred to a general public hospital in Jakarta, Indonesia. Participants were selected using purposive sampling. The inclusion criteria were mothers or primary caregivers of a child with pneumonia under five years of age, able to communicate verbally, and not having any addictions, and not using any psychological drugs. A total of ten participants were recruited. According to Colvin et al. (2013), at least three to ten participants are recruited in qualitative research. The participants were recruited during children's clinical visits, and a head nurse provided the name lists of the potential participants.

Data Collection

This study was conducted at a general public hospital in Jakarta, Indonesia, from 10 December 2019 to 28 January 2020. The primary method of data collection was semi-structured interviews with open questions. Interviews were conducted in a private and quiet room individually as schedule with the participants. At the beginning of the interview, an introduction conversation was conducted to explain and obtain written consent and build trust with participants. After obtained approval from the participants, the researcher and participants made an appointment for an interview. The interviews were recorded with permission from the participants. The interview began with questions, "How long did your child get sick?" "Could you describe the symptoms complained by your child?". After receiving the answers to the above questions, exploratory and in-depth questions, such as "Could you explain what you have done to help your child recovery?" were asked by the researcher and continued until no new data were described or the same things were repeatedly explained. The mean duration of the interviews was 30 to 45 minutes. All of the interviews were conducted by one person (NHP). The interview was audio recorded.

Data Analysis

Data were analyzed using content analysis (Creswell, 2012). In qualitative research, data analysis involves planning and organizing data (such as transcripts or photographs), followed by reducing the data into themes through coding and condensing the codes. Data are presented in figures, charts, or a discussion. In this study, the interviews were transcribed verbatim and reviewed every word to extract the codes. Then the codes were categorized into general topics. Based on their similarities, codes were put into the classified themes.

Trustworthiness/Rigor

Several evaluation methods were used to ensure the reliability and accuracy of the study. Responses were confirmed by subjects (member check) and experts (external check by a nursing expert in a qualitative study with a doctoral degree). To measure the fittingness, the results were shared with family caregivers of children with pneumonia who did not join this study, and they were agreed with the fittingness of data. Some of the observers examined the study findings and agreed that the data collection methodology was appropriate. To ensure the conformity and consistency of the study, the researcher also correctly documented the whole analysis process to allow others to follow.

Ethical Consideration

Ethical permission was obtained prior to data collection from the Institutional Review Board of the Universitas Muhammadiyah Jakarta, Jakarta, Indonesia (approval number: 078/III/UMJ/2019) and the studied hospital. Each participant was asked to sign a written informed consent prior to data collection, and they could withdraw from the study without any penalty.

Results

Characteristics of the Participants

The average age of the participants was 26.57 years old, with a standard deviation of 2.34. All of the participants in this study were mothers of children with pneumonia, and the onset of a child's disease was between the age of one and four years. Of all participants, the majority of their educational level was senior high school. The duration of the children having the disease ranged between 12 and 20 days.

Analytical Findings

The findings of this study emerged from data representing knowledge and healthcare-seeking behavior of family caregivers of children with pneumonia (Table 1).

Theme 1: Knowledge of pneumonia

Just a common cold

The family's knowledge about pneumonia experienced by their children in this study was considered low. The majority of the participants perceived that the illness experienced by

their children as a common cold, as described by the participants:

- *"What I know, my child is sick of a common cold"* (P2)
- *"I do not really know, but my child has a cold cough and must be treated"* (P3)

Also, although several triggers of pneumonia symptoms were identified by some participants, such as drinking too much ice, being exposed to cigarette smoke, and not having time to play, and eating too much, along with different combinations of external influences, some participants did not recognize the conditions that triggered the symptoms. It is described by the participants:

- *"I certainly don't know, but my child likes to eat a snack, likes drinking ice, eating is difficult. There is no coughing at home"* (P2)
- *"My husband smoked, sometimes he smoked near his son, sometimes outside too. Sometimes the windows at home are opened if the heat is opened"* (P2)

Risk of transmission

While their children got sick, the parents and children did not provide or use a mask to prevent the transmission. It is described by the participants:

- *"My kid is usually cheerful. Now he is sick, and does not want to play. He just wants to be held all the time" (without using a mask seen from the observation)"* (P5)
- *"During the sickness, she only played in bed, no mask. She kept silent, looked soft, not cheerful"* (P9)

Theme 2: Healthcare-seeking behavior

The healthcare-seeking behaviors of the family for their children with pneumonia could be seen in the two following subthemes:

Using traditional medicines

The majority of the participants used traditional medicines to take care of their children at home, such as using a red onion, hot water, and saga leaves. This is usually based on their previous experience and suggestions from other family members. This is explained in the following statements:

- *"My father-in-law uses hot water using eucalyptus or scraped using onions so can help the body getting warm or hot"* (P1)
- *"I gave herbal first such as saga leaves to reduce cough"* (P2)

The nearest health center first, hospital second

The majority of the participants preferred to bring the children to the nearest public health center or clinic than the hospital if traditional medicines are not effective. The location, condition, services, and staff attitude have become the factors of choosing health care services, as stated in the following statement:

- “Immediately, I took my kid to the public health center if there was an emergency at home, or if traditional medicine is not working” (P4)
- “I bring my kid to the clinic or public health center first, then if it cannot guarantee recovery, I bring to the hospital” (P8)
- It’s even better service in a good public health center. Sometimes the nurses are friendly, and some are not. In the hospital, there are many people” (P2 & P3)

Table 1 Themes and subthemes of knowledge and health care seeking behaviors of family caregivers of children with pneumonia

Themes	Subthemes
Knowledge of pneumonia	<ul style="list-style-type: none"> ▪ Just a common cold ▪ Risk of transmission
Healthcare-seeking behavior	<ul style="list-style-type: none"> ▪ Using traditional medicines ▪ The nearest health center first, hospital second

Discussion

This study found that most of the family caregivers considered pneumonia as a common cold. They did not know the symptoms of pneumonia correctly, even dangerous symptoms, and also a condition that might trigger symptoms became more severe. It is similar to previous research conducted in Africa, Uganda, and Thailand to more than four hundred mothers and caregivers of children with pneumonia reported their knowledge of causes, symptoms, and danger signs of pneumonia were poor (Ndu et al., 2015; Tuhebwe, Tumushabe, Leontsini, & Wanyenze, 2014). Parents perceive the symptoms are ordinary and harmless so they can treat themselves (Ferdous et al., 2014; Pajuelo et al., 2018). However, proper knowledge of pneumonia, including its dangerous symptoms, is essential to prevent death from pneumonia (Ferdous et al., 2014). Therefore, increasing health education to society in Indonesia about pneumonia is very important using a more comprehensive approach.

In our study, it has been shown that the majority of the family preferred the traditional way to take care of their sick children, such as scraping with red onion and other traditional medicines. They chose to deal directly with the disease based on their previous knowledge of child-related symptoms. If the symptoms worsened, the parent brought their children to the first or primary healthcare center. And finally, if the symptoms were no better, they headed to the hospital. The existence of a spiritual belief in the prohibition of the use of medical treatment has led to the emergence of traditional healing practices (Bedford & Sharkey, 2014; Colvin et al., 2013). Another reason is parents’ mistrust of the health-care system, which they believe is not providing proper care for their children, as well as the poor standard of service provided by government hospitals and a shortage of qualified staff (Colvin et al., 2013; Ferdous et al., 2014; Pajuelo et al., 2018). Delays in obtaining

appropriate treatment occur when health service providers, especially at the primary care level, are unable to provide the right diagnosis and treatment.

Care-seeking is one of the keys to managing children with pneumonia. According to a previous study, the average parent delay in seeking treatment for children with pneumonia ranges from three to 14 days after the onset of symptoms in children, especially fever and cough (Pajuelo et al., 2018). The primary reason for the delay in the treatment of children with pneumonia was a spiritual belief, low quality of service in government hospitals, lack of professionally qualified staff (Colvin et al., 2013; Ferdous et al., 2014; Noordam et al., 2015; Pajuelo et al., 2018). Parents perceived that symptoms appear to be common and not dangerous so that they can be self-resolved or treated on their own. If the condition does not improve, the child comes to health care at an advanced stage of the disease (Ferdous et al., 2014; Pajuelo et al., 2018). The previous study has shown that the lack of knowledge of the mother regarding signs and symptoms and the severity of the disease has resulted in ineffective treatment, i.e., either delayed treatment or unnecessary treatment (Ferdous et al., 2014).

The findings of this study indicated that a program to help parents of children with pneumonia receive treatment as soon as possible is needed through integrated management of children with illness. Nurses, especially family nurses and pediatric nurses, should provide information and education to parents about home care and ensure urgent follow-up in general practice clinics or outpatient care. The primary health education subjects are mothers and child caregivers, while secondary subjects are health workers, decision-makers, and other related sectors. However, health promotion aims to ensure that people adopt behaviors that comply with health requirements.

The study was limited to the individual differences that could have influenced caregivers’ pursuing behavior between religious, moral, social, cultural, and mental beliefs. To an extent, this would compensate for the inequality in ability levels between the participants. The study’s limitations were also more directed towards collecting data concerning the availability of the patients under five years of age. In general, children treated with pneumonia are infants and are accompanied by other comorbidities such as congenital heart disease and malnutrition. During the interview, distraction sometimes occurred because the child was mischievous, mainly if left behind, so that data might not be optimally collected. Finally, a follow-up interview must be conducted at the patient’s home.

Conclusion

This study found that the family caregivers had insufficient knowledge of pneumonia and its symptoms even though living in the urban area. They considered pneumonia the same as a common cold. Thus, this condition affected their

healthcare-seeking behaviors, in which many of the family preferred to apply traditional ways in caring for their children with pneumonia. Therefore, it is crucial for nurses, especially pediatric nurses or family nurses, to provide comprehensive and continuous education about pneumonia, its symptoms, and treatment management to enhance the family caregivers' healthcare-seeking behavior and prevent death caused by pneumonia. Our study highlights the need for more serious efforts to increase the knowledge about pneumonia in primary and other health services levels. This new information could contribute to new conceptualizations or question existing ones; it could provide data that could improve practice. Future studies exploring other potential factors that may contribute to the caregivers' knowledge and barrier to provide care for their children with pneumonia are essential.

Declaration of Conflicting Interest

All authors declare no conflict of interest.

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Authors' Contribution

NHP contributed to all the study steps, including data collection, data analysis, data interpretation, drafted and critically revised the article. YP and BS contributed to data analysis and interpretation, wrote and revised the paper critically. All authors agreed with the final version of the manuscript.

Data Availability Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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