

Phenomenology Study on Nurses' Experiences in Understanding the Comfort of Children at the End-of-Life

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Abstract

Context: Patients' need for comfort at the end of their lives is rarely fulfilled. The comfort of patients at the end of their lives, especially children, is affected by nurses' understanding of what comfort means. **Aims:** This research aims to explore and to understand the meaning of children's comfort at the end of their life for nurses. **Setting and Design:** The research applied descriptive qualitative phenomenology design. **Subject and Methods:** The study was conducted at Jakarta. Nurses who have experience in caring the child at the end of their life were in-depth interview with an open-ended question. Data were then analyzed using the Colaizzi method. **Results:** This research identified six themes: striving to reduce children's suffering, realizing what children wanted, observing the children felt comfortable in their family's acceptance of their condition, facing internal and external conflict, experiencing mixed feelings knowing the children's condition, and requiring support from all parties. **Conclusion:** Nurses should provide information regarding children's end of life conditions to the family, to achieve family acceptances. Eventhough it was hard situation and rose internal conflict to nurses. It was found that children also felt comfortable at the end-of-life when they did not experience any suffering, and their wishes were granted. Subsequently, the nurses did not have mixed feelings when the children died. Therefore, evaluation of the training effectiveness that has been given to the nurses should be done to fulfill the need of the child's comfort at the end-of-life.

Keywords: End-of-life comfort, meaning for nurses, palliative care

INTRODUCTION

Cancer is the uncontrolled growth and spread of abnormal cells inside the body with the potential to cause death.^[1] In America, it is the main cause of death in children aged 14 years or less.^[2] In Indonesia, the 2013 Basic Health Research data state that 0.5% of total cancer patients are children aged 14 years or less.^[3]

Children suffering from cancer at the end of their lives need comfort, but it is rarely fulfilled.^[4] The uncomfortable conditions experienced by children are related to pain, dyspnea, digestive problems, and neurological changes.^[5] Nurses' management of pain or other symptoms is part of the multidisciplinary model of providing comfort.^[6]

Nurses' understanding of what comfort means to children at the end of their lives affects the intervention of comfort provided to increase the children's quality of life.^[7] Therefore, exploring the nurses' understanding on the essence and meaning of children's comfort at the end of their life is a study necessarily conducted.

SUBJECT AND METHODS

This descriptive qualitative phenomenological study gathered data through in-depth interviews with semi-structured open-ended questions addressed to the participants, and they were recorded using the Sony Voice Recorder ICD-PX440. Data analysis was conducted by using the Colaizzi method and occurred simultaneously with data collection.^[8] The research took place over the course of 3 months in a Jakarta home care facility.

Key informants proposed candidates for participation and subsequently, the researchers contacted the participants through the WhatsApp Messenger. The researchers were then explained to the candidates. After obtaining the candidates'

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agreement to participate, we began the data collection process. Ten participants participated in this research. Characteristics for participant were nurses who had attended palliative care training, nurses who had certificates of palliative care training, nurses who had given pediatric nursing care to children at the end-of-life, nurses who had good Indonesian speaking skills, and nurses who were willing to be participants and to share their experiences.

This study obtained ethical approval by the Ethical Committee of Nursing Faculty of Universitas, Indonesia. Ethical principles were applied to the whole research process including data collection, data processing, and research outcome publication.

Data collection was conducted through semi-structured in-depth interviews with open-ended questions. The interview length among 10 participants was approximately 40 min to 1 h and 50 min. There were no obstacles, either physically or emotionally, in collecting the data among the ten participants.

Each recorded result of the interview was transcribed verbatim. The Colaizzi method was used to analyze the data.^[9] The transcripts were read repeatedly to determine significant statements and meaningful formulation so that they could be grouped into categories, subcategories, and themes.^[10]

RESULTS

The six themes found in this research: striving to reduce children's suffering, realizing what the children wanted, observing the children felt comfortable in their family's acceptance of their condition, facing internal and external conflict, experiencing mixed feelings knowing the children's condition, and requiring support from all parties.

Striving to reduce children's suffering

This theme illustrates the various efforts undertaken by nurses to reduce and even eliminate the pain experienced by children at the end-of-life. Those efforts begin with conducting a physical examination of pain and other symptoms that appear such as shortness of breath, fever, and digestive problems. The followings are participants' statements:

... pain, how pain it is, frequency, the length, and then its location, its intensity, until its pain scale...(Participant 5)

... they felt shortness of breath and weak, these are usually associated with pain...(Participant 4)

... when the kid was fussy and has got fever. we measure the temperature...(Participant 2)

Nursing interventions to overcome the children's pain implemented by pharmacology and nonpharmacology. This I mentioned in the statements of the participants below:

...like in cancer that usually has used morphine... by listening to music, by coloring, pain distraction is by watching TV, compressing the pain on the permitted location...(Participant 5)

Realizing what children wanted

Psychological counseling in children shows the nurses that the greatest hope and desire of the children at the end-of-life is by doing activities favored by the children. The nurses prepare for the psychosocial and spiritual conditions of the children before they can realize what the children really want before they die. This is as stated in the participants' expression:

... pray as many as possible, for Muslims, for Christians pray as many as possible to Jesus...(Participant 1)

In identifying the children's psychological comfort the nurse will clarify it directly by asking questions about comfort to them. Here are their statements:

...asking the kid's preferences, their hobbies, then their wants such as reading novel, are you bored? What do you want?... (Participant 2)

... the comfort of the child to die... do not assume yourself... we assume what the kid likes— in fact it is not, so just ask as long as we still can communicate, ask, because the kid having the body and feeling the pain, who can say comfortable or not, ask ...we as nurses do not ever assume something...(Participant 4)

Finally, the nurses embody the children's true wants to provide comfort to them at the end-of-life. This is revealed from the statement:

... comfortable if their wants have already been realized... (Participant 3)

Observing the children felt comfortable in their family's acceptance of their condition

Sincerity of the family when the child will die is something that will reassure the children's soul. The nurses also attempt to prepare the family for the child to die as stated in the following statements:

...we ask to read Yasin, mother to hug or hold, mother to say love to the kid, and mother to say if she has been relief, if mother is sincere the death process will not be long... (Participant 6)

The assistance of nurses to parents to be sincere their child who will die includes identifying their feelings, exploring their feelings, and showing care to them.

... I am mostly worried if talking about...(Participant 5)

... by asking like that I care with the emotion they feel right now...(Participant 2)

Facing internal and external conflict

The children's comfort at the end-of-life is not something that the nurses can easily get but must be striven to achieve. Internal conflicts of the nurses and external conflicts involving families as care providers must be dealt with by the nurses. This is like the following participants' statements:

... not easy to say, but it must be (eyes staring blankly)... (Participant 3)

... sometimes there is something to do (the speech such as being sarcastic, eyes slightly glanced). so this kid does not feel the pain and the cough gets better...(Participant 2)

In addition, nurses also have to accept when the family feels more comfortable if bringing the child to the hospital when the condition of the child shows signs of death even though it is not in accordance with the expectations and wishes of the nurses or the child itself.

... it is fine if the family wants to take the kid to the hospital... (Participant 4)

Experiencing mixed feelings knowing the children's condition

All the nurses' feelings will occur in line with the increase and decrease of the children's conditions at the end-of-life. Various expressions of nurses' happiness during giving life care to the children and families are depicted from one of the participant's expression that is:

... by (chuckled) realizing the kid's wants, I feel happy... (Participant 3)

The feelings of guilt, sadness, disappointment, and regret are also shown by all participants through some quotes below:

... there is feeling of regret if it has not been realized because we want to elevate the life quality at the end of the children... (Participant 1)

... it's difficult to accept, very difficult (bowing the head), feeling such as never enough always false, difficult... (Participant 3)

In addition, the participants also express feelings of pleasure and sadness that are felt at the same time knowing their child's condition, namely:

...when the child died, I felt such a success (while clenched hands as a sign of success) even though I was sad, meaning that all of the child wants had been granted at the end ... (Participant 6)

Requiring the support from all parties

The identification of the need for providing the capacity of palliative care must be done earlier, so the cares given can achieve the best possible objective. This is expressed from the statements of the participants:

... we involve social workers pekerja sosial, usually friends from the other foundations are involved such as Yellow Ribbon, friends from the Social Department, psychologists, or nutritionists...(Participant 5)

While the support provided by psychologists and doctors revealed in several participants' statements that include:

... we cannot solve the psychology of the patient or the patient gets angry or we invite a psychologist for the family... (Participant 3)

... we must coordinate with the primary physician, the what the progress are and what the decreases are at home...(Participant 1)

DISCUSSION

Nurses in this study faced internal and external conflicts related to the challenges of providing palliative care. Internal conflict arose when nurses tried to deliver news about the end-of-life to children and their families.^[11]

Furthermore, nurses mentioned that the internal conflict was caused by an uncertain disease prognosis. This cannot be avoided and ought to be faced by pediatric palliative nurses.^[12] Further complicating things, the word "die" is considered taboo in Indonesian society. However, most families want to be informed of the disease prognosis so that they can contribute meaningfully to the decision-making process.^[13]

Nurses can learn to manage internal conflict by increasing their communication skills. Good communication is an important factor in preparing parents and children to face a potentially terminal diagnosis.^[14] Efforts to increase that skill could be accomplished by creating a nursing communication standard, conducting consultations, and increasing colleague support.^[15] Good communication is key to providing comfort when facing a difficult situation.^[16]

External conflict faced by nurses was related to uncooperative caregivers and children. Caregivers, in this case, were parents or other relatives of the children, such as an uncle, aunt, or grandmother. Nurses can provide support for these families by providing complete information about the children's condition, suggesting ways the family can spend more time together and can take care of the children's needs, involving family members outside of the nuclear family unit, and asking for help from the neighborhood.^[17]

One of the nurses' primary duties is to conduct management of the patient's pain and other physical symptoms.^[18] In this way, children feel more comfortable, relieved, and calm. In assessing pain, it is important that other symptoms experienced by the children be considered.^[19]

These factors are further supported by the nurses' ability to consider the children's age, the children's level of cognitive development, the children's communication skills, the children's past experience of handling pain, and the children's conviction about the pain, so that it can be determined which pain measurement will be used.^[20]

Nonpharmacological intervention is an important part of pain management with children at the end-of-life.^[19] In this study, nurses conducted an independent intervention to decrease the children's pain by distracting their attention from the pain and making them happy such as playing such a game, drawing, or walking around. The importance of family involvement in pediatric nursing is extensively present in research. Parents are involved in planning the pediatric nurse's efforts at the end-of-life.^[21]

In this study, nurses also provided care for the psychological spiritual aspect of children and their families. Addressed to fulfillment the aspect spiritual of children or families is the

one of active total care of patients in palliative care.^[22] The psychological assistance provided to children and their families aims to prepare them for the child to die in comfort condition. Ultimately, the goal is for their families not to feel regret once their children die.

Nurses provide psychological support by being a partner to family members who want to talk about their children's condition.^[23] Therefore, it is important that the nurses' attitudes during the assistance process be suitable and individualized to the needs and conditions of the children and their families, and that they show respect and appreciation for the children's autonomy.^[24] Listening to children is another important component to nurses providing attentive care.^[25] Moreover, be someone who can be trusted, kindness, warmth, honesty, and affection are essential to building the nurse and patient relationship.^[23]

The psychological welfare of the family during the children's end-of-life proceedings is critical and can affect the children's psychological condition.^[23] At the end of the children's lives, the nurses felt that the children would be comfortable if their family were sincere with the children's condition. Family members can help children who are dying feel more comfortable by saying supportive words and convincing them of their acceptance.^[26]

Nurses providing palliative care to children also have mixed feelings about the children's conditions. The feelings of hopelessness and disappointment stated by the nurses are in line with the statement that nurses sometimes feel hopeless when they cannot do anything to relieve the torment experienced by the patients and their families. The loss and hopelessness when facing the death of a child are not only felt by the family alone but also by the health-care professionals who provide care at the end-of-life.^[16]

The feelings experienced by nurses providing care to dying children, such as hopelessness, anger, sadness, and anxiety, can cause fatigue quickly for the nurses to impact on the increased number of palliative nurses who resign,^[27] it is imperative that nurses receive support and motivation from all parties involved in providing palliative care for children.

Nurses need time to learn coping strategies that can be used to face the condition of death.^[12] This is in accordance with findings which state that a safe environment is important to overcoming challenges in providing care to dying children.^[28]

Some activities that can help nurses overcome feelings of sadness, anger, and hopelessness are the creation of a support group and the provision of training to assist with handling traumatic situations.^[27] Some other activities are identifying distressing conditions experienced by nurses, giving a lecture on techniques to help overcome those conditions, and identifying nurses who need a personal consultation. Palliative care in a multidisciplinary setting encourages optimal care.^[29] Therefore, palliative care must be supported by health-care professional teams that are proficient in symptom management,

psychosocial nursing, spiritual support, nursing care planning, communication, and the ability to be supportive during the decision-making process.^[30]

Nurses, as part of the multidisciplinary team, need to consider several things, such as appreciating other professions and supporting each individual's contributions, to provide the highest quality of care to patients and their families.^[31]

Limitation

The limitation of the study is in the population. The pediatric nurse corresponding to the participant characteristics that can be included in this study is only obtained from the Rachel Home Foundation who is engaged in pediatric palliative care.

CONCLUSION

Nurses interpret children's comfort at the end-of-life as a condition where children feel relieved, where the children's wishes are fulfilled, and when the family is accepting of the condition of their children. To foster this feeling of comfort in children, nurses need many supports, and they must work to overcome the internal and external conflicts that produce mixed feelings which can affect their provision of care. In the future, the nurse should evaluate training effectiveness and discuss supportive factors and obstacles in applying theories gathered from this training, especially to resolve communication barriers to provide the comfort of children at the end-of-life.

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Conflicts of interest

There are no conflicts of interest.

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