

Parents' Voice in Managing the Pain of Children with Cancer during Palliative Care

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Abstract

Context: Pain experienced by children can adversely affect their growth and development. Pain is a major health problem for cancer patients and remains an unresolved problem. **Aim:** To know how the experiences of mothers managing their children's pain during palliative care following cancer diagnosis. **Background:** Pain experienced by children can adversely affect their growth and development. **Subject and Methods:** Using qualitative methods within a descriptive phenomenological approach, in-depth interviews were conducted with parents (mostly mothers) of eight children diagnosed with cancer. The data were collected using the snowball sampling method. **Results:** Participants experienced in managing the pain of children with cancer. Analysis of the results identified 8 themes: the dimensions of pain experienced by children undergoing palliative care; mothers' physical and psychological responses; mothers' emotional responses; barriers encountered by mothers when taking care of their child at home; mothers' interventions to reduce their child's pain; mothers' efforts to distract their child from pain; giving encouragement when the child is in pain; and mothers' efforts and prayers to make their child comfort. **Conclusion:** It can be concluded that the child's pain is the main cause of mothers' stress and pressure and also affects the daily lives of mothers and children. Along with the most effective intervention, nurses need to provide mothers and children with adequate information about cancer pain.

Keywords: Cancer, caring for pain, child, Indonesia, lived experience, palliative care

INTRODUCTION

Cancer is caused by a group of abnormal cells that divide and spread rapidly and cannot be controlled.^[1] Malignant cancer can spread to nearby tissues, and some cancer cells can rupture and migrate to distant places in the body through the blood and lymphatic system.^[2]

Children with cancer require nursing support for issues related to pain, nutrition, weakness, infection, and hyperthermia. Among their symptoms, children commonly complain of pain.^[3] As a warning sign of trauma or disease, pain is a sensory and emotional experience that causes unpleasant effects and indicates tissue damage.^[4]

Jibb *et al.*^[5] noted that pain is among the most difficult symptoms experienced by children and young adults; in 49%–62% of such cases, the experience of pain is continuous. Pain is a major health problem for cancer patients^[3] and remains an unresolved problem. Four categories of pain have been identified in patients with cancer: pain caused by primary

cancer and/or metastasis; secondary pain due to diagnosis and treatment procedures; and pain associated with end-stage or terminal disease.

The goal of palliative care is to manage and overcome pain and other symptoms of cancer.^[6] As part of their treatment, palliative care offers cancer patients realistic hope of relief from pain.^[2] According to the WHO, palliative care seeks to improve the quality of life of patients and families dealing with life-threatening illnesses by preventing and reducing physical, psychosocial, and spiritual suffering through early identification, effective examination, and pain therapy.

Where the family has responsibility for pain management, parental involvement is an essential element in caring for children with cancer.^[7] Kiana *et al.*^[8] found that parents

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regularly observe and evaluate the location and severity of pain experienced by their children, as the pain they feel will affect their quality of life.^[6] In the present study, mothers' experience of managing pain will be explored using a phenomenological approach, which helps to deepen understanding of the meaning of life experiences arising from a given event.^[9]

SUBJECT AND METHODS

Informed by the principles of descriptive phenomenology, the methodology seeks to focus on a person's experience. The overall aim of life-world research, according to, is to describe our understanding of human being and human experience. In other words, it helps us to obtain knowledge of the essential meaning of a lived experience.^[10]

Participants

This qualitative research design used snowball sampling to recruit parents involved in managing the pain of children with cancer who were undergoing palliative care. While the research was conducted at the Rachel House Foundation in West Jakarta and Taufan Jakarta Community, data were collected in each case at a place agreed between participant and researcher. The interview guide was initially developed with the help of 1 expert supervisor. That 8 participants, comprised of female ($n = 7$) and male ($n = 1$), were interviewed during a period of 2 months. The participants were 32–50 years of age, with a mean age of 42 years. All of them had experience in managing the pain of children with cancer.

Data collection

Data were collected by means of a semi-structured interview, which was recorded using a Sony voice recorder, transcribed verbatim, and analyzed consecutively by the authors. In addition, the researcher made field notes to record nonverbal responses during the interview. Data analysis was based on the Colaizzi method as referred to in Speziale and Carpenter and Burns and Groove. Each session lasted between 45–60 min. Moreover, the transcripts themes were sent to the interviewees to assure that there were no ambiguities and to improve the validity of the research.

Ethical considerations

Informed consent for audiotaped interview had been obtained from informants. The research was informed by the ethical principles of anonymity and confidentiality, nonmaleficence, privacy and dignity, autonomy, beneficence, and justice. The study also employed 4 criteria that help to ensure the validity of qualitative data: credibility, transferability, confirmability, and dependability.

RESULTS

Based on the research objective, the study identified eight themes: The dimensions of pain experienced by children undergoing palliative care; mothers' physical and psychological responses; mothers' emotional responses; barriers encountered by mothers when taking care of their child at home; mothers'

interventions to reduce their child's pain; mothers' efforts to distract their child from pain; giving encouragement when the child is in pain; and mothers' efforts and prayers to make their child comfortable.

Theme 1. Dimensions of children's pain

The study found that, during palliative care, mothers could not know about the pain felt by their child unless the child revealed it. If the child rarely complained of pain or did not express their experience of pain in some way, the mother found it difficult to distinguish what kind of pain the child was feeling. These results confirm that some participants do not know how their child is feeling because the child rarely complains about the pain and does not tell their mother.

"... when active, my kid was getting sick ... so, if my kid did not say anything, I did not understand, right? When it feels painful. asking for swabbing..." (p. 1)

"... that's all there is, nothing else; my kid is quiet if, for example, my child never say anything when something happens" (p. 7)

Some participants also knew the level of pain felt by their child by asking their child about it. However, some participants know their child's level of pain by asking. The mothers explain the range of pain levels (0–10), following each with a description, which enables them to decide on suitable pain management for their child.

"Yes, my kid told me [about] the pain; we've asked how you rank your pain—one, two, three, four, up to ten, which is very painful. My kid is often asked like that ... "At what number do you feel the pain?" I asked ... "Number 10 mam," meaning it was very painful." (p. 2)

Some participants had a bad reaction to pain. Children's responses included reports of feeling tight, complaining, wincing, and feeling uncomfortable, and some participants cried, screamed, or rolled because of the pain.

"Yeah, becoming gloomy and just lying down..." (p. 1)

"...rolling on the bed until my kid screamed 'So painful dad'." (p. 6)

The child's reported experiences when in pain include feelings of tightness, complaining, wincing, and discomfort and some participants cried, screamed, or rolled because of the pain.

Theme 2. Mothers' physical and psychological responses

The study identified a psychological effect where mothers, feeling sorry on seeing their child's condition, hiding their feelings of sadness, fear, depression, confusion, anxiety, and panic. According to Wong and Chan,^[11] mothers experience shock on realizing that their child is in pain.

"yeah, how poorly my kid is ... until when..." (p. 2)

"... pain, pain until screaming. Oh my God. I don't have the heart to see... my neighbor

feels sad as well to see that condition." (p. 3)

"I told my kid that I'm not sad. I'm not crying, it's just that there's something in my eye." (p. 7)

"I was panicking ... we knew that my kid was in pain ... but why panic ... my kid was dying." (p. 8)

These mothers were suffering because of their children's diseases and the long-term treatment they were undergoing. As a consequence, they felt weak, found difficulty to get things done, could not eat, felt fatigued.

"Yes, already weak; as parents, we can't just cry when the doctor says 'All we can do is just keep trying for a cure and pray for the best.'" (p. 5)

"Even I lost my appetite, and it's not easy to drink when you remember that your child is sick." (p. 5)

Cancer and its associated medications have an emotional impact on children and families who are affected by the disease. Children's reactions to feelings of pain have psychological effects on their mothers. This study confirms that the psychological responses of mothers are related to the children's own reactions to the pain of cancer and to the medication. On seeing the condition of their child, mothers try to hide their feelings of sadness, fear, depression, confusion, anxiety, and panic

Theme 3. Mothers' emotional responses

As well as the emotions participants expressed because they saw their child in pain, they also had various reactions to their child's feelings, such as fighting, anger, nagging, annoyance, and upset.

"My child doesn't like screaming and complaining, and I can manage myself not to be angry..." (p. 4)

"Yes, I was depressed ... yeah, it's like feeling sick with the pain, like my child feels..." (p. 5)

"Yes, sometimes I feel angry. Ya Allah I ... we've done the medication, but my child is still sick, still in pain ...is my child's condition getting better or not?" (p. 2)

"I've got angry with Allah, what is missing in me? I've given alms to poor people, but my child is still sick..." (p. 7)

The mothers in this study suffered emotional disturbance as a result of psychological effects that manifested in reactions such as nagging, fighting, hitting, and shock. Some participants argued continually with their child when the child was sick and did not want to take their medicine. They also fought with other family members when they panicked on seeing their child in pain.

Theme 4. Barriers encountered by mothers when taking care of their child at home

Various obstacles (in terms of both care and cost) were also experienced by mothers when helping with their child's pain at home.

"Is there a nurse who wants to do homecare, I said ... for changing the bandage and taking care of other things ... there's nobody who wants to do that ..." (p. 1)

"Alhamdulillah, there is a receipt of payment to reimburse the taxi payment." (p. 3)

"The business was bankrupt because I am mostly at home." (p. 2)

The present study found that the children were in ongoing pain, and their parents used various strategies to address this. One participant reported that her child did not stop screaming even though she had already tried many things to manage the child's pain. The factors that hindered mothers in this regard included the absence of nurses who provided home care. Mothers could not manage their child's pain at home and had difficulty in terms of cost and transportation when their child was in pain at home and had to be taken to the hospital.

Theme 5. Mothers' interventions to reduce their child's pain

To manage the pain experienced by their child, mothers did various things such as administering medicine prescribed by the doctor.

"Don't need to take the medicine, my child said ... take the medicine to lessen the pain ..." (p. 2)

"If my child is sick, [I'd say] 'Dear, take the medicine, please.' That was an example ... one likes Panadol, which is one tablet; my child can swallow it" (p. 8)

As well as eliminating the child's pain with a drug, the mothers also used other techniques when the child was afraid, using things such as kencur rice, eucalyptus oil, massage, or a compress on the affected area.

"Giving medicine or applying kayu putih oil on the feet." (p. 3)

"Massaging my child's back or hip, sometimes asking to fix or place the patch, given eucalyptus oil or something warm" (p. 2)

Pain is the most common symptom experienced by children with advanced cancers, and they require appropriate and intensive pain management to improve their quality of life. The parents in this study sought to reduce the pain felt by their child by means of both pharmacological and nonpharmacological therapies. In the former case, mothers administered medicines such as morphine, morphine slow release tablet, and paracetamol every 4–6 h to relieve their child's pain, in accordance with advice from their doctor. Nonpharmacological therapies included alternative medicines, eucalyptus oil, massage, and compress.

Theme 6. Mothers' efforts to distract their child from the pain

Participants also tried to distract their child so that they did not feel the pain. Mothers tried to entertain, using touch and warmth when the child felt the pain.

"Sometimes my child likes playing, watching TV, or doing something they like to distract them from the pain." (p. 3)

Yeah, I just hug, hold, and compress while holding my child..." (p. 6)

Parents always try to eliminate the pain experienced by their children. In this study, parents made a variety of efforts to ensure that their child did not feel pain – for example, diverting the pain experienced by their child by watching TV and reading stories. Participants reported that their child felt better when watching humorous children's TV shows or YouTube. Some participants also encouraged their child to chat, make jokes, or entertain.

Theme 7. Giving encouragement when the child is in pain

To provide strength when the child was in pain, mothers stayed close to their child and encouraged them to fight the pain. Mothers always supplied their child with spirit and motivation when they felt pain.

"...the important thing is always to motivate my child ..." (p. 1)

"N must be strong in order to get healthy"—that's what I say to motivate N." (p. 4)

"...we try to stand up front his son (p. 2)

Adequate support is the most necessary requirement when the child is in pain. The parents in this study provided encouragement, motivation, and support when their child was in pain. Children felt comfortable being beside their mother, whose presence was like a cure. When their child was in pain, mothers tried to give them strength by encouraging them to fight the pain. Some participants also tried to give strength by telling their child to be tough and that all is a trial of God, giving the child the strength to live with it. Mothers always tried to be strong when beside their child and when their child was in pain, never leaving their child, even to go to the bathroom. They did not want to be sick and tried to stay healthy and to be near their child at all times.

Theme 8. Mothers' efforts and prayers to please their child

In granting their child's requests, some participants did whatever the child wanted when they were in pain; knowing that their child did not have long to live, mothers went further to please their child, without thinking.

"looking for something like a tube ... yeah, Mam is looking for it.... So my child cannot take off the oxygen...feeling of tightness ... the place to buy it is far away... I share again in Facebook; perhaps there's someone who has it" (p. 1).

"...there is nothing to do. All I can do is please my child, as long as my child is happy for the rest of their time ... and pray." (p. 3)

"Yeah, we are patient, praying from the heart, hoping the pain may decrease." (p. 8)

"Yes, my child's wish to Allah, may Allah grant it, is a mother's prayer for strength for N." (p. 4)

The mothers in this study tried to do things to please their child because they knew that they had had difficult experiences with the various treatments and medications. Although they also felt depressed that their child did not have long to live and got tired,

they kept trying to please them by granting whatever their child wanted. Some participants revealed that they tried to care for their child by doing everything they wanted, always remaining close, and watching, entertaining, and supporting their child.

DISCUSSION

This study revealed that all participants have experience in managing pain in children with cancer who underwent palliative care. Caring for children in palliative conditions is a tremendous challenge for parents where mothers should be able and skilled in managing child pain. Mothers have a purpose to make their child free from pain even though there are some parents who cannot recognize pain felt by their child in real.

According to Tutelman *et al.*,^[12] children with cancer will experience various difficulties while having palliative care, both from physical aspects of the disease process and as a result of ongoing treatment and 23% children expressed the pain experienced.

Be a child free from illness the parents need to have the ability to assess their child's pain using simple pain tools to ensure that the child is experiencing pain or not. John Wiley^[13] claims that parents often do not know the pain felt by the child, in fact, there is a child who is not able to verbalized the pain or cognitively lacking in expressing the pain.^[13] The strategy parents need to do in assessing pain is to encourage the child or ask parents to use the diary of pain.^[14] The mother needs to know how to assess the pain with the instrument pain by looking at the expression of the child's face. It helps to make decisions about the cause of the pain and to choose the most appropriate intervention.

In managing pain in a child, mothers experienced various changes both physically and psychologically. The changes on mothers who feel sorry to see the condition of their child were to hide their sadness, feeling of fear, being emotional, depressed, confused, anxious, and panicked. In line with the study conducted by Gibbins *et al.*,^[15] it is stated that a family will feel stressful when their child expresses painful and the mother feels the prolonged sadness during the care of children with cancer

Twycross *et al.*^[16] surveyed 39 Jordanian parents and this study reported that emotional pain when seeing their child in a worse condition were feelings of emotional, confused, and sad.^[16] Other studies have reported that parents were not unprepared for managing pain in their child who was being treated at home because they did not have willing to see the condition of their child.^[18]

In this study, mothers did not only experience psychological problems but also problems with physical conditions such as feelings of weak, tired, and hard to move that expressed by some participants of this study. Other studies have shown that there are disturbances on parents such as sleeping disturbances, somatic symptoms, risk of behaviors (smoking and alcoholism), dietary changes, physical perceptions, and emotional overload.^[19]

This study showed that children always felt pain even though their parents used a variety of strategies in overcoming the pain. One of the participants who screamed a lot because of the pain even though the mother had done various efforts in overcoming the pain felt by the child. The study on children with cancer by Gibbins *et al.*^[15] are large and diverse showing that children continue to experience significant pain even though parents use a variety of pain management strategies.

Parents in this study looked after their child in dying conditions through several attempts such as having talks, making jokes, touching, always being near with their child, giving strength to the child, and various approaches done in relieving pain.

In line with the study of Gibbins *et al.*,^[15] it reported that some parents were pursuing alternative treatments even though the treatments did not have any scientific evidence such as qigong treatment, using Chinese herbs, Reiki, homeopathy, and traditional healing. The study of Ferreira *et al.*,^[20] showed that parents could play an active role in supporting and training their children when experienced pain with distractions, warm compresses, warm pillows, music, games, and books.

Based on the experience of parents, the involvement of families can support them emotionally and financially.

On the other hand, the mothers were confronted with some hurdles to care their child at the end of life. For example, the absence of a nurse who visited their house to provide care to their child at home, the mother could not manage the pain of their child at home and the mother had difficulty in terms of cost and transportation when the child was in pain at home and must be taken to the hospital.

The mothers in this study tried to do things to please their child because they knew that they had had difficult experiences with the various treatments and medications. Although they also felt depressed that their child did not have long to live and got tired, they kept trying to please them by granting whatever their child wanted. Some participants revealed that they tried to care for their child by doing everything they wanted, always remaining close, and watching, entertaining, and supporting their child.

The mothers in this study also quit their job to take care of their child; some were willing to close their store to focus on their sick child. This aligns with Young *et al.*'s^[19] finding that parents are willing to leave their jobs to prioritize the treatment.

In addition, mothers tried to make their child happy by reading a prayer when their child was in pain, and the child also reveals that mothers' prayer was the strength for the child. Mothers always sang salawat, recited Al-Quran when the child was sick and tried to convince the child that the prayer delivered would be granted by God. This is in line with the study that says religious belief helps some parents to overcome the anger when confronting children with palliative conditions. Parents become more dependent on their beliefs or faith.^[21] Some parents felt overwhelmed by experience and were asked to

try to be positive and optimistic. Moreover, prayer and sibling involvement in the children's activities will be more fun.^[22]

Limitation

The limitation of the study is that the research gets difficulty to conduct bracketing process. Researcher then did reflections and fixed those things on the interview through giving open-ended questions and did not direct the answers of the participants.

CONCLUSION

This study shows that parents who cope with the pain of their child relied on family support, health-care workers, and all information about its management. Children and parents need professional palliative nurses to handle with pain. To improve the quality of palliative nursing care in children, it is required to develop a curriculum related to palliative care in children and to provide modules related to dimension of pain, pain responses in children, and appropriate pain management in children. The implication of this study on nursing practice is that nurses need to examine the pain felt by children comprehensively using a pain scale instrument. Nurses need to teach parents to be more sensitive to their child's pain scale from facial changes, behavioral changes, and how to communicate with the baby. Nurses also provide age-appropriate interventions in accordance with existing symptoms. Furthermore, nurses have an important role in encouraging parents to meet their spiritual needs, finding access to counseling professional to improve mother's knowledge. This study can be used as a reference to do a research about comparison of pain felt by children on chronic disease based on age level.

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Conflicts of interest

There are no conflicts of interest.

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