

Still Hoping for a Miracle: Parents' Experiences in Caring for their Child with Cancer Under Palliative Care

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Abstract

Context: Parents' despair and feelings of grief, as well as communication and coordination that is less than adequate between the parents and the palliative team, can affect the provision of a qualified palliative care plan for children and their families. **Aims:** This study aims to explore the parents' experience in caring for children with cancer under palliative care condition. **Setting and Design:** The research applied descriptive qualitative phenomenology design. **Subjects and Methods:** The study was conducted at Jakarta, Bogor, and Bekasi. Parents who caring their child with cancer under palliative care were in-depth interviewed with open-ended question. Data were then analyzed using the Colaizzi method. **Results:** This study resulted in two themes, still hoping for a miracle of God and always being surrendered while under palliative care. Parents still hope for a miracle of God to keep having their children during palliative care. The forms of surrendering exhibited by the parents in this study are believing in God, praying to God, saying thanks to God, relying on God, and preparing to face the deaths of their children. **Conclusion:** This study shows that during palliative care, parents cannot be separated from their relationship with God. Therefore, nurses are vital to the continuous assessment of parents' spiritual needs and to the facilitation of need fulfillment involving family and religious figures.

Keywords: Children, palliative care, parents' experiences, spiritual

INTRODUCTION

Children who have cancer commonly complain of physical and emotional symptoms affecting their quality of life.^[1,2] Meanwhile, parents who have children with cancer feel lost and experience emotional conflict because of an inability to accept the suffering and reality of losing their children.^[3] Children with cancer and their family members need comprehensive care throughout the course of the disease and until the end of life. However, they rarely have care which is effective, consistent, timely, and competently fulfilling their physical, emotional, and spiritual needs.^[4] It is our belief that by implementing a multidisciplinary approach to palliative care, we can increase the quality of life for children and their families.^[5] Palliative care is active total care of patients that addressed to fulfillment the physical, psychological, social and spiritual needs patients and family.^[6]

Qualified palliative care can increase the quality of life for children and their families. Although on the reality, palliative care also still have despair,^[7] even the feeling of grief in a long time for parents involving palliative care.^[8] In addition to noncontinuous implementation of care, ineffective

communication and lack of coordination between parents and the palliative team, ineffective symptom management, and inadequate provisions of information are still occurring during palliative care.^[9] These issues heavily impact the provision of adequate palliative care for children and their families.

Consequently, nurses need in-depth knowledge about child and family perspectives related to palliative care in order to be able to provide comprehensive and effective palliative care. The quality of palliative care depends on the assessment all dimensions of palliative care based on the patients' and families' perspectives.^[10] Since Indonesia has limited studies related to the parents perspectives, this research needs to conduct. Thus, this study aims to explore in-depth parents' experiences in caring for children with cancer under palliative care conditions.

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SUBJECTS AND METHODS

A descriptive qualitative phenomenology research design was used. Data collection was conducted between March 2017 and May 2017 in Jakarta, Bogor, and Bekasi and was facilitated by the Jakarta Rachel House Foundation. Ten participants (eight mothers and two fathers) participated in this research. Criteria for participant inclusion were parents who had experience in caring for children with cancer under palliative care conditions where the main therapy had been stopped, parents who were the primary care givers for their children, parents who had good Indonesian-speaking skills, and parents who were willing to be participants and to share their experiences. A purposive sampling technique was used, and the determination of the sample number was based on data saturation.

The 10 participants were aged 26–49 years, with educational backgrounds ranging from completion of elementary school to completion of senior/vocational high school. Of the participants, 5 had an individual child who was already deceased, and five had an individual child still under palliative care. Cancer diagnoses experienced by the children were acute lymphoblastic leukemia, acute myelogenous leukemia, chronic myeloid leukemia, osteosarcoma, rhabdomyosarcoma, medulloblastoma, craniopharyngioma, and teratoma mature.

Data collection through in-depth interviews was conducted under a duration of 39–70 min using interview guidelines and field notes. Data were then analyzed by using the Colaizzi method, where the researchers read the collected data repeatedly, chose significant statements, formulated meaning, and then grouped them into themes and subthemes.^[11] This study passed ethical testing by the Ethical Research Committee of Nursing Faculty at the Universitas Indonesia. Data validation was accomplished through credibility, dependability, confirmability, and transferability.

RESULTS

Two themes emerged from the data: still hoping for a miracle and surrendering to God.

Still hoping for a miracle

This theme was a reflection of a participant's hope that a miracle of God would occur while their child was under palliative care. Parents exhibited denial of what had been experienced and rested their hopes on God to have their children, as seen below:

Anyway what the doctor said to me, I don't believe it. Somebody says your child won't live longer... (Participant 5)

Yeah just a hope. Hoping due Rd (*child initials*) get well... (Participant 4)

Although we don't know how long Rd's age is, pretending that God gives a miracle for Rd in order to have longer age... that belongs to my sustenance... (Participant 5)

Looking at our child's smile, happy... that's what we are hoping for... (Participant 2)

Parents exhibited denial toward the judgment that their children's lives would not be long, and they held onto the hope that a miracle of God would allow their children to heal and live long happy lives.

Surrendering to god

The theme of surrendering to God figured parents' spiritual during caring their children under palliative care conditions.

So during the difficulties of my life, a true God help me. So it is truly amazing to have God. (Participant 7)

It is from that umm... I believe as well ... Uh yea ... That's why I surrender to Allah. (Participant 8)

Parents believed that God helped them to face their difficult experiences and thus surrendered to Him throughout the length of their child's palliative care. They also prayed to God to be closer to Him and asked for the healing of their children, which can be seen in the following statements:

That's what I said when I feel sad I come to God and I pray, it's true that our power comes from God. (Participant 7)

If I am sad, I usually just pray, do *sholat* (rituals of worship) that's it... (Participant 8)

Parents further embraced their spirituality by giving thanks to God for His help given during their child's palliative care, as seen below:

... so I am very grateful because God never sleeps, we don't know... suddenly there's someone came, I was speaking to myself who was that man... I don't recognize suddenly gave me an envelope. (Participant 1)

... yea Allah ... alhamdulillah thank you I said since I've been given sustenance ... I don't know where it comes from, I don't know. (Participant 2)

The form of surrendering on God was done by the parents was demonstrated by preparing in facing the death of their children, as follows:

... I've been sincere, it's pity, if it was the time, what's for holding the pain like that, if the kid died, our kid won't feel pain anymore. (Participant 10)

So we must really prepared the death. I said yes Nurse... I've been ready since Rg dying even when Rg (*child initials*) was diagnosed about it first time I am ready if Rg'd be gone. Because cancer won't let anyone live, will it? (Participant 6)

I just said that you don't be afraid to face death or anything, we don't know somebody's age. (Participant 1)

... I keep asking until at the end he is not ... (cannot survive)... I don't want if my child is applied with such tools in the body ... like inserting something ... (Participant 2)

Through these comments, parents showed that they had prepared themselves and their children to face death. The parents were sincere in their acceptance of their child's death and requested that their children rest in peace.

DISCUSSION

The theme of “still hoping for a miracle” illustrates how parents still hope for a miracle of God to keep having their children during palliative care. Despite parents being in denial at the onset of their child’s palliative care, the hope for a miracle still existed. This is in line with Smith’s^[12] study, which found that hoping is an effective coping strategy in making peace with chronic diseases and was more often connected to someone’s spirituality. Through hoping for the miracle of God, the parents’ wish being able to have their children healed from the diseases, to have their children physically or no losing their children, and to have their children happy.

The theme of “surrendering to God” in this study illustrates further how prominently spirituality features in parents during palliative care. Believing in God, praying to God, saying thanks to God, relying on God, and preparing to face the deaths of their children are the forms of surrendering exhibited by the parents in this study. The parents believed in a God that is always available to help them in the face of difficulty, and they fully surrendered to God’s mercy about the healing and life of the children. They are trying to do anything for making the children healed though the last result of their efforts is surrendering on God.

While caring for their children under palliative conditions, the parents bring themselves closer to obeying God’s command by reading the Bible and doing *sholat*. The participants stated that in their sadness, grief, and despair, getting closer to God made them feel peaceful and resilient. The research conducted by Hexem *et al.*^[13] also shows the same findings, in that, reading the Bible and praying were the primary spiritual and religious practices performed by the parents during their child’s palliative care.

The preparation in facing the death of the children also shows that the parents surrender on God in terms of death. The parents prepared their children to face death by saying and giving support to them to decrease their fears surrounding the possibility of death. This was supported in van der Geest *et al.*’s^[14] research study, where parents feel the benefits of talking with their children and decreasing their children’s fear of death. Contrast with other studies, in India, it was shown most parents reluctant to discuss dying with their child in palliative condition.^[15] The differences of culture make parents in facing death of their children in palliative care in different ways. The parents in this study further prepared themselves to face the deaths of their children by expressing a wish that their children do not die in pain, which is supported by findings in Björk *et al.*’s^[3] study, where parents prepare themselves and also the children in facing death.

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

By still hoping for a miracle and surrendering to God, the parents in this study show that during palliative care, they cannot be separated from their relationship with God. Nurses are vital to the continuous assessment of parents’ spiritual needs and to the facilitation of need fulfillment involving family and religious figures. Facilitating religious activities, such as recitation or church community in line with the religion and beliefs of the parents, can also be helpful. In the future, it would be beneficial to conduct studies implementing nursing intervention methods in order to add to evidence-based practices within the nursing field.

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Conflicts of interest

There are no conflicts of interest.

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