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## Abstract

**Background**: Children with cancer, who are at the end-of-life and facing death, need access to palliative care services, and nurses play an important role in providing these services.

**Aims**: To explore the palliative care strategies of Iranian nurses for children dying from cancer.

**Methods**: This was a qualitative study with conventional content analysis. Participants were 8 nurses, 1 social worker, 1 psychologist, 2 children, and 4 mothers from the Paediatric Oncology Unit in Semnan, Islamic Republic of Iran, who had experience in palliative care for children with cancer. Data were collected from individuals using in-depth, unstructured and semi-structured interviews and analysed using the Graneheim and Lundman approach. Data rigour increased with credibility, dependability, transferability, and confirmability criteria.

**Results**: Data analysis led to the emergence of the concept of “perceived compassion”. This theme was derived from the 2 main categories of “feeling the shadow of death on the child” and “comforting accompaniment”. Feeling the shadow of death on the child included the subcategories of “pre-death arrangements” and “an opportunity to continue interactions”. Comforting accompaniment was derived from 3 subcategories: “preparing to announce the child’s death”, “extra-role sympathy” and “ post-death interactions”.

**Conclusion**: Perceived compassion was the main strategy used by Iranian nurses to provide palliative care to children dying from cancer.

Keywords: Nursing, death, paediatric, palliative care, cancer, compassion, sympathy, Islamic Republic of Iran

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## Introduction

Palliative care for children is a comprehensive approach that begins with the diagnosis of life-threatening illness and continues even after the children die, including providing appropriate care to families (1,2). Children with cancer receiving palliative care services suffer adverse consequences such as psychological problems. Paediatric nurses in the palliative care team have multiple responsibilities, such as identifying the psycho-oncology-related symptoms, supporting children and families, strengthening the sense of hope in families, and preparing for the prognosis and challenging treatment trajectory that can lead to the child's death. Nurses need to also consider their personal and professional responses to the death of a child, and the family's mourning as the basis for optimal care (3–5).

Paediatric nurses should provide information to families about their children's end-of-life situation to help them deal with it calmly (6). Nurses in paediatric palliative care have a specific role in providing care for children who suffer from life-threatening conditions such as cancer (7). Nikfarid et al. found that mothers of children with cancer had experiences such as chronic suffering, health issues, maladaptive coping, and lack of skills due to their children's disease (8).

The death of a child due to a life-threatening disease such as cancer is a tragedy for parents and other family members (9), which disrupts the social integrity of the family (10). Paying attention to the family at the time of their mourning is a standard part of palliative care (2). Funes et al. concluded that nurses used a variety of strategies such as end-of-life care, providing comfort, and respect for patients dying of cancer (11). October et al. emphasized supporting parents when their child is admitted to the intensive care unit or at the time of death (12). Haylett et al. found that parents' deep desire after their child's death is that others come alongside them by validating their emotions and experience, providing opportunities for family renewal (13). Dong et al. found that nurses are more concerned about the physical comfort of dying patients and fulfilling their wishes (14).

Nurses' actions in palliative care for children with cancer are effective when they are appropriate to the sociocultural context of each country (15). Therefore, identifying and strengthening nursing strategies for dying children and their families before and after death are useful (16). Nursing strategies for children dying of cancer are complex phenomena that depend on the unique context and circumstances surrounding the context of their care. Exploration of this context is required to select a rigorous research methodology, and qualitative research approaches are appropriate. These approaches reveal the hidden aspects of human behaviour and answer questions with human interpretations and mindsets (17, 18). Due to the absence of a localized tool to identify and explain these strategies, this study explored the content of nursing strategies in confronting children's death from cancer using a qualitative content analysis approach.

## Methods

### Study design and participants

This study used a conventional qualitative content analysis approach to explore explicit and latent contents in the data. The latent content is expressed as themes (17). The study was conducted in the paediatric cancer ward of a reference hospital in Semnan, Islamic Republic of Iran. The inclusion criteria were willingness to participate in the study, ability to speak in Persian, and nursing experience of caring for a child with cancer for ≥ 6 months. Sudden withdrawal from the study was considered an exclusion criterion. Initially, participants were nurses who had experience of caring for children with cancer and their families. Nurses with the longest experience in paediatric oncology were selected as the key informants. Individual interviews were conducted with mothers and their children as well as other healthcare providers based on the data obtained from the analysis and their confirmation.

To explain nursing strategies in paediatric palliative care, we considered the maximum diversity in terms of characteristics like age, years of work experience and the length of time that the

children had cancer. Sampling was performed until data saturation in relation to the study context. Saturation is when no new data of importance for the study emerge and the elements of all categories are accounted (19). We used strategies such as asking questions about the data and constantly comparing coded data and categories throughout the analysis to increase the sensitivity of the data. We explored possible properties of any categories and we did not find any further data pertinent to the categories emerged during data collection. In Interviews 15 and 16, the participants expressed the same ideas. Finally, sampling was completed with 16 participants (including 8 nurses, 1 social worker, 1 psychologist, 2 children and 4 mothers).

### Data collection

The aim of this study was to gain understanding of nursing strategies for palliative care of children with cancer, and the possible emergence of a wide range of basic social processes; therefore, we decided to use interviews to gather information. Data were collected by the first author of this study through in-depth and individual interviews. Initially, the interviews were unstructured and started with an open-ended question and continued based on the participants' conversations. Then, they were based on the progress of data analysis and extraction of new concepts, using semistructured interviews. The researcher explained the purpose of the study to the participants. The time of each interview was determined according to the participant's preference. The interviews were conducted in agreement with the participants at their workplace or home. Data collection continued from 20 December 2019 to 18 April 2021. The interviews lasted between 47 and 68 minutes. Initially, face-to-face interviews were conducted, and then following limitations due to the COVID-19 pandemic, interviews were done online. The interviews with nurses began with demographic and open-ended questions about the experience of caring for a child with cancer, which gradually focused on the actions and care of the child in life-threatening and dying conditions. Questions from participants who were not nurses were designed in relation to the data obtained from interviews with nurses to confirm and make the care content more transparent. The interviews continued until the data were saturated. The researcher tried to be minimally involved in the interviews, so that most of the time was spent by the participants. Wherever the participants' statements were ambiguous, the researcher asked them to explain more about their experiences in order to gain deeper understanding of the participants' experiences. The researcher also paid attention to changes in the tone of voice and facial cues of the participants. The interviews were recorded using a digital voice recorder and transcript for analysis.

### Data analysis and trustworthiness

The Graneheim and Lundman approach was used for data analysis. This approach proposes systematic steps for a conventional qualitative content analysis (17). Based on this approach, the following steps were performed. First, the interviews were transcribed, then the parts of the interview that were to be analysed were considered as the unit of analysis. The words, sentences and paragraphs that were related to each other in terms of content were analysed as meaning units. These units were placed next to each other according to their hidden content and were considered as a code at abstract level. The codes were compared with each other

based on their similarities and differences and placed in more abstract categories. Finally, with deep reflection and continuous comparison of categories that had similar characteristics, they were introduced at a higher level of abstraction as the theme of the study. Also, the MAXQDA, 2018 software was used for data analysis and management.

According to Graneheim and Lundman, the criteria of credibility, dependability and transferability were used to increase the trustworthiness of the data (17). Data credibility increased with memo writing and the researcher's long-term interaction with the data, and peer and participant review. Two qualitative and expert researchers in palliative care examined the codes and categories in terms of appropriateness and readability. Participants' points of view were used to assess dependability. In this way, parts of text of the interview with the open codes were sent to participants to compare the appropriateness and homogeneity of the results with their own views, opinions and experiences. Transferability was achieved by accurately describing information that allows readers to evaluate the accuracy of the research and to match the results with their context. Also the external check method was used for confirmability. This means that parts of the text of the interviews along with the codes and categories were sent to 4 external observers and they commented on the accuracy of the findings.

### Ethical considerations

This study was approved by the Ethics Committee of Semnan University of Medical Sciences with the number IR.SEMUMS.REC.1398.224. The researchers observed ethical considerations by taking actions such as stating the purpose of the research to the participants, voluntary participation in the research, obtaining informed consent from the participants, ensuring anonymity and preserving their audio files.

## Results

Data analysis led to the concept of "perceived compassion". This was derived from the main categories of "feeling the shadow of death on the child" and "comforting accompaniment". Perceived compassion was the main strategy for nurses during children's death. The imminent death of children with cancer was unavoidable and beyond the control of nurses. While the nurses had a duty to prepare the children and their families for imminent death, they also took a comforting approach to the situation of the parents after their child's death. Due to the chronic nature of cancer, communication between children, parents and nurses became close and intimate. Therefore, the conditions at the end of the children's lives caused resentment and sadness in the nurses. While the nurses felt and controlled this grief, they tried to prepare the children and their families to face death. In general, the following strategies were adopted by nurses during children's death from cancer. Table 1

### Feeling the shadow of death on children

During palliative care, due to the chronic condition and multiple follow-up treatments, nurses had more contact with children with cancer and easily understood the clinical course of the disease. They knew that the children were not recovering and would eventually die. Therefore, their action was focused on creating opportunities for more interaction between parents and children and helping them face death. This category consisted of 2 subcategories: “predeath arrangements” and “an opportunity to continue interactions”.

### Pre-death arrangements

For predeath arrangements, nurses considered strategies such as informing parents of the probable time of death of their children and separating dying children from other children. The nurses believed that it was the parents’ right to know about their child’s condition and imminent death. Parents were informed of their child’s condition and that nothing could be done. Children facing imminent death may have conditions or needs that are different from those of other hospitalized children. The death of children in the presence of other hospitalized children may lead to adverse emotional reactions. Therefore, nurses transferred dying children to the intensive care unit (ICU) as soon as possible. “When a child is next to die, we do not keep him/her in the ward, in order not to affect the spirt of others. We do not even let other children know that this child has died” (Nurse).

### An opportunity to continue interactions

This subcategory included strategies to facilitate parents’ constant presence with their child and to reduce visiting restrictions for other relatives. When the children were in the ICU, despite the special conditions and rules of attending the ward, nurses facilitated the constant presence of parents and other relatives with their child. “In the last moments of life of children in the ICU, mothers were not separated from their children” (Nurse). “We reduced meeting restrictions. Some families were extrovert and liked to communicate more with relatives. We eased some of the visiting restrictions for grandparents and other relatives” (Nurse).

### Comforting accompaniment

The nurses prepared parents to hear about their child’s death by providing consolation and an opportunity for them to see their child for the last time. They maintained interaction with parents after the child died. Implementing these strategies enabled nurses to act as comforting companions for families.

### Preparing to announce the child’s death

When the nurses wanted to give news of a child’s death, they took the parents to a quiet environment, where the illness and condition of the child were explained again, assuring the parents that the care team had done their best for the child. The parents were given the

opportunity to say goodbye to their child's body. To allow parents to express their feelings when their child's death was announced, the nurses moved them away from the stressful environment to a calm environment. "We take the family to a room where the others are unaware. We keep them in a quiet environment and we do not inform them in a crowded ward or in the patient's room" (Nurse). After that, the nurses considered it was the parents' right to review the status and progress of their child's illness. For parents not to feel the blame, nurses reassured them that their child's illness was progressive and that they did everything they could for their child, but unfortunately their child died due to worsening of the illness. The nurses felt that if they allowed the parents to say goodbye to their child before transferring the body to the mortuary, they would be able to deal with the mourning process better.

### Extra-role sympathy

Extra-role sympathy included self-sacrificial actions of nurses to offer sympathy and emotional accompaniment to parents beyond the call of duty. The nurses may have been in a bad mood, but when they felt that the parents of the deceased child needed their attention, they accepted the hardship wholeheartedly and tried to comfort them. "After the child's death, although I was not in a good mood; at the request of the mother of the child, who was deeply saddened, I went to her house and stayed with her for hours until she calmed down" (Head Nurse). "I took her mother to the hospital, with her father. I was with him and no one came with us. After giving a sedative I took her home" (Head Nurse).

### Post-death interactions

Due to the chronic nature of paediatric cancer, friendly relationships were established between the nurses and the children's families, and these continued after the children's death, such as attending funerals and keeping in contact with the parents. According to the nurses, the children's families were considered as part of their own families. Therefore, in this study, many years after the children's deaths, we still witnessed the interaction of nurses with the children's families by telephone and in person.

## Discussion

The aim of this study was to explore the palliative care strategies of Iranian nurses during children's death from cancer. The concept of perceived compassion emerged from data analysis. This concept reflects the nurses' strategies for dealing with children with cancer at the end-of-life stage. As the children approached the end of life and imminent death, the nurses did their best to provide comfort for the children and their families. Seig et al. found that parents were comforted by receiving friendly care from providers of palliative care (20). Kohi et al. mentioned that children with cancer need compassionate and loving care from nurses and doctors; also that children expect healthcare providers to be close to them if necessary, listen to their needs, and help immediately (21).

When nurses become aware of the imminent death of a child, they take actions such as keeping that child away from other children and informing the child's parents. They permit more interaction between the child and their parents and other relatives. In the final days of a child's life, Lockwood and Humphrey described impactful interventions, including assisting the family transition toward acceptance of a child's pending death, using prognostication as a tool in emotional preparedness, and educating the family about the expected conditions to increase their resilience (22). Kars et al. identified 4 stages in caring at home for parents of children with cancer at the end of life: becoming aware of the unavoidable death; making the child's life pleasurable; managing the deterioration; and preserving the parent–dying child relationship (23). Johnston et al. found that bereaved parents preferred that their child died at home, and that barriers to being with their child in hospital were reduced (24). According to Malcolm and Knighting, parents of children with cancer expressed that preparing the place for their child's death, compassionate death, bereavement care, and providing a child and family-centred approach were effective aspects of end-of-life care (25).

Providing comfort for children and parents was another nursing strategy in end-of-life care. Nurses tried to help parents endure the situation by taking actions such as considering giving bad news to parents, empathizing beyond their duty with parents, and even continuing to communicate with them after their child's death. Lima et al. showed that telling bad news to parents in the palliative care unit was performed by professionals in a specific room, and then they reviewed what happened (26). Similarly, October et al. concluded that planning a meeting between staff and parents after a child's death can enhance supportive care for bereaved parents (12).

In this study, extra-role sympathy referred to actions beyond the call of duty taken by nurses during parents' bereavement for their child. McNeil et al. noted that bereavement support for parents after the death of their child was an essential component of quality palliative care (27). Also, Koch and Jones found that quality palliative care addresses the mourning needs and emotional support of parents (28). We found that nurses continued their relationship with bereaved parents after their children's deaths. In particular, they communicated with mothers by telephone or through face-to-face interaction. Similar continued communication was mentioned in other studies. Van der Geest et al. reported that continued communication and care by healthcare professionals with parents who had lost their children to cancer were associated with lower levels of long-term grief (29). Lichtenthal et al. demonstrated that contact of the healthcare team with bereaved parents after their children's death improved bereavement outcomes (30).

## Conclusion

Perceived compassion was the main strategy of nurses in palliative care for children facing

death from cancer. In perceived compassion, the nurses' whole effort was to prepare children and families to better face death; however, sometimes it was difficult for nurses to implement these strategies.

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## Stratégies de soins palliatifs du personnel infirmier iranien pour les décès d'enfants liés au cancer : étude qualitative

### Résumé

**Contexte** : Les enfants atteints de cancer, qui sont en fin de vie et confrontés à la mort, doivent pouvoir accéder à des services de soins palliatifs et le personnel infirmier joue un rôle important dans la fourniture de ces services.

**Objectifs** : Examiner les stratégies de soins palliatifs du personnel infirmier iranien pour les décès d'enfants liés au cancer.

**Méthodes** : Il s'agissait d'une étude de recherche qualitative avec analyse de contenu classique. Les participants étaient huit infirmiers, un travailleur social, un psychologue, deux enfants et quatre mères de l'Unité d'oncologie pédiatrique de Semnan (République islamique d'Iran) qui avaient une expérience liée aux soins palliatifs pour les enfants atteints de cancer. Les données ont été recueillies auprès de sujets au moyen d'entretiens approfondis non structurés et semi-structurés, et analysées selon l'approche de Graneheim et Lundman. La rigueur des données augmentait avec l'utilisation des critères de crédibilité, fiabilité, transférabilité et confirmabilité.

**Résultats** : L'analyse des données a permis l'émergence du concept de « compassion ressentie ». Ce thème était dérivé des deux catégories principales « ressentir l'ombre de la mort sur l'enfant » et « accompagnement réconfortant ». Ressentir l'ombre de la mort sur l'enfant comprenait les sous-catégories « dispositions à prendre avant le décès » et « opportunité de poursuivre les interactions ». L'accompagnement réconfortant était dérivé de trois sous-catégories : « préparation à l'annonce du décès de l'enfant », « compassion extra-rôle » et « interactions post-décès ».

**Conclusion** : La compassion ressentie était la principale stratégie utilisée par le personnel infirmier iranien pour fournir des soins palliatifs aux enfants mourant d'un cancer.

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