ORIGINAL RESEARCH ORİJİNAL ARAŞTIRMA

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End-of-Life Communication Experiences of Nurses with Family Members Before and After the Death of a Child in Paediatric Oncology Services: Qualitative Descriptive Study

Çocuk Onkoloji Servislerinde Çalışan Hemşirelerin Bir Çocuğun Ölümünden Önce ve Sonra Aile Üyeleriyle Yaşam Sonu İletişim Deneyimleri: Betimleyici Nitel Çalışma

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ABSTRACT Objective: Whilst the effective communication is essential to providing family centred bereavement care, research on this topic is still limited. The objective of this study is to explore end-of-life communication experiences of nurses with family members before and after the death of a child in paediatric oncology services. Material and Methods: A qualitative descriptive study was conducted using semistructured interviews and thematic analysis. The purposive sampling technique was employed to collect data from 14 nurses working in paediatric oncology services. In this study, 14 in-depth, semi-structured interviews were conducted by 2 researchers using the Zoom video conferencing platform. Results: The data analysis generated 5 themes and 14 subthemes. The findings reveal that nurses experience multidimensional difficulties at emotional, ethical and organisational levels when communicating with families during the process of child death. Barriers, such as difficulty in talking about death, a lack of interpreters and long working hours, negatively affect communication. On the other hand, therapeutic communication techniques, such as open and honest communication, facilitate this process. Conclusion: Our results suggest that organisational support for nurses and the development of effective end-of-life communication strategies specific to paediatric oncology services are essential to provide dignified and family-centred care. This study contributes to improving the quality of family-centred care by providing evidence-based information and important strategies from the nurse perspective for effective communication guidelines and policies tailored to paediatric palliative and end-of-life care needs.

Keywords: Bereaved parents; communication; dying child; end-of-life; palliative care

ÖZET Amaç: Etkili iletişim, aile merkezli yas bakımını sağlamada kritik bir öneme sahip olmasına rağmen bu konudaki yapılan araştırmalar hâlâ sınırlıdır. Bu çalışmanın amacı, çocuk onkoloji servislerinde bir çocuğun ölümünden önce ve sonra hemşirelerin aile üyeleriyle yaşam sonu iletisim deneyimlerini araştırmaktır. Gerec ve Yöntemler: Yarı yapılandırılmış görüşmeler ve tematik analiz kullanılarak nitel tanımlayıcı bir çalışma yürütülmüştür. Çocuk onkoloji servislerinde çalışan 14 hemşireden veri toplamak için amaçlı örnekleme tekniği kullanılmıştır. Bu çalışmada, Zoom video konferans platformu kullanılarak 2 araştırmacı tarafından 14 derinlemesine, yarı yapılandırılmış görüşme gerçekleştirilmiştir. Bulgular: Veri analizi sonucunda, 5 tema ve 14 alt tema olusturulmustur. Bulgular, hemsirelerin bir çocuğun ölümü sürecinde ailelerle iletişim kurarken duygusal, etik ve kurumsal düzeyde çok boyutlu zorluklar yaşadıklarını ortaya koymuştur. Ölüm hakkında konuşmanın zorluğu, tercüman eksikliği ve uzun çalışma saatleri gibi engeller iletişimi olumsuz etkilemektedir. Öte yandan, açık ve dürüst iletişim gibi terapötik iletişim teknikleri bu süreci kolaylaştırmaktadır. Sonuç: Sonuçlarımız, hemşireler için kurumsal desteğin ve çocuk onkoloji hizmetlerine özgü etkili yaşam sonu iletişim stratejilerinin geliştirilmesinin, onurlu ve aile merkezli bakım sağlamak için gerekli olduğunu göstermektedir. Bu çalısma, pediatrik palyatif ve yaşam sonu bakım ihtiyaçlarına yönelik uyarlanmış etkili iletişim rehberleri ve politikaları için kanıta dayalı bilgiler ve hemşire perspektifinden önemli stratejiler sunarak çocuk ile aile merkezli bakım kalitesinin artırılmasına katkı sağlamaktadır.

Anahtar Kelimeler: Yaslı ebeveynler; iletişim; ölmekte olan çocuk; yaşam sonu; palyatif bakım

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Worldwide, about 400,000 children of 0-19 years old are diagnosed with cancer each year is the 2nd most common cause of death among children after accidental death. More than 80% of children with cancer are cured in high-income countries, where comprehensive services are generally available. However, less than 30% are cured in low- and middle-income countries. In Türkiye, it was reported that 50,887 children were diagnosed with cancer between 2002-2023 and the 5-year survival rate for childhood cancer was reported to be approximately 70 per cent. For this reason, improving the quality of end-of-life care communication with family members before and after the death of a child is one of the important health priorities. ³

End-of-life communication primarily involves addressing both pre-bereavement and post-bereavement processes.⁴ The pre-bereavement refers to the period before the death of a loved one, when people make emotional and psychological adjustments in preparation for the death. The post-bereavement, on the other hand, refers to the period after the death of a loved one, which centres on grief, adaptation and the potential long-term effects.⁵ In paediatric oncology, pre- and post- bereavement processes often intertwine, as parents may begin to grieve before the death of the child, sometimes from the moment of diagnosis. Based on the results of a systematic review, many families experience prolonged grief disorder and depression after the child's death, particularly when adequate psychosocial support is lacking.6 These findings highlight the importance of early, sustained, and structured support by the healthcare team, with a particular emphasis on effective communication.7 Within this context, nurses have a central role in supporting families during both the pre- and postbereavement process.6 The quality of nurse-family communication directly affects not only affects the end of life care provided to the child but also the psychological well-being of parents.8 As part of familycentred care, communication should involve families in care planning, foster emotional preparedness, and help navigate complex decision-making processes.⁷

Despite the recognized importance of communication in paediatric oncology settings, nurses generally feel uncomfortable communicating with family member of children at the end-of-life. 9-12 This is commonly linked to a lack of formal training in end-oflife communication, limited confidence in initiating conversations about death, and insufficient mentoring to build communication skills. In addition, the emotional burden on nurses caring for dying children is substantial.¹³ Feelings of sadness, guilt, and helplessness are frequently reported, yet the ways in which these emotions influence communication practices and care quality have not been adequately explored.¹⁴ Moreover, a large number of papers have been published in recent years demonstrating the importance of communication between family members over the age of 18 and healthcare professionals. 9-11,15 However, the decision-making burden on the families of children under the age of 18 makes the process difficult.16

Given the critical role of supportive and effective communication in assisting family members who bear the burden of decision-making for children with cancer, this study is critical in that will contribute to the enhancement of family-centred care by providing nurse-informed evidence and practical strategies to strengthen end-of-life communication in paediatric oncology settings.

Aims and Objectives

This qualitative study aims to explore paediatric oncology nurses' experiences of end-of-life communication with family members during both the prebereavement and post-bereavement process.

The objectives of this study are to:

- Explore nurses' perspectives on the challenges and facilitators of end-of-life communication with family members.
- Identify the organisational barriers that negatively impact effective end-of-life communication with family members.

MATERIAL AND METHODS

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was obtained from the Muğla Sıtkı Koçman University Health Science Ethics Committee (date: February 24, 2025; no: 24). Prior to participation, all subjects were furnished with both verbal

and written information, outlining the objectives and methodologies of the study. It is noteworthy that none of the participants had any prior relationship with the research team. The information statement confirmed that participation was voluntary and that all contributions would remain anonymous. Participants were informed of their right to withdraw from the study at any time without consequence, as well as their option to pause, terminate or reschedule the interview. The participants' identifications were anonymised and coded accordingly. No incentives or payments were provided to participants.

STUDY DESIGN

A qualitative descriptive study using semi-structured interviews was conducted to gain a comprehensive and direct understanding of the experiences of end-of-life communication between nurses and family members before and after the death of a child.¹⁷ The design of the study enabled the exploration of nurses' experiences of complex and sensitive issues.¹⁸ In-depth experiences were explored through individual interviews, which were then reported in accordance with the consolidated criteria for reporting qualitative studies.

Population

The participants were nurses working in paediatric oncology services in Türkiye.

Sample and Recruitment

Purposive sampling was used to include nurses caring for children with cancer in the study. This sampling method is a methodical process of participant selection that is intended to ensure a comprehensive understanding of the issues under study. Potential participants were recruited through social media via a brief information poster about the study. Once initial participants were recruited, the team decided whether to recruit additional participants via snowball sampling. Interested nurses were contacted by one of the researchers (RK) and invited to participate in a semi-structured interview on Zoom after written and verbal consent had been obtained. In the study of the sampling of the researchers (RK) and invited to participate in a semi-structured interview on Zoom after written and verbal consent had been obtained.

The inclusion criteria were as follows: Firstly, nurses working in a paediatric oncology service for a minimum of 1 year were included. Secondly, nurses

who had experienced the death of a child within the past year were included. Thirdly, nurses who had provided informed consent to participate voluntarily were included. The following individuals were excluded from the study: Nurses with less than 1 year of experience in the paediatric oncology service and nurses who were unwilling to participate in the study were excluded.

DATA COLLECTION

In this study, 14 in-depth, semi-structured interviews were conducted by 2 researchers using the Zoom video conferencing platform. The 1st interviewer, a female assistant professor with 12 years of experience in bereavement, palliative and end of life care research, has no children, nor any personal or family history of cancer-related death, psychiatric illness, or trauma. The 2nd interviewer (RK), a male paediatric research nurse with 8 years of experience, has 1 child and similarly no relevant personal or family history.

After 10 interviews, no new theme emerged, and the interviews were concluded at the end of 14 interviews. According to the literature, researchers usually conduct 2-3 additional interviews when they observe that no new information is received.²¹

The research was conducted in accordance with the principles of the Declaration of Helsinki. The development of the interview guide was informed by the study's stated aim and objectives, with questions developed based on the literature. 9-12,15 The appropriateness of the questions was assessed through the conducting of 3 pilot interviews, and no significant modifications were required (Appendix 1). The meetings were audio recorded and lasted between 35-76 min. The semi-structured method employed in this study has enabled the participants to delve into the intricacies of their experiences and articulate their concerns in a detailed manner.²² The interview process started with a series of enquiries directed towards the participants concerning their experiences in the context of communicating with family members (See the interview guide in Appendix 1).

DATA ANALYSIS

Thematic analysis was employed to analyse the data. This approach is highly flexible and allows for the re-

APPENDIX 1

Introduction

. Thank you for agreeing to take part.

Give background&purpose to study: we want to explore end-of-life communication experiences of nurses with family members before and after the death of a child in paediatric oncology services. This can contribute to the development of end-of-life communication tools/guidelines for paediatric palliative care in future.

- · Acknowledge that the topic is upsetting/sensitive. If they want to have a break at any time (and stop the recording) that is absolutely fine.
- Explain the consent procedure, right to withdraw, confidentiality and audio recording of the discussion. Break at any time if required. Interview discussion to last 30-90 min. Check that they have understood the information sheet, confidentiality information and check understanding.
- Explain how the discussion that is going to take place will be used in the research.
- · Findings will be published in academic journals
- · Complete consent forms

I would really like to start by hearing about your end-of-life communication experience with children who have life-threatening conditions. Is that okay?

- •Can you please tell us about your experiences in communicating with family members of children at the end-of-life?
- •If these family members had questions, expressions of emotion, thoughts about death, what were these? (Probe: How was your response, reaction, etc. to these expressions of parents? Can you explain this a little more with examples)?
- •What are the difficulties you experience in communicating with family members of children at the end-of-life?
- •What are the organisational barriers that negatively impact effective end-of-life communication with family members of children at the end of life?

Closing (Any other comments, suggestions or questions)

•I would like to ask you for your final thoughts reflections as we come to the end of our discussion. You have been through a difficult experience, and I am grateful that you have shared it. Your views are very valuable to us, and we hope that you have not found it too distressing to share your experience.

porting of the experiences, meanings and realities of the participants.²³ The 6-stage method used by Braun and Clarke was applied by 2 researchers (CFD; GMK); (I) familiarising with the dataset, (II) coding, (III) generating initial themes, (IV) developing and reviewing themes, (V) refining, defining and naming themes and (VI) writing up.²³ All data were independently read, and then coded using NVivo (Version 14) by the 1st author with qualitative research experience within end of life and bereavement care (CFD) and a professor in paediatric nursing with experience in qualitative research (GKM). Regular research team meetings were planned to discuss emerging themes and resolve differences, and as a result of these meetings, 1 main theme and 2 sub-themes were renamed. Disagreements in coding were resolved by GKM.

RESULTS

In total, 14 interviews were conducted. Most participants (%85) were female, and their age ranged from 27 to 38 years, with a mean age of 31 years. The duration of employment within the paediatric oncology service was between 4-11 years. A comprehensive

overview of the participants' sociodemographic characteristics is provided in Table 1. Five main themes and 12 subthemes were generated from the study analysis. The main themes were: 1) Challenges during the pre-bereavement communication, 2) Pre-bereavement communication facilitators, 3) Communication challenges after the death, 4) Post-bereavement communication facilitators, and 5) Organisational barriers to effective communication. Table 2 and Figure 1 provides further data that supports these themes and sub-themes.

THEME 1: CHALLENGES DURING THE PRE-BEREAVEMENT COMMUNICATION

The theme of challenges during the pre-bereavement communication included the following sub-themes: (1) Difficulty in talking about death, (2) Communicate with families in denial, and (3) Burden of carrying bad news.

Difficulty in Talking About Death

Most nurses highlighted the emotional and psychological barriers faced by both families and healthcare professionals and experienced the complexity sur-

Participant	Gender	Age	Marital status	Having children	Experience in paediatric oncology service
P1	Female	36	Married	Yes	7
P2	Female	33	Married	No	7
P3	Male	29	Single	No	6
P4	Male	31	Married	No	5
P5	Female	27	Married	No	4
P6	Female	30	Married	No	6
P7	Female	35	Married	Yes	9
P8	Female	37	Married	Yes	11
P9	Female	39	Married	Yes	10
P10	Female	36	Married	Yes	8
P11	Female	35	Married	Yes	8
P12	Female	32	Married	Yes	7
P13	Female	38	Single	Yes	11
P14	Female	28	Single	No	5

rounding discussions about death in paediatric healthcare settings. For example:

"...families generally do not ask any questions about death...I also feel helpless and in a dilemma in the face of questions about death. Each time I think that maybe a miracle will happen, and the child will survive." P10

Communicate with Families in Denial

Some of the nurses who participated in this study stated that it affected their communication with families in the denial stage. In the following sentence, a nurse mentioned this situation as follows:

"A mother whose child was diagnosed with cancer became in denial after a certain point. In other words, at first, she was angry...when she went into denial, she said, "No, my child is not sick". When families are in such a stage of denial, we may experience communication difficulties..." P3

Burden of Delivering Bad News

Most of the nurses who participated in this study emphasized the emotional burden and psychological tension they experienced while delivering bad news and drew attention to the risk of emotional exhaustion and burnout. For example:

"Giving the news of someone's death or the news that someone is close to death makes us feel depressed, sometimes we even move from empathy to sympathy, you think about what I would do if it happened to my relatives...we sometimes feel that we are going through such a burnout..." P1

THEME 2: PRE-BEREAVEMENT COMMUNICATION FACILITATORS

Two facilitators have been identified in the communication with the family in the period before the child's death, namely: (I) Encouraging the family members to say goodbye, and (II) Honest and open communication.

Encouraging the Family Members to Say Goodbye

Some of the nurses mentioned the role of nurses in facilitating the pre-bereavement process of families experiencing child loss and emphasized the importance of creating a compassionate and dignified environment for farewell rituals. For example:

"...We try to make families experience that mourning process, that process of saying goodbye. We clean the child completely... then they hug, kiss, caress and let them cry. This sometimes takes fifteen minutes, sometimes much longer. We use that time for them to go through the process of saying goodbye..." P13

Honest and Open Communication

Most of the nurses who participated in our study emphasized the essential role of open and honest com-

	TABL	TABLE 2: Overview of qualitative themes
Major themes	Sub-themes	Illustrative quotes
	Difficulty in talking about death	"families generally do not ask any questions about death. I think they are prevented from asking questions and expressing their thoughts by both the family and nurses because talking about these subject upsets both the family and the healthcare team. If the child wants to talk about death, the family is against it and does not want to hear the word death from their childEach time I think that maybe a miracle will happen, and the child will survive." P10
Challenges during the pre-bereavement communication	Communicate with families in denial	"A mother whose child was diagnosed with cancer became in denial after a certain point. In other words, at first, she was angry, She had expressions such as "How is my child, why is my child". Later, when she went into denial, she said, "No, my child is not sick". When families are in such a stage of denial, we may experience communication difficulties" P3
	Burden of delivering bad news	"Giving the news of someone's death or the news that someone is close to death makes us feel depressed, sometimes we even move from empathy to sympathy, you think about what I would do if it happened to my relatives. We get tired in that respect. I mean, we sometimes feel that we are going through such a burnout P1
Pre-bereavement communication facilitators	Encouraging the family members to say goodbye	"We also allow them to experience sadness there and they hug their child, kiss their child. We try to make families experience that mourning process, that process of saying goodbye. We clean the child completely, we remove the blood, if there is saliva in the mouth, we do all the cleaning. Then we wrap the child in white sheets. Only his face is exposed. We ask them to come and see their child. They come. They hug, kiss, caress and let them cry We use that time for them to go through the process of saying goodbye" P13
	Honest and open communication	"Families are more anxious when they are not sufficiently informed about the process of their child's illness. We try to give them all the answers we can in an honest way. I think honest and open communication reinforces their trust in us." P4
	Avoidance communication with the family after death	"I mean, I don't want to come face to face with the family whose lost their child I mean, maybe I want to cover it up. I don't know what the mother will feel when she sees me, I don't know what I will feel when I see the motherWhat will the mother feel when she sees me, what will she do? That's why, to be honest, I don't want to meet with the families again and again" P5
Communication challenges after the death	Challenging emotions	"In such cases (in the case of child death), our nurses' room is like a crying wall. In other words, every nurse comes to the nurse's room with a napkin in her hand, wipes her face and eyes and goes back to the ward. I mean, I don't know, it's not just about me or because I'm a mum. You know, we also have single friends. They are affected in the same way. Because I really think that the death of a child hurts everyone deeply. As I said, let children always laugh, have fun, play, but not on their deathbed." Pr11
	Using touch and silence	"all I do is hug bereaved mothers. Give them a chance to cry. Standing silently beside them, there's nothing else I can dothat's all I can do. And I try to help them stay strong." P7
Post-bereavement communication facilitators	Telephone call after death	"! am still in contact with this family after the death of their child. We lost our child in 2016, but I am still in contact with the family. The mother didn't answer her phone for a month and a half. Afterwards, I spoke to the mother. I even asked her that if my calling you makes you more upset, I may not call. But the mother said that she remembered good memories while talking to me and that remembering her son was good for her." P2
	No private room to make the death notification	"I wish the news of death could be given in a separate room accompanied by a mental health professional. You know, not standing, not on a chair, but sitting on a chair, without other people around him/her watching him/her, I think it makes people very uncomfortable. I think that when they receive negative news about their child or news of death, the looks of the people around them disturb the families" P4
Organisational barriers to effective communication	Lack of interpreters	"In fact, we are also hospitalising foreign patients such as Syrian. If I am on duty that day, I save the person next to me. When there is a problem, a conflict, I immediately go and solve it. But if the interpreter capacity of the hospital is increased and interpreters arrive, perhaps an attack will be prevented at that moment. Previously, for example, a patient's relative walked on our female colleagues. In the meantime, they called me. I was off duty, for example. We solved that communication problem there." P3
	Low salary and long working hours	"I think the tension in the nurses and the unbearable hospital environment, the lack of wages received, the nurses are now tired of coming to work and going to work. Therefore, improving communication techniques is the last thing that hospitals think about, because nurses now have low salaries, very difficult conditions, lack of materials, and the inability to do anything sociallyMaybe if we can reduce wages and working hours a little more, we can reach communication in a healthier way. Because if nurses are now told to teach effective communication techniques, they'll say, is this our priority problem? Unfortunately, they will give such feedback." P1

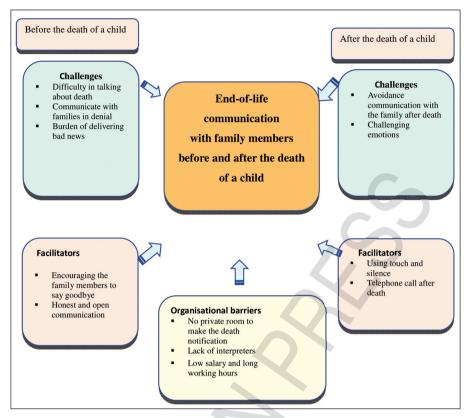


FIGURE 1: A proposed framework for end-of-life communication with family members

munication, especially in helping to reduce the anxiety of family members and to build trust between families and health care professionals. For example:

"Families are more anxious when they are not sufficiently informed about the process of their child's illness. We try to give them all the answers we can in an honest way. I think honest and open communication reinforces their trust in us." P4

COMMUNICATION CHALLENGES AFTER THE DEATH

Two communication challenges after the child's death, namely: (I) Avoidance communication with the family after death, and (II) Challenging emotions.

Avoidance Communication with the Family After Death

Many of the nurses who participated in our study stated that they avoided communicating with the bereaved family of a deceased child. One nurse expressed the emotional burden of being a reminder of the death of the child with the following sentences. For example:

"... I don't want to come face to face with a family whose child has died...What will the mother feel when she sees me, what will she do? That's why, to be honest, I don't want to meet with the families again and again..." P5

Challenging Emotions

All the nurses who participated in our study reported that the death of the children they cared for affected them deeply emotionally. The nurses expressed how they had difficulty in maintaining their professional composure while being deeply sad, which may cause compassion fatigue and emotional burnout. For example:

"In such cases (in the case of child death), our nurses' room is like a crying wall...I mean, I don't know, it's not just about me or because I'm a mum. You know, we also have single friends. They are affected in the same way. Because I really think that the death of a child hurts everyone deeply. As I said, let children always laugh, have fun, play, but not on their deathbed." P11

THEME 4: POST-BEREAVEMENT COMMUNICATION FACILITATORS

Two facilitators have been identified in the communication with the bereaved family members after the child's death, namely: (I) Using touch and silence, and (II) Telephone call after death.

Using Touch and Silence

Most of the nurses emphasized the therapeutic value of touch and silence in comforting grieving mothers, drawing attention to the emotional support role of nurses in bereavement care. For example:

"...all I do is hug bereaved mothers. Give them a chance to cry. Standing silently beside them, there's nothing else I can do...that's all I can do. And I try to help them stay strong." P7

Telephone Call After Death

Some of the nurses emphasized that telephone calls after the death help to connect with the deceased child through memories and that this can help families in the bereavement process. For example:

"...I am still in contact with this family after the death of their child. We lost our child in 2016, but I am still in contact with the family...I even asked her that if my calling you makes you more upset, I may not call. But the mother said that she remembered good memories while talking to me and that remembering her son was good for her." P2

THEME 5: ORGANISATIONAL BARRIERS TO EFFECTIVE COMMUNICATION

The theme the organisational barriers to effective communication included the following sub-themes: (I) No private room to make the death notification, (II) Lack of interpreters, and (III) Low salary and long working hours.

No Private Room to Make the Death Notification

Most of the nurses who participated in this study mentioned the importance of the need for a structured, tailored and compassionate approach to delivering news of death in settings such as paediatric oncology healthcare, where deaths are common. For example:

"...I wish the news of death could be given in a separate room... I think that when they receive negative news about their child or news of death, the looks of the people around them disturb the families. It can be in a private room within the framework of privacy, and I think it can be accompanied by a mental health professional when the news is given." P4

Lack of Interpreters

Some of the nurses mentioned the critical role of the interpreter in effective communication, especially in multicultural healthcare settings, as language barriers can lead to misunderstandings and potential conflicts. For example:

"...In fact, we are also hospitalising foreign patients such as Syrian...If the interpreter capacity of the hospital is increased and interpreters arrive, perhaps an attack will be prevented at that moment...For example, a patient's relative attacked our female colleagues..." P3

Low Salary and Long Working Hours

Most nurses participating in this study highlighted the systemic challenges facing nurses, such as low wages, excessive workload, lack of resources and limited social opportunities, which contribute to burnout and reduced job satisfaction. For example:

"...I think the tension in the nurses and the unbearable hospital environment, the lack of wages received, the nurses are now tired of coming to work and going to work. Therefore, improving communication techniques is the last thing that hospitals think about, because nurses now have low salaries, very difficult conditions, lack of materials, and the inability to do anything socially..." P1

DISCUSSION

The objectives of this study were to investigate: (I) Nurses' perspectives on the pre-and post-bereavement communication challenges and facilitators with family members and (II) Organisational barriers that

negatively impact effective end-of-life communication.

PRE-AND POST-BEREAVEMENT COMMUNICATION CHALLENGES

Most nurses highlighted that both families and health-care professionals experienced emotional challenges related to the complexity surrounding discussions about death in paediatric healthcare settings. This communication difficulty was experienced both before and after the child's death. These reported challenges are consistent with findings from other studies. According to a recent studies, families often avoid using the word "death" to protect their children, while healthcare providers similarly struggle with terms like "cancer", which has become taboo. Additionally, barriers such as lack of training and cultural differences further complicate end-of-life communication.

All the nurses who participated in our study reported that the death of the children they cared for affected them deeply emotionally. In line with this, previous research has shown that nurses experience deep sadness after the death of a child and their well-being is considerably affected in this process. ²⁸⁻³⁰

PRE-AND POST-BEREAVEMENT COMMUNICATION FACILITATORS

Most nurses in our study highlighted the importance of open and honest communication during pre-bereavement. They were also noted the therapeutic value of touch and silence in comforting grieving mothers during post-bereavement. These facilitators align with previous studies.^{24,25,31,32}

For example, effective strategies identified in earlier research include allowing silence, repeating children's questions, providing information gradually, and responding honestly.²⁵ Open communication and early end of life discussions have also been shown to enhance parental satisfaction with their child's care and symptom management.²⁴ Early conversations help clarify the family's values and preferences, ensuring care aligns with the wishes of both the child and parents.²⁴

ORGANISATIONAL BARRIERS

Most of the nurses emphasized that systemic challenges such as low wages, excessive workload, lack of resources and limited social opportunities lead to burnout and reduced job satisfaction. These reported organisational barriers that negatively impact effective end-of-life communication with family members of children at the end of life are consistent with findings from other studies, 29,33-35 According to the results of a multicenter cross-sectional study, nurses lack adequate organisational or professional support.³³ Additionally, this support is limited and consequently affects the social lives of nurses who experience traumatic events such as child death, although they can share their feelings with colleagues.³³ Instead, the organisation should promote healthy working cultures. More formal support in the workplace may help.

WHAT THIS STUDY ADDS

This study is vital because it fills a critical gap in the literature by exploring paediatric oncology nurses' communication experiences specifically during both the pre- and post-bereavement periods. This study provides an integrated perspective that highlights how nurses navigate emotional, organisational and relational challenges across the entire bereavement process. The study captures nurses' reflections on the barriers and facilitators of communication, offering nurse-informed insights and practical strategies to improve family-centred bereavement care. It is a vital contribution to the literature, emphasizing the need for structured support, early communication about death, and emotional preparedness for healthcare professionals working in paediatric oncology services. Future research should explore how structured training and emotional support programs can enhance nurses' confidence and resilience in pre- and post-bereavement communication across diverse paediatric care settings.

LIMITATIONS

Strengths of the study involved attention to reflexivity, transparency, and confirmability as strategies for enhancing the rigor of the findings. However, our study also has several limitations. First, this study was conducted in Türkiye and thus can only show the

nurses' experiences of end-of-life communication with family members before and after the death of a child in paediatric oncology wards in this country as well as it is not clear that it can be transferred and compared to other countries and other health settings, so transferability can be questioned. Secondly, the interview data was translated from Turkish to English, there is a possibility that some of the meaning of the interview data may have been misinterpreted or misrepresented in the process of translating the data from Turkish to English. Thirdly, the online method of qualitative data collection may have resulted in a restricted understanding of participants' experiences, meaning that valuable insights may have been missed.

CONCLUSION

The results of this study highlight the critical need for organisational support and the development of evidence-based communication strategies to ensure quality and family-centred care in paediatric oncology settings. These insights are highly relevant across healthcare systems globally, including those in lowand middle-income countries with limited resources.³⁶ Importantly, this study has led to the development of a framework to guide end-of-life communication with families (Figure 1). By capturing nurses' perspectives across both the pre- and postbereavement process, this study provides: (I) valuable insight into nurses' emotional and communicative experiences when supporting families; (II) evidence for the development of specific communication tools and policies for paediatric oncology settings; and (III) a

deeper understanding of how the emotional burden on nurses affects their well-being and quality of care by highlighting the need for ongoing organisational and psychological support.

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: Çiğdem Fulya Dönmez, Recep Kara, Gonca Karayağız Muslu; Design: Çiğdem Fulya Dönmez, Gonca Karayağız Muslu; Control/Supervision: Çiğdem Fulya Dönmez, Gonca Karayağız Muslu; Data Collection and/or Processing: Çiğdem Fulya Dönmez, Recep Kara; Analysis and/or Interpretation: Çiğdem Fulya Dönmez, Gonca Karayağız Muslu; Literature Review: Çiğdem Fulya Dönmez, Gonca Karayağız Muslu, Recep Kara; Writing the Article: Çiğdem Fulya Dönmez, Gonca Karayağız Muslu, Recep Kara; Critical Review: Gonca Karayağız Muslu, Recep Kara; Critical Review: Gonca Karayağız Muslu.

REFERENCES

- World Health Organization [Internet]. © 2025 WHO [Cited: March 29, 2025]. Childhood cancer. Available from: https://www.who.int/news-room/fact-sheets/detail/cancer-in-children
- Kutluk MT, Yeşilipek A. Pediatric cancer registry in Turkey 2002-2023: 22 years of achievement (TPOG&TPHD). Journal of Clinical Oncology. 2024;42(16_suppl):10051. DOI:10.1200/JCO.2024.42.16_suppl.10051
- Sawin KJ, Montgomery KE, Dupree CY, Haase JE, Phillips CR, Hendricks-Ferguson VL. Oncology nurse managers' perceptions of palliative care and end-of-life communication. J Pediatr Oncol Nurs. 2019;36(3):178-90. PMID: 30939966; PMCID: PMC7197215.
- Morris SE, Nayak MM, Block SD. Insights from bereaved family members about end-of-life care and bereavement. J Palliat Med. 2020;23(8):1030-7. PMID: 32040370.
- Matthys O, Dierickx S, Deliens L, Lapeire L, Hudson P, Van Audenhove C, et al. Is pre-bereavement collaboration between family caregivers and healthcare professionals associated with post-bereavement emotional well-being? A population-based survey. Patient Educ Couns. 2023;110:107654. PMID: 36805930.
- Ilic A, Sievers Y, Roser K, Scheinemann K, Michel G. The information needs of relatives of childhood cancer patients and survivors: a systematic review of qualitative evidence. Patient Educ Couns. 2023;114:107840. PMID: 37321115.
- Wiener L, Tager J, Mack J, Battles H, Bedoya SZ, Gerhardt CA. Helping parents prepare for their child's end of life: a retrospective survey of cancer-bereaved parents. Pediatr Blood Cancer. 2020;67(2):e27993. PMID: 31595653; PMCID: PMC8330433.

- Al-Motlaq M, Neill S, Foster MJ, Coyne I, Houghton D, Angelhoff C, et al. Position statement of the international network for child and family centered care: child and family centred care during the COVID19 pandemic. J Pediatr Nurs. 2021;61:140-3. PMID: 34052501; PMCID: PMC8135188.
- Kim MR, Chae SM. Experiences of trust in mothers of hospitalized children toward pediatric nurses. J Child Health Care. 2025;29(2):368-80. PMID: 37846487.
- Mitchell S, Spry JL, Hill E, Coad J, Dale J, Plunkett A. Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study. BMJ Open. 2019;9(5):e028548. PMID: 31072863; PMCID: PMC6528052.
- Baenziger J, Hetherington K, Wakefield CE, Carlson L, McGill BC, Cohn RJ, et al. Understanding parents' communication experiences in childhood cancer: a qualitative exploration and model for future research. Support Care Cancer. 2020;28(9):4467-76. PMID: 31927756.
- Hendricks-Ferguson VL, Sawin KJ, Montgomery K, Dupree C, Phillips-Salimi CR, Carr B, etal. Novice nurses' experiences with palliative and end-of-life communication. J Pediatr Oncol Nurs. 2015;32(4):240-52. PMID: 25556105.
- Montgomery K, Sawin KJ, Hendricks-Ferguson VL. Experiences of pediatric oncology patients and their parents at end of life: a systematic review. J Pediatr Oncol Nurs. 2016;33(2):85-104. PMID: 26219300.
- Zartaloudi A, Lekas C, Koutelekos I, Evangelou E, Kyritsi E. Dying child and nurses' mourning. European Psychiatry. 2021;64(S1):S401. https://www.cambridge.org/core/journals/european-psychiatry/article/dying-child-and-nursesmourning/C76DD285251F8B7D7850479F4D90BB5B
- Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the endof-life: a systematic review of qualitative evidence. Palliat Med. 2019;33(8):926-41. PMID: 31184529; PMCID: PMC6691601.
- Nagelschmidt K, Leppin N, Seifart C, Rief W, von Blanckenburg P. Systematic mixed-method review of barriers to end-of-life communication in the family context. BMJ Support Palliat Care. 2021;11(3):253-63. PMID: 32855230.
- Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description-the poor cousin of health research? BMC Med Res Methodol. 2009;9:52.
 PMID: 19607668; PMCID: PMC2717117.
- Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health. 2010;33(1):77-84. PMID: 20014004.
- Martínez-Mesa J, González-Chica DA, Duquia RP, Bonamigo RR, Bastos JL. Sampling: how to select participants in my research study? An Bras Dermatol. 2016;91(3):326-30. PMID: 27438200; PMCID: PMC4938277.
- Keen S, Lomeli-Rodriguez M, Joffe H. From challenge to opportunity: virtual qualitative research during COVID-19 and beyond. Int J Qual Methods. 2022;21:16094069221105075. PMID: 35692956; PMCID: PMC9167989.
- Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales.
 Qualitative research in sport, exercise and health. 2021;13(2):201-16. https://www.tandfonline.com/doi/full/10.1080/2159676X.2019.1704846

- Alsaawi A. A critical review of qualitative interviews. European Journal of Business and Social Sciences. 2014;3(4):149-56. https://papers.ssm.com/sol3/papers.cfm?abstract_id=2819536
- 23. Braun V, Clarke V. Thematic Analysis: A Practical Guide. London: SAGE; 2021.
- Montgomery KE, Sawin KJ, Hendricks-Ferguson V. Communication during palliative care and end of life: perceptions of experienced pediatric oncology nurses. Cancer Nurs. 2017;40(2):E47-57. PMID: 27044058.
- Laronne A, Granek L, Wiener L, Feder-Bubis P, Golan H. "Some things are even worse than telling a child he is going to die": Pediatric oncology healthcare professionals perspectives on communicating with children about cancer and end of life. Pediatr Blood Cancer. 2022;69(3):e29533. PMID: 34958524; PMCID: PMC9369103.
- Sisk BA, Friedrich AB, Kaye EC, Baker JN, Mack JW, DuBois JM. Multilevel barriers to communication in pediatric oncology: clinicians' perspectives. Cancer. 2021;127(12):2130-8. PMID: 33598930; PMCID: PMC8154640.
- Aydın A, Savaş EH, Bingöl H, Kebudi R. Taboo words in pediatric oncology: communication experiences of nurses and physicians with dying children and their families. Eur J Oncol Nurs. 2024;68:102466. PMID: 38101245.
- Judith Roach E, Al Omari O, Elizabeth John S, Francis F, Arulappan J, Shakman L, et al. Challenges experienced by nurses in providing pediatric palliative care: an interpretive phenomenological analysis. J Palliat Care. 2023;38(3):355-63. PMID: 37143338.
- Kellogg MB, Knight M, Dowling JS, Crawford SL. Secondary traumatic stress in pediatric nurses. J Pediatr Nurs. 2018;43:97-103. PMID: 30473163.
- Chew YJM, Ang SLL, Shorey S. Experiences of new nurses dealing with death in a paediatric setting: a descriptive qualitative study. J Adv Nurs. 2021;77(1):343-54. PMID: 33074568.
- Ghaljeh M, Mardani-Hamooleh M, Pezaro S. Nurses' perceptions of compassionate care in pediatric oncology: a qualitative interview study. BMC Health Serv Res. 2024;24(1):1165. PMID: 39358740; PMCID: PMC11445953.
- Torbert N, Taladay C, Kauer T, Hackenburg L, Weaver MS, Kellas JK. Providing "compassionate care" in the neonatal intensive care unit through infant and family needs-based care. American Journal of Perinatology. 2022;41(06):e863-9. DOI:10.1055/s-0042-1758725
- Zheng R, Guo Q, Dong F, Gao L. Death self-efficacy, attitudes toward death and burnout among oncology nurses: a multicenter cross-sectional study. Cancer Nurs. 2022;45(2):E388-96. PMID: 32511153.
- Shimoinaba K, McKenna L, Copnell B. Nurses' experiences, coping and support in the death of a child in the emergency department: a qualitative descriptive study. Int Emerg Nurs. 2021;59:101102. PMID: 34823111.
- Shorey S, Chua C. Nurses and nursing students' experiences on pediatric end-of-life care and death: a qualitative systematic review. Nurse Educ Today. 2022;112:105332. PMID: 35334222.
- Stein A, Dalton L, Rapa E, Bluebond-Langner M, Hanington L, Stein KF, et al; Communication Expert Group. Communication with children and adolescents about the diagnosis of their own life-threatening condition. Lancet. 2019;393(10176):1150-63. PMID: 30894271.