PALIATIA
revista de ingrijiri paliative

PALIATIA
journal of palliative care

Vol. 17 / No. 1 / January 2024 https://www.paliatia.eu

REVIEW

Challenges in communicating about dying in pediatric patients with oncological pathology at the end of life - narrative review

Olivia Drincă

Institutul Oncologic “Profesor Doctor Alexandru Trestioreanu”, București, România

Received: 23.11.2023 • Accepted for publication: 26.01.2024

Abstract

In today's medicine, making a decision requires close collaboration between patient, family and the medical team. Communication about disease prognosis and death in the triad of paediatric cancer patient, family and medical team plays a crucial role, with multiple moral dilemmas to balance the patient's right to be informed and the parents' obligation to act in the best interest of the child.

This narrative review presents information about the challenges that arise in this process, from the perspective of all parties involved, with the associated limitations and barriers. The majority of the accounts come from parents/carers, followed by medical staff and then patients. Early involvement of palliative care services helps to increase comfort and quality of life in patients with terminal cancer disease; however, this can also be challenging at times.

Empathetic communication from diagnosis to end of life poses some challenges for healthcare professionals. For optimal outcomes it is necessary to put the patient and his/her needs at the centre of the communication and the decision-making process. There are several general strategies to improve the way information is conveyed to the patient and their family. It would also be useful to obtain data from paediatric oncology centres in Romania related to end-of-life communication.

Rezumat

În medicina actuală, stabilirea unei decizii presupune o strânsă colaborare între pacient, familie și echipa medicală. Comunicarea despre prognosticul bolii și moarte în triada pacient pediatric cu boală oncologică, familie și echipa medicală are un rol crucial, cu multiple dileme morale pentru a echilibra balanța între dreptul pacientului de a fi informat și obligația părinților de a acționa în interesul optim al copilului.

Această revizie narativă prezintă informațiile despre provocările ce apar în acest proces, din perspectiva tuturor părților implicate, cu limitele și barierele aferente. Majoritatea relatărilor vin din partea părinților/aparținătorilor, urmate de cele ale personalului medical și apoi ale pacienților. Implicarea precoce a serviciilor de îngrijiri paliative ajută la creșterea confortului și calității vieții la pacienții cu boală oncologică în stare terminală; însă și acest demers poate fi uneori anevoios.

Comunicarea empatică de la diagnostic și până la finalul vieții ridică unele dificultăți personalului medical. Pentru rezultate optime este necesar să punem în centrul actului de comunicare și decizional pacientul și nevoile lui la momentul respectiv. Există mai multe strategii generale de îmbunătățire a modului de transmitere a informațiilor către pacient și familia lui. Ar fi utilă și obținerea de date din centrele de oncologie pediatrică din România legate de comunicarea la finalul vieții.

Introduction

According to the National Childhood Cancer Registry in Romania (RNCCR) (1) annually there are diagnosed and treated in the pediatric oncology network about 400 new cancer cases (10 cases/100.000 children). The average survival rate in children in Romania diagnosed with cancer is 69.1% (RNCCR-2018).

The current decision-making process has evolved from the paternalistic model towards autonomy of the patient and cooperation between the patient and the medical team in decision-making; concerning children, as they are under parental care, the balance tilts towards beneficence and thus the collaboration between patient, family and medical staff becomes more a crucial role. (2)

Discussions in the doctor-parent/caregiver-patient triad about disease prognosis and death raises multiple moral dilemmas and challenges. Doctors and parents need to balance between children's right to receive information, to express their opinion in issues that directly concern them (3) and the right and obligation of parents to act in the best interests of the child.

SIOP (International Society of Pediatric Oncology) encourages medical staff to provide children with relevant medical information, according to their developmental stage and culture, to actively involve children in the decision-making process regarding their health problems, mentioning also the parents' responsibility for the child's health, but not their exclusive right of decision (4).

On the other hand, the health care team needs to balance children's and parents' wishes related to treatment and their own professional even personal values (both regarding life and death issues and daily practice) (5).

In the literature, there is increasing interest in improving communication skills and decision-making regarding end-of-life care, translated into an increasing number of studies addressing this issue (6).

The purpose of this paper is to present published material on the barriers, limitations and challenges that arise in communication between the pediatric cancer patient, their parent/caregiver and the healthcare team.

Material and methods

This is a narrative review of articles on the topic of communication in the triad Physician/nurse team - parent/caregiver - patient about communication concerning end-of-life care and dying. We used searches in 2 international databases (PubMed and ScienceDirect), using key terms: 'communication' AND 'death' AND 'pediatric/child' AND 'cancer' AND 'palliative/end-of-life care', as well as 'challenges/barriers' AND 'communication' AND 'end-of-life' AND 'cancer' AND 'pediatric'; in next step we used advanced search using the key terms mentioned by the author, from the abstract or title ('end of life' and 'children').

Inclusion and exclusion criteria

Inclusion criteria were: open access articles, published in English, type of study (clinical trials, meta-analyses, randomized clinical trials, reviews and revisions systematic reviews), papers mentioning pediatric patients under care at the end-of-life care with cancer pathology and which raised the issue of patient-family communication- health care staff regarding terminal conditions and death.

Exclusion criteria were inclusion of adults in the study, other chronic non-oncological life-threatening pediatric conditions, exclusive mention of clinical symptoms.

Item selection, review and data extraction

Selected texts were entered into Mendeley Reference Manager and Zotero Bib. Article reading and data extraction were done by one person.

At the end of the search 186 articles remained eligible for review. After exclusion of duplicates (63 articles), reading abstracts (23 articles), reading articles in full and eliminating off-topic articles (10 articles), which did not provide information about communication (2 articles) or that only mentioned clinical symptoms at the end of life (3 articles) left 49 articles to be analyzed (Figure 1). We kept the 12 reviews of literature for the synthesis of the information they provided and 37 original articles remained.

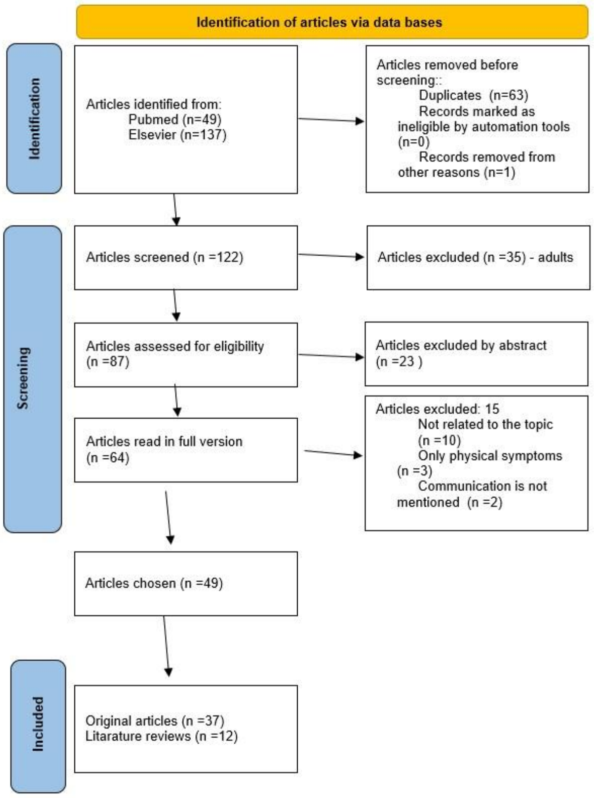

Figure 1 - **Flow diagram for selection process of articles**
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Results

The perspective of children and adolescents

Given the age and desire of parents to protect their children, pediatric patients do not participate in parent-physician discussions; however, as they grow up and if they want to, they can be increasingly involved in this type of communication. Discussions in the child-parent-health care team triad in the end-of-life period is fraught with emotions and understanding these can tip the balance from curative treatment towards more realistic goals (7).

On the other hand, children ask their parents for information about death, and the parents prefer to discuss prognosis and death with their children in person as shown by Ansley E. Kenney et al in a study of a group of parents who had lost their children by cancer - 66.7% of 131 parents discussed death with their children (8).

In a study including 23 adolescents and young adults aged 12 to 39 years with a diagnosis of stage IV cancer or recurrent cancer, the patients expressed the need to be respected, to have their priorities recognized outside of medical issues, the right to personal relationships, the possibility to maintain a state of normality (9) In the same study, many patients wished to be informed earlier about end-of-life issues and to have a therapeutic plan centered on patients and their needs.

Adolescents' acceptance of their own death has a dynamic, devastating, and long-lasting impact which is different for each surviving family member. (10). Application of specially designed questionnaires to patients with life-threatening pathology about personal, emotional needs, spiritual and medical needs (such as Five Wishes or Voicing my Choices) was considered helpful or very helpful by a set of adolescents and young adults with advanced stage cancer disease (19/20 patients) and could pave the way for better communication with family, decreasing the isolation experienced by patients (11, 12). On the same note, applying an advanced care plan specifically designed for adolescents was found to be beneficial for the patient and their family, with constant maintenance of lower stress levels (13, 14). There are other advanced care plans tailored to the needs of adolescents that are being evaluated (15).

Parent and family perspective

Most information about the type of communication at the end of life, the process of decision-making and about death and all its implications is drawn from studies reflecting parents' views. For patients at the end of life the first step is for the family to understand and accept the poor prognosis. This is not always the case; often parents of children diagnosed with a cancer with a poor prognosis do not recognize that the chances of cure are low (16). Because parents have accepted the stem cell transplant procedure as the last chance at a cure, children have experienced more intense suffering and the family failed to plan for the end of life if the transplant fails. (17).

Faced with the death of their child, parents have to go through the most difficult experience possible for their role as a parent, which remains vivid in their memory for many years (up to 4-9 years) after the event (18). 131 parents whose children had died from cancer, 40% did not feel prepared for the end-of-life medical and emotional issues, including those issues that occurred after the death of their child. In the same study, 66.4% of parents felt that they had noted significant distress in their child.

Parents are faced with extremely difficult decisions for the well-being of their terminally ill children, the emotional impact being crucial to the bereavement period. One of these decisions is the place of death: parents of patients with progressive disease, with a previous death in the family, with access to palliative care at home and who felt that their oncologist had explained all their end-of-life treatment options to them were more likely to choose home as the place of death. Choosing the place of death, even if it did not materialize as expected, resulted in fewer invasive maneuvers and less parental regret about decisions (19). In countries where the DNR (do not resuscitate) order is mandated the family faces even more feelings of giving up, frustration, guilt and regret that they did not have enough time to spend with the child (20).

In general, parents do not clearly express their emotions about their child's illness and prognosis. And the response given by the medical staff (by providing medical information) stops the communication process. It is recommended to use the empathic response to further explore parents' concerns (7).

Parents also found it useful to discuss prognosis with the pediatric oncologist, explaining symptoms and physical changes that may occur at the end of life, symptoms and signs that occur near death (21).

Parents also need support in communicating with their children on the topic of death (through discussions with health professionals on this topic, establishing contact with other parents who have lost children, involving the clergy in discussions, providing sources of information) - (8).

Most of the information about parents' perspectives comes from studies conducted in United States. However, we also have the results of Zimmerman et al. who studied negative or positive experiences of parents of children in palliative care in Switzerland; the parents' wish is an honest relationship with the medical staff throughout treatment and the provision of continuous and coordinated emotional, spiritual and cultural support (22).

There are quite a few studies on the long-term effects for siblings of children who have died from cancer. The effects are felt in the short term (anxiety, depression and substance abuse increased in the first year after the death but returned to normal afterwards) and in the long term, the data show a direct link between complicated bereavement and lower academic performance and impaired socioeconomic status in adulthood (23, 24).

In a national assessment in Sweden 174 young people who had lost a sibling when they were 12-25 years old answered a questionnaire about how they felt about the loss and its long-term effects. Several factors were identified associated with the risk of complicated bereavement: the feeling that the deceased sibling had not had a peaceful death, impressive signs and symptoms preceding the death (seizures), avoidance of discussion with medical staff (no time and space for clarification of end-of-life issues), receiving limited information in the last month of life and, an extremely important factor, the lack of discussion with family members or others about illness and death. The negative effect of these deficits translated into feelings of loneliness and the presence of complicated grief until almost 9 years after the event. (24).

An optimistic conclusion is that the risk of complicated bereavement directly decreases proportionally to the interval since the event (24). There are also individuals who believe that the death of their sibling has produced a degree of personal development, with improved personal communication style, with a greater degree of kindness and maturity compared to individuals of the same age (23).

Perspective of health professionals

Working in a pediatric oncology service is marked at the same time by burnout (due to high workload, bureaucracy, system-driven changes) and a high degree of satisfaction, as the care of children and the relationship with them is not considered stressful by medical staff. However, burnout can affect the relationship with patients, the quality of care and the physical and emotional health of healthcare staff (25. Approximately 40% of healthcare professionals in a survey of 266 people (doctors and nurses from intensive care, oncology and cardiovascular intensive care units) felt that the work with patients with poor prognosis is depressing, a view shared especially by the least experienced (26). In the same study, physicians with <10 years clinical experience experienced feelings of guilt and failure at the death of a patient compared to those with more experience.

The doctor-patient relationship with chronic pathology is more emotionally charged compared to patients with acute pathology (major trauma is not included here). For this reason, there are some issues that hinder communication in the end-of-life period. Personal powerlessness and fear of damaging the doctor-patient relationship by revealing the prognosis cause a reluctance to initiate this type of discussion (9). Another fear is also related to the lack of training for communicating directly with children and adolescents about bad news (9, 27).

Health professionals believe that they are prepared to show empathy in discussions about death, discuss an adolescent's overall goals, and support the family's hope, but feel less prepared to talk with a schoolchild or adolescent about cardiopulmonary resuscitation (26). However, doctors and nurses usually do not directly discuss with the pediatric patient or avoid certain topics such as his/her prognosis, hopes and concerns.

Although it is shown to improve the quality of life of terminally ill patients by early involvement of palliative care, oncologists are encountering some challenges. As palliative care in many countries is not available as a consultative service alongside treatment with curative intention, oncologists' experience uncertainties when to transfer to such services (uncertain prognosis, emotional involvement, fear of failure and negative emotional reaction of the family, communication concerns about choosing the right time and setting) (28).

The findings of the articles comprising the literature reviews are summarized in Table 1.

Tabel 1 - List with assessed literature reviews

	Author	**Year**	**Country**	**Articles #**	**Conclusions**
1	Aasen E.R.H.V et al. (51)	2023	Norvegia	21	● Involvement of children in advance care planning is limited, but increases as patients get older; in general, this has been beneficial for patient-caregiver communication ● There is often disagreement between adolescents and caregivers about the level of information shared, the objective of care, and how they want to spend their last days
2	Alan T. Bates, Julia A. Kearney	2015	SUA Canada		● The process of children's understanding of death evolves over a longer period of time ● Children and adolescents at the end of life usually want to receive information about their illness and prognosis; they also want to live the remaining period as intensely and fully as possible ● Death should be discussed in a step-by-step manner, through honest, concrete and patient-friendly communication ● Information should be tailored to the psycho-emotional developmental level of the children and with the close support of the family
3	Mika Hirata Kyoko Kobayashi	2022	Japonia	21	● Maintaining hope in times of uncertainty is important for patients and parents ● Hope gives patients a purpose in life at the end of life and gives them the strength to move forward
4	Johnston E.E. et al. (52)	2019	SUA	34	● Most children with cancer, parents and doctors would choose home as the place of death ● Parents who had the opportunity to plan the place of death for their child, even if it did not come to fruition, felt more at peace with their child's death and regretted their decision less ● The choice to plan the place of death may be more important than making that choice concrete ● The health care system is obliged to provide optimal conditions to ensure a 'good death' at home through tailored palliative care services
5	Khalid K. et al.	2019	Malaysia	32	● Sometimes patients and their families hesitate to share religious beliefs with medical staff ● Communicating about impending death in communities with strong religious and cultural views can be difficult due to differences in religious affiliation between family and medical staff ● The spiritual advisor is an important part of the palliative care team, providing spiritual support, officiating religious services at the request of the family and providing emotional support during bereavement
6	Perez G. K. et al.	2020	SUA		● Lack of discussion of death for adolescents and young adults with cancer disease leads to exhaustive end-of-life treatments despite their preference for comfort in the last month of life

					● Physicians' difficulties in communicating about death are related to feelings of personal failure, fear of unrealistic family expectations about prognosis, and patient and family discomfort ● Beneficial role of paediatric palliative care teams from diagnosis onwards and communication methods such as: asking/offering information/answering empathetically/questioning for any taboo topic, including death
7	Rosenberg A.R et al.	2016	SUA		● Time is needed for difficult conversations with adolescents and their families at the end of life ● Creating a trusting relationship between patient and doctor is the foundation for such conversations ● Health care staff must systematically and tactfully explore patient and family beliefs, values, needs, concerns ● Sentence patterns that can facilitate difficult conversations with adolescents at the end of life
8	Salins N. Hughes S. Preston N.	2022	India Marea Britanie		● Families prefer ongoing communication with family members and caregivers that helped end-of-life decision making and palliative care involvement ● Families value empathetic communication that maintains hope over a pragmatic approach ● Parents often felt unprepared for their child's death, either surprised by the rapidity of the event or felt it was a long ordeal ● Moving into palliative care felt like giving up the fight and they felt abandoned
9	Sansom-Daly U.M et al	2020	SUA Australia		● Provides a model of adolescent-family communication to medical staff taking into account the social, legal and community context as well as personal preferences (medical, psycho-social, developmental, family, ethical and existential)
10	Santoro J.D. Bennett M.	2018	SUA		● With parental consent, communication about death is done honestly, using terms appropriate to the cognitive and psychoemotional development of children ● The degree of patient involvement in the decision-making process should be established in advance ● Training of medical staff on ethical issues and palliative care helps the professional to provide the best care for children with cancer disease at the end of life
11	Sisk B.A et al.	2016	SUA		● First and foremost, pediatric patients should be given the opportunity to initiate discussions about prognosis in a safe and open environment ● Physicians should be trained to recognize the emotions felt by children, but without forcing unsolicited information ● Physicians need to accept the uniqueness of each patient and their family, and that their wishes and needs may change over time ● Lack of training for physicians in conveying information about prognosis and death can lead to overconfidence, with the use of inappropriate and scientifically unvalidated communication methods
12	Wiener L. et al	2013	SUA	37	● Language and cultural barriers affect the complete care of the child in palliative care which supports the use of trained medical interpreters ● There are many cultures in the world where it is acceptable to hide the lethal prognosis from the child (Chinese, Korean, Russian) ● Assessment of the spirituality of the child and family is an important aspect of palliative care

Of the ideas mentioned we noted that pediatric patients understand the idea of death as it develops gradually with age, exposure to illness and deaths in the family or of close friends (29). Most children want to learn about their illness (29, 30, 31, 32), but they do not always want to be involved in the decision-making process (31). There are many language, cultural, religious and spiritual barriers that make the communication process even more difficult (33, 34). Doctors also fear discussions about death because the loss of a patient is considered a personal failure (35). Surprisingly, patients and families prefer to keep hope in moments of uncertainty at the expense of pragmatic medical information (36, 37).

Discussion

During meetings with health care staff, parents perceive both the presence of 'good news' (related to the child's disease control and well-being) and 'bad news' (untreatable disease or adverse effects of treatments) (38). Current recommendations converge towards sharing information gradually including to patient (depending on their psycho-emotional development and their willingness), using terms understandable to parents and children, in an empathetic way, keeping in mind the patient and his/her medical, psycho-emotional, social and spiritual needs.

We have identified several barriers related to communication in the patient/parent/carer-doctor triad. In an increasing diverse world, language, racial and cultural barriers can affect prognostic understanding and consequently end-of-life care. Because parents do not understand or are unable to accept a poor prognosis, children are at risk of receiving more intense treatment without a real possibility of cure (16, 27). Out of a desire to protect their child, parents may call for the establishment of a conspiracy of silence, sometimes feeling judged by the medical staff for their decision (39, 27). Parents did not appreciate conveying to their children information that was too complex to their age or too close to the time of death and if this was not given by the doctor (oncologist) but by another person. (8).

From the perspective of parents and patients, navigating the health system and fragmented information from multiple professionals contributes to difficult communication and generate feelings of frustration (9).

The difficulty in addressing the issue of death also comes from staff discomfort to open such discussions because of reluctance to communicate with patients due to lack of communication training, personal hope in a miracle, fear to affect the therapeutic relationship and rob patients of hope for healing (27, 9). Doctors observe certain 'signs' suggestive of patient's knowledge of the prognosis: observation of physical changes occurring through evolution of the disease, verbal expression of concerns about death and direct request to be included in the decision-making process at the end of life, as well as the emotional distress given by hiding the truth. These could be used as arguments for direct communication with the patient. (27).

Fortunately, there are several ways to improve the transmission of information to the child and parent/guardian. A modified version of the SPIKES protocol for discussions that include children gives them the opportunity to present known information, their personal needs and what they want to know; this knowledge helps health care staff to develop a treatment plan centered on the patient's need (9). Patients' and parents' preferences may change over time so that they need to be reassessed periodically.

Second, parents need accurate medical information provided in clear terms, and delivered in an empathetic manner (21) which leads to a better understanding of prognosis. This translates into decreased futile treatments at the end of life. By repeating questions over time including open-ended questions about prognosis, the medical team can get a clearer picture of family's perception and expectations of disease outcome (16).

Communication skills in oncology are not innate, ongoing training is needed to better communicate diagnosis, poor prognosis, relapse and possible death. Role-play training with professional actors as early as residency (40) or later, over several encounters to achieve a 'therapeutic' relationship in a safe environment has proven acceptable to healthcare professionals and resulted in increased comfort levels for sharing bad news. In addition to role-play, there are other relatively simple strategies to encourage communication: by repeating questions, the doctor's silence encourages the child to tell additional stories (27). There is an ongoing study to find international evidence-based best practice for communicating about death and end of life with the adolescent and young adult age group, this is very challenging for healthcare professionals (41). There are also more resources for healthcare professionals to improve their knowledge of bereavement, starting with personal experience. (42).

Healthcare staff need to set their professional priorities in order to compensate for the emotional burden and soul drain they feel and to be supported to find coping resources (43). Finally, practicing this field of medicine remains a personal choice.

The beneficial role of early involvement of palliative care services helps to comfort and increase quality of life in patients with advanced neoplastic disease (44, 45), both for patients undergoing stem cell transplantation as a last therapeutic resource (46), and for those with solid tumors (47). Improved aspects relate to communication (45, 47, 46), medical care, a lower number of medical investigations and interventions (44, 46), through comprehensive pain assessment and treatment (44, 45) as well as bereavement support and overall parent satisfaction (45, 47, 46). Even in countries with limited resources, such as Tanzania, palliative care can benefit pediatric patients with poor prognosis. (48).

While aware of all the benefits listed above, doctors have to overcome several barriers and uncertainties before referring patients to specialist palliative care services: related to prognosis, communication of the decision and personal inabilities (28). In addition, for those seeking specialist training in pediatric palliative care there are training courses. (49, 50).

Although based on small cohorts of patients, given the rarity of the oncological pathology among children, the amount of information about communicating about death with pediatric patients and their families has increased significantly recently. One of the limitations of the review is that the data come from roughly the same groups of patients or parents, mostly in the United States, without having a picture of what happens in countries with a different culture such as in Europe. Another limitation is given by the selection and analysis of articles made by a single person, with the subjectivity that comes from this process, then the financial limitation by the exclusive access to open-access articles.

For a picture of what it means to communicate with children with cancer and their families, it would be interesting to conduct a study in pediatric oncology centers in Romania, which could lead to an improvement in the quality of life of this group of patients and their families, increasing the accessibility to palliative care services and improving the communication skills of the medical team.

Conclusions

Communicating with the pediatric cancer patient and family throughout the course of the disease, from diagnosis to end of life, is challenging for all discussion partners and is achieved step by step as the therapeutic relationship is established. For the best results it is necessary to put the patient at the centre of the process and his/her needs at the time. There are several generally applicable strategies to improve the way we convey information to the patient and their family. It would be useful to obtain information about the needs of pediatric patients in Romania related to communication at the end of life.

References:

1. Registrul Național al Cancerului la Copil în România (RNCCR) - Societatea Română de Onco-Hematologie Pediatrică (SROHP)
2. Weidner N. Plantz D. - Ethical considerations in the management of analgesia in terminally ill pediatric patients https://doi.org/10.1016/j.jpainsymman.2013.12.233
3. Convention on the Rights of the Child text | UNICEF
4. Spinetta, John J., et al. "Valid Informed Consent and Participative Decision-Making in Children with Cancer and Their Parents: A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology." *Medical and Pediatric Oncology*, vol. 40, no. 4, Apr. 2003, pp. 244–46. *DOI.org (Crossref)*, https://doi.org/10.1002/mpo.10262
5. Weiner C. Pergert P. Castor A. Molewijk B. Bartholdson C. - Difficult situations and moral questions raised during moral case deliberations in Swedish childhood cancer care – A qualitative nationwide study. https://doi.org/10.1016/j.ejon.2022.102189
6. Zhang M. , Li X - Focuses and trends of the studies on pediatric palliative care：A bibliometric analysis from 2004 to 2018. https://doi.org/10.1016/j.ijnss.2020.11.005
7. Sisk, Bryan A., Annie B. Friedrich, et al. "Emotional Communication in Advanced Pediatric Cancer Conversations." *Journal of Pain and Symptom Management*, vol. 59, no. 4, Apr. 2020, pp. 808-817.e2. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2019.11.005.
8. Kenney, Ansley E., et al. "End of Life Communication among Caregivers of Children with Cancer: A Qualitative Approach to Understanding Support Desired by Families." *Palliative and Supportive Care*, vol. 19, no. 6, Dec. 2021, pp. 715–22. *DOI.org (Crossref)*, https://doi.org/10.1017/S1478951521000067
9. Mastropolo, Rosemarie, et al. "Patient, Caregiver, and Clinician Perspectives on Core Components of Therapeutic Alliance for Adolescents and Young Adults With Advanced Cancer: A Qualitative Study." *JAMA Network Open*, vol. 6, no. 8, Aug. 2023, p. e2328153. *DOI.org (Crossref)*, https://doi.org/10.1001/jamanetworkopen.2023.28153.
10. Emerson, Natacha D., et al. "End-of-Life Care in Patients with Cancer 16–24 Years of Age." *Current Oncology Reports*, vol. 24, no. 2, Feb. 2022, pp. 195–202. *DOI.org (Crossref)*, https://doi.org/10.1007/s11912-021-01173-0.
11. Wiener, Lori, Elizabeth Ballard, et al. "How I Wish to Be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations." *Journal of Palliative Medicine*, vol. 11, no. 10, Dec. 2008, pp. 1309–13. *DOI.org (Crossref)*, https://doi.org/10.1089/jpm.2008.0126
12. Zadeh, Sima, et al. "Opening End-of-Life Discussions: How to Introduce Voicing My CHOiCES$^{\text{TM}}$, an Advance Care Planning Guide for Adolescents and Young Adults." *Palliative and Supportive Care*, vol. 13, no. 3, June 2015, pp. 591–99. *DOI.org (Crossref)*, https://doi.org/10.1017/S1478951514000054
13. Curtin, Katherine B., et al. "Pediatric Advance Care Planning (pACP) for Teens with Cancer and Their Families: Design of a Dyadic, Longitudinal RCCT." *Contemporary Clinical Trials*, vol. 62, Nov. 2017, pp. 121–29. *DOI.org (Crossref)*, https://doi.org/10.1016/j.cct.2017.08.016.
14. Thompkins, Jessica D., et al. "Pediatric Advance Care Planning and Families' Positive Caregiving Appraisals: An RCT." *Pediatrics*, vol. 147, no. 6, June 2021, p. e2020029330. *DOI.org (Crossref)*, https://doi.org/10.1542/peds.2020-029330.
15. Van Driessche, Anne, et al. "The BOOST Paediatric Advance Care Planning Intervention for Adolescents with Cancer and Their Parents: Development, Acceptability and Feasibility." *BMC Pediatrics*, vol. 22, no. 1, Dec. 2022, p. 210. *DOI.org (Crossref)*, https://doi.org/10.1186/s12887-022-03247-9
16. Mack, Jennifer W., Angel M. Cronin, et al. "Unrealistic Parental Expectations for Cure in Poor-prognosis Childhood Cancer." *Cancer*, vol. 126, no. 2, Jan. 2020, pp. 416–24. *DOI.org (Crossref)*, https://doi.org/10.1002/cncr.32553.
17. Ullrich, Christina K., Veronica Dussel, et al. "End-of-Life Experience of Children Undergoing Stem Cell Transplantation for Malignancy: Parent and Provider Perspectives and Patterns of Care." *Blood*, vol. 115, no. 19, May 2010, pp. 3879–85. *DOI.org (Crossref)*, https://doi.org/10.1182/blood-2009-10-250225
18. Kreicbergs, Ulrika, et al. "Care-Related Distress: A Nationwide Study of Parents Who Lost Their Child to Cancer." *Journal of Clinical Oncology*, vol. 23, no. 36, Dec. 2005, pp. 9162–71. *DOI.org (Crossref)*, https://doi.org/10.1200/JCO.2005.08.557.
19. Dussel, Veronica, et al. "Looking Beyond Where Children Die: Determinants and Effects of Planning a Child's Location of Death." *Journal of Pain and Symptom Management*,vol.37,no.1,Jan.2009,pp.33–43.*DOI.org(Crossref)*,https://doi.org/10.1016/j.jpainsymman.2007.12.017.
20. Liu, Shu-Mei, et al. "Taiwanese Parents' Experience of Making a 'Do Not Resuscitate' Decision for Their Child in Pediatric Intensive Care Unit." *Asian Nursing Research*, vol. 8, no. 1, Mar. 2014, pp. 29–35. *DOI.org (Crossref)*, https://doi.org/10.1016/j.anr.2013.12.002.
21. Wiener, Lori, Julia Tager, et al. "Helping Parents Prepare for Their Child's End of Life: A Retrospective Survey of Cancer-bereaved Parents." *Pediatric Blood & Cancer*, vol. 67, no. 2, Feb. 2020, p. e27993. *DOI.org (Crossref)*, https://doi.org/10.1002/pbc.27993.
22. Zimmermann, Karin, et al. "Bereaved Parents' Perspectives on Their Child's End-of-Life Care: Connecting a Self-Report Questionnaire and Interview Data from the Nationwide Paediatric End-of-LIfe CAre Needs in Switzerland (PELICAN) Study." *BMC Palliative Care*, vol. 21, no. 1, Dec. 2022, p. 66. *DOI.org (Crossref)*, https://doi.org/10.1186/s12904-022-00957-w.
23. Rosenberg, Abby R., Andrea Postier, et al. "Long-Term Psychosocial Outcomes Among Bereaved Siblings of Children With Cancer." *Journal of Pain and Symptom Management*, vol. 49, no. 1, Jan. 2015, pp. 55–65. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2014.05.006
24. Lövgren, Malin, et al. "Care at End of Life Influences Grief: A Nationwide Long-Term Follow-Up among Young Adults Who Lost a Brother or Sister to Childhood Cancer." *Journal of Palliative Medicine*, vol. 21, no. 2, Feb. 2018, pp. 156–62. *DOI.org (Crossref)*, https://doi.org/10.1089/jpm.2017.0029
25. Hlubocky, Fay J., et al. "Mastering Resilience in Oncology: Learn to Thrive in the Face of Burnout." *American Society of Clinical Oncology Educational Book*, no. 37, May 2017, pp. 771–81. *DOI.org (Crossref)*, https://doi.org/10.1200/EDBK_173874
26. Sanderson, Amy, et al. "Advance Care Discussions: Pediatric Clinician Preparedness and Practices." *Journal of Pain and Symptom Management*, vol. 51, no. 3, Mar. 2016, pp. 520–28. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2015.10.014.
27. Laronne, Anat, et al. "'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." *Pediatric Blood & Cancer*, vol. 69, no. 3, Mar. 2022, p. e29533. *DOI.org (Crossref)*, https://doi.org/10.1002/pbc.29533.
28. Hill, Douglas L., et al. "Seven Types of Uncertainty When Clinicians Care for Pediatric Patients With Advanced Cancer." *Journal of Pain and Symptom Management*, vol. 59,no.1,Jan.2020,pp.86–94.*DOI.org(Crossref)*,https://doi.org/10.1016/j.jpainsymman.2019.08.010.
29. Bates, Alan T., and Julia A. Kearney. "Understanding Death with Limited Experience in Life: Dying Children's and Adolescents' Understanding of Their Own Terminal Illness and Death." *Current Opinion in Supportive & Palliative Care*, vol. 9, no. 1, Mar. 2015,pp. 40–45. *DOI.org (Crossref)*, https://doi.org/10.1097/SPC.0000000000000118.
30. Rosenberg, Abby R., Joanne Wolfe, et al. "Ethics, Emotions, and the Skills of Talking About Progressing Disease With Terminally Ill Adolescents: A Review." *JAMA Pediatrics*, vol. 170, no. 12, Dec. 2016, p. 1216. *DOI.org (Crossref)*, https://doi.org/10.1001/jamapediatrics.2016.2142
31. Santoro, Jonathan, and Mariko Bennett. "Ethics of End of Life Decisions in Pediatrics: A Narrative Review of the Roles of Caregivers, Shared Decision-Making, and Patient Centered

Values." *Behavioral Sciences*, vol. 8, no. 5, Apr. 2018, p. 42. *DOI.org (Crossref)*, https://doi.org/10.3390/bs8050042
32. Sisk, Bryan A., Myra Bluebond-Langner, et al. "Prognostic Disclosures to Children: A Historical Perspective." *Pediatrics*, vol. 138, no. 3, Sept. 2016, p. e20161278. *DOI.org (Crossref)*, https://doi.org/10.1542/peds.2016-1278.
33. Khalid, Karniza, et al. "Religious and Cultural Challenges in Paediatrics Palliative Care: A Review of Literature." *Pediatric Hematology Oncology Journal*, vol. 4, no. 3, Sept. 2019, pp. 67–73. *DOI.org (Crossref)*, https://doi.org/10.1016/j.phoj.2019.11.001.
34. Wiener, Lori, Denice Grady McConnell, et al. "Cultural and Religious Considerations in Pediatric Palliative Care." *Palliative and Supportive Care*, vol. 11, no. 1, Feb. 2013, pp. 47–67. *DOI.org (Crossref)*, https://doi.org/10.1017/S1478951511001027.
35. Perez, Giselle K., et al. "Taboo Topics in Adolescent and Young Adult Oncology: Strategies for Managing Challenging but Important Conversations Central to Adolescent and Young Adult Cancer Survivorship." *American Society of Clinical Oncology Educational Book*, no. 40, May 2020, pp. e171–85. *DOI.org (Crossref)*, https://doi.org/10.1200/EDBK_279787.
36. Hirata, Mika, and Kyoko Kobayashi. "Experiences with the End-of-Life Decision-Making Process in Children with Cancer, Their Parents, and Healthcare Professionals: A Systematic Review and Meta-Ethnography." *Journal of Pediatric Nursing*, vol.69,Mar.2023,pp. e45–64. *DOI.org (Crossref)*, https://doi.org/10.1016/j.pedn.2022.12.004
37. Salins, Naveen, et al. "Palliative Care in Paediatric Oncology: An Update." *Current Oncology Reports*, vol. 24, no. 2, Feb. 2022, pp. 175–86. *DOI.org (Crossref)*, https://doi.org/10.1007/s11912-021-01170-3
38. Feraco, Angela M., et al. "Tumor Talk and Child Well-Being: Perceptions of 'Good' and 'Bad' News Among Parents of Children With Advanced Cancer." *Journal of Pain and Symptom Management*, vol. 53, no. 5, May 2017, pp. 833–41. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2016.11.013
39. Martinez, Isaac, et al. "To Disclose or Not to Disclose: A Case Highlighting the Challenge of Conflicts in Pediatric Disclosure." *Journal of Pain and Symptom Management*, vol. 61, no. 1, Jan. 2021, pp. 211–15. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2020.07.042.
40. Smink, Gayle M., et al. "Paediatric Oncology Simulation Training for Resident Education." *BMJ Simulation and Technology Enhanced Learning*, vol. 5, no. 3, July 2019, pp. 155–60. *DOI.org (Crossref)*, https://doi.org/10.1136/bmjstel-2018-000347.
41. Sansom-Daly, Ursula M., et al. "Thinking Globally to Improve Care Locally: A Delphi Study Protocol to Achieve International Clinical Consensus on Best-Practice End-of-Life Communication with Adolescents and Young Adults with Cancer." *PLOS ONE*, edited by César Leal-Costa, vol. 17, no. 7, July 2022, p. e0270797. *DOI.org (Crossref)*, https://doi.org/10.1371/journal.pone.0270797.
42. Sikstrom, Laura, et al. "Being There: A Scoping Review of Grief Support Training in Medical Education." *PLOS ONE*, edited by Manuel Fernández-Alcántara, vol. 14, no. 11, Nov. 2019, p. e0224325. *DOI.org (Crossref)*, https://doi.org/10.1371/journal.pone.0224325.
43. Gengler, Amanda M. "'The Medicine Is the Easy Part': Pediatric Physicians' Emotional Labor in End-of-Life Care." *SSM - Qualitative Research in Health*, vol. 4, Dec. 2023, p. 100324. *DOI.org (Crossref)*, https://doi.org/10.1016/j.ssmqr.2023.100324.
44. Osenga, Kaci, et al. "A Comparison of Circumstances at the End of Life in a Hospital Setting for Children With Palliative Care Involvement Versus Those Without." *Journal of Pain and Symptom Management*, vol. 52, no. 5, Nov. 2016, pp. 673–80. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2016.05.024.
45. Plaza Fornieles, Mercedes, et al. "Efficacy of the Paediatrics Palliative Care Team of Murcia According to the Experience of the Parents." *Anales de Pediatría (English Edition)*, vol.93,no.1,July2020,pp.4–15.*DOI.org(Crossref)*,https://doi.org/10.1016/j.anpede.2019.07.00
46. Ullrich, Christina K., Leslie Lehmann, et al. "End-of-Life Care Patterns Associated with Pediatric Palliative Care among Children Who Underwent Hematopoietic Stem Cell Transplant." *Biology of Blood and Marrow Transplantation*, vol. 22, no. 6, June 2016, pp. 1049–55. *DOI.org (Crossref)*, https://doi.org/10.1016/j.bbmt.2016.02.012.
47. Vern-Gross, Tamara Z., et al. "Patterns of End-of-Life Care in Children With Advanced Solid Tumor Malignancies Enrolled on a Palliative Care Service." *Journal of Pain and Symptom Management*, vol. 50, no. 3, Sept. 2015, pp. 305–12. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2015.03.008
48. Esmaili, B. Emily, et al. "Qualitative Analysis of Palliative Care for Pediatric Patients With Cancer at Bugando Medical Center: An Evaluation of Barriers to Providing End-of-Life Care in a Resource-Limited Setting." *Journal of Global Oncology*, no. 4, Dec. 2018, pp. 1–10. *DOI.org (Crossref)*, https://doi.org/10.1200/JGO.17.00047.
49. Postier, Andrea C., et al. "Education in Palliative and End-of-Life Care-Pediatrics: Curriculum Use and Dissemination." *Journal of Pain and Symptom Management*, vol. 63, no. 3,Mar.2022,pp.349–58.*DOI.org(Crossref)*,https://doi.org/10.1016/j.jpainsymman.2021.11.017
50. Friedrichsdorf, Stefan J., et al. "Development of a Pediatric Palliative Care Curriculum and Dissemination Model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics." *Journal of Pain and Symptom Management*, vol. 58, no. 4, Oct. 2019, pp. 707-720.e3. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2019.06.008
51. Aasen, Eline Randi Hildursdotter Vatne, et al. "Are We on the Same Page? Exploring Pediatric Patients' Involvement With Advance Care Planning." *Journal of Pain and Symptom Management*, vol. 66, no. 3, Sept. 2023, pp. e353–63. *DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2023.04.003
52. Johnston, Emily E., et al. "Hospital or Home? Where Should Children Die and How Do We Make That a Reality?" *Journal of Pain and Symptom Management*, vol. 60, no. 1, July2020,pp.106–15.*DOI.org (Crossref)*, https://doi.org/10.1016/j.jpainsymman.2019.12.370.