Clinical Practice Guideline on Palliative Care in Paediatrics

Short version

Clinical Practice Guidelines in the Spanish NHS

Ministry of Health

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1. Introduction

The overall aim of the Clinical Practice Guideline on Palliative Care in Paediatrics (PPC) is to provide a set of recommendations based on scientific evidence to improve the comprehensive care of children and adolescents with life-threatening and/or life-limiting illnesses, from onset, and their families.

This version in English contains the following types of information:

- **Clinical questions**
- **Recommendations**
- **Rationale**
- **Complete clinical question** (link to the version in Spanish)
- **References.**

To access the full version of the CPG (as a multilayer presentation or PDF), the methods employed, materials for patients, families and other caregivers, and other information in Spanish, please click on the following link:

https://portal.guiasalud.es/gpc/guia-de-practica-clinica-sobre-cuidados-paliativos-en-pediatria/

2. Pharmacological treatment of moderate to severe pain in paediatric palliative care

Question

Which analgesics and at what doses are most effective and safe to treat moderate to severe pain in paediatric palliative care?

Recommendations

GOOD CLINICAL PRACTICE

1. A comprehensive approach to pain management in PPC is proposed, with pharmacological and non-pharmacological measures, taking into account the aetiology of the pain, its pathophysiology (nociceptive, neuropathic or mixed pain), its intensity, and the particular characteristics of the patient and his or her family.

2. The use of strong opioid analgesics is proposed for the relief of moderate to severe pain in PPC patients.

3. Morphine is proposed as the strong opioid of first choice to treat moderate to severe persistent pain in PPC patients.

4. Do not use minor opioids (tramadol, codeine) to treat moderate pain in PPC patients. In PPC patients with moderate pain, consider using major opioid analgesics at low doses.

5. If treatment with an opioid does not provide adequate pain relief or if it causes intolerable adverse effects, it is proposed to change to another opioid.

6. The dose of opioid analgesics should be adjusted (titrated) individually and progressively until the minimum effective dose is found. The response to treatment and the occurrence of adverse effects should be monitored.

7. Treatment should be scheduled at regular intervals to provide baseline analgesia, with on-demand dosing for exacerbations (breakthrough pain), and oral/enteral dosing whenever possible.

8. If neuropathic pain is suspected, consider treatment with gabapentinoids, low doses of tricyclic antidepressants, selective serotonin reuptake inhibitors (SSRIs) or an anti-NMDA agent (ketamine).

9. Inform the patient and family about the benefits and potential adverse effects of pain management. Develop the treatment plan taking into account the personal preferences and individual needs of each patient and family.

Rationale

The CPG development group (CDG) has decided to formulate a series of general practical considerations because it believes that it is not possible to recommend specific interventions based on the scarce and very low-quality evidence found.

The CDG has taken into account the WHO guidelines on the pharmacological treatment of persistent pain in children with medical conditions, as well as its own clinical experience. The analgesic treatment of PPC patients follows a biphasic strategy based on the intensity and duration of pain.

The CDG recognizes that the management of pain in these patients is complex due to its diverse aetiology and the biological, cognitive, psychological, socio-cultural, and spiritual factors that influence the child's perception of pain. Although they are not the focus of this question, the CDG considers it necessary to recall the importance of non-pharmacological measures such as ensuring a calm environment, postural changes, local heat or cold, physiotherapy, etc.

Complete clinical question

Full information on this question (available in Spanish), see:
http://portal.guiasalud.es/guia-en-capas/cuidados-paliativos-pediatria/#question-1

References

14. García de Paso M. Analgesia y sedación en Cuidados Paliativos Pediátricos. Bol pediatr. 2013; 53: 68-73.

15. World Health Organization. WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses. Geneva: WHO; 2012.

16. Navarro S, Martino RJ. Cuidados Paliativos Pediátricos: Epidemiología, organización. Fallecimiento en el hospital. Sedación. Actualizaciones Sociedad Española de Pediatría Hospitalaria (SEPHO). 2016.

17. Hunt A, Goldman A, Devine T, Phillips M. Transdermal fentanyl for pain relief in a paediatric palliative care population. Palliat Med. 2001;15(5):405-12. https://doi.org/10.1191/026921601680419456.

18. Finkel JC, Finley A, Greco C, Weisman SJ, Zeltzer L. Transdermal fentanyl in the management of children with chronic severe pain: results from an international study. Cancer. 2005;104(12):2847-57. https://doi.org/10.1002/cncr.21497.

19. Finkel JC, Pestieau SR, Quezado ZM. Ketamine as an adjuvant for treatment of cancer pain in children and adolescents. J Pain. 2007;8(6):515-21. https://doi.org/10.1016/j.jpain.2007.02.429.

20. Ruggiero A, Barone G, Liotti L, Chiaretti A, Lazzareschi I, Riccardi R. Safety and efficacy of fentanyl administered by patient controlled analgesia in children with cancer pain. Support Care Cancer. 2007;15(5):569-73. https://doi.org/10.1007/s00520-006-0193-8.

21. Davies D, DeVlaming D, Haines C. Methadone analgesia for children with advanced cancer. Pediatr Blood Cancer. 2008;51(3):393-7. https://doi.org/10.1002/pbc.21584.

22. Vondracek P, Oslejskova H, Kepak T, Mazanek P, Sterba J, Rysava M, et al. Efficacy of pregabalin in neuropathic pain in paediatric oncological patients. Eur J Paediatr Neurol. 2009;13(4):332-6. https://doi.org/10.1016/j.ejpn.2008.06.011.

23. Ruggiero A, Coccia P, Arena R, Maurizi P, Battista A, Ridola V, et al. Efficacy and safety of transdermal buprenorphine in the management of children with cancer-related pain. Pediatr Blood Cancer. 2013;60(3):433-7. https://doi.org/10.1002/pbc.24332.

24. Madden K, Mills S, Dibaj S, Williams JL, Liu D, Bruera E. Methadone as the Initial Long-Acting Opioid in Children with Advanced Cancer. J Palliat Med. 2018;21(9):1317-21. https://doi.org/10.1089/jpm.2017.0712.

25. Goldman A, Hewitt M, Collins GS, Childs M, Hain R. Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey. Pediatrics. 2006;117(6):e1179-86. https://doi.org/10.1542/peds.2005-0683.

26. Beecham E, Candy B, Howard R, McCulloch R, Laddie J, Rees H, et al. Pharmacological interventions for pain in children and adolescents with life-limiting conditions. Cochrane Database Syst Rev. 2015;2015(3): Cd010750. https://doi.org/10.1002/14651858. CD010750.pub2.

27. Womer J, Zhong W, Kraemer FW, Maxwell LG, Ely EA, Faerber JA, et al. Variation of opioid use in pediatric inpatients across hospitals in the U.S. J Pain Symptom Manage. 2014;48(5):903-14. https://doi.org/10.1016/j.jpainsymman.2013.12.241.

28. Rosenberg AR, Orellana L, Ullrich C, Kang T, Geyer JR, Feudtner C, et al. Quality of Life in Children With Advanced Cancer: A Report From the PediQUEST Study. J Pain Symptom Manage. 2016;52(2):243-53. https://doi.org/10.1016/j.jpainsymman. 2016.04.002.

29. Reglamento (CE) nº 1901/2006 del Parlamento Europeo y del Consejo, de 12 de diciembre de 2006, sobre medicamentos para uso pediátrico. Diario Oficial de la Unión Europea, nº 378 (27 de diciembre de 2006).

3. Palliative chemotherapy and radiotherapy

Question

Does the use of palliative chemotherapy/radiotherapy in children and adolescents with PPC increase survival, their quality of life, and/or improve symptom control?

Recommendations

GOOD CLINICAL PRACTICE

1. Healthcare professionals must explain to the patient (according to their level of development), and family, the benefits, risks, and possible associated distress of the treatment options (palliative radiotherapy, palliative chemotherapy, or supportive care), in an honest, simple, approachable, accessible, and coherent way, using all relevant information so that they can participate in the decision. In addition to active listening and appropriate silence, in order to be aware of their needs at all times.

2. Healthcare professionals should reinforce information about the PPC patient's prognosis and the treatment options available at each stage of the disease, tailored to the individual needs of the patient and family, with the aim of creating realistic expectations.

For aspects related to communication and treatment decision-making processes, it is suggested to refer to the recommendations in Chapters Child participation in decision-making and end-of-life care and Communication with the patient and family of the guidelines.

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3. In the management of symptoms in PPC, an individualised assessment is suggested to diagnose and, if possible, treat the specific causes. In paediatric patients with advanced cancer in palliative care, the use of palliative radiotherapy should be considered on a case-by-case basis, depending on the location and type of tumor.

Rationale

The CDG believes that palliative RT can be integrated into the end-of-life care process for children and adolescents with incurable cancer. Although the evidence is of very low quality, all series show that palliative RT improves symptoms in most patients, without significant toxicity.

The CDG has decided not to make a recommendation on palliative QT based on the evidence identified. Further studies are needed on the effectiveness and safety of its use in the paediatric age group.

Finally, general practical considerations were made about the need to clarify the goal of treatment with the patient and family in order to avoid, as far as possible, unrealistic expectations leading to unnecessary treatment.

Complete clinical question

Full information on this question (available in Spanish), see:
http://portal.guiasalud.es/guia-en-capas/cuidados-paliativos-pediatria/#question-2

References:

30. McCulloch,R, Berde C. Difficult pain. Adjuvants or co-analgesics. En: Oxford Textbook of Palliative Medicine 3. Hain R, Goldman A, ed. 2021, p. 188-201.

31. Stachelek GC, Terezakis SA, Ermoian R. Palliative radiation oncology in pediatric patients. Ann Palliat Med. 2019;8(3):285-92. https://doi.org/10.21037/apm.2019.05.01.

32. Murphy JD, Nelson LM, Chang DT, Mell LK, Le QT. Patterns of care in palliative radiotherapy: a population-based study. J Oncol Pract. 2013;9(5):e220-7. https://doi.org/10.1200/jop.2012.000835.

33. Rao AD, Chen Q, Ermoian RP, Alcorn SR, Figueiredo MLS, Chen MJ, et al. Practice patterns of palliative radiation therapy in pediatric oncology patients in an international pediatric research consortium. Pediatr Blood Cancer. 2017;64(11). https://doi.org/10.1002/pbc.26589.

34. Rao AD, Figueiredo MLS, Yegya-Raman N, Sehgal S, Chen Q, Alcorn SR, et al. Clinical practice and outcomes of palliative radiation therapy in pediatric oncology patients: An international comparison of experiences from two distinct countries and health care systems. Radiother Oncol. 2019;140:1-5. https://doi.org/10.1016/j.radonc.2019.05.017.

35. Chen EL, Yoo CH, Gutkin PM, Merriott DJ, Avedian RS, Steffner RJ, et al. Outcomes for pediatric patients with osteosarcoma treated with palliative radiotherapy. Pediatr Blood Cancer. 2020;67(1):e27967. https://doi.org/10.1002/pbc.27967.

36. Mak KS, Lee SW, Balboni TA, Marcus KJ. Clinical outcomes and toxicity following palliative radiotherapy for childhood cancers. Pediatr Blood Cancer. 2018;65(1). https://doi.org/10.1002/pbc.26764.

37. Lazarev S, Kushner BH, Wolden SL. Short Hypofractionated Radiation Therapy in Palliation of Pediatric Malignancies: Outcomes and Toxicities. Int J Radiat Oncol Biol Phys. 2018;102(5):1457-64. https://doi.org/10.1016/j.ijrobp.2018.07.2012.

38. Varma S, Friedman DL, Stavas MJ. The role of radiation therapy in palliative care of children with advanced cancer: Clinical outcomes and patterns of care. Pediatr Blood Cancer. 2017;64(5). https://doi.org/10.1002/pbc.26359.

39. Rahn DA, Mundt AJ, Murphy JD, Schiff D, Adams J, Murphy KT. Clinical outcomes of palliative radiation therapy for children. Pract Radiat Oncol. 2015;5(3):183-7. https://doi.org/10.1016/j.prro.2014.08.015.

40. Caussa L, Hijal T, Michon J, Helfre S. Role of palliative radiotherapy in the management of metastatic pediatric neuroblastoma: a retrospective single-institution study. Int J Radiat Oncol Biol Phys. 2011;79(1):214-9. https://doi.org/10.1016/j.ijrobp.2009.10.031.

41. Pramanik R, Agarwala S, Gupta YK, Thulkar S, Vishnubhatla S, Batra A, et al. Metronomic Chemotherapy vs Best Supportive Care in Progressive Pediatric Solid

Malignant Tumors: A Randomiz Clinical Trial. JAMA Oncol. 2017;3(9):1222-7. https://doi.org/10.1001/jamaoncol.2017.0324.

42. Porkholm M, Toiviainen-Salo S, Seuri R, Lönnqvist T, Vepsäläinen K, Saarinen-Pihkala UM, et al. Metronomic therapy can increase quality of life during paediatric palliative cancer care, but careful patient selection is essential. Acta Paediatr. 2016;105(8):946-51. https://doi.org/10.1111/apa.13338.

43. Cazzaniga ME, Biganzoli L, Cortesi L, De Placido S, Donadio M, Fabi A, Ferro A, Generali D, Lorusso V, Milani A, Montagna E, Munzone E, Orlando L, Pizzuti L, Simoncini E, Zamagni C, Pappagallo GL; Metronomic Chemotherapy in Advanced Breast Cancer Study Group. Treating advanced breast cancer with metronomic chemotherapy: what is known, what is new and what is the future? Onco Targets Ther. 2019 Apr 23;12:2989-2997.

44. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutics in cancer. En: MacLeod CM, ed. Evaluation of Chemotherapeutic Agents. Columbia University Press: New York, 1949, pp 191-205.

45. Lansky SB, List MA, Lansky LL, Ritter-Sterr C, Miller DR. The measurement of performance in childhood cancer patients. Cancer. 1987 Oct 1;60(7):1651-6.

46. Sociedad Española de Hematología y Oncología Pediátricas. Centros informantes del RETI-SEHOP [Internet]. [citado mayo 2022]. Disponible en: https://www.uv.es/rnti/pdfs/Listado%20CI.pdf

47. Lee BKY, Apkon D, Wolfe J, Marcus KJ. Palliative Radiation Therapy for Pediatric Patients: Parental Perceptions. International Journal of Radiation Oncology, Biology, Physics. 2017;99(2):S86. https://doi.org/10.1016/j.ijrobp.2017.06.208.

48. Tomlinson D, Bartels U, Gammon J, Hinds PS, Volpe J, Bouffet E, et al. Chemotherapy versus supportive care alone in pediatric palliative care for cancer: comparing the preferences of parents and health care professionals. CMAJ. 2011;183(17):E1252-8. https://doi.org/10.1503/cmaj.110392.

4. Child participation in decision-making and end-of-life care

Question

What are the facilitators and barriers for the child or adolescent at the end of life to participate in therapeutic decision-making (even against the advice of parents or carers)?

Recommendations

GOOD CLINICAL PRACTICE

1. All healthcare professionals caring for a patient who is a candidate for PPC must recognize that he or she has a central role in the decision-making process.

2. Professionals should explain to children or adolescents and their families that their contribution to the decision-making for end-of-life care is significant, and that they do not have to decide alone, but that the multidisciplinary team will participate and support them at all times, taking responsibility according to their professional competence.

3. Professionals should determine the patient's capacity or maturity to make decisions, taking into account the complexity and importance of the decision and the patient's personal and family circumstances, as well as the regulatory and legal framework.

4. Ask patients how they would like to participate (level of involvement) in the therapeutic decision-making and with whom they would like to share the DM process. Repeat the consultation at each decision-making because patient preferences may vary depending on the timing of the disease and the scope of the decision.

5. Systematically record the therapeutic decisions agreed with the patient and family in the PPC patient's medical record.

6. To facilitate the patient's participation in decision-making, it is suggested that the practitioner consider the following:
    - Generate as much closeness and trust as possible.
    - Address the patient directly, to make it clear that he or she is at the center of the conversation.
    - Give clear and honest information, using language that is easy to understand and adapted to the patient’s level of maturity. Value the use of visual and technological aids.
    - Ensure that the patient understands and comprehends the information received by maintaining an active listening attitude. Verbal explanations may be accompanied by additional written information.
    - Encourage an open and honest dialogue, especially if the decision is complex or there is uncertainty about the prognosis.

7. Support parents to facilitate the patient's participation in decision-making:
    - Help them to identify their fears and suffering and to distinguish them from those of their sons and daughters.
    - Advise them to actively and frequently seek out their children's feelings and opinions.
    - Suggest that the patient can be present during discussions with the healthcare team.

8. Training of professionals in shared decision-making with patients is recommended.

9. It is suggested that, in the absence of medical contra-indications, the desire for organ and tissue donation be explored as part of the end-of-life decision-making process.

Rationale

In addition to attitudes, conducts, behaviours, and feelings about end-of-life decision-making and patient involvement in the process, the CDG has considered the fundamental practical aspect of the need to assess the patient's capacity to decide.

Complete clinical question

Full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/cuidados-paliativos-pediatria/#question-3

References

8. Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica. Boletín Oficial del Estado, nº 274, (15-11-2002).

49. Junta de Andalucía [Internet]. [citado mayo 2022]. Los derechos de los niños y niñas. Disponible en: https://www.juntadeandalucia.es/organismos/igualdadpoliticassocialesyconciliacion/areas/infancia-familias/derechos-infancia.html

50. Ley 26/2015, de 28 de julio, de modificación del sistema de protección a la infancia y a la adolescencia. Boletín Oficial del Estado nº 180 (29 de julio de 2015).

51. Coyne I, O'Mathúna DP, Gibson F, Shields L, Leclercq E, Sheaf G. Interventions for promoting participation in shared decision-making for children with cancer. Cochrane Database Syst Rev. 2016;11(11):Cd008970. https://doi.org/10.1002/14651858.CD008970.pub3.

52. Federación Española de Padres Niños con cáncer. Cambio legislativo respecto al interés superior del menor: Opiniones de adolescentes y padres/tutores de niños con cáncer. 2017.

53. Escudero Carretero MJ, Simón Lorda P, Aguayo Maldonado J, Arcos Ocón L, Cía Ramos R, Fernández López A, et al. El final de la vida en la infancia y la adolescencia: Aspectos éticos y jurídicos en la atención sanitaria. Sevilla: Junta de Andalucía; 2011.

54. Hinds PS, Drew D, Oakes LL, Fouladi M, Spunt SL, Church C, et al. End-of-life care preferences of pediatric patients with cancer. J Clin Oncol. 2005;23(36):9146-54. https://doi.org/10.1200/jco.2005.10.538.

55. Inglin S, Hornung R, Bergstraesser E. Palliative care for children and adolescents in Switzerland: a needs analysis across three diagnostic groups. Eur J Pediatr. 2011;170(8):1031-8. https://doi.org/10.1007/s00431-011-1398-5.

56. Kars MC, Grypdonck MH, de Korte-Verhoef MC, Kamps WA, Meijer-van den Bergh EM, Verkerk MA, et al. Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. Support Care Cancer. 2011;19(1):27-35. https://doi.org/10.1007/s00520-009-0785-1.

57. Matsuoka M, Narama M. Parents' thoughts and perceptions on hearing that their child has incurable cancer. J Palliat Med. 2012;15(3):340-6. https://doi.org/10.1089/jpm.2011.0410.

58. de Vries MC, Bresters D, Kaspers GJL, Houtlosser M, Wit JM, Engberts DP, et al. What Constitutes the Best Interest of a Child? Views of Parents, Children, and Physicians in a Pediatric Oncology Setting. AJOB Primary Research. 2013;4(2):1-10. https://doi.org/10.1080/21507716.2012.757254.

59. Weaver MS, Baker JN, Gattuso JS, Gibson DV, Sykes AD, Hinds PS. Adolescents' preferences for treatment decisional involvement during their cancer. Cancer. 2015;121(24):4416-24. https://doi.org/10.1002/cncr.29663.

60. Kars MC, Grypdonck MH, de Bock LC, van Delden JJ. The parents' ability to attend to the «voice of their child» with incurable cancer during the palliative phase. Health Psychol. 2015;34(4):446-52. https://doi.org/10.1037/hea0000166.

61. Ley 10/2011, de 24 de marzo, de derechos y garantías de la dignidad de la persona en el proceso de morir y de la muerte. Boletín Oficial de Aragón nº 70, (24 de marzo de 2011).

62. Ley 26/2018, de 21 de diciembre, de derechos y garantías de la infancia y la adolescencia de la Comunidad Valenciana. DOGV nº 8450, (24 de diciembre de 2018).

63. Espejo M, Miquel E, Esquerda M, Pifarré J. Valoración de la competencia del menor en relación con la toma de decisiones sanitarias: escala de la competencia de Lleida. Med Clin (Barc). 2011;136(1):26-30. https://doi.org/10.1016/j.medcli.2009.05.014.

64. Drane JF. The many faces of competency. Hasting Cent Rep. 1985;4:17-21.

5. Communication with the patient and family

Question

What aspects of communication are considered useful when discussing with patients and families the appropriateness of therapeutic measures to the clinical situation of the child or adolescent in PPC?

Recommendations

GOOD CLINICAL PRACTICE

1. Professionals should strive to ensure that communication with the patient and family takes place in an atmosphere of maximum closeness and trust. The patient and family should perceive the team's involvement and commitment to the patient's treatment and care.

2. Whenever possible, identify and appoint professionals of reference within the health care team to communicate with the patient and family.

3. Clinicians should explore and ask patient's and family's preferences about what information they want to receive and how (interlocutor(s), frequency, level of detail, and complexity), and tailor communication to their needs, values, and culture at any given time.

4. The information needs and preferences of the patient and family should be assessed regularly.

5. Try to get to know the thoughts and feelings of the patient and family by asking them questions and listening respectfully to their answers. The team should value and respect the parents' unique knowledge of their son or daughter.

6. Show compassion and empathy, expressing concern for the patient and recognising the emotional distress and family difficulties involved.

7. Meetings with the PPC patient and his or her family should be planned, with the following aspects prepared in advance:

    - Find a comfortable, quiet place with privacy, preferably with no physical barriers between people and without interruptions, and allow the necessary time.
    - Encourage the patient and family to prepare for the meeting by writing down in advance any questions, concerns or ideas they wish to raise during the meeting.
    - Identify, address and, if possible, resolve any disagreements between healthcare professionals before the meeting. If consensus is not possible, decide how to present the difference of opinion to the family and patient, and inform them of future actions to resolve the disagreement.

8. When informing the PPC patient and family, the facts should be presented clearly and honestly, using language that is easy to understand. It is advisable to give key information in short sentences. It is then important to remain silent, giving the patient and family time to express emotions, and to share their thoughts.

9. The emotions that the patient and family may be experiencing can make it difficult to understand and retain the information; so it may be necessary to repeat the information several times, and ask if it has been understood. It is recommended to invite the patient and family to the next meeting and to be available to repeat and reinforce the messages, and to clarify any further doubts.

10. Before the end of each meeting, the PPC patient and family should know when they can expect to receive more information, and when they can next ask the clinicians about any questions they may have.

11. The decision to tailor therapeutic measures to the clinical situation of the child or adolescent who has entered an advanced stage of the disease must be clear to all those involved in making decisions about the patient's treatment. The process should be recorded in the clinical record or action plan.

12. After agreeing on the need to adapt the therapeutic measures, the PPC patient and the family should be informed of the new treatment and care plan, explaining that the aims are to achieve maximum comfort and well-being for the patient, and to reduce suffering.

13. Healthcare organizations should provide appropriate training in communication skills for professionals working with paediatric patients requiring PPC.

14. Healthcare organizations and care services themselves must ensure continuity of care, 24 hours a day, 365 days a year, and coordination between different services and care settings.

Rationale

The CDG has considered the evidence on facilitators and barriers to communication from the time of diagnosis to the end of life because it understands that communication is a continuous process that takes place throughout the illness.

Complete clinical question

Full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/cuidados-paliativos-pediatria/#question-4

References

65. Herreros B, Palacios G, Pacho E. Limitación del esfuerzo terapéutico. Rev Clin Esp. 012;212(3):134-40. https://doi.org/10.1016/j.rce.2011.04.016.

66. Snaman JM, Torres C, Duffy B, Levine DR, Gibson DV, Baker JN. Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution. J Palliat Med. 2016;19(3):326-32. https://doi.org/10.1089/jpm.2015.0253.

67. Stenekes SJ, Ens CD, Harlos M, Chochinov HM, Mytopher K. A descriptive study evaluating perinatal healthcare providers' perspectives of palliative programming in 3 Canadian institutions. J Perinat Neonatal Nurs. 2014;28(4):280-9; quiz E1-2. https://doi.org/10.1097/jpn.0000000000000020.

68. Steele AC, Kaal J, Thompson AL, Barrera M, Compas BE, Davies B, et al. Bereaved parents and siblings offer advice to health care providers and researchers. J Pediatr Hematol Oncol. 2013;35(4):253-9. https://doi.org/10.1097/MPH.0b013e31828afe05.

69. Robert R, Zhukovsky DS, Mauricio R, Gilmore K, Morrison S, Palos GR. Bereaved parents' perspectives on pediatric palliative care. J Soc Work End Life Palliat Care. 2012;8(4):316-38. https://doi.org/10.1080/15524256.2012.732023.

70. Branchett K, Stretton J. Neonatal palliative and end of life care: What parents want from professionals. Journal of Neonatal Nursing. 2012;18(2):40-4. https://doi.org/https://doi.org/10.1016/j.jnn.2012.01.009.

71. Caeymaex L, Speranza M, Vasilescu C, Danan C, Bourrat MM, Garel M, et al. Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their

newborn in the NICU. PLoS One. 2011;6(12):e28633. https://doi.org/10.1371/journal.pone.0028633.

72. Midson R, Carter B. Addressing end of life care issues in a tertiary treatment centre: lessons learned from surveying parents' experiences. J Child Health Care. 2010;14(1):52-66. https://doi.org/10.1177/1367493509347060.

73. Davies B, Contro N, Larson J, Widger K. Culturally-sensitive information-sharing in pediatric palliative care. Pediatrics. 2010;125(4):e859-65. https://doi.org/10.1542/peds.2009-0722.

74. Gordon C, Barton E, Meert KL, Eggly S, Pollacks M, Zimmerman J, et al. Accounting for medical communication: parents' perceptions of communicative roles and responsibilities in the pediatric intensive care unit. Communication & medicine. 2009;6(2):177-88.

75. Meert KL, Eggly S, Pollack M, Anand KJ, Zimmerman J, Carcillo J, et al. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. Pediatr Crit Care Med. 2008;9(1):2-7. https://doi.org/10.1097/01.Pcc.0000298644.13882.88.

76. Hendricks-Ferguson VL. Parental perspectives of initial end-of-life care communication. Int J Palliat Nurs. 2007;13(11):522-31. https://doi.org/10.12968/ijpn.2007.13.11.27587.

77. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. Pediatrics. 2006;117(3):649-57.
https://doi.org/10.1542/peds.2005-0144.

78. Hsiao JL, Evan EE, Zeltzer LK. Parent and child perspectives on physician communication in pediatric palliative care. Palliat Support Care. 2007;5(4):355-65. https://doi.org/10.1017/s1478951507000557.

79. Baverstock A, Finlay F. What can we learn from the experiences of consultants around the time of a child's death? Child Care Health Dev. 2008;34(6):732-9. https://doi.org/10.1111/j.1365-2214.2008.00875.x.

80. Buckman R. Communications and emotions. BMJ. 2002;325(7366):672. https://doi.org/10.1136/bmj.325.7366.672.

81. Costey S, Martín Ruiz N, Lorente R, Martínez de Zabarte Fernández JM, Marco S, Lanceta V, et al. La experiencia de enfermedad en los hermanos de niños en cuidados paliativos. Medicina Paliativa. 2020;27. https://doi.org/10.20986/medpal. 2020.1143/2019.

82. Caballero Pérez V, Rigal Andrés M, Beltrán García S, Parra Plantagenet-Whyte F, Moliner Robredo MC, Gracia Torralba L, et al. Influencia de los recursos especializados en cuidados paliativos pediátricos en los pediatras de Atención Primaria. Pediatría Atención Primaria. 2018;20:133-42.

6. The preferred location for end-of-life care

Question

What preferences do children in PPC and their families or carers have about where they receive care?

Recommendations

GOOD CLINICAL PRACTICE

1. It is proposed that the practitioner discusses with the child or adolescent and the family their preferences about the place of care and the place of death, taking into account their cultural, spiritual, and religious values.

2. Care should be provided in the location preferred by the child and family, as long as this is appropriate to their care needs and the availability of services in their area.

3. Wherever possible, paediatric palliative care should be provided in the child's own home, 24 hours a day, as this is the place of care most often preferred by the child or adolescent and their family.

4. Patients and their families must be able to change their place of care at any time, and there must be adequate coordination between the different levels of care. This option should be communicated to them from the outset.

5. The patient's and family's preferences for the place of care should be recorded in the medical record and made available to the professionals involved in the patient's care.

Rationale

The evidence is scarce and of low quality; however, it is important to note that there is consistency across studies regarding preference for place of care. Patients and families feel most comfortable and safe in their own homes, where they believe they can maintain as normal a life as possible. Above all, the CDG recognizes the importance of respecting the wishes of the patient and family in paediatric palliative care and this is reflected in the recommendations.

Complete clinical question

Full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/cuidados-paliativos-pediatria/#question-5

References

5. Ministerio de Sanidad, Servicios Sociales e Igualdad. Cuidados paliativos pediátricos en el Sistema Nacional de Salud: Criterios de Atención. Madrid: Ministerio de Sanidad, Servicios Sociales e Igualdad; 2014.

83. Vickers J, Thompson A, Collins GS, Childs M, Hain R. Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. J Clin Oncol. 2007;25(28):4472-6. https://doi.org/10.1200/jco.2007.12.0493.

84. Hechler T, Blankenburg M, Friedrichsdorf SJ, Garske D, Hübner B, Menke A, et al. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. Klin Padiatr. 2008;220(3):166-74. https://doi.org/10.1055/s-2008-1065347.

85. Kassam A, Skiadaresis J, Alexander S, Wolfe J. Parent and clinician preferences for location of end-of-life care: home, hospital or freestanding hospice?. Pediatr Blood Cancer. 2014;61(5):859-64. https://doi.org/10.1002/pbc.24872.

86. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. J Palliat Med. 2015;18(2):143-50. https://doi.org/10.1089/jpm.2014.0285.

87. Montel S, Laurence V, Copel L, Pacquement H, Flahault C. Place of death of adolescents and young adults with cancer: first study in a French population. Palliat Support Care. 2009;7(1):27-35. https://doi.org/10.1017/s1478951509000054.

88. Astray San Martín A. Encuesta sobre cuidados paliativos a pediatras de Atención Primaria en un área sanitaria de Madrid. Rev Pediatr Aten Primaria. 2010; XII (45):33-40.

89. Arias-Casais N, Garralda E, Pons JJ, Marston J, Chambers L, Downing J, et al. Mapping Pediatric Palliative Care Development in the WHO-European Region: Children Living in Low-to-Middle-Income Countries Are Less Likely to Access It. J Pain Symptom Manage. 2020;60(4):746-53. https://doi.org/10.1016/j.jpainsymman.2020.04.028.

90. Ananth P, Melvin P, Feudtner C, Wolfe J, Berry JG. Hospital Use in the Last Year of Life for Children With Life-Threatening Complex Chronic Conditions. Pediatrics. 2015;136(5):938-46. https://doi.org/10.1542/peds.2015-0260.

91. Noyes J, Edwards RT, Hastings RP, Hain R, Totsika V, Bennett V, et al. Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. BMC Palliat Care. 2013;12(1):18. https://doi.org/10.1186/1472-684x-12-18.

92. Chong PH, De Castro Molina JA, Teo K, Tan WS. Paediatric palliative care improves patient outcomes and reduces healthcare costs: evaluation of a home-based program. BMC Palliat Care. 2018;17(1):11. https://doi.org/10.1186/s12904-017-0267-z.

7. Symptom assessment in paediatric palliative care

Question

How can we assess which physical and/or emotional symptoms cause the most distress to the PPC patient? Which are perceived as the most distressing by the patient and their family or carers?

Recommendations

GOOD CLINICAL PRACTICE

1. The assessment of both physical and psychological symptoms of the PPC patient must be multidisciplinary, individualised, adapted to the child or adolescent and their family, and ongoing over time.

2. The identification and management of both the physical and psychological symptoms of the PPC patient should preferably be carried out by professionals specialised in paediatric palliative care, especially in patients in the last days of life.

3. Professionals should be aware of the physical and psychological symptoms experienced by the PPC patient and their families. A deliberate and continuous search for all symptoms is suggested, through targeted questions about what worries or bothers the patient, in addition to the physical examination, in order to facilitate a comprehensive assessment.

4. The identification of symptoms experienced by patients with communication difficulties should be carried out by trained personnel, using adapted rating scales and taking into account the changes perceived by the primary carer concerning the patient's baseline situation.

5. Healthcare professionals should inform the PPC patient and family in advance about the physical and psychological symptoms that may appear at the end of life, in particular the signs and symptoms associated with dying.

6. Parents should be instructed in the use of effective comfort measures to alleviate or mitigate the child's distress at the end of life, such as using a sponge to moisten the mouth, anatomical positions, blankets for warmth, or having favourite toys or objects nearby.

Rationale

The CDG has decided to formulate a set of general practical considerations because it has not found scientific evidence that directly answers the research question. It has also considered scientific evidence from studies of how patients and their relatives perceive symptoms at the end of life.

Complete clinical question

Full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/cuidados-paliativos-pediatria/#question-6

References

25 .Goldman A, Hewitt M, Collins GS, Childs M, Hain R. Symptoms in children/young people with progressive malignant disease: United Kingdom Children’s Cancer Study Group/Paediatric Oncology Nurses Forum survey. Pediatrics. 2006;117(6):e1179-86. https://doi.org/10.1542/peds.2005-0683.

28. Rosenberg AR, Orellana L, Ullrich C, Kang T, Geyer JR, Feudtner C, et al. Quality of Life in Children With Advanced Cancer: A Report From the PediQUEST Study. J Pain Symptom Manage. 2016;52(2):243-53. https://doi.org/10.1016/j.jpainsymman.2016.04.002.

76. Hendricks-Ferguson VL. Parental perspectives of initial end-of-life care communication. Int J Palliat Nurs. 2007;13(11):522-31. https://doi.org/10.12968/ijpn.2007.13.11.27587.

84. Hechler T, Blankenburg M, Friedrichsdorf SJ, Garske D, Hübner B, Menke A, et al. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. Klin Padiatr. 2008;220(3):166-74. https://doi.org/10.1055/s-2008-1065347.

88. Astray San Martín A. Encuesta sobre cuidados paliativos a pediatras de Atención Primaria en un área sanitaria de Madrid. Rev Pediatr Aten Primaria. 2010;XII(45):33-40.

89. Arias-Casais N, Garralda E, Pons JJ, Marston J, Chambers L, Downing J, et al. Mapping Pediatric Palliative Care Development in the WHO-European Region: Children Living in Low-to-Middle-Income Countries Are Less Likely to Access It. J Pain Symptom Manage. 2020;60(4):746-53. https://doi.org/10.1016/j.jpainsymman.2020.04.028.

90. Ananth P, Melvin P, Feudtner C, Wolfe J, Berry JG. Hospital Use in the Last Year of Life for Children With Life-Threatening Complex Chronic Conditions. Pediatrics. 2015;136(5):938-46. https://doi.org/10.1542/peds.2015-0260.

91. Noyes J, Edwards RT, Hastings RP, Hain R, Totsika V, Bennett V, et al. Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. BMC Palliat Care. 2013;12(1):18. https://doi.org/10.1186/1472-684x-12-18.

92. Chong PH, De Castro Molina JA, Teo K, Tan WS. Paediatric palliative care improves patient outcomes and reduces healthcare costs: evaluation of a home-based program. BMC Palliat Care. 2018;17(1):11. https://doi.org/10.1186/s12904-017-0267-z.

93. Wolfe J, Orellana L, Ullrich C, Cook EF, Kang TI, Rosenberg A, et al. Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study. J Clin Oncol. 2015;33(17):1928-35. https://doi.org/10.1200/jco.2014.59.1222.

94. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, et al. Symptoms and suffering at the end of life in children with cancer. N Engl J Med. 2000;342(5):326-33. https://doi.org/10.1056/nejm200002033420506.

95. Vollenbroich R, Borasio GD, Duroux A, Grasser M, Brandstätter M, Führer M. Listening to parents: The role of symptom perception in pediatric palliative home care. Palliat Support Care. 2016;14(1):13-9. https://doi.org/10.1017/s1478951515000462.

96. von Lützau P, Otto M, Hechler T, Metzing S, Wolfe J, Zernikow B. Children dying from cancer: parents' perspectives on symptoms, quality of life, characteristics of death, and end-of-life decisions. J Palliat Care. 2012;28(4):274-81.

97. Theunissen JM, Hoogerbrugge PM, van Achterberg T, Prins JB, Vernooij-Dassen MJ, van den Ende CH. Symptoms in the palliative phase of children with cancer. Pediatr Blood Cancer. 2007;49(2):160-5. https://doi.org/10.1002/pbc.21042.

98. Ullrich CK, Dussel V, Hilden JM, Sheaffer JW, Moore CL, Berde CB, et al. Fatigue in children with cancer at the end of life. J Pain Symptom Manage. 2010;40(4):483-94. https://doi.org/10.1016/j.jpainsymman.2010.02.020.

99. Heath JA, Clarke NE, Donath SM, McCarthy M, Anderson VA, Wolfe J. Symptoms and suffering at the end of life in children with cancer: an Australian perspective. Med J Aust. 2010;192(2):71-5. https://doi.org/10.5694/j.1326-5377.2010.tb03420.x.

100 .Collins JJ, Byrnes ME, Dunkel IJ, Lapin J, Nadel T, Thaler HT, et al. The measurement of symptoms in children with cancer. J Pain Symptom Manage. 2000;19(5):363-77. https://doi.org/10.1016/s0885-3924(00)00127-5.

101. Collins JJ, Devine TD, Dick GS, Johnson EA, Kilham HA, Pinkerton CR, et al. The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12. J Pain Symptom Manage. 2002;23(1):10-6. https://doi.org/10.1016/s0885-3924(01)00375-x.