

Pediatric palliative care and childhood neurosurgery: reflections based on a quantitative analysis of a survey data

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INTRODUCTION: In recent years, the profile of pediatric patients has changed, with the need for assistance for children living with chronic and life-threatening diseases becoming increasingly frequent. In this scenario, Pediatric Palliative Care (PPC) emerges as an integral and respectful form of assistance for these patients and their families. Understanding that pediatric neurosurgery is an extremely important area within Pediatric Palliative Care, as there are many intersections between the two areas, this research aimed to reflect on how this interaction is being carried out in practice. **MATERIAL AND METHODS:** It is an observational, descriptive, cross-sectional study, of survey type, in which the study population was composed of a convenience sample, using the snowball strategy. Analyses were performed with the aid of the statistical program Stata version 13.0 (Stata Corp, L. C.). Results are presented as frequencies and 95% confidence intervals, graph, and table. **RESULTS:** The sample represented 90 PPC services, almost all of which have physicians (97.90%). Among the medical specialties, none of the services reported having a pediatric neurosurgeon on the team. **DISCUSSION:** Several themes required by the National Medical Residency Commission for the training of pediatric neurosurgeons cover Pediatric Palliative Care, such as pain, bioethics, communicating difficult news and others. Therefore, the real rapprochement of the two areas is extremely important to ensure comprehensive care for the patient. **CONCLUSIONS:** There are important gaps between Pediatric Palliative Care and Pediatric Neurosurgery, reinforcing the importance of including the topic for neurosurgery residents and continuing education for those already trained.

Keywords: Palliative Medicine; Pain; Neurosurgery; Pediatrics; Medical Education.

INTRODUCTION

In recent years, the profile of pediatric patients has changed, with the need for assistance for children living with chronic and life-threatening diseases becoming increasingly frequent. In this scenario, Pediatric Palliative Care (PPC) emerges as an integral and respectful form of assistance to these patients and their families.(1,2) PPC requires early identification and assessment, in addition to adequate treatment, to improve quality of life, promote dignity and comfort without accelerating or delaying death, and may even positively influence the course of the disease, an essential aspect for the prognosis of pediatric patients.(3)

For Pediatric Palliative Care to provide adequate assistance to patients, a multidisciplinary team is required,(4) not only in different undergraduate courses, but also within the medical field itself.(5)

According to the National Medical Residency Commission (NMRC), in its Resolution Number 9, of April 8, 2019, which

provides for the Competency Matrix of Medical Residency Programs in Neurosurgery, it is the resident's responsibility, at the end of the first year, to know "identify the patient's level of consciousness using the Glasgow Coma Scale, determine the conditions of imminent risk of death and adopt appropriate resuscitation and support measures".(6) Decisions regarding ventilation, resuscitation or use of any life-substituting measure in pediatric patients suffering from a serious illness must follow prior therapeutic planning: defining the non-use of invasive support only at the time it is necessary is unfeasible in pediatrics.(7) Therefore, Pediatric Palliative Care, in which bioethical issues are studied, must always be linked to pediatric neurosurgery training curricula.

Even in the first year of residency, communication skills must be developed, to demonstrate care and respect during interaction with patients and family members, including cultural, socioeconomic, and religious values.(6) Therefore, clear, and accurate information about the diagnosis and prognosis must be shared with the child's family in consultation with the care team.(7)



Pain is one of the most common symptoms in Pediatric Palliative Care.(2) The World Health Organization, in 2012, published the “WHO guidelines on the pharmacological treatment of persistent pain in children with medical illnesses”, which sets out basic guidelines for the assessment and treatment of pediatric pain.(8) Considering pain as a vital sign (9) and the neurosurgeon being trained to “perform anamnesis and physical and neurological examinations” already in their first year of residency,(6) the assessment of pain by these doctors must be carried out impeccably, as they deal with acute and chronic pain.

Understanding that pediatric neurosurgery is an extremely important area within Pediatric Palliative Care, as there are many intersections between the two areas, this research aimed to reflect on how this interaction is being carried out in practice.

MATERIALS AND METHODS

This is an observational, descriptive, cross-sectional study of survey type, in which the study population was composed of a convenience sample. Fifteen online invitations were sent, using the snowball strategy, through social networks (WhatsApp, Instagram, or Facebook), both from the authors and from institutions that are part of the research, to representatives of PPC or Palliative Care services operating in Brazil, that served the pediatric age group (figure 1). Recruitment occurred from February to May 2021. Only one representative per service was accepted. New entries from the same service were excluded.

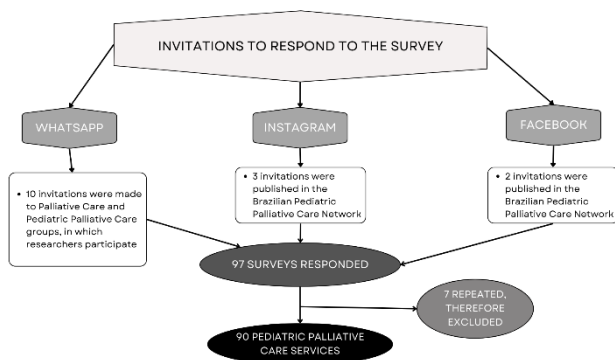


Figure 1- Contact network activated to complete the survey using the snowball method

Data were obtained through a questionnaire produced by the researchers, based on experience and the need to update, and complement information already found in other studies and documents.(2,10-13) Topics addressed in the questionnaire included institutional structure, professionals, teaching and research in the area, access to opioids, and care of professionals.

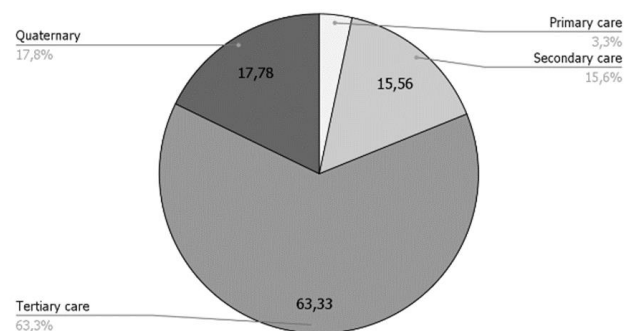
Analyses were performed with the aid of the statistical program Stata version 13.0 (Stata Corp, L. C.). Results are presented as frequencies and 95% confidence intervals (95% CI), graph, and table.

This study was approved by the Research Ethics Committee (CAAE 39915620.2.0000.5504) and all participants signed the Informed Consent Form. The Consensus-Based Checklist for Reporting of Survey Studies (CROSS) was used as the reporting guideline.(14)

RESULTS

A total of 15 invitations to participate in the survey were issued, and 97 questionnaires were returned. Details about the invitations and responses can be seen in figure 1. Seven questionnaires were excluded because they were from duplicate services in the database. The sample represented 90 PPC services. Regarding creation, 10 services reported that they were created until 2009, with the remaining 80 services created from 2010 onwards (of these, 32 services were created in the last 4 years).

As for the level of care, three (3.33%; 95% CI: 0.69% to 9.43%) services reported being exclusively primary; 14 (15.56%; 95% CI: 8.77% to 24.72%) secondary; 57 (63.33%; 95% CI: 52.51% to 73.24%) tertiary; and 16 (17.78%; 95% CI: 10.51% to 27.25%) quaternary, as per graph 1. The vast majority of services provide care through inter-consultations (76.30%; 95% CI: 65.36% to 84.00%); 44.30% (95% CI: 33.96% to 55.30%) do it through outpatient care; 33.00% (95% CI: 23.74% to 44.05%) in ward follow-ups; 25.90% (95% CI: 16.94% to 35.83%) by telecare; and 20.60% (95% CI: 12.30% to 29.75%) by home visits.



Graph 1- Level of care in Pediatric Palliative Care services

Regarding professional backgrounds, almost all of them have physicians (97.90%; 95% CI: 92.20% to 99.72%), followed by have psychologists (83.50%; 95% CI: 74.00% to 90.36%) and nurses (79.40%; 95% CI: 69.01% to 86.78%). Other backgrounds regarding professional training were Physiotherapy, Nutrition, Occupational therapy, Speech

therapy, Pharmacology, Odontology, Religious assistance and Physical Education, but in a smaller percentage. Among the medical specialties, none of the services reported having a pediatric neurosurgeon on the team.

As for access to opioids, important topic, as they are essential for post-surgical pain control, 60.00% (95% CI: 49.13% to 70.18%) of the services reported that they are fully accessible for the treatment of their patients, but still 40.00% (95% CI: 29.81% to 50.86%) reported having no access or difficulties.

DISCUSSION

The study observed that most Pediatric Palliative Care services are located in tertiary and quaternary hospitals but operating through consultations. As for team formation, most professionals are doctors but no pediatric neurosurgeons are involved. As for pain control, only 60% of services have full access to opioids.

As seen in graph 1, the majority of Pediatric Palliative Care services are located in tertiary and quaternary hospitals, that is, hospitals where pediatric neurosurgeons work. Even so, no pediatric neurosurgeons were reported to be part of the team. The NMRC brings, as neurosurgeon competencies, essential skills for Palliative Care in children, ranging from hydrocephalus care to decisions in head injuries.(6) Outpatient Palliative Care services demonstrate the importance of this professional as part of the team, and depending on the illness suffered by the patient, the pediatric neurosurgeon plays crucial roles with the patient and family, which even involve decision-making.(15)

Most Pediatric Palliative Care services operate through consultations. It is interesting to note that carrying out interconsultations appropriately is also a skill acquired by neurosurgeons in their first year, where the NMRC makes it mandatory to “value and request the need for interconsultations with other specialists when necessary”.(6) Working interdisciplinary, with the most diverse health professions, becomes ideal for the pediatric neurosurgeon to offer the best care to children and their families,(16) as required by Pediatric Palliative Care.

Pain control in pediatric neurosurgery is an essential task.(17) Regarding pain control, the study shows that only 60% of Pediatric Palliative Care services have complete access to opioids, which is far below what is needed.(17,18) In fact, the World Health Organization's ladder for treating pain in children is different from that used for adults, as has been shown since 2012 and it is in figure 2, and many health professionals do not have this knowledge:(8,17,18) the first step consists of simple analgesics and non-steroidal anti-inflammatory drugs (paracetamol/acetaminophen mainly, due to restrictions on the use of dipyrrone/metamizol in certain countries), unlike adults, in which there is an

intermediate step with weak opioids, in children there is only the second step, as they have restrictions on the use of tramadol and, especially, codeine.(8,9,18)

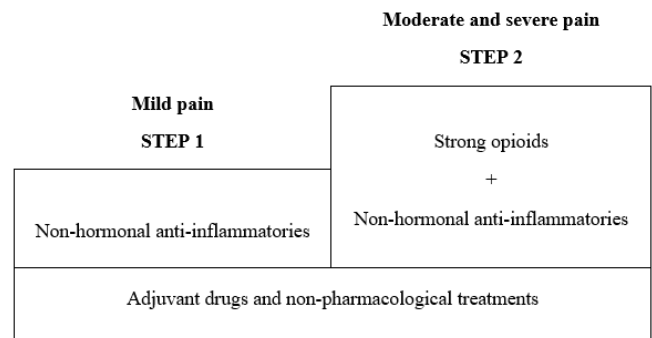


Figure 2- World Health Organization (WHO) analgesic ladder for children(2,9)

Still on pain, in its second year, the NMRC requires residents to undergo “pre- and post-operative care in neurosurgery”,(6) therefore, assessing pain in children is necessary at these times, but also a challenge, but one that more and more researchers are seeking to address.(9) Since isolated physiological parameters are not effective for this assessment, pain should always be assessed using scales already validated for the age group and condition in question.(9) There are scales for non-verbal children and adolescents, for example, which can be very useful in neurosurgery: from birth to 18 years old, children affected by cerebral palsy, whether or not they have cognitive impairment and are unable to report their pain, the neurosurgeon can use the scale FLACC - revised Face, Legs, Activity, Crying, Consolability scale (19), where scores from zero to three translate into mild pain, four to six translate into moderate pain and seven to ten translate into severe pain.(9)

Regarding the indication of Pediatric Palliative Care, since there is a lack of professionals in the area on the teams, one possibility is that they are not aware of these indications. Classic examples of patients who could be cared for by a Palliative Care team alongside the curative team are seen in scientific publications(20) and are brought by NMRC, such as Ischemic and Hemorrhagic Cerebral Vascular Disease, Traumatic Brain Injury, neoplasms of the nervous system, and congenital anomalies,(6) therefore, it is understood that training and continuing education in Pediatric Palliative Care are necessary so that pediatric neurosurgeons feel able to offer holistic care to these patients. An example of pediatric neurosurgery patients who fit into groups that can benefit from Pediatric Palliative Care is seen in Table 1.(2)

Regarding the communication of difficult news, which is so necessary for health professionals (21) and, especially, those who work with Palliative Care,(22) the NMRC requires neurosurgeons to master “verbal and non-verbal communication”, which should include theoretical and

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Table 1- Examples of pediatric neurosurgery patients who fit into groups that can benefit from Pediatric Palliative Care)^{2,9}

Groups	Situations involved	Examples of diseases and conditions in neurology and neurosurgery
Group 1	Children with acute life-threatening conditions from which recovery may or may not be possible	Any critical illness or injury, Traumatic Brain Injury
Group 2	Children with chronic, life-threatening conditions that can be cured or managed over a long period of time, but who can also die	Central Nervous System Malignancies, Severe central nervous system infections (such as tuberculosis)
Group 3	Children with progressive, life-threatening conditions for whom no curative treatment is available	Spinal Muscular Atrophy, Duchenne Muscular Dystrophy
Group 4	Children with serious neurological conditions that are not progressive but can cause deterioration and death	Stroke Survivors, Static Encephalopathy, Spastic Tetraplegia, Spina Bifida
Group 5	Newborns who are severely premature or have serious congenital anomalies	Severe prematurity with peri-intraventricular hemorrhage, anencephaly, genetic syndromes (for example, Apert Syndrome)
Group 6	Family members of a fetus or child who dies unexpectedly	Trauma from motor vehicle accident, with traumatic brain injury

Adapted from WHO (2018) and Blassioli et al (2023)^{2,9}

practical training during training.⁽²³⁾ Medical ethics is present in the competencies of all years of pediatric neurosurgeon training.⁽⁶⁾ Demonstrating respect, integrity and commitment to the precepts of medical ethics ⁽⁶⁾ are also essential pillars for Palliative Care, in addition to the fact that complex decision-making situations in pediatrics are frequently present in the routine of pediatric neurosurgery,^(24,25) which further demonstrates the need for training in bioethics, an area covered in Pediatric Palliative Care.

This research has limitations. Specifics about the services were not researched at this time, concluding with answers still pending, such as the number of consultations per period or the format in which the teams operate.

Several themes required by the NMRC for the training of neurosurgeons cover Pediatric Palliative Care, such as pain, bioethics, communicating difficult news and others. Therefore, the real rapprochement of the two areas is extremely important to ensure comprehensive care for the patient.

CONCLUSION

As pediatric neurosurgeons were not found in the Pediatric Palliative Care teams of the services studied, the question remains whether the intersections between the two areas are really being carried out and learned

appropriately. This suggests that there may be gaps between Pediatric Palliative Care and Pediatric Neurosurgery, reinforcing the importance of including the topic for neurosurgery residents and continuing education for those already trained.

ACKNOWLEDGMENTS

We would like to thank all the Pediatric Palliative Care services that participated in the research, as well as the Brazilian Network of Pediatric Palliative Care.

DISCLOSURES

Ethical approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the local Ethics Committee, number:39915620.2.0000.5504

Consent to participate

The patients gave consent to use their information and images for research purposes. *Consent for publication*

The patient gave consent to use his information and images for publication.

Conflict of interest

The authors declare no conflicts of interest with respect to the content, authorship, and/or publication of this article.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors

CONTRIBUTIONS

-Esther Angélica Luiz Ferreira: Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing

-Cristina Ortiz Sobrinho Valete: Data curation, Formal Analysis, Investigation, Methodology, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing

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REFERENCES

1. Ferreira EAL, Gramasco H, Iglesias SBO. Reumatologia infantil e cuidados paliativos pediátricos: conceituando a importância desse encontro. *Resid Pediatr.* 2019;9(2):189-192. DOI: 10.25060/residpediatr-2019.v9n2-21.
2. World Health Organization. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners, implementers and managers. Geneva: World Health Organization, 2018. ISBN 978-92-4-151445-3.
3. Ferreira EAL, Valete COS, Barbosa SMM, et al. Exploring the Brazilian pediatric palliative care network: a quantitative analysis of a survey data. *Rev Paul Pediatr.* 2023;41:e2022020. Published 2023 Mar 13. doi:10.1590/1984-0462/2023/41/2022020.
4. Volpin M, Ferreira E, Eduardo A, Bombarda T. Ensino sobre cuidados paliativos nos cursos da área de saúde. *Diálogos interdisciplinares*, 2022; 11(1):140-53. Available in: <https://revistas.brazcubas.br/index.php/dialogos/article/view/1173>.
5. Ferreira EAL, Medeiros PBS. Capítulo 63: Reumatologia Pediátrica. In: *Cuidados Paliativos Pediátricos*. Ferreira EAL, Barbosa SMM, Iglesias SBO. Rio de Janeiro: Medbook, 2023.
6. Ministério da Educação/Secretaria de Educação Superior. Resolução CNRM nº 9, de 8 de abril de 2019 – Dispõe sobre a Matriz de Competências dos Programas de Residência Médica em Neurocirurgia. *Diário Oficial da União*. Publicado em 11/04/2019, Edição 70, Seção 1, Página 201. Available in: <http://portal.mec.gov.br/docman/abril-2019-pdf/11531-09-resolucao-n-9-de-8-de-abril-de-2019-neurocirurgia/file>.
7. Ferreira EAL, Iglesias SBO, Dadalto L, Bayer AT, De-Matos DWFG. *Resid Pediatr.* 2020;10(2):1-5.
8. WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. Geneva: World Health Organization; 2012. ISBN 978-92-4-154812-0.
9. Blassioli C, Barbosa SMM, Ferreira EAL. Capítulo 16: Dor em pediatria: aguda e crônica. In: *Cuidados Paliativos Pediátricos*. Ferreira EAL, Barbosa SMM, Iglesias SBO. Rio de Janeiro: Medbook, 2023.
10. Santos AFJ, Ferreira EAL, Guirro UBP. *Atlas dos Cuidados Paliativos no Brasil 2019*. 1st ed. São Paulo : ANCP, 2020. ISBN 978-65-990595-0-6.
11. International Children's Palliative Care Network (ICPCN) [Internet]. ICPCN Estimated Levels of Children's Palliative Care Provision Worldwide. England & Wales: ICPCN; Updated May 2019 [cited 2021 Sep 09]. Available from: <https://www.icpcn.org/1949-2/>.
12. Barbosa S, Zoboli I, Iglesias S. *Cuidados Paliativos: na prática pediátrica*. Rio de Janeiro: Atheneu; 2019.
13. Oliveira NF, Lago PM. Suporte à equipe assistencial. In: Burns DAR et al. eds. *Tratado de pediatria: Sociedade Brasileira de Pediatria*. 4 ed. Barueri, SP: Manole, 2017. p. 2471-2.
14. Sharma A, Duc NTM, Thang TLL, et al. A Consensus-Based Checklist for Reporting of Survey Studies (CROSS). *J Gen Intern Med.* 2021; 36(10): 3179-87.
15. Bacheladenski EP, Carmo ALS. Cuidados paliativos ambulatoriais em pacientes crônicos. *Jornal Paranaense de Pediatria* - 2021; 22(1):1-6. Disponível em: <http://www.jornaldepediatria.org.br/>

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16. Silva AR. Nursing planning in complex pediatric neurosurgery procedures in a reference surgery center. Arch Pediatr Neurosurg [Internet]. 2022 Jan. 17 [cited 2023 Oct. 9];3(2(May-August):e752021. Available from: <https://www.archpedneurosurg.com.br/sbnped2019/article/view/75>
17. León-Álvarez E, Ortiz-Bautista JG, Ortega-Munguía C, Murata C. Analgesia postoperatoria para craneotomías en pediatría: experiencia en un Hospital de Tercer Nivel. Rev. mex. anestesiología. [revista en la Internet]. 2021 Jun [citado 2023 Oct 10] ;44(2):84-90. Disponible en: http://www.scielo.org.mx/scielo.php?script=sci_arttext&pid=S0484-79032021000200084&lng=es. Epub 04-Oct-2021.
18. Pollock JS. Pain relief in children after neurosurgery. Anaesthesia. 2000;55(4):410. doi:10.1046/j.1365-2044.2000.01378-39.x.
19. Bussotti EA, Guinsburg R, Pedreira MLG. Cultural adaptation to Brazilian Portuguese of the Face, Legs, Activity, Cry, Consolability revised (FLACCr) scale of pain assessment. Revista Latino-Americana de Enfermagem. 2015; 23(4):651-59.
20. Raposo-Amaral C, Raposo-Amaral CA, Ghizoni E. Posterior vault distraction osteogenesis in Apert syndrome. Arch Pediatr Neurosurg [Internet]. 2022 May 10 [cited 2023 Oct. 9];4(2(May-August):e1302022. Available from: <https://www.archpedneurosurg.com.br/sbnped2019/article/view/130>.
21. Ferreira EAL, Brida FD, Curcelli EM, Valette COS. Comunicação de más notícias: autopercepção de estudantes de medicina. Rev Bioét [Internet]. 2022Jan;30(1):54–62. Available from: <https://doi.org/10.1590/1983-80422022301506PT>.
22. Smith A. Communication of prognosis in palliative care. UpToDate. 2018;1–21.
23. Miranda SP, Schaefer KG, Vates GE, Gormley WB, Buss MK. Palliative Care and Communication Training in Neurosurgery Residency: Results of a Trainee Survey. Journal of surgical education. 2019;76(6), 1691–1702. <https://doi.org/10.1016/j.jsurg.2019.06.010>.
24. Shlobin NA, Sheldon M, Bernstein M. Ethics of Transitioning from Curative Care to Palliative Care: Potential Conflicts of Interest Using the Example of Neurosurgery. World Neurosurg. 2022;168:139-145. doi:10.1016/j.wneu.2022.10.003.
25. de Oliveira RS, Ballesteros MFM. Moral dilemma: To operate or not to operate. Arch Pediatr Neurosurg [Internet]. 2022 Jan. 17 [cited 2023 Oct. 9];4(1(January-April):e1272022. Available from: <https://www.archpedneurosurg.com.br/sbnped2019/article/view/127>.