REFLECTION ARTICLE

Family preparation for recognizing and relieving pain in children with intellectual disabilities

Preparo da família no reconhecimento e no alívio da dor em crianças com deficiência intelectual

Preparación de la familia para reconocer y aliviar el dolor en niños con discapacidad intelectual

Nur Mohamad Ali El Akra[1] https://orcid.org/0000-0002-7265-7736
Thaylla Mwryha Maciel Bueno[1] https://orcid.org/0000-0003-2024-6430
Gabriele Cássia Santos Silva[1] https://orcid.org/0009-0004-9945-4527
Francisneide Gomes Pego do Nascimento[2] https://orcid.org/0000-0002-0130-0385
Myriam Aparecida Mandetta[2] https://orcid.org/0000-0003-4399-2479
Maria Angélica Marcheti[1] https://orcid.org/0000-0002-1195-5465

Abstract

The objective of this study was to reflect on the importance of preparing the family to identify and treat the pain of children with intellectual disabilities. This is a reflection article which discusses the concept of a child with intellectual disabilities, the assessment tools available in the literature, the difficulty of the families to assess and treat the pain of these children and the assumptions of the Interactional Family Care Model to support the actions of nurses. This reflection provides an opportunity for health professionals to broaden their understanding of the complexity of caring for children with intellectual disabilities, highlighting the importance of assessing and relieving pain; the involvement of the family in partnership with the team and the influence of health literacy for the promotion of the best care for these children by their family.

Keywords
Child exceptional; Healthcare models; Pain; Family; Pediatric nursing

Resumo

O objetivo deste estudo foi refletir sobre a importância do preparo da família para identificar e tratar a dor da criança com deficiência intelectual. Trata-se de artigo de reflexão, em que se discutem o conceito de criança com deficiência intelectual, os instrumentos de avaliação disponíveis na literatura, a dificuldade de a família avaliar e tratar a dor dessas crianças e os pressupostos do *Interactional Family Care Model* para fundamentar as ações dos enfermeiros. A partir dessa reflexão, abre-se a oportunidade para os profissionais de saúde ampliarem sua compreensão sobre a complexidade do cuidado de crianças com deficiência intelectual, destacando a importância da avaliação e do alívio da dor; do envolvimento da família em parceria com a equipe e da influência do letramento em saúde para a família promover o melhor cuidado a essas crianças.

Descritores
Criança com deficiência intelectual; Modelos de assistência à saúde; Dor; Família; Enfermagem pediátrica

Resumen

El objetivo de este estudio fue reflexionar sobre la importancia de preparar a la familia para identificar y tratar el dolor de los niños con discapacidad intelectual. Este fue un artículo de reflexión que discute el concepto de niño con discapacidad intelectual, las herramientas de evaluación disponibles en la literatura, la dificultad de las familias para evaluar y tratar el dolor de estos niños y las premisas del *Interactional Family Care Model* para apoyar las acciones de las enfermeras. Esta reflexión ofrece una oportunidad para que los profesionales de la salud amplíen su comprensión de la complejidad de la atención a los niños con discapacidad intelectual, destacando la importancia de la evaluación y el alivio del dolor, la participación de la familia en colaboración con el equipo y la influencia de la alfabetización en salud de la familia para promover la mejor atención a estos niños.

Descriptores
Niño excepcional; Modelos de atención de salud; Dolor; Familia; Enfermería pediátrica

How to cite:
El Akra NM, Bueno TM, Silva GS, Nascimento FG, Mandetta MA, Marcheti MA. Family preparation for recognizing and relieving pain in children with intellectual disabilities. Rev Soc Bras Enferm Ped. 2023;23:eSOBEP202307001.

---

[1] Universidade Federal de Mato Grosso do Sul, Campo Grande, MS, Brazil.
[2] Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

Conflicts to interest: none to declare.
Submitted: October 10, 2023 | Accepted: December 20, 2023

Corresponding author: Maria Angélica Marcheti | E-mail: angelica.marcheti@ufms.br

DOI: 10.31508/1676-37932023007001i

Introduction

Intellectual Development Disorder or intellectual disability corresponds to deficits in skills and functions expected for age, impairing aspects of the child's life, when the individual does not reach the expected developmental milestones in several areas of intellectual functioning. These limitations may result from neurological injuries that lead to changes in neuropsychomotor development.(1)

Children with changes in neuropsychomotor development may have, for example, delayed development and reduced effectiveness in the learning process, associated or not with acquired brain injuries or some neurodegenerative disease that has affected the child.(2)

This clinical condition generally occurs before the age of 18 years and is characterized by evident limitations in intellectual functioning and adaptive behavior, such as conceptual, social and practical adaptive skills.(3) According to the American Association on Intellectual and Developmental Disabilities (AAIDD), people with cognitive/intellectual disabilities have difficulty in learning things and understanding and performing activities that are common for people who do not have these disabilities.(2)

In epidemiological surveys on intellectual disabilities in the last census conducted by the Brazilian Institute of Geography and Statistics (IBGE) in 2010, a population of 2,611,536 people had this type of disability in Brazil.

Cerebral palsy (CP), also known as chronic non-progressive encephalopathy, is the most common cause of intellectual or cognitive disability and neuromotor disorders in childhood. This condition affects the child's muscle tone, posture, and movements. In terms of prevalence, CP occurs in approximately 2.1 cases for every thousand live births. Because of the regional heterogeneity and inequalities in healthcare in Brazil, the prevalence may be higher in some populations and regions. It is important to highlight that general health conditions are strongly influenced by poverty, and 80% of people with disabilities in the world live in low- and middle-income countries. In addition, antenatal and perinatal care, as well as advanced care for at-risk newborns and developmental monitoring have a significant impact on prognosis.(4)

Children and adolescents with intellectual disabilities may experience increased sensitivity to pain compared to those without this disability. This is due to their chronic physical conditions and disabling disorders, in addition to being more frequently exposed to trauma and injuries resulting from surgical and rehabilitation procedures.(2)

Motor disorders caused by CP in children and adolescents are accompanied by sensory, cognitive, communication, behavioral and perception disorders, in addition to epileptic seizures in some cases. Children with neurological impairment are at greater risk of experiencing pain phenomena because their clinical problems may cause pain. In addition, they have peculiarities that mask the expression of pain and make it difficult to assess the painful phenomenon.(5)

In an evaluative context, pain requires technical and scientific knowledge, in addition to practical skills for its assessment, which makes this process complex for professionals, researchers and families. The complexity increases even more when the child or adolescent has neurological impairment, especially in the cognitive and speech areas.(6)

According to the International Association for the Study of Pain (IASP), pain is an unpleasant experience associated with actual or potential tissue damage, involving sensory, emotional, and cognitive aspects, and the inability to report pain does not exclude its existence.(7) Pain assessment in children with CP and severe cognitive deficits is challenging because these children have difficulty in verbalizing or expressing pain. Intellectual disability and limitations in verbal communication interfere with self-reporting and require the use of instruments that assess pain through behavioral and physiological changes, and through the family's perception.(8) The absence of specific instruments can make it difficult to detect pain in children with CP.

The Face, Legs, Activity, Cry, Consolability revised (FLACCr) stands out among the structured instruments for assessing pain in children with neurological impairment.

The FLACC pain assessment scale was developed in 1997 based on behavioral parameters for the use by health professionals, aiming to contribute to clinical practice in the assessment of pain in nonverbal children or children with speech difficulties and unable to report their pain.(9) Starting in 2002, the authors of the scale modified the assessment descriptors to adapt it to the care of children with cognitive impairment aged 4-19 years. This revised version of the scale is called “FLACC revised” or “revised FLACC” (FLACCr)(10-12) and also included four guidelines for its application. The study by Bussotti et al.(6) expanded the knowledge of Brazilian professionals about the assessment of pain in children with CP. The modified scale maintained the indicators of the FLACC scale and incorporated specific pain behaviors in children with multiple disabilities. An open-ended descriptor was added to each indicator to include specific pain behaviors of each child described by parents, such as increased muscle tone.

In this way, pain scales can provide healthcare professionals and families with tools that standardize conduct and generate clinical indicators. Validated pain assessment instruments are useful for helping in pain identification and management, enabling better conduct.

An article that analyzed the scientific production on pain assessment instruments in children and adolescents with cognitive dysfunction concluded that they can be used both by healthcare professionals and family members in home settings. This contributes to the early identification of pain and the establishment of adequate analgesia measures. The purpose of these instruments is to assist in detecting pain in nonverbal children, preventing harm to their quality of life and delays in growth and development.(13)

Another study evaluated pain in children with CP in the postoperative period of orthopedic surgeries and the perception of parents and health professionals about pain. It reached the conclusion that these children present moderate to severe pain in the postoperative period. During the hospital phase, it is more difficult to detect pain in nonverbal patients without the use of a specific scale, even for experienced parents and professionals.(14)

The evaluation of the complementarity of the FLACCr and the Inventory of Pain Behavior in Neurological Disability for measuring pain in children with severe neurological impairment revealed that most of the children evaluated had CP as their primary diagnosis (80.8%). When using the FLACCr, the presence of pain was identified in 50% of children and when using the inventory, in 34.6%. There was good agreement (84.6%) among respondents when considering both instruments (k=0.692; 95% confidence interval [95%CI] 0.437-0.967; p=0.000). This study demonstrated that the instruments should be used in a complementary manner in the assessment of pain in children with this type of disability.(15)

The complementarity between the FLACCr and the Inventory of Pain Behavior in Neurological Disability demonstrates the importance of using multiple instruments to assess pain in children and adolescents with severe neurological impairment. The good agreement between the methods reinforces the need for multifaceted approaches in the detection of pain, especially in nonverbal populations. These findings highlight the importance of training both health professionals and family members in the use of appropriate tools, promoting more precise and effective interventions. This way the quality of life of these children will be improved, ensuring a more humanized approach that is responsive to their specific needs.

The family of a child with intellectual disability

The family plays an essential role in the context of child care and is indispensable for their child’s development and healthy growth. This role includes several dimensions, such as emotional, affective and educational support, in addition to the transmission of cultural concepts and traditions. Families act as active caregivers and contribute directly to the development and well-being of children with cognitive impairment.(16)

They also act to promote autonomy and cognitive stimulation, and are fundamental for the integral development of the child, thereby collaborating with professionals in the health and education areas. This collaboration involves seeking specialized guidance and the active participation in the planning and implementation of intervention strategies, ensuring that the child’s specific needs are met in an effective and personalized manner.(17)

The child and the family must be cared for as a unit. This requires the training of professionals, so they can establish therapeutic and interdisciplinary care relationships, which implies a constant process of dialogue. Communication skills, understood as the ability to establish an effective dialogue between health professionals and users, emerge as an indispensable tool with a purpose beyond simply guiding, informing and comforting, and a crucial role in meeting fundamental needs. Furthermore, communication helps to cultivate co-responsibility, problem-solving ability and ultimately promotes quality care, empowering family members to be autonomous in their own journey of caring for these children.(18)

An important concept to promote the protagonist role of the family of children and adolescents with intellectual disabilities is health literacy or functional health literacy, defined as knowledge, motivation and competence to access, understand, evaluate and apply health information to judge and make decisions in everyday life about healthcare, disease prevention and health promotion in order to maintain or improve quality of life.(19-22) This concept highlights what each individual is capable of doing with these skills, as people with a good educational level may also have difficulty in understanding healthcare guidelines.(23)

In this text, we present a reflection on the importance of preparing the family to recognize and evaluate the pain of children with intellectual disabilities, based on the assumptions of the Interactional Family Care Model (IFCM),(24) which has the objective of promoting the empowerment of the family to deal with the adversities imposed by the chronic health condition.

Interactional Family Care Model

The concepts of the IFCM(24) were developed based on the frameworks of symbolic interactionism,(25) the family vulnerability model(26) and the family resilience model.(27)

The model considers the family as a system that interacts with and defines the situations based on their experiences, vulnerability and resilience to deal with the demands and challenges caused by the chronic health condition of one of its members. The care is focused on identifying the symbolic definition of the family and offering interventions that help them to resignify and alleviate suffering, so they can develop their sense of empowerment for decision making and modify functioning patterns in the face of the situations they experience.(18,24)

In the IFCM,(24) the nurse provides family embracement, recognizing their feelings of vulnerability and suffering, and identifies individual and family beliefs and strengths; recognizes the symbolic definition attributed by the family to the experience and establishes interaction based on respect, empathy, open communication and attentive listening; promotes the strengthening of the family's resilience, proposing interventions that help them to restructure or modify their functioning pattern and give new meaning to the situation; and values interaction with the family in a way that the interventions are proposed together with the family.

The importance of health literacy for the family of a child with intellectual disability

In our clinical practice with families of children with intellectual disability, we come across their lack of knowledge about how to identify pain and what to do in this situation. This brings a reflection on the actions we can propose to help them change this reality, contributing to minimizing the suffering of the child and their family.

Based on the IFCM, we recommend that nurses approach the reality experienced by families, embracing them and recognizing how they define the situation of having a child/adolescent with intellectual disability. From there, nurses approach the reality of the family, understanding its structure, functioning and development through the genogram, in addition to the interactions of the family nucleus with the extended family and the support network in the community, and the context of life and interactions through the ecomap. Such tools facilitate bonding with the family and provide data for nurses to deepen their knowledge about the strengths and weaknesses, as well as the difficulties faced by the family in dealing with the health-illness situations of one of its members.(28)

In our clinical practice, some aspects stand out among the demands and challenges experienced by families of children with intellectual disability: the lack of a family support network; the continuous experience of a situation of social vulnerability; the family's difficulties in managing the child/adolescent with severely compromised motor conditions and the manifestation of chronic pain, which impact family relationships.

Thus, interventions should focus on: identifying new possibilities for support networks with the extended family so the care of the child/adolescent can be shared with other members; encouraging changes in family interactions; positively reinforcing the family's strengths and abilities; and offering information about the identification and treatment of pain in order to broaden the family's understanding of episodes of pain using appropriate language with images and a visual pain assessment scale in order to provide the necessary knowledge and prepare them to deal with situations.

When reflecting on these actions, we understand their importance in strengthening the family in the decision-making process regarding the reorganization of the family with the division of tasks among its members to ensure the provision of care of the child/adolescent.

In this process, offering interventions for the family to think about and prepare for care is fundamental. Likewise, the use of adapted educational strategies prepares the family with the necessary knowledge and skills to meet the specific health needs of its members.

In this way, increases the understanding of the importance of health literacy, particularly regarding its impact on the care provided by families to children and adolescents with intellectual disability. This may include knowledge of physical indicators, such as changes in facial expression, posture or sleep patterns, and behavioral signs such as irritability, agitation or refusal to eat.(29) By being aware of these signs and symptoms, families can take action to alleviate the child's discomfort, whether through comfort measures, appropriate medication or the search for healthcare when necessary.(30)

Health professionals should value the family's experience with the pain of children/adolescents with intellectual disability, as they are the first to provide care at home. Families are more likely to recognize behavioral changes demonstrated by children/adolescents during episodes of pain.(31) However, families must be prepared to use pain assessment tools appropriately. This includes specific and ongoing training to identify signs of pain, apply scales accurately and effectively communicate their observations to health professionals. In this way, collaboration between families and professionals can be optimized, resulting in more efficient management of children/adolescents with pain and a significant improvement in their quality of life.(32)

Identifying pain can represent a significant challenge for families caring for children with intellectual disabilities, as these children are often unable to communicate or express their discomfort in conventional ways. Furthermore, pain signals may manifest differently in these children, making the interpretation of these signals even more complex.(29) Therefore, it is essential that families are equipped with specific knowledge and skills to recognize and interpret these signals, ensuring decision-making and appropriate pain management at home.

Health literacy is linked to health promotion and prevention of complications and its impairment results in inadequate use of health services with negative consequences, including high rates of hospitalization, adverse effects during the transition of care, increased incidence of chronic diseases, reduced use of preventive measures and reduced adherence to treatments. Health education has the potential to empower the population and promote recognition of the determinants of health, which can lead to collective empowerment and a critical-social approach to general well-being.(33)

Final considerations

This reflection opens the opportunity for health professionals expanding their understanding of the complexity of caring for children with intellectual disability, highlighting the importance of pain assessment and relief; family involvement in partnership with the team and the influence of health literacy for the promotion of the best care for these children by the family. These reflections have significant implications for the development of more targeted support strategies, aiming at the integral well-being of these children.

References

1. American Psychiatric Association (APA). Manual diagnóstico e estatístico de transtornos mentais DSM-5. 5a ed. Porto Alegre: Artmed; 2015 [citado 2024 Jul 18]. Disponível em: https://www.institutopebioetica.com.br/documentos/manual-diagnostico-e-estatistico-de-transtornos-mentais-dsm-5.pdf
2. D'Alpino PH, Robes AV. Dor em crianças com deficiências cognitivas: uma revisão sobre os instrumentos de avaliação comportamentais. Rev Ens Educ Cienc Hum. 2020;21(3):257-64.
3. Duarte AS, Pasin SS, Cavatá T, Heldt E. Instrumentos de avaliação de dor em idosos com prejuízo cognitivo: revisão sistemática. Rev HCPA. 2013;33(2):150-60.
4. Pereira HV. Paralisia cerebral. Residência Pediátrica. 2018;8(supl 1):49-55.
5. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007;109:8-14. Erratum in: Dev Med Child Neurol. 2007;49(6):480.
6. Bussotti EA, Guinsburg R, Pedreira ML. Cultural adaptation to Brazilian Portuguese of the Face, Legs, Activity, Cry, Consolability revised (FLACCr) scale of pain assessment. Rev Latino-Am Enfermagem. 2015;23(4):651-9.
7. International Association for the Study of Pain (IASP). IASP Curriculum Outline on Pain for Nursing. Washington: IASP; 2018 [cited 2024 Jul 24]. Available from: https://www.iasp-pain.org/education/curricula/iasp-curriculum-outline-on-pain-for-nursing/
8. Garcia M, Fernandes A. Avaliação da dor nas crianças com deficiência profunda: a escala DESS. Rev Referência. 2007;II(5):18-22.
9. Merkel SI, Voepel-Lewis T, Shayevitz JR, Malviya S. The FLACC: a behavioral scale for scoring postoperative pain in young children. Pediatr Nurs. 1997;23(3):293-7.
10. Voepel-Lewis T, Merkel S, Tait AR, Trzcinka A, Malviya S. The reliability and validity of the Face, Leg, Activity, Cry, Consolability Observational Tool as a measure of pain in children with cognitive impairment. Anesth Analg. 2002;95(5):1224-9.
11. Malviya S, Voepel-Lewis T, Burke CN, Merkel S, Tait AR. The revised FLACC observational pain tool: improved reliability and validity for pain assessment in children with cognitive impairment. Pediatr Anesth. 2006;16(3):258-65.
12. Manworren RC, Hynan LS. Clinical validation of FLACC: preverbal patient pain scale. Pediatr Nurs. 2003;29(2):140-6.
13. Seixas TO, Possi JC, Macedo IF, Nunes MD. Instrumentos de avaliação da dor em crianças e adolescentes com deficiência cognitiva: revisão integrativa. Rev Soc Bras Enferm Ped. 2020;20(2):108-15.
14. Fornelli AC, Lopes JB, Meirelles DF, Pontin JB, Lima MA. Pain in children with cerebral palsy in the postoperative: perception of parents and health professionals. BrJP. 2019;2(2):137-41.
15. Bittencourt B, Breigeiron MK, Flores FS, Pasin SS. Complementarity of pain assessment instruments in children with central nervous system impairment. Rev Gaúcha Enferm. 2021;42: e20200379
16. Massoli LP, Alves SC, Esper MV. Contexto familiar de crianças com deficiência. Constr Psicopedag. 2020;28(29):7-20.
17. Chida TH, Shaw GS. Família, escola e especialistas: o tripé que contribui para o desenvolvimento da criança autista. Horizontes. 2022;40(1):e022057.
18. Marchetti MA, Toso BR, Marques FR, Nascimento FG, Pontes EC, Mandetta MA. Interdisciplinary training for the family approach in primary healthcare. Texto Contexto Enferm. 2023;32.
19. World Health Organization (WHO). Health Literacy Development for the Prevention and Control of Noncommunicable Diseases. Volume 1: Overview. Geneva: WHO; 2022 [cited 2024 Jul 18]. Available from: https://www.who.int/publications/i/item/9789240055339.
20. World Health Organization (WHO). Health literacy development for the prevention and control of noncommunicable diseases: Volume 2. A globally relevant perspective. Geneva: WHO; 2022 [cited 2024 Jul 18]. Available from: https://www.who.int/publications/i/item/9789240055353
21. World Health Organization (WHO). Health literacy development for the prevention and control of noncommunicable diseases: Volume 3. Recommended actions. Geneva: WHO; 2022 [cited 2024 Jul 18]. Available from: https://www.who.int/publications/i/item/9789240055377
22. World Health Organization (WHO). Health literacy development for the prevention and control of noncommunicable diseases: Volume 4. Case studies from WHO National Health Literacy Demonstration Projects. Geneva: WHO; 2022 [cited 2024 Jul 18]. Available from: https://www.who.int/publications/i/item/9789240055391
23. Sampaio HA, Carioca AA, Sabry MO, Santos PM, Coelho MA, Passamai MP. Letramento em saúde de diabéticos tipo 2: fatores associados e controle glicêmico. Ciênc Saúde Coletiva. 2015;20(3):865-74.
24. Marcheti MA, Mandetta MA, Toso BR, Neves ET, Marques FR, Collet N, et al. Interactional model of caring for families of children with chronic conditions. In: Betz CL, editor. Worldwide successful pediatric nurse-led models of care. Cham: Springer; 2023.
25. Blumer H. Symbolic interactionism: perspective and method. Berkeley: University of California Press; 1969.
26. Pettengill MA, Angelo M. [Family vulnerability: concept development]. Rev Latino-Am Enfermagem. 2005;13(6):982-8. Portuguese.
27. Walsh F. Strengthening family resilience. 2nd ed. New York: Guilford Press; 2006.
28. Wright LM, Leahey M. Enfermeiras e famílias: guia para avaliação e intervenção na família. 5ª ed. São Paulo: Roca; 2012.
29. Scortegagna HM, Santos PC, Santos MI, Portella MR. Letramento funcional em saúde de idosos hipertensos e diabéticos atendidos na Estratégia Saúde da Família. Esc Anna Nery. 2021;25(4).
30. Parkes J, McCullough N, Madden A, McCahey E. The health of children with cerebral palsy and stress in their parents. J Adv Nurs. 2009;65(11):2311-23.
31. Lewandowski A, Palermo T, Stinson J, Handley S, Chambers C. Systematic review of family functioning in families of children and adolescents with chronic pain. J Pain. 2010;11(11):1027-38.
32. Knegt N, Pieper M, Lobbezoo F, Schuengel C, Evenhuis H, Passchier J, et al. Behavioral pain indicators in people with intellectual disabilities: a systematic review. J Pain. 2013;14(9):885-96.
33. Panelli BL, Barros MB, Ó DM, Monteiro EM. "Promotores da saúde" em um assentamento rural: Letramento em saúde como intervenção comunitária. Textos Contextos (Porto Alegre). 2020;19(1).