DECISION-MAKING DIFFICULTIES IN A CHILD WITH SEVERE NEUROPATHY

https://doi.org/10.56238/sevened2024.039-016

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ABSTRACT

The chapter addresses the challenges involved in decision-making for children with severe neuropathic conditions characterized by irreversible brain damage that results in severe motor, cognitive, and sensory deficits. With advances in medicine, the life expectancy of these children has increased, but this has brought new clinical, ethical, and emotional dilemmas.

Palliative care is presented as essential to improve the quality of life of these children, promoting physical, psychological, social and spiritual support. The approach must be integrated from diagnosis and throughout the entire trajectory of the disease, prioritizing not only the relief of the child's suffering, but also the support of their families.

Early diagnosis, together with the understanding of the prognosis, is fundamental for care planning. During the course of the disease, it is common to identify a tipping point, a moment when the child's clinical trajectory changes dramatically, marking the beginning of a steeper decline. Recognizing this point allows the medical team and the family to reevaluate treatment goals, prioritizing interventions that respect dignity and quality of life.

The impacts of the neuropathic condition are analyzed in four main dimensions: clinical, psychological, social, and spiritual. Clinically, complications include respiratory problems, eating disorders, and refractory seizures, which often lead to recurrent hospitalizations. Psychologically, the emotional burden on families is significant, generating feelings of guilt, social isolation and burnout of caregivers. Socially, isolation and financial difficulties aggravate the impact of the condition, while the spiritual dimension addresses the search for meaning and emotional support to face the disease.

Decision-making for these patients involves complex bioethical dilemmas, guided by principles such as beneficence, nonmaleficence, autonomy, and justice. The choice between prolonging life as invasive interventions or prioritizing palliative care requires transparent discussions between medical teams and families. The chapter proposes a multidisciplinary decision model, which includes identification of the dilemma, collection of information, team discussion, implementation of decisions and continuous adaptation to the child's needs.

Finally, proposals for improvement in the management of these cases are suggested, including: Professional training in palliative care and sensitive communication, reinforcement of public policies, such as the creation of specialized centers and financial benefits for families, promotion of support networks, strengthening interaction between families, caregivers and communities.

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It is concluded that care for severe neuropathic patients should be comprehensive and centered on both the child and his or her family. The implementation of multidimensional strategies is essential to ensure dignity and quality of life, while public policies and clinical practices must be aligned with this objective.

Keywords: Severe neuropathy. Palliative care. Multidisciplinary decision.

INTRODUCTION

Over the past three decades, there has been significant progress in child survival, particularly due to improvements in medical resources and technologies. This includes children with chronic diseases, who previously had extremely limited prognosis. This challenging scenario leads to a pressing need to adapt healthcare, especially for children with complex and limiting diseases, such as severe neuropath.[1]

PEDIATRIC PALLIATIVE CARE

Paediatric palliative care is key to improving the quality of life of children with life-threatening conditions, such as severe neuropathy. This care must be provided in an active and comprehensive, multidisciplinary and coordinated way, covering the physical, psychological, social and spiritual needs of the child and his family. This model of care is vital throughout the course of the disease, regardless of whether curative treatment is available, and persists throughout the family's grief and grief.[1]

THE SEVERE NEUROPATH SCENARIO

CHARACTERISTICS OF THE CONDITION

Severe neuropathy is often associated with irreversible brain lesions, leading to cerebral palsy, a leading cause of neonatal involvement. These lesions are usually triggered by varied reasons such as glutamate release, oxidative stress, and cell death. The severity of these lesions varies with the age of involvement and the degree of brain maturity of the patient, being more severe in younger children.[2]

DIAGNOSIS AND PROGNOSIS

Early diagnosis of neurological lesions that cause this condition is crucial to initiate a systematized intervention3 . The neurological prognosis is directly related to the child's age at the presentation of the lesion, especially during the first two years of life, when there is greater potential for neuroplasticity4 . The diagnosis is best made in a serial manner, with detailed semiological evaluations that help to understand the severity of neuromotor impairment, categorized as mild, moderate, or severe, especially in terms of mobility and adaptation to activities of daily living.

AGGRAVATING FACTORS AND CLINICAL COMPLEXITY

Severe neuropathies are generally classified in category 4 of non-progressive but irreversible diseases, with high chances of premature death due to recurrent complications.

These patients go through phases of stability and clinical deterioration that are directly due to the underlying disease, metabolic or functional alterations. These problems are very often related to: chronic respiratory problems because these children often require mechanical ventilation.

EATING DISORDERS: FREQUENT NEED FOR GASTROTOMY

Refractory seizures: these are often difficult to control with medications, sometimes in multiple associations that can lead to other complications.

INFLECTION POINT

Identification of the inflection point is crucial in the evolution of severe neuropath. This point marks an acceleration of clinical deterioration, with an increase in the frequency of symptoms, rehospitalizations, and lack of response to established treatments. The anticipation of this moment allows a critical reevaluation of therapeutic objectives and promotes a continuous adaptation of care goals.

Recognize this point to the medical team and the family, reevaluate the goals of care and reevaluate interventions that respect the dignity of the child. [6]

Graph 1: Inflection Point in the Clinical Trajectory of Severe Neuropathic Patients



REF: Comprehensive Pediatrics. (2016, Março). *Palliative approach in pediatrics*. Comprehensive Pediatrics. https://www.pediatriaintegral.es/publicacion-2016-03/enfoque-paliativo-pediatria/

Description: The graph illustrates the typical trajectory of a severe neuropath, with peaks and valleys that represent moments of stability and clinical deterioration. The "tipping point" is highlighted as a critical point where a significant decline in the patient's quality of life occurs.

PSYCHOLOGICAL, SOCIAL AND SPIRITUAL ASPECTS

PSYCHOLOGICAL IMPACT

The acceptance of a serious chronic condition in a child often causes an emotional disruption to the family, affecting the psychological well-being of parents, siblings, and caregivers. Coping with these losses and limitations is associated with the emergence of symptoms such as depression and anxiety. In addition, burnout in caregivers is a significant risk, exacerbated by the perception of guilt and powerlessness in the face of the child's limitations. There is social isolation with restrictions on participating in social activities7 .

PSYCHOLOGICAL SUPPORT STRATEGIES

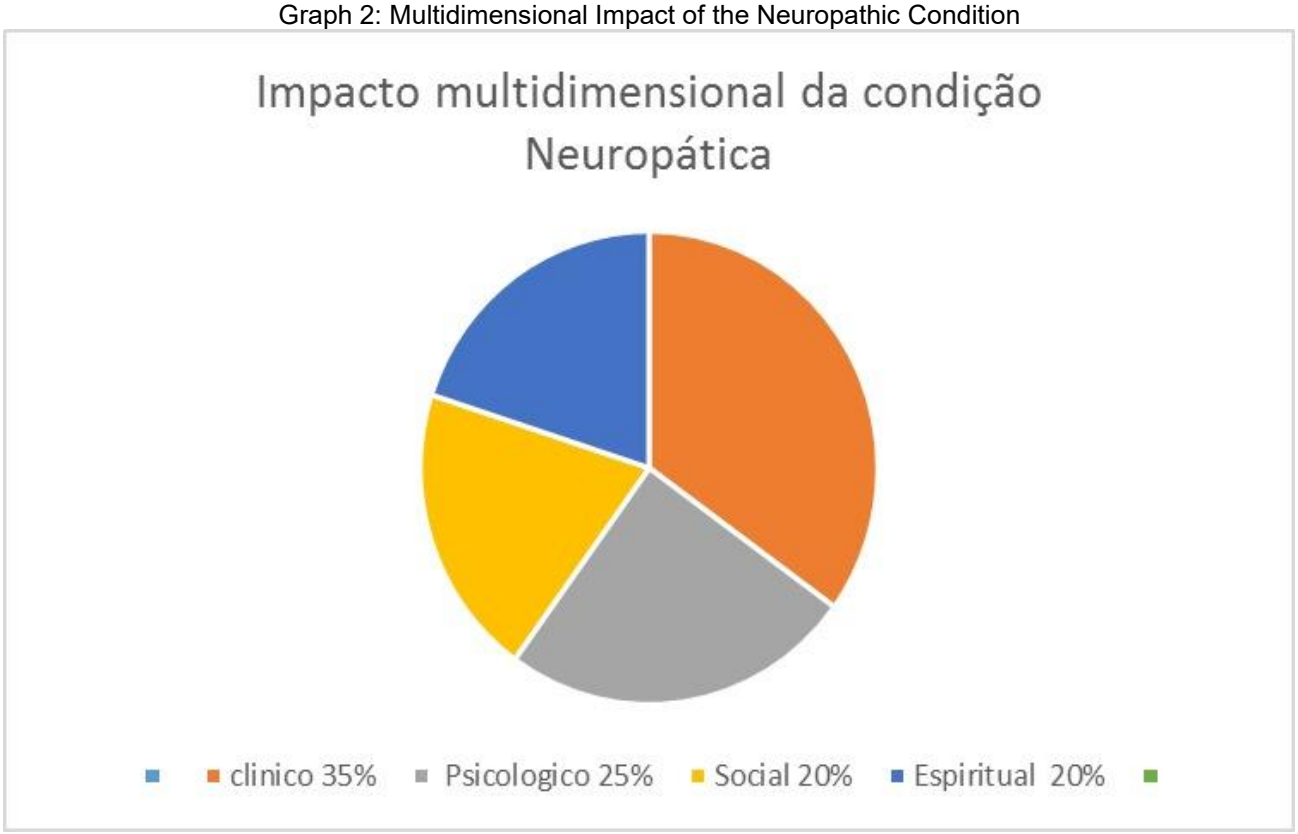
- Continuous Monitoring: Provision of individual and family psychological support to facilitate the acceptance and resignification of the disease.
- Family Therapy: Approaches that promote communication and the division of responsibilities among family members.
- Prevention of Complicated Grief: Guidelines for caregivers to deal with grief and feelings of loss, especially at critical times like the tipping point of illness.

SOCIAL ASPECTS AND SUPPORT NETWORKS

The social impact of severe neuropathy is substantial, since social isolation is common among these families. The lack of financial support, parental abandonment, and difficulties in accessing specialized services further aggravate this situation.[1]

To make matters worse, there is limited access to specialized services [6] which reinforces the social isolation of families.

Graph 2: Multidimensional Impact of the Neuropathic Condition



Description: The pie chart illustrates the distribution of impacts on the life of a severely neuropathic child and his family. Each sector represents a different aspect, such as the clinical (35%), psychological (25%), social (20%) and spiritual (20%). This diagram highlights the need for an integrated approach that considers all of these aspects for effective care.

SOCIAL SUPPORT MEASURES

- Follow-up by social workers to facilitate access to benefits and community support.
- Legal interventions in cases of neglect or abandonment.
- Training of caregivers to improve the quality of home care.

ETHICAL AND MULTIDISCIPLINARY DECISION-MAKING

The decision on the management of severe neuropathic patients involves complex bioethical dilemmas. Decision-making must balance principles such as beneficence, non-maleficence, autonomy (9) and justice, with an approach that considers the particularities of each case.

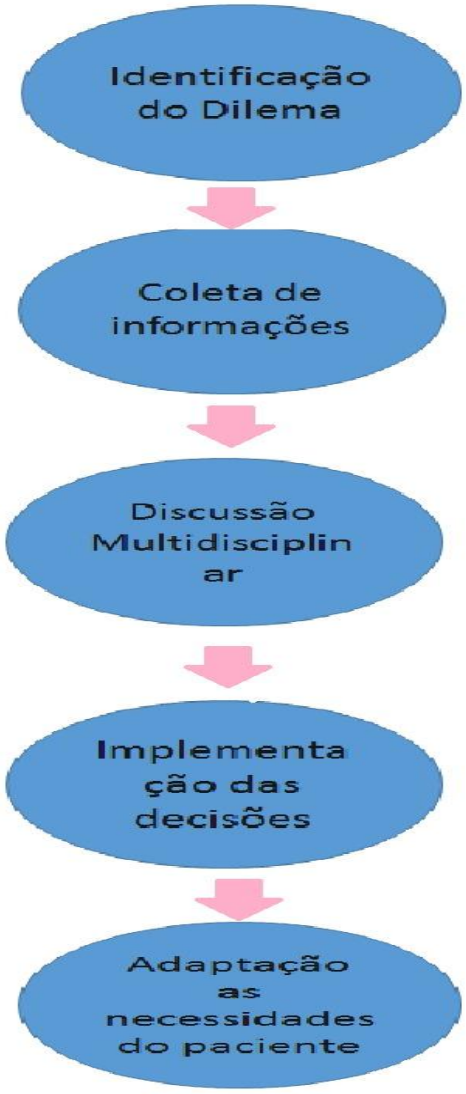
ETHICAL ALTERNATIVES

Ethical alternatives involve considering the clinical and familial implications of each treatment decision. Key options include:

1. Suspension of Invasive Interventions: Careful evaluation of life-prolonging treatments, such as mechanical ventilation, in order to avoid therapeutic obstinacy when treatments no longer have significant benefits for the patient's quality of life.

2. Transparent Discussion with Family: Engage the family in open discussions about the limits and goals of treatment, considering their beliefs, values, and expectations.
3. Transition to Palliative Care: Offer palliative care when the patient's condition deteriorates so that they can live comfortably until death, avoiding prolonging unnecessary suffering.
4. Multidisciplinary Follow-up: Implement multidisciplinary support that includes physicians, psychologists, social workers, and bioethicists to collectively discuss and decide on the most appropriate treatment for the patient and their family.

Graph 3: Multidisciplinary Decision Model



Description: This flowchart illustrates the decision-making process, starting with the identification of the dilemma, through information gathering and multidisciplinary discussion, to the implementation of decisions tailored to the patient's needs.[10,11,12]

FINAL CONCLUSION AND PROPOSALS FOR IMPROVEMENT

The care of severe neuropathic patients requires an approach that transcends the biomedical aspect, integrating emotional, social and spiritual dimensions. To improve this service, the following strategies are proposed:

- Professional Training: Ongoing training in palliative care and clinical ethics.
- Strengthening of Public Policies: Expansion of resources and infrastructure to serve patients with complex diseases.
- Promotion of Support Networks: Encouragement of the creation of communities that offer mutual support between families and caregivers.

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