Medicina Historica 2022; Vol. 6, N. 1: e2022010

Original article: bioethics

The parent as a "co-therapist" in the care of the minor: an ethical issue

Linda Alfano[1], *Roberta Monteleone*[2], *Paolo Petralia*[3,4], *Rosagemma Ciliberti*[5]

[1]Department of Science of Health, University of Genoa, Genoa, Italy; [2]University of Lumsa, Rome-Palermo, Italy; [3]University of Genoa, Genoa, Italy; [4]General Direction of the Local Health Authority ASL4, Liguria, Italy; [5]Section History of Medicine and Bioethics, Department of Science of Health, University of Genoa, Genoa, Italy

Abstract. Disease can represent a particularly complicated and sometimes traumatic event in the life of achild. The support and assistance of adults and the various reference figures (parents and health care personnel) who, with different functions and responsibilities, intervene in the care relationship, play a decisive role.The child in its complete entity must be at the center of the therapeutic intervention.The minor that must be taken care of, in fact, before being an ill person is a person with a history, a family with the experiences that characterize and shape his identity into specificity.The way in which health workers relate to parents and children affects significantly not only the course of care, but also the continuation of parental relationship and mental models that the child builds to formulate expectations about his future care experiences.To be able to adequately support the child, particular attention must be paid to promoting forms and methods of parental participation that are genuinely respectful, inclusive, and relevant.

Key words: pediatrics pain, consent, assent, vulnerable persons, children, caregivers, parents healthcare, minor, ethics, caregiving relationship

The cure of the part should not be attempted without treatment of the whole (. . .) No attempt should be made to cure the body without the soul"

(Plato)

The role of parents in the development of the caregiving relationship.

The disease represents a frequent event in the life of each child, but at the same time it constitutes a very peculiar experience to be faced with the help of adults and of the reference figures.

The comparison with a plurality of health figures and places of care, fear, pain, constitute a complex experience that is declined in successive stages, each of which requires specific adaptations. As Bettelheim (1987) states in this regard, during each phase, the child must be helped to understand what is about to happen to him, what is happening to him and, finally, what has happened to him (1).

In these moments the life of the child is easily accompanied by difficulties of understanding and anxious reactions. It is precisely in these moments that parents are called to support him, helping him to understand and find a proper place for each event.

In the early stages of an illness the child must deal with fear, disbelief, anger, feelings of bewilderment.

The sick child cries, shouting, calls, is lost, afraid. He knows nothing of this new reality of his, he does not understand it, he no longer feels safe.

The physical and emotional presence of the parent can transform this weeping into a question, a speech, a dialogue, a relationship capable of attributing a meaning, a sense, a container to loss and pain.

Through the face of the parent who welcomes him, the child knows and explores the world. It's in this look that he recognizes his own image and can find comfort in his new state of vulnerability, the disorientation that comes from hospitalization and confrontation with doctors - unknown and powerful adults. If this face will be dark, frightened, anguished; if it will be an indifferent mirror that shows nothing; if it will be obscured by the presence of the doctor, the whole world around that child will be turned off, dangerous, closed, with serious impairment of the image of himself and his relationship with the outside.

For this reason, parents must be protected and urged to respond personally, to give value, a substance to the questions and pain of their children, taking first-hand responsibility for the management of the disease and the treatment, which cannot and must not, be delegated exclusively to technicians, institutions, health professionals.

These considerations are at the basis of the progressive overcoming of those indications that still in the recent past have prevented or at least limited the entry of parents in the places of hospitalization of children.

Until the fifties of the last century, in fact, in most health facilities, parents were not allowed to visit their sick son. Only a few more liberal hospitals allowed 2-3 visits per week of half an hour each (2).

The Platt Report "*The welfare of the children in hospital*", presented by a committee of doctors and psychologists, appointed by the British Ministry of Health, denounced the harmful conditions of minors exposed to forced separation from families during admissions. The document also provided precise suggestions to reduce this discomfort and its consequences: these included the abolition of the limits of visiting hours and the possibility for parents to stay in hospital with their child (3).

The Report had the effect of stimulating interest in the subject by the whole medical class and arousing movements of opinion that led to the establishment of parents' associations to protect the needs of hospitalized minors. These movements promoted the writing of hospital regulations closer and respectful of the needs of children, attentive also to the psychological implications that illness and hospitalization can determine in family dynamics.

The physical presence of the parent in the place of care, however, is not a sufficient element to safeguard the parent-child relationship, nor to guarantee an authentic participation of the family member in the processes of care of the child.

Research by Spitz and all early institutionalized child attachment theorists, and even earlier Harlow's experiments on Reshus macaques, reveal that the physical presence of the parent is not sufficient to ensure the care and survival of the newborn. If the child is treated by technically perfect caregivers, but emotionally indifferent, he withdraws, wraps himself, dies; the disease presses, the therapies do not work, the pain gets worse (4).

The radical transformations that in the last two centuries have affected the world of children, have profoundly changed the relationship between parents and children, making it increasingly dialogical, object of negotiation, played on the register of interpersonal freedoms. These social changes now force adults to gain that credibility, that trust that tradition assigned them with authority, in a pre-established and undisputed way.

Today, the child is configured from birth as an individuality capable of participating in the process of building his own personality and parental figures. The child is a subject capable of agency, self-determination and influence with his actions, his counter-conducts to the definition of relationships (5).

Parenting has therefore assumed a dialogical nature, of continuous reciprocity; a work in progress that requires continuous and daily negotiations.

This unprecedented family dialogue, made of incessant bargaining, agreement, uncertain balances, requires that the forms and modalities of parental participation in the care of the child are also redesigned.

In this complex family dynamic, which in illness and in contact with health, is certainly colored with intense and intense feelings, both the activities of mediation and negotiation of conflicts, both collaborative practices, attention to compliance, alliance, consensus.

The intervention of the health professional must therefore be expressed in seeking compositions between the different needs and the multiple demands: an increasingly mild, more conciliatory, more respectful, but at the same time timely, able to avoid unnecessary and irreversible delays and to simplify and encourage concrete, personalized agreements, micro-rules, commitments, real presences.

A model of intervention conforming to the rule of minimum intrusiveness, which enhances the solidarity and consensual power of the institution.

In this context, the delicate question of the active participation of the child in the treatment process is also included. It is now increasingly recognized that the active involvement of the child in care plays a key role that can positively affect the therapeutic path and improve healing results (6, 7).

Today, international conventions and legislative interventions increasingly enhance the self-determination not only of assisted adults, but also of the child by expressly providing for its involvement in decisions that affect him, in relation to age and maturity, although there are still obstacles and critical issues, especially regarding the definition of the ability to discern at a young age and for the identification of the most appropriate methods of listening and interaction (8, 9).

The Role of Internal Operating Models: The Ethics of Parent Involvement and Participation.

The involvement of parents in the management of the child's disease is an essential element to pay specific attention to, not only to reduce the inevitable situations of discomfort and suffering, but also to ensure a better effectiveness of treatments.

The disease constitutes an existential experience like that which everyone has experienced at birth, in the early stages of development, when, still without adequate resources, he had to deal with a foreign environment, unknown and in some ways threatening.

Also, in this new context the child will try to elaborate functional and adaptive responses, activating patterns of adaptation similar to those activated in early childhood.

As Bowlby and Ainsworth point out, attachment behavior is structured in the early moments of life around that figure that ensures closeness and protection, which is more accessible, easily identifiable, which appears capable of facing the world in an adequate way, but can be observed throughout life, especially in times of emergency and in those situations that belong to the dimension of danger and disease.

Careless meddling of the doctor in the parent - child relationship at a time of such vulnerability can compromise the quality of attachment responses that the minor will use, affecting, not only in that specific situation, but in all subsequent experiences of relationship with significant figures in the healthcare world.

As Bowlby recalls, the attachment response, once it is established, lasts over time and plays a fundamental role: first it guarantees the protection against the hostility of the environment and therefore the survival of the individual, later it functions as an internal memory, as a cognitive map (what the technicians define as an internal operating model), which directs the way in which the person will face all subsequent experiences of relationship and, specifically of our discourse, care.

The experience generates expectations about the nature of the interactions, expectations that are coordinated with each other to foster the maturation of the reflective function.

This ability is defined by Fonagy (10) as "mentalization" and represents the ability of an individual to read the minds of other people, to understand their behavior, to foresee it, thus representing the prerequisite to respond adaptively and effectively to the stresses of the environment, the challenges of disease and pain.

Therefore, a specific attention must be paid to the introduction of the health practitioner into the family relationship of care, in order not to engender dysfunction in the structuring of attachment patterns.

The parent excluded from his priority task of choice and care could, in fact, be experienced by the child as a detached, in abandon caregiver, who tends to remove the child from himself, both physically, and emotionally, who avoids the treatment of the disease, of disability, of pain.

Based on Ainsworth's indications, this relational situation could prompt anxious-avoiding responses in the child with a reduced inclination to seek comfort and engage in intimate relationships. Responses of self-sufficiency that, in fact, hide a disappointed child, distrustful of the adult world, who is forced to control the sense of need to defend himself from a potential disappointment.

An inadequate inter-relationship between the parent and the health professionals could still engender in the child the idea of a caregiver suddenly and incomprehensibly inconstant, unpredictable, intermittent. Such experience could elicit anxious-resistant (ambivalent) responses typical of a child swinging between positions of dependence to others of detachment; a confused child, rather entangled in family relationships, which tends at times to please adults, to deny their pain in order not to make them suffer and, in others, to challenge them, to refuse treatment, not to respect the rules, the boundaries. A child characterized by a passive and fatalistic attitude towards events, who has an angry, demanding, dissatisfied, needy, defensive, provocative approach to relationships. A child who has little control over his own emotional condition.

Finally, the tension of the parent forced in spite of himself to a marginal role of subordination, as well as to a state of impotence in the face of the pain of his child, could fuel reactions aggressive, violent and induce in the child a state of disorientation and disorganization. A child who cannot put together his story, who has inappropriate, contradictory, bizarre, inappropriate answers; all these answers, which underlie dangerous dissociative mechanisms. A child whose mind shorted because the one who had to protect him was the same person he needed to be protected from.

A compromise of the first experiences of care is therefore able to determine a series of consequences that go beyond the here and now and that propagate in subsequent experiences of childcare exponentially.

This knowledge should therefore be taken very seriously by health professionals who care for children.

It is therefore necessary to encourage the conscious participation of parents in the care of the minor child, help them to understand, discuss and co-construct the treatment protocol, so that they can play an active role in the containment of his state of suffering and in the management of fear and anguish elicited by the new and difficult health situation.

Underestimation of pain in minors

The construction of a team that includes the presence of family members is particularly significant when the problem of the treatment of pain in the minor arises.

In the pediatric field, pain is in fact the symptom that, among all, the more it undermines the physical and psychological integrity of the child and the more anguish and worries his family members, affecting significantly the quality of life and the relationship during and after the disease.

From an ethical point of view, the treatment of pain is now an unavoidable element of caring, in accordance with the principle of benefit and expressly sanctioned by recent regulatory interventions.

Pain is therefore no longer considered as a simple symptom, but as a composite experience to be prevented and treated appropriately. In this perspective, pain control must be approached with a multidimensional approach, with appropriate guidelines, abandoning many prejudices and foreclosures.

This position is expressed not only by medical ethics, but also by the morals of a religious matrix that essentially agree on this point. This appeal applies to Christianity, to which an unhealthy cultivation of pain has sometimes been wrongly attributed (11). Already, in the occasion of the congress of the Italian Society of Anesthesiology on 24 February 1957, Pius XII acknowledged that in the long run, pain prevents the attainment of higher goods and interests. It may happen that it is preferable for a given person and in each concrete situation; but, in general, the damage it causes forces men to defend themselves against it. Undoubtedly it will never be possible to make it disappear completely from humanity, but its harmful effects can be contained in tighter limits». Consequently, according to Catholic moral doctrine «the patient desirous of avoiding or calming pain can, without anxiety of conscience, avail himself of the means found by science» (11). Based on these considerations, the doctrine admits the use of analgesics to alleviate suffering even when such recourse can lead to the loss of consciousness and to anticipate the end of life, provided this result is only a secondary and unintended negative effect (so-called double effect theory). In Italy it is only since 2010 that children have had access to the use of opiates (Law n. 38 of 2010).

In general, however, ethical reflection on these issues is still lacking and not sufficiently explored when referring to the minor. Only recently and with specific reference to the clinical obstinacy or unreasonable obstinacy of treatments on young children with limited life expectancy, the Italian National Committee of Bioethics (NCB) has presented a specific motion.

In this document the NCB rejects therapeutic obstinacy and makes recommendations aimed at assigning a cardinal role to a shared care plan, supporting pain therapy and pain relief, opposing ineffective and disproportionate clinical care and defensive medicine. In addition, the document underlines the need to create, by law, clinical ethics committees in pediatric hospitals with limited recourse to the courts-only as a last resort-in the event of irremediable disagreement between the medical team and family members (12, 13).

Although the treatment of pain has always been considered an unavoidable principle of solidarity and ethics, for a long time, doctors, professionals from different disciplines of care have largely underestimated and neglected the fulfillment of this duty towards the minor.

In the past there have been opposing conceptions about the perception of pain by children, in favor either of the concept of hypoalgesia or of hyperalgesia of the minor or of a greater or lesser sensitivity to the painful stimulus and its memorization (14, 15).

In 1612, Felix Wurtz in his work "The children's book" argued that the intensity of pain experienced was, with equal stimulation, inversely proportional to the patient's age, to the extent that the minor was more exposed to painful sensations (16, 17).

Wurtz's considerations on infantile hyperalgesia were revived and developed in 1858 by John Forsyth Meigs who, in his book "Practical treatise on the diseases of children", stressed that "pain may always be detected by the expression of the almost face" of children (18, 19).

After the second half of the nineteenth century the thesis of pediatric hyperalgesia was almost abandoned in favor of that of hypoalgesia. At that time, Paul Emil Flechsig (1847-1929) demonstrated that the myelination of nerve fibers was not complete at birth, but it developed and perfected over time in a progressive manner. According to this research, this immaturity of the nervous system limited both the transmission of painful somatic sensations from the periphery to the central system, and their memorization and integration (20).

This interpretation provided scientific support for the theory of the absence of pain perception in children for decades.

Unfortunately, these theories found a broad foundation in the clinical practice of the time, determining the execution on small patients of invasive and painful medical operations (such as abdominal operations for pyloric stenosis and chest surgery for congenital heart pathologies) without any control of algesia (21).

Again, Jacobi, president of the American Medical Association and father of the American pediatrics, proposed the theme of the sensitivity of the minor to painful stimuli.

In 1898, in his book "Therapeutics of infancy and childhood", Jacobi, he recommended the use of anesthetics in infant care and denounced the resistance and serious shortcomings of the time in providing young patients with adequate pain control. He stated:

"The greatest gift America has given in the world is not realization of a Republican government... it is anesthesia" (22).

However, this focus on the use of anesthetics on children died out once again in the 1930s, when results on early neuro-anatomical and behavioral studies of children and their response to painful stimuli, they demonstrated the incomplete maturation of the nerve pathways responsible for the transmission of harmful stimuli in newborns. At that time the erroneous belief that the use of analgesics favored respiratory blockages with serious danger to the health of young patients also constituted a further and heavy obstacle to their application.

The decisive contribution to the treatment of pediatric pain was made by Dr. Kanwaljeet Anand, great advocate for babies in their quest to be acknowledged as fully sentient and sensitive human beings) (21). He developed sophisticated methods of measuring stress responses using micro samples of blood (23).

In an article published in the New England Journal of Medicine (1987), Anand stated that infants were not only able to feel pain, but, with the same stimulus, experienced it more intensely than adults, already from the twenty-sixth gestational age of the anatomical and physiological bases of pain perception. Anand pointed out that the lack or inadequate administration of analgesics during any painful medical maneuver determined in the small patient a high metabolic response, such as to negatively affect the course and duration of hospitalization.

Anand's work on pain in England is intertwined with the debates prompted by the story of Jeffrey Lawson in the United States.

The child born in February 1985, at 25-26 weeks of gestational age, underwent surgery at the Washington National Children's Hospital to bind the Botallo ductus arteriosus by thoracotomy, with an anesthesia which consisted in the administration of pancuronium to obtain muscle paralysis, without any analgesic or associated anesthetic agent.

In a letter published in the Journal Birth (1986), Jeffrey's mother denounced the doctors, claiming that the death of his son had contributed to the lack of anesthesia and analgesia.

The woman described her son's condition after the surgery and reported that Jeffrey had many postoperative scars on the sides of his neck, chest, and sternum. The operation lasted many hours.

The mother said: "Jeffrey had holes cut on both sides of his neck, another cut in his right chest, an incision from his breastbone around to his backbone, his ribs pried apart, and an extra artery near his heart tied off. This was topped off with another hole cut in his left side. The operation lasted hours. Jeffrey was awake through it all. The anesthesiologist paralyzed him with Pavulon, a drug that left him unable to move, but totally conscious. When I questioned the anesthesiologist later, she said Jeffrey was too sick to tolerate powerful anesthetics. Anyway, she said, it had never been demonstrated to her that premature babies feel pain (24).

Jeffrey died five weeks later, in March 1985.

Jeffrey's story told in an article in the Washington Post on August 13, 1986, by Rovner (25) sparked an intense debate nationwide about the importance of adequately controlling pediatric pain surgery (26).

Since then, published research on pediatric pain has grown dramatically: among the many, we remember the contributions of Mather & Mackie (1983) and Schechter, Allen, & Hanson (1986) that have documented the possible techniques of operative and postoperative pain relief in the pediatric field and their use.

Later research demonstrated the dramatic negative effects that uncontrolled algesia can cause at the neuronal level in the transmission of harmful stimuli and physiological response patterns (Grunau, Whitfield, & Petrie, 1994; Taddio, Goldbach, Ipp, Stevens, & Koren, 1995; Johnston, & Stevens, 1996; Taddio, Katz, Ilersich, & Koren, 1997; Grunau, Whitfield, & Petrie, 1998).

Dalens' studies in 1995 showed that incomplete myelination only implies a slower conduction rate of peripheral nerves or central nerve traits of the newborn, according to Anand and Hickey (1987) completely compensated by the shortest distance of the route. These authors have shown that term and preterm infants have a complete development of pain transmission pathways; they have also shown that at birth the presence of mature opioid receptors and the simultaneous absence of anti-pain neurotransmitters nociceptive causes a more intense, diffused, and lasting perception of the painful stimulus (27).

Today the treatment of pain is certainly considered by the medical sciences that have dedicated specific studies and great attention to it (28, 29).

Lately, as a matter of fact, the knowledge developed on neonatal and pediatric pain is of such a varied nature that it may ensure a correct and effective painless approach in almost all cases. At the clinical level, important progress has been made, both regarding the assessment of pain in different pediatric ages and clinical situations, as well as within the therapeutic, pharmacological, and non-pharmacological approach.

Nevertheless, in the pediatric field, this type of intervention cannot be limited to the mere prescription of analgesic or sedative drugs, but as already mentioned, must provide for the effective involvement of parents in the treatment project.

Any pain therapy, pharmacological or not, cannot, in fact, be separated from an adequate communication-relationship with the child and his family, also considering the Italian recent legislative provisions (Law 219/2017) that explain how the time of communication is a time of care, that is an integral and indispensable part of health care (30).

Conclusions

Today, the focus on pediatric pain has improved and research has developed further. However, some general ethical issues relating to the active involvement of parents, the inclusive modalities of children in care and the relations between the team-parents-children still require in-depth study and careful consideration also from an ethical point of view.

The care of the child must certainly be approached with competence and seriousness through the collaboration between professionals in multidisciplinary areas and with a particular attention to the role of the family members.

It is not easy, neither for the parent, nor for the child, nor for the health-care professionals, to find a position of balance that respects the needs of all, especially if we consider the whirling and pressing exchange of freedom, determination, responsibility that continually exists between the protagonists of the care relationship and the background of unprecedented ethical dilemmas and continuous changes of social and cultural paradigms of reference.

Complex and differentiated situations that no longer concern the mere survival and preservation of physical health, but rather concern new areas of reflection that require composite skills, both in the medical-health field, as well as in the ethical and cultural field (31).

In this brief treatment we have tried to recall the particular importance that the role of parents in identifying and managing pain treatment and we have also tried to recall some of the most harmful consequences that arise from the separation of parents of children in hospital care, as occurred especially in the emergency pandemic, through measures to prevent contagion and routine care, in many Italian hospitals still in force, which have imposed harmful restrictions on parents and in general to the various caregivers, hindering the family relationship and limiting their particular role of assistance (access denied, limited in time, addressed only to one parent). All this without any consideration about the role of the parent/caregiver, a true provider of care, directly involved in the context of the child's care and therefore indispensable and irreplaceable (32-34).

The acknowledged close relationship for the child from his family context of belonging requires us to review the paths of care so that they do not introduce unknown and unaware forms of dissociation and threat the continuity of construction processes of identity. The experience of disease, even if it is always a bitter and intricate moment in a person's life, it furthermore is certainly more complex in the case of a minor.

The experience of hospitalization can significantly affect the integrity of the child, ignoring or at least by underestimating his specific needs and in particular his need to preserve, with constant comparison and reference to his family figures, the continuity of affective and identity contributions.

The parents' discontinuous and inadequate support for the control of pain and the experiences of caring for their child incurs into the risk of interrupting the process child and, further, hindering its progressive autonomy from adults, with negative drifts from the processes of building the Self, consolidation of self-esteem and assertiveness.

To help the child understand his relationship to disease, pain and suffering, it is necessary to reset the relationship of the adult with the child (parent, but also caregivers) by illuminating through experience such as loss of well-being, disruption of socialization activities and established habit which may not only generate a state of high insecurity and anxiety, but also significantly affect the quality of family relationships and identity building processes.

For this reason, the support of people (parents and caregivers) around the child is of paramount importance, which can be achieved through shared moments of care practice assessments, as well as through a collaborative action strategy.

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Correspondence:
Roberta Monteleone
University of Lumsa, Rome-Palermo, Italy
E-mail: roberta.monteleone92@gmail