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Management of the suffering child: a medical and operational challenge

Elba Rahmouni and Olivier Guillard • Médecins Sans Frontières

This article presents a troubling example of the effects of adultcentrism. While the treatment of pain in adults and children in rich countries has made remarkable progress, its application to children in fragile countries is severely lagging. It is a credit to the authors' that they raise this issue in light of their NGO's work. But it is a concern that should be of interest to many others in the sector.

Although acute pain has a diagnostic value and can play a positive role as a warning sign to promote the body's own survival, there is no question that it is necessary to treat and prevent it, particularly in the context of care. It is both a medical necessity, to avoid complications, and an ethical necessity, based on the principles of benevolence and *primum non nocere* ("First, do no harm").[1] It is also a social necessity: injuries can lead to chronic pain which can then lead to disabilities.[2] In France, care has been a legal obligation since it passed the Kouchner Act in 2002.[3] The responsibility for it falls to both medical professionals and health institutions.

Compared to adults, pain in children was only taken into account relatively late, towards the end of the twentieth century. Children, and especially newborns, were considered to be neurologically immature and therefore insensitive. The difficulty they had in expressing their pain and the non-recognition of their inability to play their social role of learning and playing in the event of pain (or disability) also contributed to this delay. The pain management of the suffering child became commonplace in the English-speaking world and then in France from the 2000s.

In order to explore the contemporary issues surrounding the suffering child in the humanitarian field, we began by observing the non-management of pain in a hospital in Moïssala in Chad.[4] The non-governmental organisation (NGO) Doctors Without Borders (*Médecins Sans Frontières* – MSF in French) is active in this hospital, where 46.5% of the population is under 15 years old.[5] Since July 2010, the NGO has been fighting against a particularly severe form of seasonal malaria in this area. From 2018, MSF began reorienting its action towards a "continuum of care", focused on the mother-child couple. During a first mission in 2020, we were able to observe (and hear from the

[1] Conseil national de l'Ordre national des médecins, *Code de déontologie médicale*, février 2021, https://www.conseil-national.medecin.fr/sites/default/files/codedeont.pdf
[2] « Loi n° 2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées », *Journal officiel de la République française*, 12 février 2005, https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000000809647
[3] « Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé », *Journal officiel de la République française*, 5 mars 2002, https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000000227015
[4] The country is ranked 187th out of 189 countries in the 2019 Human Development Index ranking developed by the United Nations Development Programme. It is included in the list of least developed countries established by the Organisation for Economic Co-operation and Development's Development Assistance Committee and the list of highly indebted poor countries published by the International Monetary Fund.
[5] UNESCO Institute for Statistics, "Chad", http://uis.unesco.org/en/country/td

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screaming) that painful treatments were carried out without sedation or analgesia. More broadly, there was no pain management of the suffering child in this project; pain was never evaluated and therefore never treated. Morphine was unavailable in the hospital as a result of diverted supplies: there was some in the central pharmacy but not at the hospital. According to a number of witness accounts from within the organisation, it would appear that similar situations exist in other MSF projects.

Given that children (and especially children under 5) are a priority target in the humanitarian field, how can we explain the relative non-management of pain of the suffering child in the practices of and concerns faced by the Moïssala hospital where MSF works?

Pain and its paediatric particularities

The International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential physical injury. Pain is always subjective.[6] The painful experience begins with specific sensory receptors called nociceptors, which are distributed over the skin and in certain organs and unconsciously detect tissue lesions. This message is then transmitted through the spinal cord to the brain. The brain integrates information from several cerebral systems, including the amygdala (centre of emotional reactions) before transforming them into a perception of pain in the cerebral cortex.[7]

This integrated pain system was only partially understood in the 1980s. The idea that newborns could feel pain was therefore disputed. Two events contributed to the evolution of society and medicine. In 1986, following the intraoperative death of her newborn child, a mother discovered the absence of analgesia during surgery in the medical records. She then published a series of articles in the press.[8] In 1987, the first randomised controlled trials were published which objectivising the benefits of adding an analgesic and then a curare muscle relaxant[9] during surgery.[10] In the 1990s, studies of foetuses showed that the conditions necessary for the transmission of nociceptive information from the periphery to the cerebral cortex are met as early as the twenty-fifth week of gestation. The response threshold is also lower in children and this response has a longer duration and is of higher intensity.[11]

Accurate, systematic and repeated pain assessment is the essential first step in the treatment of pain.[12] The definition of pain and its functioning explains its great inter- and intra-individual variability, which makes self-assessment necessary. However, this is difficult for children who are not capable of intelligible verbalisation, whether related to a vigilance disorder due to their illness or to limited physiological psychomotor development at certain ages. The caregiver must then use a

[6] International Association for the Study of Pain, "IASP announces revised definition of pain", 16 July 2020, https://www.iasp-pain.org/publications/iasp-news/iasp-announces-revised-definition-of-pain
[7] Leora Kuttner, *L'enfant et sa douleur : identifier, comprendre, soulager*, Dunod, 2011.
[8] S. and Y. Rovner, "Surgery without anesthesia: can preemies feel pain?", *The Washington Post*, 13 August 1986, https://www.washingtonpost.com/archive/lifestyle/wellness/1986/08/13/surgery-without-anesthesia-can-preemies-feel-pain/54d32183-8eed-49a8-9066-9dc7cf0afa82
[9] Curares paralyse the muscles. Together with analgesics and hypnotics, they make up the triptych of general anaesthesia.
[10] Kanwaljeet Anand and Albert Aynsley-Green, "Randomised trial of fentanyl anaesthesia in preterm babies undergoing surgery: effects on the stress response", *The Lancet*, 10 January 1987, pp. 62–66; Kanwaljeet Anand *et al.*, "Does halothane anaesthesia decrease the metabolic and endocrine stress responses of newborn infants undergoing operation?", *British Medical Journal*, 5 March 1988, pp. 668–672.
[11] Claude Ecoffey et Claude Annequin, *La douleur chez l'enfant*, Éditions Lavoisier, 2011.
[12] Pédiadol, « Évaluation de la douleur chez l'enfant », https://pediadol.org/evaluation

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hetero-evaluation, that is, the assessment of the child's pain from the observation of their behaviour: facial expression and activity, crying, limited body movements or analgesic positions, muscle tone and so on. The quantification of pain through the routine use of self- or hetero-assessment scales improves the quality of care. Their result is called the fifth vital sign. The French National Authority for Health (*Haute Autorité de Santé* – HAS in French) publishes a list of age-appropriate scales.[13]

In the 1960s, a distinction was made between "caring" and "curing".[14] While the essence of humanitarian aid is care, MSF's emergency medical aid dimension tends to favour the cure; there is therefore sometimes a competition between care and cure within the projects. Beyond the assessment and treatment of the child's pain (cure), the overall management of the suffering child (care) means taking care of their well-being and that of their family. The paediatric adaptation of care[15] shows the indispensable role of the family in the administration of care, including when the child is hospitalised. Care improves the relationship of trust between caregivers and carers, which in turn promotes a better quality of cure. Children are not small adults, and their management (cure and care) must be specifically adapted to them. That is why we prefer the expression "management of the suffering child" rather than "treatment of pain in the child".

Difficulties in pain management, both at individual and institutional levels

In 2020, when the issue of the non-management of pain of the suffering child was discussed with the team at Moïssala, the team answered "that's how it is here". And yet the subject of pain management for patients has existed for many years at MSF. Given that the issue is under consideration at headquarters, by heads of anaesthesia and paediatrics departments and by hospital managers, how can we explain the discrepancy between the medical and operational intentions regarding pain management and the practices in certain fields?

In order to explain the individual behaviour of the non-management of pain, we found it possible to determine four ideal types of resistance, which are often interrelated. They concern both caregivers and children or their parents: the caregiver does not manage the pain and the patient (or their family) does not express it.

The *negationist* denies the existence of pain in the child. This historical figure is the product of a series of beliefs, some of which are supported by erroneous scientific arguments. Cultural biases may lead to some groups of people being considered as being less sensitive to pain.

The *dolorist* knows that the child is in pain, but their utilitarian vision of this pain prevents them from managing it. They are part of a doctrine inspired by Catholicism and Stoicism which ascribes a high moral, aesthetic and intellectual value to pain. Some doctors still mistakenly believe that pain is a useful clinical sign for monitoring illnesses.

The *fatalist* knows that the child is in pain, but there is no link between the acknowledgement of pain and the necessity or possibility of relieving it. There is no better illustration of this Catholic heritage

[13] Haute Autorité de Santé, L*iste des échelles acceptées pour mesurer la douleur*, 2019, https://www.has-sante.fr/upload/docs/application/pdf/2019-02/liste_echelles_douleur_2019.pdf
[14] Chantal Cara et Louise O'Reilly, « S'approprier la théorie du *Human Caring* de Jean Watson par la pratique réflexive lors d'une situation clinique », *Recherche en soins infirmiers*, vol. 4, n° 95, 2008, p. 37-45.
[15] Agata Zielinski, « L'éthique du care. Une nouvelle façon de prendre soin », *Études*, vol. 12, 2010, p. 631-641.

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than the character of Father Paneloux in Albert Camus' *The Plague*. This fatalism can also be explained by a feeling of powerlessness, a kind of institutionalised burn-out.[16]

Finally, the *abuser* knows that the child is in pain but intends to take advantage of this dependency. The resulting sense of power brings the abuser the personal and professional satisfaction that they may be lacking from patients or institutions. This behaviour can lead to corruption: the caregiver can monetise the delivery of care or divert equipment and medicines for commercial ends.[17]

The responsibility for the management of the suffering child falls as much to medical professionals as to health institutions. This is all the more important since we are talking about a humanitarian context in which the organisation provides care in the absence or incapacity of the State. Beyond these individual and universal behaviours, it is at the institutional level that it is possible to understand the discrepancy between medical and operational objectives and practices.
In current MSF projects, adult pain is better managed than that of children because of the work largely carried out by the anaesthesia department. Since 2008, the IASP in association with the World Health Organization has promoted the ChildKind initiative with the aim of reducing pain in children worldwide. It is an international accreditation which fosters a standardised approach to the management of the suffering child based on five principles: pain assessment, training, protocols, internal audits and written policy.[18] These had already been mandatory in France since June 2005 as the result of a professional practice framework jointly signed by the HAS and the French Society for Anaesthesia and Resuscitation (*Société Française d'Anesthésie-Réanimation*).[19] At MSF, these principles are rarely applied to paediatric projects, partly because of a lack of political will and partly because of the conviction that they are difficult to apply in the fields of intervention.

Pain assessment

If pain was never assessed in Moïssala, there was nothing in the medical records to encourage it. MSF paediatric clinical guides explain the use of certain scales, but there is resistance to their use, often related to the caregiver's feeling of incompetence: some are paralysed by the range of choice; others are not familiar with how the scales work, which requires learning time. Because of these doubts, the caregiver anticipates the tool's low reliability by simple transfer of incompetence.[20] Moreover, the use of scales requires a period of observation or even dialogue with the child or their family (all the more difficult for expatriates when there is a language barrier in the field). Their use is therefore experienced as a waste of time.

Training

It is the policy of the organisation not to question the skills of its medical expatriates; there is therefore no training about the management of pain in adults or children before they head off for their mission. To compensate for this gap, the anaesthesia department decided to make the departure of expatriates for which it is responsible contingent on the signing of documents about pain management, similar to opposable medical references. However, by definition, these

[16] Didier Cohen-Salmont *et al.*, L*e jeune enfant, ses professionnels et la douleur*, Éditions Érès, 2007.
[17] Yannick Jaffré et Jean-Pierre Olivier de Sardan, *Une médecine inhospitalière : les difficiles relations entre soignants et soignés dans cinq capitales d'Afrique de l'Ouest*, Éditions Karthala, 2003.
[18] Neil L. Schechter *et al.*, "ChildKind: A global initiative to reduce pain in children", Pediatric Pain Letter, *Special Interest Group on Pain in Childhood*, vol. 12, no. 3, December 2010, http://ppl.childpain.org/issues/v12n3_2010/v12n3_schechter.pdf
[19] Agence française de sécurité sanitaire des produits de santé, *Recommandations de bonne pratique, Prise en charge médicamenteuse de la douleur aiguë et chronique chez l'enfant*, juin 2009, https://www.chu-toulouse.fr/IMG/pdf/AFSSAPS_RBP-Douleur-enfant.pdf
[20] Didier Cohen-Salmont *et al.*, *Le jeune enfant, ses professionnels…, op. cit.*

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expatriates are only present on surgical projects, and other departments, including paediatrics, have not appropriated this tool. Although training for doctors in America and Europe now includes pain management, this is not always the case for national medical staff. The need for surveillance and the undeclared feeling of incompetence in the management of complications are major obstacles. However, in Western countries, experience has shown that the protocolisation of various analgesics and sedatives by trained professionals ensures their safe use. For surgical projects, one solution for MSF was to train local anaesthetists, who now do most of the work.

Many caregivers are unaware of non-pharmacological adjuvant treatments, which are often safer and less expensive. The scientifically established effectiveness of psychological and physical pain treatments can be explained by the modulation of the perception of pain by emotions and other cognitive experiences.[21] None of these therapeutic possibilities are detailed in MSF's paediatric clinical guides.

The fear of opiate addiction can be raised by families, institutions (ministries) but also health professionals. This debate is no longer necessary: it has been recognised that their proper use does not cause addiction. The latter is the result of abusive behaviour on the part of both prescribing doctors and at-risk patients.

Protocols

As we have seen above, the safe use of analgesics is promoted by the use of written protocols. These exist at MSF but are published in disparate guides making them difficult to apply, especially at the patient's bedside.

Internal audits

In the 2000s, an internal evaluation process was put in place for surgical projects, with good results. This is a simple and inexpensive procedure that is an end-of-chain indicator: if the criteria are good, it means that the whole anaesthetic chain works. But its durability requires constant pressure to obtain data from the field. To our knowledge, no such evaluation exists for paediatric projects, at least not in Moïssala.

When these self-assessments were put in place, the institution was somewhat reluctant to transfer Western tools to the field. However, in the 2000s, the mortality rate following anaesthesia in surgical projects by MSF was comparable to that in France in the 1980s with the same causes. It was precisely by implementing all the international structural reforms used in France since the 1980s that the mortality rate following anaesthesia has been reduced tenfold in twenty years.

Written policy

In our opinion, the absence of written policy at the institutional level is one of the reasons for the underuse of existing tools in paediatrics compared to surgical projects. In French healthcare establishments, it was the Kouchner Act of 2002 that was the impetus for change. This political force is probably underestimated at MSF.

Reasons for a slow evolution

In the 1980s, the ambition emerged to manage pain in surgical projects. In order to use morphine, MSF had to contend with the legal difficulties of its delivery and storage. Thanks to the work of

[21] Leora Kuttner, *L'enfant et sa douleur : Identifier, comprendre…*, *op. cit.*

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Jacques Pinel, a pharmacist and the inventor of humanitarian logistics, the cost of pain treatments has decreased, and their logistical management has been simplified. In the 2000s, the question re-emerged, because although everybody at headquarters agreed to consider pain management as a necessity, there was a complicated transition from theory to practice. Prior to any change, it was necessary to make the institutional failure in pain management visible. The data showed that MSF had performed 12,000 surgical procedures in 2000, for which 25,000 ampoules of Ampicillin (an antibiotic) and only ten ampoules of morphine were sent from Bordeaux. Xavier Lassalle, the pain consultant for the surgical projects at the time, remembers that this data ignited strong reactions: "It was a real blow, impossible to deny, we had to do something." Yet other voices were raised to recall the medical and operational priorities: "Malaria is more important. A million people have died. There is an emergency. Pain must be treated, but in contexts as appalling and specific as MSF fields, you can't transpose it so easily."[22]

MSF is currently advocating for a patient-centred approach, and the tools necessary for effective pain management are now available. Although much has been accomplished in the field of surgery, the management of the suffering child in paediatrics, and particularly in the Moïssala project, remains to be strengthened. What does the lack of pain management mean when it comes to the perception of childhood in the humanitarian field? How can the work of the different departments of the organisation be linked up in order to improve the cross-cutting management of the suffering child? In surgical projects, the local anaesthesiologists trained by MSF have proven to be good ambassadors, but the responsibility of managing the suffering child falls to both institutions and caregivers. We acknowledge the political complexity of this subject, which is reflected by the lack of discussion. We are tempted to question the political under-representation of children in this regard.

Translated from the French by Juliet Powys

Biographies

Elba Rahmouni • Dissemination officer at the *Centre de réflexion sur l'action et les savoirs humanitaires* at Doctors Without Borders – France since April 2018. Elba Rahmouni holds a Research Master's in the history of classical philosophy and a Professional Master's in editorial consulting and digital knowledge management. During her studies, she worked on questions of moral philosophy with a particular focus on practical necessity and the moral, legal and political prohibition of lying in Kant's work.

Olivier Guillard • Paediatrician at the Paris Urgent Medical Aid Service (*Service d'aide médicale urgente* – SAMU in French) since June 2020. Olivier Guillard also holds a Master's in political science, development and humanitarian aid. During his professional practice, he worked in teaching positions in paediatric cardiology and cardiac resuscitation units (*hôpital Necker – Enfants malades and hôpital Marie Lannelongue*), at Doctors Without Borders, and as project manager at the *Samusocial* de Paris. He develops projects at the Paris SAMU in partnership with the *Samusocial* de Paris and *Samusocial* International.

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[22] Interview carried out in Paris on 10 December 2020 with Xavier Lassalle, an anaesthetist nurse, a former anaesthesia consultant and a member of MSF's board of directors until 2021.