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Painful Call About the Under-Reporting of Children's Pain During Humanitarian Crises

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Abstract

Humanitarian crises often require urgent medical care to people of concern. Such medical aid includes assessing and treating acute medical needs and ongoing chronic health conditions. Among the people of concern there are children, who are often the most vulnerable population in humanitarian contexts because they often lack the experience, independence, and cognitive and verbal skills to deal with the ordeals they are facing. These limitations might prevent identification and diagnosis of pain. The under-diagnosis and under-treated pain by health care providers might be also due to the perceived urgency of more acute or life-threatening medical needs with limited medical equipment and personnel, lack of awareness, or assessment tools in such contexts. Additionally, due to issues of anonymity and lack of formal guidelines, there is a severe lack of standardized registration of children's pain conditions in humanitarian crises. Finally, acute pain is also a predictor of post-traumatic stress disorder, a common outcome in such disasters. We call on health care providers to use standardized scales to assess children's pain intensity, frequency, and duration, and to treat it appropriately. These will not only reduce children's physical suffering but may also prevent subsequent risk of PTSD.

In humanitarian settings, the priorities of assistance provision are often focused on urgent medical support. Within this realm, data collection and usage of validated measurements of medical conditions are generally low. Several organizational and personal reasons are associated with the failure to collect data in these settings. First, in many cases there is no data collection procedure as part of the organizational protocol. Yet, if such a procedure does exist, the mere sense of emergency does not always enable the medical staff to record its actions. Moreover, humanitarian agencies are often avoiding sharing or publishing data due to considerations of confidentiality, organizational concerns, awareness, or low quality of the data collected. Even if published, it is difficult to draw a policy from such publications due to the lack of standardization amongthe measures described in the publications. The above challenges were addressed by the World Health Organization (WHO) standards, enabling databases to be analyzed, compared, and validated. Yet few agencies will follow the standard reporting system developed by the WHO.[1]

The phenomena of under-reporting and the lack of data may have more severe implications when it comes to the condition of pain.[2] Pain in these humanitarian contexts could be chronic or acute, due to disaster-related injuries or its consequences (migration, malnutrition, infections, etc). Generally, pain is defined by the International Association of the Study of Pain (IASP) as: "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage."[3] In the general population, based on reviews, the prevalence of different types of pain is 10.6% for chronic widespread pain[4], 52.2% for headaches, 14% for migraines[5], and 3.9%–19.6% for chronic low back pain subject to age.[6]

Data on various types of pain and palliative care are even more difficult to obtain from published field reports compiled during or after humanitarian assistance. Several publications have shown under-reporting and under-treatment of pain in such contexts.[7–12] This under-reporting is in line with the general perception around addressing pain as presented in a systematic review of a handful of programs thataddressed palliative care or pain in humanitarian contexts.[13]

Within the described programs in that review, we failed to find a report addressing the subject of pain related to age, and specifically to pediatric pain. This leads to the conclusion that pain in children is a topic that has been overlooked and neglected as an important issue in humanitarian actions.

Neglecting pain assessment and treatment in children is a known phenomenon in general hospitals out of the humanitarian context as well.[14–23] This phenomenon may be a result of children's ways of expressing pain, which are different from those of adults,[17–24] or due to barriers held by the medical staff, such as unfamiliarity and discomfort with pediatrics, unfamiliarity with the protocols, insufficient clinical education, or concerns from adverse effects of analgesics.[25] As it comes to humanitarian settings, research shows that children are more vulnerable to

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consequences of disasters and conflicts because they often lack the experience, independence, and cognitive and verbal skills to deal with the ordeals they are facing. Therefore, these all impair children's pre-existing ability to cope with such stressful events.[26–31] Such limited skills and the inability to verbalize their pain, especially among infants, might also affect the level and nature of reported pain. In such cases, children learn fast that expressing pain is futile and it does not lead to pain relief. This might lead to developing helplessness, particularly in prolonged and uncontrollable disasters. Such a sense of helplessness is part of the broader concept of catastrophizing, a set of negative pain-related cognitions, which is correlated with pain in general and more specifically with pediatric pain.[32]

Another reason for under-reporting pain could be related to culture. In some cultures, or situations, children may have been told not to complain or cry because they should be brave or silent in cases of a consistent violent threat to their life and the lives of their close ones. Finally, observed and reported pain are not always a result of a measurable physical malfunction or injury, but rather a stress related symptom requiring psychosocial care rather than typical medical care.[33–35] This requires adequate communication with children who speak other languages, which is not always possible in urgent humanitarian contexts.

Assessment of Pain

The science of assessing pain, algometry,[36] faces methodological challenges, partly because of imperfect inter-rater variability of pain. Among children, assessment of pain includes visual analogue scales (VAS) of pain with numbers or faces. The face scale is especially suitable for younger children and in cases of existence of a linguistic gap between the child and the health care providers. Some biases and inaccuracies using face scales emerge when using drawn faces because children may have difficulties in distinguishing the sensory dimension of pain from its affective dimension. In addition, using smiling faces in the scale can result in overestimation of pain levels.[37] Lastly, according to a meta-analysis of 40 studies (4 628 children), there is a moderate association between pain ratings of children and their caregiver and a weaker association between child and health care provider,[38] but in some studies the pattern was opposite.[39]

Implications

Considering these difficulties, we make the following suggestions. First, health care teams involved in humanitarian actions should be aware of pain in children as a hidden burden. Second, this should be incorporated into staff training programs and policies prior to deployments. Third, humanitarian organizations should be familiar with the existing standards of palliative care and pain treatment. Moreover, these standards should be implemented into the protocols of the medical staff or clinics providing medical care. Fourth, tools to assess pain, such as VAS-pain and face scales, should be available to the teams. Fifth, following inconsistent findings concerning estimating children's pain, it is recommended that both caregivers and health care providers assess the child's pain levels. In addition, clinics should include a checklist for caregivers concerning the observed behavioral expression of their child's pain (e.g., grimaces, unusual body movements), especially for children with cognitive or linguistic difficulties. These would raise the general awareness of the medical staff about this challenge. Finally, organizations should be held accountable for diagnosing, treating, and adequately reporting pain in children.

To conclude, we need to keep in mind that within the humanitarian context, children are often the most vulnerable population, often without the ability to express their pain and stress. Therefore, it is our obligation through good clinical practice and ethics to reduce agony in children as part of their medical care.

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