End-of-Life Decisions and the “Pain Principle”

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The commentaries about the recent cases of withdrawing pediatric life-saving treatments [1], which have been highlighted by mass media, have regrettably registered an important absence: that of pain-treatment professionals. Two babies with devastating brain damage were at the centre of an argument between their parents and the hospital doctors: the former wanted their lifesaving treatment were continued, the latter argued to stop it. Politicians and bioethicists had their say, as well as the authorities of several important hospitals; nonetheless, though the main matter in withdrawing treatment is to avoid suffering, and pain-treatment professionals may have a pivotal role in leading the discussion, their voice has not been heard.

Instead, it would have been important: pain is the main measurable feature in end-of-life matters, and this should be the keystone of all guidelines on this topic.

Usually, in end-of-life matters, the best interest principle (BIP) is used to assess when intensive treatments are futile or noxious, but the BIP is unclear, subjective, and in the above cases it has been used by both sides of the argument. It is too difficult to say what is a patient’s best interest, when anyone can hardly say which is his/her own best interest. Some authors proposed to use instead the harm principle (HP), i.e. to arrest the cures when a harm is produced [2]; but also the concept of harm is obscure and variable, as several species of harm exist: existential, economic, physical, moral harm.

What remains, is to rely upon an easy parameter, that nonetheless is measurable and evident: pain. When intensive cures provoke pain, they should be turned into less invasive or palliative care, with the supreme aim of relieving pain. So, instead of unclear parameters such as those used in BIP or HP, pain will be the key parameter to use; we can call this approach the “pain principle” (PP). Unfortunately, no pain measures and assessment in the two above quoted pediatric cases became known: it would have been a good possibility of using the PP. That was a lost opportunity: usual criteria for the suspension or refusal of treatment (disproportionality, uselessness, unbearability) acquire their strenght and stop being generic and subjective, when they are aimed to prevent an excessive level of suffering, and measuring it would have been hugely useful: it is not enough to identify disproportionality, uselessness and unbearability to suspend treatment, but they must provoke (or should be about to provoke) measurable and objective pain to remove treatments. In fact, even unnecessary treatments can sometimes act with a placebo effect, so that the uselessness in these rare and selected cases bows in front of the psychological effect; but never in front of pain. And disproportionateness and unbearability can be difficult to spot, because the subjects can underscore their own suffering under the influence of shame or fear, and no external person can evaluate the tolerability of a treatment in place of the subject who suffers it; introducing the PP, makes them more objective, in particular in non-verbal people, namely in comatose patients or babies, where pain can be measured by EEG assessment, dosing of stress hormones, measuring sympathetic system activity, or other ways [3]. Two different standards for the allowed pain threshold (APT) should be defined, for either people with devastating brain damage that annihilates any relationship life, and the rest of the population: the former should receive more guarantees, and should not be exposed to any suffering or pain or discomfort because the absence of any conscious interaction makes that they would not get any advantage from painful treatments, so the APT will be minimal; the latter (including any type of disability) may have a higher APT, defined by scientific societies according to age (baby vs adult) and to what can be defined as “unbearable pain”.

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In a terminal patient, when the APT is exceeded, or is about to be (and that is rare because of available pain treatments), new surgery, new drugs, new resuscitation maneuvers should be avoided; and if a vital treatment provokes pain beyond the APT, it can be withheld, in favor of a less painful though less effective treatment. Pain-treatment professionals have a prominent role: promoting and spreading palliative care, too often considered a second-line treatment, instead than a frontline discipline, to be used when invasive treatments should be discontinued. This will also defuse three risks in this field: therapeutic obstinacy, euthanasia and unjustified treatment withdrawing. PP is an important approach: a more central role should be committed to pain-treatment professionals in end-of-life decisions, and their work will be precious in establishing definitively the APT for terminal patients.

Bibliography


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