

Forum: the end of life

Of all topics in bioethics, situations related to the end of life are those that most intensely challenge the public health field. The population's increasing ageing has demanded a redefinition of death, from a moral taboo to an emerging public health issue. Together with this change in Brazilian society's generational structure, the consolidation of ethical values in the human rights culture – like individual autonomy – facilitates a new understanding of end-of-life ethics: although previously seen only as a patient's bedside issue, death now comes to be seen as a public health issue and one of individual rights.

This transition from secrecy to public negotiation is not simple. Although death is intrinsic to the human condition, its enunciation and moral negotiation presuppose a redefinition of moral values rooted in the socialization of health professionals. The first redefinition shifts death from the field of technical failure to that of individual experience. Death is a personal issue, at most a family matter. This affirmation of the death experience as something essentially moral requires a redefinition of who legitimately decides on how, where, and in what form one wishes to die. The forum's four authors agree that this should be an individual decision and that health professionals can be important partners in this process of caring for death as an individual physical and moral experience.

The first article, *When Death is an Act of Care: Refusing Life Support for Children*, by anthropologist Debora Diniz, discusses a real-life case of refusal to authorize mechanical ventilation for an eight-month-old infant with an incurable degenerative disease. The parents' petition to the courts was not to hasten their infant's death, but to have the right to choose which medical procedures were considered adequate for their child's palliative care. Similar cases are handled daily in hospitals, but the ethical negotiation is restricted to bedside ethics. If the health team agrees to the parents' wishes, no extraordinary life support measures are applied; otherwise, the patient's fate can be therapeutic obstinacy. In this case the courts ruled in favor of the parents, who chose not to use invasive artificial life support measures. The infant died a week after the ruling.

The second article, *Autonomy: to Live One's Own Life and to Die One's Own Death*, by jurist Diaulas Costa Ribeiro, provides an in-depth discussion of the right to refuse therapeutic obstinacy, as an expression of each patient's individual autonomy. According to Ribeiro, each person should have the right to decide how he or she wishes to die, in hospital or at home, under intense medicalization or free of any technical intervention. To ensure the exercise of this right, the author contends that there are no legal restrictions in Brazil, but that there are legal provisions in the *Civil Code*, *Penal Code*, and *National Constitution*, in addition to State laws and government rulings. The ethical basis for this rereading of Brazilian law is that death is an extension of the way each individual experiences his or her life, and as such should be the result of an individual moral decision.

The third article, *Human Finitude and Public Health*, by physicians Sérgio Rego and Marisa Palácios, analyzes how the understanding of death as an individual moral experience presupposes a review of the training curricula for health workers. The authors do not limit their analysis to the challenge posed by this redefinition for health professionals. Rather, the article is purposely ambitious: bioethics can be an effective strategy for this passage from care of death as a duty towards medicalization to care of death as a relational ethical experience between patients and health professionals.

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