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Ars Moriendi. Ethical Challenges of the Ultimate Realities of Life

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Abstract: The aim of this issue of Ethics in Progress is to provide a provisional, open-ended view on the ultimate realities of life and the ethical challenges they pose in medical, sociological, and existential contexts. The issue explores axiologies and meta-ethical narratives related to the art of dying, or in other words the moral domain encompassing the quest for a good life and a good death. Two problematic aspects emerge from the latest body of research: (1) the difficulty involved in tackling ethical challenges in medical and sociological contexts; and (2) the marginal role of the patient's agency and narrative-ownership of end-of-life decision-making. A direction is pointed out that suggests that interventions across interdisciplinary groups involved in medical aid to dying should focus on promoting ethical behaviour on the side of healthcare personnel. Finally, attention to language, discourse, communication, and the narratives of death and dying call this edition of Ethics in Progress to examine the ontological and epistemological categories that underlie the study of lifeworlds and 'discourse communities', which are those associated with moral agents interlacing historical motives, language, communication, normative beliefs, social norms and roles, power relations, hard clinical evidence, and contested values in the context of medical practices and, broadly speaking, practices surrounding death.

Keywords: Ars moriendi; art of dying; good death; ethical death; end-of-life decision-making; palliative care; discourse community.

his new issue of *Ethics in Progress* aims at advancing a provisional, open-ended view on the ultimate realities of life and the ethical challenges they pose in medical, sociological, and existential contexts. Rather than electing a preferred normative framework, it explores axiologies and meta-ethical narratives related to the art of dying. In other words, this issue offers a multifaceted perspective on a problem rather than a systematic philosophical analysis, and includes a cluster of ideas intended to shed light, combined altogether, on the vastness of the moral domain encompassing the quest for a good life and a good death, i.e., human flourishing. The issue presents an interdisciplinary body of research primarily informed by philosophical and medical theoretical frameworks, but also by sociology and political philosophy, thus revealing how historical motives, language, communication, normative beliefs, social norms and roles, power relations, hard clinical evidence, and contested values (Epstein 1995; Rabeharisoa et al. 2014) interlace and complicate the bioethical discourse of medical practices and, broadly speaking, practices surrounding death (including the killing of animals) (Perliński 2022, in this volume).

It is not a surprise, after all, that the attention to language, discourse, communication, and narratives of death and dying characterizes this issue of Ethics in Progress, as a reflection on the ontological and epistemological categories underlying the examination of lifeworlds and 'discursive communities' (Little et al. 2003), in affinity with continental philosophers like Thomas Aquinas, Spinoza, Hegel, Heidegger, Lévinas, Blanchot, and Habermas (Kaushal 2022, in this volume).

The discursive nature of the narrative surrounding death and dying is obvious in the conflictual real-life moral choices wherein two types of moral injunctions interlap, namely, the voices of 'justice' vs. 'care'. As Brown et al. (1989) explain, justice and care are heuristic indicators for two distinct narrative styles concerning moral conflict in real-life situations: *justice* is an indicator for equality, while *care* is an indicator for attachment. Clearly, justice and care are different units of measures for complementary, and yet distinct, aspects of human experience and relations: "A justice perspective draws attention to problems of inequality and oppression by holding up an ideal of reciprocity and respect between persons. A care perspective draws attention to problems of attachment and abandonment by holding up an ideal of attention and responsiveness in relationships" (Brown et al. 1989, 142).

Importantly, justice and care detect two different moral injunctions – to treat others fairly, and not to refrain from helping someone in need, respectively – and therefore they play a role in one's discernment of different moral concerns. Moreover, these moral concerns do not arise in a vacuum, but in the context of relationships occurring among people playing different social roles, and embodying a hierarchy of values through the fulfilment of social and moral expectations. In this sense, following Habermas, discourse, language and narratives reflect political, social and moral qualities at the same time. Thus, the relational nature of justice and care narratives is extremely relevant for addressing the causes of moral adversity in context-sensitive situations, such as end-of-life decision-making or life-sustaining forms of medical treatment. More concisely, the relational-discursive nature of illness and dying narratives is relevant to different sorts of moral concerns.

A study conducted by Poškutė et al. (2022) on the contribution of nurses' professional autonomy in advancing ethical behaviour in healthcare supports these claims. In fact, nurses do have a body of knowledge and way of experiencing the relationship with patients that significantly affects their professional values, and leads to wide disagreements with physicians in regard to care treatment and end-of-life decision-making, especially in countries where nurses' professional autonomy is not enhanced as much as that of physicians'. The study suggests that nurses' perspectives play a fundamental role in navigating moral conflicts, and that the values they embody as professionals (i.e., care values as predominant to justice values) are on an equal footing with physicians' normative beliefs.

However, nurses and physicians are not the only ones who have a say in end-of-life decision-making. We can also infer that parents, due to the fact that they look at the situation through 'parents' eyes', embrace values of different content, or values that have the same content as those of nurses and physicians, but in a different preferential order. The narratives surrounding death and dying are multiple and diverse, and carry out not only moral principles and ethical beliefs, but also sentiments and attachments, as in the case of parents' opinions affecting end-of-life decision-making with regard to neonates and children (Zaal-Schuller et al. 2022). The values and sentiments at stake might coincide in content, but completely diverge in heuristics, meaning that some factors might be seen as facilitators of end-of-life decision-making by physicians, while parents see them as barriers, and vice versa. Also, while certain statements create agreement among some parents and physicians, other statements are more markedly expressive of one's role and responsibility in the decision-making. More specifically, while parents' strong opinions about death and dying created agreement between some parents and some physicians, and disagreement among others – physicians, as facilitators, generally prioritize minimizing physical deterioration and ensuring that parents are aware of the prognosis, while parents tend to value more 'personalized treatment', 'empathy' and 'trust'.

The conclusions reached by Rothschild et al. (2022) concur with these findings. In fact, the researchers have found out that mere compliance with bio-law and building on professional expertise are not enough to disentangle the intricacies of unthinkable scenarios where child maltreatment and palliative care overlap. These 3 archetypal cases are regarded as the most difficult and emotionally taxing aspects of paediatric care: (1) life-limiting illness in a child for whom parental rights have been terminated; (2) life-threatening injury under chronic pain syndrome investigation; and (3) complex end-of-life care which may warrant chronic pain syndrome involvement. The authors have concluded that empathic communication with families plays a fundamental role in aiding end-of-life decision-making, in affinity with the sort of moral effort that has recently been advocated for (Petriceks 2022), following in the footsteps of Simone Weil's ethics of attention:

> [A] process of *becoming less aware of yourself and more aware of the patient and what they are going through, while holding onto the skills, knowledge, and*

> *compassion that will benefit the patient and respond to their particular needs and context* (Petriceks 2022, 2).

Two problematic aspects emerge from the latest body of research: (1) the difficulty of tackling moral adversity and emotional distress in healthcare ethics; and (2) the marginal role of patient's agency and narrative-ownership of the illness.

When it comes to the first aspect, voices have been raised in defence of the thesis that in healthcare moral resilience should be enhanced in interdisciplinary groups. Moral distress has been identified as one of the major factors contributing to burnout in the context of healthcare professions (Antonsdottir et al. 2022). Each clinician might have their own body of knowledge and their own specific expertise, and yet it has been observed that moral distress is experienced across interdisciplinary groups of professionals, thus we can infer that medical areas of expertise, taken singularly, do not provide sufficient knowledge to enable individuals to cope with the distress caused by ethical challenges. More specifically, what causes distress is the dissonance produced by the conflict between one's normative beliefs and core values surrounding one's profession, on the one hand, and the concrete factors that condition one's decision-making in the working environment, on the other. It can be said that moral distress is the moral counterpart of psychological dissonance occurring at the level of practical reasoning. As Antonsdottir et al. (2022, 197) phrase it, moral distress "arises when a clinician's integrity is threatened as a result of conflicting or unmet fundamental professional values that create dissonance between what an individual believes one ought to do and what one is actually doing."

The moral, psychological and practical reasoning-related aspects that contribute to one's resilience to moral distress have been conceptualized with the aid of a novel construct in interdisciplinary healthcare ethics, namely, *moral resilience*. According to the Rushton Moral Resilience Scale (Antonsdottir et al. 2022), moral resilience is constituted by 4 subscales: Responses to Moral Adversity, Personal Integrity, Moral Efficacy and Relational Integrity. Each of them reveals different patterns and links with individual scores in moral distress and resilience, and affect clinicians' scores in moral resilience above and beyond the variance expressed by demographic and work characteristics alone. That means that religious preference, years worked in a healthcare profession, practice location, race, patient age, profession and education level, etc., show unique relationships with the 4 subscales of moral resilience, and differently affect professionals' coping strategies with regard to moral adversity. Therefore, the authors suggest, interventions across interdisciplinary groups involved in providing medical aid to the dying should focus on preventing moral adversities from arising. This suggestion gains even more significance if we observe that organizational climate in the healthcare industry turned out to be one of the top-3 categories related to the causes of moral distress, based on the study conducted by Jones et al. (2022) on hospice interdisciplinary teams working with patients affected by COVID-19, thus indicating that the unorganized prevention of moral adversity leads to clinicians' poor emotional and ethical attunement to their patients

(Jones et al. 2022).

In the same fashion, others (de Gioia-Carabellese & Della Giustina 2022; Semplici 2022) have advocated for a ‘strategy of preparedness’ as the linchpin of ethics in times of emergency, in order to prevent scenarios involving a risk of disruption related to healthcare, but also to basic principles of democratic participation, as illustrated by the extraordinary efforts to make compromises during the COVID-19 pandemic. In fact, when medical decisions involve not simply postponing treatment but letting someone die, when lockdowns are aimed at containing the pandemic at the expense of individual freedoms and economic activities, when the proposal for mandatory vaccination exacerbates conflicting values, it becomes clear that, even though science offers the premises to make informed choices, such decisions ultimately remain within the domain of ethics and politics (Semplici 2022), while bio-law, far from offering the necessary guidance in a situation characterized by scarcity of healthcare resources (e.g., the first phase of the pandemic), turns out to be at the mercy of another factor: bio-law-and-economics (de Gioia-Carabellese & Della Giustina 2022). Therefore, preparedness is a crucial organizational feature for bio-ethical policies and has a great strategic impact. But is it sufficient to unfold and address other morally relevant aspects? And is it inclusive when it comes to the different moral standings represented by clinical and lay members of palliative care communities (patients included)?

On a further reflection, it seems that dignity and narrative-ownership should reframe decision-making in palliative care communities. Whereas the strategy of preparedness is intended to advance ethical behaviour on the side of healthcare personnel, other tools to support inclusive decision-making in palliative care communities have been advanced, such as the Patients Changing Things Together (PATCHATT) framework (Roberts 2022). The framework explores six different cards[1] that encompass the factors determining how each stage of the decision-making process ultimately influences the result, i.e., how to bring about a good change in the patient’s life in an ethical manner. However, the objective is not just to make a compilation of the existing ethical theories, moral principles, and contextual factors shaping the understanding of ethical concerns related to a community’s palliative care agenda. The scope of the PATCHATT pack is to ensure not only compliance with established bio-laws and ethical guidelines, but to concretely empower the patients’ agency and autonomy, as well as to impact their quality of life for the greater sake of human flourishing, as opposed to just living as pain-avoiders. In fact, while on the one hand “the intersect between autonomy and beneficence becomes vital,” on the other hand participants should be enabled to “to express their ‘dignity in action’, having control of their own narrative through values-based change-making, while also making a difference

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[1] (1) Moral intention – which we paraphrase as inner discernment of one’s personal understanding of the endorsed, inherited, entrenched moral beliefs about what is good and desirable; (2) normative ethical theories (i.e., deontology, consequentialism, virtue ethics); (3) principalism (i.e., autonomy, beneficence, non-maleficence, justice); (4) the facts-law-professional guidance triad; (5) ethical dilemmas; and (6) deciding, implementing, and evaluating.

to the lives of others" (Roberts 2022, 7–8). In other words, innovation in palliative care communities, whose members are both medical and lay, is needed in a way that re-centers patients at the core of our vision and care. Crucially, the role of the narrative-ownership constitutes a decisive factor for enhancing the individual's agency, sense of self-worth and self-respect – in one word, *dignity* – in a way that their decision-making is not only informed, autonomous, and benefit-oriented, but also *deserved* and *owned*.

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