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Audu Aishat et al., Choosing a Side: Clinician Perspective Taking in Ethics Consultations, in Journal of Clinical Ethics, 34(2023)1, 40-50 p.
Soggetto: *consulenza etica, etica medica*
Abstract: Ethics consultation is a service provided to patients, families, and clinicians to support decisions during ethical dilemmas. This study is a secondary qualitative analysis of 48 interviews from clinicians involved in an ethics consultation at a large academic health center. An inductive secondary analysis of this data settled to the emergence of one key theme, the apparent perspective the clinicians adopted as they recalled aspecific ethics case. This article presents a qualitative analysis of the propensity of clinicians involved in an ethics consultation to adopt the subjective view points of their team, their patient, or both simultaneously. Clinicians demonstrated an ability to take the patient perspective (42%), the clinician perspective (31%), or the clinician patient perspective (25%). Our analysis suggests the potential for narrative medicine to build the empathy and moral imagination necessary to bridge the gap in perspectives between key stakeholders.

Barzun Charles, Alzheimer's, Advance Directives, and Interpretive Authority, in Journal of Medicine and Philosophy, 48(2023)1, 50-59 p.
Soggetto: *Alzheimer, direttive anticipate, interpretazione*
Abstract: Philosophers have debated whether the advance directives of Alzheimer's patients should be enforced, even if patients seem content in their demented state. The debate raises deep questions about the nature of human autonomy and personal identity. But it tends to proceed on the assumption that the advance directive's terms are clear, whereas in practice they are often vague or ambiguous, requiring the patient's healthcare proxy to make difficult judgment calls. This practical wrinkle raises its own, distinct but related, philosophical question: what criteria may the proxy bring to bear when making such interpretive judgments on which the patient's life may depend? After defending a general policy of enforcing advance directives on normative (rather than metaphysical) grounds, I argue that when advance directives are vague, a patient's proxy may permissibly make her own fresh evaluation of the patient's life as a whole and, in so doing, consider how the patient's character as a demented person contributes or fails to contribute to that life.

Bowman Smart Hilary, Non-Invasive Prenatal Testing for "Non-Medical" Traits: Ensuring Consistency in Ethical Decision-Making, in AJOB-American Journal of Bioethics, 23(2023)3, 3-20 p.
Soggetto: *tecniche di riproduzione, diagnosi prenatale, bioetica, metodo decisionale, aborto*
Abstract: The scope of non invasive prenatal testing (NIPT) could expand in the future to include detailed analysis of the fetal genome. This will allow for the testing for virtually any trait with a genetic contribution, including "non-medical" traits. Here we discuss the potential use of NIPT for these traits. We outline a scenario which highlights possible inconsistencies with ethical decision-making. We then discuss the case against permitting these uses. The objections include practical problems; increasing inequities; increasing the burden of choice; negative impacts on the child, family, and society; and issues with implementation. We then outline the case for permitting the use of NIPT for these traits. These include arguments for reproductive liberty and autonomy; questioning the labeling of traits as "non-medical"; and the principle of procreative beneficence. This summary of the case for and against can serve as a basis for the development of a consistent and coherent ethical framework.

Busatta L. et al., Gli abortion rights e il costituzionalismo contemporaneo, in Biolaw (2023)1 Special issue, 1-525 p.
Soggetto: *aborto, diritto legislazione, Usa, Europa, biodiritto, studio di casi, sentenza Dobbs, bioetica laica, pluralismo etico, principio di autodeterminazione*

Canali C. et al. (a cura di), Percorsi clinici, organizzativi e assistenziali delle persone con malattia oncologica, in Studi Zancan, numero monografico (2022)4, 5-71 p.
Soggetto: *politica sanitaria, assistenza, oncologia, servizi sanitari, percorsi di cura, banca dati, relazione medico-paziente*

Cognato Pietro, Sul suicidio assistito. Riflettere ancora, in Bioethos, (2021-22)3, 5-19 p.
Soggetto: *suicidio assistito, bioetica, bio-politica, biodiritto*

Dees Richard et al., The Ethics of Implementing Emergency Resource Allocation Protocols, in Journal of Clinical Ethics, 34(2023)1, 58-68 p.
Soggetto: *allocazione delle risorse, bioetica, emergenza, protocollo*
Abstract: We explore the various ethical challenges that arise during the practical implementation of an emergency resource allocation protocol. We argue that to implement allocation plan in a crisis, a hospital system must complete five tasks: (1) formulate a set of general principles for allocation, (2) apply those principles to the disease at hand to create a concrete protocol, (3) collect the data required to apply the protocol, (4) construct a system to implement triage decisions with those data, and (5) create a system for managing the consequences of implementing the protocol, including the effects on those who must carry out the plan, the medical staff, and the general public. Here we illustrate the complexities of each task and provide tentative solutions, by describing the experiences of the Coronavirus Ethics Response Group, an interdisciplinary team formed to address the ethical issues in pandemic resource planning at the University of Rochester Medical Center. While the plan was never put into operation, the process of preparing for emergency implementation exposed ethical issues that require attention.

Di Giandomenico Felice, Sulla cognizione bioculturale del dolore, in L'Ancora nell'Unità di Salute, 44(2022)6, 525-536 p.
Soggetto: *dolore, significato, pluralismo etico, pluralismo culturale*
Abstract: Nella prospettiva dell'evoluzione delle specie, quadro da cui l'antropologia non può in alcun caso prescindere, il dolore si mostra, in prima istanza, come sofisticato meccanismo di adattamento all'ambiente. Nel senso più generale del termine, il dolore è pertanto certamente natura, ma questa natura ha valenza talmente ampia da includere qualsiasi specie dotata di un pur minimo apparato sensorio; si tratta in definitiva di una natura così

generale da perdere qualsiasi possibilità interpretativa delle trame articolate del dolore umano.

Doomen Jasper, Existential Suffering as a Legitimization of Euthanasia, in Cambridge Quarterly of Healthcare Ethics, 32(2023)1, 14-25 p.
Soggetto: *eutanasia, suicidio assistito, sofferenza*
Abstract: Several countries have legalized euthanasia on the basis of medically diagnosable suffering over the last decennial; the criteria to which they adhere differ. The topic of this article is euthanasia on the basis of existential suffering. This article presents a recent proposal to legalize euthanasia for people who experience such suffering and then discusses the issue of what the value of life may be, and whether the standard that life is normally something positive should be accepted. This provides the foundation to answer the question of whether euthanasia on the basis of existential suffering should be allowed.

Elsner Magdalena, "Accompanied Only by My Thoughts": A Kantian Perspective on Autonomy at the End of Life, in Journal of Medicine and Philosophy, 47(2022)6, 688-700 p.
Soggetto: *autonomia, bioetica, etica medica, fine vita, malattia, narrativa-racconto, Kant, filosofia morale*
Abstract: Within bioethics, Kant's conception of autonomy is often portrayed as excessively rationalistic, abstract, and individualistic, and, therefore, far removed from the reality of patients' needs. Drawing on recent contributions in Kantian philosophy, we argue that specific features of Kantian autonomy remain relevant for medical ethics and for patient experience. We use contemporary end-of-life illness narratives—a resource that has not been analyzed with respect to autonomy—and show how they illustrate important Kantian themes, namely, the duty to know oneself, the interest in elaborating universalizable principles, and the emphasis on ideals as points of orientation that guide behavior without ever being fully realized. As Kant does, the patient-authors discussed here perceive the end of life as a moment to reflect on the constitutive principles which have governed that life, thereby offering a privileged moment to pursue self-knowledge. We argue that bioethical conceptions of autonomy stand to gain if they revise their conception of Kantian moral philosophy as too formal, abstract, and detached from emotions and personal relationships to be helpfully applied.

Ferrenz-Kaddari Michall et al., Psychiatric Hospital Ethics Committee Discussions Over a Span of Nearly Three Decades, Hec Forum, 35(2023)1, 55-71 p.
Soggetto: *comitati etici, psichiatria, Israele*
Abstract: Various types of health settings use clinical ethics committees (CEC) to deal with the ethical issues that confront both healthcare providers and their patients. Although these committees are now more common than ever, changes in the content of ethical dilemmas through the years is still a relatively unexplored area of research. The current study examines the major topics brought to the CEC of a psychiatric hospital in Israel and explores whether there were changes in their frequency across nearly three decades.

Fins Joseph, Bioethics, Ukraine and the peril of silence, in Cambridge Quarterly of Healthcare Ethics, 32(2023)1, 1-3 p.
Soggetto: g*uerra, bioetica*

Freni Cristiana, La sofferenza oltre la finzione letteraria, in L'Ancora nell'Unità di Salute, 44(2022)6, 555-563 p.
Soggetto: *sofferenza, dolore, letteratura*
Abstract: Il mistero del dolore ha costituito uno dei temi più significativi e ricorrenti nella letteratura di tanti paesi. Specialmente nell'800 e nel '900, a partire dall'età romantica, l'*homo patiens* ha sperimentato, in modo sempre più cogente e drammatico, l'esigenza di dare un significato al proprio soffrire con risposte diverse, com'è noto, secondo l'angolo prospettico acquisito.

Green Sara et al., The practical ethics of repurposing health data: how to acknowledge invisible data work and the need for prioritization, in Medicine Healthcare and Philosophy, 26(2023)1, 119-132 p.
Soggetto: *dati sanitari, privacy, sistema sanitario, digitalizzazione, practical-ethics*
Abstract: Throughout the Global North, policymakers invest in large-scale integration of health-data infrastructures to facilitate the reuse of clinical data for administration, research, and innovation. Debates about the ethical implications of data repurposing have focused extensively on issues of patient autonomy and privacy. We suggest that it is time to scrutinize also how the everyday work of healthcare staff is affected by political ambitions of data reuse for an increasing number of purposes, and how different purposes are prioritized. Our analysis builds on ethnographic studies within the Danish healthcare system, which is internationally known for its high degree of digitalization and well-connected data infrastructures. Although data repurposing ought to be relatively seamless in this context, we demonstrate how it involves costs and trade-offs for those who produce and use health data. Even when IT systems and automation strategies are introduced to enhance efficiency and reduce data work, they can end up generating new forms of data work and fragmentation of clinically relevant information. We identify five types of data work related to the production, completion, validation, sorting, and recontextualization of health data. Each of these requires medical expertise and clinical resources. We propose that the implications for these forms of data work should be considered early in the planning stages of initiatives for large-scale data sharing and reuse, such as the European Health Data Space. We believe that political awareness of clinical costs and trade-offs related to such data work can provide better and more informed decisions about data repurposing.

Gustavsson Erik (a cura di), Health care priority setting – Lessons learned from Covid 19, in De Ethica, 7(2023)2, Special issue, 1-83 p.
Soggetto: *Covid 19, assistenza sanitaria, politica sanitaria, allocazione delle risorse*

Hartmann Kris Vera, Lost in translation? Conceptions of privacy and independence in the technical development of AI-Based AAL, in Medicine Healthcare and Philosophy, 26(2023)1, 99-110 p.
Soggetto: *intelligenza artificiale, autodeterminazione, AAL-Ambient assisted living privacy*
Abstract: AAL encompasses smart home technologies that are installed in the personal living environment in order to support older, disabled, as well as chronically ill people with the goal of delaying or reducing their need for nursing care in a care facility. Artificial intelligence (AI) is seen as an important tool for assisting the target group in their daily lives. A literature search and qualitative content analysis of 255 articles from computer science and engineering was conducted to explore the usage of ethical concepts. From an ethical point of view, the concept of independence and self-determination on the one hand and the possible loss of privacy on the other hand are widely discussed in the context of AAL. These concepts are adopted by the technical discourse in the sense that independence, self-determination and privacy are recognized as important values. Nevertheless, our research shows that these concepts have different usages and meanings in the ethical and the technical discourses. In the paper, we aim to map the different meanings of independence, self-determination and privacy as they can be found in the context of technological research on AI-based AAL systems. It investigates the interpretation of these ethical and social concepts which technicians try to build into AAL systems. In a second step, these interpretations are contextualized with concepts from the ethical discourse on AI-based assistive technologies.

Horton Rachel et al., Ethical consideration in research with genomic data, in The New Bioethics, 29(2023)1, 37-51 p.
Soggetto: *ricerca, genoma, bioetica, diversità*
Abstract: Our ability to generate genomic data is currently well ahead of our ability to understand what they mean, raising challenges about how best to engage with them. This article considers ethical aspects of work with such data, focusing on research contexts that

are intertwined with clinical care. We discuss the identifying nature of genomic data, the medical information intrinsic within them, and their linking of people within a biological family. We go on to consider what this means for consent, the importance of thoughtful sharing of genomic data, the challenge of constructing meaningful findings, and the legacy of unequal representation in genomic datasets. We argue that the ongoing success of genomic data research relies on public trust in the enterprise: to justify this trust, we need to ensure robust stewarding, and wide engagement about the ethical issues inherent in such practices

Iacone Ignazio, La riscoperta del limite come via etica alla discussione sull'aborto, in Medicina e Morale, (2023)1, 59-68 p.
Soggetto: *aborto, Chiesa, limite, ruolo dell'etica, bioetica*
Abstract: La sentenza del giugno 2022 della Corte Suprema USA sull'aborto è stata letta da molti organismi politici e associazioni pro-choice come un passo indietro nel cammino dei diritti civili, trascurando le sue implicazioni etiche pericolose in senso opposto e confermando un'idea della gravidanza difficile come problema da eliminare e non come opportunità da proteggere. Tanto il caso americano come il dibattito italiano sulla legge 194 chiamano in causa il concetto filosofico del limite, del quale andrebbe riscoperto il valore per la conoscenza umana, come per la prima volta dichiarato da Kant. Quanti si schierano a difesa della vita, e tra costoro la Chiesa, chiedono politiche in grado di tutelare tanto la madre quanto il figlio, e insieme gli obiettori di coscienza. L'etica ha il compito di cercare vie di dialogo realmente aperto, in direzione di una verità che trascenda le diversità di opinioni e culture e guidi l'umanità nel progresso verso il Bene.

Jotterand Fabrice, Promoting equity in healthcare through human fluorishing, justice and solidarity, in Journal of Medicine and Philosophy, 48(2023)1, 98-109 p.
Soggetto: *giustizia, solidarietà, equità, sanità, allocazione delle risorse, Amartya Sen*
Abstract: In this article, we develop a non-rights-based argument based on beneficence (i.e., the welfare of individuals and communities) and justice as the disposition to act justly to promote equity in health care resource allocation. To this end, we structured our analysis according to the following main sections. The first section examines the work of Amartya Sen and his equality of capabilities approach and outlines a framework of health care as a fundamental human need. In the subsequent section, we provide a definition of health equity based on the moral imperative to guarantee that every individual ought to have the freedom to pursue health goals and well-being. In the later part of the article, we outline a non-right approach to health care based on three pillars: (1) human flourishing, (2) justice as a disposition not a process, and (3) solidarity.

Kenny Belinda et al., Ethics of care and moral resilience in health care practice: A scoping review, in Clinical Ethics, 18(2023)1, 88-96 p.
Soggetto: *etica della cura, resilienza*
Abstract: This review identified a dearth of research in ethics of care and moral resilience in healthcare practice. Further empirical investigation may provide a deeper understanding of the translation of ethics of care and moral resilience to health care practice to facilitate workplace culture.

Lagree Jacqueline, La deliberation en Comitè de Bioethique, in Études, (2023)3, 43-54 p.
Soggetto: *consulenza etica, comitati etici, decisione, metodo decisionale, bioetica, etica medica*
Abstract: La pratique de la délibération a profondément modifié la profession médicale en mettant l'accent sur la collaboration et l'accord du patient, ainsi que sur la dimension collégiale de certaines décisions. À quoi engage-t-elle et peut-on espérer son extension à d'autres domaines?

Langmann Elisabeth, Vulnerability, ageism, and health: is it helpful to label older adults as a vulnerable group in health care?, in Medicine Healthcare and

Philosophy, 26(2023)1, 133-142 p.
Soggetto: *vulnerabilità, anziani*
Abstract: Despite the diversity of ageing, society and academics often describe and label older persons as a vulnerable group. As the term vulnerability is frequently interchangeably used with frailty, dependence, or loss of autonomy, a connection between older age and deficits is promoted. Concerning this, the question arises to what extent it may be helpful to refer to older persons as vulnerable specifically in the context of health care. After analyzing different notions of vulnerability, I argue that it is illegitimate to conclude that older age is related to increased vulnerability.

Ley Madelaine, Care ethics and the future of work: a different voice, in Philosophy and Technology, 36(2023)1, 36-77 p.
Soggetto: *etica della cura, futuro, robotica, emozioni*
Abstract: The discourse on the future of work should learn from a turn in philosophy that occurred in the 1980s, one that recognizes the good life towards which ethics strives can only be reached on a foundation of caring relationships (Gillian, 1982; Noddings, 1984). Care ethics recognizes that human well-being is a group project, one that involves strong relationships, and concern for bodies and emotions. Too often, these features are left out of research exploring robotics in the workplace. This paper outlines the main tenets of care ethics, then applies the moral framework to the context of industrial and retail settings using robots. This approach sees these contexts through a relational lens, helping to identify, evaluate, and improve relationships critical to ensuring workers' well-being. Second, care ethics considers taking care of people's bodies beyond mere safety, examining how working with robots can exacerbate societal or economic pressures. Lastly, care ethics takes emotions as an important source of knowledge in building and supporting care. Additionally, this paper contributes to the care ethics literature by applying the framework to the context of robotized industrial workplaces, which has yet to be done.

Maldonado Manuel, What's in a Pandemic? COVID-19 and the Anthropocene, in Environmental Values, 32(2023)1, 45-63 p.
Soggetto: *pandemia, antropocene, cambiamenti climatici, ambiente naturale*
Abstract: After the viral outbreak that hit populations across the planet in the first half of 2020, it has been argued that the coronavirus pandemic can be described as a quintessential phenomenon of the Anthropocene, i.e. the result of a particular stage of socionatural relations in which wild habitats are invaded and anthropogenic climate change creates the conditions for the emergence of more frequent viral pathogens. Likewise, it has also been argued that the pandemic is an event that shares structural features with climate change itself and, consequently, offers some lessons about how best to fight the latter. I will consider these arguments, offering an alternative view of the relationship between the pandemic and the Anthropocene. I will argue that although the pandemic should not be primarily seen as an event of the Anthropocene, it can end up reinforcing the Anthropocene frame for several reasons.

Milo Caterina, The role of knowledge and medical involvement in the context of informed consent: a curse or a blessing?, in Medicine Healthcare and Philosophy, 26(2023)1, 49-54 p.
Soggetto: *consenso informato, etica della conoscenza, diagnosi prenatale, screening prenatale, studio di casi, informazione al paziente*
Abstract: Informed consent (IC) is a key patients' right. It gives patients the opportunity to access relevant information/knowledge and to support their decision-making role in partnership with clinicians. Despite this promising account of IC, the relationship between 'knowledge', as derived from IC, and the role of clinicians is often misunderstood. I offer two examples of this: (1) the prenatal testing and screening for disabilities; (2) the consent process in the abortion context. In the first example, IC is often over-medicalized, that is to say the disclosure of information appears to be strongly in the clinicians' hands. In this context, knowledge has often been a *curse* on prospective parents. Framing information in

a doctor-centred and often negative way has hindered upon prospective parents' decision-making role and also portrayed wrong assumptions upon disabled people more widely. In the second context, information is more often than not dismissed and, in a de-medicalized scenario, medical contribution often underplayed. The latter leads to an understanding of the dialogue with clinicians as a mere hinderance to the timely access to an abortion. Ultimately, I claim that it is important that knowledge, as derived from IC, is neither altogether dismissed via a process of de-medicalization, nor used as a *curse* on patients via a process of over-medicalization. None of the two gives justice to IC. Only when a better balance between medical and patients' contribution is sought, knowledge can aspire to be a *blessing* (i.e. an opportunity for them), not a *curse* on patients in the IC context.

Mitchell Polly et al., Patient Safety and the Question of Dignitary Harms, in Journal of Medicine and Philosophy, 48(2023)1, 33-49 p.
Soggetto: *dignità del paziente, sicurezza, qualità delle cure*
Abstract: Patient safety is a central aspect of healthcare quality, focusing on preventable, iatrogenic harm. Harm, in this context, is typically assumed to mean physical injury to patients, often caused by technical error. However, some contributions to the patient safety literature have argued that disrespectful behavior towards patients can cause harm, even when it does not lead to physical injury. This paper investigates the nature of such dignitary harms and explores whether they should be included within the scope of patient safety as a field of practice.

Moore Bryanna, The Fraught Notion of a "Good Death" in Pediatrics, in Journal of Medicine and Philosophy, 48(2023)1, 60-72 p.
Soggetto: *pediatria, fine vita, morte, attitudine verso la morte, metodo decisionale medico*
Abstract: In this article, I sort through some of the confusion surrounding what constitutes the controversial notion of a "good death" for children. I distinguish, first, between metaphysical and practical disagreements about the notion of a good death, and, second, between accounts of a good death that minimally and maximally promote the dying child's interests. I propose a narrowed account of the dying child's interests, because they differ from the interests of non-dying children. Importantly, this account illustrates how disagreements at the end of a child's life are sometimes the result of a shift from a future to a present-oriented understanding of the child's interests on the part of some stakeholders but not others, and sometimes the result of a values-based disagreement about how different interests should be weighted. This brings into sharper focus the questions of for whom, and in what way, a child's death might be considered good.

Nyholm Sven et al., Meaning in life in AI ethics; some trends and perspectives, in Philosophy and Technology, 36(2023)2, 20-44 p.
Soggetto: *valore della vita, intelligenza artificiale, relazioni*
Abstract*:* In this paper, we discuss the relation between recent philosophical discussions about meaning in life (from authors like Susan Wolf, Thaddeus Metz, and others) and the ethics of artificial intelligence (AI). Our goal is twofold, namely, to argue that considering the axiological category of meaningfulness can enrich AI ethics, on the one hand, and to portray and evaluate the small, but growing literature that already exists on the relation between meaning in life and AI ethics, on the other hand.

Palazzani Laura, Gene-editing: ethical and legal challenges, in Medicina e Morale, (2023)1, 49-58 p.
Soggetto: *gene-editing, biopotenziamento, autodeterminazione, sicurezza, bioetica*
Abstract: L'articolo si concentra sull'editing genetico, tecnologia con prospettive senza precedenti ma anche con emergenti questioni etiche. La principale domanda generale riguarda l'urgenza del progresso della scienza, da una parte, e la responsabilità degli scienziati rispetto al valore della vita umana e ai diritti fondamentali dell'uomo, dall'altra. L'articolo analizza la discussione etica, considerando il tipo di intervento (sulla linea somatica o sulla linea germinale) e lo scopo (preventivo-terapeutico o migliorativo), nel contesto del dibattito pluralistico. L'autore discute di argomenti a favore delle posizioni liberali e

utilitariste e le obiezioni della prospettiva personalista, per poi analizzare le opinioni dei comitati di bioetica a livello nazionale, europeo e internazionale.

Picozzi Mario, Nicoli Federico et al., The Circle Method: A Novel Approach to Clinical Ethics Consultation, in Journal of Clinical Ethics, 34(2023)1, 79-91 p.
Soggetto: *consulenza etica, principi etici, metodo, etica clinica*
Abstract: Different methods are available in clinical ethics consultation. In our experience as ethics consultants, certain individual methods have proven insufficient, and so we use a combination of methods. Based on these considerations, we first critically analyze the pros and cons of two well-known methods in the working field of clinical ethics, namely Beauchamp and Childress's four principles approach and Jonsen, Siegler, and Winslade's four-box method. We then present the circle method, which we have used and refined during several clinical ethics consultations in the hospital setting.

Pilotto Franco Davide, Autonomia nel rapporto medico-paziente: aspetti etici, in L'Ancora nell'Unità di Salute, 44(2022)6, 547-554 p.
Soggetto: *rapporto medico-paziente, autonomia, principi etici, bioetica*
Abstract: L'interesse bioetico per il tema dell'autonomia deriva dal dibattito sul consenso informato. Beauchamp e Childress conducono la loro trattazione sul principio di autonomia soprattutto pensando alle implicazioni nelle scelte terapeutiche da parte del paziente.

Pizzi Simone, Tra etica e cura. Il fine vita nella Terapia Intensiva Pediatrica "aperta" ai familiari, in Medicina e Morale, (2023)1, 11-26 p.
Soggetto: *fine vita, terapia intensiva pediatrica "aperta", etica della cura, cure palliative, pediatria, comfort care, famiglia-familiari*
Abstract: L'articolo esplora alcune importanti questioni collegate al tema del fine vita nelle Terapie Intensive Pediatriche (TIP) "aperte" ai familiari del bambino ricoverato. Come è stato sottolineato dall'Organizzazione Mondiale della Sanità nel documento Integrating palliative care and symptom relief into paediatrics, c'è un peso emotivo maggiore sia per i familiari che per i clinici quando si è di fronte alla malattia grave e severa di un bambino. La presenza dei famigliari nella TIP può essere talvolta percepita dallo staff medico come un ostacolo, ma l'esperienza – nella TIP "aperta" dell'ospedale pediatrico "G. Salesi" di Ancona, oggetto specifico dell'articolo, e anche di altri ospedali, come riportato in letteratura – dimostra che si tratta di una pratica positiva, di una buona pratica, perfino essenziale per il bambino negli ultimi giorni o nelle ultime ore di vita ed anche per i genitori che sono posti nelle condizioni di assistere il figlio o la figlia e di verificare che è stato fatto tutto ciò che era umanamente possibile fare da parte del personale medico e infermieristico – elemento cruciale per evitare sensi di colpa in futuro. Le TIP "aperte" devono essere concepite e disegnate non soltanto come luoghi in cui si forniscono le cure cliniche più avanzate e innovative, ma anche come dei veri e propri "luoghi etici", in cui uno staff ben istruito si fa carico di provvedere per quanto umanamente possibile all'alleviamento dei sintomi, del dolore e della sofferenza, con atteggiamenti e comportamenti virtuosi, usando gli strumenti della medicina narrativa e della comfort care nella prospettiva di un'etica della compassione.

Phungh Binh, Rationing in pediatric hospitalizations during COVID-19: A step back to move forward, in Clinical Ethics, 18(2023)1, 3-6 p.
Soggetto: *bioetica clinica, pediatria, allocazione delle risorse, COVID 19*
Abstract: The latest Omicron variant of the novel coronavirus has itself created a novel situation—bringing attention to the topic of healthcare rationing among hospitalized pediatric patients. This may be the first time that many pediatricians, nurses, parents, and public health officials have been compelled to engage in uncomfortable discussions about the allocation of medical care/resources. Simply put, finite budgets, resources, and a dwindling healthcare workforce do not permit all patients to receive unlimited medical care. Triage and bedside rationing decisions are happening in a range of difficult everyday circumstances both implicitly and explicitly, but in ways not recognized by even the best ethically framed intentions. Clinicians and hospital administrators have largely been left on their own "to flatten the rationing curve" in hopes that resources never have to be explicitly rationed at

their facility. Unfortunately, the downstream result is a misinformed and distrustful public (i.e. parents, guardians, and caregivers) filled with people who are already burdened with inflammatory pseudoscience narratives and deficits in health literacy. This paper aims to elevate a more thoughtful conversation about healthcare rationing by analyzing some existing ethical principles/framework developed for rationing decision making during previous emergency responses and drawing from the day-to-day clinical perspectives of a frontline pediatric acute care/hospitalist.

Rasanen Joona et al., Controversial arguments in bioethics, in Theoretical Medicine and Bioethics, 44(2023)2 numero monografico, 107-189 p.
Soggetto: *bioetica, bioetica clinica*

Sacchini Dario et al., Neonata con Sindrome di Ohtahara e assenza di trigger respiratorio: questioni etiche in Terapia Intensiva Neonatale, in Medicina e Morale, (2023)1, 69-82 p.
Soggetto: *studio di casi, consulenza etica, terapia intensiva neonatale, cure palliative, accanimento terapeutico*
Abstract: Introduzione: La Sindrome di Ohtahara (SO) è un'encefalopatia epilettica rara resistente ai farmaci, caratterizzata da frequenti spasmi tonici o crisi focali motorie associati allo specifico quadro elettroencefalografico di burst suppression...
Obiettivo: Attraverso il caso di M, neonata di 38 settimane, intubata e ventilata meccanicamente sin dalla nascita per assenza di attività respiratoria spontanea, per la quale a circa 4 mesi di vita si è giunti alla diagnosi clinica di SO, si intendono approfondire le questioni etiche connesse: a. alla proporzionalità e appropriatezza etico-clinica dei trattamenti in pazienti per i quali si giunga a una prognosi infausta quoad vitam; b. al processo decisionale da condividere con i genitori, che nel caso specifico non riuscivano ad accettare l'irreversibilità della malattia della figlia, nonostante il supporto psicologico offerto sin dall'inizio.Discussione: In una situazione di patologia probabilmente irreversibile, come nel caso di grave encefalopatia, con disfunzione cortico-sottocorticale e quadro elettro-clinico di SO, associata ad assenza di trigger respiratorio, in cui non emergono elementi in grado di modificare la prognosi quoad vitam , e della cui gravità i genitori possono far fatica ad elaborare la consapevolezza, diventa difficile individuare i limiti dei trattamenti, che potrebbero configurarsi come ostinazione irragionevole e penoso prolungamento del processo del morire. Nel caso di M, durante il suo ricovero nella Terapia Intensiva Neonatale (TIN) della Fondazione Policlinico "A. Gemelli" IRCCS di Roma, i neonatologi hanno costantemente coinvolto i neuropsichiatri infantili per ricercare una causa eziologica e opzioni terapeutiche percorribili, e hanno richiesto il supporto in più fasi delle consulenze di etica clinica per valutare in maniera interdisciplinare la proporzionalità e l'appropriatezza etico-clinica dei trattamenti in atto (in particolare del ventilatore meccanico) e da attuare.
Conclusioni: I limiti dei trattamenti e più in generale gli interrogativi legati al fine vita sono questioni etiche sempre più frequenti, anche in TIN, e devono essere costantemente discussi, approfonditi e condivisi all'interno dell'équipe medica e con i genitori, anche quando la comunicazione si presenta difficile. Nel caso di M, solo dopo diverse valutazioni interdisciplinari, si è giunti a una decisione condivisa anche con i genitori di continuare le cure palliative già in essere, di astenersi da interventi intensivi/invasivi in caso di eventi critici, e di favorire il benessere dell'intera famiglia, trasferendo M in un Hospice Pediatrico, dove la morte è avvenuta quando la piccola aveva 11 mesi.

Smaidor Anna, Whole body gestational donation, in Theoretical Medicine and Bioethics, 44(2023)2, 113-124 p.
Soggetto: *gravidanza, donazione gestazionale del corpo, morte cerebrale, procreazione*
Abstract: Whole body gestational donation offers an alternative means of gestation for prospective parents who wish to have children but cannot, or prefer not to, gestate. It seems plausible that some people would be prepared to consider donating their whole bodies for gestational purposes just as some people donate parts of their bodies for organ donation. We already know that pregnancies can be successfully carried to term in brain-dead women.

There is no obvious medical reason why initiating such pregnancies would not be possible. In this paper, I explore the ethics of whole-body gestational donation. I consider a number of potential counterarguments, including the fact that such donations are not life-saving and that they may reify the female reproductive body. I suggest if we are happy to accept organ donation in general, the issues raised by whole-body gestational donation are differences of degree rather than substantive new concerns. In addition, I identify some intriguing possibilities, including the use of male bodies–perhaps thereby circumventing some potential feminist objections.

Testa Giuliano, Living donor ethics and uterus transplantation, in Perspectives in Biology and Medicine (2023)1, 195-209 p.
Soggetto: *donazione da vivente, trapianto di utero, bioetica, principi etici*
Abstract: This article provides an in-depth ethical analysis of living donor uterus transplantation, incorporating clinical, psychological, and qualitative study data into the discussion. Although the concept of living organ donors as patients in their own right has not always been present in the field of transplantation, this conceptualization informs the framework for living donor ethics that we apply to living uterus donation. This framework takes root in the principles of research ethics, which include respect for persons, beneficence, and justice. It incorporates an analysis based on eight potential vulnerabilities of living donors: capacitational, juridic, deferential, social, medical, situational, allocational, and infrastructural. Finally, it recognizes that special relationships—such as that of the living donor advocate with the potential donor—require special responsibilities, including identifying vulnerabilities and engaging donors in a shared decision-making process. Directed and non-directed uterus donors require separate ethical analyses because their different relationships with recipients will influence the types of vulnerabilities, they are subject to as well as the potential benefits they may gain from donation.

Thiel Maria-Jo*,* Engineering cellular systems: modify, repair, but not at all costs. Which ethical benchmarks?, in Medicina e Morale, (2023)1, 39-47 p.
Soggetto: *sistema cellulare, ingegneria genetica, editing genetico*
Abstract: Questo contributo esamina l'ingegneria dei sistemi molecolari e cellulari da un punto di vista etico. È possibile oggi modificare, riparare e curare (...) ma non deve essere a tutti i costi. La fascinazione non deve accecare rispetto alle problematiche etiche in gioco. Per affrontare queste sfide, l'autore propone cinque insiemi di principi intrecciati che suggeriscono livelli sistematici e sistemici di ragionamento. Il primo insieme riguarda il riconoscimento di un essere umano libero, dignitoso, autonomo ma anche vulnerabile, che è al centro dell'approccio etico. Un secondo insieme mira all'utilità e all'affidabilità dell'ingegneria implementata. Legato ai primi due insiemi, il terzo si riferisce al luogo dell'informazione e dell'educazione, assumendo le incertezze inerenti a tutte le conoscenze umane e la rapida evoluzione delle tecniche di ingegneria cellulare e molecolare e le loro ripercussioni sull'intera società. Un quarto insieme si riferisce ai valori sociali: giustizia, pari accesso alle cure, non discriminazione, costo del trattamento e solidarietà... e inoltre: prospettive culturali e religiose che a volte possono essere freni, a volte acceleratori. L'ultimo principio riunisce queste diverse problematiche etiche sottolineando l'obbligo di avere una visione globale: integrando tempo e spazio e le prospettive aperte e le loro implicazioni a livello antropologico, sociale e societario, politico, ambientale, economico, culturale e religioso.

Weber Erik et al., The structure of analogical reasoning in bioethics, in Medicine Healthcare and Philosophy, 26(2023)1, 69-84 p.
Soggetto: *bioetica, metodo, principi etici, casistica*
Abstract: Casuistry, which involves analogical reasoning, is a popular methodological approach in bioethics. The method has its advantages and challenges, which are widely acknowledged. Meta-philosophical reflection on exactly how bioethical casuistry works and how the challenges can be addressed is limited. In this paper we propose a framework for structuring casuistry and analogical reasoning in bioethics.

Zuffa Grazia, Per un'etica della differenza femminile, in Biolaw, (2023)1, 179-190 p.
Soggetto: *autodeterminazione riproduttiva, differenza di genere, bioetica cattolica, bioetica laica*
Abstract: La sentenza della Corte Suprema Dobbs vs. Jackson, che ha cancellato il diritto costituzionale all'autodeterminazione riproduttiva, mostra, ben oltre i confini americani, la persistenza del conflitto etico e politico sull'aborto, a oltre cinquanta anni dalla fine del regime di proibizione. L'articolo ripercorre il dibattito italiano a partire dagli anni settanta e dall'approvazione della l.194/78, mettendo in evidenza la posizione etica e politica ispirata al primato femminile nella procreazione, radicato nella esperienza delle donne di mettere al mondo il vivente. In coerenza col riconoscimento della differenza di genere, l'autodeterminazione è un principio etico che vede la donna come soggetto libero e insieme responsabile: negandolo, si riduce la donna a muta corporeità, degradandola a "sistema di approvvigionamento" di vita. L'etica del primato femminile nella procreazione restituisce la piena umanità del "venire al mondo", contro l'essenzialismo biologico della dottrina cattolica e di settori della cultura laica.

Libri:

Mancini Elena (a cura di), *The elephant in the room. Etica delle malattie neglette e della povertà,* ed. CNR 2023, 187 p.
Soggetto: *malattie rare, bioetica globale, povertà, ricerca terapeutica, CNR*
Abstract: Il volume è frutto dell'attività di ricerca svolte per il progetto Centro per la ricerca di nuovi farmaci per le malattie rare, trascurate e della povertà. Il progetto nasce nell'ambito di una convenzione operativa tra il CNR e il consorzio CNCCS, rinnovata da ultimo nel 2020, con l'obiettivo di sostenere la ricerca, la sperimentazione, l'allocazione e la diffusione di farmaci per le malattie rare, neglette e della povertà. In particolare, le attività di ricerca affidate al CID Ethics del CNR sono dedicate all'analisi etica dei bisogni ed esigenze inerenti i gruppi di popolazione maggiormente colpiti e in cui la diffusione delle NTDs è endemica, l'individuazione di principi etici cui orientare gli obiettivi e le metodologie di intervento per la prevenzione, il trattamento e l'eliminazione delle NTDs, nonché alla proposta di indicazioni operative e modelli di governance per la più concreta tutela dei diritti individuali dei malati. Obiettivo principale del volume è evidenziare il ruolo del principio di equità sia nel definire gli obiettivi e gli strumenti di intervento sia in quanto indicatore dell'eticità dei trattamenti sanitari: assicurare l'accesso a cure di qualità è elemento cardine per la tutela dei diritti alla salute, alla sicurezza e al rispetto della dignità, universalmente riconosciuti quali diritti umani fondamentali.