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La *Revue de presse nationale et internationale* de l'Espace éthique Île-de-France et du Département de recherche en éthique de l'Université Paris-Saclay propose, tous les deux mois, un aperçu des publications récentes en bioéthique et en éthique de la santé en France et dans les autres pays.

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L'objectif n'est pas de recenser exhaustivement les travaux, empiriques ou réflexifs, qui sont publiés, mais bien d'inviter les lectrices et les lecteurs, à travers une sélection raisonnée, à découvrir les publications qui nous paraissent les plus remarquables au cours de la période écoulée.

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Respecter les libertés et protéger

La dualité entre et protéger et respecter les libertés est une tension fondamentale dans de nombreux domaines éthiques, sociaux et politiques. Cette tension émerge de la nécessité de trouver un équilibre délicat entre la promotion de la liberté individuelle et la responsabilité collective de protéger la dignité, la sécurité et l'intégrité de tous les membres d'une société.

La décision de la Cour suprême des États-Unis en 2022, qui a restreint l'accès à l'avortement, illustre sur le plan politique l'antagonisme entre la liberté individuelle des femmes et la volonté de protéger la vie présumée du fœtus et de l'être humain en devenir. Si nous avons été ébranlé-es, en Europe, par cette jurisprudence historique parce qu'elle est révélatrice des conflits idéologiques contemporains au monde occidental, cette décision a avant tout des implications très concrètes pour la liberté, la santé des femmes et des enfants à naître outre-Atlantique. Les États-Unis ont ainsi basculé dans une ère qualifiée de *post-Dobbs* (du nom de la décision *Dobbs v. Jackson Women's Health Organization*) qui nécessite de développer un nouveau paradigme éthique concernant les questions de justice reproductive.

Le *Journal of Law, Medicine & Ethics* reprend dans son dernier numéro de nombreuses contributions présentées lors du symposium « Seeking Reproductive Justice in the Next 50 Years »¹ et dresse un panorama vertigineux de toutes les questions qui se posent (à nouveau ?) aux États-Unis.

Du fait de la limitation de l'accès à l'avortement, les femmes peuvent se retrouver dans des situations où leur autonomie et leur santé sont compromises, ce qui peut les contraindre à des choix désespérés et dangereux pour leur vie. La décision de la Cour suprême soulève également des questions de justice sociale et d'égalité. Les femmes les plus marginalisées et vulnérables, souvent confrontées à des barrières d'accès aux soins de santé, sont les plus susceptibles de subir les conséquences les plus graves de telles restrictions.



<https://www.cambridge.org/core/journals/journal-of-law-medicine-and-ethics/issue/D4F93BE3E1A32D4CC9336282FBB8355C>

¹ En français : « Aller vers une justice reproductive pour les 50 prochaines années »



<https://www.em-consulte.com/revue/SOIN/derniernumero/soins>

La tension entre respecter les libertés et protéger est régulièrement retrouvée, non pas dans le contexte politique, mais dans celui des soins. La contention, physique ou chimique, peut parfois sembler nécessaire pour protéger la sécurité des patients ou du personnel médical. Une différence notable avec la situation précédente est qu'il s'agit alors souvent d'arbitrer entre liberté et protection de la même personne, là où le débat sur l'avortement met en jeu le respect des intérêts supposément opposés de « personnes différentes ». Mais même mise en œuvre au nom de l'intérêt de la personne contrainte, la contention peut avoir des conséquences délétères sur la santé et la dignité des patient-es, et générer des sentiments de frustration, de peur et de déshumanisation.

L'excellent dernier numéro de la revue francophone *Soins* nous donne à penser le sujet sous des angles très différents. Le sujet est souvent traité dans le contexte de la psychiatrie, où la contention peut être utilisée pour faire face aux comportements dangereux ou autodestructeurs des patients atteints de troubles psychiques sévères : cela soulève des questions d'éthique complexes, relatives au respect de la dignité et de l'autonomie, à la prise en compte des préférences du patient et à la minimisation des effets néfastes de la contention sur la santé mentale et le bien-être psychosocial. Plus largement, ce numéro de *Soins* aborde le problème de la contention à travers des réflexions philosophiques, juridiques et ancrées dans des spécialités médicales telles que la réanimation, les urgences, la pédiatrie et la gériatrie, où les enjeux de la contention se renouvellent avec des nuances propres au champ en question.

Ainsi, la dualité entre respecter les libertés et protéger est le reflet d'un dilemme éthique profondément enraciné dans la condition humaine. Naviguer à travers cette tension exige un engagement continu envers les principes de justice, de responsabilité et de respect des droits fondamentaux de tous les membres d'une société. Ces questions sont en renégociation permanente et l'actualité récente aux États-Unis en est un exemple criant. Une des tâches de la réflexion éthique est de reconnaître la complexité et l'incertitude inhérentes à la quête de l'équilibre entre liberté individuelle et bien commun, pour mieux aider à trouver des réponses au plus proche des valeurs mouvantes de nos sociétés.

Alexis Rayapoullé & Fabrice Gzil

DANS CE NUMÉRO...

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THÉORIES ET CONCEPTS



« Sujets », « participant·es », « volontaires » ? Les bons mots pour une bonne éthique de la recherche

Corpuz J.C.

[Reconsidering the Terminology: Study Participants as « Subjects » or Not?](#)

Substance Abuse: Research and Treatment 2023;17:11782218231217783.

The article highlights the importance of semantics in shaping our perception of this relationship and the ethical, psychological, and practical dimensions of conducting research on human beings. The term « subjects » implies passivity and contradicts the principles of informed consent and participant autonomy, whereas research physicians often maintain a similar patient-physician relationship with participants. The article suggests that adopting more appropriate terminology, such as « participants » or « volunteers, » can better acknowledge their active role and foster collaboration. The author emphasizes that language in scientific discourse plays a significant role in upholding ethical principles and preserving the unique physician-participant relationship in clinical research.

<https://doi.org/10.1177/11782218231217783>

Le bien-être doit-il être subjectivement défini ?

Davies B.

[A new paradox for well-being subjectivism](#)

Analysis 2023;83(4):673-682.

Subjectivists think that our well-being is grounded in our subjective attitudes. Many such views are vulnerable to variations on the « paradox of desire », where theories cannot make determinate judgements about the well-being of agents who take a positive valuing attitude towards their life going badly. However, this paradox does not affect all subjectivist theories; theories grounded on agents' prudential values can avoid it. This paper suggests a new paradox for subjectivist theories which has a wider scope, and includes such prudential judgement theories. I outline the new paradox and show how two plausible idealisations (coherence and consideration) will not help. Subjectivists about well-being must either add an additional idealization that can solve the paradox of judgement or explain why such paradoxes do not constitute serious objections to a theory of well-being.

<https://doi.org/10.1093/analys/anad040>

Réhabiliter le concept de dignité dans les soins

Ferdynus M.P.

[Is Dignity Still Necessary in Health Care? From Definition to Recognition of Human Dignity](#)

Journal of Religion and Health 2024

The concept of dignity is not, as some scholars claim, an unnecessary moral idea, and nor need it have religious overtones or be characterised by speciesism. In this article, I try to show that dignity can be defined and recognised. The starting point for the argumentation is the four typologies of dignity, which show that the term « dignity » can denote significantly different concepts, and that the different concepts of dignity can have significantly different ontological senses. A unified typology of dignity allows for five categories to be distinguished: inherent dignity, dignity based on changeable qualities, moral dignity, bestowed dignity and compartment dignity. I take the first two categories of dignity as the object of the analysis, with which I seek to formulate a philosophical response to the charge of speciesism and to show on what basis it can be maintained that all human beings possess dignity. To this end, I distinguish between existential dignity, actual dignity, and potential dignity. Distinguishing these types of dignity becomes possible in the light of Aquinas' and Aristotle's views. In the final section, I point to two ways of recognising dignity. The first is based on certain narratives and emotional states ('ecumenical model of dignity'), while the second is related to a specific moral experience developed within ethical personalism.

<https://doi.org/10.1007/s10943-023-01995-1>

La vertu mène-t-elle au bonheur ?

Jurist E., Greenberg D., Pizziferro M., et al.

[Virtue, well-being, and mentalized affectivity](#)

Research in Psychotherapy (Milano) 2024;26(3).

Virtue ethics, featuring the claim that virtue leads to wellbeing, has been imported by psychologists from philosophy. In the first part of the paper, we re-examine the source of virtue ethics in Aristotle's philosophy and question whether virtues can be the path to eudaimonistic well-being for us, given that contemporary society differs from ancient society in terms of a lack of consensus about virtues. We focus on the modulation of emotions as a good starting place for reconstruing virtue ethics, and we affirm a connection to well-being through the construct of « mentalized affectivity », which is a specific kind of emotion regulation. In the second half of this hybrid paper, we provide evidence for the link between mentalized affectivity and well-being, based upon an empirical study with an adult sample (N=558). Our study examined how the Mentalized Affectivity Scale (MAS) predicts subjective well-being compared to five commonly used and related measures: Difficulty with Emotion Regulation Scale; Emotion Regulation Questionnaire; Flexibility Regulation of Emotional Expression scale; Reflective Functioning Questionnaire; Toronto Alexithymia Scale. The most important finding is that the MAS and Difficulties in Emotion Regulation Scale are most predictive of satisfaction with life. A second finding, less relevant for the present paper, is that the MAS (namely, its components of Identifying and Processing) strongly predicted psychopathology, including anxiety and mood disorders. This suggests that the MAS is a valuable tool for research on emotion regulation, well-being, and psychopathology, and that mentalized affectivity ought to be regarded as a promising construct for re-describing and specifying the contemporary relevance of virtue ethics.

<https://doi.org/10.4081/ripppo.2023.710>

Le droit moral à ne pas mourir seul·e

Lederman Z.

Dying a lonely death: A conceptual and normative analysis.

Bioethics 2024

This paper argues that a lonely death is, by definition, a bad death and that society as a whole, as well as individuals in society are obligated to assure a certain degree of well-being, flourishing, or care among and for fellow individuals. Individuals can then be said to have a right against dying a lonely death. Such a right has corresponding duties. The paper further specifies what such duties may entail based on what individuals may need on their deathbed, specifically focusing on the need for human touch. Assuming that human touch might indeed be needed by some individuals in order to avoid a lonely death, the paper explores potential implications from a public health perspective, particularly during infectious disease outbreaks such as COVID.

<https://doi.org/10.1111/bioe.13267>

Faut-il considérer le vieillissement comme une maladie ?

Marín Penella G.

Should the European Medicines Agency consider ageing a disease?

Bioethics 2024

The classification of ageing as a disease is fundamental to developing new pharmacological strategies that can target said phenomenon. The European Medicines Agency does not do this and maintains a questionable perspective based on the traditional naturalistic argument and the value-free ideal. An alternative is proposed which, inspired by consequentialism, is committed to considering ageing as a disease in European regulatory contexts as long as the ethical consequences are desirable. Within a realistic framework, I show that making this decision would have moderate positive effects such as increased knowledge about antiageing pharmacology or potential greater chances of completing vital projects. Furthermore, we will see that the main arguments used by critics to show that the negative effects outweigh the positive ones are not sound. Therefore, I conclude that it would be beneficial for the European Medicines Agency to change its position on ageing.

<https://doi.org/10.1111/bioe.13265>

La portée éthique de l'humour

Pierron J.-P.

La sagesse comique et l'éthique : Les enjeux éthiques de l'humour dans la formation médicale et dans l'exercice de la médecine

Revue française d'éthique appliquée 2023;N° 14(1):124-139.

La mobilisation de l'humour en matière d'éthique ne relève pas d'une décision abstraite mais d'une pratique située, très délicate à saisir, soutenant pourtant un climat de soins sécurisant. Mais pourquoi la sagesse comique est-elle si peu reconnue sinon déconsidérée par la sagesse pratique ? Y a-t-il une contradiction entre le sérieux du soin et la portée éthique de l'humour ? Pourquoi l'humour n'est pas la dérision ? Parce qu'il est contextuel, l'humour invite à habiter une situation d'existence toujours singulière. Aussi l'humour tire-t-il l'éthique moins du côté de la forme rigide de l'application d'un principe moral que de la force d'ajustement contextuelle à des situations subtiles. Il est moins du côté formel de la règle ou du principe que du côté dynamique et vitalisant d'une attitude engagée dans l'exigence de l'instant ou de la relation. Il active une intelligence rusée dans l'exercice du métier au long cours par le jeu avec les normes déontologiques du professionnel aguerri. Il y établit un jeu relationnel portant ; il mobilise une position d'extériorité s'essayant à d'autres possibles qui résiste à toute réification ; et il a une portée élucidatrice et libératrice. Finalement, l'humour, en travaillant sur nos croyances pratiques, en sonde aussi les limites. Mettant à distance nos inquiétudes aliénantes, dans le tiers espace du jeu, il nous aide à les surmonter et à oser initier.

<https://doi.org/10.3917/rfeap.014.0124>

La place de la culpabilité dans le jugement moral d'autrui

Sirgiovanni E., Smolenski J., Abelson B., et al.

The Moralizing Effect: self-directed emotions and their impact on culpability attributions

Frontiers in Integrative Neuroscience 2023;17:1232523.

INTRODUCTION: A general trend in the psychological literature suggests that guilt contributes to morality more than shame does. Unlike shame-prone individuals, guilt-prone individuals internalize the causality of negative events, attribute responsibility in the first person, and engage in responsible behavior. However, it is not known how guilt- and shame-proneness interact with the attribution of responsibility to others. METHODS: In two Web-based experiments, participants reported their attributions of moral culpability (i.e., responsibility, causality, punishment and decision-making) about morally ambiguous acts of killing in different conditions. In Study 1 the vignettes were presented in the 1st person, while in Study 2 in the 3rd person. To test proneness to guilt and shame, we utilized the GASP scale, which differentiates between the affective and behavioral components of each emotion. Statistical analyses were performed in Matlab and R. RESULTS: We found that guilt- and shame-proneness were associated with the severity of attributions in both the first and the third person, but the effect was strong only in the guilt case (both subtypes) and shame-affect case, and not in the shame-behavior case. We call this the Moralizing Effect. DISCUSSION: We wonder whether our finding that guilt-prone people tend to attribute a higher degree of culpability to others is really consistent with the view that guilt motivates people to choose the « moral paths in life ». This echoes views about the harmful aspects of guilt, which have been expressed historically in philosophy, for example, by Friedrich Nietzsche.

<https://doi.org/10.3389/fnint.2023.1232523>

Le concept de « mort prématurée »

Sørheim P., Barra M., Norheim O.F., et al.

Premature Death as a Normative Concept

Health care analysis: HCA: journal of health philosophy and policy 2024

The practical goal of preventing premature death seems uncontroversial. But the term « premature death » is vague with several, sometimes conflicting definitions. This ambiguity results in several conceptions with which not all will agree. Moreover, the normative rationale behind the goal of preventing premature deaths is masked by the operational definition of existing measures. In this article, we argue that « premature death » should be recognized as a normative concept. We propose that normative theories should be used to justify measures of premature death to provide them with normative validity and public legitimacy.

<https://doi.org/10.1007/s10728-023-00471-x>

Donner du sens à ce qui nous arrive : un enjeu éthique

Weichold M., Candiotta L.

The ethics of sense-making

Frontiers in Psychology 2023;14:1240163.

In this paper, we contribute to the arising field of « enactive ethics, » that is, the application of enactive cognitive science to the field of ethics. To this end, we will make a case that an « ethics of sense-making » should exist. With « sense-making, » we mean the permanent everyday embodied activity of interpreting the surroundings we are in, as well as our role in them. In other words, we mean the activity of understanding our environments in such a way that certain things, but not others, stand out as meaningful and relevant to us. We argue that sense-making can be performed in ethically better or worse ways. For example, one might make sense of a potentially provocative comment either as an insult or as an invitation for a respectful discussion. How one makes sense in this case will affect oneself, the other, and their present and future relations. We propose that it is often helpful to hold humans responsible for their ways of sense-making. This opens up the possibility to transform their sense-making and the worlds they inhabit. This also has significance for their eudaimonic well-being. Our ethics of sense-making focusses on the ubiquitous activities of sense-making, which, when changed, will lead to great ethical improvements of people's actions, choices, and character traits.

<https://doi.org/10.3389/fpsyg.2023.1240163>

Faire des enfants est-il immoral ?

Yoshizawa F.

Anti-natalism is incompatible with Theory X

Bioethics 2023

The anti-natalist philosopher David Benatar defends a position asserting that all life is harmful, and that it is, therefore, wrong to have children. In this paper, I critique Benatar's less-discussed claim that his anti-natalism provides solutions to population ethics problems, such as the Non-Identity Problem, the Repugnant Conclusion, and the Mere Addition Problem, all of which are presented in Derek Parfit's Reasons and Persons. Since the publication of his Better Never to Have Been, Benatar has continued to claim that its provision of such solutions strengthens his defense of anti-natalism. Although Benatar's view has received much criticism, this argument has not been discussed at length. I undertake a thorough examination of the argument and identify reasons to reject it. The central point of my critique is that the implications of Benatar's views in determining ranges of wrong and not-wrong cases of procreation are extensionally inadequate when applied to the problems of population ethics.

<https://doi.org/10.1111/bioe.13248>

ÉTHIQUE DU SOIN



Soigner les enfants au nom de l'évitement d'un « tort significatif » plutôt que de leur « meilleur intérêt »

Archard D., Cave E., Brierley J.

[How should we decide how to treat the child: harm versus best interests in cases of disagreement](#)

Medical Law Review 2023;fwad040.

Where parents seek treatment for their young child that healthcare professionals cannot agree to, the High Court can determine what is in the child's best interests. Some activists and academics seek change to impose threshold criteria that would bolster the decision-making rights of parents and reduce deference to clinicians and the courts. We defend the best interests standard against arguments that a higher threshold of « significant harm » should apply. We do so from ethical, legal, and clinical perspectives. The matter is of significant moral and practical importance, especially in light of the divergence of academic opinion, the burgeoning number of cases coming before the courts and recent case law and statutory attempts to effect change. We begin by disputing ethical claims that a significant harm threshold is preferable to the best interests standard, and then we set out jurisprudential and practical arguments that demonstrate the imprudence of a significant harm threshold and defend the established yardstick of best interests.

<https://doi.org/10.1093/medlaw/fwad040>

Quels risques peut-on légitimement faire encourir à un·e enfant pour sa santé ?

Turnham H.L., Bowen S.-J., Ramdas S., et al.

[As low as reasonably practicable \(ALARP\): a moral model for clinical risk management in the setting of technology dependence](#)

Journal of Medical Ethics 2023;;jme-2023-109111.

Children dependent on life-prolonging medical technology are often subject to a constant background risk of sudden death or catastrophic complications. Such children can be cared for in hospital, in an intensive care environment with highly trained nurses and doctors able to deliver specialised, life-saving care immediately. However, remaining in hospital, when life expectancy is limited, can be considered to be a harm in of itself. Discharge home offers the possibility for an improved quality of life for the child and their family but comes with significant

medical risks. When making decisions for children, two ethical models predominate, the promotion of the child's best interests or the avoidance of harm. However, in some circumstances, particularly for children with life-limiting and/or life-threatening illness, all options may be associated with risk. There are no good options, only potentially harmful choices. In this paper, we explore decisions made by one family in such circumstances. We describe a model adopted from risk management programmes beyond medicine, which offers a potential framework for identifying risks to the child that are morally permissible. Some risks and harms to a child, not ordinarily permitted, may be acceptable when undertaken in the pursuit of a specified desired good, so long as they are as low as reasonably practicable.

<https://doi.org/10.1136/jme-2023-109111>

Le sens de la « dignité » en réanimation pendant la pandémie de Covid-19

Buonaccorso L., De Panfilis L., Chochinov H.M., et al.

The meaning of dignity in care during the COVID-19 pandemic: a qualitative study in acute and intensive care

BMC palliative care 2023;22(1):192.

BACKGROUND: The pandemic Era has forced palliative care professionals to use a dignity-in-care approach in different settings from the classic ones of palliative care: acute and intensive care. We explored the meanings of dignity for patients, their family members, and clinicians who have experienced COVID-19 in the acute and intensive care setting. **METHODS:** A qualitative, prospective study by means of semi-structured interviews with patients hospitalized for COVID-19, family members, and clinicians who care for them. **FINDINGS:** Between March 2021 and October 2021, we interviewed 16 participants: five physicians, three nurses, and eight patients. None of the patients interviewed consented for family members to participate: they considered it important to protect them from bringing the painful memory back to the period of their hospitalization. Several concepts and themes arose from the interviews: humanity, reciprocity, connectedness, and relationship, as confirmed by the literature. Interestingly, both healthcare professionals and patients expressed the value of informing and being informed about clinical conditions and uncertainties to protect dignity. **CONCLUSIONS:** Dignity should be enhanced by all healthcare professionals, not only those in palliative care or end-of-life but also in emergency departments.

<https://doi.org/10.1186/s12904-023-01311-4>

Les outils d'évaluation de la dignité en soins palliatifs

Lim Y.X., Quah E.L.Y., Chua K.Z.Y., et al.

A Systematic Scoping Review on Dignity Assessment Tools

Journal of Pain and Symptom Management 2023;S0885-3924(23)00831-X.

CONTEXT: The provision of person-centered dignity-conserving care is central to palliative care. It is important to reevaluate current methods of assessing dignity as the concept of dignity is multi-faceted. **OBJECTIVES:** The aim of this study is to understand the tools which are used to assess a patient's dignity and the elements of dignity evaluated in these tools. **METHODS:** Two independent and concurrent Systematic Evidence-Based Approach guided systematic scoping reviews (SSR in SEBA) on existing dignity assessment tools and on accounts of assessments of dignity were carried out. The SSR in SEBA on dignity assessment tools involving PubMed, Embase, PsycINFO, Cochrane Database of Systematic Reviews, Scopus, and CINAHL databases saw 22 full-text articles included from the 645 articles reviewed. The SSR in SEBA on accounts of assessments of dignity featured in the PubMed database identified 102 full-text articles which saw 46 articles included. **RESULTS:** domains identified were factors affecting patient's definition of dignity; elements of dignity conserving care; and components of effective tools. **CONCLUSION:** Current accounts to assess dignity and assessment tools fail to capture shifting self-concepts of dignity holistically. A portfolio-like appraisal of dignity is proposed to achieve assessments which are timely, longitudinal, and patient-specific. Portfolio-based assessments by members of the multidisciplinary team will better direct timely evaluations of relevant aspects of changing concepts of dignity, without losing the patient's holistic perception of dignity.

<https://doi.org/10.1016/j.jpainsymman.2023.12.008>

La valeur de la dignité humaine dans les soins gériatriques

Pageau F., Fiasse G., Nordenfelt L., et al.

Care of the older person and the value of human dignity

Bioethics 2023

As the world population is rapidly aging, stakeholders must address the care of the elderly with great concern. Also, loss of dignity is often associated with aging due to dementia, mobility problems and diminished functional autonomy. However, dignity is a polysemic term that is deemed useless by some ethicists. To counter this claim, we propose four concepts to define it better and make use accurately of this notion. These are human dignity, dignity of identity, dignities of excellence and attributed dignities. Finally, we explain the importance of solicitude and human dignity in the care of the elderly. This will ensure the respect, friendship and dignity of the elderly in providing geriatric ethical care.

<https://doi.org/10.1111/bioe.13251>

L'usage des opioïdes, entre bienfaisance et malfaisance

Cascella M., Laudani A., Scarpati G., et al.

Ethical issues in pain and palliation

Current Opinion in Anaesthesiology 2024

PURPOSE OF REVIEW: Increased public awareness of ethical issues in pain and palliative care, along with patient advocacy groups, put pressure on healthcare systems and professionals to address these concerns. Our aim is to review the ethics dilemmas concerning palliative care in ICU, artificial intelligence applications in pain therapy and palliative care, and the opioids epidemics. RECENT FINDINGS: In this focus review, we highlighted state of the art papers that were published in the last 18 months, on ethical issues in palliative care within the ICU, artificial intelligence trajectories, and how opioids epidemics has impacted pain management practices (see Visual Abstract). SUMMARY: Palliative care in the ICU should involve a multidisciplinary team, to mitigate patients suffering and futility. Providing spiritual support in the ICU is an important aspect of holistic patient care too. Increasingly sophisticated tools for diagnosing and treating pain, as those involving artificial intelligence, might favour disparities in access, cause informed consent problems, and surely, they need prudence and reproducibility. Pain clinicians worldwide continue to face the ethical dilemma of prescribing opioids for patients with chronic noncancer pain. Balancing the need for effective pain relief with the risk of opioid misuse, addiction, and overdose is a very controversial task.

<https://doi.org/10.1097/ACO.0000000000001345>

Les injonctions contradictoires dans les métiers du soin

Crépeau A.

Enjeu personnel, éthique et politique : des injonctions contradictoires dans les domaines professionnels du care

Revue française d'éthique appliquée 2023;N°14(1):34-49.

Cet article réfléchit à la façon dont les injonctions contradictoires dégradent notre attention, comme entendue par la philosophe Simone Weil, ainsi qu'aux conséquences de cette dégradation. L'attention weillienne, qui implique un mouvement de décentrement du sujet, réfère à la capacité de faire abstraction de soi pour recevoir l'autre dans son altérité et sa complexité. Nous abordons plus particulièrement les injonctions contradictoires dans les domaines du soin. Elles découlent en partie de tensions entre les exigences du care – qui demande un effort d'adaptation au particulier et, ce faisant, d'attention – et celles de la structure bureaucratique qui l'encadre – qui elles exigent la standardisation, l'anonymat et la schématisation. Le soignant doit octroyer un bon soin tout en respectant les procédures établies par les gestionnaires, qui tendent cependant à l'entraver. Ces injonctions contradictoires contribuent à diminuer notre capacité à porter attention au travail, car cette dernière exige des conditions adéquates (du bien-être physique et psychologique, de l'autonomie, du temps) pour se déployer. En plus de dégrader la qualité des soins, cela cause aux travailleurs une douleur psychologique considérable. Au-

delà du plan personnel, la perte de la capacité à porter attention au travail entraîne des conséquences socio-politiques manifestes. À travers la pratique de l'attention, le travailleur apprend à entrer en relation avec le monde d'une manière qui échappe à l'instrumentalisation d'autrui. L'attention aux autres exercée via le travail constitue donc pour Weil l'une des bases du tissu social. Regagner nos capacités attentionnelles exige une refonte du travail selon des conditions temporelles, techniques et organisationnelles.

<https://doi.org/10.3917/rfeap.014.0034>

Perte d'autonomie et contrainte chez les femmes enceintes

Eichinger J., Büchler A., Arnold L., et al.

Women's and Provider's Moral Reasoning About the Permissibility of Coercion in Birth: A Descriptive Ethics Study

Health care analysis: HCA: journal of health philosophy and policy 2024

Evidence shows that during birth women frequently experience unconsented care, coercion, and a loss of autonomy. For many countries, this contradicts both the law and medical ethics guidelines, which emphasize that competent and fully informed women's autonomy must always be respected. To better understand this discordance, we empirically describe perinatal maternity care providers' and women's moral deliberation surrounding coercive measures during birth. Data were obtained from 1-on-1 interviews with providers (N = 15) and women (N = 14), and a survey of women (N = 118). Analyses focused on an in-depth exploration of responses to a question on the permissibility of coercion in birth whose wording was borrowed from a Swiss medical-ethical guideline. Reasons for and against a principle permissibility of coercive measures in birth were grouped into clusters of reasons to build a coherent explanatory framework. Factors considered morally relevant when deliberating on coercion included women's decisional capacity, beneficence/non-maleficence, authority through knowledge on the part of providers, flaws of the medical system, or the imperative to protect the most vulnerable. Also, we identified various misconceptions, such as the conviction that a pathological birth can justify coercion or that fetal rights can justifiably infringe on women's autonomy. Information and education on the issue of coercion in birth are urgently needed to enable women to fully exercise their reproductive autonomy, to prevent long-term adverse health outcomes of women and children, and to reconcile the medical vigilance which has led to a reduction of perinatal morbidity and mortality with women's enfranchisement in their own care.

<https://doi.org/10.1007/s10728-024-00480-4>

Les jugements moraux sur l'allaitement

Subramani S., Vinay R., März J.W., et al.

Ethical Issues in Breastfeeding and Lactation Interventions: A Scoping Review

Journal of Human Lactation: Official Journal of International Lactation Consultant Association 2023;8903344231215073.

BACKGROUND: Infant feeding interventions that promote and support breastfeeding are considered important contributions to global public health. As these interventions often target private settings (e.g., individuals' homes) and involve vulnerable populations (e.g., pregnant women, infants, and underprivileged families), a keen awareness of ethical issues is crucial. **RESEARCH AIM:** The purpose of this scoping review was to capture the key elements of the current ethical discourse regarding breastfeeding and lactation interventions. **METHOD:** A scoping review was conducted using Arksey and O'Malley's (2005) methodology to identify the ethical issues of breastfeeding and lactation interventions as they are reflected in the scholarly literature published between January 1990 and October 2022. Abstracts (N = 3715) from PubMed, ScienceDirect, JSTOR and the Cochrane Database of Systematic Reviews were screened. The final sample consisted of 26 publications. **RESULTS:** The recurring ethical issues identified in these studies were: the normative assumptions of motherhood; maternal autonomy and informed choice; information disclosure, balancing risks and benefits, and counseling practices; stigma and social context; ethics of health communication in breastfeeding campaigns; and the ethical acceptability of financial incentives in breastfeeding interventions. **CONCLUSION:** This review illustrated that, while a wide range of ethical arguments were examined, the emphasis has been primarily on accounting for

mothers' experiences and lactating persons' choices, as well as achieving public health objectives relating to infant nutrition in breastfeeding interventions. To effectively and ethically implement breastfeeding and lactation interventions, we must consider the social, economic, and cultural contexts in which they occur. One key learning identified was that women's experiences were missing in these interventions and, in response, we suggest moving beyond the dichotomous approach of individual health versus population health.

<https://doi.org/10.1177/08903344231215073>

Refus de transfusion et chirurgie

Gavrilovska-Brzanov A., Gjambaz D., Naumovski F., et al.

Major abdominal surgery for Jehovah's Witnesses: Challenge while practicing bloodless medicine in a middle income country

SAGE open medical case reports 2023;11:2050313X231220836.

We present a 59-year-old female Jehovah's Witness patient transferred from another facility to our tertiary center as an emergency case owing to anemia due to gastrointestinal bleeding. A computed tomography scan and gastroscopy confirmed an invasion of the duodenum by a malignant process. The patient underwent a Whipple procedure and a right hemicolectomy refusing blood transfusion. On the 17th postoperative day, the patient was discharged following a successful surgery. This article's objectives are to first highlight the moral and ethical quandary and then share our surgical experiences with this particular patient population. In conclusion, Jehovah's Witnesses' management of major abdominal surgery poses considerable clinical, moral, and legal difficulties. Despite them, doctors must put the patients' needs first while also honoring their religious convictions. However, urgent situations continue to arise, forcing medical professionals to weigh their religious convictions against the need to save a patient's life.

<https://doi.org/10.1177/2050313X231220836>

La détresse morale de ne pas pouvoir administrer les meilleurs soins

Gustavsson M.E., Schreeb J. von, Arnberg F.K., et al.

Being prevented from providing good care: a conceptual analysis of moral stress among health care workers during the COVID-19 pandemic

BMC medical ethics 2023;24(1):110.

BACKGROUND: Health care workers (HCWs) are susceptible to moral stress and distress when they are faced with morally challenging situations where it is difficult to act in line with their moral standards. In times of crisis, such as disasters and pandemics, morally challenging situations are more frequent, due to the increased imbalance between patient needs and resources. However, the concepts of moral stress and distress vary and there is unclarity regarding the definitions used in the literature. This study aims to map and analyze the descriptions used by HCWs regarding morally challenging situations (moral stress) and refine a definition through conceptual analysis. **METHODS:** Qualitative data were collected in a survey of 16,044 Swedish HCWs who attended a COVID-19 online course in autumn 2020. In total, 643 free-text answers with descriptions of moral stress were analyzed through content analysis. **RESULTS:** Three themes emerged from the content analysis (1) « Seeing, but being prevented to act; feeling insufficient/inadequate and constrained in the profession, » (2) « Someone or something hindered me; organizational structures as an obstacle, » and (3) « The pandemic hindered us; pandemic-related obstacles. » The three themes correspond to the main theme, « Being prevented from providing good care. » **DISCUSSION:** The main theme describes moral stress as various obstacles to providing good care to patients in need and acting upon empathic ability within the professional role. The themes are discussed in relation to established definitions of moral stress and are assessed through conceptual analysis. A definition of moral stress was refined, based on one of the established definitions. **CONCLUSIONS:** On the basis of the study results and conceptual analysis, it is argued that the presented definition fulfils certain conditions of adequacy. It is essential to frame the concept of moral stress, which has been defined in different ways in different disciplines, in order to know what we are talking about and move forward in developing prevention measures for the negative outcomes of this phenomenon.

<https://doi.org/10.1186/s12910-023-00993-y>

La consultation d'éthique clinique en soins primaires

Labrunie A., Wittke L., Durand G.

Consultations d'éthique clinique : quels apports pour la pratique des soins primaires ?

Éthique & Santé 2023;20(4):260-266.

Dans certains hôpitaux français, des personnes soignantes et non soignantes, membres de consultations d'éthique clinique, rencontrent des patients, des proches et des professionnels de santé confrontés à des dilemmes éthiques. Par leurs regards citoyens et l'utilisation des principes communs de l'éthique, ils apportent une réponse singulière éclairant ces situations difficiles. Les soignants de premiers recours pourraient-ils bénéficier de dispositifs similaires ? L'objectif de cette étude est d'explorer les apports d'une consultation d'éthique clinique en soins primaires.

<https://doi.org/10.1016/j.eti.2023.09.009>

Les jugements moraux des professionnel·les envers les usager·es de drogues

Lee A.Y., Lehmann C., Zhou P., et al.

A quantitative survey measure of moral evaluations of patient substance misuse among health professionals in California, urban France, and urban China

Philosophy, ethics, and humanities in medicine: PEHM 2023;18(1):18.

BACKGROUND: The merits and drawbacks of moral relevance models of addiction have predominantly been discussed theoretically, without empirical evidence of these potential effects. This study develops and evaluates a novel survey measure for assessing moral evaluations of patient substance misuse (ME-PSM). **METHODS:** This measure was tested on 524 health professionals (i.e., physicians, nurses, and other health professionals) in California (n = 173), urban France (n = 102), and urban China (n = 249). Demographic factors associated with ME-PSM were investigated using analyses of variance (ANOVAs) and t-tests, with results suggesting that ME-PSM is higher among younger health professionals, nurses (when compared with physicians and other health professionals), and Chinese health professionals (when compared with French and American health professionals). **RESULTS:** Results provide preliminary support for the psychometric quality of the survey measure introduced in this study, including the existence of a single latent structure and partial invariance of collected data across countries. **CONCLUSION:** The survey measure for ME-PSM which was developed and tested in the current study appears to hold potential utility for use as a measure of moral views of patient substance misuse. With development, this measure may be used to examine moral evaluations, both as factors of stigma and of other clinical factors associated with the treatment of patients with substance use disorders.

<https://doi.org/10.1186/s13010-023-00148-2>

Le soin aux femmes enceintes atteintes de cancer

Linkeviciute A., Canario R., Peccatori F.A., et al.

Caring for Pregnant Patients with Cancer: A Framework for Ethical and Patient-Centred Care

Cancers 2024;16(2):455.

(1) **Background:** Caring for pregnant cancer patients is clinically and ethically complex. There is no structured ethical guidance for healthcare professionals caring for these patients. (2) **Objective:** This concept paper proposes a theoretically grounded framework to support ethical and patient-centred care of pregnant cancer patients. (3) **Methodological approach:** The framework development was based on ethical models applicable to cancer care during pregnancy—namely principle-based approaches (biomedical ethics principles developed by Beauchamp and Childress and the European principles in bioethics and biolaw) and relational, patient-focused approaches (relational ethics, ethics of care and medical maternalism)—and informed by a systematic review of clinical practice guidelines. (4) **Results:** Five foundational discussion themes, summarising the key ethical considerations that should

be taken into account by healthcare professionals while discussing treatment and care options with these patients, were identified. This was further developed into a comprehensive ethics checklist that can be used during clinical appointments and highlights the need for a holistic view to patient treatment, care and counselling while providing ethical, patient-centric care. (5) Conclusion: The proposed framework was further operationalised into an ethics checklist for healthcare professionals that aims to help them anticipate and address ethical concerns that may arise when attending to pregnant cancer patients. Further studies exploring clinicians' attitudes towards cancer treatment in the course of pregnancy and patient experiences when diagnosed with cancer while pregnant and wider stakeholder engagement are needed to inform the development of further ethical, patient-centred guidance.

<https://doi.org/10.3390/cancers16020455>

Recevoir des remerciements en tant que soignant·es

Marcucci L., Laudrin V., Lague E., et al.

Éthique de la relation et du don : l'accueil des remerciements dans la construction du rôle professionnel du soignant en soins palliatifs

Éthique & Santé 2023;20(4):246-250.

À partir d'une situation vécue en unité de soins palliatifs par un étudiant infirmier s'interrogeant sur son positionnement professionnel face aux remerciements des proches d'un patient accompagné jusqu'à sa mort, l'article expose les résultats d'une discussion menée dans l'unité selon une démarche d'éthique appliquée. L'authenticité de la rencontre éthique et la dynamique du don et du contre-don, au cœur des valeurs du soin, sont apparues comme structurantes et porteuses de sens pour le groupe.

<https://doi.org/10.1016/j.etiqe.2023.08.002>

Les jugements moraux autour de l'allaitement

Subramani S., Vinay R., März J.W., et al.

Ethical Issues in Breastfeeding and Lactation Interventions: A Scoping Review

Journal of Human Lactation: Official Journal of International Lactation Consultant Association 2023;8903344231215073.

BACKGROUND: Infant feeding interventions that promote and support breastfeeding are considered important contributions to global public health. As these interventions often target private settings (e.g., individuals' homes) and involve vulnerable populations (e.g., pregnant women, infants, and underprivileged families), a keen awareness of ethical issues is crucial. **RESEARCH AIM:** The purpose of this scoping review was to capture the key elements of the current ethical discourse regarding breastfeeding and lactation interventions. **METHOD:** A scoping review was conducted using Arksey and O'Malley's (2005) methodology to identify the ethical issues of breastfeeding and lactation interventions as they are reflected in the scholarly literature published between January 1990 and October 2022. Abstracts (N = 3715) from PubMed, ScienceDirect, JSTOR and the Cochrane Database of Systematic Reviews were screened. The final sample consisted of 26 publications. **RESULTS:** The recurring ethical issues identified in these studies were: the normative assumptions of motherhood; maternal autonomy and informed choice; information disclosure, balancing risks and benefits, and counseling practices; stigma and social context; ethics of health communication in breastfeeding campaigns; and the ethical acceptability of financial incentives in breastfeeding interventions. **CONCLUSION:** This review illustrated that, while a wide range of ethical arguments were examined, the emphasis has been primarily on accounting for mothers' experiences and lactating persons' choices, as well as achieving public health objectives relating to infant nutrition in breastfeeding interventions. To effectively and ethically implement breastfeeding and lactation interventions, we must consider the social, economic, and cultural contexts in which they occur. One key learning identified was that women's experiences were missing in these interventions and, in response, we suggest moving beyond the dichotomous approach of individual health versus population health.

<https://doi.org/10.1177/08903344231215073>

La place de la douleur dans l'autonomie décisionnelle

Ussel M. d', Lombart B., Masselin-Dubois A., et al.

Respect de l'autonomie du patient, clé de voûte de la prise en charge en douleur chronique : intégration dans le débat sur la fin de vie

Éthique & Santé 2023;20(4):234-238.

Peut-on librement décider de sa mort ? La question est au cœur du débat actuel sur la fin de vie qui pourrait aboutir à une nouvelle loi. L'autonomie décisionnelle du patient est reconnue partout dans le monde comme une valeur. L'idée d'autonomie a été la clé de voûte des changements accomplis dans l'histoire contemporaine du droit de la santé. Il s'agit du respect pour chacun de disposer soi-même de sa santé et de choisir les options qui correspondent à ses souhaits, ses valeurs ou ses projets de vie. La douleur est toujours une expérience personnelle qui est influencée à des degrés divers par des facteurs biologiques, psychologiques et sociaux. C'est particulièrement prégnant lorsque la douleur devient chronique, i.e. persistant au-delà de ce qui est habituel pour la cause initiale présumée (le plus souvent au-delà de 3 mois), et induisant une détérioration significative et progressive des capacités fonctionnelles et relationnelles. Comme pour toute maladie chronique, le patient souffrant de douleurs chroniques doit retrouver une nouvelle autonomie. Les structures pluriprofessionnelles vont, en transformant le patient en auto-soignant, guider et accompagner la personne dans cette démarche en utilisant également leur autonomie comme moyen thérapeutique. Nous proposons ici de questionner les enjeux de l'un des principaux principes éthiques : le respect de l'autonomie, sa place en médecine de la douleur et son rôle dans les réflexions autour de la fin de vie et de l'aide active à mourir.

<https://doi.org/10.1016/j.etiqe.2023.09.004>

INFORMATION ET CONSENTEMENT



Défendre le meilleur intérêt des patient·es sans capacité juridique

Avci E.

Protecting Incapacitated Patients' Rights and Best Interests

Indian Journal of Palliative Care 2023;29(4):343-347.

Contemporary medical ethics requires providing healthcare services in accordance with the patient's values, preferences and interests based on the rights to self-determination and privacy. Incapacitated patients utilise these rights through substitute decision-makers in light of the substituted judgement and best interest standards. In this context, the article aims to briefly study informed consent and focus on protecting incapacitated patients' rights and best interests. The article underscores the importance of promoting the autonomy of every patient as much as possible. However, in the case of the lack of decisional capacity and advance directives, surrogates should decide for incapacitated patients based on patients' known/documented/expressed wishes/ preferences and best interests. Nevertheless, due to the high possibility of the misinterpretation of patients' values, preferences and interests by surrogates as well as potential financial and social conflicts between patients and their surrogates, in the event of medical procedures with serious consequences, such as life-sustaining support, surrogates should be requested to provide convincing evidence proving that their decisions are in line with the patient's values, preferences and interests.

https://doi.org/10.25259/IJPC_173_2022

Redéfinir le consentement éclairé dans le cas de la thérapie génique

Dalal V., Jotwani G., Yadav M.L.

Redefining informed consent form in cell and gene therapy trials

Perspectives in Clinical Research 2024;15(1):4-9.

Informed consent is a foundation of the ethical conduct of research involving human participants. Based on the ethical principle of respect for persons, the goal of informed consent is to ensure that participants are aware of the risks and potential benefits and make a voluntary decision about participating in clinical trial research. The extraordinary scientific advances happening globally, have demonstrated the potential of regenerative therapies in transforming the health of the nation by providing a therapeutic option for diseases that were previously considered incurable. These therapies, which include cells and gene therapy (GT) labeled as Advanced

Therapeutic Medicinal Products globally, have complex mechanisms of action. Owing to their highly personalized and intricate nature of these therapies, developing the latter often presents unique challenges above and beyond those encountered for small molecule drugs. We recently looked through some cell and GT clinical trials and realized the lacunae in the informed consent form (ICF) provided by the investigators. Especially in a country like India, where the general understanding and perception of patients is limited regarding clinical trials, it is felt that any lapses in the consent process may jeopardize the informed decision-making and safety of the participants and tarnish the reputation of India globally. The present article highlights the need for appropriate patient and public education on the various aspects of cell and gene therapies and aims to address all the elements of ICF in light of the challenges associated with these innovative therapies.

https://doi.org/10.4103/picr.picr_244_22

Obtenir un consentement éclairé chez des personnes avec un handicap mental

Dunn M., Strnadová I., Scully J.L., et al.

Equitable and accessible informed healthcare consent process for people with intellectual disability: a systematic literature review

BMJ quality & safety 2023;bmjqs-2023-016113.

OBJECTIVE: To identify factors acting as barriers or enablers to the process of healthcare consent for people with intellectual disability and to understand how to make this process equitable and accessible. **DATA SOURCES:** Databases: Embase, MEDLINE, PsychINFO, PubMed, SCOPUS, Web of Science and CINAHL. Additional articles were obtained from an ancestral search and hand-searching three journals. **ELIGIBILITY CRITERIA:** Peer-reviewed original research about the consent process for healthcare interventions, published after 1990, involving adult participants with intellectual disability. **SYNTHESIS OF RESULTS:** Inductive thematic analysis was used to identify factors affecting informed consent. The findings were reviewed by co-researchers with intellectual disability to ensure they reflected lived experiences, and an easy read summary was created. **RESULTS:** Twenty-three studies were included (1999 to 2020), with a mix of qualitative (n=14), quantitative (n=6) and mixed-methods (n=3) studies. Participant numbers ranged from 9 to 604 people (median 21) and included people with intellectual disability, health professionals, carers and support people, and others working with people with intellectual disability. Six themes were identified: (1) health professionals' attitudes and lack of education, (2) inadequate accessible health information, (3) involvement of support people, (4) systemic constraints, (5) person-centred informed consent and (6) effective communication between health professionals and patients. Themes were barriers (themes 1, 2 and 4), enablers (themes 5 and 6) or both (theme 3). **CONCLUSIONS:** Multiple reasons contribute to poor consent practices for people with intellectual disability in current health systems. Recommendations include addressing health professionals' attitudes and lack of education in informed consent with clinician training, the co-production of accessible information resources and further inclusive research into informed consent for people with intellectual disability.

<https://doi.org/10.1136/bmjqs-2023-016113>

Les pratiques du consentement chez les sage-femmes

Elf R., Nicholls J., Ni Y., et al.

Consent practices in midwifery: A survey of UK midwives

Midwifery 2023;129:103893.

OBJECTIVE: To explore midwives' knowledge and understanding of the law and practice of consent in the post-Montgomery world. **DESIGN:** Cross-sectional online survey. Descriptive statistical analysis of midwives' survey responses. **SETTINGS:** Social media: Instagram, Facebook and Twitter. Survey distribution was via the UCL Opinion survey platform. **PARTICIPANTS:** A total of 402 midwives, surveyed over a four month-period between 2nd March and 2nd July 2021. **MEASUREMENTS:** Knowledge of legal consent, "sureness" of meeting current legal requirements and competence to gain consent. **FINDINGS:** 91% of participants acknowledged correctly that consent must be voluntary. 91% reported that women must be informed of all the risks associated with their care, although 26% reported that women should be informed of some of the risks associated with their care. Most participants were « sure » that their discussions of consent meet current legal requirements (91%). 21% rated their competence to gain consent as "excellent", 71% rated themselves as "very good", whilst 1% rated their

competence as “poor”. Deficiencies in fundamental knowledge of consent were noted in some participants rating themselves highest in “sureness” of meeting legal requirements and competence to consent. **KEY CONCLUSIONS:** Fundamental gaps in midwives’ knowledge of legal consent were identified. Participants demonstrated uncertainty regarding the extent of risk disclosure and discussion of alternative care options. Participants generally rated themselves highly in their consenting practices, despite lacking in basic knowledge of legal consent, revealing a discrepancy between midwives’ self-perceptions and their actual knowledge. **IMPLICATIONS FOR PRACTICE:** The overconfidence displayed by some participants is concerning for clinical midwifery practice. Professional education and guidance for midwives on legal consent in keeping with Montgomery is urgently required to ensure that midwives are legally compliant in their consenting practices.

<https://doi.org/10.1016/j.midw.2023.103893>

Le consentement dématérialisé en gynécologie

Ellis L.B., Barcroft J., St John E., et al.

Digital consent in gynecology: an evaluation of patient experience

Archives of Gynecology and Obstetrics 2023

INTRODUCTION: The surgical consent process is a crucial discussion between patient and surgeon, which is predominantly documented utilizing hand-written forms. The exchange of individualized information allows the patient to make a truly informed decision. Digital consent (also known as electronic consent or e-consent) has been shown to improve accuracy of information provided without increasing the time taken to consent patients. We aimed to evaluate patient experience and effectiveness of digital consent in a gynecology department in a tertiary London Teaching Hospital. **METHODS:** A questionnaire was designed and completed by 100 patients undergoing gynecological surgery: 50 consented using paper and 50 consented digitally. The questionnaire included 8 statements, with five possible answers to select, ranging from strongly agree to strongly disagree, on a standard five-point Likert Scale. Patients were all female and categorized into age groups (deciles) and asked whether consent was taken digitally or on paper. Data were collected between January and July 2021. **RESULTS:** Most responses were positive with 87% (694/800) of responses to the questions being either strongly agree or agree. Patients who were consented using paper selected « strongly agree » 43.5% (174/400) of the time in comparison to 64.8% (259/400) of the time when they were consented digitally. The majority, 86% (43/50), of digitally consented patients received a copy of the consent form in comparison to 18% (9/50) of those consented using paper. On average, the patients consented digitally were older than their paper-consented counterparts (49-58 and 59-68 respectively). The mean scores for the questions relating to the ease of reading the form, ease of understanding the form, understanding of the potential complications, and overall satisfaction were higher in those digitally consented ($p < 0.05$). **DISCUSSION:** Overall, patients were satisfied with both methods of consent. However, individuals who were consented digitally reported higher levels of satisfaction throughout the consent process, compared to paper consent. These data suggest that digital consent is an acceptable alternative to paper consent for patients and facilitates adherence to national consent guidance, which stipulates patients should be given the information they request.

<https://doi.org/10.1007/s00404-023-07304-1>

Les difficultés du consentement à la recherche clinique

Godskesen T., Björk J., Juth N.

Challenges regarding informed consent in recruitment to clinical research: a qualitative study of clinical research nurses’ experiences

Trials 2023;24(1):801.

BACKGROUND: Clinical research nurses (CRNs) have first-hand experience with ethical challenges and play a crucial role in upholding ethical conduct and adherence to the principles of informed consent in clinical research. This study explores the ethical challenges encountered by CRNs in the process of obtaining informed consent for clinical research. **METHODS:** A qualitative exploratory design. Semistructured interviews ($n = 14$) were conducted with diverse CRNs in Sweden. These CRNs covered a wide range of research fields, including pharmaceutical and academic studies, interventions, and observational research, spanning different trial phases, patient categories, and medical conditions. The interviews were analysed using inductive qualitative content analysis. **RESULTS:** The

analysis identified three main categories: (i) threats to voluntariness, (ii) measures to safeguard voluntariness, and (iii) questionable exclusion of certain groups. CRNs face challenges due to time constraints, rushed decisions, information overload, and excessive reliance on physicians' recommendations. Overestimating therapeutic benefits in stages of advanced illness emerged as a risk to voluntariness. CRNs outlined proactive solutions, such as allowing ample decision-making time and offering support, especially for terminally ill patients. Concerns were also voiced about excluding certain demographics, such as those with language barriers or cognitive impairments. CONCLUSIONS: In conclusion, upholding ethical research standards requires recognising various factors affecting patient voluntariness. Researchers and CRNs should prioritise refining the informed consent process, overcoming participation challenges, and aligning scientific rigour with personalised care. Additionally, a concerted effort is vital to meet the diverse needs of patient populations, including equitable inclusion of individuals with language barriers or cognitive limitations in clinical studies. These findings have significant implications for enhancing the ethics of clinical research and advancing person-centred care.

<https://doi.org/10.1186/s13063-023-07844-6>

Obtenir un consentement valide à la recherche chez des individus avec une faible littératie

Greer R.C., Kanthawang N., Roest J., et al.

The challenges and potential solutions of achieving meaningful consent amongst research participants in northern Thailand: a qualitative study

BMC medical ethics 2023;24(1):111.

BACKGROUND: Achieving meaningful consent can be challenging, particularly in contexts of diminished literacy, yet is a vital part of participant protection in global health research. **METHOD:** We explored the challenges and potential solutions of achieving meaningful consent through a qualitative study in a predominantly hill tribe ethnic minority population in northern Thailand, a culturally distinctive population with low literacy. Semi-structured interviews were conducted with 37 respondents who had participated in scrub typhus clinical research, their family members, researchers and other key informants. A thematic analysis was conducted. **RESULTS:** Our analysis identified four interrelated themes surrounding participants' ability to give consent: varying degrees of research understanding, limitations of using informal translators, issues impacting decisions to join research, and voluntariness of consent. Suggestions for achieving more meaningful consent included the use of formal translators and community engagement with research populations. **CONCLUSIONS:** Participant's agency in decision making to join research should be supported, but research information needs to be communicated to potential participants in a way that they can understand. We found that improved understanding about the study and its potential benefits and harms goes beyond literacy or translation and requires attention to social and cultural factors.

<https://doi.org/10.1186/s12910-023-00991-0>

L'autonomie des femmes dans les décisions de santé

Idris I.B., Hamis A.A., Bukhori A.B.M., et al.

Women's autonomy in healthcare decision making: a systematic review

BMC women's health 2023;23(1):643.

OBJECTIVES: Although there are calls for women's empowerment and gender equity globally, there are still large disparities regarding women's autonomy in healthcare decision making. The autonomy of women is believed to be crucial in improving their health-related outcomes. This review discusses factors that influence autonomy among women in healthcare decision making. **DESIGN:** Systematic review. **DATA SOURCES:** PubMed, Web of Science and Scopus were searched from 2017-2022. **ELIGIBILITY CRITERIA:** The inclusion criteria include original articles, case studies and reports that has been written in the English Language, while manuscripts with no full article, reviews, newspaper reports, grey literatures, and articles that did not answer the review objectives were excluded. **DATA EXTRACTION AND SYNTHESIS:** We carried out data extraction using a standardized data extraction form, that has been organized using Microsoft Excel. A narrative synthesis was carried out to combine the findings of all included articles. **RESULTS:** A total of 70 records were identified and 18 were reviewed, yielding

eight articles to be included in the accepted list of studies. All studies were conducted in developing countries and most of the studies were cross sectional. Factors that were associated with women's autonomy in healthcare decision making were age, women's education and occupation, husbands'/partners' education and occupation, residential location or region of residence, household wealth index as well as culture and religion. CONCLUSIONS: Identification of these factors may help stakeholders in improving women's autonomy in healthcare decision making. Policymakers play a crucial role in healthcare decision making by enacting laws and policies that protect women's rights, promoting gender-sensitive healthcare services, ensuring access to comprehensive information, promoting health education, and supporting vulnerable populations. These efforts ensure women's autonomy including able to access to unbiased and effective healthcare services.

<https://doi.org/10.1186/s12905-023-02792-4>

Ne pas informer : dans quel cas est-ce légitime ?

Lindberg J., Broström L., Johansson M.

An Egalitarian Perspective on Information Sharing: The Example of Health Care Priorities

Health care analysis: HCA: journal of health philosophy and policy 2023

In health care, the provision of pertinent information to patients is not just a moral imperative but also a legal obligation, often articulated through the lens of obtaining informed consent. Codes of medical ethics and many national laws mandate the disclosure of basic information about diagnosis, prognosis, and treatment alternatives. However, within publicly funded health care systems, other kinds of information might also be important to patients, such as insights into the health care priorities that underlie treatment offers made. While conventional perspectives do not take this as an obligatory part of the information to be shared with patients, perhaps through viewing it as clinically « non-actionable, » we advocate for a paradigm shift. Our proposition diverges from the traditional emphasis on actionability. We contend that honoring patients as equal moral agents necessitates, among other principles, a commitment to honesty. Withholding specific categories of information pertinent to patients' comprehension of their situation is inherently incompatible with this principle. In this article, we advocate for a recalibration of the burden of proof. Rather than requiring special justifications for adding to the standard set of information items, we suggest that physicians should be able to justify excluding relevant facts about the patient's situation and the underlying considerations shaping health care professionals' choices. This perspective prioritizes transparency and empowers patients with a comprehensive understanding, aligning with the ethos of respect for the patient as person.

<https://doi.org/10.1007/s10728-023-00475-7>

L'ignorance empêche-t-elle que le consentement soit éclairé ?

Villiger D.

Informed Consent Under Ignorance

The American journal of bioethics: AJOB 2024:1-13.

In recent years, an old challenge to informed consent has been rediscovered: the challenge of ignorance. Several authors argue that due to the presence of irreducible ignorance in certain treatments, giving informed consent to these treatments is not possible. The present paper examines in what ways ignorance is believed to prevent informed consent and which treatments are affected by that. At this, it becomes clear that if the challenge of ignorance truly holds, it poses a major problem to informed consent. The paper argues, however, that from both an empirical and a theoretical point of view, it is not convincing that ignorance prevents informed consent. Still, it seems important that the presence of irreducible ignorance is openly discussed during the informed consent process.

<https://doi.org/10.1080/15265161.2023.2296429>

Ce que le consentement éclairé à la chirurgie apporte aux patient·es

Mihiretu M.M., Bekele E., Ayele K., et al.

Patient knowledge of surgical informed consent and shared decision-making process among surgical patients in Ethiopia: a systematic review and meta-analysis

Patient Safety in Surgery 2024;18(1):2.

BACKGROUND: Informed consent is one of the safeguarding of the patient in medical practice at different standards such as ethical, legal, and administrative purposes. Patient knowledge and perception of informed consent are one of the priority concerns in surgical procedures. Patient knowledge and perception towards informed consent increased patient satisfaction, feeling high power on their determination, and accountability for the management, and facilitated positive treatment outcomes. Despite this, in Ethiopia, there are small-scale primary studies with inconsistent and inconclusive findings. Therefore, this systematic review and meta-analysis study estimated the pooled prevalence of patient knowledge and perception of informed consent and its determinants in Ethiopia. **METHODS:** We searched major databases such as PubMed, Hinary, MEDLINE, Cochrane Library, EMBASE, Scopus, African Journal Online (AJO), Semantic Scholar, Google Scholar, google, and reference lists. Besides this, University databases in the country were also searched from August 20, 2023, until September 30, 2023,. All published and unpublished studies that report the prevalence of patient knowledge and perception toward informed consent and its associated factors were included. All studies reported in English were included. Studies conducted between January 01, 2015 to September 30, 2023 were included. There are three outcome measurements pooled level of patient knowledge towards informed consent, pooled level of patient perception towards informed consent, and pooled effect that affects patient knowledge of informed consent. Three reviewers (MMM, NK, and YT) independently screened the articles that fulfilled the inclusion criteria to avoid the risk of bias. The studies' quality was appraised using a modified Newcastle-Ottawa Scale (NOS) version. **RESULTS:** The pooled prevalence of appropriate patient knowledge and perception towards informed consent was 32% (95% CI: 21, 43) and 40% (95% CI: 16, 65) respectively. Having formal education 2.69 (95% CI: 1.18, 6.15) and having a history of signed informed consent before 3.65 (95% CI:1.02,13.11) had a statistically significant association with good patient knowledge towards informed consent. **CONCLUSION:** The appropriate patient knowledge and perception of informed consent in Ethiopia is low. Formal education and history of signed informed consent were positive factors for appropriate patient knowledge of informed consent in Ethiopia. Physicians, policymakers, and health facility managers should focus on patients without prior experience with signed informed consent and not have formal education to improve patient knowledge towards informed consent.

<https://doi.org/10.1186/s13037-023-00386-5>

Pratiquer un consentement culturellement approprié aux populations autochtones du Canada

Peltier C., Dickson S., Grandpierre V., et al.

Culturally appropriate consent processes for community-driven indigenous child health research: a scoping review

BMC medical ethics 2024;25(1):3.

BACKGROUND: Current requirements for ethical research in Canada, specifically the standard of active or signed parental consent, can leave Indigenous children and youth with inequitable access to research opportunities or health screening. Our objective was to examine the literature to identify culturally safe research consent processes that respect the rights of Indigenous children, the rights and responsibilities of parents or caregivers, and community protocols. **METHODS:** We followed PRISMA guidelines and Arksey and O'Malley's approach for charting and synthesizing evidence. We searched MEDLINE, PsycINFO, ERIC, CINAHL, Google Scholar, Web of Science, Informit Indigenous Collection, Bibliography of Native North Americans, and Sociological Abstracts. We included peer-reviewed primary and theoretical research articles written in English from January 1, 2000, to March 31, 2022, examining Indigenous approaches for obtaining informed consent from parents, families, children, or youth. Eligible records were uploaded to Covidence for title and abstract screening. We appraised the findings using a Two-Eyed Seeing approach. These findings were inductively coded using NVivo 12 and analyzed thematically. **RESULTS:** We identified 2,984 records and 11 eligible studies were included after screening. Three

key recommendations emerged: addressing tensions in the ethics of consent, embracing wise practices, and using relational approaches to consent. Tensions in consent concerned Research Ethics Board consent requirements that fall short of protecting Indigenous children and communities when culturally incongruent. Wise practices included allowing parents and children to consent together, land-based consenting, and involving communities in decision-making. Using relational approaches to consent embodied community engagement and relationship building while acknowledging consent for Indigenous children cannot be obtained in isolation from family and community. CONCLUSIONS: Very few studies discussed obtaining child consent in Indigenous communities. While Indigenous communities are not a monolith, the literature identified a need for community-driven, decolonized consent processes prioritizing Indigenous values and protocols. Further research is needed to examine nuances of Indigenous consent processes and determine how to operationalize them, enabling culturally appropriate, equitable access to research and services for all Indigenous children.

<https://doi.org/10.1186/s12910-023-00996-9>

L'autonomie des mineur·es en chirurgie

Rodríguez-Domínguez F.J., Osuna-García T., Guillén A., et al.

Involvement and Autonomy of Minors in Medical Settings: Perceptions of Children Undergoing Surgery and Parents

Children (Basel, Switzerland) 2023;10(12):1844.

Informed consent presupposes competence and represents a formal decision by an informed person who has the legal capacity to accept medical action or participate in research. Our aim was to analyze the perceptions of minors and their parents about the age at which they consider that a minor is competent for making health decisions. A descriptive observational study was carried out in 302 minors between 12 and 17 years of age undergoing elective surgery, and 302 parents (range 30 to 62 years). Two semistructured questionnaires were designed, one for the minors and the other, for the parents. A total of 20.1% of minors and 31.1% of parents believe that patients should not make decisions related to their health until they are 18 years old. A total of 74.9% of the minors surveyed consider that from 16 years of age, the minor is empowered to make decisions. In parents, this percentage is 60%. In the pediatric setting, each case and situation must be examined individually to determine if the minor meets the condition of maturity to decide. The ideal is to promote the minor's participation in decision-making, giving them the opportunity to participate in the process in a manner appropriate to their capacity.

<https://doi.org/10.3390/children10121844>

L'obtention du consentement éclairé assisté par IA

Aydin F., Yildirim Ö.T., Aydin A.H., et al.

Comparison of artificial intelligence-assisted informed consent obtained before coronary angiography with the conventional method: Medical competence and ethical assessment

Digital Health 2023;9:20552076231218141.

OBJECTIVE: At the time of informed consent (IC) for coronary angiography (CAG), patients' knowledge of the process is inadequate. Time constraints and a lack of personalization of consent are the primary causes of inadequate information. This procedure can be enhanced by obtaining IC using a chatbot powered by artificial intelligence (AI). METHODS: In the study, patients who will undergo CAG for the first time were randomly divided into two groups, and IC was given to one group using the conventional method and the other group using an AI-supported chatbot, chatGPT3. They were then evaluated with two distinct questionnaires measuring their satisfaction and capacity to understand CAG risks. RESULTS: While the satisfaction questionnaire was equal between the two groups ($p = 0.581$), the correct understanding of CAG risk questionnaire was found to be significantly higher in the AI group (<0.001). CONCLUSIONS: AI can be trained to support clinicians in giving IC before CAG. In this way, the workload of healthcare professionals can be reduced while providing a better IC.

<https://doi.org/10.1177/20552076231218141>

La place de l'IA dans le consentement

Saccà R., Turrini R., Ausania F., et al.

The ménage à trois of healthcare: the actors in after-AI era under patient consent

Frontiers in Medicine 2023;10:1329087.

INTRODUCTION: Artificial intelligence has become an increasingly powerful technological instrument in recent years, revolutionizing many sectors, including public health. Its use in this field will inevitably change clinical practice, the patient-caregiver relationship and the concept of the diagnosis and treatment pathway, affecting the balance between the patient's right to self-determination and health, and thus leading to an evolution of the concept of informed consent. The aim was to characterize the guidelines for the use of artificial intelligence, its areas of application and the relevant legislation, to propose guiding principles for the design of optimal informed consent for its use. *MATERIALS AND METHODS:* A classic review by keywords on the main search engines was conducted. An analysis of the guidelines and regulations issued by scientific authorities and legal bodies on the use of artificial intelligence in public health was carried out. *RESULTS:* The current areas of application of this technology were highlighted, divided into sectors, its impact on them, as well as a summary of current guidelines and legislation. *DISCUSSION:* The ethical implications of artificial intelligence in the health care system were assessed, particularly regarding the therapeutic alliance between doctor and patient, and the balance between the right to self-determination and health. Finally, given the evolution of informed consent in relation to the use of this new technology, seven guiding principles were proposed to guarantee the right to the most informed consent or dissent.

<https://doi.org/10.3389/fmed.2023.1329087>

Déléguer son consentement : l'avis a posteriori de patient·es passé·es par la réanimation

Wal L.I. van der, Grim C.C.A., Del Prado M.R., et al.

Perspectives of ICU Patients on Deferred Consent in the Context of Post-ICU Quality of Life: A Substudy of a Randomized Clinical Trial

Critical Care Medicine 2024

OBJECTIVES: Deferred consent enables research to be conducted in the ICU when patients are unable to provide consent themselves, and there is insufficient time to obtain consent from surrogates before commencing (trial) treatment. The aim of this study was to evaluate how former ICU patients reflect on their participation in a study with deferred consent and examine whether their opinions are influenced by the quality of life (QoL) following hospital discharge. *DESIGN:* Survey study by questionnaire. *SETTING:* Eight ICUs in The Netherlands. *PATIENTS:* Former ICU patients who participated in the ICONIC trial, a multicenter randomized clinical trial that evaluated oxygenation targets in mechanically ventilated ICU patients. *INTERVENTIONS:* Participants enrolled in the ICONIC trial in one of the eight participating centers in The Netherlands received a questionnaire 6 months after randomization. The questionnaire included 12 close-ended questions on their opinion about the deferred consent procedure. QoL was measured using the EQ-5D-5L questionnaire. By calculating the EQ-5D index, patients were divided into four QoL quartiles, where Q1 reflects the lowest and Q4 is the highest. *MEASUREMENTS AND MAIN RESULTS:* Of 362 participants who were contacted, 197 responded (54%). More than half of the respondents (59%) were unaware of their participation in the ICONIC study. In total 61% were content with the deferred consent procedure, 1% were not content, 25% neutral, 9% did not know, and 9% answered « other. » Those with a higher QoL were more likely to be content ($p = 0.02$). In all QoL groups, the legal representative was the most often preferred individual to provide consent. *CONCLUSIONS:* Former ICU patients who participated in the ICONIC study often did not remember their participation but were predominantly positive regarding the use of deferred consent. Those with a higher QoL were most likely to be content.

<https://doi.org/10.1097/CCM.0000000000006184>

Le consentement à l'usage des données de santé des enfants

Wild C.E.K., Rawiri N.T., Taiapa K., et al.

In safe hands: child health data storage, linkage and consent for use

Health Promotion International 2023;38(6):daad159.

While there is potential for societal benefit from linkage and integration of large datasets, there are gaps in our understanding of the implications for children and young people, and limited inclusion of their views within this discourse. We aimed to understand the views and expectations of children, young people and their parents/caregivers in Aotearoa New Zealand regarding child health data storage, linkage and consent for use. This qualitative study included 24 Māori and non-Māori children, young people and their families across five focus groups, recruited from a community-based health service. A mixed Māori and non-Māori research team facilitated participant recruitment and data collection. Child, adolescent and parent/caregiver groups were held separately. Sessions were audio-recorded and the verbatim transcripts were analysed thematically. We identified three themes: (i) I am more than a number: seeing patients as people; (ii) In safe hands: data as power; and (iii) What are your intentions with my data? Consent as an active relationship. A key challenge was the reductive and stigmatizing potential of data integration for minoritised groups. Hypothetical discussions of data sharing and linkage were contingent on trust between the participant and the health professional, with negotiated data ownership. Consent was conceived as an active relationship needing renewal and renegotiation as children reached adulthood. Current consent processes for ongoing use of child data require further deliberation. Without a strong ethical and child rights-based approach to issues of child health data management, consent and linkage, we risk exacerbating health inequities and experiences of breach of trust.

<https://doi.org/10.1093/heapro/daad159>

LIEUX ET MÉTIRS DU SOIN



L'éthique en psychiatrie

Arcas P.-M.

Quelle place pour l'éthique en psychiatrie ?

Soins. Psychiatrie 2024;45(350):10-13.

À l'heure où les établissements de soins font face à des défis financiers et institutionnels sensibles, comment donner une place à l'éthique en psychiatrie ? Dans la société, les débats éthiques sont axés sur la gestation pour autrui, l'euthanasie active ou suicide assisté et les recherches sur l'embryon. En psychiatrie, la question se cristallise souvent autour de faits divers violents peu représentatifs du quotidien des professionnels et des patients. La parole militante préside à l'écoute des personnes concernées. La loi oblige les établissements à mener une réflexion sur les questions éthiques posées par l'accueil et la prise en charge médicale sans en préciser les contours. L'éthique en structure de santé s'intéresse particulièrement aux situations de soins – ce qui est possible ou souhaitable –, sans modèle théorique unique servant d'exemple à suivre.

<https://doi.org/10.1016/j.spsy.2023.11.003>

Une « éthique de la retenue » dans les soins psychiques

Hazif-Thomas C.

Du soin psychiatrique au soin psychique, pour une éthique de la retenue

Soins. Psychiatrie 2024;45(350):17-21.

L'analyse des difficultés éthiques soulevées par les relations soignants-malades s'appuie sur l'histoire de la psychiatrie et la sensibilité aux tensions éthiques qui parcourent le champ de la psychiatrie et de la santé mentale. Se permettre de prendre du recul face à l'injonction de la bienveillance, ne pas la fétichiser, adopter une démarche holistique, se donner les moyens de parer à la stigmatisation et à l'autostigmatisation qui accompagnent si souvent le handicap psychique et/ou psychosocial, et inviter à une réflexion sur la proportionnalité en santé mentale sont autant de priorités éthiques insuffisamment investies dans la clinique psychiatrique.

<https://doi.org/10.1016/j.spsy.2023.11.005>

Les dilemmes éthiques en santé mentale pendant la pandémie de Covid-19

Kane H., Gourret Baumgart J., Fond-Harmant L., et al.

Les dilemmes éthiques des professionnels des services de santé mentale face à la crise sanitaire

Revue française d'éthique appliquée 2023;N° 14(1):78-93.

La crise sanitaire de la Covid-19 a bouleversé l'organisation et le fonctionnement des services de santé mentale, impactant les conditions de travail des professionnels qui y exercent. Le projet de recherche Psy- gipo2c a documenté l'expérience de ces professionnels. Une attention particulière a été portée à la manière dont ils ont appréhendé les nouveaux dilemmes éthiques, dans un contexte où il leur était demandé de mettre en application des mesures sanitaires inédites visant à limiter la transmission du sars-c o v -2 tout en assurant une continuité des soins de santé mentale auprès des patients. Le présent article propose de s'intéresser, au travers du prisme d'une anthropologie de l'éthique, à la manière dont ces professionnels ont fait face aux dilemmes éthiques qui se sont manifestés dans de nombreuses situations allant de l'obligation de port du masque à la suppression d'activités thérapeutiques. Les mesures de distanciation physique ont interféré avec les valeurs attribuées aux soins en psychiatrie, dans lesquels le relationnel est central ; la limitation des libertés des patients a contredit les efforts pour stimuler des parcours de rétablissement basés sur l'autonomie et l'inclusion sociale. Face aux dilemmes éthiques, les professionnels, du fait d'un arbitrage différentiel, ont adopté diverses postures, articulées à leur « carrière éthique » et à leur position sociale. Certains professionnels ont souffert des dilemmes éthiques générés par des injonctions contradictoires dans leur vie professionnelle, contribuant à la dégradation de leur propre santé mentale. Ces constats plaident en faveur de la mise en place d'espaces de réflexion éthique qui permettront aux professionnels de santé mentale de se soutenir mutuellement face aux dilemmes qu'ils rencontrent.

<https://doi.org/10.3917/rfeap.014.0078>

La contention en pédopsychiatrie

Lefèvre-Utile J.

La contention en pédopsychiatrie

Soins; La Revue De Reference Infirmiere 2024;69(882):31-33.

En pédopsychiatrie, il existe des défis éthiques importants lorsque les jeunes se mettent en danger ou ne coopèrent pas à leurs soins. Cet article illustre deux situations de violence et de contention, et ouvre une réflexion sur la prise en compte de la vulnérabilité des soignants pour trouver le meilleur équilibre entre les impératifs de protection et le respect des jeunes hospitalisés en pédopsychiatrie.

<https://doi.org/10.1016/j.soin.2023.12.007>

L'isolement et la contrainte en psychiatrie

Picquet G.

Envisager la question de l'isolement et de la contention en psychiatrie

Soins. Psychiatrie 2024;45(350):33-37.

Dans un contexte en constante transformation, la question du sens donné au soin dans un cadre éthique et bienveillant est primordiale. Le développement d'une approche centrée sur le patient repose sur la compréhension de cet Autre. La sollicitude et l'empathie sont des fondements essentiels propres à cette approche. Un essai d'analyse des pratiques par le biais de quelques notions d'éthique peut être proposé.

<https://doi.org/10.1016/j.spsy.2023.11.009>

La justice sociale au prisme des patient·es expert·es

Feijoo-Cid M., Arreciado Marañón A., Fernández-Cano M.I., et al.

[Expert patients leading activities on social justice: towards patient-centered education](#)

Nursing Ethics 2023;09697330231217038.

Background: Social justice is recognized by reputable international organizations as a professional nursing value. However, there are serious doubts as to whether it is embodied in Catalan nursing education. *Objectives:* To explore what nursing students take away from two teaching activities led by expert patients (one presentation and three expert patient illness narratives) on the topics of social justice, patient rights, and person-centered care. *Research design:* Qualitative study using a content analysis approach. The research plan included (1) think-pair-share activities (additional faculty-assisted presentation and three faculty-assisted, semi-structured scripted narratives); (2) paired reflections; (3) focus groups; and (4) content analysis of paired reflections and focus groups. *Participants and research context:* Fourth-year nursing degree students at the Autonomous University of Barcelona (UAB), Spain. Convenience sampling was used. *Ethical considerations:* The UAB Research Ethics Committee did not deem it necessary to apply any specific measures. We fully explained to patients that they could decide what medical information they would share with the students that was relevant to their learning, and we provided students with guidelines about patient confidentiality, dignity, and respect. *Findings/results:* The students engaged in reflection about their education (recognizing that it had been centered on the professional and not the patient) and their relationship with the patient, in which they reproduced low-involvement patient care by modeling behaviors of their nurse educator. Moreover, they valued a person-centered care model with an emphasis on the emotional part but left out decision-making as an individual right of people. *Conclusions:* The think-pair-share activities were useful to spark self-reflection among students, who identified aspects to change in their own practice, and reflected about their own education process, both of which promote change.

<https://doi.org/10.1177/09697330231217038>

L'éthique au SAMU

Frank C., Rantala A., Svensson A., et al.

[Ethics rounds in the ambulance service: a qualitative evaluation](#)

BMC medical ethics 2024;25(1):8.

BACKGROUND: It is a common ethical challenge for ambulance clinicians to care for patients with impaired decision-making capacities while assessing and determining the degree of decision-making ability and considering ethical values. Ambulance clinicians' ethical competence seems to be increasingly important in coping with such varied ethical dilemmas. Ethics rounds is a model designed to promote the development of ethical competence among clinicians. While standard in other contexts, to the best of our knowledge, it has not been applied within the ambulance service context. Thus, the aim of this study was to describe ambulance clinicians' experiences of participating in ethics rounds. *METHODS:* This was a qualitative descriptive study, evaluating an intervention. Data were collected through sixteen interviews with ambulance clinicians who had participated in an intervention involving ethics rounds. The analysis was performed by use of content analysis. *RESULTS:* Two themes describe the participants' experiences: (1) Reflecting freely within a given framework, and (2) Being surprised by new insights. The following categories form the basis of the themes; 1a) Gentle guidance by the facilitator, 1b) A comprehensible structure, 2a) New awareness in the face of ethical problems, and 2b) Shared learning through dialogue. *CONCLUSION:* Incorporating structured ethics rounds seems to create a continuous development in ethical competence that may improve the quality of care in the ambulance service. Structured guidance and facilitated group reflections offer ambulance clinicians opportunities for both personal and professional development. An important prerequisite for the development of ethical competence is a well-educated facilitator. Consequently, this type of ethics rounds may be considered a useful pedagogical model for the development of ethical competence in the ambulance service.

<https://doi.org/10.1186/s12910-024-01002-6>

L'autonomie dans les soins à domicile

Hertzberg C.K., Heggstad A.K.T., Magelssen M.

Blurred lines: Ethical challenges related to autonomy in home-based care

Nursing Ethics 2023;9697330231215951.

BACKGROUND: Home-based care workers mainly work alone in the patient's home. They encounter a diverse patient population with complex health issues. This inevitably leads to several ethical challenges. **AIM:** The aim is to gain insight into ethical challenges related to patient autonomy in home-based care and how home-based care staff handle such challenges. **RESEARCH DESIGN:** The study is based on a 9-month fieldwork, including participant observation and interviews in home-based care. Data were analysed with a thematic analysis approach. **PARTICIPANTS AND RESEARCH CONTEXT:** The study took place within home-based care in three municipalities in Eastern Norway, with six staff members as key informants. **ETHICAL CONSIDERATIONS:** The Norwegian Agency for Shared Services in Education and Research evaluated the study. All participants were competent to consent and signed an informed consent form. **FINDINGS:** A main challenge was that staff found it difficult to respect the patient's autonomy while at the same time practicing appropriate care. We found two main themes: Autonomy and risk in tension; and strategies to balance autonomy and risk. These were explicated in four sub-themes: Refusing and resisting care; when choosing to live at home becomes risky; sweet-talking and coaxing; and building trust over time. Staff's threshold for considering the use of coercion appeared to be high. **CONCLUSIONS:** Arguably, home-based care staff need improved knowledge of coercion and the legislation regulating it. There is also a need for arenas for ethics reflection and building of competence in balancing ethical values in recurrent ethical problems.

<https://doi.org/10.1177/09697330231215951>

La décision thérapeutique en éthique dentaire

Kovács S.D.

Suggestion for Determining Treatment Strategies in Dental Ethics

Journal of Bioethical Inquiry 2023

Contemporary medicine views health as the individual's physical, mental, and social well-being. Oral health plays a crucial role in one's well-being, as the oral cavity and its surrounding regions execute essential functions in verbal and nonverbal communication, sensing, digestion, and significantly contribute to aesthetic appearance. The multifaceted nature of the notion of oral health, as well as the patient's needs and autonomous will result in various treatment options for the same oral state, favouring often contrasting ethical values and different aspects of oral health. The objective of this article is to suggest alternative treatment strategies in dentistry with respect to the following factors: extent of rehabilitation, preserving one's anatomical structures, aesthetic outcome, number of sessions, patient autonomy. Additionally, this article describes the suggested treatment strategies in an ethical context and determines the conditions of their employment. The suggested treatment strategies are divided in two categories, extensive treatment strategies focusing on the patient's entire craniofacial complex, while specific treatment strategies focus on specific paramount issues.

<https://doi.org/10.1007/s11673-023-10310-2>

Penser la diversité sociale dans les services de soin

Kröger C., Molewijk B., Muntinga M., et al.

The Diversity Compass: a clinical ethics support instrument for dialogues on diversity in healthcare organizations

BMC medical ethics 2024;25(1):4.

BACKGROUND: Increasing social pluralism adds to the already existing variety of heterogeneous moral perspectives on good care, health, and quality of life. Pluralism in social identities is also connected to health and care disparities for minoritized patient (i.e. care receiver) populations, and to specific diversity-related moral

challenges of healthcare professionals and organizations that aim to deliver diversity-responsive care in an inclusive work environment. Clinical ethics support (CES) services and instruments may help with adequately responding to these diversity-related moral challenges. However, although various CES instruments exist to support healthcare professionals with dealing well with morally challenging situations in healthcare, current tools do not address challenges specifically related to moral pluralism and intersectional aspects of diversity and social justice issues. This article describes the content and developmental process of a novel CES instrument called the Diversity Compass. This instrument was designed with and for healthcare professionals to dialogically address and reflect on moral challenges related to intersectional aspects of diversity and social justice issues that they experience in daily practice. **METHODS:** We used a participatory development design to develop the Diversity Compass at a large long-term care organization in a major city in the Netherlands. Over a period of thirteen months, we conducted seven focus groups with healthcare professionals and peer-experts, carried out five expert interviews, and facilitated four meetings with a community of practice consisting of various healthcare professionals who developed and tested preliminary versions of the instrument throughout three cycles of iterative co-creation. **RESULTS:** The Diversity Compass is a practical, dialogical CES instrument that is designed as a small booklet and includes an eight-step deliberation method, as well as a guideline with seven recommendations to support professionals with engaging in dialogue when they are confronted with diversity-related moral challenges. The seven recommendations are key components in working toward creating an inclusive and safe space for dialogue to occur. **CONCLUSIONS:** The Diversity Compass seeks to support healthcare professionals and organizations in their efforts to facilitate awareness, moral learning and joint reflection on moral challenges related to diversity and social justice issues. It is the first dialogical CES instrument that specifically acknowledges the role of social location in shaping moral perspectives or experiences with systemic injustices. However, to make healthcare more just, an instrument like the Diversity Compass is not enough on its own. In addition to the Diversity Compass, a systemic and structural approach to social justice issues in healthcare organizations is needed in order to foster a more inclusive, safe and diversity-responsive care and work environment in health care organizations.

<https://doi.org/10.1186/s12910-023-00992-z>

Enjeux éthiques de la pratique médicale rurale

Menezes S., Eggleton K.

Rural general practice and ethical issues. A rapid review of the literature

Journal of Primary Health Care 2023;15(4):366-375.

Introduction: Key New Zealand ethical documents that describe appropriate ethical behaviour for doctors do not consider rurality and how this might impact on the practice of medicine. *Aim* The aim of this study was to understand the literature on key ethical issues experienced by general practitioners in a rural context that might inform the development of a New Zealand agenda of rural medical ethics. *Methods:* A rapid review was undertaken of three databases using a variety of key words relating to rurality, ethics, professionalism and medicine. *Inclusion criteria* were research articles focussing on the experience of doctors working in a rural healthcare setting, commentaries and narratives. *The findings from the paper* were synthesised and broad ethical categories created. *Results:* Twelve studies were identified that met the inclusion and exclusion criteria. Synthesis of the data revealed five ethical issues that predominately arose from living and working within communities. These ethical issues related to juggling personal and professional lives, managing friendships with patients, managing loss of privacy and anonymity, assuring confidentiality and practicing outside of comfort zones. *Discussion:* The majority of ethical issues arose from managing overlapping relationships. However, these overlapping relationships and roles are considered normal in rural settings. A tension is created between adhering to urban normative ethical guidelines and the reality of living in a rural environment. Professional ethical guidelines, such as those developed by the New Zealand Medical Council, do not account for this rural lived reality. Rural practitioners in New Zealand should be engaged with to progress a specific rural ethics agenda.

<https://doi.org/10.1071/HC23069>

La contention aux urgences

Renouf T., Lapoussin S., Peyronnin B., et al.

La contention des patients aux urgences : une difficulté au quotidien

Soins; La Revue De Reference Infirmiere 2024;69(882):37-40.

Le contexte du service d'accueil des urgences expose particulièrement les professionnels à des situations où la question du recours à la contention se pose. Les indications et les modalités de la contrainte physique sont exposées dans cet article. Celle-ci doit être envisagée comme le dernier recours et exige un questionnement éthique systématique.

<https://doi.org/10.1016/j.soin.2023.12.009>

La contention en réanimation

Souppart V., Zafrani L.

Contention en réanimation : entre sécurité du patient et respect de son autonomie

Soins; La Revue De Reference Infirmiere 2024;69(882):51-53.

Le recours à la contention physique dans le contexte de la réanimation médicale est relativement fréquent. Bien que la contrainte physique passagère ou prolongée soit justifiée par la sécurité du patient (possibilité d'auto-extubation, etc.), cette pratique est elle-même source de risques, entraîne de la souffrance chez le soigné, et soulève dilemmes et questionnements éthiques au sein des équipes. Inhérente aux conditions de travail et à la formation des professionnels, la contention doit néanmoins être pondérée et conduire à la recherche d'alternatives.

<https://doi.org/10.1016/j.soin.2023.12.012>

Validation d'une échelle de souffrance morale chez les infirmier·es

Tao H., Nieuwsma J.A., Meador K.G., et al.

Validation of the Moral Injury Outcome Scale in acute care nurses

Frontiers in Psychiatry 2023;14:1279255.

INTRODUCTION: Moral injury, predominantly studied in military populations, has garnered increased attention in the healthcare setting, in large part due to the psychological and emotional consequences of the COVID-19 pandemic. The measurement of moral injury with instrumentation adapted from military settings and validated by frontline healthcare personnel is essential to assess prevalence and guide intervention. This study aimed to validate the Moral Injury Outcome Scale (MIOS) in the population of acute care. METHODS: A sample of 309 acute care nurses completed surveys regarding moral injury, depression, anxiety, burnout, professional fulfillment, spiritual wellbeing, and post-traumatic stress disorder symptoms. Confirmatory factor analysis was conducted as well as an assessment of reliability and validity. RESULTS: The internal consistency of the 14-item MIOS was 0.89. The scale demonstrated significant convergent and discriminant validity, and the test of construct validity confirmed the two-factor structure of shame and trust violations in this clinical population. Regression analysis indicated age, race, and marital status-related differences in the experience of moral injury. DISCUSSION: The MIOS is valid and reliable in acute care nursing populations and demonstrates sound psychometric properties. Scores among nurses diverge from those of military personnel in areas that may inform distinctions in interventions to address moral injury in these populations.

<https://doi.org/10.3389/fpsy.2023.1279255>

La violence obstétrique

Waal R. van der, Nistelrooij I. van, Leget C.

The Undercommons of Childbirth and Their Abolitionist Ethic of Care. A Study into Obstetric Violence Among Mothers, Midwives (in Training), and Doulas

Violence Against Women 2023;10778012231205591.

Engaging in dialogue with critical mothers, midwives, midwives in training, and doulas in the Netherlands, this study furthers the theoretical understanding of both obstetric violence and the activist resistance against it. Obstetric violence is understood as part of a process of relational separation, leaving the pregnant person isolated. The activist resistance against it is consequently theorized as the abolitionist building of an alternative "otherworld" of radical relational care. The themes established are: (1) « institutionalized separation » with the subtheme's "expropriation," "carcerality," and "obstetric violence;" and (2) "undercommoning childbirth" with subthemes "fugitive planning," "anarchic relationality," and "obstetric abolition."

<https://doi.org/10.1177/10778012231205591>

Le lien entre le respect de l'éthique médicale et le vécu de la grossesse

Yadollahi P., Bozorgian L., Janghorban R.

The relationship between Iranian women's perception of their birth team's compliance with medical ethics and their perception of labor pain

BMC pregnancy and childbirth 2024;24(1):70.

BACKGROUND: A safe and satisfactory childbirth experience with the least amount of pain constitutes one of the main domains of reproductive healthcare. The most important aspect of labor pain management is the moral and professional commitment of the health professionals and caregivers involved in creating a pleasant delivery. The present study examines the relationship between Iranian women's perceptions of their birth team's compliance with medical ethics and their perception of labor pain. **METHODS:** This cross-sectional study was conducted on 200 women opting for natural childbirth. The samples were selected by convenience sampling. Three questionnaires, including a demographic information questionnaire, the perception of labor pain questionnaire, and the medical ethics attitude in vaginal delivery questionnaire, were used to collect data. The data were entered into SPSS 22 and analyzed using correlation coefficient and multiple regression tests. The significance level for data analysis was set as less than 0.05. **RESULTS:** The results of the regression analysis showed that among the four principles of medical ethics, only the second and third principles (beneficence and non-maleficence) predicted the perception of labor pain ($B = -0.267, P < 0.037$). Among the different domains of these principles, the areas of giving the necessary information to the mother ($B = -0.199, P = 0.001$), respecting the mother's privacy ($B = -0.194, P = 0.001$), interaction with the mother ($B = -0.287, P = 0.001$) and assurance of fetal health ($B = -0.492, P = 0.001$) were predictors of labor pain perception score. **CONCLUSIONS:** Compliance of the birth team with respecting the mother's privacy, having friendly interactions with the mother and giving fetal health assurance to the mother can be a predictor of the mother's decreased perception of labor pain.

<https://doi.org/10.1186/s12884-024-06269-6>

ÉTHIQUE INFIRMIÈRE



L'engagement des infirmier-es pendant la pandémie de Covid-19 malgré le risque infectieux

Chaudhary P., Payal null, Nain P., et al.

Perceived risk of infection, ethical challenges and motivational factors among frontline nurses in Covid-19 pandemic: prerequisites and lessons for future pandemic

BMC nursing 2024;23(1):5.

BACKGROUND: Infection risk was significant for front-line nurses during the Covid-19 outbreak. The pandemic presented several ethical difficulties and sapped nurses' drive to labor harder for longer periods. This study evaluates registered nurses' perceptions of Covid-19 infection risk, ethical dilemmas, and motivating factors. **MATERIALS AND METHODS:** During March and April 2022, 400 registered nurses from a newly established tertiary care hospital participated in this cross-sectional exploratory survey. The risk assessment scale, motivation to work scale, and ethical dilemma scale were used to assess the perceived risk of infection, motivational factors and ethical challenges experienced by the nurses. Appropriate descriptive and inferential statistics were applied to compute the results. **RESULTS:** 76.4% of nurses feared working as a nurse put them at higher risk of infection. Besides the fear of contracting infection, nurses believed they were the source of infection to family members (70.8%) and people around (67.5%). 63.3% of nurses agree that they do not have the right to refuse treatment and every patient has the right to receive optimal care, regardless of age, gender, and medical conditions. Professional obligation to treat patients (72.3%) and sound professional knowledge and experience (83.5%) are important motivating factors to work during the pandemic. Multilinear regression analysis revealed that professional education (95% CI, 3.845 - 0.694, $p = 0.005$), Covid-19 positive status (95% CI, 0.455-2.756, $p = 0.006$), and post-Covid-19 hospitalization (95% CI, 1.395-6.978, $p = 0.003$) and duration of hospitalization (95% CI, 0.754-0.058, $p = 0.022$) are independent predictors of higher perceived risk of infection among nurses. **CONCLUSIONS:** During the pandemic, nurses were afraid to work and faced personal and family risks of contracting the virus. Despite these challenges, they still feel a strong sense of commitment and dedication to providing the best possible care. Nurse administrators need to create a supportive environment that follows ethical principles and meets the needs of nurses to boost their motivation and encourage them to continue working for longer periods.

<https://doi.org/10.1186/s12912-023-01653-7>

Quels principes doivent régir un code de déontologie infirmière ?

Chiappinotto S., Igoumenidis M., Galazzi A., et al.

[Between mandatory and aspirational ethics in nursing codes: a case study of the Italian nursing code of conduct](#)

BMC nursing 2024;23(1):30.

BACKGROUND: Over the years, national and international nurses' organisations have drawn up Codes of Conduct and Codes of Ethics. A new differentiation has emerged over time between mandatory and aspirational approaches underlying how nurses can be supported by documents with rules to be respected (mandatory ethics) or by incentives (aspirational ethics). However, to date, no research has applied these approaches to analyse available Codes and to identify which approach are predominantly used. **METHODS:** In this case study, the Italian Nursing Code of Conduct (NCC), published in 2019, composed of 53 articles distributed in eight chapters, was first translated, and then analysed using a developed matrix to identify the articles that refer to mandatory or aspirational ethics. A nominal group technique was used to minimise subjectivity in the evaluation process. **RESULTS:** A total of 49 articles addressing the actions of the individual nurse were considered out of 53 composing the NCC. Articles were broken down into 97 units (from one to four for each article): 89 units (91.8%) were attributed to a unique category, while eight (8.2%) to two categories according to their meaning. A total of 38 units (39.2%) were categorised under the mandatory ethics and 58 (59.8%) under the aspirational ethics; however, one (1.0%) reflected both mandatory and aspirational ethics. **CONCLUSIONS:** According to the findings, the Italian Professional Body (FNOPI) has issued a modern code for nursing professionals in which an aspirational perspective is dominant offering a good example for other nursing organisations in the process of updating their codes when aimed at embodying an aspirational ethics.

<https://doi.org/10.1186/s12912-024-01697-3>

L'usage de la génomique par les infirmier·es pour lutter contre les inégalités en santé

Dordunoo D., Limoges J., Chiu P., et al.

[Genomics-informed nursing strategies and health equity: A scoping review protocol](#)

PLoS One 2023;18(12):e0295914.

OBJECTIVE: The objective of this scoping review is to map the available evidence on strategies that nurses can use to facilitate genomics-informed healthcare to address health disparities. **INTRODUCTION:** Advancements in genomics over the last two decades have led to an increase in the delivery of genomics-informed health care. Although the integration of genomics into health care services continues to enhance patient outcomes, access to genomic technologies is not equitable, exacerbating existing health disparities amongst certain populations. As the largest portion of the health workforce, nurses play a critical role in the delivery of equitable genomics-informed care. However, little is known about how nurses can help address health disparities within the context of genomics-informed health care. A review of the literature will provide the necessary foundation to identify promising practices, policy, and knowledge gaps for further areas of inquiry. **INCLUSION CRITERIA:** We will include papers that explore strategies that nurses can undertake to facilitate genomics-informed care to address health disparities. **METHODS:** This review will be conducted using JBI methodology for scoping reviews. We will search electronic databases including MEDLINE (OVID), EMBASE, Cochrane Library, PsychInfo, and CINAHL for quantitative and qualitative studies, systematic reviews and grey literature. Theses, books, and unavailable full-text papers will be excluded. The search will be limited to papers from 2013 and beyond. Two reviewers will screen titles and abstracts followed by full-text and disagreements will be resolved by a third reviewer. We will use a data extraction tool using Microsoft Excel and analyse data using descriptive statistics and conventional content analysis. Findings will be presented in the form of evidence tables and a narrative summary. We will report findings using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). **DISCUSSION:** Genomics will continue to transform all aspects of health care across the wellness continuum from prevention, assessment, diagnosis, management, treatment, and palliative care. The identification of nursing strategies to address health disparities will build the foundation for policy and practice to ensure that the integration of genomic technologies benefits everyone.

<https://doi.org/10.1371/journal.pone.0295914>

Dire la vérité aux enfants gravement malades

El Ali M., Licqurish S., O'Neill J., et al.

Truth-telling to the seriously ill child – Nurses' experiences, attitudes, and beliefs

Nursing Ethics 2023;09697330231215952.

Background: Nurses play an integral role in the care of children hospitalised with a serious illness. Although information about diagnostics, treatments, and prognosis are generally conveyed to parents and caregivers of seriously ill children by physicians, nurses spend a significant amount of time at the child's bedside and have an acknowledged role in helping patients and families understand the information that they have been given by a doctor. Hence, the ethical role of the nurse in truth disclosure to children is worth exploring. *Methods:* A systematic academic database and grey literature search strategy was conducted using CINAHL, Medline Psych Info, and Google Scholar. Keywords used included truth, children, nurse, disclosure, serious illness, and communication. A total of 17 publications of varying types were included in the final data set. *Ethical Considerations:* As this was a review of the literature, there were no direct human participants. Empirical studies included in the review had received ethics approval. *Results:* Of the 17 articles included in the review, only one directly reported on the experiences of nurses asked to withhold the truth from patients. Empirical studies were limited to HIV-positive children and children diagnosed with cancer and the dying child. *Conclusion:* A paucity of literature exploring the experiences, attitudes, and beliefs of nurses with regard to truth-telling to seriously ill children is evident. Little consideration has been given to the role nurses play in communicating medical information to children in a hospital setting. The 17 articles included in the review focused on cancer, and HIV, diagnosis, and end-of-life care. Further research should be undertaken to explore the experiences and attitudes of nurses to clinical information sharing to children hospitalised with a wide range of serious illnesses and in diverse clinical scenarios.

<https://doi.org/10.1177/09697330231215952>

Perspectives d'étudiant·es infirmier·es sur la dignité en fin de vie

Farfán-Zúñiga X., Jaman-Mewes P.

Reflections of nursing students on the care of the person's dignity at the end of life: A qualitative study

Nurse Education Today 2023;133:106067.

BACKGROUND: The education of nursing students not only implies transmitting knowledge and clinical skills, but also values, attitudes, and behaviours. In healthcare, it is considered essential to respect and preserve the dignity of people. This is even more important in palliative care, where the fragility of people makes them potentially vulnerable. There is limited knowledge regarding the conceptualization and experience of nursing students and human dignity in palliative care. *AIM:* To describe how 5th-year nursing students conceptualise and experience human dignity, while caring for people with terminal illness. *DESIGN:* Qualitative descriptive design, with thematic content analysis as per Graneheim and Lundman. *SETTING:* A palliative care centre for people on low incomes with terminal illnesses which no longer respond to curative treatments. *PARTICIPANTS:* A total of 11 fifth-year nursing students who completed their professional practice in a palliative care unit. *METHODS:* Data collection was conducted through guided online reflections via reflective journaling between April and November 2020. The study protocol was reviewed and approved by the Scientific Ethical Committee within the educational institution (CEC2021065). *RESULTS:* Four thematic categories were identified (1) Concept of dignity; (2) Dignity: an essential element in the relationship with others, (3) Instances when the dignity of the person is not considered; (4) The value of reflection on dignity in clinical practice. *CONCLUSION:* Dignity is one of the main values recognized in the person. Dignity should be promoted in the education of future nursing professionals, particularly with people who are in the final stage of life, where fragility and vulnerability it is more palpable.

<https://doi.org/10.1016/j.nedt.2023.106067>

Pratiquer la contrainte en psychiatrie

Haines S., Stanton R., Anderson C., et al.

Ethical challenges for nurses delivering coercive interventions in community mental health settings: A scoping review

International Journal of Mental Health Nursing 2024

The number of Australians subject to coercive interventions in community mental health services continues to increase. This is in the context of a growing awareness of the harms from coercion, increasing concerns about potential breaches of human rights and an ongoing uncertainty regarding the clinical benefits of community treatment orders, the primary instrument of legislated coercion in community mental health services. Nurses in community mental health services are on the frontline with regard to coercion. They police the requirements of the community treatment order, administer medication to people in community settings without their consent and facilitate re-hospitalisation if indicated. Coercive practice contradicts the person-centred, recovery-oriented and trauma-informed care principles that inform contemporary mental health nursing. This contradiction may generate ethical challenges for nurses and result in ethical distress. The aim of this scoping review was to map the research literature on how nurses in community mental health settings recognise and manage the harm associated with the administration of coercive interventions and consider the ethical challenges that may arise within this practice. The search strategy yielded 562 studies with author consensus determining a total of three articles as meeting the inclusion criteria. The resulting literature identified three themes: (1) maintaining the therapeutic relationship, (2) promoting autonomy and (3) using subtle forms of control. This review demonstrated that there is minimal research that has considered the ethical challenges related to the use of coercion by nurses in community mental health settings.

<https://doi.org/10.1111/inm.13290>

Les liens entre le courage moral et la sécurité des soins

Kashani M., Bozorgzad P., Masror Roudsary D., et al.

The relationship between moral courage and providing safe care in nurses: A cross-sectional study

Journal of Education and Health Promotion 2023;12:352.

BACKGROUND: Moral courage is one of the moral virtues, which can have a great impact on the provision of safe care for patients. Providing safe care is one of the most significant and fundamental principles of healthcare. This study aimed to determine the relationship between moral courage and safe care among nurses and explain the factors predicting safe care. **MATERIALS AND METHODS:** This is a cross-sectional study conducted on 172 nurses who worked in selected hospitals affiliated with the Iran University of Medical Sciences in 2019. For this purpose, self-report questionnaires on moral courage and safe nursing care were used. The collected data were analyzed in the Statistical Package for Social Sciences (SPSS) version 23.0 using descriptive (mean, standard deviation, percentage, and frequency) and inferential (Pearson's correlation coefficient and multiple linear regression) statistics. *P* values less than 0.05 were considered statistically significant. **RESULTS:** Mean scores of nurses' moral courage and safe care were desirable (407.57 ± 53.97) and satisfactory (311.31 ± 39.48), respectively. There was a significant correlation between the scores of nursing safe care and moral courage ($r = 0.69$, $P < 0.001$). Moral courage, gender, and work experience explained 54% of the variance of nursing safe care. **CONCLUSION:** The results showed that there is a positive and significant relationship between safety care and moral courage. It seems that increasing nurses' awareness of ethical principles leads to their courageous ethical behaviors, and safety and high-quality care should be one of the goals of all healthcare professionals. Also, the results of this study support the need to improve the knowledge and awareness of nurses and nurse managers regarding the importance of moral courage in providing safe nursing care and improving patient safety.

https://doi.org/10.4103/jehp.jehp_977_22

La tension entre l'empathie et la détresse morale

Kovanci M.S., Atli Özbaş A.

Moral distress and moral sensitivity in clinical nurses

Research in Nursing & Health 2023

Health care providers are expected to have a certain moral sensitivity (MS) to make an ethical assessment. Moral distress (MD) is a common phenomenon in nursing. It can negatively affect nurses physically, psychologically, socially, and spiritually. This study aimed to investigate the relationship between MD and MS among nurses using a cross-sectional descriptive design. The study was conducted in two stages. The first stage was a methodological study that analyzed validity and reliability of the Measure of MD-Healthcare Professionals. The second stage was a descriptive-predictive analysis that investigated the relationship between MD and MS. The MD intensity and frequency scores of the participants were high and moderately high, respectively. There was no direct effect on the total score and frequency of MS and MD. However, a direct and significant negative effect of MS was seen on the intensity of MD. Based on the results of this study, MS should be considered as a measure in studies aimed at understanding MD among clinical nurses. Empowerment programs should be established to increase the awareness of health workers about ethical and moral situations and to support them to cope with the problems they experience in these areas.

<https://doi.org/10.1002/nur.22366>

L'impact des conflits de valeurs sur la santé des infirmier-es et des patient-es

Larsman P., Pousette A., Skyvell Nilsson M., et al.

Ethical value conflicts in healthcare and their effects on nurses' health, turnover intent, team effectiveness, and patient safety: a longitudinal questionnaire study

Scandinavian Journal of Work, Environment & Health 2024:4138.

OBJECTIVE: Moral distress emanating from value conflicts comprising ethical dimensions pose a threat to nurses' health and retention, as well as to the quality of care. The aim of the present study was to investigate the relationships between the frequency of ethical value conflicts (EVC), and the perceived distress when they occur, respectively, and nurses' work-related stress, burnout symptoms, turnover intent, team effectiveness, and patient safety. **METHODS:** A two-wave longitudinal cohort questionnaire study was performed among registered nurses at six hospitals in two Swedish regions. Cross-sectional analyses (T1) were based on 1817 nurses in 228 care units (CU), and longitudinal analyses (T1 - T2) on 965 nurses in 190 CU. Hypothesis testing was performed using multilevel controlled regression modeling. **RESULTS:** The results indicated that nurses who were often exposed to EVC also to a higher extent tended to report these conflicts as stressful. Frequent exposure to EVC induced by insufficient resources, inapt organizational structures or interpersonal staff relations were cross-sectionally associated with work-related stress, burnout symptoms, turnover intent, and team effectiveness. The longitudinal analyses indicated that EVC induced by a lack of resources primarily had negative effects on nurses' health and well-being. At the CU level, such conflicts also impaired team effectiveness. At the individual level, EVC induced by organizational constraints or interpersonal relations negatively affected care effectiveness. **CONCLUSIONS:** EVC are related to negative consequences in healthcare, and such processes take place both on the individual and organizational levels.

<https://doi.org/10.5271/sjweh.4138>

Faut-il nécessairement un engagement éthique pour bien pratiquer le métier d'infirmier·e ?

Lipscomb M.

Can professional nursing value claims be refused? Might nursing values be accepted provisionally and tentatively?

Nursing Inquiry 2024;;e12621.

Value-act relationships are less secure than is commonly supposed and this insecurity is leveraged to address two questions. First, can nurses refuse professional value claims (e.g., claims regarding care and compassion)? Second, even when value claims are accepted, might values be held provisionally and tentatively? These questions may seem absurd. Nurses deliver care and nursing is, we are told, a profession the members of which hold and share values. However, focusing attention on the problematic nature of professional value claims qua claims permits a more conciliatory and realistic stance to be taken towards nurses holding alternative values and value interpretations. This could prove beneficial.

<https://doi.org/10.1111/nin.12621>

Les facteurs d'un climat propice à l'éthique infirmière dans les services hospitaliers

Noh Y.G., Kim S.Y.

Factors of hospital ethical climate among hospital nurses in Korea: a protocol for systematic review and meta-analysis

BMJ open 2024;14(1):e078102.

INTRODUCTION: The hospital ethical climate refers to the ethical work environment within a hospital, which may positively or negatively impact individual nurses, nursing organisations and patient care. Most of studies investigating the hospital ethical climate among Korean nurses have been published in Korean. However, papers addressing the hospital ethical climate in Korean were excluded from the systematic review. To enhance our comprehension of the hospital ethical climate, a systematic review specifically focusing on Korean nurses is imperative. Additionally, it is crucial to ascertain the factors associated with the hospital ethical climate and their respective effect sizes through meta-analyses. **METHODS AND ANALYSIS:** The systematic search will be conducted for papers published in both Korean and English, encompassing the hospital ethics climate of Korean nurses from 10 database inception to May 2023. Two reviewers will independently review each article based on the inclusion and exclusion criteria, and any differences in opinion will be resolved through discussion and consensus. The study selection process will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. Quality assessment will be conducted using the Checklist for Analytical Cross-Sectional Studies provided by Joanna Briggs Institute. Effect size will be analysed using Comprehensive Meta-Analysis software V.2.0. The results of this study will identify factors related to the hospital ethical climate and the effect size of these factors among nurses in Korea. **ETHICS AND DISSEMINATION:** Ethical approval is not required, as the data will be collected from existing literature. Findings will be disseminated through peer-reviewed journal.

<https://doi.org/10.1136/bmjopen-2023-078102>

L'éthique infirmière du soin aux personnes transgenre

Rodríguez E.O., López E.G., Álvarez S.O., et al.

The ethics of nursing care for transgender people

Revista Brasileira De Enfermagem 2023;76Suppl 3(Suppl 3):e20220797.

OBJECTIVES: to discuss ethical aspects in nursing care for transgender people. **METHODS:** reflective study based on the dilemmas that emerges in nursing care for transgender people. The report was structured around the four bioethical principles. **RESULTS:** health care for trans people is complex, transversal to many devices and specialties

and longitudinal in time, that is why it requires coordinated action. There is an ethical framework in which the nursing care must be observed in the care of this group. FINAL CONSIDERATIONS: the nurse as a health worker can assume several general lines in the care of transgender patients. So, complementary training should be provided not only to professionals, but also to students of nursing and other health sciences.

<https://doi.org/10.1590/0034-7167-2022-0797>

L'influence du courage moral dans la pratique des infirmier·es en oncologie

Zheng H., Luo L., Tan X., et al.

Moral courage and its influencing factor among oncology specialist nurses: A multi-centre cross-sectional study

Nursing Open 2024;11(1):e2096.

AIM: Moral courage among healthcare workers has been extensively studied. However, few studies have been conducted on oncology specialist nurses, who frequently encounter complex moral situations. This study aimed to describe the current situation regarding moral courage and explored its influence on oncology specialist nurses in China. *DESIGN:* This was an exploratory, descriptive study. *METHODS:* A convenience sample of 390 nurses was conducted from 15 hospitals in Sichuan Province, China, between March and May 2023. Participants were assessed using the Moral Distress Scale-Revised, Nurses' Moral Courage Scale and the Moral Sensitivity Questionnaire. *RESULTS:* The results demonstrated that moral courage was negatively associated with moral distress, and positively associated with moral sensitivity. Having a master's degree or above, an intermediate title or senior title, medical ethics training, moral distress or moral sensitivity contributed to explaining 54.1% of the variance in moral courage. *CONCLUSIONS:* Moral courage was associated with several factors. Developing clinical intervention strategies and effective teaching methods will be critical for improving moral courage.

<https://doi.org/10.1002/nop2.2096>

BIOÉTHIQUE



Les enjeux de la contraception définitive

American College of Obstetricians and Gynecologists

Permanent Contraception: Ethical Issues and Considerations: ACOG Committee Statement No. 8

Obstetrics and Gynecology 2024;143(2):e31-e39.

Permanent contraception is the most used method of contraception among women aged 15-49 years and is one of the most straightforward surgical procedures an obstetrician-gynecologist can perform. At the same time, this therapeutic option is enormously complex when considered from a historical, sociological, or ethical perspective. This Committee Statement reviews ethical issues related to permanent contraception using a reproductive justice framework. Ethical counseling and shared decision making for permanent contraception should adopt a nonjudgmental, patient-centered approach, using up-to-date information about permanent contraception procedures and alternatives. Obstetrician-gynecologists should strive to avoid bringing into the clinical encounter biases around gender, race, age, and class that affect thoughts on who should or should not become a parent. Obstetrician-gynecologists should also ensure that permanent contraception requests reflect each patient's wishes, come from a desire to permanently end childbearing, and come from a preference for permanent contraception over all reversible methods as well as permanent contraception for the male partner. When difficulties in meeting a postpartum permanent contraception request are anticipated and permanent contraception is desired by the patient, transfer of care for the remainder of pregnancy should be offered. ACOG recognizes the right of all patients to unimpeded access to permanent contraception as a way of ensuring health equity, but it is unclear how to craft policies that protect from coercion but also do not create barriers to autonomously desired care. Determining the ethical balance between access and safeguards will require a collaborative interdisciplinary approach that involves a variety of stakeholders with varying perspectives.

<https://doi.org/10.1097/AOG.0000000000005474>

Le dépistage préconceptionnel

Cogan G.

Motifs de choix et de légitimité du dépistage préconceptionnel

Revue française d'éthique appliquée 2023;N° 14(1):155-171.

Jusqu'à présent réservé uniquement aux couples à risque élevé de transmettre une maladie génétique, l'extension du dépistage préconceptionnel (dpc) à l'ensemble de la population générale a été débattue lors de la dernière révision des lois de bioéthique, sans aboutir à une inscription dans la loi. Le dpc consisterait à proposer un test génétique aux futurs parents avant la conception. Cette analyse permettrait aux couples de connaître leur risque de transmettre certaines maladies génétiques et de les prévenir le cas échéant. Dans l'hypothèse d'une autorisation, ce dépistage pourrait concerner 750 000 couples par an en France. Les différentes études réalisées à ce jour semblent montrer qu'une large majorité est en faveur du dpc. Sous condition de respect du principe d'autonomie, les défenseurs du dpc mettent en avant la possibilité d'éviter des pathologies lourdes à de futurs enfants. À l'inverse, d'autres craignent que ce dépistage ne développe une vision perfectionniste de la société et crée de l'anxiété chez les futurs parents. Constatant qu'il n'existe aucune étude qualitative sur le processus décisionnel des couples dans le contexte du dpc, nous proposons d'explorer dans cet article les motifs de choix et de légitimité convoqués par quatre couples. Cette approche inductive permet en outre de faire émerger les interrogations, les perceptions, les réflexions mais aussi les tensions voire les disputes qui pourraient bientôt traverser les couples français dans l'hypothèse où un tel choix se poserait à eux dans quelques années.

<https://doi.org/10.3917/rfeap.014.0155>

La gestation ex-utero

Kennedy S.

Ectogenesis and the value of gestational ties

Bioethics 2024

Ectogenesis technology would make it possible to support the complete gestational development of a human being outside the female body. Proponents argue that this technology offers a welcome opportunity to expand reproductive options for those unable or unwilling to gestate. However, by completely bypassing pregnancy, the use of ectogenesis prevents the formation of gestational family ties. Consequently, it has faced criticism for perpetuating a patriarchal view of the family that undermines the moral significance of gestation. The concern is that the introduction of this technology might result in the loss of reproductive autonomy for those who desire to experience pregnancy, as they face pressures to opt for ectogenesis instead. Existing accounts of family values define parents' rights to rear a child, but they fail to establish a right to gestate that can protect an individual's interest in bearing a child. To provide a more comprehensive account of family values, I argue that pregnancy involves a unique quality of intimacy and can make distinct contributions to one's flourishing. Based on this premise, I defend a fundamental moral right to gestate that can help safeguard the option of pregnancy for those who desire it. In conclusion, I consider how a prospective gestator need not provide optimal conditions for fetal development in the way that ectogenesis promises in order for their choice of pregnancy to be justified.

<https://doi.org/10.1111/bioe.13260>

La cryoconservation ovocytaire pour des raisons sociales

Lahoti U., Pajai S., Shegekar T., et al.

Exploring the Landscape of Social Egg Freezing: Navigating Medical Advancements, Ethical Dilemmas, and Societal Impacts

Cureus 2023;15(10):e47956.

This narrative review article comprehensively explores the multifaceted landscape of social egg freezing, delving into its medical, ethical, societal, psychological, legal, and cultural dimensions. Oocyte cryopreservation, a developing procedure, gives women the chance to match their life goals with fertility goals. Informed decision-making, morally sound guidance, and open communication are all stressed by ethical considerations. Family planning practices, workplace cultures, and gender equality all have an impact on societal dynamics. The process's

emotional toll and associated coping mechanisms are highlighted by psychological elements. Legal and policy frameworks need constant ethical reflection and understanding of the regulatory environment. Religious and cultural views highlight the variety of perspectives that influence attitudes toward this practice. For responsible practice to ensure individual liberty while navigating the evolving landscape of reproductive options, it is essential to comprehend how these aspects interact.

<https://doi.org/10.7759/cureus.47956>

Une perspective internationale sur la justice reproductive

Arguedas-Ramírez G., Wenner D.M.

Reproductive Justice Beyond Borders: Global Feminist Solidarity in the Post-Roe Era

The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 2023;51(3):606-611.

The global impact of *Dobbs v. Jackson Women’s Health Organization* and the backlash towards reproductive justice that it represents warrant a global feminist response informed by broad theoretical and geopolitical lenses. We consider how a solidaristic, transnational feminist movement might learn from Latin American feminist movements that have been successful in uniting broad coalitions in the fight for reproductive justice as situated within far-reaching political goals. The success of such a global movement must be decolonial and must contend with the fact that overlapping realities of global inequality, severe poverty, extractivism, and western-backed violence are fundamentally implicated in reproductive justice.

<https://doi.org/10.1017/jme.2023.101>

L’éuthanasie pour souffrance psychologique irréversible

Bersani G., Rinaldi R., Iannitelli A.

The case of Geneviève Lhermitte’s euthanasia between psychiatric evaluation, legal aspects and ethical reflection

Rivista Di Psichiatria 2023;58(6):305-309.

A recent euthanasia case in Belgium has garnered attention due to its particularly dramatic aspects, sparking clinical and ethical questions about end-of-life choices in cases of mental suffering. A 56-year-old woman, convicted of the murder of her five minor children and sentenced to life imprisonment, has been granted euthanasia for “irreversible psychological suffering”. The clinical and psychodynamic aspects of the case, primarily deduced from press reports, are highly complex and give rise to numerous clinical, medico-legal, and bioethical questions. These include inquiries into the true nature of psychopathology, its actual irreversibility, its impact on the ability to express a euthanasia request with adequate awareness, the preserved capacity for self-determination, and broader issues related to end-of-life requests from patients with mental disorders. These aspects are considered in the context of the legislation in various European countries. The unique details of this case underscore the critical challenges associated with these complex issues.

<https://doi.org/10.1708/4143.41411>

La place de la psychiatrie dans l’aide médicale à mourir

Chastang F.

Autonomie revendiquée et aide médicale à mourir, la place de la psychiatrie

Soins. Psychiatrie 2024;45(350):22-25.

L’autonomie devenue valeur supérieure de notre société, tout en impactant le débat sur une future loi autour de l’aide médicale à mourir, ouvre la porte à une réflexion sur les vulnérabilités. Bien qu’en apparence non concernée, du moins dans un premier temps, la psychiatrie pourrait rejoindre le champ de cette réflexion et en faire émerger les pistes d’un renouveau.

<https://doi.org/10.1016/j.spsy.2023.11.006>

Les perspectives d'étudiant·es en médecine sur l'euthanasie

Dedivitis R.A., Matos L.L. de, Castro M.A.F. de, et al.

Medical students' and residents' views on euthanasia

BMC medical ethics 2023;24(1):109.

BACKGROUND: Doctors are increasingly faced with end-of-life decisions. Little is known about how medical students approach euthanasia. The objective of this study was to evaluate, among medical students and residents, the view on euthanasia and its variants; correlate such a view with empathy and religiosity/spiritualism; and with the stages of medical training in Brazil. **METHODS:** This is an exploratory cross-sectional study using an online questionnaire to be filled out on a voluntary basis among medical students and residents, consisting of: socio-demographic data, an empathy questionnaire and questions with elaborate clinical cases that typify situations of the variants of euthanasia. **RESULTS:** From 1550 invitations, 273 volunteer participants responded (17.6%). The percentages of strong agreement/agreement on the concepts were: passive euthanasia (72.9%); active euthanasia (22.3%), orthothanasia (90.1%), dysthanasia (18.7%), assisted suicide (33%) and sedation (82.8%). Passive euthanasia, active euthanasia, dysthanasia and assisted suicide showed greater refusal with increasing length of medical training. Religious belief and degree of empathy did not significantly influence the opinion about the concepts. Strong agreement/agreement were: passive euthanasia (72.9%); active euthanasia (22.3%), orthothanasia (90.1%), dysthanasia (18.7%), assisted suicide (33%) and sedation (82.8%). **CONCLUSIONS:** Passive euthanasia, active euthanasia, dysthanasia and assisted suicide showed greater refusal with increasing length of medical training. The external validation of our findings relies on the distinct legal, cultural, and religious frameworks found across various countries.

<https://doi.org/10.1186/s12910-023-00986-x>

Les enjeux de la transplantation de visage

Boppana S.H., Kutikuppala L.V.S., Kalyani P.S.V.

Face Transplantation: What You Need to Know?

Journal of Cutaneous and Aesthetic Surgery 2023;16(3):232-236.

Since the 1990s, face transplants have gotten a lot of press and public attention across the world. After a transplant was disclosed in November 2005, the first recipient, Isabelle Dinoire, found herself at the center of a spectacular event of surgical innovation. Up till August 2020, 47 transplants have been performed globally (including two retransplants), all of which have received substantial media attention. Hundreds of publications addressing the procedure's medicinal, physical, psychological, and ethical ramifications have been published in the scholarly literature, far outnumbering the procedure's occurrence. Face transplants have also appeared in films, television shows, and novels, indicating a desire to explore the social and interpersonal consequences of face variance. This is an attempt to present a comprehensive context of face transplantation progress and practice, based mostly on extant documentary sources. It traces the history of face transplants, identifying major milestones and themes along the way and focusing on its development as a therapeutic option for individuals with severe facial abnormalities. There are still important questions to be asked about the patient's perspective, as well as the complex philosophical and sociological meanings of the face, but this article focuses on the institutional and cultural factors that have allowed for such an ethically complex and radical surgery to take place. Opportunity and financial feasibility are among them, as are expertise, ambition, and an awareness of patient needs.

https://doi.org/10.4103/JCAS.JCAS_45_22

La souffrance morale des équipes de transplantation

David H.S., Rosell T., Hughes D.

Moral Injury Among Transplant Providers: Evaluating the Effects of Training in End-of-Life Counseling

Kansas Journal of Medicine 2023;16:324-327.

INTRODUCTION: Ethical issues are pervasive in healthcare, but few specialties rival the moral complexity of transplant medicine. Transplant providers must regularly inform patients that they are no longer eligible to receive

a potentially life-saving operation and the stress of these conversations poses a high risk of moral injury. Training in end-of-life counseling (EOLC) has proven to significantly reduce provider stress and burnout. The purpose of this study was to determine whether training in EOLC reduces levels of moral injury among transplant providers. METHODS: This was a mixed methods study. We interviewed 10 patient participants and administered a survey to staff in the solid organ transplant department at the University of Kansas Health System. Respondents indicated whether they had received training in EOLC and completed the standardized Moral Injury Symptom Scale-Healthcare Professionals version (MISS-HP). A two-sample, one-sided t-test compared levels of moral injury between trained and untrained staff. Subsequently, we conducted semi-structured interviews with transplant providers, then performed inductive coding followed by thematic network analysis. RESULTS: Thirty-seven percent (14/38) of respondents reported a moral injury score at or above the threshold for psychosocial dysfunction associated with moral injury. Analysis revealed no difference in moral injury scores between the trained and untrained groups ($p = 0.362$, power $(1-\beta) = 0.842$). Thematic network analysis demonstrated high-level themes of « challenges », « training », and « stress relief ». CONCLUSIONS: Our study demonstrated a concerning prevalence of moral injury among transplant staff and suggested that EOLC training did not significantly mitigate the threat of moral injury.

<https://doi.org/10.17161/kjm.vol16.21171>

La manipulation des gènes dans la culture de plantes

Idris S.H., Mat Jalaluddin N.S., Chang L.W., et al.

Ethical and legal implications of gene editing in plant breeding: a systematic literature review

Journal of Zhejiang University. Science. B 2023;24(12):1093-1105.

Biotechnology policies and regulations must be revised and updated to reflect the most recent advances in plant-breeding technology. New Plant Breeding Techniques (NPBT) such as gene editing have been applied to address the myriad of challenges in plant breeding, while the use of NPBT as emerging biotechnological tools raises legal and ethical concerns. This study aims to highlight how gene editing is operationalized in the existing literature and examine the critical issues of ethical and legal issues of gene editing for plant breeding. We carried out a systematic literature review (SLR) to provide the current states of ethical and legal discourses surrounding this topic. We also identified critical research priority areas and policy gaps that must be addressed when designing the future governance of gene editing in plant breeding.

<https://doi.org/10.1631/jzus.B2200601>

Modifier les génomes est-il un risque évolutif majeur ?

Kozan D.W., Farber S.A.

Is It Ever Wise to Edit Wild-Type Alleles? Engineered CRISPR Alleles Versus Millions of Years of Human Evolution

Arteriosclerosis, Thrombosis, and Vascular Biology 2023

The tremendous burden of lipid metabolism diseases, coupled with recent developments in human somatic gene editing, has motivated researchers to propose population-wide somatic gene editing of PCSK9 (proprotein convertase subtilisin/kexin type 9) within the livers of otherwise healthy humans. The best-characterized molecular function of PCSK9 is its ability to regulate plasma LDL (low-density lipoprotein) levels through promoting LDL receptor degradation. Individuals with loss-of-function PCSK9 variants have lower levels of plasma LDL and reduced cardiovascular disease. Gain-of-function variants of PCSK9 are strongly associated with familial hypercholesterolemia. A new therapeutic strategy delivers CRISPR/Cas9 specifically to liver cells to edit the wild-type alleles of PCSK9 with the goal of producing a loss-of-function allele. This direct somatic gene editing approach is being pursued despite the availability of FDA-approved PCSK9 inhibitors that lower plasma LDL levels. Here, we discuss other characterized functions of PCSK9 including its role in infection and host immunity. We explore important factors that may have contributed to the evolutionary selection of PCSK9 in several vertebrates, including humans. Until such time that more fully understand the multiple biological roles of PCSK9, the ethics of permanently editing the gene locus in healthy, wild-type populations remains highly questionable.

<https://doi.org/10.1161/ATVBAHA.123.318069>

Les différents sens de l'identité et leurs liens avec l'altération du génome

Liaw Y.-Q.

An analysis of different concepts of « identity » in the heritable genome editing debate

Medicine, Health Care, and Philosophy 2024

Human heritable genome editing (HHGE) involves editing the genes of human gametes and/or early human embryos. Whilst « identity » is a key concept underpinning the current HHGE debate, there is a lack of inclusive analysis on different concepts of « identity » which renders the overall debate confusing at times. This paper first contributes to reviewing the existing literature by consolidating how « identity » has been discussed in the HHGE debate. Essentially, the discussion will reveal an ontological and empirical understanding of identity when different types of identity are involved. Here, I discuss genetic, numerical, qualitative and narrative and how each of them is relevant in the HHGE context. Secondly, given the different types of identity, the paper explores how we could navigate these different interpretations of identity in a way that promotes an inclusive and informed discussion between primary stakeholders and the general public in the HHGE debate. Here, I argue for and refine a multi-faceted concept of identity as a suitable framework for discussing the ethical and societal implications of HHGE because it not only could integrate different understandings of identity but also highlight the interconnectedness between these different understandings.

<https://doi.org/10.1007/s11019-023-10189-1>

Ce que les hémophiles attendent de la thérapie génique

Baas L., Meijer K., Driessens M., et al.

Ethical aspects of hemophilia gene therapy: a qualitative interview study with stakeholders

Research and Practice in Thrombosis and Haemostasis 2023;7(7):102237.

BACKGROUND: There are great expectations for the potential role of gene therapy in the treatment of hemophilia. At the same time, developments in the field of hemophilia gene therapy have always raised ethical issues. It remains unknown how these ethical issues are perceived by stakeholders, particularly regarding the most recent developments in the field. **OBJECTIVES:** To obtain insight into stakeholders' morally reasoned opinions on gene therapy for hemophilia. **METHODS:** We conducted qualitative research with Dutch people with hemophilia (n = 13), parents of children with hemophilia (n = 5), physicians (n = 4), nurses (n = 3), a regulator (n = 1), and a representative from a pharmaceutical company (n = 1). We conducted semistructured interviews based on a topic list and reported the results according to the Consolidated Criteria for Reporting Qualitative Research guidelines. **RESULTS:** We identified 3 main themes. The theme freedom and independence describes the hope people with hemophilia have of increasing their freedom through gene therapy, as well as concerns that gene therapy increases their dependence on their treatment center. The theme trust and altruism describes how people with hemophilia have a high level of trust in their physician and treatment center as well as in scientific research. As a result of this trust, they are willing to participate in research to help other people with hemophilia. The theme incremental benefits describes doubts respondents have about the added value of gene therapy compared to standard treatment. **CONCLUSION:** Stakeholders embrace the theoretical potential of gene therapy, while several people with hemophilia question the added value of the current gene transfer products for themselves.

<https://doi.org/10.1016/j.rpth.2023.102237>

Les embryons humains génétiquement modifiés

Ouzaid A., Oancea V.G., Ravel C.

Embryons humains génétiquement modifiés: entre progrès scientifique et dilemmes éthiques

Éthique & Santé 2023;20(4):278-284.

Les premiers êtres humains dont le génome a été modifié sont nés en Chine en 2018. Le développement vertigineux des outils de manipulation génétique nous amène à nous questionner sur les risques potentiels pour ces enfants. Si les conséquences à long terme sont encore inconnues, on sait déjà que leur génome germinal

génétiquement modifié sera transmis de façon irréversible à leur descendance. Le but de cet article est de comprendre et analyser les enjeux éthiques de la modification du génome humain.

<https://doi.org/10.1016/j.etiqe.2023.09.001>

Les modèles embryonnaires dérivés de cellules souches humaines

Villalba A., Rueda J., Miguel Beriain Í. de

[Human stem-cell-derived embryo models: When bioethical normativity meets biological ontology](#)

Developmental Biology 2024;508:88-92.

The use of human stem-cell-derived embryo models in biomedical research has recently sparked intense bioethical debates. In this article, we delve into the ethical complexities surrounding these models and advocate for a deeper exploration of their biological ontology to discuss their bioethical normativity. We examine the ethical considerations arising from the implementation of these models, emphasizing varying viewpoints on their ethical standing and the ethical obligations associated with their development and utilization. We contend that a nuanced comprehension of their biological ontology is crucial for navigating these ethical quandaries. Furthermore, we underscore the indispensability of interdisciplinary cooperation among bioethicists, biologists, and philosophers to unravel the complex interplay between biological ontology and the normative framework of bioethics. Moreover, this article introduces a novel combinatorial approach to resolve the ethical dilemma surrounding these models. We propose a distinction between models that closely emulate natural embryos, based on the status of synthetic embryos, and those capable of reproducing specific dimensions of embryonic development. Such differentiation allows for nuanced ethical considerations while harnessing the value of these models in scientific research, paving the way for a more comprehensive ethical framework in the context of evolving biotechnologies.

<https://doi.org/10.1016/j.ydbio.2024.01.009>

La recherche en bioéthique à l'intersection entre machine learning et génomique

Sen S.K., Green E.D., Hutter C.M., et al.

[Opportunities for basic, clinical, and bioethics research at the intersection of machine learning and genomics](#)

Cell Genomics 2023:100466.

The data-intensive fields of genomics and machine learning (ML) are in an early stage of convergence. Genomics researchers increasingly seek to harness the power of ML methods to extract knowledge from their data; conversely, ML scientists recognize that genomics offers a wealth of large, complex, and well-annotated datasets that can be used as a substrate for developing biologically relevant algorithms and applications. The National Human Genome Research Institute (NHGRI) inquired with researchers working in these two fields to identify common challenges and receive recommendations to better support genomic research efforts using ML approaches. Those included increasing the amount and variety of training datasets by integrating genomic with multiomics, context-specific (e.g., by cell type), and social determinants of health datasets; reducing the inherent biases of training datasets; prioritizing transparency and interpretability of ML methods; and developing privacy-preserving technologies for research participants' data.

<https://doi.org/10.1016/j.xgen.2023.100466>

La bioéthique translationnelle

Baerøe K.

[Translational bioethics: Reflections on what it can be and how it should work](#)

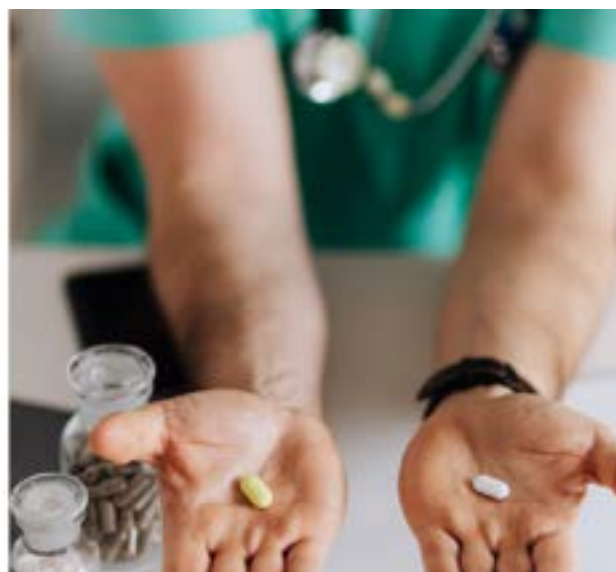
Bioethics 2024

Translational ethics (TE) has been developed into a specific approach, which revolves around the argument that strategies for bridging the theory-practice gap in bioethics must themselves be justified on ethical terms. This

version of TE incorporates normative, empirical and foundational ethics research and continues to develop through application and in the face of new ethical challenges. Here, I explore the idea that the academic field of bioethics has not yet sufficiently analysed its own philosophical foundation for how it can, and should, be practically relevant; neither has it comprehensively discussed the limitations on what impacts bioethicists should pursue. As a result, there has not been adequate training on how to suitably and appropriately impact real-world practices. Moreover, bioethical perspectives are often competing with other strong interests, for example, economic and political, which may weaken their impact on policy-making. The TE approach I propose can not only facilitate practical impacts of academic bioethics by being better informed by real-world ethical issues but it also supports targeted and ethical justifications of the actual impact of academic work in real-world contexts. In this paper, I clarify the premises for this TE approach, identify further challenges and sketch out potential solutions for the implementation of this methodological framework.

<https://doi.org/10.1111/bioe.13263>

ÉTHIQUE DE LA RECHERCHE



L'éthique en recherche préclinique

Buedo P., Prieto E., Perek-Białas J., et al.

[More ethics in the laboratory, please! Scientists' perspectives on ethics in the preclinical phase](#)

Accountability in Research 2024;1-16.

In recent years there have been calls to improve ethics in preclinical research. Promoting ethics in preclinical research should consider the perspectives of scientists. Our study aims to explore researchers' perspectives on ethics in the preclinical phase. Using interviews and focus groups, we collected views on ethical issues in preclinical research from experienced (n = 11) and early-stage researchers (ESRs) (n = 14) working in a gene therapy and regenerative medicine consortium. A recurring theme among ESRs was the impact of health-related preclinical research on climate change. They highlighted the importance of strengthening ethics in relations within the scientific community. Experienced researchers were focused on technicalities of methods used in preclinical research. They stressed the need for more safeguards to protect the sensitive personal data they work with. Both groups drew attention to the importance of the social context of research and its social impact. They agreed that it is important to be socially responsible - to be aware of and be sensitive to the needs and views of society. This study helps to identify key ethical challenges and, when combined with more data, can ultimately lead to informed and evidence-based improvements to existing regulations.

<https://doi.org/10.1080/08989621.2023.2294996>

La recherche participative avec les personnes âgées

Dahlin-Ivanoff S., Berge I., Barenfeld E., et al.

[Research collaboration with older people as a matter of scientific quality and ethics: a focus group study with researchers in ageing and health](#)

Research Involvement and Engagement 2024;10(1):6.

BACKGROUND: Society is placing increasing demands on collaboration with actors outside the academia to be involved in the research process, and the responsibility for turning this into reality lies with the researchers. As research collaboration is a way to increase the societal relevance of research and since older people have the right to be actively involved in research that concerns them, this study is addressed to researchers who work with and

for older people. The purpose of this article is to explore researchers' experiences of research collaboration with the heterogeneous group of older people, from healthy to frail. **METHODS:** The focus group method was applied based on a qualitative approach that is based on a social constructivist research tradition. It differs from other qualitative methods, such as interviews, in that it encourages interaction between research participants and contributes to shedding light on a collective understanding of the world. A total of 14 researchers participated in four focus groups (three to five participants/group). **RESULTS:** The results provided support for the overall theme: « Good scientific quality and ethics are balanced against the needs and abilities of older people ». This means a balance between the researcher and the older people collaborating with them to receive the best possible scientific quality. This is highlighted in the core category « Positioning for research collaboration » with the subcategories « Involvement or not », « Traditional or innovative thinking » and « Selectivity or representativeness », and the core category « Research collaboration - an ethical issue of power » with the subcategories « Research collaboration a risk for freedom of research », « Research collaboration a risk of abuse of power » and « Discriminatory academic power structures create ethical issues ». **CONCLUSIONS:** Addressing the balancing act of collaborating with older people in research, the findings contribute with an understanding of the importance of researchers' awareness of social and academic structures to minimise the risk of epistemic injustices in research on ageing and health. We want to highlight the researchers' voice and clarify the role that researchers have in terms of the opportunities for older people to become part of the collective understanding of ageing and health and make their voices heard.

<https://doi.org/10.1186/s40900-024-00540-y>

L'équité dans la recherche participative translationnelle

Modlin C., Sugarman J., Chongwe G., et al.

Towards achieving transnational research partnership equity: lessons from implementing adaptive platform trials in low- and middle-income countries

Wellcome Open Research 2023;8:120.

BACKGROUND: Use of adaptive clinical trials, particularly adaptive platform trials, has grown exponentially in response to the coronavirus disease (COVID-19) pandemic. Implementation of these trials in low- and middle-income countries (LMICs) has been fostered through the formation or modification of transnational research partnerships, typically between research groups from LMICs and high-income countries (HICs). While these partnerships are important to promote collaboration and overcome the structural and economic disadvantages faced by LMIC health researchers, it is critical to focus attention on the multiple dimensions of partnership equity. **METHODS:** Based on informal literature reviews and a meeting with leaders of one of the multinational COVID-19 adaptive platform trials, we describe some important considerations about research partnership equity in this context. **RESULTS:** We organize these considerations into eight thematic categories: 1) epistemic structures, 2) funding, 3) ethics oversight, 4) regulatory oversight, 5) leadership, 6) post-trial access to interventions, data, and specimens, 7) knowledge translation and dissemination, and 8) research capacity strengthening and maintenance. Within each category we review normative claims that support its relevance to research partnership equity followed by discussion of how adaptive platform trials highlight new dimensions, considerations, or challenges. **CONCLUSION:** In aggregate, these observations provide insight into procedural and substantive equity-building measures within transnational global health research partnerships more broadly.

<https://doi.org/10.12688/wellcomeopenres.18915.2>

Le concept de justice dans la recherche par analyse secondaire de données

Herington J., Li K., Pisani A.R.

Expanding the role of justice in secondary research using digital psychological data

The American Psychologist 2024;79(1):123-136.

Secondary analysis of digital psychological data (DPD) is an increasingly popular method for behavioral health research. Under current practices, secondary research does not require human subjects research review so long as data are de-identified. We argue that this standard approach to the ethics of secondary research (i.e., de-identification) does not address a range of ethical risks and that greater emphasis should be placed on the ethical principle of justice. We outline the inadequacy of an individually focused research ethic for DPD and describe

unaddressed « social risks » generated by secondary research of DPD. These risks exist in the « circumstances of justice »: that is, a circumstance where individuals must cooperate to create a public good (e.g., research knowledge), and where it is impractical to individually exempt individuals. This requires researchers to emphasize the just allocation of benefits and burdens against a background of social cooperation. We explore six considerations for researchers who wish to conduct research with DPD without explicit consent: (a) create socially valuable knowledge, (b) fairly share the benefits and burdens of research, (c) be transparent about data use, (d) create mechanisms for withdrawal of data, (e) ensure that stakeholders can provide input into the design and implementation of the research, and (f) responsibly report results. (PsycInfo Database Record (c) 2024 APA, all rights reserved).

<https://doi.org/10.1037/amp0001190>

L'éthique de la parole des experts

Desmond H.

The ethics of expert communication

Bioethics 2023

Despite its public visibility and impact on policy, the activity of expert communication rarely receives more than a passing mention in codes of scientific integrity. This paper makes the case for an ethics of expert communication, introducing a framework where expert communication is represented as an intrinsically ethical activity of a deliberative agent. Ethical expert communication cannot be ensured by complying with various requirements, such as restricting communications to one's area of expertise or disclosing conflicts of interest. Expert communication involves morally laden trade-offs that must be weighed by a deliberative agent. A basic normative framework is introduced, and concrete provisions are proposed for codes of scientific integrity.

<https://doi.org/10.1111/bioe.13249>

La distinction entre recherche et soins

Heynemann S., Lipworth W., McLachlan S.-A., et al.

Therapeutic misunderstandings in modern research

Bioethics 2023

Clinical trials play a crucial role in generating evidence about healthcare interventions and improving outcomes for current and future patients. For individual trial participants, however, there are inevitably trade-offs involved in clinical trial participation, given that trials have traditionally been designed to benefit future patient populations rather than to offer personalised care. Failure to understand the distinction between research and clinical care and the likelihood of benefit from participation in clinical trials has been termed the « therapeutic misconception ». The evolution of the clinical trials landscape, including greater integration of clinical trials into healthcare and development of novel trial methodologies, may reinforce the significance of the therapeutic misconception and other forms of misunderstanding while at the same time (paradoxically) challenging its salience. Using cancer clinical trials as an exemplar, we describe how methodological changes in early- and late-phase clinical trial designs, as well as changes in the design and delivery of healthcare, impact upon the therapeutic misconception. We suggest that this provides an impetus to re-examine the ethics of clinical research, particularly in relation to trial access, participant selection, communication and consent, and role delineation.

<https://doi.org/10.1111/bioe.13241>

L'équité de l'inclusion dans les essais cliniques

Igwe J.-K., Wangdak Yuthok T.Y., Cruz E., et al.

Opportunities to Increase Science of Diversity and Inclusion in Clinical Trials: Equity and a Lack of a Control

Journal of the American Heart Association 2023;12(24):e030042.

The United States witnessed a nearly 4-fold increase in personal health care expenditures between 1980 and 2010. Despite innovations and obvious benefits to health, participants enrolled in clinical trials still do not accurately represent the racial and ethnic composition of patients nationally or globally. This lack of diversity in cohorts limits the generalizability and significance of results among all populations and has deep repercussions for patient equity. To advance diversity in clinical trials, robust evidence for the most effective strategies for recruitment of diverse participants is needed. A major limitation of previous literature on clinical trial diversity is the lack of control or comparator groups for different strategies. To date, interventions have focused primarily on (1) community-based interventions, (2) institutional practices, and (3) digital health systems. This review article outlines prior intervention strategies across these 3 categories and considers health policy and ethical incentives for substantiation before US Food and Drug Administration approval. There are no current studies that comprehensively compare these interventions against one another. The American Heart Association Strategically Focused Research Network on the Science of Diversity in Clinical Trials represents a multicenter, collaborative network between Stanford School of Medicine and Morehouse School of Medicine created to understand the barriers to diversity in clinical trials by contemporaneous head-to-head interventional strategies accessing digital, institutional, and community-based recruitment strategies to produce informed recruitment strategies targeted to improve underrepresented patient representation in clinical trials.

<https://doi.org/10.1161/JAHA.123.030042>

Désigner équitablement les auteurs et autrices d'articles de recherche

Lewis H., Biesecker B., Lee S.S.-J., et al.

Promoting equity, inclusion, and efficiency: A team science approach to the development of authorship guidelines for a multi-disciplinary research team

Journal of Clinical and Translational Science 2023;7(1):e265.

Large research teams and consortia present challenges for authorship. The number of disciplines involved in the research can further complicate approaches to manuscript development and leadership. The CHARM team, representing a multi-disciplinary, multi-institutional genomics implementation study, participated in facilitated discussions inspired by team science methodologies. The discussions were centered on team members' past experiences with authorship and perspectives on authorship in a large research team context. Team members identified challenges and opportunities that were used to create guidelines and administrative tools to support manuscript development. The guidelines were organized by the three values of equity, inclusion, and efficiency and included eight principles. A visual dashboard was created to allow all team members to see who was leading or involved in each paper. Additional tools to promote equity, inclusion, and efficiency included providing standardized project management for each manuscript and making « concept sheets » for each manuscript accessible to all team members. The process used in CHARM can be used by other large research teams and consortia to equitably distribute lead authorship opportunities, foster coauthor inclusion, and efficiently work with large authorship groups.

<https://doi.org/10.1017/cts.2023.685>

Utiliser l'IA pour rédiger des articles de recherche

Miao J., Thongprayoon C., Suppadungsuk S., et al.

Ethical Dilemmas in Using AI for Academic Writing and an Example Framework for Peer Review in Nephrology Academia: A Narrative Review

Clinics and Practice 2023;14(1):89-105.

The emergence of artificial intelligence (AI) has greatly propelled progress across various sectors including the field of nephrology academia. However, this advancement has also given rise to ethical challenges, notably in scholarly writing. AI's capacity to automate labor-intensive tasks like literature reviews and data analysis has created opportunities for unethical practices, with scholars incorporating AI-generated text into their manuscripts, potentially undermining academic integrity. This situation gives rise to a range of ethical dilemmas that not only question the authenticity of contemporary academic endeavors but also challenge the credibility of the peer-review process and the integrity of editorial oversight. Instances of this misconduct are highlighted, spanning from lesser-known journals to reputable ones, and even infiltrating graduate theses and grant applications. This subtle AI intrusion hints at a systemic vulnerability within the academic publishing domain, exacerbated by the publish-or-perish mentality. The solutions aimed at mitigating the unethical employment of AI in academia include the adoption of sophisticated AI-driven plagiarism detection systems, a robust augmentation of the peer-review process with an « AI scrutiny » phase, comprehensive training for academics on ethical AI usage, and the promotion of a culture of transparency that acknowledges AI's role in research. This review underscores the pressing need for collaborative efforts among academic nephrology institutions to foster an environment of ethical AI application, thus preserving the esteemed academic integrity in the face of rapid technological advancements. It also makes a plea for rigorous research to assess the extent of AI's involvement in the academic literature, evaluate the effectiveness of AI-enhanced plagiarism detection tools, and understand the long-term consequences of AI utilization on academic integrity. An example framework has been proposed to outline a comprehensive approach to integrating AI into Nephrology academic writing and peer review. Using proactive initiatives and rigorous evaluations, a harmonious environment that harnesses AI's capabilities while upholding stringent academic standards can be envisioned.

<https://doi.org/10.3390/clinpract14010008>

Les enjeux éthiques de l'approche photovoix en santé communautaire

Ng C.G., Ting S.Q., Saifi R.A., et al.

Ethical Issues in Photovoice Studies involving Key Populations: A Scoping Review

Asian Bioethics Review 2024;16(1):109-129.

Photovoice, a community-based participatory research method, employs images and words to convey participants' needs, concerns, and desires. It proves particularly valuable in researching marginalized communities who face elevated health risks, disease transmission, and social and health disparities. This paper seeks to investigate the ethical considerations inherent in photovoice research projects. We conducted an extensive literature review spanning four databases to identify pertinent photovoice studies. Ethical issues from the selected articles were identified, categorized, and summarized. Our analysis of twenty-five photovoice studies uncovered various ethical concerns, which had been grouped into informed consent, participant safety and disclosure, privacy and confidentiality, misrepresentation, power dynamics, and compensation. In essence, our findings underscore the importance of addressing these ethical concerns to uphold the rights and autonomy of participants, even as photovoice research strives for authenticity, inclusivity, and empowerment.

<https://doi.org/10.1007/s41649-023-00264-3>

Les enjeux éthiques de la recherche génomique

Nuffield Council on Bioethics

Towards a gold standard of ethics across genomic healthcare and research: Where are we?

Nuffield Council on Bioethics 2024

Key points: Individuals and organisations across the genomic healthcare and research field should work together to share thinking, embed existing work and, where possible, reach consensus. This will require engagement from all those involved across genomics including patients, research participants, researchers, clinicians, policymakers and funders. We conclude that a UK-wide co-ordination role will be required to ensure that these actions can be taken forward.

Développer un living lab en éthique

Racine E., D'Anjou B., Dallaire C., et al.

Developing a living lab in ethics: Initial issues and observations

Bioethics 2023

Living labs are interdisciplinary and participatory initiatives aimed at bringing research closer to practice by involving stakeholders in all stages of research. Living labs align with the principles of participatory research methods as well as recent insights about how participatory ways of generating knowledge help to change practices in concrete settings with respect to specific problems. The participatory, open, and discussion-oriented nature of living labs could be ideally suited to accompany ethical reflection and changes ensuing from reflection. To our knowledge, living labs have not been explicitly trialed and reported in ethics literature. In this discussion paper, we report and discuss four initial issues that marked the process of setting up a living lab in ethics: (1) determining the goals and expected outcomes of an ethics living lab; (2) establishing operational procedures; (3) selecting communities and defining pilot projects; and (4) adopting a lens to tackle emerging questions and challenges. We explain these four issues and present the paths taken based on the novel and specific orientation, that is, living ethics, at the basis of this project. In alignment with living ethics and É-LABO, we approach challenges as learning opportunities to ask not only « how » questions but also « why » questions. We hope that this discussion paper informed by our experience helps to clarify the theoretical, methodological, and practical approaches necessary to successfully adopt and employ living labs in ethics.

<https://doi.org/10.1111/bioe.13246>

Pour quels bénéfices peut-on justifier les risques d'une recherche

Rijssel T.I. van, Thiel G.J.M.W. van, Gardarsdottir H., et al.

Which Benefits Can Justify Risks in Research?

The American journal of bioethics: AJOB 2024;:1-11.

Research ethics committees (RECs) evaluate whether the risk-benefit ratio of a study is acceptable. Decentralized clinical trials (DCTs) are a novel approach for conducting clinical trials that potentially bring important benefits for research, including several collateral benefits. The position of collateral benefits in risk-benefit assessments is currently unclear. DCTs raise therefore questions about how these benefits should be assessed. This paper aims to reconsider the different types of research benefits, and their position in risk-benefit assessments. We first propose a categorization of research benefits, based on the types of benefits that can be distinguished from the literature and ethical guidelines. Secondly, we will reconsider the position of collateral benefits. We argue that these benefits are not fundamentally different from other benefits of research and can therefore be included in risk-benefit assessments of DCTs.

<https://doi.org/10.1080/15265161.2023.2296404>

Les volontaires sains dans la recherche sur la tuberculose

Rohrig A., Morrison J., Kleinwaks G., et al.

[Exploring the ethics of tuberculosis human challenge models](#)

Journal of Medical Ethics 2023;jme-2023-109234.

We extend recent conversation about the ethics of human challenge trials to tuberculosis (TB). TB challenge studies could accelerate vaccine development, but ethical concerns regarding risks to trial participants and third parties have been a limiting factor. We analyse the expected social value and risks of different challenge models, concluding that if a TB challenge trial has between a 10% and a 50% chance of leading to the authorisation and near-universal delivery of a more effective vaccine 3-5 years earlier, then the trial would save between 26 400 and 1 100 000 lives over the next 10 years. We also identify five important ethical considerations that differentiate TB from recent human challenge trials: an exceptionally high disease burden with no highly effective vaccine; heightened third party risk following the trial, and, partly for that reason, uniquely stringent biosafety requirements for the trial; risks associated with best available TB treatments; and difficulties with TB disease detection. We argue that there is good reason to consider conducting challenge trials with attenuated strains like *Bacillus Calmette-Guérin* or attenuated *Mycobacterium tuberculosis*.

<https://doi.org/10.1136/jme-2023-109234>

La régulation IRB des essais cliniques personnalisés

Samuel J.P., Wootton S.H.

[Personalized Trial Ethics and Institutional Review Board Submissions](#)

Harvard Data Science Review 2022;2022(Spec Iss 3).

The ethical and regulatory oversight of any clinical activity related to human subjects is commonly determined based on its categorization as either clinical practice or research. Prominent bioethicists have criticized the traditional distinctions used to delineate these categories, calling them counterproductive and outmoded, and arguing that learning and clinical practice should be deliberately and appropriately integrated. Personalized trials represent a clinical activity with characteristics that overlap both categories, making ethical and regulatory oversight requirements less straightforward. When the primary intent of the personalized trial is to assist in the conduct of individualized patient care with an emphasis on protecting the clinical decision from the biases inherent in usual clinical practice, how should this activity be regulated? In this article, we will explore the ethical underpinnings of personalized trials and propose various approaches to meeting regulatory requirements. Instead of imposing standard research regulations on the conduct of all personalized trials, we recommend that personalized trialists and IRB panels should consider whether participation in a personalized trial results in any foreseeable incremental increase in risk to the participant compared with usual care. This approach may reduce regulatory barriers, which could promote more widespread uptake of personalized trials.

<https://doi.org/10.1162/99608f92.2ded0fc5>

La compréhension des enjeux éthiques de leur recherche par des ingénieurs en biologie moléculaire

Silva R.G.L. da, Blasimme A., Vayena E., et al.

[How Do Molecular Systems Engineering Scientists Frame the Ethics of Their Research?](#)

AJOB empirical bioethics 2024;1-10.

BACKGROUND: There are intense discussions about the ethical and societal implications of biomedical engineering, but little data to suggest how scientists think about the ethics of their work. The aim of this study is to describe how scientists frame the ethics of their research, with a focus on the field of molecular systems engineering. **METHODS:** Semi-structured qualitative interviews were conducted during 2021-2022, as part of a larger study. This analysis includes a broad question about how participants view ethics as related to their work, with follow up probes about the topics they consider most important. Interviews were transcribed, inductively coded by two researchers to consensus, and analyzed thematically. **RESULTS:** Twenty-four scientists participated

in the study. Interviewees hold positions as professors, principal investigators, and senior staff researchers in universities or research institutes in the United States and Europe. Among those scientists who reported reflecting on ethical considerations in their work, many equated ethics with research ethics topics (e.g., safety, replicability), or with regulation and guidelines. Participants expressed the view that ethical issues are primarily relevant for clinical trials of bioengineered products, or for those working with animal or human subjects. Scientists described their research as « too early » or « not examining anything living » with regard to ethical reflection. Finally, many felt that ethics is seen as territory for experts and therefore beyond scientists' competencies. **CONCLUSIONS:** Molecular systems engineering scientists currently focus on regulatory aspects as the framework for their ethical analyses. They describe using a framework to define when life arises, as a means to determine when further ethical engagement is warranted. Further research is needed to investigate how scientists relate to the ethics of their scientific work, and build consensus around concepts of life, autonomous behavior, and physiological relevance of bioengineered systems.

<https://doi.org/10.1080/23294515.2024.2302994>

Enjeux éthiques de la recherche avec du personnel militaire

Townsend M.L., Green H., Fabrianesi B., et al.

Ethical issues when conducting health research with military personnel: a scoping review protocol

JBI evidence synthesis 2023

OBJECTIVE: The objective of this scoping review is to understand the scope and nature of evidence in relation to the ethical issues that arise when conducting health research with military personnel. **INTRODUCTION:** Ethical obligations in human research have been debated for centuries. Historically, research conducted with military personnel has led to ethical controversies regarding autonomy, harm, and informed consent. In particular, the power dynamics, hierarchical nature, and culture that are inherent in military structures may compromise the voluntary nature of research participation. **INCLUSION CRITERIA:** This scoping review will include all sources of evidence that identify ethical issues, such as autonomy, beneficence, non-maleficence, and justice, within health research with military personnel, including reservists. This review will exclude sources of evidence that include health research conducted during combat or on new technologies for fighting in wars. **METHODS:** This scoping review will be conducted in accordance with JBI methodology for scoping reviews. A 3-step search strategy will be used to obtain both published and unpublished sources of evidence. Two independent reviewers will screen sources of evidence against the inclusion and exclusion criteria. No limits on language will be applied; we will use Google Translate to translate sources of evidence in languages other than English. Sources of evidence published since 1964 will be included. Data will be extracted using a purpose-designed spreadsheet and the results will be summarized descriptively and presented in a tabular format.

<https://doi.org/10.11124/JBIES-23-00330>

La transparence dans les recherches controversées

Venkatesh A., Iltis A.S., Matthews K.R.W.

Transparency in controversial research: A review of human embryo research publication ethical disclosure statements

Stem Cell Reports 2023:S2213-6711(23)00455-1.

In 2021, the International Society for Stem Cell Research (ISSCR) released updated guidelines that included human embryo research guidance. Requiring ethics statements in publications using human embryos is one way to verify adherence to these guidelines. A review of top-tier biomedical journal requirements identified only one publisher that requires a human embryo statement. A review of articles using human embryos from top-tier biomedical journals found that all contain some form of ethics statement, but they differ in content and location. Requiring ethics statements with specific elements could improve transparency and adherence to research guidelines.

<https://doi.org/10.1016/j.stemcr.2023.11.006>

Les liens entre éthique de la recherche et intégrité scientifique

Muthanna A., Chaaban Y., Qadhi S.

A model of the interrelationship between research ethics and research integrity

International Journal of Qualitative Studies on Health and Well-Being 2024;19(1):2295151.

Purpose: The purpose of this article is to explore the interrelationship between research ethics and research integrity with a focus on the primary forms of research misconduct, including plagiarism, fabrication, and falsification. It also details the main factors for their occurrence, and the possible ways for mitigating their use among scholars. *Methods:* The method employed a detailed examination of the main ethical dilemmas, as delineated in literature, as well as the factors leading to these ethical breaches and the strategies to mitigate them. *Further,* the teaching experiences of the primary author are reflected in the development of the model. *Results:* The results of this article are represented in a model illustrating the interrelationship between research ethics and research integrity. *Further,* a significant aspect of our article is the identification of novel forms of research misconduct concerning the use of irrelevant or forced citations or references. *Conclusion:* In conclusion, the article highlights the substantial positive effects that adherence to research ethics and integrity have on the academic well-being of scholars.

<https://doi.org/10.1080/17482631.2023.2295151>

L'intégrité scientifique : où en sommes-nous ?

Zhaksylyk A., Zimba O., Yessirkepov M., et al.

Research Integrity: Where We Are and Where We Are Heading

Journal of Korean Medical Science 2023;38(47):e405.

The concept of research integrity (RI) refers to a set of moral and ethical standards that serve as the foundation for the execution of research activities. Integrity in research is the incorporation of principles of honesty, transparency, and respect for ethical standards and norms throughout all stages of the research endeavor, encompassing study design, data collecting, analysis, reporting, and publishing. The preservation of RI is of utmost importance to uphold the credibility and amplify the influence of scientific research while also preventing and dealing with instances of scientific misconduct. Researchers, institutions, journals, and readers share responsibilities for preserving RI. Researchers must adhere to the highest ethical standards. Institutions have a role in establishing an atmosphere that supports integrity ideals while also providing useful guidance, instruction, and assistance to researchers. Editors and reviewers act as protectors, upholding quality and ethical standards in the dissemination of research results through publishing. Readers play a key role in the detection and reporting of fraudulent activity by critically evaluating content. The struggle against scientific misconduct has multiple dimensions and is continuous. It requires a collaborative effort and adherence to the principles of honesty, transparency, and rigorous science. By supporting a culture of RI, the scientific community may preserve its core principles and continue to contribute appropriately to society's well-being. It not only aids present research but also lays the foundation for future scientific advancements.

<https://doi.org/10.3346/jkms.2023.38.e405>

SANTÉ PUBLIQUE, ÉCONOMIE ET ORGANISATION DE LA SANTÉ



L'obligation de recherche en santé publique en temps de crise

Barosa M., Jamrozik E., Prasad V.

[The Ethical Obligation for Research During Public Health Emergencies: Insights From the COVID-19 Pandemic](#)

Medicine, Health Care, and Philosophy 2023

In times of crises, public health leaders may claim that trials of public health interventions are unethical. One reason for this claim can be that equipoise-i.e. a situation of uncertainty and/or disagreement among experts about the evidence regarding an intervention-has been disturbed by a change of collective expert views. Some might claim that equipoise is disturbed if the majority of experts believe that emergency public health interventions are likely to be more beneficial than harmful. However, such beliefs are not always justified: where high quality research has not been conducted, there is often considerable residual uncertainty about whether interventions offer net benefits. In this essay we argue that high-quality research, namely by means of well-designed randomized trials, is ethically obligatory before, during, and after implementing policies in public health emergencies (PHEs). We contend that this standard applies to both pharmaceutical and non-pharmaceutical interventions, and we elaborate an account of equipoise that captures key features of debates in the recent pandemic. We build our case by analyzing research strategies employed during the COVID-19 pandemic regarding drugs, vaccines, and non-pharmaceutical interventions; and by providing responses to possible objections. Finally, we propose a public health policy reform: whenever a policy implemented during a PHE is not grounded in high-quality evidence that expected benefits outweigh harms, there should be a planned approach to generate high-quality evidence, with review of emerging data at preset time points. These preset timepoints guarantee that policymakers pause to review emerging evidence and consider ceasing ineffective or even harmful policies, thereby improving transparency and accountability, as well as permitting the redirection of resources to more effective or beneficial interventions.

<https://doi.org/10.1007/s11019-023-10184-6>

La détresse morale spécifique aux professionnel·les de la santé publique pendant la pandémie de Covid-19

Bow S.M.A., Schröder-Bäck P., Norcliffe-Brown D., et al.

'Telling them "that's what it says in the guidance" didn't feel good enough': moral distress during the pandemic in UK public health professionals

Journal of Public Health (Oxford, England) 2023:fdad220.

BACKGROUND: The study aimed to identify the causes of moral distress in public health professionals associated with the COVID-19 pandemic, and the potential ways of avoiding or mitigating the distress. **METHODS:** The survey was distributed to all members of the UK Faculty of Public Health between 14 December 2021 and 23 February 2022. Conventional qualitative content analysis was conducted to explore the situations in which moral distress arises, the moral judgments that led to distress and the proposed ways to address moral distress. **RESULTS:** A total of 629 responses were received from respondents broadly representative of the public health professional workforce. The main situations causing moral distress were national policy, guidance and law; public health advice; and workplace environments. Moral distress was precipitated by judgments about having caused injury, being unable to do good, dishonest communications and unjust prioritization. The need to improve guidance, communication and preparedness was recognized, though there was disagreement over how to achieve this. There were consistent calls for more subsidiarity, moral development and support and freedom to voice concerns. **CONCLUSIONS:** The causes of moral distress in public health are distinct from other healthcare professions. Important proposals for addressing moral distress associated with the COVID-19 pandemic have been voiced by public health professionals themselves.

<https://doi.org/10.1093/pubmed/fdad220>

Prioriser des ressources rares en radiothérapie

DeBoer R.J., Ho A., Mutoniwase E., et al.

Ethical dilemmas in prioritizing patients for scarce radiotherapy resources

BMC medical ethics 2024;25(1):12.

BACKGROUND: Radiotherapy is an essential component of cancer treatment, yet many countries do not have adequate capacity to serve all patients who would benefit from it. Allocation systems are needed to guide patient prioritization for radiotherapy in resource-limited contexts. These systems should be informed by allocation principles deemed relevant to stakeholders. This study explores the ethical dilemmas and views of decision-makers engaged in real-world prioritization of scarce radiotherapy resources at a cancer center in Rwanda in order to identify relevant principles. **METHODS:** Semi-structured interviews were conducted with a purposive sample of 22 oncology clinicians, program leaders, and clinical advisors. Interviews explored the factors considered by decision-makers when prioritizing patients for radiotherapy. The framework method of thematic analysis was used to characterize these factors. Bioethical analysis was then applied to determine their underlying normative principles. **RESULTS:** Participants considered both clinical and non-clinical factors relevant to patient prioritization for radiotherapy. They widely agreed that disease curability should be the primary overarching driver of prioritization, with the goal of saving the most lives. However, they described tension between curability and competing factors including age, palliative benefit, and waiting time. They were divided about the role that non-clinical factors such as social value should play, and agreed that poverty should not be a barrier. **CONCLUSIONS:** Multiple competing principles create tension with the agreed upon overarching goal of maximizing lives saved, including another utilitarian approach of maximizing life-years saved as well as non-utilitarian principles, such as egalitarianism, prioritarianism, and deontology. Clinical guidelines for patient prioritization for radiotherapy can combine multiple principles into a single allocation system to a significant extent. However, conflicting views about the role that social factors should play, and the dynamic nature of resource availability, highlight the need for ongoing work to evaluate and refine priority setting systems based on stakeholder views.

<https://doi.org/10.1186/s12910-024-01005-3>

Politique d'action sociale et traitement innovant

Dusserre S.

Mucoviscidose : enjeux éthiques d'une politique d'action sociale associative à l'aune d'un traitement innovant

Revue française d'éthique appliquée 2023;N°14(1):173-178.

La mucoviscidose, maladie génétique rare et incurable, bénéficie d'une nouvelle trithérapie médicamenteuse depuis juillet 2021. Ce nouveau traitement, qualifié de révolutionnaire par les médecins et de miraculeux par les profanes, se traduit par une amélioration spectaculaire de l'état de santé et de l'espérance de vie. Expérience aussi radicale que soudaine, ce retour à la vie pour des personnes dont l'âge moyen de décès était de 35 ans, porte en lui de nombreuses questions existentielles, sociales et politiques. L'association Vaincre la mucoviscidose a été créée en 1965 par des parents d'enfants malades et des médecins autour de quatre missions, dont l'amélioration de la qualité de vie. L'arrivée des nouveaux traitements, en ouvrant l'horizon de vie des personnes atteintes par la maladie, bouleverse le paradigme et invite l'association à repenser sa politique d'action sociale, à l'aune de cette nouvelle donne et de ses enjeux éthiques.

<https://doi.org/10.3917/rfeap.014.0173>

Les déterminants structureaux de la rareté des ressources

Filho L.B.

The Legal Determinants of Scarcity: Expanding Human Rights Advocacy for Affordability of Health Technologies

Health and Human Rights 2023;25(2):205-217.

Recognizing law as a determinant of scarcity in health care is vital. This paper underscores the need for a comprehensive approach to manage scarcity beyond intellectual property, using targeted regulations to promote affordability and counter market distortions. I argue that relying on law solely to ensure democratic deliberations for resource allocation overlooks market failures and economic inequalities that contribute to scarcity. I examine different « legal determinants of scarcity » that can be used, on the basis of the right to health, to improve or positively influence the availability and affordability of health technologies through complementary policies such as direct price control, competitive procurement, competition laws, and public-private partnerships. I conclude by asserting that health care affordability must be a central positive human rights obligation in economic and health policies and that states must strive to diversify their approaches to eliminate persistent economic barriers.

[PMID: 38145133](https://pubmed.ncbi.nlm.nih.gov/38145133/)

L'éthique des maladies infectieuses

Guadarrama-Orozco J.H.

Ethics in infectious diseases: latent challenges. Part I

Boletin Medico Del Hospital Infantil De Mexico 2023;80(6):323-330.

Infectious diseases socially imply individual and community medical problems. Therefore, they require actions aimed at social processes that affect the well-being of the individuals without losing sight of social groups. Faced with this panorama, we ask ourselves: is there a direct relationship between ethics and infectious diseases? To elucidate an answer, let us remember the peak period of the COVID-19 pandemic when guidelines based on ethical principles were issued to facilitate medical decisions on allocating scarce resources in periods of maximum demand. In those moments, since there was no inclusive component of society, the decisions made produced massive criticism. The reactions demonstrated the need to analyze in detail the criteria that had been considered correct. Consequently, we affirm that bioethical principles are transcendental in medical decisions and must be examined, not only for the individual but also with a view to public health. Moreover, the acquired immunodeficiency syndrome (AIDS) epidemic has lived with us for decades, and it continues to show its tragic face in the form of new cases, chronic illnesses, and deaths. Joint United Nations Programme on HIV/AIDS brings us closer to a complex reality where the fight against disease and global health are interrelated with other problems, such as the need to reduce inequality, for which human rights, gender equality, social protection, and the

development of research projects, where the ethics committees in research in community processes are constituents.

<https://doi.org/10.24875/BMHIM.23000051>

Recommandations de l'ASCO sur la gestion de la pénurie d'anticancéreux

Hantel A., Spence R., Camacho P., et al.

[ASCO Ethical Guidance for the Practical Management of Oncology Drug Shortages](#)

Journal of Clinical Oncology 2023;JCO.23.01941.

To aid clinicians, ASCO has issued clinical recommendations and ethical principles for the development and implementation of allocation plans.⁸ This article expands on ASCO's guidance⁹ to move toward practical strategies for the ethical management of shortages. We begin with an overview of ethical frameworks for drug shortages to educate and inform oncologists. Then, we highlight the process and principles of multistakeholder deliberation in allocation planning and enactment. We conclude by touching on practical considerations for blending process strategies with allocation principles to develop a functional plan for oncology practices.

<https://doi.org/10.1200/JCO.23.01941>

L'éthique de la régulation pharmaceutique

Hermosilla M.

[Regulating ethical experimentation: Impacts of the breakthrough therapy designation on drug R&D](#)

Journal of Health Economics 2024;94:102855.

This article investigates patterns of pharmaceutical development activity around the 2012 creation of the FDA's Breakthrough Therapy Designation (BTD). The BTD introduced regulatory flexibility and support to avoid ethical challenges created by experimental therapies of exceptional performance in early stage clinical trials. We argue that the program's design indirectly created substantial incentives for the industry to pursue the designation. Consistent with this hypothesis, our evidence links the creation of the program with a substantial increase in the number of new drug indications entering the clinical trial process. This surge in introductions has resulted in a discernible increase in approvals, which has manifested with a lag and may strengthen in the future. Countering theoretical predictions, BTD incentives have not led to increased risk taking in project selection.

<https://doi.org/10.1016/j.jhealeco.2023.102855>

Enjeux éthiques de la maladie à Nipah virus

Johnson T., Jamrozik E., Hurst T., et al.

[Ethical issues in Nipah virus control and research: addressing a neglected disease](#)

Journal of Medical Ethics 2023;jme-2023-109469.

Nipah virus is a priority pathogen that is receiving increasing attention among scientists and in work on epidemic preparedness. Despite this trend, there has been almost no bioethical work examining ethical considerations surrounding the epidemiology, prevention, and treatment of Nipah virus or research that has already begun into animal and human vaccines. In this paper, we advance the case for further work on Nipah virus disease in public health ethics due to the distinct issues it raises concerning communication about the modes of transmission, the burdens of public health surveillance, the recent use of stringent public health measures during epidemics, and social or religious norms intersecting with preventive measures. We also advance the case for further work on Nipah virus disease in research ethics, given ethical issues surrounding potential vaccine trials for a high-fatality disease with sporadic spillover events, the different local contexts where trials may occur, and the potential use of unproven therapeutics during outbreaks. Further bioethics work may help to ensure that research and public health interventions for Nipah virus disease are ethically acceptable and more likely to be effective.

<https://doi.org/10.1136/jme-2023-109469>

L'hésitation vaccinale en contexte pandémique

Krastev S., Krajden O., Vang Z.M., et al.

[Navigating the uncertainty: A novel taxonomy of vaccine hesitancy in the context of COVID-19](#)

PloS One 2023;18(12):e0295912.

Vaccine hesitancy remains a significant and evolving public health challenge. The COVID-19 pandemic has created a unique decision context with significant uncertainty caused by the novelty of the disease being targeted, unfamiliarity with the vaccines being offered, misinformation, and strong handed government measures. In an effort to extend our understanding of vaccine hesitancy to the high uncertainty decision environment presented by COVID-19, we present a novel taxonomy of the determinants of vaccine hesitancy, based on an inductive analysis of qualitative data gathered during the COVID-19 pandemic. We report on focus group data from a purposive sample of 18 Canadians with varying sociodemographic characteristics and COVID-19 vaccination attitudes. An inductive thematic analysis of this data reveals eight core themes related to vaccine hesitancy: values, trust, social environment, personal anecdotes, environmental fluctuation, prior knowledge, perceived risk & systems of care. We explore these core themes as well as 25 sub-themes, contrasting them with previous models of vaccine hesitancy and suggesting potential strategies for public health professionals.

<https://doi.org/10.1371/journal.pone.0295912>

La confiance en les institutions comme non déterminant de l'hésitation vaccinale

Krastev S., Krajden O., Vang Z.M., et al.

[Institutional trust is a distinct construct related to vaccine hesitancy and refusal](#)

BMC public health 2023;23(1):2481.

BACKGROUND: Vaccine hesitancy is driven by a heterogeneous and changing set of psychological, social and historical phenomena, requiring multidisciplinary approaches to its study and intervention. Past research has brought to light instances of both interpersonal and institutional trust playing an important role in vaccine uptake. However, no comprehensive study to date has specifically assessed the relative importance of these two categories of trust as they relate to vaccine behaviors and attitudes. **METHODS:** In this paper, we examine the relationship between interpersonal and institutional trust and four measures related to COVID-19 vaccine hesitancy and one measure related to general vaccine hesitancy. We hypothesize that, across measures, individuals with vaccine hesitant attitudes and behaviors have lower trust-especially in institutions-than those who are not hesitant. We test this hypothesis in a sample of 1541 Canadians. **RESULTS:** A deficit in both interpersonal and institutional trust was associated with higher levels of vaccine hesitant attitudes and behaviors. However, institutional trust was significantly lower than interpersonal trust in those with high hesitancy scores, suggesting that the two types of trust can be thought of as distinct constructs in the context of vaccine hesitancy. **CONCLUSIONS:** Based on our findings, we suggest that diminished institutional trust plays a crucial role in vaccine hesitancy. We propose that this may contribute to a tendency to instead place trust in interpersonally propagated belief systems, which may be more strongly misaligned with mainstream evidence and thus support vaccine hesitancy attitudes. We offer strategies rooted in these observations for creating public health messages designed to enhance vaccine uptake.

<https://doi.org/10.1186/s12889-023-17345-5>

Y a-t-il un devoir de traiter les non-vaccinés ?

Lederman Z., Corcos S.

[The duty of care and the right to be cared for: is there a duty to treat the unvaccinated?](#)

Medicine, Health Care, and Philosophy 2024

Vaccine hesitancy or refusal has been one of the major obstacles to herd immunity against Covid-19 in high-income countries and one of the causes for the emergence of variants. The refusal of people who are eligible for vaccination to receive vaccination creates an ethical dilemma between the duty of healthcare professionals (HCPs) to care for patients and their right to be taken care of. This paper argues for an extended social contract between

patients and society wherein vaccination against Covid-19 is conceived as essential for the protection of the right of healthcare providers to be taken care of. Thus, a duty of care is only valid when those who can receive vaccination actually receive it. Whenever that is not the case, the continuing functioning of HCPs can only be perceived as supererogatory and not obligatory.

<https://doi.org/10.1007/s11019-023-10186-4>

Les inégalités d'accès à l'eau

Kuntla S.K., Saharia M., Prakash S., et al.

Precipitation inequality exacerbates streamflow inequality, but dams moderate it

The Science of the Total Environment 2023:169098.

Access to clean water is a fundamental human right, yet millions worldwide face the dire consequences of water scarcity and inadequate sanitation. Water inequality, characterized by disparities in access and availability of water resources, has emerged as a critical global challenge with far-reaching social, economic, and environmental implications. Using a globally representative observational streamflow dataset and Gini coefficients, this study investigates how streamflow inequality, which has a large impact on inequality of water availability, varies spatially and temporally, and its relationship with different underlying catchment characteristics. This study finds that watersheds in arid climates exhibit a higher degree of streamflow inequality than polar and equatorial ones. Africa experiences the highest streamflow inequality, followed by Australia, while South America experiences relatively lower streamflow inequality. Around 19.6 % of the catchments in Australia display an increasing trend in streamflow inequality, pointing to worsening conditions. Conversely, South America experiences a decreasing trend in streamflow inequality in 18.3 % of its catchments during the same period. It is also found that a more evenly distributed precipitation within the catchment and higher dam storage capacity corresponds to more evenly distributed streamflow availability throughout the year. This study enhances our understanding of streamflow inequality worldwide, which will aid policy formulation to foster sustainable development.

<https://doi.org/10.1016/j.scitotenv.2023.169098>

La précarité menstruelle

Mann S., Byrne S.K.

Period Poverty from a Public Health and Legislative Perspective

International Journal of Environmental Research and Public Health 2023;20(23):7118.

Period poverty is a global issue that needs to be addressed as a public health crisis. It is directly related to Sustainable Health Goals three, four, five, six, and eight. Period poverty adversely affects the health of anyone capable of menstruating, which is nearly half of the world population, at the physiological, emotional, and psychosocial level. Biases, cultural beliefs, ethical reproductive justice issues, social stigma, and systemic factors contribute to period poverty. Every month, certain menstruators are disproportionately impacted by period poverty and struggle to access basic hygienic necessities. Important stakeholders include not only the individual who experiences menses but also educators and school systems, healthcare professionals, policymakers, public health officials, and researchers. Everyone has a role in addressing period poverty by voting for officials that proactively support legislation, policy, and programs at all levels to effectively advocate for menstrual equity and address barriers contributing to period poverty. This includes policies that increase access to menstrual hygiene products, safe menstrual management methods, and reproductive and women's health education. Programs globally that focus on capacity building and sustainability strategies can be used as models to reduce period poverty, thereby fostering a sense of empowerment and menstruators' sense of autonomy, dignity, and equality.

<https://doi.org/10.3390/ijerph20237118>

L'intégration de la médecine ayurvédique dans les systèmes de santé

Pratibha N., E M., Mv V.

Ayurvedic practice, education and research, beyond dilemmas and confessions

Journal of Ayurveda and Integrative Medicine 2023;14(6):100814.

Emergent diseases and the pursuit of universal health coverage have incited a renewed interest in the role of traditional medicines (TM) in healthcare. Ayurveda, a widely accepted and practised system in India, is gaining attention globally owing to its holistic and individualised therapeutic approaches. Addressing the contemporary relevance of Ayurveda in healthcare, the article examines concerns surrounding its core principles, educational methodologies, and research validation. Pertinent queries are raised about Ayurveda's relevance today and challenges in aligning Ayurvedic theories with current scientific paradigms and pedagogical dilemmas in Ayurvedic education. Further, we propose solutions, charting a course for Ayurveda's evolution in contemporary healthcare. This includes bridging epistemological differences by integrating modern scientific methodologies with Ayurvedic concepts. Addressing the educational challenges, we recommend comprehensive curriculum revisions considering contemporary healthcare needs. The teaching methodologies are to be enhanced to impart Ayurvedic principles effectively, acknowledging the limitations of ancient anatomical and physiological constructs. Training programs must prioritise equipping teachers with the ability to impart a critical understanding of Ayurveda's philosophy without undermining modern scientific concepts. In conclusion, this article underscores the importance of policy reforms in Ayurvedic curriculum design and teaching methodologies to ensure Ayurveda's sustained relevance and integration within contemporary healthcare systems.

<https://doi.org/10.1016/j.jaim.2023.100814>

Les enjeux éthiques de l'épidémiologie contemporaine

Salerno J., Weed D.L., Pandey C.M., et al.

Global matters of epidemiology and the ethical challenges of addressing the health of populations

Annals of Epidemiology 2024;91:8-11.

PURPOSE: The American College of Epidemiology (ACE) held its 2022 Annual Meeting, September 8-11, with a conference theme of "Pandemic of Misinformation: Building Trust in Epidemiology". The ACE Ethics Committee hosted a symposium session in recognition of the global spotlight placed on epidemiology and public health due to the COVID-19 crisis. The ACE Ethics Committee invited previous Chairs of the Ethics Committee and current President of the International Epidemiological Association to present at the symposium session. This paper aims to highlight the ethical challenges presented during the symposium session. **METHODS:** Three speakers with diverse backgrounds representing expertise from the fields of ethics, epidemiology, public health, clinical trials, pharmacoepidemiology, statistics, law, and public policy, covering perspectives from the U.S., Europe, and Southeast Asia were selected to present on the ethical challenges in epidemiology and public health applying a global theme. Dr. D. Weed presented on "Causation, Epidemiology and Ethics"; Dr. C.M. Pandey presented on the "Ethical Challenges in the Practice of Digital Epidemiology"; and Dr. J. Acquavella presented on 'Departures from Scientific Objectivity: A Cause of Eroding Trust in Epidemiology.' **RESULTS:** The collective goal to improve the public's health was a mutually shared theme across the three distinct areas. We highlight the common ethical guidance and principle-based approaches that have served epidemiology and public health in framing and critical analysis of novel challenges, including autonomy, beneficence, justice, scientific integrity, duties to the profession and community, and developing and maintaining public trust; however, gaps remain in how best to address health inequalities and the novel emergence and pervasiveness of misinformation and disinformation that have impacted the health of the global community. We introduce an ethical framework of translational bioethics that places considerations of the social determinants of health at the forefront. **CONCLUSIONS:** The COVID-19 pandemic required an expedited public health response and, at the same time, placed the profession of epidemiology and public health, its system, and structures, under the microscope like never before. This article illustrates that revisiting our foundations in research and practice and orienting contemporary challenges using an ethical lens can assist in identifying and furthering the health of populations globally.

<https://doi.org/10.1016/j.annepidem.2024.01.003>

Les marchés en santé : réguler ou mettre en concurrence ?

Trottmann M., Stam P., Visser J., et al.

Balancing between competition and regulation in healthcare markets

Health Economics, Policy, and Law 2023:1-10.

Systems of managed competition naturally seek the middle ground between competition and regulation. This debate essay makes the case for adjusting the level of regulation according to the characteristics of the submarket in question. We first develop a theoretical framework that can be used to identify the services in which relatively free competition will be beneficial. The framework is grounded in the economic literature and consists of eight criteria. Targeted regulatory tools are then discussed that can be used to structure submarkets in which these criteria are not (fully) met. Applying this framework and targeted interventions, regulators gain the flexibility to react to potential market failures, without foregoing the benefits of managed competition where it works well. This analysis is highly relevant for countries in transition to managed competition. Regulators can identify potential failure in submarkets for medical services, and apply the necessary regulatory tools to prepare for a smooth transition.

<https://doi.org/10.1017/S1744133123000312>

NUMÉRIQUE, INTELLIGENCE ARTIFICIELLE ET TECHNOLOGIES



La conscience artificielle est-elle nécessaire à une éthique de l'IA ?

Chella A.

Artificial consciousness: the missing ingredient for ethical AI?

Frontiers in robotics and AI 2023;10:1270460.

Can we conceive machines that can formulate autonomous intentions and make conscious decisions? If so, how would this ability affect their ethical behavior? Some case studies help us understand how advances in understanding artificial consciousness can contribute to creating ethical AI systems.

<https://doi.org/10.3389/frobt.2023.1270460>

Les dangers de l'IA pour l'être humain

Chen C., Chen Z., Luo W., et al.

Ethical perspective on AI hazards to humans: A review

Medicine 2023;102(48):e36163.

This article explores the potential ethical hazards of artificial intelligence (AI) on society from an ethical perspective. We introduce the development and application of AI, emphasizing its potential benefits and possible negative impacts. We particularly examine the application of AI in the medical field and related ethical and legal issues, and analyze potential hazards that may exist in other areas of application, such as autonomous driving, finance, and security. Finally, we offer recommendations to help policymakers, technology companies, and society as a whole address the potential hazards of AI. These recommendations include strengthening regulation and supervision of AI, increasing public understanding and awareness of AI, and actively exploring how to use the advantages of AI to achieve a more just, equal, and sustainable social development. Only by actively exploring the advantages of AI while avoiding its negative impacts can we better respond to future challenges.

<https://doi.org/10.1097/MD.00000000000036163>

Recommandations pour limiter les biais algorithmiques renforçant les inégalités ethnoraciales

Chin M.H., Afsar-Manesh N., Bierman A.S., et al.

Guiding Principles to Address the Impact of Algorithm Bias on Racial and Ethnic Disparities in Health and Health Care

JAMA network open 2023;6(12):e2345050.

IMPORTANCE: Health care algorithms are used for diagnosis, treatment, prognosis, risk stratification, and allocation of resources. Bias in the development and use of algorithms can lead to worse outcomes for racial and ethnic minoritized groups and other historically marginalized populations such as individuals with lower income. **OBJECTIVE:** To provide a conceptual framework and guiding principles for mitigating and preventing bias in health care algorithms to promote health and health care equity. **EVIDENCE REVIEW:** The Agency for Healthcare Research and Quality and the National Institute for Minority Health and Health Disparities convened a diverse panel of experts to review evidence, hear from stakeholders, and receive community feedback. **FINDINGS:** The panel developed a conceptual framework to apply guiding principles across an algorithm's life cycle, centering health and health care equity for patients and communities as the goal, within the wider context of structural racism and discrimination. Multiple stakeholders can mitigate and prevent bias at each phase of the algorithm life cycle, including problem formulation (phase 1); data selection, assessment, and management (phase 2); algorithm development, training, and validation (phase 3); deployment and integration of algorithms in intended settings (phase 4); and algorithm monitoring, maintenance, updating, or deimplementation (phase 5). Five principles should guide these efforts: (1) promote health and health care equity during all phases of the health care algorithm life cycle; (2) ensure health care algorithms and their use are transparent and explainable; (3) authentically engage patients and communities during all phases of the health care algorithm life cycle and earn trustworthiness; (4) explicitly identify health care algorithmic fairness issues and trade-offs; and (5) establish accountability for equity and fairness in outcomes from health care algorithms. **CONCLUSIONS AND RELEVANCE:** Multiple stakeholders must partner to create systems, processes, regulations, incentives, standards, and policies to mitigate and prevent algorithmic bias. Reforms should implement guiding principles that support promotion of health and health care equity in all phases of the algorithm life cycle as well as transparency and explainability, authentic community engagement and ethical partnerships, explicit identification of fairness issues and trade-offs, and accountability for equity and fairness.

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L'IA pour déterminer les préférences des patient·es juridiquement protégé·es

Earp B.D., Porsdam Mann S., Allen J., et al.

A Personalized Patient Preference Predictor for Substituted Judgments in Healthcare: Technically Feasible and Ethically Desirable

The American journal of bioethics: AJOB 2024:1-14.

When making substituted judgments for incapacitated patients, surrogates often struggle to guess what the patient would want if they had capacity. Surrogates may also agonize over having the (sole) responsibility of making such a determination. To address such concerns, a Patient Preference Predictor (PPP) has been proposed that would use an algorithm to infer the treatment preferences of individual patients from population-level data about the known preferences of people with similar demographic characteristics. However, critics have suggested that even if such a PPP were more accurate, on average, than human surrogates in identifying patient preferences, the proposed algorithm would nevertheless fail to respect the patient's (former) autonomy since it draws on the "wrong" kind of data: namely, data that are not specific to the individual patient and which therefore may not reflect their actual values, or their reasons for having the preferences they do. Taking such criticisms on board, we here propose a new approach: the Personalized Patient Preference Predictor (P4). The P4 is based on recent advances in machine learning, which allow technologies including large language models to be more cheaply and efficiently "fine-tuned" on person-specific data. The P4, unlike the PPP, would be able to infer an individual

patient's preferences from material (e.g., prior treatment decisions) that is in fact specific to them. Thus, we argue, in addition to being potentially more accurate at the individual level than the previously proposed PPP, the predictions of a P4 would also more directly reflect each patient's own reasons and values. In this article, we review recent discoveries in artificial intelligence research that suggest a P4 is technically feasible, and argue that, if it is developed and appropriately deployed, it should assuage some of the main autonomy-based concerns of critics of the original PPP. We then consider various objections to our proposal and offer some tentative replies.

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Les enjeux éthiques de l'IA et de la robotique en santé

Elendu C., Amaechi D.C., Elendu T.C., et al.

Ethical implications of AI and robotics in healthcare: A review

Medicine 2023;102(50):e36671.

Integrating Artificial Intelligence (AI) and robotics in healthcare heralds a new era of medical innovation, promising enhanced diagnostics, streamlined processes, and improved patient care. However, this technological revolution is accompanied by intricate ethical implications that demand meticulous consideration. This article navigates the complex ethical terrain surrounding AI and robotics in healthcare, delving into specific dimensions and providing strategies and best practices for ethical navigation. Privacy and data security are paramount concerns, necessitating robust encryption and anonymization techniques to safeguard patient data. Responsible data handling practices, including decentralized data sharing, are critical to preserve patient privacy. Algorithmic bias poses a significant challenge, demanding diverse datasets and ongoing monitoring to ensure fairness. Transparency and explainability in AI decision-making processes enhance trust and accountability. Clear responsibility frameworks are essential to address the accountability of manufacturers, healthcare institutions, and professionals. Ethical guidelines, regularly updated and accessible to all stakeholders, guide decision-making in this dynamic landscape. Moreover, the societal implications of AI and robotics extend to accessibility, equity, and societal trust. Strategies to bridge the digital divide and ensure equitable access must be prioritized. Global collaboration is pivotal in developing adaptable regulations and addressing legal challenges like liability and intellectual property. Ethics must remain at the forefront in the ever-evolving realm of healthcare technology. By embracing these strategies and best practices, healthcare systems and professionals can harness the potential of AI and robotics, ensuring responsible and ethical integration that benefits patients while upholding the highest ethical standards.

<https://doi.org/10.1097/MD.00000000000036671>

L'intelligence artificielle en imagerie nucléaire

Herington J., McCradden M.D., Creel K., et al.

Ethical Considerations for Artificial Intelligence in Medical Imaging: Data Collection, Development, and Evaluation

Journal of Nuclear Medicine: Official Publication, Society of Nuclear Medicine 2023;jnumed.123.266080.

The development of artificial intelligence (AI) within nuclear imaging involves several ethically fraught components at different stages of the machine learning pipeline, including during data collection, model training and validation, and clinical use. Drawing on the traditional principles of medical and research ethics, and highlighting the need to ensure health justice, the AI task force of the Society of Nuclear Medicine and Molecular Imaging has identified 4 major ethical risks: privacy of data subjects, data quality and model efficacy, fairness toward marginalized populations, and transparency of clinical performance. We provide preliminary recommendations to developers of AI-driven medical devices for mitigating the impact of these risks on patients and populations.

<https://doi.org/10.2967/jnumed.123.266080>

Avoir un usage responsable de l'IA

Lyons J.B., Hobbs K., Rogers S., et al.

Responsible (use of) AI

Frontiers in Neuroergonomics 2023;4:1201777.

Although there is a rich history of philosophical definitions of ethics when applied to human behavior, applying the same concepts and principles to AI may be fraught with problems. Anthropomorphizing AI to have characteristics such as « ethics » may promote a dangerous, unrealistic expectation that AI can be trained to have inherent, guaranteed ethical behavior. The authors instead advocate for increased research into the ethical use of AI from initial ideation and design through operational use and sustainment. The authors advocate for five key research areas: (1) education in ethics and core AI concepts for AI developers, leaders, and users, (2) development and use of model cards or datasheets for datasets to provide transparency into the strengths, limits, and potential biases of a trained model, (3) employing human-centered design that seeks to understand human value structures within a task context and enable effective human-machine interaction through intuitive and transparent interfaces, (4) targeted use of run time assurance that monitors and modifies the inputs or outputs of a trained model when necessary to enforce ethical principles such as safety or limiting bias, and (5) developing best practices for the use of a joint human-AI co-creation and training experience to enable a shared mental model and higher performance through potential emergent behavior.

<https://doi.org/10.3389/fnrgo.2023.1201777>

S'inspirer de l'éthique militaire en IA

Oniani D., Hilsman J., Peng Y., et al.

Adopting and expanding ethical principles for generative artificial intelligence from military to healthcare

NPJ digital medicine 2023;6(1):225.

In 2020, the U.S. Department of Defense officially disclosed a set of ethical principles to guide the use of Artificial Intelligence (AI) technologies on future battlefields. Despite stark differences, there are core similarities between the military and medical service. Warriors on battlefields often face life-altering circumstances that require quick decision-making. Medical providers experience similar challenges in a rapidly changing healthcare environment, such as in the emergency department or during surgery treating a life-threatening condition. Generative AI, an emerging technology designed to efficiently generate valuable information, holds great promise. As computing power becomes more accessible and the abundance of health data, such as electronic health records, electrocardiograms, and medical images, increases, it is inevitable that healthcare will be revolutionized by this technology. Recently, generative AI has garnered a lot of attention in the medical research community, leading to debates about its application in the healthcare sector, mainly due to concerns about transparency and related issues. Meanwhile, questions around the potential exacerbation of health disparities due to modeling biases have raised notable ethical concerns regarding the use of this technology in healthcare. However, the ethical principles for generative AI in healthcare have been understudied. As a result, there are no clear solutions to address ethical concerns, and decision-makers often neglect to consider the significance of ethical principles before implementing generative AI in clinical practice. In an attempt to address these issues, we explore ethical principles from the military perspective and propose the « GREAT PLEA » ethical principles, namely Governability, Reliability, Equity, Accountability, Traceability, Privacy, Lawfulness, Empathy, and Eutonomy, for generative AI in healthcare. Furthermore, we introduce a framework for adopting and expanding these ethical principles in a practical way that has been useful in the military and can be applied to healthcare for generative AI, based on contrasting their ethical concerns and risks. Ultimately, we aim to proactively address the ethical dilemmas and challenges posed by the integration of generative AI into healthcare practice.

<https://doi.org/10.1038/s41746-023-00965-x>

La transformation du soin néonatal par l'IA

Sullivan B.A., Beam K., Vesoulis Z.A., et al.

Transforming neonatal care with artificial intelligence: challenges, ethical consideration, and opportunities

Journal of Perinatology: Official Journal of the California Perinatal Association 2023

Artificial intelligence (AI) offers tremendous potential to transform neonatology through improved diagnostics, personalized treatments, and earlier prevention of complications. However, there are many challenges to address before AI is ready for clinical practice. This review defines key AI concepts and discusses ethical considerations and implicit biases associated with AI. Next we will review literature examples of AI already being explored in neonatology research and we will suggest future potentials for AI work. Examples discussed in this article include predicting outcomes such as sepsis, optimizing oxygen therapy, and image analysis to detect brain injury and retinopathy of prematurity. Realizing AI's potential necessitates collaboration between diverse stakeholders across the entire process of incorporating AI tools in the NICU to address testability, usability, bias, and transparency. With multi-center and multi-disciplinary collaboration, AI holds tremendous potential to transform the future of neonatology.

<https://doi.org/10.1038/s41372-023-01848-5>

La protection des données à l'ère de l'IA

Yadav N., Pandey S., Gupta A., et al.

Data Privacy in Healthcare: In the Era of Artificial Intelligence

Indian Dermatology Online Journal 2023;14(6):788-792.

Data Privacy has increasingly become a matter of concern in the era of large public digital repositories of data. This is particularly true in healthcare where data can be misused if traced back to patients, and brings with itself a myriad of possibilities. Bring custodians of data, as well as being at the helm of designing studies and products that can potentially benefit products, healthcare professionals often find themselves unsure about ethical and legal constraints that undelie data sharing. In this review we touch upon the concerns, leal frameworks as well as some common practices in these respects.

https://doi.org/10.4103/idoj.idoj_543_23

L'éthique des modèles de langage au prisme de l'empathie et de l'équité

Koranteng E., Rao A., Flores E., et al.

Empathy and Equity: Key Considerations for Large Language Model Adoption in Health Care

JMIR medical education 2023;9:e51199.

The growing presence of large language models (LLMs) in health care applications holds significant promise for innovative advancements in patient care. However, concerns about ethical implications and potential biases have been raised by various stakeholders. Here, we evaluate the ethics of LLMs in medicine along 2 key axes: empathy and equity. We outline the importance of these factors in novel models of care and develop frameworks for addressing these alongside LLM deployment.

<https://doi.org/10.2196/51199>

Les enjeux des modèles de langage en chirurgie plastique

Oleck N.C., Naga H.I., Nichols D.S., et al.

[Navigating the Ethical Landmines of ChatGPT: Implications of Intelligent Chatbots in Plastic Surgery Clinical Practice](#)

Plastic and Reconstructive Surgery. Global Open 2023;11(9):e5290.

ChatGPT is a cutting-edge language model developed by OpenAI with the potential to impact all facets of plastic surgery from research to clinical practice. New applications for ChatGPT are emerging at a rapid pace in both the scientific literature and popular media. It is important for clinicians to understand the capabilities and limitations of these tools before patient-facing implementation. In this article, the authors explore some of the technical details behind ChatGPT: what it is, and what it is not. As with any emerging technology, attention should be given to the ethical and health equity implications of this technology on our plastic surgery patients. The authors explore these concerns within the framework of the foundational principles of biomedical ethics: patient autonomy, nonmaleficence, beneficence, and justice. ChatGPT and similar intelligent conversation agents have incredible promise in the field of plastic surgery but should be used cautiously and sparingly in their current form. To protect patients, it is imperative that societal guidelines for the safe use of this rapidly developing technology are developed.

<https://doi.org/10.1097/GOX.0000000000005290>

Les avancées technologiques des prothèses

Gavette H., McDonald C.L., Kostick-Quenet K., et al.

[Advances in prosthetic technology: a perspective on ethical considerations for development and clinical translation](#)

Frontiers in Rehabilitation Sciences 2023;4:1335966.

Technological advancements of prostheses in recent years, such as haptic feedback, active power, and machine learning for prosthetic control, have opened new doors for improved functioning, satisfaction, and overall quality of life. However, little attention has been paid to ethical considerations surrounding the development and translation of prosthetic technologies into clinical practice. This article, based on current literature, presents perspectives surrounding ethical considerations from the authors' multidisciplinary views as prosthetists (HG, AM, CLM, MGF), as well as combined research experience working directly with people using prostheses (AM, CLM, MGF), wearable technologies for rehabilitation (MGF, BN), machine learning and artificial intelligence (BN, KKQ), and ethics of advanced technologies (KKQ). The target audience for this article includes developers, manufacturers, and researchers of prosthetic devices and related technology. We present several ethical considerations for current advances in prosthetic technology, as well as topics for future research, that may inform product and policy decisions and positively influence the lives of those who can benefit from advances in prosthetic technology.

<https://doi.org/10.3389/fresc.2023.1335966>

Les technologies de surveillance émotionnelle

Hartmann K.V., Rubeis G., Primc N.

[Healthy and Happy? An Ethical Investigation of Emotion Recognition and Regulation Technologies \(ERR\) within Ambient Assisted Living \(AAL\)](#)

Science and Engineering Ethics 2024;30(1):2.

Ambient Assisted Living (AAL) refers to technologies that track daily activities of persons in need of care to enhance their autonomy and minimise their need for assistance. New technological developments show an increasing effort to integrate automated emotion recognition and regulation (ERR) into AAL systems. These technologies aim to

recognise emotions via different sensors and, eventually, to regulate emotions defined as « negative » via different forms of intervention. Although these technologies are already implemented in other areas, AAL stands out by its tendency to enable an inconspicuous 24-hour surveillance in the private living space of users who rely on the technology to maintain a certain degree of independence in their daily activities. The combination of both technologies represents a new dimension of emotion recognition in a potentially vulnerable group of users. Our paper aims to provide an ethical contextualisation of the novel combination of both technologies. We discuss different concepts of emotions, namely Basic Emotion Theory (BET) and the Circumplex Model of Affect (CMA), that form the basis of ERR and provide an overview over the current technological developments in AAL. We highlight four ethical issues that specifically arise in the context of ERR in AAL systems, namely concerns regarding (1) the reductionist view of emotions, (2) solutionism as an underlying assumption of these technologies, (3) the privacy and autonomy of users and their emotions, (4) the tendency of machine learning techniques to normalise and generalise human behaviour and emotional reactions.

<https://doi.org/10.1007/s11948-024-00470-8>

Le statut moral des organoïdes cérébraux

Hartung T., Morales Pantoja I.E., Smirnova L.

[Brain organoids and organoid intelligence from ethical, legal, and social points of view](#)

Frontiers in Artificial Intelligence 2023;6:1307613.

Human brain organoids, aka cerebral organoids or earlier « mini-brains », are 3D cellular models that recapitulate aspects of the developing human brain. They show tremendous promise for advancing our understanding of neurodevelopment and neurological disorders. However, the unprecedented ability to model human brain development and function in vitro also raises complex ethical, legal, and social challenges. Organoid Intelligence (OI) describes the ongoing movement to combine such organoids with Artificial Intelligence to establish basic forms of memory and learning. This article discusses key issues regarding the scientific status and prospects of brain organoids and OI, conceptualizations of consciousness and the mind-brain relationship, ethical and legal dimensions, including moral status, human-animal chimeras, informed consent, and governance matters, such as oversight and regulation. A balanced framework is needed to allow vital research while addressing public perceptions and ethical concerns. Interdisciplinary perspectives and proactive engagement among scientists, ethicists, policymakers, and the public can enable responsible translational pathways for organoid technology. A thoughtful, proactive governance framework might be needed to ensure ethically responsible progress in this promising field.

<https://doi.org/10.3389/frai.2023.1307613>

La santé digitale comme levier pour la démocratie sanitaire

Hendl T., Shukla A.

[Can digital health democratize health care?](#)

Bioethics 2024

Much has been said about the potential of digital health technologies for democratizing health care. But how exactly is democratization with digital health technologies conceptualized and what does it involve? We investigate debates on the democratization of health care with digital health and identify that democratization is being envisioned as a matter of access to health information, health care, and patient empowerment. However, taking a closer look at the growing pool of empirical data on digital health, we argue that these technologies come short of materializing these goals, given the unequal health outcomes they facilitate. Building on this evidence, we argue that not only debates on democratization need to be connected to concerns of social determinants of health but also debates on the impact of digital health need to go far beyond democratization and engage with concerns of health justice.

<https://doi.org/10.1111/bioe.13266>

L'usage des drones dans la recherche en santé environnementale

Hoek Spaans R., Drumond B., Daalen K.R. van, et al.

[Ethical considerations related to drone use for environment and health research: A scoping review protocol](#)

PLoS One 2024;19(1):e0287270.

INTRODUCTION: The use of drones in environment and health research is a relatively new phenomenon. A principal research activity drones are used for is environmental monitoring, which can raise concerns in local communities. Existing ethical guidance for researchers is often not specific to drone technology and practices vary between research settings. Therefore, this scoping review aims to gather the evidence available on ethical considerations surrounding drone use as perceived by local communities, ethical considerations reported on by researchers implementing drone research, and published ethical guidance related to drone deployment. **METHODS AND ANALYSIS:** This scoping review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) and the Joanna Briggs Institute (JBI) guidelines. The literature search will be conducted using academic databases and grey literature sources. After pilot testing the inclusion criteria and data extraction tool, two researchers will double-screen and then chart available evidence independently. A content analysis will be carried out to identify patterns of categories or terms used to describe ethical considerations related to drone usage for environmental monitoring in the literature using the R Package RQDA. Discrepancies in any phase of the project will be solved through consensus between the two reviewers. If consensus cannot be reached, a third arbitrator will be consulted. **ETHICS AND DISSEMINATION:** Ethical approval is not required; only secondary data will be used. This protocol is registered on the Open Science Framework (osf.io/a78et). The results will be disseminated through publication in a scientific journal and will be used to inform drone field campaigns in the Wellcome Trust funded HARMONIZE project. HARMONIZE aims to develop cost-effective and reproducible digital infrastructure for stakeholders in climate change hotspots in Latin America & the Caribbean and will use drone technology to collect data on fine scale landscape changes.

<https://doi.org/10.1371/journal.pone.0287270>

La technologie mène-t-elle à une meilleure connaissance de soi ?

Leuenberger M.

[Track Thyself? The Value and Ethics of Self-knowledge Through Technology](#)

Philosophy & Technology 2024;37(1):13.

Novel technological devices, applications, and algorithms can provide us with a vast amount of personal information about ourselves. Given that we have ethical and practical reasons to pursue self-knowledge, should we use technology to increase our self-knowledge? And which ethical issues arise from the pursuit of technologically sourced self-knowledge? In this paper, I explore these questions in relation to bioinformation technologies (health and activity trackers, DTC genetic testing, and DTC neurotechnologies) and algorithmic profiling used for recommender systems, targeted advertising, and technologically supported decision-making. First, I distinguish between impersonal, critical, and relational self-knowledge. Relational self-knowledge is a so far neglected dimension of self-knowledge which is introduced in this paper. Next, I investigate the contribution of these technologies to the three types of self-knowledge and uncover the connected ethical concerns. Technology can provide a lot of impersonal self-knowledge, but we should focus on the quality of the information which tends to be particularly insufficient for marginalized groups. In terms of critical self-knowledge, the nature of technologically sourced personal information typically impedes critical engagement. The value of relational self-knowledge speaks in favour of transparency of information technology, notably for algorithms that are involved in decision-making about individuals. Moreover, bioinformation technologies and digital profiling shape the concepts and norms that define us. We should ensure they not only serve commercial interests but our identity and self-knowledge interests.

<https://doi.org/10.1007/s13347-024-00704-4>

Les « boîtes noires » en médecine : une méfiance saine

Wolkenstein A.

Healthy Mistrust: Medical Black Box Algorithms, Epistemic Authority, and Preemptionism

Cambridge quarterly of healthcare ethics: CQ: the international journal of healthcare ethics committees 2024:1-10.

In the ethics of algorithms, a specifically epistemological analysis is rarely undertaken in order to gain a critique (or a defense) of the handling of or trust in medical black box algorithms (BBAs). This article aims to begin to fill this research gap. Specifically, the thesis is examined according to which such algorithms are regarded as epistemic authorities (EAs) and that the results of a medical algorithm must completely replace other convictions that patients have (preemptionism). If this were true, it would be a reason to distrust medical BBAs. First, the author describes what EAs are and why BBAs can be considered EAs. Then, preemptionism will be outlined and criticized as an answer to the question of how to deal with an EA. The discussion leads to some requirements for dealing with a BBA as an EA.

<https://doi.org/10.1017/S0963180123000646>

SANTÉ ET SOCIÉTÉ



Les enjeux de la chirurgie de féminisation faciale

Barnett S.L., Choe J., Aiello C., et al.

Facial Feminization Surgery: Anatomical Differences, Preoperative Planning, Techniques, and Ethical Considerations

Medicina (Kaunas, Lithuania) 2023;59(12):2070.

Facial Feminization Surgery (FFS) is a transformative surgical approach aimed at aligning the facial features of transgender women with their gender identity. Through a systematic analysis, this paper explores the clinical differences between male and female facial skeletons along with the craniofacial techniques employed in FFS for each region. The preoperative planning stage is highlighted, emphasizing the importance of virtual planning and AI morphing as valuable tools to be used to achieve surgical precision. Consideration is given to special circumstances, such as procedure sequencing for older patients and silicone removal. Clinical outcomes, through patient-reported outcome measures and AI-based gender-typing assessments, showcase the efficacy of FFS in achieving proper gender recognition and alleviating gender dysphoria. This comprehensive review not only offers valuable insights into the current state of knowledge regarding FFS but also emphasizes the potential of artificial intelligence in outcome evaluation and surgical planning to further advance patient care and satisfaction with FFS.

<https://doi.org/10.3390/medicina59122070>

Comment utiliser en pratique les travaux documentant les inégalités d'accès aux soins ?

Bloy G., Rigal L.

Des gradients sociaux dans la dispensation des soins, et après ? Usages cliniques, dilemmes éthiques et réflexivité sociologique

Revue française d'éthique appliquée 2023;N°14(1):63-77.

L'article propose une réflexion sur les usages cliniques et éthiques possibles de la floraison de travaux de sciences sociales sur les inégalités sociales de santé en France, qui soulignent de plus en plus la contribution des soins à ces dernières. Un bilan des enquêtes récentes révèle que les façons de dispenser les soins et d'interagir avec les patients peuvent être la fois marquées par une méconnaissance du social et chargées de stéréotypes. Nos propres travaux ont contribué à mettre en évidence une tendance à un profilage social des pratiques préventives, en médecine générale en l'occurrence. Nous revenons sur les formes d'interpellation éthico-politique des

professionnels portées par la sociologie de la santé française et engageons une réflexion en termes d'injonction contradictoire inhérente au soin. La démonstration d'une production endogène d'inégalités sociales de santé complexifie, par une sorte d'injonction sociale, la tension éthique classique entre universalisme et personnalisation des soins. Une juste adaptation des pratiques soignantes consisterait-elle alors à prendre en compte les rapports sociaux inégaux tout en essayant d'en désamorcer la portée ? Quelle est et quelle pourrait être la contribution des travaux de sociologie de la santé à ce programme ? Nous proposons quelques repères pour une éthique socialement informée, mobilisant les sciences sociales tout en prenant appui sur la réflexivité des cliniciens, pour tenter de rendre moins dommageable le paradoxe du soin égalitaire dans une société inégalitaire.

<https://doi.org/10.3917/rfeap.014.0063>

Impliquer les personnes âgées dans la préparation aux crises humanitaires

Boetzelaer E. van, Kamp J. van de, Keating P., et al.

Involving older people in the preparedness, response, and recovery phases in humanitarian emergencies: a theoretical framework on ageism, epistemic injustice, and participation

The Lancet. Healthy Longevity 2024;5(1):e76-e82.

Humanitarian emergencies disproportionately affect older people. Although defining an older person by an age range can help alert us to emerging or changing needs and potential vulnerabilities during humanitarian emergencies, ageing is not necessarily synonymous with increasing vulnerability, and individual variations exist due to the heterogeneity of older people. In general, reduced access to safety, health services, clean water, and appropriate food puts older people at increased risk of poor health outcomes during humanitarian emergencies, including disability, injury, malnutrition, and mental health issues. The theoretical framework presented in this Personal View explains how ageism, further compounded by intersecting oppression, leads to the exclusion of older people from the preparedness, response, and recovery phases of humanitarian emergencies. The exclusion of older people is discriminatory, violates core humanitarian and bioethical principles, and leads to an epistemic injustice. We suggest that humanitarian actors implement participatory approaches with older people in humanitarian contexts. Through these approaches, solutions will be identified by and together with older people, leading to community-driven and context-appropriate ways to include the needs and strengths of older people in the preparedness, response, and recovery phases of humanitarian emergencies.

[https://doi.org/10.1016/S2666-7568\(23\)00244-1](https://doi.org/10.1016/S2666-7568(23)00244-1)

Applications de l'épigénétique en contexte militaire

Dalpe G., Huerne K., Dupras C., et al.

Defusing the legal and ethical minefield of epigenetic applications in the military, defense, and security context

Journal of Law and the Biosciences 2023;10(2):lsad034.

Epigenetic research has brought several important technological achievements, including identifying epigenetic clocks and signatures, and developing epigenetic editing. The potential military applications of such technologies we discuss are stratifying soldiers' health, exposure to trauma using epigenetic testing, information about biological clocks, confirming child soldiers' minor status using epigenetic clocks, and inducing epigenetic modifications in soldiers. These uses could become a reality. This article presents a comprehensive literature review, and analysis by interdisciplinary experts of the scientific, legal, ethical, and societal issues surrounding epigenetics and the military. Notwithstanding the potential benefit from these applications, our findings indicate that the current lack of scientific validation for epigenetic technologies suggests a careful scientific review and the establishment of a robust governance framework before consideration for use in the military. In this article, we highlight general concerns about the application of epigenetic technologies in the military context, especially discrimination and data privacy issues if soldiers are used as research subjects. We also highlight the potential of epigenetic clocks to support child soldiers' rights and ethical questions about using epigenetic engineering for soldiers' enhancement and conclude with considerations for an ethical framework for epigenetic applications in the military, defense, and security contexts.

<https://doi.org/10.1093/jlb/lsad034>

Le droit de vote des personnes avec des fonctions mentales très altérées

Desjeux C.

Éthique, droit de vote et polyhandicap

Revue française d'éthique appliquée 2023;N°14(1):140-154.

Depuis la loi du 23 mars 2019, un juge des tutelles ne peut plus retirer le droit de vote à une personne en tutelle. En outre, les personnes auxquelles ce droit avait été retiré l'ont automatiquement retrouvé. Cependant, cette réforme soulève plusieurs questions éthiques quant à la manière d'exercer ce droit, en particulier lorsque l'on s'intéresse aux personnes qui sont dans l'incapacité de comprendre le système électoral du fait d'altération de fonctions mentales (au sens de la Classification internationale du fonctionnement, du handicap et de la santé – cif) trop importantes. Plus particulièrement, certains proches envisagent cette réforme comme leur permettant de voter à la fois en leur nom et en celui de la personne en situation de handicap. Cet article propose de s'intéresser aux conditions éthiques qui permettent la légitimité de ce « double vote » à partir de trois questions : est-ce que ce double vote revêt le même type de logique quel que soit l'acteur qui le met en pratique ? Quel est le seuil à partir duquel on peut déterminer si une personne est à même de voter par elle-même ou non ? Est-ce que ce double vote remet en cause le principe personnel de ce droit et son caractère secret ?

<https://doi.org/10.3917/rfeap.014.0140>

L'interdiction de l'avortement pour cause de handicap sévère est une injustice reproductive

Francis L.

The Reproductive Injustices of Abortion Bans for Disability

The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 2023;51(3):490-496.

This article argues that state laws banning abortions for disability violate reproductive justice for parents with disabilities. These bans deprive people with disabilities of choices that may be important to their possibilities of becoming parents, including possibilities for abortion of pregnancies that have become risky to continue. Far from protecting disability civil rights, these state law bans restrict the abilities of people with disabilities to choose to have children and to parent.

<https://doi.org/10.1017/jme.2023.127>

L'instrumentalisation des comités d'éthique pour justifier l'alimentation de force

Lederman Z., Essex R.

Using Ethics Committees to Justify Force-Feeding Political Prisoners in Israel

Health and Human Rights 2023;25(2):53-65.

Thousands of Palestinian prisoners are held in Israeli prisons without trial. For some of them, engaging in hunger strikes is the last resort in opposing unlawful detention and inhumane prison conditions. While mainstream bioethics deliberation, reasonable arguments, and international legal and medical professional declarations prohibit force-feeding, local ethical deliberations, professional medical guidelines, and legislation allow the use of medical judgment and clinical ethics committees to force-feed these prisoners. Until now, Israeli physicians have refused to do so, but this may change in the future. The international medical and bioethics communities need to stand behind these medical professionals, as well as prisoners. Clinical ethics committees in Israel must choose whether they serve the interests of these prisoner-patients and perhaps their political or human rights agenda, or whether they are subservient to an unjust, oppressive regime.

[PMID: 38145140](https://pubmed.ncbi.nlm.nih.gov/38145140/)

Les restriction sélectives de liberté selon l'âge en contexte pandémique

Motorniak D., Savulescu J., Giubilini A.

[Reelin' In The Years: Age and Selective Restriction of Liberty in the COVID-19 Pandemic](#)

Journal of Bioethical Inquiry 2023

During the COVID-19 pandemic, focused protection strategies including selective lockdowns of the elderly were proposed as alternatives to general lockdowns. These selective restrictions would consist of isolating only those most at risk of COVID-19 hospitalization and subsequent use of healthcare resources. The proposal seems to have troubling implications, including the permissibility of selective lockdown on the basis of characteristics such as ethnicity, sex, disability, or BMI. Like age, these factors also correlated with an increased risk of hospitalization from COVID-19. In this paper, we argue that age has meaningful differences as a morally relevant characteristic in the justification for selective restrictions of liberty. Thus, it might justify selective freedom restrictions in a way in which other factors might not. We offer four moral domains that separate age from other proxies: empiricism, operationality, discrimination, and disparity.

<https://doi.org/10.1007/s11673-023-10318-8>

Dilemmes éthiques en fin de vie

Nogueira V.P., Furtado M.A., Pessoa V.L.M. de P., et al.

[Ethical dilemmas at the end of life: a reflection from the Philosophical Perspective of Luigina Mortari](#)

Revista Brasileira De Enfermagem 2023;76Suppl 3(Suppl 3):e20220759.

OBJECTIVES: to reflect on the ethical dilemmas involved in the care of patients at the end of their lives. METHODS: this is a theoretical-reflective study based on the ethics of care proposed by Luigina Mortari. RESULTS: discussing care involves addressing the ways of being inherent to human existence and understanding the unique characteristics of this condition. Ethical care constitutes an action driven by interest in the other and by the perception of their need. Ethical dilemmas are a part of end-of-life care, making it essential to maintain respectful assistance that considers the patient's autonomy, using strategies for expressing their wishes, and ensuring continuous clear and empathetic communication among all those involved in providing care. FINAL CONSIDERATIONS: issues related to being, stemming from one's reality of dependency and vulnerability, contribute to the emergence of ethical dilemmas present in care actions.

<https://doi.org/10.1590/0034-7167-2022-0759>

Les enfants vivant avec leurs mères emprisonnées

Ogrizek A., Radjack R., Moro M.R.

[Réflexions éthiques autour des enfants vivant auprès de leurs mères incarcérées](#)

Soins. Psychiatrie 2024;45(350):29-32.

En France, les femmes enceintes ou avec un enfant de moins de 18 mois, exceptionnellement 24 mois, peuvent purger leur peine d'incarcération dans des nurseries ou des cellules mères-enfants spécialement aménagées. Cette situation pourrait vraisemblablement exercer un impact négatif sur la santé de l'enfant et sur la qualité du lien avec sa mère à plus ou moins long terme. Les bénéfices du maintien de ce lien sont indiscutables, quel que soit le cadre. Des améliorations de ce dispositif pourraient être pensées et mises en place.

<https://doi.org/10.1016/j.spsy.2023.11.008>

L'histoire du mouvement pour une justice sanitaire mondiale

Parker R.

[On the genealogy of the global health justice movement](#)

Global Public Health 2023;18(1):2288686.

In the wake of the COVID-19 pandemic, it is clear that the struggle for global health justice must be our highest priority. To understand the challenges that such a priority faces, we must recognise that this struggle has a long history, and to analyse current challenges within this historical perspective. This commentary explores the gradual construction of the global health justice movement during different historical periods (tropical/colonial medicine, international health, and global health) in the history of approaches to health worldwide. It examines the changing relationship between the political economy of capitalism, colonialism, and racism. It analyses attempts to confront injustice through both human rights and social justice movements in seeking to address stigma and discrimination as well as poverty and social exclusion. It highlights emerging battlegrounds such as access to medical treatments and healthcare services as well as the ways in which private interests continue to undercut such efforts. But it also points to windows of opportunity for defending principles such as solidarity and social inclusion, for building advocacy/analysis alliances and toolkits to inform social movements, and possibilities to reconstruct global health "governance" mechanisms and institutions in accord with the most basic principles of health justice.

<https://doi.org/10.1080/17441692.2023.2288686>

L'opinion publique face aux pratiques de fin de vie pour les nouveaux-nés

Schneider K., Roll S., Tissen-Diabaté T., et al.

[Public Attitudes Toward Ethics and Practices in End-of-Life Decision-Making for Neonates](#)

JAMA network open 2024;7(1):e2353264.

IMPORTANCE: Attitudes toward end-of-life decision-making in neonatology have been studied in physicians and other health care professionals and are mostly shaped by their clinical education and work experiences. In contrast, attitudes among the general public have not yet been investigated. **OBJECTIVE:** To assess (1) attitudes in the general public toward euthanasia and withdrawal of life-prolonging treatment in neonates with severe life-limiting conditions, (2) knowledge of current German recommendations, and (3) values in the German society regarding ethical issues and proxy decisions at the beginning of life. **DESIGN, SETTING, AND PARTICIPANTS:** This cross-sectional study was performed in Germany and used an exploratory design to analyze responses to an interview conducted by an independent, established commissioned polling institute in March and April 2022. Participants were 16 years or older, with German language fluency and comprehension and living in Germany. **MAIN OUTCOMES AND MEASURES:** Knowledge about recommendations for euthanasia and withdrawal of life-prolonging treatment as well as personal attitudes toward (1) euthanasia and withdrawal of life-prolonging treatment and (2) surrogate end-of-life decision-making for newborn infants were assessed. **RESULTS:** The study included 2116 participants (1077 females [50.9%]; mean [SD] age 52.1 [18.7] years). Of the participants, 16.8% (311 of 1851) reported knowing the German recommendations for euthanasia and withdrawal of life-prolonging treatment for neonates. Euthanasia and withdrawal of life-prolonging treatment were supported by 64.7% (1369 of 2116) and 77.9% (1649 of 2116) of respondents, respectively. Shared decision-making between parents and physicians for neonates in end-of-life situations was supported by 65.6% of participants (1388). In situations where shared decision-making was not possible, 73.4% of respondents (1019 of 1388) put the ultimate decision to the parents. The magnitude of the associations was low between sociodemographic factors and views on ethical issues and customary practices involved in end-of-life decisions for neonates. **CONCLUSIONS AND RELEVANCE:** Results of this cross-sectional study suggested that most respondents were not aware of the national German recommendations for euthanasia and withdrawal of life-prolonging treatment for sick and extremely preterm newborns. When counseling parents of periviable newborns, clinicians may need to exert more effort in explaining the legal and ethical framework; a highly individualized approach is warranted.

<https://doi.org/10.1001/jamanetworkopen.2023.53264>

Confiner dans une démocratie libérale

Schroeder S.A.

[Lockdowns, Bioethics, and the Public: Policy-Making in a Liberal Democracy](#)

The Hastings Center Report 2023;53(6):11-17.

Commentaries on the ethics of Covid lockdowns nearly all focus on offering substantive guidance to policy-makers. Lockdowns, however, raise many ethical questions that admit of a range of reasonable answers. In such cases, policy-making in a liberal democracy ought to be sensitive to which reasonable views the public actually holds—a topic existing bioethical work on lockdowns has not explored in detail. In this essay, I identify several important questions connected to the kind of influence the public ought to have on lockdown decision-making, including how policy-makers ought to handle misinformed or morally suspect viewpoints, and how policy-makers ought to respond to minority viewpoints. I argue that questions like this, concerning the appropriate influence of the public on decision-making, will be central to the field of bioethics as it increasingly focuses on policy and population-level issues and therefore ought to be priorities for future work.

<https://doi.org/10.1002/hast.1539>

Les enjeux éthiques des véhicules autonomes

Krügel S., Uhl M.

[The risk ethics of autonomous vehicles: an empirical approach](#)

Scientific Reports 2024;14(1):960.

How would people distribute risks of autonomous vehicles (AVs) in everyday road traffic? The rich literature on the ethics of autonomous vehicles (AVs) revolves around moral judgments in unavoidable collision scenarios. We argue for extending the debate to driving behaviors in everyday road traffic where ubiquitous ethical questions arise due to the permanent redistribution of risk among road users. This distribution of risks raises ethically relevant questions that cannot be evaded by simple heuristics such as « hitting the brakes. » Using an interactive, graphical representation of different traffic situations, we measured participants' preferences on driving maneuvers of AVs in a representative survey in Germany. Our participants' preferences deviated significantly from mere collision avoidance. Interestingly, our participants were willing to take risks themselves for the benefit of other road users, suggesting that the social dilemma of AVs may be mitigated in risky environments. Our research might build a bridge between engineers and philosophers to discuss the ethics of AVs more constructively.

<https://doi.org/10.1038/s41598-024-51313-2>

Les dilemmes moraux soulevés par les véhicules autonomes

Sui T.

[Exploring moral algorithm preferences in autonomous vehicle dilemmas: an empirical study](#)

Frontiers in Psychology 2023;14:1229245.

INTRODUCTION: This study delves into the ethical dimensions surrounding autonomous vehicles (AVs), with a specific focus on decision-making algorithms. Termed the « Trolley problem, » an ethical quandary arises, necessitating the formulation of moral algorithms grounded in ethical principles. To address this issue, an online survey was conducted with 460 participants in China, comprising 237 females and 223 males, spanning ages 18 to 70. **METHODS:** Adapted from Joshua Greene's trolley dilemma survey, our study employed Yes/No options to probe participants' choices and Likert scales to gauge moral acceptance. The primary objective was to assess participants' inclinations toward four distinct algorithmic strategies—Utilitarianism, Rawlsianism, Egoism, and a Hybrid approach—in scenarios involving AVs. **RESULTS:** Our findings revealed a significant disparity between participants' preferences in scenarios related to AV design and those focused on purchase decisions. Notably, over half of the respondents expressed reluctance to purchase AVs equipped with an « egoism » algorithm, which

prioritizes the car owner's safety. Intriguingly, the rejection rate for « egoism » was similar to that of « utilitarianism, » which may necessitate self-sacrifice. **DISCUSSION:** The hybrid approach, integrating « Utilitarianism » and « Egoism, » garnered the highest endorsement. This highlights the importance of balancing self-sacrifice and harm minimization in AV moral algorithms. The study's insights are crucial for ethically and practically advancing AV technology in the continually evolving realm of autonomous vehicles.

<https://doi.org/10.3389/fpsyg.2023.1229245>

Les services publics dans les territoires ruraux

Taulelle F., Courcelle T., Fijalkow Y.

Égalité, accessibilité, solidarité : les renoncements de l'État

Le Bord de l'eau 2024; Lormont.

À la suite de la crise des gilets jaunes et de la COVID, la question des services publics dans les territoires de faible densité s'est imposée fortement dans l'espace public et médiatique. Les termes du débat sont connus mais les évolutions en cours sont rarement analysées de manière systémique au plus près des territoires. Les contributions rassemblées dans cet ouvrage sont celles de spécialistes reconnus qui apportent des éclairages inédits à partir d'études localisées, de données quantitatives et d'enquêtes effectuées auprès d'habitants, d'élus, d'opérateurs de services publics et d'autres acteurs. La réorganisation des services publics (dématérialisation, regroupement au sein d'espaces France Services) et ses conséquences sont finement étudiées. Après deux ouvrages consacrés au délaissement des territoires (2012) et à l'évolution des services publics dans les territoires (2017) cette équipe de recherche pluridisciplinaire, composée de sociologues, géographes et économistes apporte un complément indispensable à la connaissance des recompositions à l'œuvre dans la France des petites villes et des villages.

[ISBN : 978-2-35687-994-3](https://www.editions-leborddeleau.com/)

Pourquoi l'inclusion est-elle souhaitable ?

Weele S. van der, Bredewold F.

What's Good About Inclusion? An Ethical Analysis of the Ideal of Social Inclusion for People with Profound Intellectual and Multiple Disabilities

Health care analysis: HCA: journal of health philosophy and policy 2023

"Social inclusion" is the leading ideal in services and care for people with intellectual disabilities in most countries in the Global North. « Social inclusion » can refer simply to full equal rights, but more often it is taken to mean something like « community participation ». This narrow version of social inclusion has become so ingrained that it virtually goes unchallenged. The presumption appears to be that there is a clear moral consensus that this narrow understanding of social inclusion is good. However, that moral consensus is not clear in the case of people with profound intellectual and/or multiple disabilities (PIMD), who are not able to express their needs and preferences verbally. Moreover, social inclusion has proven to be difficult to conceptualize and implement for people with PIMD. Therefore, it becomes imperative to ask about the ethical rationale of the narrow understanding of social inclusion. For what reasons do we think social inclusion is good? And do those reasons also apply for people with PIMD? This article addresses these questions by providing an ethical analysis of the ideal of social inclusion for people with PIMD. It discusses four ethical arguments for social inclusion and probes their relevance for people with PIMD. The article argues that none of these arguments fully convince of the value of the narrow understanding of social inclusion for people with PIMD. It ends with advocating for an ethical space for imagining a good life for people with PIMD otherwise.

<https://doi.org/10.1007/s10728-023-00470-y>

L'évolution du tabagisme en fonction des inégalités

Wehrli D., Gilljam H., Koh D.M., et al.

Smoking trends and health equity in Switzerland between 1992 and 2017: dependence of smoking prevalence on educational level and social determinants

Frontiers in Psychiatry 2023;14:1258272.

BACKGROUND: Switzerland ranks among the top three healthcare systems in the world with regards to healthcare access, suggesting a high degree of health equity. However, Switzerland has few preventive strategies against smoking abuse. The aim of this study is to clarify whether educational level and citizenship status have an influence on the prevalence of smoking in Switzerland and whether there is health inequity related to a lack of preventive strategies. **METHODS:** We based our analysis on publicly available health data published in the Swiss government's Swiss health survey (1992-2017). We compared the prevalence of smoking across the years and correlated these data with levels of educational attainment, citizenship status and age. **RESULTS:** A continuous significant decline in smokers is observed in the highest education group (TERT). Over time, prevalence was reduced from 29% in 1992 to 23% in 2017 ($p < 0.001$). The intermediate-level educational group (SEK 2) showed smaller but also significant decline on a 0.05 significance level over the same period, from 31% to 29% ($p = 0.003$). The lowest educational group showed a nonsignificant decline from 28% to 27% ($p = 0.6$). The population who holds Swiss citizenship showed a decrease in smoking from 28% to 26% within the time frame ($p < 0.001$). People without Swiss citizenship had a much higher prevalence of smokers, at 38% in 1992 and declining to 32% in 2017 ($p < 0.001$). All cohorts from age 15 to age 64 have a far higher prevalence of smokers than cohorts at an older age, with the highest prevalence in the 25-34 age group. **CONCLUSION:** In Switzerland, individuals with lower levels of education and non-Swiss populations are more susceptible to health risk of smoking. This is despite the existence of a high-quality healthcare system that has nevertheless failed to negated health inequities.

<https://doi.org/10.3389/fpsy.2023.1258272>

ENSEIGNEMENT ET FORMATION



Le lien entre sensibilité morale des étudiant·es et comportement professionnel

Bagheri M., Shahriari M., Hassanvand P., et al.

The Relationship between Moral Sensitivity and Professional Behaviour and Its Comparison in First- and Last-Year Undergraduate Nursing Students

Nursing Research and Practice 2023;2023:5368045.

BACKGROUND: Nursing students should be equipped with ethical sensitivity and professional behaviour because they will face challenging ethical issues in their future work environment. This study aimed to determine the relationship between moral sensitivity and professional behaviour and compare it in first- and last-year undergraduate nursing students. **METHODS:** This study was a cross-sectional, correlational study that was conducted at Isfahan University of Medical Sciences in 2019. The sample size of this study was 238 nursing students. The tools used in this study were the Persian versions of the moral sensitivity questionnaire and the professional behaviour questionnaire. The data were analyzed using SPSS 18 software. **RESULTS:** Linear regression showed that the total score of moral sensitivity of nursing students had a significant relationship with their professional behaviour ($p < 0.05$). The result of the univariate analysis showed that the mean total score of moral sensitivity and professional behaviour was significantly higher in the last year than in first-year students ($p < 0.05$). **CONCLUSION:** Considering the relationship between moral sensitivity and the professional behaviour of nursing students, the promotion of moral sensitivity can become the basis for the development of the professional behaviour of nursing students. Therefore, it is suggested to focus on teaching the principles of nursing ethics to develop the moral sensitivity of undergraduate nursing students.

<https://doi.org/10.1155/2023/5368045>

L'enseignement de l'éthique infirmière au Brésil

Bueno A. de A., Evangelista R.A., Potrich T., et al.

Overview of nursing ethics teaching in Brazilian public higher education institutions

Revista Brasileira De Enfermagem 2023;76Suppl 3(Suppl 3):e20220808.

OBJECTIVES: to outline the teaching of ethics in undergraduate Nursing programs in Brazilian public higher education institutions. **METHODS:** descriptive and exploratory study, carried out through the documentary analysis of pedagogical projects of undergraduate Nursing programs in Brazil. **RESULTS:** 153 active undergraduate Nursing programs were found, of which 106 provide the pedagogical project. In addition to deontological teaching, the

teaching of ethics was identified in a transversal way associated with themes such as Social Context, Hospital and Community Care, Pharmacology, Systematization of Nursing Care, Surgical Nursing, Epidemiology, Palliative Care, Management in Nursing, Diversity, Women's, Children's, Adolescent's, Adult's and Older People's Health, and Mental Health. FINAL CONSIDERATIONS: the challenge in teaching nursing ethics is its integration with each action of caring, teaching and managing.

<https://doi.org/10.1590/0034-7167-2022-0808>

L'usage de l'IA dans les sciences de l'éducation

Gouvea J.S.

Ethical Dilemmas in Current Uses of AI in Science Education

CBE life sciences education 2024;23(1):fe3.

The purpose of the Current Insights feature is to highlight recent research and scholarship from outside the LSE community. In this installment, I review a series of recently published articles which examine ethical dilemmas concerning the use of artificial intelligence (AI), more specifically machine learning, in science education. The articles in this set are intended to stimulate discussions about whether and how AI can and should be used in education research.

<https://doi.org/10.1187/cbe.23-12-0239>

L'application de principes de justice distributive par des étudiant·es

Hsieh H.-Y., Lin C.-H., Huang R., et al.

Challenges for medical students in applying ethical principles to allocate life-saving medical devices during the COVID-19 pandemic: a qualitative study

JMIR medical education 2023

BACKGROUND: The emergence of the COVID-19 pandemic has posed a significant ethical dilemma in the allocation of scarce, life-saving medical equipment to critically ill patients. It remains uncertain whether medical students are equipped to navigate this complex ethical process. **OBJECTIVE:** To assess the ability and confidence of medical students to apply principles of medical ethics in allocating critical medical devices through the scenario of virtual patients. **METHODS:** The study recruited third- and fourth-year medical students during clinical rotation. We facilitated interactions between medical students and virtual patients experiencing respiratory failure due to COVID-19 infection. We assessed the students' ability to ethically allocate life-saving resources. Subsequently, we analyzed their written reports using thematic analysis to identify the ethical principles guiding their decision-making. **RESULTS:** We enrolled a cohort of 67 out of 71 medical students with its mean age of 34 and 60 percent of them were female students for this study. Seventy-three percent of them cited the principle of justice while analyzing this scenario. A majority of them expressed hesitancy in determining which patient should receive life-saving resources, with 46% citing the principle of non-maleficence, 31% advocating for a first-come-first-serve approach, and 25% emphasizing respect for patient autonomy as key influencers in their decisions. Notably, medical students exhibited a lack of confidence in making ethical decisions concerning the distribution of medical resources. A minority, comprising 12%, proposed the exploration of legal alternatives, while 4% suggested medical guidelines and collective decision-making as potential substitutes for individual ethical choices to alleviate the stress associated with personal decision-making. **CONCLUSIONS:** The study highlights the importance of improving ethical reasoning under time constraints using virtual platforms. More than seventy percent of medical students identified justice as the predominant principle in allocating limited medical resources to critically ill patients. However, they exhibited a lack of confidence in making ethical determinations and leaned toward principles such as non-maleficence, patient autonomy, adherence to legal and medical standards, and collective decision-making to mitigate the pressure associated with such decisions.

<https://doi.org/10.2196/52711>

L'évolution du rapport des étudiant·es en santé au travail avant/après la pandémie

Kaldjian A.M., Shinkunas L., Peter T.K., et al.

Epidemics and the healthcare professional's duty to care: Students' attitudes about work requirements before and during Covid-19 (2017-2021)

Medical Education 2023

CONTEXT: The Covid-19 pandemic has added a new chapter to discussions about the professional duty to care. To understand how Covid-19 may have changed medical students' ethical attitudes towards this duty, we analysed policies written before and during the pandemic by first-year students completing a yearly educational exercise focused on work requirement expectations for healthcare professionals during a hypothetical epidemic. **METHODS:** Within a repeated cross-sectional design, consensus coding was performed on policies written over 5 years (2017-2021) using a codebook based on eight questions from the educational exercise for summative content analysis. Frequencies provided summative results and comparisons across years used Fisher's exact test. **RESULTS:** We analysed 142 written policies from 2017 to 2021 representing 884 first-year students working in small groups. Students' commitment to the duty to care remained stable during the Covid-19 pandemic, but during the pandemic, students were more likely to support exceptions to the duty to care (e.g. for healthcare professionals with medical conditions or concern for household members' health) and more likely to expect institutions to provide safe working conditions. Ethical values supporting students' policies were largely consistent before and during the pandemic, the most common being beneficence, justice, duty to care, non-maleficence and utility. **CONCLUSIONS:** Our results suggest that students' support for the duty to care remained strong during the Covid-19 pandemic. We also found that students supported exceptions to this duty to reflect the needs of healthcare professionals and their families and that they expected institutions to provide safe working conditions. These findings can help inform ethics education and future pandemic preparedness.

<https://doi.org/10.1111/medu.15285>

L'influence abusive des informations génétiques sur la prise de décision des étudiant·es en médecine

Lane A.S., Lynch K.E., Arnold M., et al.

The undue influence of genetic information on senior medical students' treatment decisions

BMC medical education 2023;23(1):938.

BACKGROUND: Knowledge of the genetic basis of health conditions can influence how the public perceives their own and others' health. When there are known genetic associations for such conditions, genetic essentialist biases facilitate deterministic thinking and an over-emphasis of genetic causality. This study investigates the role that genetic essentialist biases play in medical decision-making. **METHODS:** Senior postgraduate medical students (N = 102) read a scenario in which a patient presents with gastroenterological symptoms. Half of the students were told that the patient tested positive for HLA-DQ2 - a gene implicated in, but not deterministic of, coeliac disease. The other half received no genetic information. Students were assessed on their recommendations for investigation and management using a multiple-choice questionnaire. Twenty-two of these students participated in a qualitative follow-up which used focus groups and semi-structured interviews to explore the reasoning behind students' responses. **RESULTS:** Management recommendations differed between the two groups, with those receiving genetic information more likely to recommend a gluten free diet. Recommendations for further investigation did not differ significantly between groups. Interviews suggested that these findings arose despite the students' good understanding of the common non-deterministic nature of genes, such as HLA-DQ2. **CONCLUSION:** Differences in management recommendations suggest that the inclusion of genetic information unduly biased students towards a premature diagnosis of a serious health condition, coeliac disease. Follow-up interviews introduced the possibility that observed manipulation-based differences may have been based on anticipated expectations of examiners, rather than perceived future clinical practice. Based on the present results it is unclear whether intentional exam-taking strategies fully account for medical students' decisions, or if they contribute in addition to the activation of genetic essentialist biases. Further research in clinical settings may ascertain whether genetic essentialist biases would truly influence medical student and doctors within their clinical practice environment.

<https://doi.org/10.1186/s12909-023-04895-w>

Les dilemmes éthiques des enseignants en santé pendant la pandémie

Lim K.M., Sok S.

Health teachers' ethical conflict experiences in the COVID-19 situation: a qualitative content analysis

Frontiers in Public Health 2023;11:1265589.

BACKGROUND: In the context of the COVID-19 pandemic, health teachers who are responsible for the health of school staff and students are experiencing many ethical conflicts, and research on this is needed. **OBJECTIVE:** This study was to investigate and explore the ethical conflicts experienced by health teachers during the COVID-19 pandemic situation. **METHODS:** This was a qualitative study using directed content analysis applied to the four principles of biomedical ethics. Study participants were a total of 26 health teachers in Seoul, South Korea. In-depth individual interviews were conducted with 14 health teachers, and focus group interviews were conducted with the other 12 (2 teams with each 6 persons). Data were collected between May-June 2022, and analyzed using a deductive approach among the qualitative content analysis of Elo and Kyngäs. This study satisfied the four aspects of credibility, transferability, dependability, and confirmability presented by Guba and Lincoln (1989) to secure the reliability of qualitative research. **RESULTS:** The ethical conflicts related to the four principles of biomedical ethics advocated by Beauchamp and Childress (autonomy, non-maleficence, beneficence, and justice), and the ethical conflicts in which overlap with the two principles of autonomy and non-maleficence, and the ethical conflicts related to miscellaneous matters or relationships, which were not included in the four principles, were investigated as the main 6 categories of ethical conflicts experienced by health teachers. Based on this, 10 generic categories and 17 subcategories were derived. **CONCLUSION:** This study could be used as primary data for policy development and intervention research. Such engagements can help identify ethical conflicts faced by health teachers in infectious disease crises, thus improving their ability to cope.

<https://doi.org/10.3389/fpubh.2023.1265589>

L'effet des compétences d'empathie chez les étudiant·es infirmier·es

Liu F., Zhou H., Yuan L., et al.

Effect of empathy competence on moral sensitivity in Chinese student nurses: the mediating role of emotional intelligence

BMC nursing 2023;22(1):483.

BACKGROUND: Ethical issues may pose challenges to nursing students entering clinical practice. Moral sensitivity can assist them in recognising existing moral situations and then taking adequate action. Identifying the variables associated with moral sensitivity may be useful in preparing to improve nursing students' moral sensitivity. **OBJECTIVES:** This study investigated empathy, emotional intelligence, and moral sensitivity in Chinese student nurses to explore the association among these three factors and to verify the mediating function of emotional intelligence in determining the connection between empathy and moral sensitivity. **DESIGN:** This study used a cross-sectional correlational design. **SETTING AND PARTICIPANTS:** Through convenience sampling, 239 fourth-year nursing undergraduates at a university in Western China were enrolled in this study. **METHODS:** Nursing students who volunteered to participate in the study completed self-reported scales on empathy, emotional intelligence, and moral sensitivity between September and October 2022. The potential mediating effect was explored using the Process Macro and bootstrap method. **RESULTS:** The nursing students' average scores were 39.62 ± 5.27 on moral sensitivity, 108.21 ± 15.49 on empathy, and 124.41 ± 13.66 on EI. Moral sensitivity was positively correlated with emotional intelligence ($r=0.454$, $p<0.001$) and empathy ($r=0.545$, $p<0.001$). Furthermore, empathy exerted a substantial direct effect on nursing students' moral sensitivity ($B=0.1424$, $p<0.001$). Emotional intelligence could mediate the indirect path from empathy to moral sensitivity. ($B=0.0372$, $p<0.001$). **CONCLUSION:** Emotional intelligence mediated the association between empathy and moral sensitivity. Thus, educational activities and programmes placing an emphasis on empathy and emotional intelligence may offer an alternative way to promote moral sensitivity in Chinese student nurses. **IMPLICATIONS:** Nursing educators can organise programmes to improve nursing students' emotional competence and

professional values. Early exposure to clinical practice benefits nursing students a lot in terms of building interactions with patients and increasing emotional resonance. In addition, nursing educators should develop situational teaching in nursing ethics courses to help students cope with ethical issues.

<https://doi.org/10.1186/s12912-023-01650-w>

Intégrer les questions de justice sociale à la formation médicale

Mathieu I.P., Martin B.J.

The art of equity: critical health humanities in practice

Philosophy, ethics, and humanities in medicine: PEHM 2023;18(1):19.

BACKGROUND: The American Association of Medical Colleges has called for incorporation of the health humanities into medical education, and many medical schools now offer formal programs or content in this field. However, there is growing recognition among educators that we must expand beyond empathy and wellness and apply the health humanities to questions of social justice - that is, critical health humanities. In this paper we demonstrate how this burgeoning field offers us tools for integrating social justice into medical education, utilizing the frameworks of critical consciousness and structural competency. **PRACTICE OF HEALTH HUMANITIES:** Critical health humanities can be applied at multiple levels of learners, and in a variety of contexts. We are two physician-writers who have developed several educational programs that demonstrate this. We taught a seminar that introduced first-year and second-year undergraduates to concepts such as social determinants of health, intergenerational trauma, intersectionality, resilience, and cross-cultural care through works of fiction, poetry, film, podcasts, stand-up comedy, and more. Through creative projects and empathic reflection, students engaged with the complexities of structural forces that create and maintain health disparities. Medical students in their clinical years can engage in critical health humanities learning experiences as well. We teach several multidisciplinary electives that address social (in)justice in medicine, as well as mentor fourth-year students engaged in independent electives that foster critical awareness around health equity and ethics. Beyond the classroom, we have actively engaged in critical health humanities practices through story slams, literary journal clubs, conference presentations, and Grand Rounds. Through these activities we have included learners at GME and CME levels. These examples also demonstrate how community engagement and multidisciplinary partnerships can contribute to the practice of critical health humanities. **CONCLUSION:** In this paper, we explore the growing field of critical health humanities and its potential for teaching health equity through narrative practices. We provide concrete examples of educational activities that incorporate critical consciousness and structural competency - frameworks we have found useful for conceptualizing critical health humanities as a pedagogical practice. We also discuss the strengths and challenges of this work and suggest future directions.

<https://doi.org/10.1186/s13010-023-00149-1>

L'usage de la pédagogie critique pour l'enseignement de l'antiracisme dans les professions de santé

Onuoha C., Tsai J., Khazanchi R.

Using Critical Pedagogy to Advance Antiracism in Health Professions Education

AMA journal of ethics 2024;26(1):E36-47.

This article draws on Paulo Freire's *Pedagogy of the Oppressed* to model how health professions education can advance health equity. It first introduces 3 well-known frameworks that can be meaningfully applied as critical pedagogy: structural competency, critical race theory, and participatory action research. It then highlights applications of these frameworks that can prepare trainees for reflection and action that motivate health equity.

<https://doi.org/10.1001/amajethics.2024.36>

L'enseignement de l'éthique doit nécessairement traiter des questions sociales clivantes

Tilburt J., Hafferty F., Leep Hunderfund A., et al.

Ethics Education in Health Sciences Should Engage Contentious Social Issues: Here Is Why and How

Cambridge quarterly of healthcare ethics: CQ: the international journal of healthcare ethics committees 2024:1-5.

Teaching ethics is crucial to health sciences education. Doing it well requires a willingness to engage contentious social issues. Those issues introduce conflict and risk, but avoiding them ignores moral diversity and renders the work of ethics education irrelevant. Therefore, when (not if) contentious issues and moral differences arise, they must be acknowledged and can be addressed with humility, collegiality, and openness to support learning. Faculty must risk moments when not everyone will 'feel safe,' so the candor implied in psychological safety can emerge. The deliberative and social work of ethics education involves generous listening, wading into difference, and wondering together if our beliefs and arguments are as sound as we once thought. By forecasting the need for candid engagement with contentious issues and moral difference, establishing ground rules, and bolstering due process structures for faculty and students, a riskier and more relevant ethics pedagogy can emerge. Doing so will prepare everyone for the moral diversity they can expect in our common life and in practice.

<https://doi.org/10.1017/S0963180123000567>

L'enseignement de l'éthique médicale comme bioéthique translationnelle

Young P.D., Papanikitas A.N., Spicer J.

Medical ethics education as translational bioethics

Bioethics 2024

We suggest that in the particular context of medical education, ethics can be considered in a similar way to other kinds of knowledge that are categorised and shaped by academics in the context of wider society. Moreover, the study of medical ethics education is translational in a manner loosely analogous to the study of medical education as adjunct to translational medicine. Some have suggested there is merit in the idea that much as translational research attempts to connect the laboratory scientist's work to its implications for patient care, translational ethics focuses on bringing ethics scholarship into the sphere of personal and public action. We distinguish the term « translational ethics » (the study of ethics being translated between academy, classroom and clinic) from other prominent definitions in the bioethics literature. To do this, we build off a notion of knowledge translation that focuses on the nonlinear movement of information that comes to professionals through multiple competing sources. We suggest that this knowledge, and particularly knowledge about ethics, becomes embodied by the individual. It is through a reflective practice that internally embedded ethics knowledge might be modified, and this work might be best carried out with a moral community that maintains a sense of practical wisdom. Applying this translational approach to the study of medical ethics education can be both academically relevant and practically useful. This view of translation can help bridge the evident, multidirectional relationships between research, education and performance. It might also create further opportunities to develop medical ethics education theory.

<https://doi.org/10.1111/bioe.13257>

INTERNATIONAL



Afrique : Biobanques et usage de données génomiques

Amoakoh-Coleman M., Vieira D., Abugri J.

[Ethical considerations for biobanking and use of genomics data in Africa: a narrative review](#)

BMC medical ethics 2023;24(1):108.

BACKGROUND: Biobanking and genomic research requires collection and storage of human tissue from study participants. From participants' perspectives within the African context, this can be associated with fears and misgivings due to a myriad of factors including myths and mistrust of researchers. From the researchers angle ethical dilemmas may arise especially with consenting and sample reuse during storage. The aim of this paper was to explore these ethical considerations in the establishment and conduct of biobanking and genomic studies in Africa. **METHODS:** We conducted a narrative synthesis following a comprehensive search of nine (9) databases and grey literature. All primary research study designs were eligible for inclusion as well as both quantitative and qualitative evidence from peer reviewed journals, spanning a maximum of 20 years (2000-2020). It focused on research work conducted in Africa, even if data was stored or analysed outside the region. **RESULTS:** Of 2,663 title and abstracts screened, 94 full texts were retrieved and reviewed for eligibility. We included 12 studies (7 qualitative; 4 quantitative and one mixed methods). Ethical issues described in these papers related to community knowledge and understanding of biobanking and genomic research, regulation, and governance of same by research ethics committees, enrolment of participants, types of informed consents, data collection, storage, usage and sharing as well as material transfer, returning results and benefit sharing. ca. Biospecimen collection and storage is given in trust and participants expect confidentiality of data and results generated. Most participants are comfortable with broad consent due to trust in researchers, though a few would like to be contacted for re-consenting in future studies, and this would depend on whether the new research is for good cause. Sharing data with external partners is welcome in some contexts but some research participants did not trust foreign researchers. **CONCLUSION:** Biobanking and genomic studies are a real need in Africa. Linked to this are ethical considerations related to setting up and participation in biobanks as well as data storage, export, use and sharing. There is emerging or pre-existing consensus around the acceptability of broad consent as a suitable model of consent, the need for Africans to take the lead in international collaborative studies, with deliberate efforts to build capacity in local storage and analysis of samples and employ processes of sample collection and use that build trust of communities and potential study participants. Research ethics committees, researchers and communities need to work together to work together to adapt and use clearly defined ethical frameworks, guidelines, and policy documents to harmonize the establishment and running of biobanking and genomic research in Africa.

<https://doi.org/10.1186/s12910-023-00985-y>

Afrique : Le « dumping éthique » à travers les lunettes décoloniales

Ewuoso C.

Decolonial health literature can increase our thinking about ethics dumping

Journal of Medical Ethics and History of Medicine 2023;16:10.

This article draws on the underexplored or novel accounts of inclusion and the moral accounts of decolonization in African health decolonial literature to increase our understanding of how ethics dumping manifests in health research partnerships, and what more ought to be done to eliminate this phenomenon. African decolonial health literature proposes « inclusion that matters » - conceptualized as substantial, respectful and deep engagement with African agency - as a solution to end domination or mitigate the « appearance » of inclusion. Based on this supposition, the harm of ethics dumping - and I demonstrate how - is that it fails to engage the agency of Africans, and listen to or echo their voices in health and health research collaborations on the continent, or research collaborations that have significant implications for them. This account of inclusion can usefully increase our thinking about ethics dumping, which is ultimately and in several ways a failure to practice responsible science. Research is required to increase our understanding of what could reasonably constitute responsible science from a variety of perspectives.

<https://doi.org/10.18502/jmehm.v16i10.14305>

Belgique : Comment est régulée la pratique de l'euthanasie ?

Archer M., Willmott L., Chambaere K., et al.

What Domains of Belgian Euthanasia Practice are Governed and by Which Sources of Regulation: A Scoping Review

Omega 2023;;302228231221839.

BACKGROUND: Multiple sources of regulation seek to shape euthanasia practice in Belgium, including legislation and training. This study comprehensively mapped which of these sources govern which domains of euthanasia practice, such health professionals' obligations, or managing patient requests. METHOD: Scoping review methodology was used to search for scholarly records which discussed Belgian euthanasia regulation. Template analysis was used to generate themes describing the domains of euthanasia practice governed by sources of regulation. RESULTS: Of 1364 records screened, 107 records were included. Multiple sources of regulation govern each domain, which are: the permissible scope of euthanasia; the legal status of a euthanasia death; the euthanasia process; the rights, obligations, and roles of those involved; system workings; and support for health professionals who provide euthanasia. CONCLUSIONS: Domains with significant yet fragmented regulation may lead to inconsistent care provision. Policymakers should develop coherent guidance to support health professionals to navigate this regulatory landscape.

<https://doi.org/10.1177/00302228231221839>

Inde : Le profil social des victimes de la drépanocytose

Chattoo S., Jain D., Nashine N., et al.

A social profile of deaths related to sickle cell disease in India: a case for an ethical policy response

Frontiers in Public Health 2023;11:1265313.

India accounts for 14.5 percent of the global SCD newborns, roughly over 42,000 a year, second to sub-Saharan Africa. Despite the availability of cheap diagnostic and treatment options, SCD remains a largely neglected disease within healthcare policy and practice. Epidemiological modeling based on small, often dated, regional studies (largely from sub-Saharan Africa) estimate that between 50 and 90 percent of affected children will/die before the age of 5 years. This premise, coupled with targets of reducing under 5 mortality (SDG 4), privileges public health

interventions for screening and prevention of new births, undermining investments in long-term health and social care. This paper presents a retrospective, descriptive analysis of the socio-demographic profile of 447 patients diagnosed with sickle cell or sickle-beta thalassemia, who died following admission at a tertiary care centre in India. We used anonymized hospital records of 3,778 sickle cell patients, admitted in pediatric and adult/medical wards between January 2016 and February 2021. A majority of hospital deaths occurred in the second and third decades of life, following a hospital admission for a week. The overall mortality during 2016-2019 was 14% with little gender difference over time. Contrary to our expectations, the number of hospital deaths did not increase during the first year of the COVID-19 pandemic, between 2020 and 2021. The conclusion highlights the importance of longitudinal, socio-demographic data on deaths as providing important insights for identifying ethical policy interventions focused on improving SCD outcomes over time, reducing inequities in access to care, and preventing what might be considered 'excess' deaths.

<https://doi.org/10.3389/fpubh.2023.1265313>

Nicaragua : La recherche en génétique dans un pays pauvre

Delgado I.S., Outtersson A., Ramesh V., et al.

Ethical considerations for genetic research in low-income countries: perceptions of informed consent, data sharing, and expectations in Nicaragua

European journal of human genetics: EJHG 2023

Genetic research presents numerous ethical, legal, and social implications (ELSI), particularly when the research involves collaborations between investigators in high and low-income countries. Some ELSI issues are universal, and others are specific to context and culture. This study investigates perceptions of genetic research in Nicaragua, Central America, where local and U.S. based researchers have collaborated for over a decade. A total of 43 residents from northwestern Nicaragua, a region with high mortality rates attributed to chronic kidney disease of non-traditional causes (CKDnt), were interviewed, including research participants in ongoing studies (n = 36), health professionals (n = 3), labor leaders (n = 2), and family members of research participants (n = 2). Questions focused on informed consent, data-sharing, and post-study expectations. Audio recordings of interviews conducted in Spanish were transcribed and translated into English. English transcripts were coded and analyzed using NVivo 12 software. The lack of familiarity with terms in the consent form presented a barrier to participant comprehension of key elements of the genetic research study, raising concerns about the validity of informed consent. Research participants often viewed their participation as access to health care. Health professionals emphasized the importance of long-term partnerships between foreign-based researchers and local health institutions. Leaders and family members recommended that they be informed of research studies and allowed the opportunity to consent, as they felt the benefits and risks of research also apply to them. Our findings identified genetic research practices to be improved upon in order to be more responsive to the contextual realities of collaborators living in low-resource settings.

<https://doi.org/10.1038/s41431-023-01505-7>

Asie du Sud-Est : L'acceptabilité de l'autopsie verbale auprès des proches

Htun N.S.N., Perrone C., Phyo A.P., et al.

Ethical and cultural implications for conducting verbal autopsies in South and Southeast Asia: a qualitative study

BMJ global health 2023;8(12):e013462.

INTRODUCTION: Causes of deaths often go unrecorded in lower income countries, yet this information is critical. Verbal autopsy is a questionnaire interview with a family member or caregiver to elicit the symptoms and circumstances preceding a death and assign a probable cause. The social and cultural aspects of verbal autopsy have gotten less attention than the technical aspects and have not been widely explored in South and Southeast Asia settings. **METHODS:** Between October 2021 and March 2023, prior to implementing a verbal autopsy study at rural sites in Bangladesh, Cambodia, Laos, Myanmar and Thailand, focus group discussions were conducted

with village heads, religious leaders and community members from varied demographic backgrounds. Thematic analysis elucidated customs and traditional views surrounding death to understand local ethnocultural sensitivities. RESULTS: We found that death rituals varied greatly among religions, ethnicities and by socioeconomic status. Mourning periods were reported to last 3-100 days and related to the cause of death, age and how close the deceased person was to the family. Participants advised that interviews should happen after mourning periods to avoid emotional distress, but not long after so as to avoid recall bias. Interviewers should be introduced to respondents by a trusted local person. To provide reassurance and confidentiality, a family's residence is the preferred interview location. Interview questions require careful local language translation, and community sensitisation is important before data collection. CONCLUSION: Verbal autopsy is acceptable across a wide range of cultural settings in Southeast Asia, provided that local norms are preidentified and followed.

<https://doi.org/10.1136/bmjgh-2023-013462>

Ouganda : Développer un nouveau cadre d'enseignement de l'éthique de la recherche

Kiwanuka G.N., Bajunirwe F., Alele P.E., et al.

Public health and research ethics education: the experience of developing a new cadre of bioethicists at a Ugandan institution

BMC medical education 2024;24(1):1.

Research ethics education is critical to developing a culture of responsible conduct of research. Many countries in sub-Saharan Africa (SSA) have a high burden of infectious diseases like HIV and malaria; some, like Uganda, have recurring outbreaks. Coupled with the increase in non-communicable diseases, researchers have access to large populations to test new medications and vaccines. The need to develop multi-level capacity in research ethics in Uganda is still huge, being compounded by the high burden of disease and challenging public health issues. Only a few institutions in the SSA offer graduate training in research ethics, implying that the proposed ideal of each high-volume research ethics committee having at least one member with in-depth training in ethics is far from reality. Finding best practices for comparable situations and training requirements is challenging because there is currently no « gold standard » for teaching research ethics and little published information on curriculum and implementation strategies. The purpose of this paper is to describe a model of research ethics (RE) education as a track in an existing 2-year Master of Public Health (MPH) to provide training for developing specific applied learning skills to address contemporary and emerging needs for biomedical and public health research in a highly disease-burdened country. We describe our five-year experience in successful implementation of the MPH-RE program by the Mbarara University Research Ethics Education Program at Mbarara University of Science and Technology in southwestern Uganda. We used curriculum materials, applications to the program, post-training and external evaluations, and annual reports for this work. This model can be adapted and used elsewhere in developing countries with similar contexts. Establishing an interface between public health and research ethics requires integration of the two early in the delivery of the MPH-RE program to prevent a disconnect in knowledge between research methods provided by the MPH component of the MPH-RE program and for research in ethics that MPH-RE students are expected to perform for their dissertation. Promoting bioethics education, which is multi-disciplinary, in institutions where it is still « foreign » is challenging and necessitates supportive leadership at all institutional levels.

<https://doi.org/10.1186/s12909-023-04974-y>

Pakistan : Pratiques du consentement en situation d'urgence

Munawar T., Ismail F., Mehmood Qadri H., et al.

Practices of Informed Consent for Emergency Procedures at a Tertiary Care Hospital in Lahore, Pakistan

Cureus 2023;15(12):e50322.

Background: The purpose of obtaining informed consent is to ensure that patients undergoing any medical or surgical intervention are neither deceived nor coerced. Accurately estimating surgical risks is critical for shared decision-making and informed consent. Probable complications and alternative procedures should be presented to the patient so that they can freely choose an operative option. However, this factor is difficult to carry on in emergencies where an urgent decision is required. *Objective:* This study aimed to assess the ongoing clinical practices of informed consent in emergency surgeries at a tertiary care facility. *Materials and methods* A cross-sectional survey was carried out from March 2022 to June 2022 at the Department of General Surgery, Lahore General Hospital, Lahore, Pakistan, with patients who had undergone surgical procedures under local, spinal, or general anesthesia within 24 hours of presentation. A Google Form (Google Inc., Mountainview, CA) was designed, containing a predefined set of 32 standard questions, and patients were interviewed in their native language to assess their satisfaction regarding the pattern and components of emergency informed consent. *Categorical data* were assessed using measures of central tendency, frequencies, and percentages. *Results:* A total of 169 patients were selected for the study. Only 1.6% of them signed the consent form themselves, while 93.5% of the forms were signed by their first-degree relatives. Verbal consent was taken in 4.8% of cases. In 88% of cases, informed consent was obtained by the house surgeons. The majority of patients, i.e., 78.2%, were not able to read the written consent form; however, 83.1% understood the verbal information. About 66.3% of patients agreed that they were informed about the nature of their disease, while 67.5%, 14.8%, and 13.7% affirmed that they were explained the nature of surgical intervention, associated risks, and type of anesthesia, respectively. Overall, 59.5% of patients felt satisfied with the process of informed consent. About 91.1% of the patients believed that their decisions were unaffected by the procurement of informed consent. *Conclusion:* The existing practices of informed consent and comprehension by the population were found to be substandard. Physicians seem to ignore bioethics, and patients appear to be unaware of their basic rights. Although practiced at our center, not all components of informed consent were communicated to the patients. The risks of the procedures and the mode of anesthesia used were not well addressed by doctors. There is a grave need to educate the medical community about the legal and ethical aspects of informed consent, as well as the public masses regarding their rights.

<https://doi.org/10.7759/cureus.50322>

Japon : Les consultation d'éthique clinique

Nagao N., Takimoto Y.

Clinical Ethics Consultation in Japan: What does it Mean to have a Functioning Ethics Consultation?

Asian Bioethics Review 2024;16(1):15-31.

This research examines the current status of clinical ethics consultation (CEC) in Japan through a nationwide study conducted with chairs of ethics committees and clinical ethics committees among 1028 post-graduate clinical teaching hospitals. We also qualitatively analyzed their viewpoints of the CEC's benefits and problems related to hospital consultation services to identify the critical points for CEC and inform the development of a correctly functioning system. The questionnaire included structured questions about hospital CEC organization and service purpose and operation and open-ended questions about the benefits and problems of initiating CEC. The questionnaire comprised the presence/absence of an ethics committee, CEC services and membership when services were implemented, users, and the number of cases handled since inception. In addition, the respondents also provided their impressions of the CEC system's impact on their hospital by describing (a) the benefits of CEC services and (b) the ineffectual or harmful aspects of the CEC system. Qualitative data were examined using qualitative content analysis to determine the impact of establishing a CEC and the difficulties of practice. One

hundred twenty-five questionnaires were returned from either the chair of the ethics committee or clinical ethics committee in teaching hospitals. Of these, 90 (72%) reported they provided CEC services. Additionally, 36 respondents (34.6%) reported that their existing research and clinical ethics committees had conducted CEC services, and 35 (33.7%) reported having a newly established clinical ethics committee conducting CEC services. Three positive effects of establishing and four challenges in managing CEC were also identified.

<https://doi.org/10.1007/s41649-023-00257-2>

Afrique du Sud : Les barrières de la langue dans l'obtention du consentement éclairé

Pillay N., Ncube N., Moopelo K., et al.

Translating the consent form is the tip of the iceberg: using cognitive interviews to assess the barriers to informed consent in South African health facilities

Sexual and Reproductive Health Matters 2023;31(4):2302553.

The increasing digitisation of personal health data has led to an increase in the demand for onward health data. This study sought to develop local language scripts for use in public sector maternity clinics to capture informed consent for onward health data use. The script considered five possible health data uses: 1. Sending of general health information content via mobile phones; 2. Delivery of personalised health information via mobile phones; 3. Use of women's anonymised health data; 4. Use of child's anonymised health data; and 5. Use of data for recontact. Qualitative interviews (n = 54) were conducted among women attending maternity services in three public health facilities in Gauteng and Western Cape, South Africa. Using cognitive interviewing techniques, interviews sought to: (1) explore understanding of the consent script in five South African languages, (2) assess women's understanding of what they were consenting to, and (3) improve the consent script. Multiple rounds of interviews were conducted, each followed by revisions to the consent script, until saturation was reached, and no additional cognitive failures identified. Cognitive failures were a result of: (1) words and phrases that did not translate easily in some languages, (2) cognitive mismatches that arose as a result of different world views and contexts, (3) linguistic gaps, and (4) asymmetrical power relations that influence how consent is understood and interpreted. Study activities resulted in the development of an informed consent script for onward health data use in five South African languages for use in maternity clinics.

<https://doi.org/10.1080/26410397.2024.2302553>

États-Unis : Les impacts de la levée du droit à l'avortement

Manian M.

The Impact of Dobbs on Health Care Beyond Wanted Abortion Care

The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 2023;51(3):592-600.

While empirical evidence has exposed the harms and health disparities flowing from being denied a wanted abortion, we know less about how anti-abortion laws and policies impact health care more broadly. This article surveys the public health impacts of Dobbs on health care beyond wanted abortion care. The article argues that focusing the public's attention on the harmful consequences of abortion bans for healthcare beyond wanted abortion care could help to fend off further restrictions on abortion.

<https://doi.org/10.1017/jme.2023.108>

États-Unis : Les nouvelles limites à l'autodétermination des patientes enceintes

Sawicki N.N., Kukura E.

From Constitutional Protections to Medical Ethics: The Future of Pregnant Patients' Medical Self-Determination Rights After Dobbs

The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 2023;51(3):528-532.

This article argues that the Supreme Court's decision in Dobbs is likely to impact medical decision-making by pregnant patients in a variety of contexts. Of particular concern are situations where a patient declines treatment recommended for its potential benefit to the fetus and situations where treatment is withheld due to potential risk to the fetus. The Court's elevation of fetal interests, combined with a history of courts using abortion jurisprudence to guide their reasoning in compelled treatment cases, means that Dobbs has the potential to limit patient autonomy in a wide array of clinical settings. The article calls on professional medical associations to issue ethical guidance affirming the duty to respect the medical self-determination of pregnant patients.

<https://doi.org/10.1017/jme.2023.125>

États-Unis : L'injustice de la levée du droit à l'avortement pour les parents porteurs de maladies génétiques

Suter S.M., Hercher L.

Reproductive Genetic Medicine in a Post-Dobbs World: Will it Make Life Harder for People with Genetic Disease?

The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 2023;51(3):511-517.

Post-Dobbs abortion restrictions impact access and choice in the context of reproductive genetic medicine, raising serious reproductive justice concerns. The consequences of these restrictions are particularly acute and far-reaching for individuals with genetic conditions and their families.

<https://doi.org/10.1017/jme.2023.128>

États-Unis : Comment continuer à protéger le droit à l'avortement par les lois des États ?

Thomas T.

Protecting Abortion with State Health Care Freedom of Choice

The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 2023;51(3):601-605.

This essay examines the right of health care freedom of choice contained in some state constitutions. It explores how courts have, and could, use this constitutional health care right as a basis for recognizing or reinforcing a fundamental right to choose an abortion.

<https://doi.org/10.1017/jme.2023.93>

États-Unis : Incarcération de masse, santé publique et bioéthique

Valles S.A.

Fifty Years of U.S. Mass Incarceration and What It Means for Bioethics

The Hastings Center Report 2023;53(6):25-35.

A growing body of literature has engaged with mass incarceration as a public health problem. This article reviews some of that literature, illustrating why and how bioethicists can and should engage with the problem of mass incarceration as a remediable cause of health inequities. « Mass incarceration » refers to a phenomenon that emerged in the United States fifty years ago: imprisoning a vastly larger proportion of the population than peer countries do, with a greatly disproportionate number of incarcerated people being members of marginalized racial and ethnic groups. Bioethicists have long engaged with questions of health justice for incarcerated people,

including consent issues for those participating in research and access to health care. This article provides an overview of the individual and public health impacts of mass incarceration. The article argues that mass incarceration is a bioethics issue that should be addressed in medical education, identifies opportunities for bioethicists to guide hospitals' interactions with law enforcement officials, and calls on bioethicists to be in conversation with medical and nursing students and health care professionals about these groups' advocacy efforts concerning structural racism, police violence, and mass incarceration.

<https://doi.org/10.1002/hast.1541>

Bulgarie : Le dilemme moral de l'euthanasie

Tsranchev I.I., Mileva B., Goshev M., et al.

[The Moral Dilemma of Euthanasia Through the Eyes of the Medical Society in Bulgaria](#)

Cureus 2023;15(11):e49615.

INTRODUCTION: With the development of human society, the question of the value and inviolability of human life begins to occupy a central place in the various social strata and social structures. With the adoption of the Universal Declaration of Human Rights after the Second World War, the basic postulates protecting the right to inviolability of human life were laid. The question focused on euthanasia has been discussed in several European countries, such as Germany, Ireland, France, and Italy, leading to considerable interest in the medical community in Bulgaria. **MATERIALS AND METHODS:** A prospective study was performed using approved sample cards, analyzing the general knowledge of the medical community in the Republic of Bulgaria about euthanasia and assisted suicide over a period of four months, between January 2023 and May 2023. In this process, 623 people were surveyed, and the questionnaire included several targeted questions through electronically generated samples on the Microsoft Forms platform. The target group had doctors with and without a specialty in various fields of hospital and pre-hospital care, dentists, and students from the fields of medicine and dentistry. **RESULTS AND DISCUSSION:** The results show that the majority of medical professionals clearly state their positive opinion on the adoption of a law to legalize euthanasia in the Republic of Bulgaria, clearly taking into account the fact that the right to life has always been and always will be the most absolute and fundamental human right. Contrary to the above, it is implied that it is inevitably linked to a quality and fulfilling life without suffering. Identically, they also answered that a person should have the right to know exactly when to end his own life. The medical society in Bulgaria clearly shows its positive opinion regarding the idea that the different forms of euthanasia (active euthanasia and assisted suicide) should be defined as morally and legally permissible. Our research confirms the Bulgarian medical community's opinion that the subject of the problems of euthanasia and its legal regulation are already ripe for public discussion, similar to many other European countries. **CONCLUSION:** The actual issue of euthanasia as a conclusion raises several questions related to the process of acceptance of standard algorithms for action in such cases where the same action is legalized by law. It also includes the process of acceptance of strict regulations by the countries for the so-called negative phenomenon « death tourism » and several other administrative actions related to the mandatory registration of every case of euthanasia, the implementation of mandatory consultations with a psychiatrist and psychologist for patients seeking euthanasia as the only possible option, and providing possible alternatives regarding their illness. This is the unchangeable cornerstone for standardizing the legalization process and acceptance of 'good death' in Bulgaria. In its essence, euthanasia creates both a social and an ethical conflict in our modern society, appearing at the same time as a kind of 'stress test' for the health system.

<https://doi.org/10.7759/cureus.49615>

Malaisie : Développer la thérapie génique et cellulaire

Vasodavan K., Theva Das K.

[Advancing precision medicine with gene and cell therapy in Malaysia: Ethical, Legal, and Social Implications \(ELSI\)](#)

Human Gene Therapy 2023

A new era of gene and cell therapy for treating human diseases has been envisioned for several decades. However, given that the technology can alter any DNA/cell in human beings, it poses specific ethical, legal, and social difficulties in its application. In Malaysia, current bioethics and medical ethics guidelines tackle clinical trials and

biomedical research, medical genetic services, and stem cell research/therapy. However, no comprehensive framework and policy is available to cater to ethical gene and cell therapy in the country. Incorporating ethical, legal, and social implications (ELSI) would be crucial to guide the appropriate use of human gene and cell therapy in conjunction with precision medicine. Policy experts, scientists, bioethicists, and public members must debate the associated ELSI and the professional code of conduct while preserving human rights.

<https://doi.org/10.1089/hum.2023.139>

Iran : L'accès aux services de santé pour les réfugiés afghans

Zakian Khorramabadi F., Moazzen V., Parsapour A., et al.

[Access to health care for Afghan immigrants and refugees: an ethico-legal analysis based on the Iranian health law system](#)

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The right to health is an internationally recognized and established human right with a long history of appreciation, indicating that governments should guarantee the highest possible level of access to health and provide health-care services with no discrimination based on nationality, race, gender, language or religion. The present study explored this topic using an analytic-descriptive approach. We reviewed related laws, policies and other available documents with the aim to investigate the ethico-legal aspects of Afghan refugees' and immigrants' access to health care and the challenges in this regard within the Iranian health law system. According to the results of this study, the Iranian health law could be interpreted to include all Afghan immigrants in the country's public health system as a legal commitment. In addition, while basic and primary health coverage is available for all Afghan immigrants in Iran, provision of other medical and rehabilitative health services to documented and undocumented immigrants follow different methods. In order to alleviate the current situation, we recommend strategies such as supporting policy changes intended to register undocumented immigrants, which naturally results in an increase in their access to health care.

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