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From the Editor

De Ethica is published by Linköping University Electronic Press, and we are currently participating in a project to develop ethical guidelines for this publisher. This work is, of course, both interesting and important, especially since the world of scientific writing and publishing has recently perhaps transformed. Chat-GPT not only changed how we approach examinations in education but also opened up new opportunities and risks in the research process.

Large language models (LLMs) promise to be of tremendous help in the work of research. An often-used example is how AI helped solve the protein folding problem that biochemists have worked on for over 50 years. However, using AI also comes with risks that can put rather severe stress on standard approaches to publishing ethics.¹ Examples could range from publishing AI hallucinations as scientific facts via new forms of plagiarism to an even stronger pressure to publish or perish, with attendant so-called salami publishing as a result.²

Indeed, recently, the Vancouver Principles for publishing ethics were revised to take these developments into account. The following are now the principles for regulating who will count as an author:

1. Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND

2. Drafting the work or reviewing it critically for important intellectual content; AND

3. Final approval of the version to be published; AND

4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.³

It might seem that some forms of AI could satisfy several of these criteria; however, ICMJE continues to add that "[a]uthors should not list AI and AI-assisted technologies as an author or co-author, nor cite AI as an author." This principle implies that using an LLM to generate an article does not give one the status of author and, hence, no claim to the merit that authorship entails. However, it also implies that there may exist articles that do not have any authors. This seems to be the proper implication for publishing ethics, but it may seem puzzling.

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¹ Resnik, D., & Hosseini, M. (2023, October 27). The Ethics of Using Artificial Intelligence in Scientific Research: New Guidance Needed for a New Tool. https://doi.org/10.31235/osf.io/rbg9z 2 Helgesson, Gert. (Forthcoming) Ethical Aspects of the Use of AI in Research. In Research Ethics: Ethical Review and Beyond, Elin Palm & Lars Lindblom (eds). Linköping: Linköping University Electronic Press.

³ ICMJE. 2024. Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals. https://www.icmje.org/recommendations/

These guidelines also give instructions on how to quote and use AI in the publication process: "The journal should require authors to disclose whether they used Artificial Intelligence (AI)-assisted technologies (such as Large Language Models [LLMs], chatbots, or image creators) in the production of submitted work."⁴ These emerging guidelines on AI use are helpful. But, of course, there will, for the foreseeable future, be borderline cases and unforeseen developments. At De Ethica, we are at present spending quite some time thinking about such possible puzzles and problems at present.

However, luckily, we are spending much more time thinking about new and exciting work in ethics broadly construed. In this issue, we are happy to publish part 2 of our special issue on vulnerability and integrity, expertly guest-edited by Michael Coors and Lea Chilian. They will present the articles on this issue in their introduction, which follows this brief note from the editors.

Lars Lindblom, Executive Editor

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⁴ ICMJE. 2024. Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals. https://www.icmje.org/recommendations/

From the Guest Editors – Challenging Vulnerability and Integrity

This special issue of "De Ethica" is the second of two volumes, which both contain papers presented at Societas Ethica's annual conference in 2022 in Zurich on the topic "Vulnerability & Integrity."

In recent academic discourse, the concepts of vulnerability and integrity have emerged as pivotal frameworks for understanding human experiences, social dynamics, and ethical considerations. However, the interplay between these two concepts has sparked considerable debate and critique within scholarly circles. To delve into the tensions and criticisms surrounding the notion of vulnerability, particularly in relation to the concept of integrity, aiming to provide a nuanced understanding of these complex constructs – this was the aim of 2022's conference and the papers presented in the two volumes.

Even though there is a varied and wide-ranging discussion on the understanding of vulnerability, in its essence, it pertains to the susceptibility of individuals or groups to physical, emotional, social, or economic harm. It underscores the inherent fragility and interdependence of human existence, acknowledging that all individuals are subject to various forms of vulnerability throughout their lives. Scholars such as Judith Butler and Martha Fineman have significantly contributed to the conceptualization of vulnerability, emphasizing its intersectional nature and its embeddedness within broader power structures.¹ If vulnerability is used to describe a threat to personal integrity, then talk of resilience as a resource follows on seamlessly from this, particularly in scientific, psychological and medical discourse. However, if vulnerability is seen as a description of the subject's openness to being "de-" or "reformed", vulnerability can also be understood as a resource and a gift, as enabling empathy and the ability to transform. The term is more than ambivalent.

Ambivalent concepts of vulnerability

Despite its significance, the vulnerability paradigm has faced notable critique from scholars across disciplines. One primary criticism revolves around its perceived essentialism, wherein vulnerability is often portrayed as a static and universal condition, overlooking the dynamic and context-specific nature of human experiences. Additionally, critics argue that the emphasis on vulnerability could inadvertently reinforce stigmatization and marginalization, as it may pathologize certain identities or experiences.

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¹See for example: Fineman's research team website: https://web.gs.emory.edu/vulnerability/; cf. Judith Butler et al. (ed.), *Vulnerability in Resistance* (Durham: Duke University Press, 2016); cf. Gunda Werner, 'Relational und vulnerabel. Die Subjektphilosophie Judith Butlers im theologischen Diskurs' (*Theologische Revue* 114:3 (2018)), pp. 179-202; for an overview cf. Florian Pistrol, 'Vulnerabilität: Erläuterungen zu einem Schlüsselbegriff im Denken Judith Butlers' (*Zeitschrift für Praktische Philosophie*, 3:1 (2016)), pp. 233–272.

The problem with an universalistic understanding of vulnerability is that it can have negative implications and consequences for the perception of concrete human suffering as well as disadvantage, marginalization and injustice. For example, it has been argued against a universalization of vulnerability that, on the one hand, it could have the tendency to overlook, trivialize or level out the concrete injuries of certain people or groups against the background of an undifferentiated observation of the general human vulnerability of all people and thus weaken the socio-political struggle against concrete injustice. This problem also applies to criticism of care ethics: with the general talk of relationality, the special need for protection and dependency of individuals may not be taken into account. It is therefore questionable whether care ethics can capture moral vulnerability.² Furthermore, a universalistic understanding of vulnerability is criticized to the effect that the understanding of vulnerability as a general susceptibility and openness of people leads to a trivialization. The intensified negativity associated with specific experiences of injury in the form of violent damage or trauma to the subject may be ignored.

A particularized understanding of vulnerability, on the other hand, has the advantage of representing the interests and needs of individuals or minorities over (selfproclaimed) majorities - but only if the attribution of vulnerability is also equated with their right to protection. In this respect, vulnerability has a socio-critical potential for addressing injuries and vulnerable subjects and should not lead to general acceptance and indifference towards the injuries of others through generalization. However, the fact that the social discourse on victimization has contributed to a moral polarization and division of society since the 1980s, as recent social history studies have shown, speaks against a onesided, particularistic view. Political scientists have observed that an understanding of vulnerability that sees it as a mere state of a subject and equates this state with suffering, passivity, powerlessness, helplessness, need for protection or weakness can be used to justify prophylactic protective measures or even "preventive detention" of injured or vulnerable people.³ However, adopting an anthropologically broad perspective proves to be advantageous when the focus is directed towards the consequences that can result from narrowing down a subject's condition or status as vulnerable. The particular concept of vulnerability is therefore suspected of supporting paternalistic logics. In this context, Hille Haker points out that the supposed personal integrity of invulnerable groups implied by particular vulnerability attributions can also imply the exercise of power where there is none.4

² Cf. Pamela Sue Anderson, 'Arguing for "ethical" vulnerability. Towards a politics of care?', in *Exploring Vulnerability*, edited by Heike Springhart and Günter Thomas (Göttingen: Vandenhoeck & Ruprecht, 2017), pp. 147-162.

³ Cf. Rebekka A Klein, 'Der ethische Sinn der Verletzlichkeit. Moralische Dimensionen der Verletzlichkeit des Menschen', in Moralische Dimensionen der Verletzlichkeit des Menschen. Interdisziplinäre Perspektiven auf einen anthropologischen Grundbegriff und seine Relevanz für die Medizinethik, edited by Michael Coors (Berlin, Boston: De Gruyter, 2022), pp. 57-84.

⁴ Cf. Hille Haker, 'Vom Umgang mit der Verletzlichkeit des Menschen', in Zwischen Parteilichkeit und Gerechtigkeit. Schnittstellen von Klinikseelsorge und Medizinethik (Ethik in der Klinikseelsorge 3), edited by Monika Bobbert (Münster, Berlin: LIT, 2015), pp. 195-22; Hille Haker, 'Verletzliche Freiheit. Zu einem neuen Prinzip der Bioethik', in *Theologische Vulnerabilitätsforschung. Gesellschaftsrelevant und interdisziplinär*, edited by Hildegund Keul (Stuttgart: Kohlhammer, 2021), pp. 99-118.

These considerations on the pros and cons of an universal or particularized understanding of vulnerability can be summarized under the term "ambivalent potentiality" proposed by Butler and Kristine Culp.⁵ Vulnerability is then understood in the sense of an openness that is to be regarded as ambivalent and potential. Vulnerability as openness to affliction need not only include painful and disruptive experiences, but also means the opening up of life possibilities. Some even go so far as to describe vulnerability as openness and thus as the basis for passions and for sensitivity to the passions of others. Hildegud Keul states that it is not possible to love one another without being vulnerable.⁶ For Christian charity, this understanding of vulnerability is a starting point for theological research. Is research on vulnerability merely an analysis of weak points or can vulnerability represent an opportunity for humanity, empathy and solidarity?⁷ Is shared, universal vulnerability the reason for social and human cohesion, even solidarity?

Dynamic vulnerabilty

This leads to the perspective that vulnerability cannot be seen as a disempowering *conditio humana*, but rather as a *conditio humana* that empowers the subject. Vulnerability is then not a static state in which the subject would be trapped, but vulnerability can rather be understood as a dynamic, enabling and empowering starting position that could constitute not only suffering, but also resistance, not only despair, but also a subject's power to act. In short, vulnerability is the "constitution of self-becoming", according to Heike Springhardt.⁸ Vulnerability would not be passive exposure, but an opportunity to shape one's own life. Perhaps that sounds too positively euphemistic and possibly romanticizing. It certainly does for me. "Do it yourself?" and if not, is it your own fault? That sounds a lot like resilience against and the elimination of suffering. But the precariousness of openness and vulnerability threatens to disappear. There is a threat of overcoming instead of enduring and suffering.

From a socio-ethical perspective, vulnerability is closely related to recognition theories of the social sphere, as found in Axel Honneth and Emmanuel Levinas, among others. Vulnerability presents itself as a deep dimension of human existence, in which people are addressed at the core of their individuality and uniqueness, i.e. are called by name, and are ultimately vulnerable. The human being is exposed to the gaze of the Other, who can reify it, i.e. negate and ultimately destroy it or keep it in existence. This is where humans reach the extreme limit of their existence and where vulnerability presents itself. However, despite all exposure, this is also the place to understand vulnerability not only as an existential threat, but also as a gift. Because it enables people to be "touched by others". According to Lisa Achathaler, vulnerability thus becomes the basis for empathy. Christian theology "is characterized by the fact that it does not assign a purely negative meaning to the vulnerable existence of human beings, but rather understands it as

⁵ Cf. Kristine A. Culp, *Vulnerability and Glory: A Theological Account* (Louisville, KY: Westminster John Knox, 2010).

⁶ Cf. Hildegund Keul, 'Verwundbarkeit, Sicherheit und Resilienz. Der Vulnerabilitätsdiskurs als Chance für eine gesellschaftsrelevante Theologie', *Stimmen der Zeit* 09 (2017), pp. 589-598.
⁷ Cf. Keul, *Verwundbarkeit, Sicherheit und Resilienz*, pp. 589-598.

⁸ Cf. Heike Springhardt, 'Exploring life's vulnerability. Vulnerability in vitality', in *Exploring Vulnerability*, edited by Heike Springhart and Günter Thomas (Göttingen: Vandenhoeck & Ruprecht, 2017), pp. 13-34.

necessary and necessary for people to live together in a way that is open to others."⁹ Its constructive contribution is that it has developed forms of life and practices in which a bodily self can experience and shape its life by including and not ignoring its vulnerability (cf. Bieler; Keul).¹⁰ Insofar vulnerability is not a subjective and isolated condition, but a characteristic of shared life.

Challenging integrity

In juxtaposition to vulnerability, the concept of integrity underscores notions of wholeness, coherence, and moral soundness – as often is assumed. Integrity is often associated with autonomy, agency, and the capacity to act in accordance with one's values and principles: integrity serves as a guiding principle for ethical action and moral responsibility. However, the pursuit of integrity can sometimes clash with the recognition of vulnerability. For instance, the valorization of individual autonomy may downplay or dismiss the inherent vulnerabilities that shape human existence, leading to an oversimplified understanding of ethical responsibility. But is it also possible to think of vulnerability and integrity in an intertwined and interdependent relation? No integrity without vulnerability and vice versa – this experience somehow arises in many daily experiences. Integrity is far away from being a state beyond and conquered vulnerability.

At the same time, Rebekka Klein identifies a "spiral of violence" in the concept of vulnerability that stands in contrast to people's striving for integrity. Klein points out that the phenomenon of violence is based on the openness to injury shared by all people.¹¹ Seen in this light, vulnerability becomes a curse and pushes into a spiral of violence that entangles us in lifelong relationships of violation, as we cannot escape the violating power of others, according to Butler. The "wounding power" as a willingness to wound others out of fear of one's own wounding clearly points to the tensions inherent in the concept of vulnerability.¹²

Navigating the tensions between vulnerability and integrity necessitates a nuanced approach that acknowledges the complexities of human experiences and social realities. Rather than treating vulnerability and integrity as diametrically opposed concepts, one can make up an integrated framework that recognizes the dialectical relationship between them. While one can embrace vulnerability as a fundamental aspect of human existence simultaneously it is an ethical question to uphold the importance of integrity. By critically engaging with these concepts and their intersections, scholars can contribute to a more holistic understanding of human live and social justice in contemporary society.

With regard to the question of the relationship between vulnerability and integrity, it should be noted that, following Alasdaire MacIntyre, it is precisely the pursuit of autonomy and self-empowerment that can make people particularly vulnerable and

¹² Cf. Judith Butler, *Die Macht der Gewaltlosigkeit: Über das Ethische im Politischen* (Frankfurt: Suhrkamp, 2020, pp. 41-87; Werner, Relational und vulnerabel, pp. 179-202.

⁹ Klein, Der ethische Sinn der Verletzlichkeit, p. 76 (translation L.C.).

¹⁰ Cf. Hildegund Keul (ed.), Theologische Vulnerabilitätsforschung: gesellschaftsrelevant und interdisziplinär (Stuttgart: Kohlhammer, 2021); Andrea Bieler, Verletzliches Leben. Horizonte einer Theologie der Seelsorge (Göttingen: Vandenhoeck & Ruprecht, 2017).

¹¹ Klein, Der ethische Sinn der Verletzlichkeit, p. 74 (translation L.C.).

endanger them.¹³ This leads to fundamental reflections on the sovereignty of the subject: if the subject were completely sovereign, then being vulnerable would only be an option that could be accepted or rejected. But this is not the case. Rather, the subject can only "live out of vulnerability and not away from it".¹⁴ This leads to fundamental questions of subject theory, but also to the challenge of developing an ethics that is sensitive to vulnerability and integrity.

Vulnerability and integrity in theological and philosophical research

A few years ago it was still the case that theology was largely absent from the emerging vulnerability discourse, despite the many opportunities to connect to the existing discourse in the various sciences;¹⁵ the only early exception is Dorothee Sölle's "Die Fenster der Verwundbarkeit" published in 1987. This has since changed somewhat¹⁶ and we are happy to start this second volume with an article that dares the undertaking to search for linking points in Butler's and Thomas Aquinas' work, to connect philosophical and theological approaches on vulnerability:

Keenan takes up Butler's elaboration of the concept of vulnerability and draws a comparison with the concept of conscience found in Thomas Aquinas. He thus undertakes a search between philosophical and theological ethics. The fact that vulnerability is also excellently suited to Christian ethical discourse is illustrated by the question of turning to one's neighbor. In this way, vulnerability offers an opportunity to bring philosophical and theological discourses into conversation with one another. The ethical scope clearly emerges in the form of the actions of the individual in social coexistence and its recognition of the other.

Martina Vuk pursues considerations beyond that when she addresses the relationship between vulnerability and flourishing in her article. Using the practical example of friendship between unequals, she examines how these two concepts are intertwined and which understanding of flourishing incorporates the circumstances of vulnerability.

Margrit Shildrick discusses the exploration of vulnerability in the field of bioethics from a phenomenological view, emphasizing embodiment as the defining element of the self and taking into account feminist approaches. Shildrick argues that human beings are inherently open to changes in their physical experiences due to their embodiment, which is crucial for ongoing development across their lifespan. Conditions such as disability, pain, aging, and dying are seen not as rare instances of vulnerability in an otherwise secure existence, but rather as core experiences that challenge the limits of Western ideologies,

¹³ Cf. Alasdair MacIntyre, Dependent Rational Animals. Why Human Beings Need the Virtues (Chicago: Open Court, 1999).

¹⁴ Klein, Der ethische Sinn der Verletzlichkeit, p.66 (translation L.C.).

¹⁵ Cf. Hildegund Keul, 'Resilienz der Verwundbarkeit. Der Vulnerabilitätsdiskurs als Chance für eine gesellschaftsrelevante Theologie', *Hermeneutische Blätter* 1 (2017), pp. 105-120, at p. 109; Marie-Theres Igrec, 'Vulnerabilität. Die Verwundbarkeit des Humanen im Spiegel der Theologie', *Salzburger Theologische Zeitschrift* 23:1 (2020), pp. 1-10; Hildegund Keul, 'Diskursgeschichtliche Einleitung zur theologischen Vulnerabilitätsforschung', in: Keul, *Theologische Vulnerabilitätsforschung*, pp. 7-18.

¹⁶ Cf. Issue 'Verwundbarkeit', *Hermeneutische Blätter*, 23:1 (2017); issue 'Vulnerabilität', *Salzburger Theologische Zeitschrift* 23:1 (2019); Keul, *Theologische Vulnerabilitätsforschung*.; Coors, *Moralische Dimensionen der Verletzlichkeit des Menschen*.

especially in the realms of modern Western biomedicine and conventional healthcare. The critique of the positivist model of biomedicine leads to a proposed rethinking of embodiment, taking into account Gilles Deleuze's work that carries profound implications for the field of bioethics.

Another article on vulnerability in the field of medicine is by Michael Braunschweig. His paper integrates vulnerability ethics into the debate on human germline genome editing, which has been largely overlooked in ethics discussions. He argues for a nuanced classification beyond the basic therapeutic vs. enhancement dichotomy, warning that labeling applications as 'therapeutic' might increase existing vulnerabilities. The author also refutes claims that germline editing inherently harms intergenerational relations and emphasizes the need for careful ethical scrutiny from a vulnerability perspective before making irreversible decisions.

Lea Chilian & Michael Coors, guest editors

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Vulnerability, Conscience, and Integrity

James F. Keenan

This essay explores how vulnerability, understood not as precarity but as capacious responsiveness, much as the philosopher Judith Butler identifies it, and recognition are key moral concepts that are prior conditions for the expression of conscience. Appreciating Thomas Aquinas' argument that conscience is neither a power or a habit, but rather an act, the essay argues that Aquinas' inclination synderesis, that prompts us to the good and away from evil, functions in a way similar to vulnerability. Fundamentally, vulnerability prompts us to recognize the neighbor who needs our response.

Vulnerability Ethics

These years I am trying to develop a vulnerability ethics.¹ I have been arguing that vulnerability and recognition are the necessary preconditions for preparing for the moral life and need to be addressed even before the question of conscience comes into ethical play. I arrived at my thesis on vulnerability, recognition and conscience after facing an on-going concern of mine. It seemed to me that in the United States we were designing ethics courses with the hope that they could have moral, formative impact on our students. We were thinking that through ethics courses we were forming their consciences and in this way we were teaching norms, values and virtues to get our students to make good judgments about ethical issues.

But I began to see that I was having little impact on whether they would be ethically responsive in the first place. For instance, I teach a course on HIV/AIDS and public health; my students learn a lot about public health ethics; but for only about half of them do they actually become more ethically disposed to be responsive in the first place.

¹ James F. Keenan, "Vulnerability and Hierarchicalism," *Melita Teologica* 68.2 (2018) 129-142; "The World at Risk: Vulnerability, Precarity and Connectedness" *Theological Studies* 81.1 (2020) 132-149 doi.org/10.1177/0040563920907633; "Rethinking Humanity's Progress in Light of COVID-19," *Asian Horizons* 14.3 (September 2020) 713-735; "Linking Human Dignity, Vulnerability and Virtue Ethics," *Interdisciplinary Journal for Religion and Transformation in Contemporary Society* 6 (2020) 56-73; https://doi.org/10.30965/23642807-00601004; "Building Blocks for Moral Education: Vulnerability, Recognition and Conscience," David DeCosse, ed. *Conscience and Catholic Education* (Maryknoll: Orbis Books, 2021). Bringing both into the University see "Vulnerable to Contingency," *Journal of the Society of Christian Ethics* 40.2 (2021) 221-236. https://muse.jhu.edu/article/787428/pdf; "The Community Colleges: Giving Them the Ethical Recognition They Deserve," *Journal of Moral Theology* 9.2 (2020) 143-164. https://jmt.scholasticahq.com/article/18040-the-community-colleges-giving-them-the-ethical-recognition-they-deserve

In fact, some of the students who perform best in my courses are among the least ethically responsive. They do well in discussions and on tests; they *know* the material better than others, but while they know what to do if they *had* to do something, they are not per se *inclined* to be responsive in the first place. If they had a roll in the Good Samaritan parable they would be like the priest and the Levite. Like them, they knew about the law and principles of conduct but in many instances, they do not vulnerably recognize the wounded one.

Is there something about preparing students for the moral life that precedes conscience formation? If we are forming the conscience prudentially and justly, is there something else we could do that would get them to stop and recognize the need to respond in conscience in the first place? This is the question that has guided me these years.

I began to see that we were thinking of conscience as a disposition, as something the students had, that we wanted to form. Now I am beginning to think that conscience is not a disposition at all and that Thomas Aquinas was right in saying it is not a faculty or a habit, but an act, that is something we need to do. I believe now that prior to conscience there are two steps: being vulnerable to others and actually recognizing others. The act of recognition I believe is the threshold for engaging ethical activity and once we recognize, we need conscience to actually respond. In other words, I locate vulnerability and recognition as prior to the act of conscience; vulnerability is the capacity to recognize a situation calling for a response and thus the capacity and its act of recognition prompts us to be responsive. On the dawn of responsiveness, we need in conscience to act so as to sort out how to proceed prudentially. Returning to our students then, what the non-responsive students lack is not knowledge, but vulnerability, a call to responsiveness, a call to be answerable. In short, we make appeals to conscience when we should be making appeals to their vulnerability

Before explaining what I mean on vulnerability and recognition, let me say something about Aquinas on conscience and *synderesis* and note that I think he had similar, but mostly undeveloped ideas on the topic.

In the *Pars Prima* of the *Summa*, Thomas wrote that conscience was not a faculty or a habit, but simply an act (*Summa Theologiae* I. 79. 13). According to him, when we act in conscience, we try to descend into the particulars to consider what we should prudentially do so as to act morally. In fact, in the *Prima Secunda* when he asks whether it is a sin to disobey the dictates of conscience and answers yes always (I-II. 19.5), the word he uses is "ratio," reason.

In the *Pars Prima*, before he writes on conscience, Thomas asked about a closely related aspect of the moral life called *synderesis*. There he argued that *synderesis* is a habit that *inclines* us to the good and murmurs at evil; this initial habit is for Thomas what eventually launches the act of conscience (*Summa Theologiae* I. 79. 12). Here, Thomas first notes that the human's "act of reasoning...is a kind of movement." His "*synderesis*" is a prompt, a "kind of movement" that starts us to consider that we should be responsive in pursuing the good and avoiding evil. I think of it as a capacious disposition toward the other. About this idea of movement, he writes that it has "a special natural habit, which we call *synderesis*. Whence *synderesis* is said to incite to good, and to murmur at evil, inasmuch as through first principles we proceed to discover, and judge of what we have discovered." This prompting to discover is, I think, akin to recognition. I think, therefore, this notion of *synderesis* that "incites to good, and to murmur at evil" resonates very much with that disposition that I and others call "vulnerability," a vulnerability that leads to a recognition of the other in need.

In fact, when Thomas moves to the next article on conscience, he acknowledges that we confuse conscience with *synderesis* but insists that conscience is an act, in fact, as subsequent or an effect of *synderesis*. This is not far from my suggestion that the act of conscience is the effect of recognizing out of vulnerability the presence of another in need. Thomas explains his terms:

Now, it is clear that all these things follow the actual application of knowledge to what we do. Wherefore, properly speaking, conscience denominates an act. But since habit is a principle of act, sometimes the name conscience is given to the first natural habit – namely, *synderesis*: thus Jerome calls *synderesis* conscience (Gloss. Ezech. 1:6); Basil, the *natural power of judgment*, and Damascene says that it is the *law of our intellect*. For it is customary for causes and effects to be called after one another. (ST I.79. 13)

Like Thomas, I want to argue that something precedes conscience that inclines us toward recognizing the neighbor in the first place. Thomas called this inclination *synderesis*. I want to explore what that something is in different, more contemporary terminology like "vulnerability," so that we can better educate our students to be responsive, that is to vulnerably recognize those in need and then act in conscience.

Of course, I am at the beginning of this project. I do not know yet how we train students to be vulnerably responsive. I do know, however, that we do not need to be teaching them more norms from conscience for acting prudentially, that is, wisely. The problem is not that they do not know how to act, but that they should respond in the first place. Like the priest and the Levite, they cross the road and avoid the situation. Vulnerability helps educators to recognize the prompt that as Thomas suggests everyone has but not everyone allows to incline them to respond.

So as illustrate how I am thinking of conscience, let us return to the Good Samaritan parable: I believe neither the priest or the Levite were vulnerably disposed to the injured man and, therefore, neither recognized him as injured and in need. On the other hand, the Good Samaritan's recognition of the man gives evidence of his vulnerability to the injured man. Then, after the Samaritan recognized the man as being in need, he in conscience went about considering the details of what he needed to do. Acting in conscience, he needed to address a wide array of matters that he had yet to consider: assess the man's condition, clean the wounds, get him to a safe place, make inquiries about the appropriate person and place for him to leave the man to heal, negotiate and secure from the newly found innkeeper his oversight of the injured man, dispense with his funds, redesign his return to this particular inn and innkeeper so as to take the man with him, and then to bring him with him to his own homeland. The Good Samaritan's conscience got a workout, but the work of his conscience only began after his vulnerable disposition recognized the man; the vulnerable recognition led then to the conscience question: now what do I do? And in conscience he worked out an enormous set of ethical answers to the central question of conscience, Now what do I do?

Before leaving Thomas it is necessary to acknowledge that Thomas wrote very little on *synderesis*, beyond what I wrote earlier. Still, when Thomas writes about the Holy Spirit, he sees the Spirit as the one who prompts us to recognize others. In his new book, *The Holy Spirit and Moral Action in Thomas Aquinas*, Jack Mahoney notes that Thomas often talked about the "prompting" of the Holy Spirit (*instinctus Spiritus Sancti*)² Prompting is not

² Jack Mahoney, *The Holy Spirit and Moral Action in Thomas Aquinas* (Lanham: Rowman and Littlefield, 2021) 49.

simply being led or guided, it is an internal awakening, a counsel to take heed, to act, to respond, that is, I dare suggest, to recognize.

Elsewhere, In his *Commentary on Romans* Thomas also writes that "The Holy Spirit does not just teach us what we ought to be done by enlightening our mind on what we should do; he also inclines our desires to act rightly."³ Mahoney notes how Thomas asserts that "in every action of the spiritual person, it is the initiative of the Holy Spirit which is the source and the principle of the action and that God's children are truly acted upon" though in such a way that "they themselves act."⁴ Noting the principle which Thomas regularly observes that "no habit proceeds to act spontaneously; it needs to be aroused by some agent," Mahoney suggests we are prompted by the counsel of the Spirit opening our eyes to the other.⁵

I think of that vulnerable inclination, what Thomas calls *synderesis*, that tendency "that inclines us to the good and murmurs at evil" is what the Spirit prompts: it inclines us to act vulnerably and with recognition.

Before leaving Aquinas let me acknowledge that by introducing now the Holy Spirit in Thomas' thought, it leads us with even more questions about how we can teach vulnerability and such promptings to recognition. But what it does do, at least for the argument that I am proposing here, it reiterates again that Thomas saw that conscience is not the start of the moral life. The moral life begins with the inclination to the other needing somehow to be first prompted and that is what we in education need to attend to if we want our students to be responsive in conscience.

So now let me explain what I mean by vulnerability and recognition.

Vulnerability and Recognition

Like many others, when I first thought of vulnerability, I considered it singularly as being wounded, weak, at sea, as primarily a condition that raises in others alarm and concern. Then I recognized that the word "vulnerable" does not mean "having been wounded," but rather "being able to be wounded." More importantly, from the writings of the philosopher, Judith Butler, I began to see vulnerability as less about being wounded and more about being what I call capaciously responsive.

Butler realizes that too many people think of vulnerability as primarily being in an unstable context, but she wants us to understand that all of us as human beings are vulnerable to one another; however, she describes when one is at risk as being in "precarity." She notes: "Precarity exposes our sociality, the fragile and necessary dimensions of our interdependency."⁶

In a very fine book, *The Ethics of Vulnerability: A Feminist Analysis of Social Life and Practice*, Erinn C. Gilson considers the implications of a reductively negative view of vulnerability as being in need, being precarious, or even being wounded. She argues rightly that if vulnerability is only the object of concern and *not* the very condition for responsiveness, then when we are in precarity, we would be inevitably looking for moral

³ Ibid., 83-83, See In Rom 8, lect. 1.

⁴ Ibid., 58.

⁵ Ibid., 68. See *De Virtutibus* 1. ad 14.

⁶ Judith Butler, "Precarious Life, Vulnerability, and the Ethics of Cohabitation," The Journal of

Speculative Philosophy 26./2 (2012): 134-151, at 148; See also her Precarious Life: The Power of Mourning and Violence (Brooklyn: Verso, 2004).

responsiveness from someone who is anything but vulnerable, that is, those who "occupy the role of the invulnerable" one.⁷

Butler insists on how foundational vulnerability is. She writes: "Ethical obligation not only depends upon our vulnerability to the claims of others but establishes us as creatures who are fundamentally defined by that ethical relation."⁸ Vulnerability is what defines and establishes us as capable of being moral among one another. As such, our vulnerability precedes everything else that we can say about ourselves.

Again, emphasizing the priority of vulnerability, she contends: "This ethical relation is not a virtue that I have or exercise; it is prior to any individual sense of self. It is not as discrete individuals that we honor this ethical relation. I am already bound to you, and this is what it means to be the self I am, receptive to you in ways that I cannot fully predict or control."⁹

She acknowledges that our vulnerability is woundable and adds: "This is also, clearly, the condition of my injurability as well, and in this way my answerability and my injurability are bound up with one another. In other words, you may frighten me and threaten me, but my obligation to you must remain firm."¹⁰ I am answerable to you and therein I am injurable or woundable, as I prefer to say. But it is our answerability that vulnerability first signifies, or as the theological ethicist Charles Mathewes writes: "Vulnerability seems better understood as a description of our openness than our woundable-ness; the way we are porous to what is not self."¹¹

Vulnerability essentially is what most qualifies ourselves as being bound to and among others and this, we shall see, is what prompts our recognition of the other. In fact, the act of recognition reciprocates and affirms our vulnerability.

Butler returns to the priority of vulnerability, this notion that "I am *already* bound to you" that is prior even to the moan from another in need. She writes: "You call upon me, and I answer. But if I answer, it was only because I was already answerable; that is, this susceptibility and vulnerability constitutes me at the most fundamental level and is there, we might say, prior to any deliberate decision to answer the call. In other words, one has to be already capable of receiving the call before actually answering it. In this sense, ethical responsibility presupposes ethical responsiveness."¹² Our vulnerability is our answerability; like *synderesis* it incites and prompts us to recognize, to respond, to communicate, in short, to what in the Christian tradition we call love.

⁷ Erinn C. Gilson, *The Ethics of Vulnerability: A Feminist Analysis of Social Life and Practice* (New York: Routledge, 2014) at 35. In fact, she advertises her book as a corrective to the discourse: "The meaning of vulnerability is commonly taken for granted and it is assumed that vulnerability is almost exclusively negative, equated with weakness, dependency, powerlessness, deficiency and passivity. This reductively negative view leads to problematic implications, imperiling ethical responsiveness to vulnerability, and so prevents the concept from possessing the normative value many theorists wish it to have. When vulnerability is regarded as weakness and, concomitantly, invulnerability is prized, attentiveness to one's own vulnerability and ethical response to vulnerable others remain out of reach goals.' At p. i.

⁸ Butler, Notes Toward a Performative Theory of Assembly (Cambridge: Harvard University Press, 2015) 110; See also her Giving an Account of Oneself (New York: Fordham University Press, 2005).

⁹ Butler, *Notes* 110.

¹⁰ Butler *Notes* 110.

 ¹¹ Charles Mathewes, "Vulnerability and Political Theology," Heikke Springhart and Günther Thomas, eds., *Exploring Vulnerability* (Bristol, CT.: Vandenhoeck & Ruprecht, 2017, p. 165-184, at 168.
 ¹² Ibid., 110. See also Judith Butler, Zeynep Gambetti, and Leticia Sabsay, eds., *Vulnerability in*

Resistance (Durham: Duke University Press, 2016).

Still there are questions here. From Lisa Tessman effectively comes the question whether everyone is as able to be vulnerable to the other *and* like Hille Haker, she asks whether everyone should be as vulnerable to the other.¹³ Indeed these are questions that ethicists are rightly answering.¹⁴ For instance, in the U.S., the Latina theologian, Neomi De Anda, introduces the difference between chosen and *forced* vulnerability and Amanda Osheim argues that privilege is the denial of vulnerability.¹⁵

Though I enjoy much of Judith Butler for developing a virtue ethics of vulnerability and though like most of us I depend on Axel Honneth (and to some extent) Nancy Fraser on recognition, I most depend on Hille Haker for her theological, critical engagement of both.

This only started about five years ago, because it was only then that I began developing a vulnerability ethics. Much earlier Haker noted the influence of Levinas in contemporary theological work on vulnerability and raised the issue: "What becomes important for the concept of the moral self, however, is that from the ethical perspective of 'giving an account of oneself,' both the narrative and the failure of the narrative are addressed toward the other."¹⁶

At that point she introduced the significance of narrative in order to fill out the exchange. "The role of narrative goes far beyond being a constitutive part of self-identity. The self—who is indeed, as Butler and Ricœur claimed, dependent on the narratives of others, as well as on self-narratives, to develop or uphold an identity over time—is likewise dependent on narrative as a moral self, questioning moral convictions and visions of the 'other' from the point of view of the self as sameness."¹⁷ These narratives though require an account not only of the self to others, but of the self to oneself, and those self-reflexive narratives do not, as Haker wisely remarks, always get resolved. On the contrary, the "deeply reflexive narratives" highlight that invariably there is no final resolution.¹⁸ In short, these narratives reveal more a dilemma than a solution.

More recently in *Towards a Critical Political Ethics: Catholic Ethics and Social Challenges,* Haker develops the area of "vulnerable agency" in which she further develops both Levinas and Butler and incorporates a moral self, now not only in a self-reflexive narrative but as clearly having moral agency within it. She writes, implicitly presupposing that shaped by vulnerability we are first answerable, but that our agency *subsequently*

¹³ Lisa Tessman, Burdened Virtues: Virtue Ethics for Liberatory Struggles (New York: Oxford University Press, 2005).

¹⁴ Keenan, "Linking Human Dignity, Vulnerability and Virtue Ethics," *Interdisciplinary Journal for Religion* and Transformation in Contemporary Society 6 (2020) 56-73, at 73. Among such accounts, see the essays in Catriona Mackenzie, Wendy Rogers, and Susan Dodds, eds., *Vulnerability: New Essays in Ethics and Feminist Philosophy* (New York: Oxford University Press, 2013). Among such accounts, see the essays in Catriona Mackenzie, Wendy Rogers, and Susan Dodds, eds., *Vulnerability: New Essays in Ethics and Feminist Philosophy* (New York: Oxford University Press, 2013). Among such accounts, see the essays in *Feminist Philosophy* (New York: Oxford University Press, 2013).

¹⁵ Neomi De Anda, "Spirit of Community: Forced Vulnerability, the Little Details as realized hope and Lament as prophetic protest," Response at Holy Spirit Lecture, Duquesne University (October 5, 2021.). ibid. See another Amanda C. Osheim who raised up privilege as "the denial of vulnerability," in her response, "Vulnerable as Christ: Privilege and the Kenotic Marks of the Church."

¹⁶ Hille Haker, "The Fragility of the Moral Self.," *Harvard Theological Review*, 97(4), 359-381, at 366. doi:10.1017/S0017816004000756

¹⁷ Ibid., 377.

¹⁸ She writes: "Thus, what is expressed through the medium of narrative is the impossibility of overcoming the tension between speaking and keeping silent, between agency and non-agency (by way of passivity or suffering), between being oneself and another, between fragility and sovereignty, between forgetting and memory, and finally between life and death." Ibid 380.

shapes that answerability: "Vulnerability encompasses the radical ambiguity of human relations. We do not 'naturally' develop into agents; rather, we are addressed and shaped by others *as* (potential, actual, or former) *agents*, in order to *see* ourselves *as* agents, beings who are able to act on one's own account. Vulnerability refers as much to the social constitution of the self as to the general affectability of human beings."¹⁹ In sum, she writes: "In any action we take the risk to affect the other and be affected by them, and morally speaking, we aim to affect others (and be affected) in a positive way."²⁰

I like this move very much. To remedy the overlooking of the self as agent, she integrates a notion of autonomy into this vulnerable context. She concludes, "The ethics of vulnerable agency embraces autonomy, but it understands it and reinterprets it, in part, as the capacity to open up to the other, in part as the capability to respond to the other, including in the right to say no to the other's demands or desires."²¹

This agency in a vulnerable context then takes account of one's freedom and one's burdens but is still shaped and constituted as moral because it is first vulnerable, before, if you will, being agential or autonomous. Haker's proposals take us further than anyone I know into making vulnerability more attainable and expressible for ordinary life. Vulnerability is still prior to all, but we need agency to decide whether and how we should recognize and respond.

Finally, to close on vulnerability, I want to note that Linda Hogan of Trinity College Dublin, like Haker, highlights vulnerability's social significance. In 2018 in Sarajevo, at the close of the third international conference of Catholic Theological Ethics in the World Church (CTEWC), Hogan, the co-chair of CTEWC, gave the final plenary proposing an ethics of vulnerability for a divided world, describing "vulnerability as a way of being, as the ground of our relationality, and as the mode of social engagement."²²

She asks, "Can this existential experience of vulnerability be deployed in the service of a politics that unites rather than divides? This depends on whether this recognition of vulnerability can generate a new kind of conversation: about how we act in the world; about our ethical obligations towards each other; about how to oppose the conditions under which some lives are more vulnerable than others."²³

She concludes: "Mutual dependence, shared vulnerability, these are elements of human experience that have rarely featured in the ways in which politics is constructed or ethical theories are framed. Indeed, much of our politics and ethics seems to be intent on foreclosing this recognition. And yet shared vulnerability and mutual dependence may be precisely the qualities that have a resonance with the individuals and communities worldwide who are struggling to find the grounds for the hope of shared future in a world divided."²⁴

¹⁹ Hille Haker, *Towards a Critical Political Ethics: Catholic Ethics and Social Challenges* (Würzburg: Echter Verlag, 2020) 138-139.

²⁰ Ibid., 143.

²¹ Ibid., 157.

²² Hogan, Linda: "Vulnerability: An Ethic for a Divided World," in James F. Keenan, Kristin Heyer and Andrea Vicini, (ed.): *Building Bridges in Sarajevo: The Plenary Papers of Sarajevo 2018*. Maryknoll: Orbis Books, 2019, p. 216.

²³ Ibid., p. 219.

²⁴ Ibid., pp. 219-20.

Along with others,²⁵ Hogan amply shows how vulnerability could well animate the discourse regarding how we encounter human dignity across the world.²⁶

Recognition

From the feminist psychoanalyst Jessica Benjamin, I learned that the experience of mutual recognition in infancy provides a constitutive foundation of the personal and social realization of the good life, the moral life.²⁷ I think that her work in exploring how young children encounter mutual recognition might be a source for inviting students to recognize and consider their own capacity for vulnerability. By helping them see that mutual recognition is a part of growing into moral agency, we might be able to explore how to teach them to be attentive to the very stirrings, promptings or inclinations of vulnerability.

Still, rather than entering into that later investigation, here we need to explore the theological meaning of recognition and again it is Haker who provides, what I think is the theological and moral urgency of the issue when she reflects not on recognizing but, rather, on the experience of being recognized. She writes: "It is through recognition---or, more precisely, through the experience of being recognized by others---that the self is enabled to keep the *tension* between sameness and uniqueness or one's otherness in balance."²⁸ Then she asks the question, "Why does recognition matter so much?"²⁹ After reflecting on the spectrum of the three-fold meanings of recognition as awakening, identification and acknowledgment, she highlights the power of recognition, when it is given and when it is withheld or positively refused and here again she advances recognition discourse by looking at not its benefits but the way it is used to harm: "The evaluations and selfevaluations constitute one's standing in the eyes of others and oneself, and it is through acts of misrecognition as well as through systemic forms of misrecognition that foster denigrative gestures and/or acts that persons are morally harmed."³⁰ I think her emphasis on the refusal to recognize is a way of understanding how recognition can be weaponized and in fact, this is what is experienced by those most in need of recognition.

Last year in an article, entitled, "Recognition and Responsibility," Haker rightly noted "While the concept of responsibility is a cornerstone of Christian ethics, recognition theory still lacks a thorough theological–ethical analysis."³¹ In response to the lack of theological ethical engagement with recognition theory, she proposes a consideration of

²⁵ See Vincent Leclerq, AA, *Blessed are the Vulnerable: Reaching out to Those with AIDS* (New London: Twenty-Third Publications, 2010).

²⁶ Indeed Hogan is one who has offered a significant and hope-filled apology for a human rights discourse, animated by the language of human dignity. Insisting that our expectations ought to be more modest and realistic, she suggests in her work that human rights discourse can amply support our work to achieve greater equity universally. For her, vulnerability, human dignity, and human rights are mutually engaging and illuminating.Linda Hogan, *Keeping Faith with Human Rights*. Washington, D.C.: Georgetown University Press, 2015.

²⁷ Jessica Benjamin, *The Bonds of Love: Psychoanalysis, Feminism, and the Problem of Domination* (New York: Pantheon, 1988); Jessica Benjamin, *Beyond Doer and Done to: Recognition Theory, Intersubjectivity and the Third* (New York: Routledge, 2017).

²⁸ Haker, Towards a Critical Political Ethics, 143.

²⁹ Haker, Towards a Critical Political Ethics, 143.

³⁰ Haker, *Towards a Critical Political Ethics*, 144.

³¹ Haker, "Recognition and Responsibility," Religions 2021, 12(7), 467;

https://doi.org/10.3390/rel12070467

the murder of Abel by Cain in Genesis 4:1–16,³² which she calls "the paradigmatic story of morality told as part of the narrative of the origins of humans and the history of their faith."

She describes the famous narrative in this way: "The story depicts Cain's desire to be recognized by God, spelling out the tragic consequences of misunderstanding God's love and demands. Cain becomes as much the symbol of the desire for recognition as for the failure of responsibility. Being marked *and* put under God's protection in one symbol, Cain survives his moral failure, just as the people of God survive all following failures and mistakes despite all the catastrophes that pile up over the course of history."³³ Through Haker we see Cain's terror in the face of never being recognized as human and his relief in finding in God's own mark a way that he and his people will survive and grow.

Through the fear of not being recognized, what Haker calls misrecognition, we see the true power of recognition. Still, so as to appreciate what this misrecognition actually entails, I return to Butler again, but this time to her comments on the concept of grievability. Here she writes: "The most individual question of morality---how do I live this life that is mine?---is bound up with biopolitical questions distilled in forms such as these: Whose lives matter? Whose lives do not matter as lives, are not recognizable as living, or count only ambiguously as alive?"³⁴ In short "whose lives are grievable and whose are not?"

Butler talks about how we individually and collectively live out the matter of grievability in powerful and prophetic terms. She writes: "The biopolitical management of the ungrievable proves crucial to approaching the question, how do I lead this life." Terrifyingly, Butler reflects on the person who understands themselves as not grievable. This, of course, is Cain's terror. He fears that his life (and inevitable death) is not grievable and therefore does not matter. Butler notes: "this question becomes most acute for someone, anyone, who already understands him- or herself to be a dispensable sort of being, one who registers at an affective and corporeal level that his or her life is *not* worth safeguarding, protecting, and valuing."³⁵ She adds, "If it turns out that I have no certainty that I will have food or shelter, or that no social network or institution would catch me if I fall, then I could come to belong to the ungrievable."

Powerfully Butler sums up her argument about how social structures effectively make the determination of the ungrievable.

The reason that someone will not be grieved for, or have already been established as one who is not to be grieved for, is that there is no present structure of support that will sustain that life, which implies that it is devalued, not worth supporting and protecting as a life by dominant schemes of value. The very future of my life depends upon that condition of support, so if I am not supported, then my life is established as tenuous, precarious, and in that sense not worthy to be protected from injury or loss, and so not grievable. If only a grievable life can be valued, and valued through time, then only a grievable life will be eligible for social and economic support, housing, health care, employment, rights of political expression, forms of social recognition, and the conditions for political agency (*Handlungsfähigkeit*). One must, as it were, be grievable before one is lost, before any question of being neglected or abandoned, and

³² Writing on Cain and Abel, Haker refers to Emmanuel Levinas, *Difficult Freedom: Essays on Judaism*.(London: Athlone Press, 1990.) LaCocque, Andre. 2015. *Onslaught against Innocence: Cain, Abel and the Yahnist.* Cambridge: James Clarke & Co; Vermeulen, Karolien. 2014. Mind the Gap: Ambiguity in the Story of Cain and Abel. *Journal of Biblical Literature* 133: 29–42.

³³ Haker, "Recognition and Responsibility."

³⁴ Butler, Notes Toward a Performative Theory of Assembly, 196.

³⁵ Butler, Notes, 196-7.

³⁶ Butler, *Notes*, 197.

one must be able to live a life knowing that the loss of this life that I am would be mourned and so every measure will be taken to forestall this loss.³⁷

I think Butler's concept of the social demarcation of those whose lives are grievable and those whose lives are not, helps us to realize the social impact of mutual recognition.

Before we move to the question of social structures that make, in part, these determinations, I wish to propose a brief concrete meditation on the misrecognized or the ungrievable so as to see the actual import of these categories. Here I turn to the actual public murder of George Floyd on the streets of Minneapolis on May 25, 2020. The murder was committed by a police officer with other officers assisting over the period of 9 minutes and 29 seconds of having a knee pressed down on Floyd's throat as he died uttering "I can't breathe." ³⁸ That death that white supremacists tried to let pass as ungreivable provided the social instruction by the Black Lives Matter movement for all Americans to kneel in grief for the same 9 minutes and 29 seconds as a counter practice not only to George Floyd's death but so as to recognize all the murders and lynchings of Black Americans over the past 400 years.

The history of lynching is instructive for understanding grievability. In 2015 Bryan Stevenson's Equal Justice Initiative released a study "that detailed over 4,400 documented racial terror lynchings of Black people in America between 1877 and 1950." In June 2020, EJI reported "during the 12-year period of Reconstruction (1865-1877) at least 2,000 Black women, men, and children were victims of racial terror lynchings."³⁹ Not only were these deaths not grieved, their murders were horrendously celebrated with white men, white women and white children participating. Against that social culture, the Black Lives Matter movement insisted that white culture be taught how to grieve the death of George Floyd, by kneeling for 9 minutes and 29 seconds, by uttering "I can't breathe," and by remembering the name of George Floyd and all those others murdered in the United States.

Black Lives Matter is a way of teaching white Americans to acknowledge that George Floyd mattered, that he was and is grievable. As were Ahmaud Arbery and Breonna Taylor and all other Black Americans killed by white American supremacists. Black Lives Matter calls us to remember their names, their lives, and their deaths as grievable. The movement prompts us to recognize how these people died and how until this moment, we could simply overlook these killings, without taking note. BLM is a social movement summoning white America to a mutual recognition of Black America. That due recognition is theirs and always was theirs.⁴⁰

Here then we see recognition as not simply a personal summons but a social one and on that insight I want to conclude this essay.

³⁷ Butler, *Notes*, 197-8.

³⁸ Eliott McLaughlin, "Three videos piece together the final moments of George Floyd's life," *CNN* (June 23, 2020) https://www.cnn.com/2020/06/01/us/george-floyd-three-videos-minneapolis/index.html

³⁹ Equal Justice Initiative, "Reconstruction in America: Racial Violence after the Civil War https://eji.org/report/reconstruction-in-america/;

⁴⁰ Keenan, "The Color Line, Race and Caste: Structures of Domination and the Ethics of Recognition," *Theological Studies*, 82.1 (2021) 69-94; On other needs for recognition, Keenan, "The Community Colleges: Giving Them the Ethical Recognition They Deserve," *Journal Of Moral Theology* 9.2 (2020) 143-164 https://jmt.scholasticahq.com/article/18040-the-community-colleges-givingthem-the-ethical-recognition-they-deserve; Keenan, "Vulnerability, Hierarchicalism, and Recognition," Philip McCosker, Luigi Gioia, and Travis LaCouter, ed *Clericalism and Sexuality* (Cambridge: Cambridge University Press, forthcoming)..

The question of cultures insulating us from the need to recognize our neighbor was raised in the United States nearly ninety years ago by one of the most famous Protestant American ethicists, Reinhold Niebuhr. In 1932 Niebuhr warned ethicists that they lacked "an understanding of the brutal character of the behavior of all human collectives, and the power of self-interest and collective egoism in all inter-group relations."⁴¹ There, in *Moral Man and Immoral Society: A Study in Ethics and Politics*, he insisted that we do not see "the limitations of the human imagination, the easy subservience of reason to prejudice and passion, and the consequent persistence of irrational egoism, particularly in group behavior."⁴² In many ways we go on teaching today nearly ninety years later failing to heed the forces that empower "the inequalities of privilege (that) are greater than could possibly be defended rationally."⁴³ It is in the interests of such forces that we continue to fail to recognize those whose inequities pay the price of our privilege.

More recently Isabel Wilkerson, in her magnificent *Caste: The Origins of Our Discontent*, argues that Americans need to recognize racism is a caste system. Throughout her influential work she provokes the reader to see how our society keeps us from seeing the structures that frame American racism. To awaken us from our compliance with these structures, she proposes the image of a "wordless usher," whose flashlight keeps our gaze focused, not letting our eyes avert to any recognition that caste itself is guiding us to look only at what caste wants us to recognize. She writes:

As we go about our daily lives, caste is the wordless usher in a darkened theater, flashlight cast down in the aisles, guiding us to our assigned seats for a performance. The hierarchy of castes is not about feeling or morality. It is about power - which groups have it and which do not. It is about resources, about which caste is seen as worthy of them and which are not, and about who gets to acquire and control them and who does not. It is about respect, authority and assumptions of competence - who is accorded these and who is not.⁴⁴

Wilkerson defines caste as "the granting or withholding of respect, status, honor, attention, privileges, resources, benefit of the doubt, and human kindness to someone on the basis of their perceived rank or standing in the hierarchy."⁴⁵ In short, her wordless usher, the white supremacist culture that many Americans still live within, guide the way we see reality and how we distinguish human lives as grievable or ungrievable.

Early in her work she explains how caste can help us understand how race is structured in my country, the United States. "Caste is the infrastructure of our divisions. It is the architecture of human hierarchy, the subconscious code of instructions for maintaining, in our case, a four-hundred-year-old social order. Looking at caste is like holding the country's X-ray up to the light."⁴⁶ She sums up the compelling way they correlate: "Race, in the United States, is the visible agent of the unseen force of caste. Caste is the bones, race the skin."⁴⁷

⁴¹ Reinhold Niebuhr, *Moral Man and Immoral Society: A Study in Ethics and Politics* (Louisville: Westminster John Knox Press, 2001) xxxiv.

⁴² Niebuhr, *Moral Man*, xxxiv.

⁴³ Niebuhr, *Moral Man*, 117.

⁴⁴ Isabel Wilkerson, Caste: The Origins of Our Discontent (New York: Random House, 2020), 17-18.

⁴⁵ Wilkerson, Caste, 70.

⁴⁶ Wilkerson, Caste, 17.

⁴⁷ Wilkerson, Caste, 19.

She proposes that we consider how early caste was formed. The arrival of the slave ships in 1619 helps us to see that "before there was a United States of America, there was a caste system, born in colonial Virginia."⁴⁸ Against the Blackness of the American slave, "the general white population... was hardening into a single caste."⁴⁹ The impact of slavery was not simply "a dark chapter in the country's history."⁵⁰ Nor was it "merely an unfortunate thing that happened to black people."⁵¹ Rather, slavery "was an American innovation, an American institution created by and for the elites of the dominant caste and enforced by poorer members of the dominant caste."⁵² Its impact was ferocious: "the vast majority of African-Americans who lived in this land in the first 246 years of what is now the United States lived under the terror of people who had absolute power over their bodies and their very breath, subject to people who faced no sanction for any atrocity they could conjure."⁵³ She added, "Slavery so perverted the balance of power that it made the degradation of the subordinate caste seem normal and righteous."⁵⁴

Whiteness developed for the sake of caste. Europeans, before coming to America, were Italian, German, French, English, Serb, Swede, and Russian. When they arrived in America, they became identified as "white" and "were fused together...solely...to strengthen the dominant caste in the hierarchy."⁵⁵ As white, they learned that "hostility toward the lowest caste became part of the initiation rite into citizenship."⁵⁶ Through caste, immigrants became white supremacists.⁵⁷

Wilkerson notes that caste is, she writes, "not necessarily personal." Rather, caste is constituted by "patterns of a social order that have been in place for so long that it looks like the natural order of things."⁵⁸ It a word, in the United States caste is familiar, "the investment in keeping the hierarchy as it is in order to maintain your own ranking, advantage, privilege, or to keep yourself above others or keep others beneath you."⁵⁹

The power of these arguments by Niebuhr and Wilkerson is that they remind us how prevalent the forces are that keep us from reverting our gaze and discovering a mutual recognition in the other whose conditions we are socially trained to ignore. Recognition is therefore the act that liberates the vulnerability of both the agent and the other in the face of the distorting power of the castes or social systems that structure our lives.

As Haker and Honneth noted, by misrecognition or disrespect, we see those who are not recognized and generally they are not individuals but collectives, organized by race, tribe, ethnicity, class, caste, gender, sexual orientation, etc. Similarly for Butler too the ungrievable are not preeminently singular persons but collectives again. Social structures

⁴⁸ Wilkerson, *Caste*, 41.

⁴⁹ Wilkerson, *Caste*, 42.

⁵⁰ Wilkerson, *Caste*, 43.

⁵¹ Wilkerson, *Caste*, 44.

⁵² Wilkerson, Caste, 44.

⁵³ Wilkerson, Caste, 47.

⁵⁴ Wilkerson, Caste, 47.

⁵⁵ Wilkerson, Caste, 49.

⁵⁶ Wilkerson, Caste, 50.

⁵⁷ Throughout her work, though there is no space here to engage it, Wilkerson discusses the middle caste, e.g., at 52, "slavery built the man-made chasm between blacks and whites that forces the middle castes... and new immigrants of African descent to navigate within what began as a bipolar hierarchy." Helpfully, see Ki Joo Choi, *Disciplined by Race: Theological Ethics and the Problem of Asian American Identity* (Eugene: Cascade Books, 2019).

⁵⁸ Wilkerson, Caste, 70.

⁵⁹ Wilkerson, Caste, 70.

like those created by capitalism or by a slave market helped to manage us and in particular to distinguish those who count as recognizable or grievable from those who do not.

Conclusion

We began this essay on the problematic that in teaching our students to be morally upright we have depended too much on the norms of conscience rather than on matters that prompt us to act morally responsively in the first place. That investigation led us first back to Thomas Aquinas who reminded us that conscience is an act that needs to be prompted by what he called, synderesis, the disposition in us that inclines us to do good and avoid evil. Following Aquinas we found in the writings of Butler and Haker the development of human vulnerability as our capacity to be morally responsive, a responsiveness that leads us first to recognizing another or others as having been misrecognized, or overlooked, or worse as discardable as Pope Francis calls them or ungrievable as Butler suggests. This connection between vulnerability and recognition helps us see how much of human nature depends on recognition, and yet, how often our cultures keep us from recognizing those whose condition so desperately need to be so recognized. And yet, it is by looking not at how individuals act, but rather how collectives are influenced that we see the true nature of this problematic. From Niebuhr and Wilkerson, we could see the ways that culture guides our gaze to recognize or not others. By concluding on the matter of race and caste in the United States I think we can see that in any of our cultures there are social structures that make the original question with which I began this essay all the more urgent. For I believe that in many instances the failure to recognize is not that some have not yet considered the other as grievable, but rather that social influences have already dimmed in many any interest in the need to recognize others in the first place. Until we heed the warnings of Niebuhr, Wilkerson and the others, we might think all that is needed is for us to teach more norms of conscience, when actually we let go uncheck those social influences that condition many to look at the other in need as not a human but rather like Cain, but without even the mark.

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Theological and Ethical Perspectives on Rethinking the Co-existence of Flourishing and Vulnerability

Martina Vuk

The aim of this article is to explore the evolving discussion surrounding vulnerability and flourishing. This conversation has gained significant relevance in the aftermath of the COVID-19 pandemic and amid global uncertainties, including the effects of violence and war-trauma. The central idea here is to reconsider vulnerability and flourishing not simply as universal experiences tied to one's own humanity and social context, but rather as co-existing, interdependent, and contingent aspects of human existence. Without proposing that human flourishing is conditioned by vulnerability, this perspective seeks to challenge the notion that vulnerability and flourishing are fundamentally separate. The following discussion will not only examine vulnerability and flourishing as theoretical concepts but will also address their practical significance as integral components of the human experience, and how they intersect in a real-life situation. It's important to note that both vulnerability and flourishing are influenced by specific contexts and circumstances, including personal, social, economic and cultural factors. In the course of this discussion, I will provide examples to illustrate these points. The first section will focus on vulnerability, while the second will delve into the concept of flourishing from a Christian perspective, drawing on Miroslav Volf's ideas about a flourishing life.

Introduction

In 2016 I interviewed two persons, one with and one without a disability, who have long been friends in a community support centre in England. When I asked them to characterize their relationship and name the key elements of their friendship, they responded:

"This friendship was a place where they could feel well, the place where they did not need to pretend. It helps them to discover that people can have something in common on the

© The authors, This work is licensed under a Creative Commons Attribution 4.0 International License level of their humanity and for such a reason can be friends for reasons other than mutual interests and mutual strengths."¹

This friendship has brought them to accept each other as real and important persons, with their weaknesses, strengths, gifts, and incapacities. Thus, the recognition of each other's vulnerability did not stop them from a possibility to flourish in a relationship of friendship.

To begin this discussion with this anecdote, I aim to look at vulnerability and flourishing as complex and interweaved among examples of daily life circumstances. This will address on one hand, that facing some degree of vulnerability is necessary for a flourishing life. On the other hand, it is possible to flourish despite situational and contextual vulnerabilities and limitations. However, vulnerability is not always a cause or indicator of flourishing, nor does flourishing always result from negotiated vulnerability. Yet, being open to our vulnerabilities can help us recognize our human limitations, which in turn can open us up to more possibilities or simply help us embrace our uncertain and not-knowing selves.

The situations of people with disabilities are typical relevant examples since society at large holds ableist stereotypes and misinterprets the differently abled functioning and related vulnerability of people with disability as incapable of friendship relationships. Due to being labelled as dependent and vulnerable, atypical functioning, and of lower intellectual capacities, disabled people were historically—and even today—considered vulnerable² and isolated groups of individuals, which deprived them of the possibility of social contact.³ However, several studies on social acceptance have demonstrated that people with disabilities do have the capacity and potential to develop and perform meaningful friendly relationships⁴ with others and that the very same people whom society often limits relationally and marks as vulnerable address, as in our example, friendships as a possibility for growth due to the value of mutual dependency.⁵

In addition to individuals with disabilities, this also applies to many other life situations where flourishing is achieved through accepting vulnerability or where vulnerability, in a broader sense, does not hinder one's flourishing but rather actualized it. For example, providing care for others in challenging situations, despite the potential risks involved, typically enhances one's ability to practice empathy, compassion, and respect for individuals' dignity.⁶ When faced with economic social and political instability, individuals

¹Martina Vuk, Reconsidering Disability, Friendship and Otherness – Theological and Ethical Perspectives, (Fribourg: University of Fribourg Press, 2020)., pp. 195-229.

² Deborah Marks, Disability: Controversial Debates and Psychological Perspectives (London: Routledge, 1999).

³ Jacques H. Stiker, *A History of Disability*, transl. W. Sayers (Ann Arbor: The University of Michigan Press, 1999).

⁴Angela N. Amado, ed., Friendships and Community Connections Between People with and without Developmental Disabilities, Baltimore, MD: Paul H. Brookes Publishing Company, 1993, pp. 299-326. See also Anne L. Chappell. "A Question of Friendship: Community Care and the Relationships of People with Learning Difficulties." Disability & Society 9 (4): 419-434.

⁵Robert Bogdan. – Steven. Taylor. "Toward a Sociology of Acceptance: The Other Side of the Study of Deviance." *Social Policy* 1987, 18 (2):34-39. See also Kevin Reimer, *Living L'Arche. Stories of compassion, Love, and Disability*, New York: Continuum, 2009.

⁶ F. A. McGilloway. "Dependency and Vulnerability in the Nurse/Patient Situation." *Journal of Advanced Nursing* 1976 1 (3): 229–236. Angel S, Vatne S. "Vulnerability in patients and nurses and the mutual vulnerability in the patient-nurse relationship." *J Clin Nurs.* 2017 5 (26)

^{:1428-1437.} doi: 10.1111/jocn.13583. Epub 2017 Feb 16. PMID: 27626897.

and communities often feel compelled to take action and voice their concerns through various means such as protests, strikes, resistance movements, or by exerting influence on social and economic change. These forms of social activism can be powerful tools for expressing discontent, demanding justice, and advocating for positive transformations in society.⁷ The periods of isolation and lack of social contacts, such as those experienced in a recent global pandemic, can be challenging. However, such periods also provide individuals with the opportunity for self-reflection and introspection. The tension involved in these experiences often leads to negative emotions due to isolation, loneliness, and a lack of social contact. However, simultaneously to some, it resulted in more positive outcomes, such as appreciating the significance of relationships, friendship, love, and caring for others. This recognition has the potential to reshape our perspectives and foster a greater sense of community, interdependence and togetherness.⁸

The argument I want to make is that although vulnerability can threaten our agency, it is not simply an obstacle to human flourishing. A life of flourishing cannot be completely free of encountering and developing vulnerability. Rather, life's situations and complexities entail not only the coexistence of vulnerability and flourishing, but sometimes, in seeking to flourish in terms of being more authentic, honest, and self-aware, we need to let go of our rigid agenda of control and allow ourselves to be open to embrace our human limitations, not-knowing and our uncertainty.⁹

The discussion's definition of vulnerability perceives it as a natural condition that is specific to living beings and an situational circumstance to be at risk of harm or exposure, but also a possibility towards change and growth in life's circumstances. The notion of flourishing is seen as an inclination to live a true, good and fulfilled life and as the ability to act rightly towards one self and others. From such a perspective, I will argue for a concept of flourishing life as true life, inclusive of life's complexities. Life complexities, in my view, include not only the perspective of a person's inner attitudes and outer life circumstances, but within life circumstances, the search for a proper meaning, purpose and life interdependence constitute one's reasons for flourishing. Understood that way, the question that arises is how the acceptance of one's weakness or vulnerability can be a contributing factor to experience a measure of true flourishing? What inner dispositions or practices, as well as what outward circumstances, make one flourish despite awareness of one's embodied or heightened vulnerability? To show this correlation, I will support my argument by first outlining current thinking on vulnerability. In the second part, I will utilize Miroslav Volf's and Matthew Croasmun's threefold aspects of a flourishing life – life going well (circumstantial), life led well

⁷ Petkovšek R. and Žalec B. eds. *Ethics of Resilience: Vulnerability and Survival in Times of Pandemics and Global Uncertainty*. Berlin: Lit Verlag, 2022

⁸ Andrew Sommerlad, at all. "Social relationships and depression during the COVID-19 lockdown: longitudinal analysis of the COVID-19 Social Study." *Psychological medicine* 2022 52 (15): 3381-3390; Wong, P. T. P., Mayer, C.-H., & Arslan, G. (Eds.). (2021b). "COVID-19 and Existential Positive Psychology (PP 2.0): The new science of self-transcendence [Special Issue]." *Frontiers*. https:// www. frontersin. Org/ research- topics/ 14988/ covid- 19- and- existential-positive-psychology-pp20- the- new-science- of- selftranscendence

⁹Carse, L. Alisa. "Vulnerability, Agency, and Human Flourishing," in *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology*, eds. Carol Taylor and Roberto Dell'Oro, Georgetown: Georgetown University Press 2006: 35

(agential), and life feeling good (affective) to perceive flourishing as circumstantial and beyond our control. In the conclusion, I will propose integration between the concepts emphasizing that the entangled correlation between the two is possible when a flourishing life is, on the one hand, understood as one that cannot be divorced from life-threatening situations such as occurrences of vulnerability, and, on the other hand, where vulnerability is understood beyond its negative connotations such as being a threat or impediment to one's flourishing.

Vulnerability - a brief exposé and assessment of the idea

The use of vulnerability in recent years has increased. According to a Google Scholar search, the frequency of the term human vulnerability from 2020 until 2023 was about 82,800 and the searched term *life-related vulnerabilities* have appeared around 108,000 times in review articles including those in Social Sciences, Medicine, and Health; Business, Economics, and Management; as well as Humanities and Arts. The conventional meaning of vulnerability (lat. vulnus) conveys being weak, fragile, or physically or emotionally damaged or attacked.¹⁰ However, the use and application of vulnerability in different contexts and disciplines such as in the contexts of healthcare and healthcare ethics, human rights, psychology, popular spiritual literature, ecology, and economics employ slightly different meanings. Moreover, it is applied as a topic of feminist debates, a characteristic of low-class people's social or cognitive status such for example, people with Alzheimer's disease, persons with intellectual and developmental disabilities, migrants, etc. There is a distinction between those who think vulnerability is a universal category for all humans¹¹ and those who think vulnerability is only a characteristic of members of groups that need protection.¹² Major contemporary dictionaries such as Merriam-Webster and the Cambridge Online Dictionary describe vulnerability alongside terms such as weakness, defencelessness, fragility, helplessness, dependency; open to risk or as an ability to be wounded or to wound others.¹³

Despite such thinking, vulnerability is not merely a synonym for fragility or weakness or even a human capacity to be wounded and dependent.¹⁴ Neither is it a *terminus technicus* for an explanation of situations, conditions, or concepts that do not even pertain to the concept of vulnerability or are etymologically different from the very concept of vulnerability (such as disability or suffering). Instead, vulnerability is a concept, a manifestation, and a human experience. Grounded in life experiences, vulnerability is a complex and ambivalent condition. It is an experience, and therefore discourses on vulnerability are often perplexing and challenging. Not only do they apply differently in particular contexts, but continuous

¹⁰Nathalie Maillard, La vulnérabilité, une nouvelle catégorie morale? Genève: Labor et Fides 2011.

¹¹Barry Hoffmaster. What Does Vulnerability Mean? *The Hastings Center Report* 2006 36 (2): 38–45. See also Henk ten Have. Respect for Human Vulnerability. The Emergence of a New Principle in Bioethics. *Bioethical Inquiry* 2015 17 (2): 395-408; doi: https://doi.org/10.1007/s11673-015-9641-9.

 ¹²Mary C. Ruof. "Vulnerability, Vulnerable Populations and Policy." *Journal of the Kennedy Institute of Ethics* 2004 (14): 411–425; See also Doris Schroeder and Eugenijus Gefenas. Vulnerability: too vague and too broad? *Camb Q Healthc Ethics* 2009 18(2):113-21. doi: 10.1017/S0963180109090203. PMID: 19250564.
 ¹³Laurent Lemoine, Eric Gaziaux, Denis Muller (eds.) *Dictionnaire Encyclopédique D'Éthique Chrétienne*, Paris: Les Editions du Cerf 2013.

¹⁴ Brown, Brene. "The power of vulnerability.," *Teds Talk: June 2010*. Online at https: // www.ted.com / talks / brene_brown_the_power_of_vulnerability (accessed 25. June 2023).

conceptual division in opinion between positive and negative sides continues. Recently, there has been an initiative for recognizing vulnerability not merely as negative and undesired but as an inhabited and shared element of humanity, essential to human embodiment and living existence and often essential for initiating the development of resilience or flourishing.¹⁵

Vulnerability as a concept, manifestation, and experience

The context of scholarly discourses concerning the use of the term vulnerability is multifaceted and varied. Until 1970, the term "vulnerability" appeared within biomedical discourses referring to human corporeality, including bodily and psychological conditions,¹⁶ susceptibility to illness, and the physical condition of the patient. The larger biomedical discourses gave attention to vulnerability concerning the principle of autonomy.¹⁷ After 1976, the implication of the meaning of vulnerability moved from a marginal academic interest to the centre stage of bioethics,¹⁸ sociology,¹⁹ feminist and care ethics,²⁰ nursing ethics,²¹ philosophy,²² as well as religion and theology.²³ Since each of these disciplines operates

¹⁵ Margrit Shildrick and Price, Janet., "Uncertain thoughts on the dis/abled body." In M. Shildrick and J. Price (Eds). *Vital signs: feminist reconfigurations of the bio/logical body*. (Edinburgh: Edinburgh University Press, 1998.), pp. 224–249. See also Margrit, Shildrick and Price, Janet., "Bodies Together: Touch, Ethics and Disability." In R. Corker, T. Shakespeare (Eds). *Disability/Postmodernity*, (London/New York: Bloomsbury Publishing, 2002), pp. 62–75. Garland-Thomson, Rosemarie, "Welcoming the unexpected." In Parens, E. and Johnston, J. (Eds). *Human flourishing in an age of gene editing*. (Oxford: Oxford University Press, 2019.), pp. 15–28.

¹⁶ Steve Matthews and Bernardette Tobin. "Human vulnerability in medical contexts." *Theoretical Medicine* and Bioethics 2016 (37): 1–7. https://doi.org/10.1007/s11017-016-9357-9

¹⁷ Daniel Callahan. "Autonomy: A Moral Good Not a Moral Obsession." *The Hastings Centre Report* 1984 (14) 5: 40–42. Soren Holm. "Not just autonomy – the principles of American biomedical ethics." *Journal of Medical Ethics*, 1995 (21)6: 332-338.

¹⁸ Henk ten Have. "Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics." *Journal of Bioethical Inquiry* 2015 (12) 3:395-408; Jacob D. Rendtorff, "Basic ethical principles in European bioethics and biolaw: Autonomy, dignity, integrity and vulnerability—towards a foundation of bioethics and biolaw." *Medicine, Healthcare and Philosophy* 2002 (5)3: 235–244.

¹⁹Mary.C. Ruof. "Vulnerability, Vulnerable Populations and Policy." *Journal of the Kennedy Institute of Ethics* 2004 (14): 411–425; See also Deborah S.K. Thomas at all. (eds.). *Social Vulnerability to Disasters*, Boca Raton: CRC Press 2009. https://doi.org/10.4324/9781420078572

²⁰ Wendy Rogers, Catriona Mackenzie and Susan Dodds. "Why bioethics needs a concept of vulnerability." *International Journal Of Feminist Approaches To Bioethics* 2012 5 (2):11-38; See also Florencia Luna. Elucidating the Concept of Vulnerability: Layers Not Labels. *International Journal of Feminist Approaches to Bioethics* 2009 2 (1):121–39. http://www.jstor.org/stable/40339200; Margrit Shildrick. Becoming Vulnerable: Contagious Encounters and the Ethics of Risk. *Journal of Medical Humanities* 2000 21 (4): 215–227.

²¹ Chris Gastmans. "Dignity-enhancing nursing care: a foundational ethical framework." *Nursing Ethics* 2013 20(2):142-9. doi: 10.1177/0969733012473772. PMID: 23466947.

²² Robert Goodin, *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities,* Chicago: University of Chicago Press, 1985; Barry Hoffmaster. "What does vulnerability mean?" *Hastings Center Report* 2006 36 (2): 38–45.

²³ Elisabeth Gandolfo, *The Power and Vulnerability of Love.* Augsburg: Fortress Publisher 2015; Kristine Culp, *Vulnerability and Glory.* Presbyterian Publishing Corporation 2010; Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality*, Grand Rapids: Brazos Press 2008. Heike Springhart and Gunter Thomas (eds). *Exploring Vulnerability,* Gottingen: Vandenhoeck & Ruprecht 2017.

differently, scholars have conceptualized notions of vulnerability in various ways and from various approaches. Though the majority of scholarly discourses show inclinations towards valuing vulnerability either as an existential condition, context-related term, or a characteristic of individuals or groups who need protection, the broad discourses on vulnerability, as mentioned above, remain rather divided between those who consider it to be something positive and those who take vulnerability to be negative or even a threat. The typical negative impact of vulnerability implies unavoidable circumstances or voluntary or accidental causes as well as existential struggles that can deeply challenge our welfare, dignity, behaviour, and moral agency. Such circumstances can cause deprivation, degradation, and disrespect which is the reason vulnerability is perceived in a negative sense as susceptibility to something such as illness, injury, or harm. Additionally, in my view, the negative perception of the term also implies situations where vulnerability is either perceived as a label or stigma of vulnerable individuals who require special protection (e.g. persons with disabilities, people with addiction, children, the elderly) or where vulnerability is romanticized or used as a sign of manipulation²⁴, projection, rejection, or is reduced to a sentiment of merely pity and suffering.²⁵ Contrarily, a positive perception of vulnerability accounts for situations where acceptance and recognition of vulnerability was a source of building a relationship, or its outcomes and exposures became an opportunity for growth, increasing a person's strength, a factor positively impacting resilience and endurance or a sign of spiritual and mental transformation.26

Because of this, the meaning of vulnerability fails to be attributed univocally with either positive or negative connotations which is the reason why continuous conceptual inconsistency in opinion continues. Being recognized as an existential human condition and part of a person's social environment, vulnerability, as already mentioned, manifests and increases through economic and environmental factors such as poverty, exclusion, harm,

²⁴ There are cases of spiritual and psychological manipulation with the notion of vulnerability and vulnerability of other persons that resulted in spiritual or sexual abuse of power. For more see in Céline Hoyeau, *La trahison des pères. Emprise et abus des fondateurs de communautés nouvelles.* (Montrouge, Bayard, 2021.). See also Conley, J. John, *My conversations with Jean Vanier raised many questions. I have no answers.* America Magazine (New York March 2020). Online at https://www.americamagazine.org/faith

^{/2020/03/13/}my-conversations-jean-vanier-raised-many-questions-i-have-no-answers. (accessed 20-12-2023); Nepryakhin, Nikita. 'Classification of vulnerability factors in the process of psychological manipulation.' *Proceedings of The International Conference on Advanced Research in Social Sciences:* Diamond Scientific Publishing (London 2019). Online at https://www.dpublication.com/proceeding/icarss/ (accessed 21-12-2023).

²⁵ The history of disability demonstrated the misuse of disabled people's conditions as the source of charity, pity and projection of vulnerable-izing attitudes towards people with disability from non-disabled people. See Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (Englewood Cliffs, New Jersey: Prentice Hall, 1963.); Henri – Jacques Stiker, *A History of Disability*, transl. Williams Sayers, (Ann Arbor: The University of Michigan Press, 1999.), pp. 65-91.

²⁶ Richter, C. (Hg.). An den Grenzen des Messbaren. Die Kraft von Religion und Spiritualität in Lebenskrisen. Religion und Gesundheit 3, Stuttgart 2021. Petkovšek R. and Žalec B. eds. Ethics of Resilience: Vulnerability and Survival in Times of Pandemics and Global Uncertainty. Berlin: Lit Verlag, 2022. Ho, S.M.Y. 2011"Resilience, growth, and distress after a traumatic experience", in *Healing trauma: a professional guide*, eds. by K.K. Wu, C.S. Tang, and E.Y. Leung. Hong Kong: Hong Kong University Press, 2011. Michael Hryniuk, *Theology, Disability, and Spiritual Transformation: Learning from the Communities of L'Arche,* Amherst, NY: Cambria Press, 2010.

oppressive behaviours, human relationships, or war trauma. The manifestations of vulnerability occur due to interactions between persons or a person with their social environment and, for this reason, vulnerability requires a pragmatic approach – one that not only counterbalances its manifestations and its impact on persons and their social environment but where manifestations of vulnerabilities and its interactions in the context of life experience are regarded to each other and the totality of the experience.

This entails that the pragmatic or practical relevance of vulnerability has a twofold application. First, it is an indispensable part of human experience — it is an intrinsic property of being a person; secondly, it interacts with life circumstances through different types of ruptures and manifestations. In this perspective, vulnerability, besides being a pragmatic notion, is also context-specific and circumstantial. Additionally, vulnerability within the context of life experience sometimes implies complexity and controversy but the coincidence of contradictions. First of all, there are ruptures of vulnerabilities that cannot be prevented such as accidental or treatment injuries, natural hazards, social injustices, or non-intentional attacks. Second, the manifestations of vulnerability that occur in the interaction of an individual with someone or something are reciprocal in the context of life experience each person can be the one who hurts others or is hurt by others. In such cases, we can talk about the active (natural, embedded) and passive (accidental or advanced) aspects of vulnerability as well as about the positive or negative experiences of vulnerability. Nevertheless, such experiences and understandings also depend on a type of personal response and moral agency as well as the particular cultural context of inflicted persons.

In her book *Power and Vulnerability of Love*, Elisabeth Gandolfo addresses women's diverse experiences of maternity and natality, providing particularly powerful examples of painful ambiguities of motherhood experiences as a reality of unconditional love and vulnerability but also as proof of the concurrence between power and vulnerability in human life and love.²⁷ As she says, *"Their resilience in the wake of harm and their resistance to the violation of themselves and vulnerable others is a powerful testament to the possibility of passing beyond the wall of paradise and embodying the power and vulnerability of love"* (Gandolfo, p.314). In the context of patient–nurse relationships, the confrontation between patients' limitations and vulnerability and limitations. It can also impact their view that the concern for the pain and suffering of the patient is caring for a real person, not merely an abstract object of cure.²⁸ Friendship without the involvement of recognition of vulnerability and solidarity can become a contractual and utilitarian relationship of false representations.²⁹

The excessive vulnerability of a person to environmental stimuli or vulnerabilities caused by others or socio-political injustices can threaten personal integrity or increase the inherent vulnerability of the impacted person. This can result either in the realization of personal limits, repression, or in a person's motivation to fight against injustices, increase a person's potential for survival capacities, or contribute to the development of resistance and

²⁷ Gandolfo, The Power and Vulnerability of Love, p.313

²⁸ Olderbak, Sally and Oliver Wilhelm. "Emotion Perception and Empathy: An Individual Differences Test of Relations". *Emotion* 17 (2017):1092–1106. See also Mok, Esther, and Pui Chi Chiu. "Nurse-patient relationships in Palliative care". *J Adv Nurs* 48 (2004):475–83.

²⁹ Vuk, Reconsidering Disability, Friendship and Otherness – Theological and Ethical Perspectives, p. 344.

resilience. Such can be, for instance, exemplified in the non-violent protest of Mohandas Karamchand Gandhi, the well-known activist against racism, discrimination, and violence. Imposed vulnerability increased by social injustices and psychological disturbances did not stop his strivings for peace and non-violence which instead resulted in resilience composed of non-violent social and political responses. The testimony of Nobel Prize for Peace Laureate 2011, Leymah Gbowee - who led a non-violent fight for peace in Liberia - demonstrated that the coexistence of vulnerability and love among the impossible became a source for bearing resistance and resilience.³⁰

As Alisa L. Carse has indicated, a life worth living requires us to be vulnerable.³¹ Yet vulnerability is not just a condition that limits us but rather one that enables us to be open, to learn, to love, or to find comfort in the presence of the other.³² The abovementioned examples demonstrate that truth. The particular social environment could indeed impact and reveal vulnerabilities of the persons involved, but when applied to life circumstances, it can also stimulate resilience and resistance or could at times potentially increase a person's experience of endurance and strength.

Thus, the outcomes of vulnerability as circumstantial, accidental, or embedded conditions reveal a process of life circumstances that interchangeably intertwine risk and openness as well as exposures to and recognitions of vulnerability. In other words, the meaning of vulnerability here presented is not a utopian liberation from its negative side (e.g., suffering and oppression), but it rather points to a person's earthly existence lamenting salvation and the reality of the vulnerability of life circumstances which is a reality of striving for peace, well-being, love and relationship in unlikely settings.

Flourishing life in its theological and ethical relevance

The question of happiness, the good life, or how to live well preoccupied the ancient Greeks (e.g., Aristotle, *Nicomachean Ethics*) and has often been associated with the theme of flourishing. Central to much ancient philosophy (*eudaimonia*) and early Christian theology (the beatitudes; common good; spiritual transformation), the theme of flourishing has continued to draw the attention of modern scholars in fields such as economics,³³ psychology,³⁴ medical ethics,³⁵

³⁰ The Nobel Peace Prize 2011. Leymah Gbowee. For their non-violent struggle for the safety of women and women's rights to full participation in peace-building work: December 2011. Online at https: // www.nobelprize.org / prizes/peace/2011/gbowee/biographical/ (accessed 2023-9-8). A similar can be also found in a recent 2023 Nobel Prize for Peace Laureate Narges Mohammadi, an Iranian woman, who fought for the life of Iranian women against systematic discrimination and oppression of their dignity and freedom. See https: // www.nobelprize.org / prizes/peace/2023/press-release/

³¹Carse, 'Vulnerability, Agency, and Human Flourishing', p. 33-52.

³² Erinn Gilson. "Vulnerability, Ignorance, and Oppression." *Hypatia*, 26:2 (2011): 308–332.

 ³³Paul H. Dembinski, *The Logic of the Planned Economy*. Oxford: Oxford University Press 1991.
 ³⁴Lawrence G. Calhoun and Richard G.Tedeschi (eds.)., *Handbook of posttraumatic growth: Research and practice*.

New York: Routledge 2014. Chan E. Y. Diener. "Happy people live longer: Subjective well-being contributions to health and longevity." *Applied Psychology: Health and Well-being* 2011 (3):1–43.

³⁵ Omar Sultan Haque at all., "From disability to human flourishing: how fourth wave psychotherapies can help to reimagine rehabilitation and medicine as a whole." *Disability and Rehabilitation* 2020 42 (11):1511-1517.

sociology,³⁶ as well as philosophy³⁷ and theology.³⁸ There are various and often contradictory meanings and conceptions of what flourishing is proliferated. From the idea associated with material prosperity, personal well-being, positive feelings, good mental functioning, quality of life, and good health, to the distribution of individual rights and freedoms, supportive social relationships, virtue, and the common good, as well as spiritual transformation, meaningful life, and the life of the Beatitudes. Despite such endeavours, contemporary society with its global challenges and standards—including its deliberate lifestyle of high speed and dependence on technology—affects the modern notion of morality and the idea of the other. The biggest influences in this framework, as Charles Taylor points out, are modern moral intuitions about the meaning of human life; a person's dignity and respect; and concerns about human welfare, power, and suffering.³⁹ Not only does this mean that the idea of the good life and the concept of flourishing have become highly materialized, but also that considerations of joy and happiness are often notionally detached from less desirable life situations such as vulnerability and suffering.

In the recent pandemic, many people lost their assumed protections, material security, privileges, and fundamental freedoms which exacerbated long-suppressed wounds and unresolved intrapsychic and interpersonal conflicts.⁴⁰ However, according to research in psychology, not only was this a period of massive hysteria, stress, and anxiety, but also an opportunity for growth.⁴¹

The search for meaning and what makes a meaningful life, as well as well-being, became essential human needs despite life circumstances (especially those that threaten our well-being and life trajectory). The theological account of flourishing requires it to be different from mainstream cultural practices that often deny the inward and outward realities required for a person's complete functioning. In what sense, then, is the Christian vision of a flourishing life different from other approaches, and to what exactly does this perspective on the meaning of flourishing apply? To answer this question, I look at Miroslav Volf's notion of the flourishing

³⁶ Corey Lee Keyes M. "Social Well-Being." Social Psychology, 1998 61 (2): 121-140.

³⁷ Martha C. Nussbaum, *Frontiers of Justice: disability, nationality, species, membership*, Cambridge: Harvard University Press 2006; See also Julia Annas, *The Morality of Happiness*, New York: Oxford University Press 1995.

³⁸ Robert Dell 'Oro and Carol Taylor (eds.)., *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology*, Washington, D.C.: Georgetown University Press. 2006; Mathias Nebel and Thierry Collaud (eds.)., *Searching for the Common Good: Philosophical, Theological and Economic Approaches*. Munich: Nomos, 2018; See also John Reader at all., (eds.)., *Theological Reflection for Human Flourishing: Pastoral Practice and Public Theology*, London: SCM Press 2013. Miroslav Volf, *Flourishing: Why We Need Religion in a Globalized World*, New Haven: Yale University Press 2015.

³⁹ Charles Taylor, *Sources of the Self: The Making of the Modern Identity*, (Cambridge: Harvard University Press, 1989).

⁴⁰ Ravi Philip Rajkumar. 'COVID-19 and mental health: A review of the existing literature.' *Asian Journal of Psychiatry* 52 (2020.). https://doi:10.1016/j. ajp.2020.102066 (20. 4. 2021.). Daniel A. González-Padilla – Leonardo, Tortolero-Blanco. 'Social media influence in the COVID-19 Pandemic', *Int Braz J Urol* 46 (2020.) 1, 120-124. https:// doi.org/10.1590/S1677-5538.IBJU.2020.S121 (26. 4. 2021.).

⁴¹ Steven M. Southwick – George A. Bonanno – Ann S. "Masten. Resilience definitions, theory, and challenges: interdisciplinary perspectives," *European Journal of Psychtraumatology*, 5 (2014.) https://doi.org/10.3402 /ejpt.v5.25338 (23. 4. 2021).

life in *For the Life of the World*⁴² which, in my reading, goes beyond often arbitrary ideas of flourishing (such as living well without valuing suffering and limitation) and defines the true flourishing life from the perspective of the Kingdom of God as a this-worldly reality.

The notion of flourishing according to Miroslav Volf's account of flourishing life

The central aspect of the world becoming the home of God is the message of the kingdom of God as a this-worldly reality within a person's life circumstances. This address, however, might sound unrealistic in today's culture with its violence and racism, hostile attitudes towards one's neighbours, utility-oriented personhoods, ecological crises, and greed for material pleasures. These have shaken people's belief that God cares for the world or that this world can be a place for a flourishing life. Yet as a long tradition of Christian theology interpreting the kingdom of God suggests, Christ came proclaiming the kingdom, doing good, and healing the sick despite and within each person's earthly circumstances.⁴³ He did not only proclaim such Good News. His sacrifice was for the sake, salvation, and redemption of many. This is the reason why his vision of flourishing life was not a single story but rather concerned every person and the whole world. The vision of a flourishing life set forward by Volf is specific. It implies its own twist of personal, political, economic, and environmental aspects. Instead of reducing the whole conception of flourishing to a single facet – such as leading a morally good life or feeling happy – this vision of a flourishing life concerns the whole world in all particularities. Such an aspect of the idea of flourishing life is particularly present when concerned with social justice, peacebuilding, or the protection of the environment. The previously mentioned examples of individuals who put their lives at risk and exposed for the greater sake and benefit of others (such as previously mentioned M. Gandhi and L. Gbowee) are typical realizations of such a vision of flourishing life. Their vision to achieve justice and peace as well as fight against discrimination compromises their social status and brings them into deprived or threatened situations. Yet it also brings about flourishing through liberation, justice, and freedom even in challenging circumstances.

According to Volf, the unpacking of the three dimensions of a flourishing life includes life circumstances, human agency, and affections. He relates this to Romans 14:17, with its convictions of life going well, leading well and feeling good. In other words, the reality of life portrayed within a *this-worldly* perspective includes the social, natural, and personal life *circumstances*; the search for justice, peace, respect, tolerance, right acts, virtues and habits; and affections intertwined between positive and negative emotions, feelings, and sentiments.⁴⁴ In this perspective, a vision of a flourishing life that attends to circumstances, agency, and affect surpasses the search for basic needs (though without denying their necessity) and inclines

⁴²Miroslav Volf and Matthew Croasmun, For the Life of the World: Theology That Makes a Difference, Grand Rapids: Brazos Press, 2019. I will also use the correspondence of Miroslav Volf and Ryan McAnnally-Linz, Public Faith in Action: How to Think Carefully, Engage Wisely and Vote with Integrity, Grand Rapids: Brazos Press, 2016.; Miroslav Volf and Justin E. Crisp (eds)., Joy and Human Flourishing: Essays on Theology, Culture, and the Good Life, Minneapolis: Fortress Press, 2015.

⁴³See for instance Gustavo Gutiérrez, *A Theology of Liberation: History, Politics, and Salvation,* transl. Caridad Inda and John Eagleson, Maryknoll, NY: Orbis 1973; Jurgen Moltmann, *The Crucified God*, London: SCM Press 1974.

⁴⁴ Volf and Croasmun, For the Life of the World: Theology That Makes a Difference, 16.

human life toward the search for righteousness, love, and truth. Moreover, this vision of a flourishing life is not a complete liberation from strivings, suffering, and oppressions (as we have noticed in previously mentioned examples) but includes a person's earthly existence and the reality of his/her circumstances which certainly are strivings for peace, love, and healing. Nevertheless, the horizontal axis of a flourishing life, according to Volf, cannot be separated from its vertical axis which includes the idea of the Kingdom of God as *this-worldly*, not separated from earthly life circumstances but neither completely identified with *this-worldly* realities. Theologically speaking, the flourishing life in such a perspective is a life that depends on the fulfilment of basic needs or the pursuit of happiness, but it is also the life of beatitudes (Matthew 5:3-12), the life of righteousness, love, and peace (Romans 14:17). In this perspective the idea of the Kingdom of God is, according to Volf, a necessary impetus to recall theology to reclaim it as God's home, the world with God and God with the world.⁴⁵

Flourishing life as the ethically relevant notion

In this further discussion, I will outline the perspective of flourishing life as an ethically relevant matter, in as much that it impacts one's personhood.

As a true flourishing life includes a person's agency, circumstances, and affect, it is a matter of both subjective and objective concern for one's circumstances, agency, and affect. Grounded within this premise of flourishing life as well as vulnerability about circumstances, agency, and affection is the notion that a flourishing life is also an ethically relevant term. But what does it mean from a concrete perspective? Let's unpack this assumption. The vision, as it touches a person, includes a person's character (what kind of a person one ought to be), a person's life circumstances (what processes and uncertainty of life situations determine current experience and future aspirations about flourishing), and a person's affections (what sort of emotions the previously mentioned agency and circumstances involve).⁴⁶ Neither within a context nor as a process of living experience can flourishing life be "released" from burdensome or challenging life situations. Instead, such life situations often demonstrate the actual entangledness of vulnerability and flourishing.

For instance, the process of reconciliation and forgiveness (the outcome of which is often greater freedom and inner peace) risks the openness towards facing the occurrence of suppressed negative memories and trauma or the encounter of painful emotions of hurt, anger, and anxiety whether voluntarily or involuntarily produced in us through interactions with others. The pursuit of inclusion by UPIAS⁴⁷ disability activists in the seventies; equal social standing for women or the struggles to combat social injustices, discrimination, and racism (as in previously mentioned examples) necessitates risk. To overcome the economic and socio-

⁴⁵ Volf and Croasmun, For the Life of the World, 71.

⁴⁶ This distinction congruences with the threefold vision of flourishing life that attends to circumstances, agency and affect in *Life of the World*. See Volf and Croasmun, *For the Life of the World*, 16. Here it is portrayed in an ethical tone within the perspective of life circumstances.

⁴⁷ Union of the Physically Impaired Against Segregation. *Fundamental Principles of Disability*, 1976. Online at https://disabledpeoplesarchive.com/fundamental-principles-of-disability-union-of-the-physically-impaired-against-segregation/?fbclid=IwAR1dWQY30-

fvlPaJHHAEA64GFuG9tk0qERJk8exCHyEfKAjCga6yLNXD-Tk (accessed 11- 11 - 2023).

cultural pressures and injustices individuals faced various vulnerabilities, including social, economic, and political threats and risks. These challenges often tested their resilience and determination to bring about positive change. Despite the difficulties, there were notable outcomes that had a lasting impact on the socio-cultural structures of the era. One such outcome was the emergence of social movements that advocated for equality and justice. These movements, driven by passionate individuals, sought to address the systemic issues that perpetuated economic and socio-cultural disparities. Through protests, advocacy, and collective action, they were able to raise awareness and push for reforms that aimed to level the playing field for all members of society.

Therefore, a flourishing life as an ethically relevant concept is a context-sensitive process. It is a practical experience and therefore, in the thought of Volf and McAnnally-Linz, there is neither a formula informing a person how precisely to flourish well nor an univocally accepted way to flourish that is independent of particular life circumstances, traditions, and contexts.⁴⁸ This means that flourishing includes personal embodiment, his/her life experiences, and his/her life circumstances which are not exempt from suffering, life-threatening situations, inner attitudes and dispositions. Nor are they exempt from the encounter with one's vulnerability and the vulnerability of the other.

Based on the above-mentioned elements, flourishing as an ethically relevant term includes human agency, affection, and a person's life circumstances and choices.⁴⁹ Such entails that a flourishing life addresses aspects of mutual belonging understood as interdependency; it is not merely a conceptual exchange of life circumstances, agency, and affection, but it rather concerns how each person's life strivings intersect with such a vision. Put slightly differently, the interdependent character of flourishing life intersects with the circumstances, agency, and affections of every person's life yet each in his or her way experiences it differently depending on one's experience and the degree of personal or situational vulnerability. A flourishing life interchangeably employs the experience of rejoicing and suffering for both the so-called nonvulnerable and vulnerable individuals. Furthermore, the interdependent character of flourishing referring to life circumstances, agency, and affection is the indicator that flourishing cannot merely be reduced to autonomous individuals. Neither is it exclusive to those who are potentially more vulnerable and dependent. Reaching a more realistic vision of flourishing-within life circumstance and agency-neither releases an individual from suffering nor can complete suffering deprive an individual of the experience of joy. This is to say that the interplay of vulnerability and flourishing as constitutive of one's life circumstances are not separated but intertwined concepts. The vision of a flourishing life presented here is not insulated from the vulnerability that often involves sad feelings and anxiety regarding life circumstances. Such a vision of a flourishing life is neither insulated from joy nor the life of the Beatitudes. Each person within such a perspective, flourishes not because it is right but because this brings righteousness and truth to the overall character of interdependent belonging.

Exemplified within narratives of life circumstances of persons indicated in the context of this intertwinedness such as abovementioned stories of M. Gandhi and L. Gbowee, people with disability and mother – child relationship in Gandolfo's narrative, highlights various aspects of the individuals' life circumstances, and sheds light on their remarkable resilience

⁴⁸Volf and McAnnally-Linz, Public Faith in Action, 11-17.

⁴⁹Volf and McAnnally-Linz, Public Faith in Action, 13-17.

and determination. Despite facing challenging and risky circumstances, including openness to exposed weaknesses and limitation, the attitudes of these individuals can be interpreted as they would refuse to be defined and obscured by them. Instead, they used their experiences as fuel to drive their determination and resilience. Their stories serve as a reminder that even in the face of adversity and uncertainty, it is possible to overcome obstacles and bring about changes.

Conclusion

The undertaken discussion aims to indicate a complex, reciprocal and mutually generative relationship between vulnerability and flourishing within life circumstances. The examples taken from lived experience and stories picked up here demonstrated that despite challenging situations, and disturbing and inevitable failures — including the manifestation or recognition of vulnerability — it is possible to flourish amid impossible, frightening, unknown and painful circumstances. People who face economic and social challenges do not shy away from them but learn to develop positive strategies and responses to overcome them. Isolation and loneliness can threaten our agency, but they can also be catalysts for recognising our human need for others. They show that the fulfilment of human life is relational and depends on the quality of one's *agape* and *philia*, rather than on material possessions or socio-political influences.

Nevertheless, vulnerability does not only affect human flourishing, either positively or negatively; sometimes to flourish requires us to face our vulnerability or limitations, or even to *let go* our self-control. However, it is important to note that vulnerability is not always a cause for flourishing. Rather, the two conditions are partially interdependent and complex within life circumstances.

In this discussion, I have attempted to demonstrate that human flourishing in the context of life experiences and circumstances does not require the accumulation of wealth or remaining 'invulnerable' to suffering. Instead, flourishing is inclusive of all people, despite their level of vulnerability, social and economic status, religion and culture, depending on their agency and life circumstances. If vulnerability is a human condition, then there should be no anthropological gap or distinction between vulnerable and non-vulnerable individuals. Vulnerability is a constituent of our humanity, as is flourishing. In other words, a flourishing life is not an indication of a perfectly lived life or a life without encountering some form of suffering, obstacles, and uncertainty within life situations. Vulnerability is not merely the universal natural capacity with only a negative inclination that limits us, degrade and expose to the consequences of harm, but rather a complex and challenging condition that does not prevent one from flourishing. In other words, being open to facing our vulnerabilities can lead to something positive, such as openness to new possibilities, recognition of our ignorance and limitations, or simply finding strength in accepting the truth about ourselves.

The outcome of this discussion thus entails situations in which encountering one's vulnerability and the vulnerability of another did not stop a person from continuing to fight and live but resulted in developing more resilient attitudes or finding the sense of meaning in suffering and care for others; appreciation of life and freedom; or flourishing beyond and seemingly despite hardships.

Moving towards a more realistic vision of vulnerability and flourishing as mutually interdependent, a flourishing life is not presented as a utopian liberation of life from strivings, suffering and oppression, but rather points to a person's earthly existence and the reality of life circumstances. Given this premise, both the concepts of flourishing and vulnerability are not merely vital to human life, but also essential within a cycle of life circumstances, and for this reason are interdependent within the perplexities of not knowing and uncertainty of life circumstances and contexts.

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Beyond Bodily Integrity: the bioethics of the disordered body

Margrit Shildrick

My focus on vulnerability and bioethics – which acknowledges but goes beyond mainstream feminist ethics - will take a phenomenological perspective that understands the self as having no meaning or existence beyond its embodiment. As such we are always open, and therefore vulnerable, to the constant changes of embodied experience. The transformations in embodiment are both necessary for development and continuous over the life course, but it is only when something breaks the cycle of normative development that the intimation of vulnerability and disorder arise. Corporeal disorder operates in a highly individual and differentiated way as it manifests, for example, in the experience of disability, pain, ageing and dying. These are not exceptional moments of vulnerability in a life otherwise secure and predictable, but they do clearly set out the limits of the western imaginary, and more particularly of modern western biomedicine and conventional healthcare. In offering a critique of the positivist enterprise of biomedicine, I want to suggest a different understanding of the embodiment that has radical implications for bioethics.

In going beyond the notion of bodily integrity to focus instead on vulnerability, I want to suggest from the start that there is nothing intrinsically negative about the state on being vulnerable. I explicitly reject the notion that the vulnerability and integrity of the self are binary opposites and question whether vulnerability must always signal some breakdown in integrity and must follow after it. That latter approach would surely presuppose that there is something unharmed, some integrity (Latin *integer*: unharmed) that could be wounded or harmed, but such a notion is by no means self-evident. Levinas, for example, takes a very different view and attempts to position vulnerability as the mobilising feature of an ethics that precedes and thus constitutes the ontological moment. As he works through it in *Otherwise than Being*,¹ it is my pre-ontological vulnerability – induced by the naked claim of the other – that is the provocation of ethical subjectivity. My own approach takes an initially phenomenological perspective that follows on from the work of Merleau-Ponty before briefly addressing some feminist accounts of vulnerability and finally turning

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¹ Levinas, Emmanuel Otherwise than Being, or, Beyond Essence, trans. Alphonso Lingis. Pittsburg, PA: Duquesne University Press.

to a more radical postmodernist approach. For Merleau-Ponty, the self is conceived as having no meaning or existence beyond its embodiment and as such is always open, and therefore vulnerable, to the constant changes of embodied experience; while for later theorisations such contingency is rejected and vulnerability is no less than the very possibility of becoming an embodied self at all. Indeed, I take it as axiomatic – though in preferring to focus on the implications, I am not fully arguing for it here – that vulnerability is an inherent and irreducible aspect of the human condition.

What, then, is that is meant by vulnerability? Given that the phenomenological approach posits that body and mind are inseparable. I will dispense with any purely abstract argument and insist on the material register of human corporeality where the transformations in bodily form are both necessary for development - from a new-born infant to an adult - and enduring over the life course. Such transformations are not considered vulnerabilities as such precisely because it is taken for granted that it is only when something breaks the cycle of *normative* development that the full intimation of vulnerability and disorder arise. Two aspects of vulnerability are in play here: first a grounded and very material sense of indeed being open to contingent harm; and second an existential mode which speaks to a profound counter to any sense of a stable, fullyintegrated and invulnerable self that endures over time. Despite the continued privileging of mind in western discourse, our embodied selfhood is a matter of complex interweaving. Whenever the body is at risk, it is the integrity of the self that is threatened. In short corporeal and ontological disorder are inseparable. And if we understand embodiment as a highly dynamic modality, none of us can finally escape the realisation that the invulnerable self is an illusion.

It should be stressed, nonetheless, that bodily disorder operates in a highly individual and differentiated way as it arises, for example, in the experience of disability, ill-health, pain, and dying, with the everyday transformations of ageing serving as a less dramatic scenario for similar considerations. My invocation of those areas is not because they are singular moments of vulnerability in a life otherwise secure, predictable, and controlled but because they so clearly set out the limits and shortcomings of the western imaginary, and more particularly of modern western biomedicine and conventional healthcare. In offering a critique of the positivist enterprise of biomedicine in particular, I want to suggest that a different understanding of the embodiment has implications not only for the operative models of many substantive areas of health care, but for the arena of bioethics. It is salutary to recall that bioethics has been a relatively recent addition to the philosophical canon, tainted perhaps by its too close association with the messy materiality of living bodies and not easily lending itself to the imposition of abstract principles. It is more suited to the practicalities of applied morality where a utilitarian calculus can guide and judge bioscientific behaviour while appearing to take specific circumstances into account. And yet, bioethics is too often out of touch, disembodied, and still clinging the sense of the subject as an autonomous self detached from a more or less unruly body.² The emergence of phenomenology as an alternative perspective on embodiment is hardly new, and yet it is still a somewhat niche concern within bioethics, while challenges emanating from a postmodernist - let alone a posthumanist - approach are strikingly rare. And though I strongly favour the latter post-conventionalities, the trajectory in this paper is limited to a questioning of what the privileged terms of biomedical discourse imply.

² See Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykitiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press. for a fuller analysis of the shortcomings of bioethics.

If we take pain, ageing, and death - and all are heavily medicalised - as overt instances of vulnerability, the remarkable thing is that despite their ubiquity as life experiences, relatively little bioethical attention has been paid to the materiality of those conditions. In effect, any real sense of embodiment tends to be left out. With few exceptions, we will all age, and experience pain, and all of us will die, as an intrinsic part of the life course, and yet those experiences are threaded through with forms of silencing, not simply in the realm of biomedicine - which is strongly oriented to threats that are temporary and manageable - but as a kind of disavowal that operates widely in everyday life. There are of course several specific discourses that deal with such experiences. Feminist academics of the 2nd wave have increasingly addressed the issue of aging and the disabilities that may accompany it;³ while life-writing, which often focuses on the disorders of embodiment, has become a prominent literary form.⁴ Too often, the narrative themes of loss and precarity hold sway, resulting in either grief and anger, or transcendent tales of vulnerability survived. Either approach is problematic, but perhaps partially escape the more general context in which whenever those experiences are spoken, it is as an external description, rather than as the phenomenological experience.

Until recently, the notion of human vulnerability has played very little part in the standard parameters of philosophy, except indirectly in the context of death and suffering. Yet even death which has been a significant focus of classical philosophy, and a necessary topic in bioethics insofar as it relates to the relative value of life or invites interventionary procedures, has been largely dematerialised or hidden away. Even though it is a modality that encompasses us all. event of dying clearly evokes a disturbance to epistemological and ontological certainty that constrains discussion. As something that is finally unpredictable, and irreversibly transformative of the embodied subject, it remains a disruptive point of ambiguity and disorder that grounds both anxiety and denial. Equally pain is at the centre of much biomedical research and clinical practice, but it remains poorly understood even in those limited contexts,⁵ largely unspoken as such in the wider medical encounter, and mostly absent from philosophical discourse. The main issue appears to be to establish protocols for the management of pain as though bioethics were no more a strategy of effective control, rather than the pursuit of flourishing in a fleshy encounter.

If as many commentators note, biomedicine can often be characterised by its committed defences against uncertainty, and by the practice of warding off and denying

³ Mackenzie, Catriona, Wendy Rogers and Susan Dodds (eds) (2013) *Vulnerability: New Essays in Ethics and Feminist Philosophy.* Oxford University Press. Sandberg, Linn (2013) 'Affirmative Old Age – The Ageing Body and Feminist Theories on Difference.' *International Journal of Ageing and Later Life* 8.1: 11-40. Finlay, Jessica (2021) 'Intimately Old: From an Embodied to Emplaced Feminist Approach to Aging', *Hypatia* 36(1), 80-100.

⁴ Couser, Thomas (2016) 'Body Language: Illness, Disability, and Life Writing', *Life Writing* 13:1, 3-10,doi: 10.1080/14484528.2016.1132376 Adams Rachel (2017) 'Disability Life Writing and the Problem of Dependency in The Autobiography of Gaby Brimmer', *Journal of Medical Humanities* 38(1):39-50.

⁵ See Raffaeli and Arnaudo who write: 'despite the scientific knowledge already available on the pathologic mechanisms underlying this condition and the socioeconomic burden of chronic pain, pain does not gain the attention it deserves.' Raffaeli William and Arnaudo Elisa (2017) 'Pain as a disease: an overview', J. *Pain Research* 10: 2003-2008, p.2007. A recent editorial in Nature reiterates the point: 'Approaches that fail to prioritize the many complex drivers of chronic pain and even deny its existence are causing unnecessary suffering for millions.' Nature Editorial (2023) 'Treat pain as a priority, not an afterthought', *Nature* 615: 765.

death even to the point of disembodying those it seeks to aid,⁶ then it becomes clearer why a condition like pain - that we would expect to be central to the endeavour - is so marginalised, even covered over within the positivist and objectifying ideals of medical enterprise. Corporeal unpredictability or fluidity in any form is a discomforting problem to a discourse that has worked traditionally through classification, normalisation and regulation. In particular, chronic pain contests the imposition of definitive strategies by frustrating the legitimating search for localization and causal connections. But even beyond the rationalism of the clinic, pain struggles to find adequate expression. Like the experience of ageing and disability, it is both a matter of exterior public display, and an interior transformation of the embodied subject that remains largely unacknowledged. And perhaps ageing has been most silenced of all, in western culture at least. Elders are both deprived of a voice and scarcely spoken of except as somewhat burdensome others. Their experience is so effectively privatised, considered so peripheral to socio-cultural normativities, that the ordinary effects of ageing can come as a surprise, the changes about which our mothers neglected to speak.

What sets pain, ageing, death and the like apart is that each challenges the normative imaginary of the embodied self as properly self-determining, constant and well integrated. Given the vastly differential experiences of embodiment, we should acknowledge the impossibility of that ideal state, and yet we continue to hold onto the model of always being in control of both mind and body. As Rosemarie Garland-Thomson, puts it in relation to disability: 'One of our most tenacious cultural fantasies is a belief in bodily stability, more particularly the belief that bodily transformation is predictable and tractable. Our cultural story of proper human development dares not admit to ... vagaries, variations and vulnerabilities.'7 What is at stake is the postEnlightenment fantasy that drives the cultural imaginary of the invulnerable self, an image that biomedicine has taken as its own ideal. The problem is that the more potential human vulnerabilities are made manifest, the more they projected onto the bodies of others, and those others held apart. The point is not simply that we habitually refuse to acknowledge the distress of others, but that it *cannot be seen* without risk because it threatens the stability of the normative selfimage. The western modernist tradition dictates that bodies are at our disposal, subject to our will, whole and integrated, and not liable to cast doubt on our ontological security, even though few people really live the Cartesian mind/body split, if only because most of us are obsessed with our corporeality and never quite certain of it. What matters is the tension between the aspiration to normative standards of self-management and the actual struggle (and failure) to maintain that control. Aside from the biomedical interventions that respond to evident crises in personal health, our society's preoccupation with keep-fit regimes, dieting, cosmetic surgeries, wearable digital monitors and more, speaks to a constant need to discipline the body in order to circumvent its own inherent instability and lack of order.

The problem is that as we become disabled, experience ill-health or simply age, the body increasingly falls short of self-determination and becomes visibly more limited in its capacities. Alongside the negative perception of any inability to participate fully in the

⁶ Brown, Nik and Andrew Webster (2004) New Medical Technologies and Society: Reordering Life.

Cambridge: Polity Press. Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykitiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press. Bishop, Jeffrey (2011) *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*. Notre Dame, IN: University of Notre Dame Press. ⁷ Garland-Thomson, Rosemarie (2007) 'Shape Structures Story: Fresh and Feisty Stories about Disability', *Narrative* 15, 1: 113-123, p.114.

capitalist labour market, the representation of the physical and cognitive changes of old age as unquestionably a decline can only be understood within the normative standards of specific socio-cultural contexts. This seems particularly unthinking in the case of the *ageing* that will affect the majority of us. Long before literal death, older people commonly experience social death, a culturally mediated shrinking of horizons that is both material and metaphorical.8 On a phenomenological level, the external context in which a self takes shape and is continually transformed becomes increasingly limited so that older people in the global North at least⁹ - are devalued, not fully seen, and yet simultaneously made subject to increased surveillance over, and management of, their putative vulnerabilities. Either way, ageing bodies must not be allowed to disorder the familiar norms of sociality. Certainly, changes both in health care and social policy could alleviate some of the distress borne by older people, but my argument is that that process of othering – properly called in this case gerontophobia, which the Oxford Companion to Medicine defines as 'a morbid dislike of old people or a dread of growing old' - is entrenched as much at a psychic, as material, level. The underlying issue is our refusal to accept the innate instability of the body and the embodied self regardless of its material condition. It is not that bodies in *extremis* are the problem, but that all bodies are inherently precarious and vulnerable. At best the body is in a state of provisional stability and equilibrium that can never fully escape the imminence of breakdown. In other words, the ambiguity of ageing is no more than the ambiguity that informs all bodies. It is the unspoken meaning of ageing – the intimation of instability and uncertainty - not the condition itself that is unacceptable and must be disavowed.

It might be expected that the conventional characterisation of overt vulnerability as a quality of the other would elicit a sense of moral responsibility and invoke care, as for example in the normative philosopher Robert Goodin's claim¹⁰ that the degree of our obligation to offer aid is proportionate to the level of dependent vulnerability suffered by the other. In reality, the opposite is often the case. As with people with disabilities, women who are pregnant, infants, and children, it is well-established that those who are elderly experience higher levels of physical and mental violence than the interpersonal norm. In short, the disembodied ethics of the modernist convention fails to account for the depth of ontological anxiety that may motivate such violence. The non-normative body, the body that cannot be classed as 'clean and proper' and may present as especially vulnerable, is not just disavowed but abject. Above all, there is no sense in conventional discourse that there might be a mutual ethical encounter. Rather than Goodin's ideal moral actor taking responsibility for an other, could we at very least rethink the encounter with the other's vulnerability as an openness that renders the self vulnerable? The task then would be to take the risk of working through the incommensurable layers of power and emotion that mediate the relational economy.

⁹ The popular view that elders have a much more positive status in traditional societies than in the global North is undercut by the encroachment of westernised ideals throughout the world. See: North, Michael and Fiske, Susan (2015) 'Modern Attitudes Toward Older Adults in the Aging World: A Cross-Cultural Meta-Analysis', *Psychological bulletin* 141. 5: 993-1021. Nonetheless, concepts such as autonomy and consent in health care can show significant differences in meaning.

⁸ Brannelly Tula (2011) 'Sustaining citizenship: People with dementia and the phenomenon of social death', *Nursing Ethics.*;18 (5): 662-671. Králová, Jana (2015) 'What is social death?' *Contemporary Social Science* 10 (3): 235-248.

¹⁰ Goodin, Robert E. (1998) 'Vulnerabilities and Responsibilities: An Ethical Defence of the Welfare State' in Gillian Brock (ed.) *Necessary Goods*. Lanham: Rowman and Littlefield.

A further complexity is that older people inevitably internalise the same cultural norms that mobilise the experience of alienation to the extent that many may refuse to acknowledge their own corporeal transformations. The autobiographies of Simone de Beauvoir in which she confronts both death and ageing are a good illustration. In the account¹¹ of her mother's terminal illness with an aggressive cancer, the older woman's fear of dying is eased only insofar as Françoise, the mother - with the collusion of Simone, her sister, and the attending physician - tacitly refuses to accept that death is imminent. To the end Françoise clings to some semblance of control, even as her body dis-integrates. In the later books,¹² Beauvoir often seems repelled by her own ageing process, experiencing a protective sense of self-distancing. As she puts it: 'Old age is something beyond my life, outside it - something of which I cannot have any full inward experience.'13 But if one strategy of attempting to maintain self-determination is to deny the materiality of ageing and death, then we might notice that the alternative of acceptance - which may include opting for physician-assisted suicide - perhaps represents only another form of control, a conscious act of self-will that would cover over the embodied anxiety of approaching death.

The bioethical import of such struggles is not that of resolving the tension between the control of denial and the control of acceptance, but that the ambiguity and uncertainty of embodiment should be so threatening to human selfhood, at least in the sphere of western influence. Insofar as death has meaning both as a materiality and in the cultural imaginary, the impulse of all those involved is to intervene to settle on one or another path, not so much for the sake of the one who is dying as for the need to exercise control over unruly elements. Amongst terminal patients – and dying *is* usually institutionalised - the 'good' ones are those who are docile and manageable, who have suspended their own anxieties and ceded agency and control to their familial or professional carers. It is an aspect of what Heidegger calls a tranquilisation about death.¹⁴ As with the lay public, the medical profession itself seems singularly unwilling to openly admit to uncertainty.¹⁵ The urge to impose order and rationality in the face of disorder, and to give hope where none is justified, finds expression in biomedical procedures that may postpone the moment of dying, but fails to attend to the on-going changes to the being-in-the-world of the patient.

The apparent binary choice between the two extremes of high-tech intervention to preserve life at all costs, and the shutting down of care attendant on the decision of clinical futility, have much in common: both are about the desire to impose rational control. Neither is necessarily bioethically wrong in any particular case; rather, the imperative to do something - to exercise a determining agency - may calm lay and professional anxieties alike, but at the cost of disregarding other less reductionist alternatives. In the case of Françoise, it could be argued that her daughters' implicit agreement to endorse her denial is morally permissible. In the context of our society's shared investments in disavowing anxiety it could scarcely be wholly altruistic, but that is very different from the distanced

¹¹ Beauvoir, Simone de (1965) A Very Easy Death. New York: Pantheon Books.

¹² Beauvoir, Simone de (1968) *Force of Circumstance*. Harmondsworth: Penguin. Beauvoir, Simone de (1972) *Old Age*. London: Andre Deutsch and Weidenfeld and Nicholson.

¹³ Beauvoir, Simone de (1972) *Old Age*, p.291. London: Andre Deutsch and Weidenfeld and Nicholson.

¹⁴ Heidegger, Martin (1962) *Being and Time*, trans. J. Macquarrie and E. Robinson. London: SCM Press.

¹⁵ Schneiderman, Lawrence and Nancy Jecker (2011) *Wrong medicine: doctors, patients, and futile treatment.* Baltimore Johns Hopkins University Press. Gawande, Atul (2014) *Being Mortal: Medicine and What Matters in the End.* New York: Metropolitan Books.

control of the clinicians who authorise a supposedly life-saving operation, even though knowing that its effects will be temporary at best. Beauvoir worries about agreeing to participate in the highly deceptive scenario, but finally compromises in order to satisfy the bodily needs and desires of her dying and vulnerable mother. As such, there is a case to be made that hers is an ethics of relationship which does not simply fall back on abstract principles in order to enact the good. Healthcare professionals, in contrast, are traditionally trained to defy that emotive, affective relation, and find instead a trajectory through the messiness of life and death without becoming personally unsettled. In the convention, the biomedical encounter is a relation in which the one acts, within their own moral framework and professional protocols, on the vulnerable other. The material and psychological status of the professional's embodiment is considered irrelevant. In effect, the rigid hierarchical structure, faith in technology, and emotional detachment of modern western medicine, combine with an understanding of death as adversarial¹⁶ to mobilise procedures that are broadly unreceptive to human needs and desires. I do not mean that conventional approaches are always ethically inadequate, but that often they fail to respond to the embodied specificity of a given situation.

As an alternative approach, a recognition of the phenomenological significance of the interdependency of living in a world of others more readily lends itself to a corporeal ethics that might acknowledge the insecurities and vulnerabilities on all sides of an encounter. While no patient should be compelled to partake of a different relationship and some might prefer the convention of 'doctor knows best' - that does not diminish the ethical necessity of exploring other ways of openly negotiating the biomedical encounter to respond more productively to the overt and hidden needs and desires at stake. The difficulty for bioethics is that the change to a radically less objectifying approach demands a reconsideration of the conventional Western intellectual tradition and its investments in ontological and epistemological certainties. In relation to death, there is already a substantial body of literature on the significance of self-determination around contentious issues like euthanasia, compliance or non-compliance with living wills, or on the ethics of organ and tissue transplantation, but little of it shows any awareness of the mutually constitutive relation between patients and practitioners. In recent years, feminist bioethicists have led the way in rethinking the biomedical encounter in general,¹⁷ they too remain largely silent with regard to the materiality of dying.¹⁸

Let us consider now a specific area that encompasses the vulnerability of both aging and impending death. The incidence of dementia in older age groups – and it is by no means a purely western concern – grows year on year and constitutes an area of unresolved ethical concern, even though that may be rarely spoken of as such. Despite its ubiquity, the mental and physical state of dementia carries - in many societies but not all - a postulation of pathology, reflecting an assumption in the global North that alterations in the embodied self signify a loss of value. The experience of dementia is seen to exemplify precisely the breakdown of integrity that vulnerability implies. Dementia care seems either

¹⁶ Pascalev, Assya (2018) 'Is death the enemy? The normative power of metaphor in bioethics' in *Ethics of emerging biotechnologies: From educating the young to engineering posthumans*, 87-106. Trivent Publishing.

¹⁷ O'Neill, Onora (2002) *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press. Prainsack, Barbara (2018). "The "We" in the "Me": Solidarity and Health Care in the Era of Personalized Medicine', *Science, Technology, & Human Values* 43. 1: 21–44.

¹⁸ The leading journal of feminist bioethics (IJFAB) exemplifies the omission. Despite publishing 6-8 articles twice a year, over the last 10 years, just three dealt directly with death or dying.

directed towards preserving some form of autonomy - or at least self-direction - or to an infantilisation that scarcely acknowledges agency at all. In the face of cognitive decline and an increasing inability to negotiate the functions of everyday living that eventually ends in death, sensitive care focuses on strategies of eliciting a recognisable interaction that intimates continuing sociality. Nonetheless, dementia *is* taken to herald a collapse in communicative competence that finally puts the subjectivity of the one affected beyond recall.

In research for my recent book, *Visceral Prostheses*,¹⁹ I have looked at the care for those living with dementia in residential homes through the specific locus of new robotic technologies that are claimed to emulate some dimensions of human affective relations. These come in many forms, but my interest is in what are called empathy robots that are designed to engage in a life-like way with the users. Many are designed with a humanoid face, but I am more interested in the zoomorphic forms that resemble small animals such as cats, dogs and baby seals.²⁰ The usual aim of such biotechnological interventions is to offer people with dementia ways of prolonging the expression of their previous sense of self. Regardless of the evident breakdown of the usual markers of autonomy and rationality – and remembering of course that dementia is always socio-culturally inflected²¹ - western-based interventions occur within a socio-cultural imaginary saturated with notions of the singular self. What should interest us as philosophers and bioethicists is not primarily the empirical mechanics of providing alternative forms of care, but the extent to which the ideal integrity of the self is thrown into question.

There is of course nothing exceptional about the use of technological enhancements in the pursuit of flourishing life, and the normative life course necessarily co-evolves with multiple prosthetic practices. Nonetheless, in the case of empathy robots, the dominant focus on preserving selfhood and having a positive impact on sustaining sociability has generated a plethora of moral concern.²² Sceptics offer a very limited discussion of robot care in terms of the putative ethical dangers of replacing human with mechanized or digital support, raising fears that it undermines the value of in-person human to human interaction and neglects the real needs of those with dementia. In contrast, a recent paper by Karen Lancaster²³ offers a robust defence of both the practical and emotional caring aspects of so-called carebots. While many agree that robots can potentially offer invaluable physical care, Lancaster argues that their simulation of emotional care is sufficient to satisfy user needs. As she puts it: 'What is of paramount importance is the patient's feeling that someone or something cares for them – and when a carebot can... simulate emotional care, there will be no good reason to prefer "the human

¹⁹ Shildrick, Margrit (2022) Visceral Prostheses: Somatechnics and Posthuman Embodiment. London: Bloomsbury.

 ²⁰ See Shildrick, Margrit (2023) 'Robotic Technologies, Touch and Posthuman Embodiment in Queer Dementia Care', *Senses and Society* 18. 2: 126-138. https://doi.org/10.1080/17458927.2023.2179239
 ²¹ In many non-western societies, dementia is typically seen as a normal and acceptable part of ageing. See: Tanaka, Shogo (2015) 'Reconsidering the Self in Japanese Culture from an Embodied Perspective', *Civilizations* 20. 3: 35–39

²² Sharkey, Amanda and Noel Sharkey (2012) 'Granny and the robots: ethical issues in robot care for the elderly', *Ethics and Information Technology* 14 (1): 27-40. Ienca, Marcello, Jotterand, Fabrice, Vică, Constantin et al. (2016) 'Social and Assistive Robotics in Dementia Care: Ethical Recommendations for Research and Practice', *International J of Social Robotics* 8, 565–573. Sparrow, Robert (2016) 'Robots in aged care: a dystopian future?' *AI & Society* 31: 445–454.

²³ Lancaster, Karen (2019) 'The robotic touch: Why there is no good reason to prefer human nurses to carebots', *Philosophy in the Contemporary World* 25 (2): 88-109.

touch" to "the robotic touch."²⁴ For Lancaster the actual absence of emotions within a robot is irrelevant, particularly as human nurses may well 'fake' emotional care and compassion, without their patients feeling uncared for. Within a normative framework, some ethicists may want to consider whether such deception – robotic or human - is ever morally permissible, but there is general agreement that even those who understand that a care robot is non-living can be touched by its emotionally evocative behaviours.²⁵

For the most part, however, robots are carefully positioned as pragmatic technologies intended to augment, not supersede, the interhuman aspects of the caring situation.²⁶ Whether explicit or not, the underlying anxiety concerns the supposed affront to autonomous agency, even though the injunction to respect the dignity and intrinsic value of every human being whatever their physical or cognitive status,²⁷ is widely overridden in end-of-life scenarios. In any case, such sentiments are grounded in a highly exclusionary liberal humanist conception of what constitutes worthwhile life. Any critique of the notions of rights, dignity, and interests as referencing a deeply normative standard of human being has little traction in the practicalities of dementia care where vulnerability is taken for granted and dependency is both denied and inevitable. With this in mind, consider the much-researched benefits of PARO - a widely used empathy robot that resembles a baby seal. Predictably, what most research studies stress is not the affective interaction between human and non-human, but the extent to which users demonstrate greater social engagement - whether physical, verbal or visual - with other human beings in care settings. Despite plentiful evidence that users experience increased calm and comfort in their interactions with PARO, a user focus on the human-robot interaction may be seen as an unwanted substitution for human-human relations in that it lacks any symmetry.28

My argument is that we should we look beyond the entrenched humanist principles that focus on the ethics and practicalities of asymmetrical power, user vulnerability, and the artificiality – and implicitly the in-humanity - of robot touch. Why should such interactions be symmetrical? In any lifespan, especially for people with moderate or advanced dementia, few relationships are truly symmetrical. And with a shift of perception to thinking the encounter in terms of mutuality that particular ethical problem disappears. Typically, however, little value is given to human-machine sensory interactions even as they expand the limits of normative human behaviour. In any case, relations between human carers and those they assist are often fraught, with *human* tactile proximity perceived by disabled elders as painful, uncontrollable and unwanted. Yet, as multiple studies have demonstrated, opponents of the digitalisation of dementia care continue to privilege human to human interaction above any evidence of the efficacy of robot mediations, including zoomorphic ones. With regard to bioethics, we need to rethink

²⁴ Lancaster, Karen (2019) "The robotic touch: Why there is no good reason to prefer human nurses to carebots', *Philosophy in the Contemporary World* 25 (2): 88-109, p.103.

²⁵ Calo C.J., N. Hunt-Bull, L. Lewis et al. (2011) 'Ethical Implications of using the Paro Robot', AAAI Workshop WS-2011-2012: 20–24.

²⁶ Khaksar, Seyed Mohammad Sadegh, Rajiv Khosla, Mei Tai Chu et al. (2016). "Service Innovation Using Social Robot to Reduce Social Vulnerability among Older People in Residential Care Facilities." *Technological Forecasting & Social Change* 113: 438–453.

²⁷ Barcaro, Rosangela, Martina Mazzoleni and Paolo Virgili (2018) "Ethics of Care and Robot Caregivers." *Prolegomena* 17 (1): 71–80.

²⁸ Turkle, Sherry (2011) 'Authenticity in the age of digital companions' in M. Anderson & Susan Leigh Anderson (eds) *Machine Ethics*. New York: Cambridge University Press.

what new forms of non-conventional and potentially non-organic connections might entail and ask which encounters best promote comfort for people with dementia.

Leaving aside the often brute reality of death and dying, what does the phenomenological account of embodiment faced with its own vulnerability have to offer? I am not implying that we are all ready to go beyond the modernist ideals that privilege integrity, but it seems to me that phenomenology offers better resources to deal with some very common but deeply disordering encounters with vulnerability, such as living with cancer. The feminist writer Audre Lorde's Cancer Journals29 offers a powerful illustration of what those experiences intend.³⁰ Lorde is never dismissive of the fear and often hopelessness that she and others with cancer feel, but she sees survival in terms of the subject's capacity to make meaning out of the experience. After her mastectomy operation, Lorde is swiftly faced with the normalising forces of society - that seek to obscure bodily differences, and particularly those that signal vulnerability - by the expectation that she will wear a breast prosthesis, not least because as one of her consultants tells her, her evident breastlessness is bad for the morale of others who attend the same clinic. In response, Lorde declares that she is more interested in maintaining her own control over what she calls 'the new me'. Like Simone de Beauvoir's mother, Lorde's desire for selfcontrol is scarcely surprising - it is the ideal of both postEnlightenment culture in general, and a specific aim of early Women's Liberation, where women explicitly sought to escape the gendered attribution of vulnerability, seeking instead to exercise autonomy, particularly in relation to biomedical care. But where Francoise desperately tried to deny that her embodied self had changed, Audre is determined to celebrate her new self, or as she puts it, to 'live myriad selves'. Her very personal account moves instinctively towards the theorisation of embodiment as insecure, fragmented, and - despite the desire for control ultimately ungraspable.

In the model most associated with Merleau-Ponty,³¹ phenomenology positions embodiment as a concept in which both mental and physical components are always intimately intertwined as the structure of all lived experience. I live not *in* or *through* my body as though the 'I' were somehow already existent: I *am* my body such that all experiences of and changes to my corporeal interface with the world of others establish and continually re-establish my shifting sense of self. For most of the time, while my body is operative within the normative parameters of biological function, social interaction, affective experience and so on, my acquired habitus is so familiar that I have no ongoing awareness of my corporeality as such. In mainstream phenomenological theory at least, the body in good health is not a conscious presence for me, but simply the unremarkable ground of my well Being. It is the body that is forgotten. But we need to be cautious here; as Iris Marion Young pointed out,³² the propensity to eliminate conscious thought of one's own corporeality may be less apparent in women – and indeed other subjugated groups for whom body awareness is a matter of paying attention to specific vulnerabilities. Even besides such pressures, it is clear that the supposedly healthy body itself is subjected to

²⁹ Lorde, Audre (1985) The Cancer Journals. London: Sheba Feminist Publishers.

³⁰ I have deliberately chosen examples from 2nd wave feminist scholarship (work by Beauvoir followed by Lorde, Brison and Sedgwick) to demonstrate that issues of vulnerability have always had the potential to disrupt feminist thought long before the turn to a fully embodied bioethics or to new materialism.

³¹ Merleau-Ponty, Maurice (1962) *The Phenomenology of Perception*. London: Routledge and Kegan Paul. ³² Young, Iris Marion (1990) *Throwing Like a Girl and Other Essays in Feminist Social Theory*. Bloomington: Indiana University Press.

ongoing conscious oversight to avoid slippage beyond the norms. That everyday performative awareness may be substantially different from the awareness that imposes itself when the body shows signs of putatively 'biological' breakdown in terms of illness, ageing and so on, but we cannot claim that the embodied self is invulnerable or ever in a state of static integration. The usual phenomenological understanding is that the body that fails to operate as expected demands attention by opening up a dissonance between self and body. It becomes an unwelcome presence that makes us aware of our limitations and vulnerabilities. Arthur Kleinman provides the classic phenomenological account: 'The fidelity of our bodies is so basic that we never think of it....illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost.'³³ In effect, the previously taken-for-granted integration of embodiment is challenged by a scenario in which the security and stability of the self appears threatened by the otherness of bodily affects. Body and mind appear antagonistic.

Now, if body and mind *are* irreducibly intertwined as phenomenology insists, then the restoration of well Being - call it good health, though it is as much ontological as empirical - cannot finally rest on strategies that privilege the one over the other, but only on re-incorporation. Nonetheless, the goal of modern healthcare is more likely to attempt to once more cover over the uncertainty of the body, by restoring self-control over corporeality, and by renewing the illusion of invulnerability. And even when - as Kleinman asserts it must - biomedicine assists in the bioethical task of re-embodiment, that too is misdirected if the ultimate goal is to discount the body once again by restoring normative forgetfulness. If, as I've suggested the body is already inconstant in the normal course of events, and not simply at exceptional moments, then disorder is a dimension of embodiment that is not susceptible to remedial practices. At most, certain specific procedures may restore ordinary disorder, but embodiment as such can never be made invulnerable. In the face of illness, disability, pain or simply ageing, the body can be experienced as estranged, and yet so overwhelmingly present that it threatens to fragment the self.³⁴ One self-protective response to that condition of vulnerability is to imagine the abstract self as a would-be controlling agent in opposition to the materiality of the body that resists control. For the sake of maintaining the supposed integrity of selfhood, we make an object of the body that demands attention. That reiteration of the modernist mindbody split appears to be a strange way of dealing with the dis-ease of an ontological vulnerability and can ground only a bioethics that stresses abstract principles such as autonomy detached from their material operation³⁵. What does seem clear is that however much we might wish to transcend the body, our being in the world is always embodied, and therefore intrinsically vulnerable and uncertain.

In this light, consider how ontological and material vulnerability come together in multiple instances of individual and institutional violence that not only threatens the body,

³³ Kleinman, Arthur (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*, p.45. New York: Basic Books.

³⁴ Jean-Luc Nancy's account of his failing heart and subsequent organ transplantation in L'Intrus speaks precisely to this scenario. Nancy, Jean-Luc (2002) L'Intrus, trans. Susan Hanson. East Lansing: Michigan State University Press.

³⁵ Most scholars promoting a relational ethics do not fully reject the notion of autonomy but argue that the principle should be reconceptualised as non-individualist and reflective of values such as justice and social solidarity. Gómez-Vírseda, C., de Maeseneer, Y. & Gastmans, C. (2019) 'Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature' *BMC Med Ethics* 20, 76. My own approach gives no place to autonomy and turns to distributed agency instead.

but disorders the embodied self. In this time of nationalist wars, racism, misogyny, heterosexism and more, assaults on corporeality have far-reaching consequences evidenced, for example, in the public acceptance of the reality of post-traumatic stress disorder. It is not my claim that all those who experience substantive vulnerability situate its effects within a wider understanding of the irreducibility of the body-mind union, but that it is always at work. In many personal narratives the horror of the material situation may overwhelm further philosophical analysis, but I turn here to the highly self-aware account of the aftermath of a violent, life-threatening, rape, experienced by the philosopher Susan J. Brison. Brison characterises herself as someone whose self-image had previously been highly abstract, yet whose response to the violation of her body is phenomenologically complex. She writes:

My body was now perceived as an enemy...a site of increased vulnerability. But rejecting the body and returning to the life of the mind was not an option, since body and mind had become nearly indistinguishable. My mental state ... felt physiological, like lead in my veins, whereas my physical state ... was the incarnation of a cognitive and emotional paralysis resulting from shattered assumptions about my safety in the world.³⁶

Brison refers to trauma as 'the undoing of the self' which compels her to accept that the fragility and vulnerability of the embodied self is a permanent condition of being, and that she should not attempt to regain her former self by further objectifying her body. Instead, she must heal the dissonance of mind and body and remake her self by building on the embodied connections of living-in-the-world-with-others, rather than chasing after an illusory state of transcendence. Certainly, reaching for some form of corporeal detachment may bring some temporary relief to the dis-integrated body, but as a more permanent strategy for living in the world it is limited and invites the very discordance that underpins ontological anxiety. Despite its significance, however, does the phenomenological model itself, which Brison adopts, imply too great a possibility of an integrated bodyliness?

A rather different way of understanding embodiment that acknowledges the impossibility of it ever settling in a predictable form, is offered by a more explicitly postmodernist approach that moves from a deconstruction of a fixed notion of embodiment to the Deleuzian notion of assemblage. The literary scholar and queer theorist, Eve Kosofsky Sedgwick had already written extensively about AIDS and death, before her own unexpected encounter with breast cancer. Whilst acknowledging the experience of diagnosis and treatment as 'draining and scary', Sedgwick also characterises it as 'an adventure in applied deconstruction'. Rather than accepting the relative calm of determinate prognosis, she sets out to trace out the imbrication of her now 'turbulent' material embodiment with her theoretical resources. As she puts it:

The phenomenology of life-threatening illness; the performativity of a life threatened, relatively early on, by illness; the recent crystallisation of a politics explicitly oriented around grave illness: exploring these connections *has*...to mean hurling my energies outward to inhabit the very furthest of the loose ends where representation, identity, gender, sexuality, and the body can't be made to line up neatly together.³⁷

³⁶ Brison, Susan J. (1997) 'Outliving Oneself: Trauma, Memory and Personal Identity' in Diana Tietjens Meyers (ed.) *Feminists Rethink the Self*, p.13. Boulder, CO: Westview Press.

³⁷ Brison, Susan J. (1997) 'Outliving Oneself: Trauma, Memory and Personal Identity' in Diana Tietjens Meyers (ed.) *Feminists Rethink the Self*, p.13. Boulder, CO: Westview Press.

Unlike Brison and earlier Lorde who speak of remaking themselves, Sedgwick's experience of overt vulnerability and the threat of death leads her to an *embrace* of dislocation as an intrinsic dimension of human embodiment, which marks every aspect of living-in-theworld. Her reflections illustrate is that while body and self are surely indivisible, that does not imply any stable conjunction of the multiple elements that constitute lived experience. Things fall apart in ways that resist her conscious agency. As Sedgwick understands it, her ongoing survival is not ensured by the attempt to reintegrate an illusory wholeness, but by an appreciation that her self-*disorder* has been there from the start and could not be otherwise.³⁸

All such reflections are deeply discomforting not only for the operation of biomedicine, where the fundamental drive is to eliminate uncertainty, but also for the socio-cultural context in which our values, expectations and bioethics are constructed. Disability, illness, ageing and dying are all about indeterminate transformations in which dis-integration is more or less inevitable, and the desire to enforce some degree of order, to reintegrate the embodied self, is bound to end in failure. I have long favoured a (bio)ethics of uncertainty and believe that Derrida's meditations on death in works such as Adieu to Emmanuel Levinas³⁹ are full of insights that do much to enrich our understanding of the consequences of the undecidability that marks both the sick and healthy body. What Derrida always makes clear is that predetermined ethical principles will not suffice, and that following a clear and easy path finally evades ethical responsibility. That is not to say, however, that principles play no part but that they must be recognised as less than adequate to a fully evolved ethical relation where ambiguity and uncertainty are inevitable. Where Derrida focuses on responsibility toward the other, feminist theory in particular has long promoted an ethics of relationality which better opens up the bidirectionality of the encounter and makes clear the commonalities of vulnerable embodiment without sacrificing the specificity of this or that condition or form of distress. Clearly an empathetic reaching out to, and reception of otherness is vital to such an ethics, but more important is the acknowledgment of internal anxieties about our own fragility and vulnerability that so often compel us to silence and disavowal, or to an attempt to impose order on distress. And whatever the claim to corporeal separation, there is finally no division between the embodied self and other but only an effective and affective relationality that is as much internal as external.

Within feminist theory, the work of Judith Butler,⁴⁰ and my own⁴¹ has gone further in widely addressed the issue of how vulnerability could form the grounds for thinking ethical relationality in a way that goes beyond the more usual acceptance of a distinct self and other. The argument in summary is that we are always already not just interconnected, but inextricably dependent on others by virtue of our shared corporeal vulnerability. Butler in particular has linked this vulnerability to the wider notion of precarity which opens up the problematic to social and political concerns, and their associated ethics. The turn to vulnerability and precarity moves away from the humanist ethics of how we might care

³⁸ Again, Nancy comes to mind when he comes to the realisation that '(t)he intrus is none other than me, my self.' Nancy, Jean-Luc (2002) *L'Intrus*, trans. Susan Hanson, p.13. East Lansing: Michigan State University Press.

³⁹ Levinas, Emmanuel (1999) Otherwise than Being, or, Beyond Essence, trans. Alphonso Lingis. Pittsburg, PA: Duquesne University Press.

⁴⁰ Butler, Judith (2006) Precarious Life: The Power of Mourning and Violence. London: Verso.

⁴¹ Shildrick, Margrit (2005) 'Beyond the Body of Bioethics' in M. Shildrick and R. Mykitiuk (eds) *Ethics of the Body*. Cambridge, MA: MIT Press. Shildrick, Margrit (2022) *Visceral Prostheses: Somatechnics and Posthuman Embodiment*. London: Bloomsbury.

for suffering others, and instead exposes the fundamental interdependencies and entanglements of living in the world with others. In that sense, the disembodied and abstract principles that have dominated western ethics segue into a highly material bioethics. As Butler puts it: 'we cannot understand bodily vulnerability outside of this conception of its constitutive relations to other humans, living processes, and inorganic conditions and vehicles for living,'⁴² The ethical debt is mutual and unavoidable, and allows us, then, to think beyond *human* vulnerability alone. If we think ethical responsibility through our interconnectedness and relationality, then it operates not just with human beings but should extend to our relations with animals and environmental others. This of course is precisely what has long been suggested by Deleuze's notion of assemblage.

In the Deleuzian canon, what is called the *body-without-organs* – that is a disorganised and uncertain body - is a dynamic assemblage that emerges at the cross-over point of multiple relations, variously human, animal and inorganic. This approach moves away from both the humanist and phenomenological aspects of embodiment, which presuppose a series of singular embodied subjects, and expands onto the shifting materiality of the relations between bodies and their environments. For Deleuze, to be a subject at all is merely a provisional state that is always in a process of unravelling,⁴³ which can surely be read as a form of vulnerability. Each one of us is enmeshed in a fluctuating series of assemblages that constitute life itself. The webs of interconnections are multiple and fluid, encompassing both organic and inorganic elements. There is no necessary structure to the assemblage; rather it is no more than an impermanent constellation of contingent relations that over time coalesce, evolve and transform, before equally unpredictably disassembling. The subject itself does not entirely disappear but it is no longer privileged in its putative agential singularity. But it is not only ontology that must be rethought, but the very process of ethical engagement. In evoking multiple heterogeneous orders, Deleuzian philosophy directs attention to the effects and ethics of mutual interactions, not to identifying individual moral agents who might respond to the perceived vulnerability of others. In terms of the bodily conditions of dis-order that I have focused on, what that implies is that the push for relational autonomy - much endorsed by reformist bioethicists - is misdirected. And although we should welcome any turn towards a recognition that ethical responsibility is multiple, it shows little awareness of the inadequacy of existing principles. We need to reconfigure relational economies as transitory, complex, decentred and multifaceted.

The Deleuzian approach makes no claim to provide final answers, and there is no suggestion that it exempts everyday ethics from the task of adequately protecting the interests of all equally. The unpredictability of what shape a fully interrelational ethics might take, can - and must - operate alongside a clear recognition of what constitutes the unethical at the present time. The bioethical question of how to respond to the encounter with those whose vulnerability has become overt, nevertheless, cannot be detached from the interlinked and mutual exposure and opportunity that marks the vulnerability of all living beings. Beyond the limits of material relief, the task is to remain open to the varying needs and desires of inconsistent embodiment, and to engage in making and remaking

⁴² Butler, Judith (2014) 'Bodily Vulnerability, Coalitions, and Street Politics', *Critical Studies*, 37: 99–119, p.103

⁴³ Deleuze, Gilles and Guattari Felix (1984) Anti-Oedipus, trans. Robert Hurley. Minneapolis:

Minnesota University Press. Deleuze, Gilles and Guattari Felix (1987) A Thousand Plateaus: Capitalism and Schizophrenia, trans. Brian Massumi. Minneapolis: Minnesota University Press.

connections, not as settled vectors of communication, but as dynamic and fluid networks. It is not that we have arrived at an impasse, but that our responses must subject the limits of current principles and protocols to a thoroughgoing critique. The remit is to open up present structures to continual re-evaluation and renewal. In declining to settle on immediate answers, and with assemblage thinking in mind, we can encompass both vulnerability and strength, and offer the hope, and risk, of thinking differently. Finally, let us think vulnerability, not as an exposure to risk but as the threshold to an imaginary of irreducible interconnections – more properly entanglements - in which self and other (whether human, animal or inorganic) are mutually constitutive and provisional entities. without independent agency. For all of us, it signals that resistance to the comforting lure of stable certitude is a move towards a necessary recognition of vulnerability and ambiguity as the very condition of life.

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Overcoming vulnerability by editing the germline? Human germline genome editing in the light of vulnerability ethics

Michael Braunschweig

The concept of vulnerability has become widely acknowledged as a fundamental concept for medical ethics and research ethics, yet rarely considered with respect to ethical assessments of human germline genome editing. A first aim of this paper is to make vulnerability ethics considerations fruitful for issues related to these technical innovations. The possibility of altering the genome promises to overcome forms of vulnerability inherently connected to our existence as physical beings and would hence allow to increase the resilience of human nature or even to move evolution forward by equipping people with new character traits and enhanced capabilities. I suggest a more fine-grained distinction of various applications purposes than the dichotomy of therapeutic and enhancement. I support the rejection of most application purposes as 'therapeutic' and claim that framing them as 'therapeutic' in the context of the current discursive constellation runs the risk of accentuating existing vulnerabilities. With respect to intergenerational responsibilities, I reject the view that editing the germline necessarily leads to corrupt intergenerational relations based on which it must be categorically excluded. I conclude that it is nevertheless important to take a very close look at the challenges that arise, especially from a vulnerability perspective, before irreversible facts are created overhastily.

1. Introduction¹

The concept of vulnerability has gained wide acknowledgment as a fundamental concept for medical ethics and research ethics over the last two decades.² As our bodies are susceptible to numerous diseases and physical ailments, the ability to increase our resilience against such 'plagues of humanity' as serious hereditary diseases by precisely modifying the human genome has given rise to hopes for better and sustainable protection

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¹ This article was supported by the University Research Priority Program "Human Reproduction Reloaded" of the University of Zurich.

² For a thorough overview cf. Hank ten Have, *Vulnerability. Challenging Bioethics* (London: Routledge, 2016).

against them, since we might become enabled to treat them causally instead of merely soothing their symptoms. Moreover, the possibility of altering the genome also promises to overcome other forms of vulnerability inherently connected to our existence as physical beings and would hence allow to move evolution forward by equipping people with new character traits and enhanced capabilities.³ Notwithstanding this apparent suitability, the concept of vulnerability has so far hardly found explicit let alone overarching thematization in the specific context of human germline genome editing (= HGGE), or has been considered focusing mainly on questions related to further research.⁴ The general motivation of this paper is to contribute to a broader reception of vulnerability ethics in the context of germline genome editing. I try to achieve this by looking at various application purposes from an ethical perspective based on a nuanced concept of vulnerability. Nevertheless, methodically, the following investigations have a strongly exploratory character, insofar as I try to show that and to what extent the vulnerability perspective can be ethically meaningful for the analysis and articulation of some challenges that arise in connection with the possibility of germline genome editing and that go beyond a purely safety- and efficacy-centred approach.

I proceed as follows: First, in a discussion of relevant literature, I briefly develop a theoretical and ethically meaningful concept of vulnerability, which, in the interest of better analytical clarity, I differentiate into various dimensions. Then I distinguish between different possible applications of germline genome editing and point out the technical challenges and the current state of the international debate. In the main section, I bring the two strands together and consider the various applications from the perspective of the previously developed vulnerability taxonomy. In doing so, I try to show that the vulnerability perspective proves suitable for considering different ethically relevant dimensions of germline modification under a unified conceptual paradigm, while at the same time articulating in a differentiated way different ethical challenges that go beyond safety and effectiveness considerations. In terms of content, I draw attention to some problems related to HGGE by way of example, arguing firstly that in particular the widespread assumption that HGGE is a 'therapeutic' procedure runs the risk of accentuating existing vulnerabilities, while secondly, with regard to the question of the changes in intergenerational relations that HGGE entails, I reject the view that this must necessarily give rise to an argument on the basis of which HGGE must be categorically excluded.

2. The ethical concept of vulnerability

To introduce the concept of vulnerability, I begin by drawing on the account of Martha Fineman⁵, which she developed against the backdrop of how the individual is conceptualized in traditional liberal political philosophy.⁶ This tradition, she argues, is

³ Cf., e.g., John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton: Princeton University Press, 2011).

⁴ Markus Labude *et al.*, 'Vulnerability and the Ethics of Human Germline Genome Editing', *The CRISPR journal* 5:3 (2022), pp. 358-363.

⁵ First developed in Martha Albertson Fineman, "The Vulnerable Subject: Anchoring Equality in the Human Condition", *Yale Journal of Law & Feminism* 20:1 (2008), pp. 8-40.

⁶ For Fineman vulnerability serves as the starting point for a more adequate conception of persons, which in turn provides the basis for an alternative political theory. Fineman's critique is one of a series of criticisms of the self-sufficient subject of liberal individualism, voiced especially by authors of communitarian or feminist perspectives as, e.g., Michael J. Sandel, *Liberalism and the Limits of Justice*

based on a too narrow conception of persons as self-reliant, independent, autonomous subjects and, thus, fails to capture the full range of human experience and development:

"S/he can only be presented as an adult. As such, the liberal subject stands not only outside of the passage of time, but also outside of human experience. The construction of the adult liberal subject captures only one possible developmental stage – the least vulnerable – from among the many possible stages an actual individual might pass through if s/he lives a "normal" lifespan."⁷

Fineman, by contrast, sees vulnerability as the foundational aspect of human existence inherent in our embodiment. For an even more nuanced understanding of vulnerability, the taxonomy proposed by Rogers and her colleagues is helpful in distinguishing different layers of vulnerability.⁸ The "inherent vulnerability"⁹ essential to all corporeal beings exposes us to the possibility of harm and misfortune from adverse events, both accidental and intentional. Although the possibility of harm is not a necessary condition, the disposition to experience harm is inherent to bodily life. While individuals can take steps to mitigate these risks, they cannot eliminate them entirely.¹⁰ Age, gender, health status, and disability are important determining factors and influence how and in what intensity inherent vulnerability is manifest in different individuals since they modulate the extent to which vulnerability is realized.¹¹

The human condition, thus, is characterized by vulnerability, which brings about the "ever-constant possibility of dependency"¹² and the need for care.¹³ Dependency is a special form of vulnerability where individuals rely on others for their needs and the development of their autonomy.¹⁴ This "situational vulnerability"¹⁵ determines the extent to which we are affected by harm and our ability to cushion it. It is influenced by the resources available to us, both at the individual and societal levels. While vulnerability is universal, it is also unique to each person and influenced by the quantity and quality of resources of which they can make use.¹⁶ No individual can completely avoid ever becoming vulnerable or dependent. Society's solidarity mechanisms help mediate,

⁽Cambridge: Cambridge University Press, 1982), Charles Taylor, Sources of the Self: The Making of the Modem Identity (Cambridge, Mass.: Harvard University Press, 1989), Eva Feder Kittay, Love's Labor: Essays on Women, Equality, and Dependency (New York: Routledge, 1999), Alasdair MacIntyre, Dependent rational animals: Why human beings need the virtues (Chicago: Open Court, 1999).

⁷ Fineman, 'The Vulnerable Subject', p. 11f.

⁸ Wendy Rogers, Catriona Mackenzie, Susan Dodds, 'Why bioethics needs a concept of vulnerability', *International Journal of Feminist Approaches to Bioethics* 5:2 (2012), pp. 11-38.

⁹ Rogers et al. 'Why bioethics'.

¹⁰ Fineman, 'The Vulnerable Subject', p. 9.

¹¹ Catriona Mackenzie, "The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability', in *Vulnerability: New Essays in Ethics and Feminist Philosophy*, edited by Catriona Mackenzie, Wendy Rogers, and Susan Dodds. New York: Oxford University Press, 2014, 33-59, p. 38.
¹² Fineman, "The Vulnerable Subject', p. 9.

¹³ For Fineman, dependency is a mostly temporary (though possibly long-lasting), certainly not necessarily permanent, property that does not affect everyone equally, while she sees vulnerability as a necessary, universal, ontological constant.

¹⁴ Susan Dodds, 'Dependence, Care, and Vulnerability', in *Vulnerability: New Essays in Ethics and Feminist Philosophy*, edited by Catriona Mackenzie, Wendy Rogers, and Susan Dodds. New York: Oxford University Press, 2014, pp. 181-203, p. 183.

¹⁵ Rogers et al. 'Why bioethics'.

¹⁶ Fineman, 'The Vulnerable Subject', p. 10.

compensate, and erase vulnerability through policies, programs, and institutions, thereby strengthening individual resilience.¹⁷

Because situational vulnerability is tied to social interactions, there is also the possibility that the social and political structures organized in response to and to mitigate the effects of vulnerability may themselves lead to the creation of new vulnerabilities or to the amplification, prolongation, or perpetuation of existing ones. This can lead to the creation of "pathogenic vulnerability"¹⁸, which includes "all those morally unacceptable vulnerabilities and dependencies which we should, but have not yet managed to, eliminate".¹⁹ Pathogenic vulnerability can result interpersonally from paternalism, mistreatment, or violence, or be the result of structural injustices such as oppression, domination, or even unconscious prejudice.

Hence, to address vulnerability without exacerbating existing vulnerabilities, guiding principles are necessary. Contrary to Fineman, I do not support the view that the concept of vulnerability should replace the concept of autonomy but rather agree with those who maintain the continuing importance of the concept of autonomy for the ethics of vulnerability.²⁰ Neglecting autonomy can lead to paternalism and new forms of vulnerability. Therefore, promoting autonomy and empowering self-determined action should be a central aim in responding to vulnerability. The concepts of autonomy and capabilities thus serve as guiding principles for interventions aimed at mitigating vulnerability and enhancing resilience.²¹

Finally, the concept of vulnerability extends beyond physical, psychological, and social aspects to include moral vulnerability. This refers to the potential threats to one's autonomy, dignity, and integrity. Every individual, regardless of their status, possesses dignity and should be respected.²² Respecting the integrity, autonomy, and dignity of others goes beyond non-interference; it also involves providing assistance to help them realize their potential.²³ Vulnerability is not just a descriptive concept; it carries normative implications. When someone is harmed or at risk of harm, action must be taken to prevent or rectify the situation.²⁴ Both inherent and situational vulnerability give rise to moral and political responsibilities. These responsibilities include supporting those who are currently vulnerable and reducing the risks that certain individuals, groups, and populations face. Targeted interventions aimed at addressing specific vulnerabilities can help mitigate occurrent vulnerabilities. Overall, recognizing and addressing vulnerability is essential for creating a society that promotes dignity and autonomy for all individuals.²⁵

²¹ Mackenzie, 'The Importance of Relational Autonomy', p. 45.

¹⁷ *Ibid*.

¹⁸ Cf. Rogers et al., 'Why bioethics'.

¹⁹ Robert E Goodin, *Protecting the vulnerable. A reanalysis of our social responsibilities* (Chicago and London: Chicago University Press, 1985), p. 203; ten Have, *Vulnerability*, at p. 203.

²⁰ Cf. Mackenzie, "The Importance of Relational Autonomy'; Corine Pelluchon, L'autonomie brisée. Bioéthique et philosophie (Paris: Presses Universitaires de France, 2008); Corien Pelluchon, "Taking Vulnerability Seriously: What Does It Change for Bioethics and Politics?', in Human Dignity of the Vulnerable in the Age of Rights, edited by Aniceto Masferrer and Emilio García-Sánchez. Cham: Springer, 2016, pp. 293-312; Paul Ricoeur, 'Autonomy and vulnerability', in Reflections on the Just, translated by Dave Pellauer (Chicago: University of Chicago Press, 2007), pp. 72-90.

²² Jacob D. Rendtorff, 'Basic ethical principles in European bioethics and biolaw: autonomy, dignity, integrity and vulnerability - towards a foundation of bioethics and biolaw', *Medicine, health care, and philosophy* 5:3 (2002), pp. 235-244, p. 243.

²³ Ibid.

²⁴ ten Have, *Vulnerability*, p. 129.

²⁵ Rogers et al., 'Why bioethics', p. 25

Healthcare and medicine are obviously permeated by phenomena of vulnerability. Their very raisons d'être, disease and illness, are visible signs of the physical (yet also psychological and social) vulnerability of human beings. It comes as no surprise that overcoming vulnerability has often played a crucial role as a driving motivation for those who argue that methods that allow intervening in the human genome promise to become a powerful tool to strengthen human resilience since in medical contexts vulnerability frequently refers to states that ought to be overcome.²⁶ Medical progress is, therefore, for many synonymous with the development of therapies and treatment approaches that allow for the reduction, elimination, or prevention of physical vulnerabilities. In diseases based on pathological mechanisms on the molecular level of the genome technologies that allow to precisely target, correct, or alter the disease-causing molecular structures appear to be particularly appealing to increase resilience and reduce vulnerability. The discovery of CRISPR-Cas²⁷ technology has fuelled such old hopes²⁸ of curing diseases through direct intervention in the genome and has also given new impetus to the debate about which applications should ethically, legally, and socially be acceptable. To be able to shed light on these questions from a vulnerability ethics perspective, it is first necessary to have a more precise picture of the technical possibilities and the various fields of application.

3. Genome editing: technique, applications, ethical debate

A first fundamental and ethically relevant distinction between different forms of genome editing must be drawn with respect to the targeted tissue type: whether the cells whose genetic material is changed are somatic cells (basically any tissue cell including blood cells) or cells of the germ line (i.e., sperms, oocytes, and their respective precursor cells, and fertilized oocytes).²⁹

3.1. Genome editing in somatic and germline cells

It is largely undisputed that therapeutic applications in somatic cells are to a much lesser extent regarded as ethically, legally, or socially problematic if they meet the standards of safety, benefit-risk ratio, and effectiveness that usually apply to medical treatments. In their character as therapeutic applications on living persons, they are, in principle, capable of fulfilling the requirement of informed consent of the treated person. Genome modification in somatic cells is limited locally or to a certain type of cells or tissue. They can, in principle, be interrupted, and are (potentially) reversible. Moreover, the induced genetic modification is limited to the organism of the respective patient and not passed on to the offspring. Provided that the usual safety standards of medical therapies are met, and the informed consent of the patient is available, there is nothing fundamentally opposing

²⁶ Joachim Boldt, "The concept of vulnerability in medical ethics and philosophy, *Philosophy, Ethics, and Humanities in Medicine* 14:6 (2019).

²⁷ Martin Jinek *et al.*, 'A programmable dual-RNA-guided DNA endonuclease in adaptive bacterial immunity', *Science* 337:6096 (2012), pp. 816-821. Jennifer A. Doudna and Emmanuelle Charpentier, 'Genome editing. The new frontier of genome engineering with CRISPR-Cas9', *Science* 346:6213 (2014), 1258096.

²⁸ Cf. Theodore Friedmann and Richard Roblin, 'Gene therapy for human genetic disease?', *Science* 175:4025 (1972), pp. 949-955.

²⁹ Cf. Edward M. Berger and Bernard M. Gert B. 'Genetic disorders and the ethical status of germ-line gene therapy', *The Journal of medicine and philosophy* vol. 16:6 (1991), pp. 667-683.

their use. Consequently, there are several therapies approved for or undergoing clinical trials.³⁰

The situation is fundamentally different, however, for applications in the germline which aim at changing the genetic material passed on to the offspring.³¹ The ethical challenges are fundamentally different in nature: There is no person suffering from an illness and therefore dependent on medical therapy, but an embryo, from which a child develops, is created in the first place as part of the procedure.³² It is, therefore, also different from pediatrics or neonatology where parents or next of kin can provide proxy consent to medical procedures. All decisions have to be made by the prospective parents and would have to take place in a hypothetical space about possible effects that would affect a potential future child, which raises questions about the best interests of the child and the justifiability of selective reproduction. Furthermore, an intervention in germline cells would not only affect the person growing from it, but would be passed on to her offspring, and would hence affect the genome of the human population, which underlines the importance of a thorough and society-wide debate on various scopes of applications.

In their extensive review of the ethical implications of HGGE, the National Academy of Sciences and the Royal Society, sketch a translational pathway for various application purposes. But they leave open the question of which purposes HGGE could be deemed acceptable.³³ To get an idea of various purposes HGGE can serve I shall briefly sketch them before going on to discuss them in light of the involved vulnerabilities.

3.2. Purposes of genome editing in the germline

In the literature, the different applications of HGGE are usually distinguished either as therapeutic and therefore acceptable or as enhancement and therefore problematic. The dichotomy of therapy and enhancement is often too simplistic for biomedical applications, and especially in the context of genetic interventions. I give two reasons for this claim: First, in the literature on HGGE, 'therapeutic' is usually used to describe the modification of the germline in descendants of parents who are carriers of a severe genetic condition, yet, as seen, this is a problematic use of the term. Second, 'enhancement' is usually used to describe treatments that go beyond what is necessary to restore or sustain good health.³⁴

³² Cf. Roberto Andorno *et al.*, 'Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction', *Trends Biotechnology* 38:4 (2020), pp. 351-354, p. 352. Christoph Rehmann-Sutter, 'Why Human Germline Editing is More Problematic than Selecting Between Embryos: Ethically Considering Intergenerational Relationships', *The New Bioethics* 24:1 (2018), 9-25.

³⁰ The continuously updated website https://crisprmedicinenews.com/clinical-trials/ (accessed 2022-11-09), run by Danish company COBO Technologies, lists over hundred gene editing studies

⁽including other modalities than CRISPR like Zinc Finger Nucleases, TALENS, MegaTALS, CAS-CLOVER, MegaNuclease) that have advanced to clinical trials over 60 based on CRISPR. For various examples of medical application see also Mohammed F. Rasul *et al.*, 'Strategies to overcome the main challenges of the use of CRISPR/Cas9 as a replacement for cancer therapy', *Molecular Cancer* 21:64 (2022).

³¹ The first experiment with CRISPR-Cas9 on human embryos was reported in 2015; the authors demonstrated that the GE system performed targeted cleavage in the β -globin gene, which when mutated causes β -thalassemia. Puping Liang *et al.*, 'CRISPR/Cas9-mediated gene editing in human tripronuclear zygotes', *Protein Cell* 6:5 (2015), pp. 363-372.

³³ National Academy of Medicine, National Academy of Sciences, and the Royal Society. *Heritable Human Genome Editing* (Washington, DC: The National Academies Press, 2020), p. 96

³⁴ Cf. Eric T. Juengst, 'What Does Enhancement Mean?', in *Enhancing Human Traits: Ethical and Social Implications*, edited by Erik Parens (Washington, D.C.: Georgetown University Press, 1998), pp. 29-47, at p. 29. Or similarly and more recently Catherine Gee, 'What is Enhancement?', *Journal of Cognition and Neuroethics* 3:4 (2016), pp. 41-54.

But, as the case of vaccines illustrates, many treatments can be necessary to sustain good health but are at the same time applied to "perfectly normal and perfectly healthy human beings", which justifies calling them "enhancements".³⁵ We, therefore, need a more nuanced account of the various purposes germline genome editing can serve since modifications of the human germ line can be associated with different goals, aim at different target structures, produce different effects (intended and unintended), and be associated with different methods, which leads to different ethical questions in each case.

In the following, I will distinguish between genetic germline modifications that a) aim at the therapy of infertility, b) aim at the correction of a pathogenic gene to achieve normal function in the potential offspring, c) aim at the modification of a gene to introduce a variant into the genome that is considered to lead to better health conditions (health-based enhancement), and d) wish-fulfilling enhancement beyond medical benefit.³⁶

a) Therapeutic purposes

The term therapy usually presupposes that there is a subject with a need that can be overcome by a certain treatment. Both are true in infertile adults, and therefore infertility treatments are one possible realm of *therapeutic* applications of germline genome editing.³⁷ When infertility is caused by a genetic mutation in germline cells with the effect that no fertilizable gametes can be produced, genetically modifying the mutation that causes infertility in gamete precursor cells might be an option to restore reproductive capabilities in infertile couples. Since idiopathic infertility is thought to have a genetic component in half of cases³⁸, infertility treatment by editing the germ cells could once become a welcomed approach to individualized therapy.³⁹ Examples in male patients are nonobstructive azoospermia, where spermatogonial stem cells would need to be genetically altered to pass the altered genetic material to all mature spermatozoa and progeny, and would allow the production of mature spermatozoa either using stem cells or by gene therapy.⁴⁰ An example of therapeutic germline gene editing in infertile female patients is the missense mutation TUBB8 which causes oocytes to undergo developmental arrest after fertilization.⁴¹ Genetically correcting the missense mutation TUBB8 in premature oocytes could recover their developmental potential. Both applications are still in the experimental stage.⁴² Another, yet clinically approved, therapy that involves modification of the germline is mitochondrial replacement therapy, where nuclear genetic material is moved from an egg or single-cell embryo with dysfunctional mitochondria to a donor egg that has

³⁵ Harris, Enhancing Evolution, p. 21.

³⁶ Since every conceptual definition also relies on evaluative assumptions, to distinguish therapy from enhancement thoroughly, a case by case discussion with broad public engagement would be necessary. Cf. National Academies of Sciences, Engineering, and Medicine, *Human Genome Editing: Science, Ethics, and Governance* (Washington, DC: The National Academies Press, 2017), p. 176f.

³⁷ Giovanni Rubeis and Florian Steger, 'Risks and benefits of human germline genome editing: An ethical analysis', *Asian Bioethics Review* 16:10 (2018), pp. 133-141.

³⁸ Priti Singh and John C. Schimenti, "The genetics of human infertility by functional interrogation of SNPs in mice", *Proceedings of the National Academy of Sciences of the United States of America* 112:33 (2015), pp. 10431-10436.

³⁹ Tetsuya Ishii, 'Reproductive medicine involving genome editing: clinical uncertainties and embryological needs', *Reproductive BioMedicine Online* 34:1 (2017), pp. 27-31.

⁴⁰ Sarah C. Vij, Edmund Sabanegh Jr., Ashok Agarwal, 'Biological therapy for non-obstructive azoospermia', *Expert Opinion on Biological Therapy*. 18 (2018), pp. 19–23.

⁴¹ Ruizhi Feng *et al.*, 'Mutations in *TUBB8* cause a multiplicity of phenotypes in human oocytes and early embryos', *Journal of Medical Genetics* 53 (2016), pp. 662-671.

⁴² Ishii, 'Reproductive medicine'.

had its nuclear genetic material removed.⁴³ Since mitochondria in maternal gamete cells are transmitted to offspring stemming from these cells, the mitochondrial DNA they contain is passed on to the offspring as well, wherefore the procedure qualifies as germline therapy.

b) Correcting a pathogenic trait

Germline modifications that aim at correcting a pathogenic version of a gene to restore normal function in the offspring of parents, of which at least one is a carrier of a severe hereditary genetic disorder, are the most discussed applications of HGGE. They are sometimes called 'therapeutic' which is not without conceptual difficulties, because, as mentioned above, there is no patient in need of therapy.⁴⁴ It would rather be convincing to consider them as a subset of enhancement, e.g., "disease prevention-enhancement"⁴⁵. However, the aim is to make it possible for future parents to have children that are genetically related to both parents even if at least one partner is a carrier of a severe genetic disease that would most likely be passed on to a child conceived from the gametes of the future parents.

c) Health-aimed enhancement

Health-aimed enhancement aims at modifying the genome of the offspring in a way to prevent a phenotype that could have less adverse, but not life-threatening, health effects by replacing genetic sequences with other sequences, that are naturally occurring in the population. This form of enhancement can be seen as a form of "normal range human enhancement" because it might be narrowed down by introducing so-called 'wild-type' alleles that occur naturally in the population.⁴⁶ The genetic modification performed on the first babies born after HGGE was of this kind.

It is often preventive enhancement and could be motivated by various reasons: To replace naturally occurring, but disadvantageous alleles with better alternatives and thus facilitate better metabolic functions, adapt the human organism to changing environmental circumstances such as providing resistance to infectious pathogens or other potential threats due to changing physical environment such as, e.g., climate change.

d) Wish-fulfilling enhancement beyond medical benefit

Some of the strategies of wish-fulfilling enhancement beyond medical benefit include producing a certain ability in the offspring by introducing a rare allele of a specific gene known or believed to be associated with a desired phenotype (e.g., the constitutive activation of the EPO gene has been proposed to confer advantages in endurance sports),

⁴³ Ewen Callaway, 'First UK children born using three-person IVF', *Nature* 617 (2023), pp. 443-444. ⁴⁴ These applications are sometimes called "therapeutic", which is not without conceptual difficulties, because there is no patient in need of therapy, cf. Tina Rulli, 'Reproductive CRISPR does not cure disease', *Bioethics* 33:9 (2019), pp. 1072-1082, in contrast to César Palacios-González, 'Reproductive genome editing interventions are therapeutic, sometimes', *Bioethics* 35:6 (2021), pp. 557-562.

⁴⁵ This category is sometimes considered to be a subsset of enhancement, namely "disease preventionenhancement", cf. Emilia Niemiec and Heidi Carmen Howard, 'Ethical issues related to research on genome editing in human embryos', *Computational and structural biotechnology journal* 18 (2020), pp. 887-896.

⁴⁶ Cf. Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: social and ethical issues* (London: Nuffield Council on Bioethics, 2018), p. 70 and p. 92, and Guy Kahane and Julian Savulescu, 'Normal human variation: refocussing the enhancement debate', *Bioethics* 29 (2015), pp.133-143.

modifying traits such as height or cognitive ability that are influenced by hundreds or thousands of genetic variants across the genome. They might often be 'innovative' as it could involve introducing new variants into the genome, that is alleles or genes that are naturally not or only rarely occurring in a given population, and that progeny would not have been able to receive through sexual or assisted reproduction. There are many goals these *innovative enhancement* strategies could strive for including attempts to acquire new genetic traits that have not been part of human DNA during the development of mankind but are supposed to be beneficial, such as, for instance, resistance to radiation exposures encountered during extended spaceflight.

The four categories differ in terms of the goal to be achieved by germline intervention. The difference between a) and b) to d) is that in a) the beneficiaries are the infertile adults, whereas b) to d) aim at creating offspring with certain traits that are expected to be beneficial to them. b) and c) are not categorically distinct but only qualitatively, b) aims at correcting a genetic disorder with life-threatening consequences, whereas c) is about genetic traits without life-impairing impact, while in d) health is not a primary issue.

They can also be distinguished in terms of the layer of vulnerability addressed and the individuals affected by them. While categories a) to c) can be understood as means to overcome inherent vulnerabilities, because they target structures that have a direct influence on the normal physiological function of the organisms, health benefits are not the primary intention of applications in category d). Nevertheless, they can be envisaged as a response to situational vulnerabilities: in many societies, for example, it may be advantageous to be born a white male with a high IQ. I will come back to the question of evaluating these different applications below and will now first point out the technical challenges that still exist.

3.3. Technical challenges of HGGE and the state of the ethical debate

Regardless of the wide range of possible applications, several technical hurdles such as safety, effectiveness, appropriateness, and cost-efficiency must still be overcome before thinking about possible translational pathways.⁴⁷

The first problem is related to the accuracy of genome editing. Undesired modifications can occur outside of the targeted sequence (off-target) or within or next to the targeted sequence (on-target), both leading to unintended changes in the genetic code. Unintended changes do not necessarily lead to a problematic health condition. They can be silent, i.e., they don't alter the sequence of amino acids and hence don't change the function of the resulting protein. But they can also affect the expression of a gene when a) the DNA change also alters the amino acid sequence (missense mutation⁴⁸), b) the DNA modification creates a premature stop codon which truncates the polypeptide the DNA sequence codifies for (nonsense mutation)⁴⁹, or c) the insertion or deletion of a DNA base alters the reading frame of the gene which may have various effects as, e.g., unfunctional proteins or dysregulation of the cellular translational process (frameshift mutation⁵⁰).

⁴⁷ Don P. Wolf *et al.*, 'Principles of and strategies for germline gene therapy', *Nature Medicine* 25 (2019), pp. 890-897.

⁴⁸ Sickle cell anaemia is an example of a disease caused by a substitution of a single DNA base (GAG \rightarrow GTG; Glu \rightarrow Val).

⁴⁹ Cystic fibrosis can, among other possible causes, result from a nonsense mutation.

⁵⁰ Crohn's disease can be caused by a frameshift mutation.

Another type of problem is increased mosaicism due to genome editing: When HGGE is performed on multicellular embryos, the targeted modification is not equally effective in all cells.⁵¹ This may result in cell lines with (slightly) different DNA sequences (genotypes), which in turn might lead to different cell phenotypes or cell behavior. Mosaicism, which also occurs spontaneously⁵² and is supposed to be very common⁵³, can, but doesn't have to, increase the risk of autoimmune diseases.⁵⁴ In fact, healthy babies with correct chromosome numbers can be born from mosaic embryos.⁵⁵

In accordance with these still high technical hurdles, there seems to be widespread international consensus in the scientific community that clinical applications of HGGE are inappropriate.⁵⁶ However, there is no consensus (anymore) on the question of whether germline applications are merely premature at this stage of development of the technique, its accuracy, potential risks, and long-term implications, or whether there are categorical reasons prohibiting germline interventions. Based on risk-benefit considerations some people categorically call for a complete international ban on this research⁵⁷, while others opt for a temporary moratorium.⁵⁸ Yet, there seems to be growing consensus that if studies based on a significant cohort of edited human embryos can provide preclinical evidence of safety and efficacy and demonstrate that the procedure can generate and select, with high accuracy, suitable numbers of viable embryos, HGGE may be considered safe enough for initial clinical use.⁵⁹ As I will argue in the following section, technical questions of safety and effectiveness cannot be the sole deciding factor in the evaluation of possible applications of HGGE. As an evaluation from a vulnerability perspective shows, HGGE brings with it numerous other ethical challenges.

4. Relevant vulnerabilities in reproductive germline editing

As we have seen earlier, we have to distinguish various layers and dimensions of vulnerability. Inherent vulnerability is an essential feature of embodied life and depends on various factors, including age, gender, health status, and disability. Given the possibility of reducing the genetic causes of serious diseases, or more generally, factors

⁵¹ Maryam Mehravar *et al.*, 'Mosaicism in CRISPR/Cas9-mediated genome editing', *Developmental Biolology* 445:2 (2019), pp. 156-162.

⁵² Cery E. Currie *et al.*, 'The first mitotic division of human embryos is highly error prone', *Nature Communications* 13:6755 (2022).

⁵³ Evelyne Vanneste *et al.*, 'Chromosome instability is common in human cleavage-stage embryos', *Nature Medicine* 15 (2009), pp. 577-583.

 ⁵⁴ Barbara R. Migeon, "The role of X inactivation and cellular mosaicism in women's health and sex-specific diseases', *Journal of the American Medical Association* 295:12 (2006), pp. 1428-1433.
 ⁵⁵ Currie *et al.*, "The first mitotic division".

⁵⁶ Cf. Carolyn Brokowski, 'Do CRISPR Germline Ethics Statements Cut It?', *The CRISPR journal* 1:2 (2018), pp. 115-125.

⁵⁷ Jeffrey R. Botkin, "The case for banning heritable genome editing", *Genetics in Medicine* 22 (2020) pp. 487-489.

⁵⁸ Eric S. Lander *et al.*, 'Adopt a moratorium on heritable genome editing', *Nature* 567: 7747 (2019), pp. 165-168.

⁵⁹ The studies should show that embryos have the intended edit(s) and no other modification at the target(s); lack additional variants introduced by the editing process at off-target sites—that is, the total number of new genomic variants should not differ significantly from that found in comparable unedited embryos; lack evidence of mosaicism introduced by the editing process; are of suitable clinical grade to establish a pregnancy; and have aneuploidy rates no higher than expected based on standard assisted reproductive technology procedures. Cf. National Academies, *Heritable Human Genome Editing*.

that increase inherent vulnerability, editing the germline appears to hold considerable potential for improving human resilience in general and – presumably – quality of life. Some argue that, if germline genome editing were once safely and effectively possible, the principle of procreative beneficence would imply a duty to edit the genome of the offspring.⁶⁰

However, the question of whether the consequences of HGGE can be regarded as predominantly beneficial or predominantly harmful is one of the most challenging problems for the ethical evaluation of HGGE. This is also because the question must be answered very differently depending on the goal HGGE is meant to achieve, the method used, and the possible outcomes.

HGGE procedures that aim at the treatment of a) infertility, b) the correction of a genetic disorder, or c) enhancements that promise to prevent susceptibility to not life-threatening health conditions basically promise to improve inherent resilience by fundamentally or gradually decreasing inherent vulnerabilities.

However, germline interventions aimed at overcoming situational vulnerabilities, such as height, muscle strength, or complex features such as intelligence (category d)), seem highly problematic, as they take certain contingent societal values and structural inequalities as an occasion to adapt the genome to them. This does not seem to be a convincing motive or justification, given the fact that the induced changes occur *in the germline* and are thus preserved far beyond the first generation of offspring, while social conditions are subject to constant change. The induced modification might, therefore, prove detrimental already in the first generation of offspring. It also seems to be the wrong tool to change the germline when social structures could be changed with the effect of enabling instead of disabling people. Since it seems morally dubious, I will therefore not pursue this form of HGGE any further.

From a public health perspective, it can be argued that safe and effective germline modification for a large variety of genetic conditions with more and less impact on health may significantly reduce the overall burden of disease and hence public health care costs, which then might free up public or health care resources that can be redirected to other people in need of support. It is doubtful, however, that state policies to promote HGGE can be designed in such a way that they do not lead to the problematic discriminations of the type of authoritarian eugenics of the first half of the 20th century and thus become the origin of new pathogenic vulnerability. If we want to remain true to the values of a human rights-based liberal society, reproductive choices must be left to the autonomy of individuals, as long as their decisions do not lead to harm to others (i.e., in the first place, their offspring) or society. We must therefore look more closely at the prospective parents and future children.

As seen in the therapy case a), some infertile couples could potentially benefit from HGGE. Provided that these procedures can be used so precisely that the technical intervention would merely restore the normal functionality of the gamete cells without having any other effects, such applications would also have no ethically relevant influence

⁶⁰ Julian Savulescu, 'Procreative Beneficence: Why We Select the Best Children', *Bioethics* 15:5-6 (2002), pp. 413-426; Savulescu, Julian and Guy Kahane. 'The Moral Obligation to Create Children with the Best Chance of the Best Life', *Bioethics* 23:5 (2009), pp. 274-290; Marcelo de Araujo, 'Editing the genome of human beings: CRISPR-Cas9 and the ethics of genetic enhancement', *Journal of Evolution and Technology* 27 (2017), pp. 24-42; Harris, *Enhancing evolution*; Christopher Gyngell, Hilary Bowman-Smart, and Julian Savulescu, 'Moral reasons to edit the human genome: picking up from the Nuffield report', *Journal of Medical Ethics* 45 (2019), pp. 514-523.

on future offspring. The relevant counterfactual would simply be that no child would be born, or, if the parents were to switch to the alternative use of donor gametes instead of HGGE, that another child would be born. HGGE to restore fertility is, in Derek Parfit's framework⁶¹, only identity affecting⁶², not person affecting⁶³, with the consequence that children born from the procedure could neither benefit nor be harmed by it.

It is, however, different with applications that aim at changing the genome in a way that leads to a different phenotype in the offspring (categories b) to d)). First, we must remember that this form of HGGE is not a method to "treat, cure, or prevent disease in any existing person."⁶⁴ Rather, it is used to create embryos with a genome altered in a particular way, which are then transferred to a uterus to achieve, after a successful pregnancy, the birth of a child with certain traits chosen by the prospective parents. So, it would be wrong to think of HGGE as a particularly early form of pediatric medicine, but rather as a form of reproductive medicine for parents who want children with certain genetic traits. Vulnerability considerations now come into play on both sides, the parents' and the future child's.

4.1. Direct and immediate vulnerabilities

Given their absolute dependency on their environment, children are quintessentially vulnerable, since they are absolutely dependent on the decisions of their (future) parents. And although they are children of their parents, parents do not own their children. Rather, children depend on parents to exercise their stewardship in the best interest of the child, since (future) children are the ones who must live with the consequences of the decision their (future) parents made. Whether a decision can be regarded as morally acceptable or not, therefore depends on the effects it has on the life of the future children.

In prospective parents who are carriers of a genetic disease, and who could generate only embryos that carry a disposition for developing a potentially lethal disease, their desire for 'healthy' genetically related offspring makes them especially dependent, and thus vulnerable, on the possibilities of medically assisted reproduction. We do not need to enter into a debate about the legitimacy of a desire to have children, whatever the cost, but can simply acknowledge that the desire for a genetically related child of one's own is to be valued as a legitimate expression of reproductive self-determination. Methods that allow this wish to be fulfilled should therefore be examined in this respect as potentially valuable means of strengthening the reproductive autonomy of genetically predisposed future parents. Having access to assisted reproduction enhances their reproductive autonomy, and denying them access needs to be justified on solid grounds.

When parents who, despite being carriers of a severe genetic disease, want to give birth to their own genetic children, they have basically two options: negative selection using IVF and PGT, in which as many embryos are conceived in vitro as necessary to have at least one embryo without the disease-causing gene among them, which is then transferred into the uterus. This method of preventing that a sick child is born has the advantage that it does not require any intervention in the genome, which could result in undesirable side effects of an unknown magnitude. The procedure also has limitations: in couples with one parent homozygous for a dominant genetic disorder or when both parents are homozygous for a recessive genetic disease, the disorder will be passed on to

⁶¹ Derek Parfit, Reasons and persons. Oxford: Clarendon Press, 1984.

⁶² Parfit, Reasons and persons, pp. 356-359.

⁶³ Parfit, Reasons and persons, pp. 361-379.

⁶⁴ Andorno et al., 'Geneva Statement', p. 352.

all children, or in situations, where just one parent is a carrier, but it is simply not possible to achieve a suitable number of unaffected embryos for transfer. Even though they are very rare, in such cases, genome editing could produce the desired result of genetically own children without the detrimental hereditary predisposition.

From an ethical perspective, the two procedures differ fundamentally regarding the children born from them. Negative selection by IVF and PGT is ethically neutral for the children born from it: A different child is born in each case, depending on which embryo is selected and transferred. The procedure affects the numerical identity but is not personaffecting. HGGE procedures, on the other hand, do not affect the numerical identity of the child born from them: It is the same child (numerical identity), but it does not have the same properties (qualitative non-identity), because its genetic makeup has been genetically modified. The procedures are therefore person-affecting.⁶⁵ Person-affecting procedures raise the question of whether the resulting child was better off as a result of the treatment compared to a birth without this intervention. This seems to depend crucially on how safe and efficient the treatment is. According to the authors of the Consensus Report "the most favorable balance of potential harms and benefits" may be found in "prospective parents for whom there are no available alternatives, and on diseases or conditions for which mortality is high and/or morbidity is severe."66 This seems to lead to the argument that a child that would be affected by a serious genetic disease if it wouldn't have undergone HGGE, would benefit from genetic modification that corrects the genetic disorder even if there would be a risk of harmful side effects as long as they are considerably less harmful than the genetic disorder prevented by the intervention. But, as has been noted with reference to an earlier statement by the same body, this argument is not convincing because the child will only be born because of the germline modifying procedure. "Seen from the future child's perspective, the side effects of [H]GGE treatment cannot be justified through comparison with the potential for living with disease or disability, which is prevented."⁶⁷ Only a minimal risk comparable to the risk every other child faces could be justified.⁶⁸ This sets very tight ethical limits to all attempts to justify HGGE (in all the categories of application differentiated above). They are not categorical limits, however, but hypothetical ones, since they depend essentially on the safety and effectiveness of the technique. It is possible, though possibly not very likely, that the technology will turn out

⁶⁵ Recently, there has been some doubt whether reproductive germline modifications are always person-affecting. Robert Sparrow, 'Human Germline Genome Editing: On the Nature of Our Reasons to Genome Edit', *The American Journal of Bioethics* 22:9 (2022), pp. 4-15, argues that, since in probably most cases modifying the genome would involve PGT to make sure the intended editing was successful and without unintended effects that would compromise the suitability of the embryo for implantation, germline modifications will "for the foreseeable future" not be "person affecting" and, therefore, fail "to benefit [or harm] the genome edited individual" (p. 10.). I am not convinced by the argument because it seems to rely on a perspective that only considers the various procedures involved (the "history of events", *ibid.*). But the ethically relevant perspective, in my opinion, is the "history of the particular embryo that developed into the genome-edited individual" (p. 9.), and the ethically relevant question is whether the editing was beneficial to this individual, even if the particular individual that came into existence was selected out of multiple embryos that were grown after the genetic modification. The selection step is identity affecting, but before there was a person affecting step of genetic modification that affected all the embryos grown afterwards, irrespective of whether they would later be implanted or not.

⁶⁶ National Academies, Heritable Human Genome Editing, p. 98.

⁶⁷ Rehmann-Sutter, 'Why Germline Editing is More Problematic', p. 17.

⁶⁸ Ibid.

to be virtually risk-free. Only we do not know that today, and it is questionable whether we ever will if the search for translational pathways were to move within these limits.

However, there is little hope for this assumption. If we look at the ethical debate about HGGE, it seems that the interest in enhancement applications is much greater than that in corrective applications. This is indicated on the one hand by the significantly higher interest in enhancement both in the philosophical and scientific communities⁶⁹, but also by the fact that the field of possible targets is just much larger for enhancement than for such 'therapeutic' purposes and, therefore, financially more attractive for industrial developers of such applications. Unsurprisingly, the first reported germline modifications in humans didn't aim at correcting a pathogenic trait but at conferring resistance against HIV, clearly an enhancement purpose. In addition, the application of HGGE in the context of reproductive treatments of carrier pairs of genetic diseases is, in the majority of these anyway few cases, probably not the best method to achieve the goal of healthy offspring, since there are alternative options such as the use of donor gametes, embryo adoption, or adoption of a child with (at least for now) much lesser risks than HGGE. Given that these alternatives exist, the claim that the case of prospective parents, who would have no success even after several attempts to achieve enough unaffected embryos suitable for transfer, has the "most favorable balance of potential harms and benefits"⁷⁰ seems to be preconceived in a presumably non-neutral way because it is contingent on the assertion that the wish of prospective parents to not use donor gametes has a normative relevance that outweighs (or at least balances) the risks for the child born through HGGE.⁷¹ The depiction of these case situations in this presumably non-neutral manner and framing these situations as 'therapeutic', as it is usually done in the literature, seems to serve the purpose of presenting them in a more morally favorable way, with the actual aim of gaining public approval for at least such 'therapeutic' uses. The underlying logic seems to work something like this: If the safety and effectiveness of the procedures could be proven in these 'therapeutic' cases, other application goals from categories c) and d) would also come into the range of options to be considered. The successful implementation of 'therapeutic' HGGE would then function as a gate-opener to the many more numerous and financially far more lucrative possible enhancement applications. Future parents, who

⁶⁹ Cf. the authors arguing in favor of this application: Nick Bostrom, 'Human Genetic Enhancements: A Transhumanist Perspective', The Journal of Value Inquiry 37 (2003), pp. 493-506; George M. Church and Edward Regis, Regenesis: How synthetic biology will reinvent nature and ourselves. New York: Basic Books (2014), de Araujo, 'Editing the Genome', Ronald M. Green, Babies by design: The ethics of genetic choice (New Haven: Yale University Press, 2007); Gyngell, Bowman-Smart, and Savulescu, 'Moral Reasons'; Harris, Enhancing Evolution; Russell Powell and Allen Buchanan. 'Breaking evolution's chains: the prospect of deliberate genetic modification in humans', Journal of Medicine and Philosophy 36:1 (2011), pp. 6-27; Ingmar Persson and Julian Savulescu, Unfit for the Future: The Need for Moral Enhancement (Oxford: Oxford University Press, 2012); Antonio Regalado, 'Engineering the perfect baby', MIT Technologoy Review 118:3 (2015), pp. 27-33; Savulescu, Julian. New breeds of humans: the moral obligation to enhance', Reproductive BioMedicine Online 10 (2005), pp. 36-39; Savulescu, Julian. 'Genetic interventions and the ethics of enhancement of human beings', Readings in the Philosophy of Technology (2009), pp. 417-430; Lee M. Silver, Remaking eden: Cloning, genetic engineering and the future of humankind (London: Phoenix, 1999); Kevin R Smith, Sarah Chan, and John Harris. 'Human germline genetic modification: scientific and bioethical perspectives', Archives of medical research 43:7 (2012), pp. 491-513; Gregory Stock, Redesigning humans: Our inevitable genetic future (Boston: Houghton Mifflin Harcourt, 2002).

⁷⁰ National Academies, Heritable Human Genome Editing, p. 98.

⁷¹ Cf. Sparrow, 'Nature of Our Reasons', and Giulia Cavaliere, 'Genome editing and assisted reproduction: Curing embryos, society or prospective parents?', *Medicine, Health Care, and Philosophy* 21:2 (2018), pp. 215-225.

are already burdened by their hereditary disease, are thus exposed to an increased risk that the realisation of their wish for a genetically related child without the hereditary disease is only ostensibly the goal of an HGGE treatment but is actually itself a means to the end of establishing reproductive germline modifications. Such a discursive constellation, then, brings with it the danger that the situation and the risks to be weighed up will be presented to the prospective parents in a manner according to the rules of the discourse. It wouldn't even happen out of malicious intent but just as an effect of such a discursive constellation. An element that supports this view can be found in surveys on the acceptance of HGGE: When people are asked whether they would allow HGGE for 'therapeutic reasons' such as the prevention of severe hereditary genetic disorder in the offspring, reference to possible alternatives such as donor gametes is very rare and, additionally, the media hardly ever talk about IVF & PGT as a possible alternative to HGGE.⁷² Eventually, the already inherently vulnerable prospective parents, due to their dependence on access to appropriate fertility treatment (including adequate information), become additionally vulnerable to exploitation by research interests in a highly competitive field influenced by the "promise of scientific fame and immense grant-funding in a multibillion-dollar industry [...] for scientists developing this technology."73

If prospective parents are recruited for the motivation of achieving research success, they may be at risk of not being adequately informed about the risks of using HGGE and thereby not giving their consent appropriately informed. This risk is significant since epistemic hurdles are high due to the complex matter at hand. The complexity of the biotechnology involved, the knowledge of biological interactions, and the understanding of statistical probabilities necessary to make a truly informed decision clearly demonstrate the dependence of prospective parents on numerous situational factors (educational background, access to information, financial opportunities, social inclusion, etc.) and may easily lead to epistemic and moral overload.

From a vulnerability perspective, HGGE has, therefore, a high risk of exacerbating existing vulnerabilities and creating new vulnerabilities on various levels: Unsafe germline modifications would increase inherent vulnerability and probably violate the dignity and integrity of future children, and the discursive interest in "revolutionary techno-scientific breakthroughs"⁷⁴ through HGGE is highly probable to contribute to an increase of prospective parents' situational and moral vulnerability.

4.2. Intergenerational vulnerabilities

The future parents' decision to use HGGE not only influences the life of the future child but also actively influences the framework for the future child's own reproductive decisions when he or she reaches reproductive age because the hereditary changes brought about will also be passed on to their offspring. With respect to the direct descendants, this can be seen as a problematic predetermination of children's living conditions brought about by the parents' decision to have a child through HGGE, which may conflict with children's right to an open future. In view of the unknown possible long-term effects of the method, it would be irresponsible not to accompany and monitor children born by means of an HGGE procedure over a longer period (or even lifelong) in order to be able to provide them with support as quickly as possible should any undesirable health effects occur.

 ⁷² Marcy Darnovsky, and Katie Hasson, '2020. CRISPR's Twisted Tales: Clarifying Misconceptions about Heritable Genome Editing', *Perspectives in Biology and Medicine* 63:1 (2020), pp. 155-176, p. 167.
 ⁷³ Labude *et al.*, 'Vulnerability', p. 360.

⁷⁴ Darnovsky and Hasson. 'CRISPR's Twisted Tales', p. 159.

Having to adhere to such a plan can be perceived as a significant restriction of one's freedom and can easily conflict with the realisation of one's life dreams.

Accepting such consequences might amount to an instrumentalization that violates the dignity of the (future) child for the purpose of fulfilling the wishes of the (future) parents for a child of their own. This would be a weighty argument for a categorical ban on HGGE, as demanded by UNESCO, for example.⁷⁵

Since these problems are not limited to the first generation born out of HGGE but affect all the descendants, a common concern about HGGE is that it generally affects the intergenerational relationship in a profound and, as is claimed, detrimental way.⁷⁶ The reason for this is that editing the germline is not only a matter of changing one specific trait for which parents would be accountable, but they would be equally responsible for all other features that were not changed.⁷⁷ This leads to the reproductive process becoming more than before a process of "(co-)construction"⁷⁸ of the specific composition of the offspring's genome, which brings along a new kind of responsibility.

However, I am not convinced that this must necessarily lead to incurably destroyed or perverted parent-child or, more generally, intergenerational relationships. The argument that if reproduction involves procedures of germline modification, then this must change what it means to have been born in such a way that the offspring can no longer congruently integrate this into their own identity and life story or into the generational context, seems to tacitly presuppose normative premises according to which a morally valuable intergenerational relationship is tied to certain forms of reproduction, which cannot include the alteration of genetic traits in the germ line. Intergenerational relationships are complicated matters, I agree, but it is not impossible for ancestors to take responsibility for their decisions, motives, and intentions and to justify them to their descendants, neither is it impossible for the descendants to take note of these decisions, to see them in their context and next to the then possible alternatives and thus to integrate them into one's own life story and the intergenerational context. I do not claim that this is an easy task and I agree that the conceptual and psychological challenges posed by HGGE may be of a new kind. But I doubt that it can only fail.⁷⁹ This is not an argument that HGGE should be allowed, but an indication that no fundamental argument against it arises from this concern. Nevertheless, weighty question marks remain.

4.3. Hermeneutic vulnerabilities

Finally, some further aspects of moral vulnerability have to be taken into account: The parents' decision for a reproductive procedure involving germline genome editing will

⁷⁵ UN Educational, Scientific and Cultural Organisation (UNESCO), *Universal Declaration on the Human Genome and Human Rights*, 11 November 1997, available at:

https://www.refworld.org/docid/404226144.html [accessed 10 July 2023].

⁷⁶ Cf., e.g., Jürgen Habermas, *The Future of Human Nature* (Cambridge: Polity Press, 2003), Michael J. Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Cambridge: Harvard University Press, 2007), Christina S. Schües, *Philosophie des Geborenseins* (München: Alber 2016), Rehmann-Sutter, 'Why Germline Editing is More Problematic'.

⁷⁷ Rehmann-Sutter, 'Why Germline Editing is More Problematic', p. 22.

⁷⁸ Rehmann-Sutter, 'Why Germline Editing is More Problematic', p. 20.

⁷⁹ A meaningful concept of interpretation of oneself and one's own coming into being presupposes that the respective interpretation is precisely *an interpretation* and thus *one* attribution of meaning *among other possible* attributions of meaning. Self-interpretations are always contingent, even if this is sometimes difficult to see through from the interpreter's inner perspective. In this respect, it must be conceded that the concrete circumstances of one's own emergence are, in principle, always open to interpretation and reinterpretation.

certainly determine the life of the future child in a fundamental way. One cannot anticipate what it will mean for the child and its self-perception to be brought into the world by means of a germline editing procedure.

As long as HGGE procedures are not established and widely used procedures in reproductive medicine, children born through HGGE procedures can easily become victims of stigmatisation. They could be branded as 'non-natural' children or as 'not fully human'. On the other hand, this could also lead parents to conceal the circumstances of conception. This would amount to a violation of children's right to know the circumstances of their creation. An analogous situation is that of in vitro conceived children using anonymous donor gametes: in order to protect them, the origin of the gametes is concealed, which can lead to difficult psychological conflicts and strained relationships with the parents for some of them who, later in life, learn about the circumstances of their conception. It is impossible to foresee in what way this would influence the psychological development of the children, but also the relationship between parents and children.

There is, therefore, a significant danger that HGGE can lead to hermeneutic injustices in the individuals affected by it, insofar as they may lack the hermeneutic and conceptual resources to articulate experienced suffering.⁸⁰ We are also hermeneutically vulnerable beings and HGGE would bring a new kind of conceptual and hermeneutical challenges in reconceptualizing intergenerational responsibility and accountability. However, the need to reconceptualize our moral and social vocabulary is a challenge that is not limited to HGGE, but is, to a significant part, tied to the development of individuals and society over time, since, as Kierkegaard once noted: life can only be understood backwards but must be lived forward.⁸¹ Important elements of dealing with challenges of technological developments in a socially responsible way are to cultivate a culture of sensitivity and attention to needs and wants, and to try to anticipate as well as possible the potential implications for individuals and society before allowing them into application, and to take measures to avoid potential vulnerabilities as far as possible.

5. Conclusion

My aim in this paper has been to look at the emerging technology of germline editing from a vulnerability ethics perspective and to explore the extent to which this perspective can be fruitfully applied to the challenges associated with this technology. In doing so, the starting point of the vulnerable subject has proven particularly helpful and fruitful for application in this biomedical context. Liberal conceptions of ethics based on a model of (hypothetical) balancing of interests among contemporaries find it difficult to adequately consider the position of future persons. Here, the approach through a lens of vulnerability offers a helpful supplement without having to give up central aspects of traditional liberal ethics such as the importance of autonomy. Precisely because the perspective on vulnerability does not start from an ideal state of an adult, capable of action, well-informed and autonomous subject, but rather "recognizes that individuals are anchored at each end

⁸⁰ Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford: Oxford University Press, 2007), pp. 147-175.

⁸¹ Kierkegaard, Søren, Kierkegaard's Journals and Notebooks, Volume 2: Journals EE-KK, edited by Bruce H. Kirmmse, K. Brian Söderquist, Niels Jørgen Cappelørn, Alastair Hannay, David Kangas, Vanessa Rumble, and George Pattison (Princeton: Princeton University Press, 2015), Journal JJ:167 1843, p. 179.

of their lives by dependency and the absence of capacity^{"82}, the beginning of life, which is characterised by radical dependency, and both the vulnerability of the (future) parents and the vulnerability of the (future) children could be taken into account, without making the mistake of considering the latter merely as deficient compared to the ideal state of autonomous adults, but as a phase of life that is to be valued in its own right.

I adopted the taxonomy proposed by Rogers *et al.* to differentiate different layers and aspects of vulnerability and enriched it with the dimension of moral vulnerability. In the application to HGGE it became apparent that all these aspects are important in the evaluation of HGGE in light of vulnerability ethics.

I distinguished various applications of HGGE according to their primary objectives and the method by which these objectives are sought to be achieved roughly into four categories. All of them are based on a claim that HGGE can (and should) be used to reduce vulnerability of some sort. In light of the taxonomy of vulnerability, HGGE applications that aim to enhance individuals by introducing genetic traits into the germline without a direct health benefit, I assumed that they are most often based on a perception of situational vulnerability, and I have argued that it is unacceptable to try to address situational vulnerabilities, which could be responded to with political or social measures, through the use of germline modification techniques. Provided that HGGE could ever be said to be safe and effective, I have argued that only applications aimed at restoring normal physiological functioning, correcting, and preventing health-impairing or even life-threatening genetic conditions, are acceptable objectives of germline modifications, since in these cases, the technique might be a mean to reduce overall vulnerability in future generations.

However, I emphasized that the proviso of safety and effectiveness is a considerable one, since in view of a child born through a procedure of germline editing no additional risk would be morally acceptable. However, as I have tried to show that a particularly neuralgic point seems to lie precisely at this point, which is particularly prominent in the vulnerability perspective: in the bioethical discourse on HGGE, the situation of couples who are carriers of a severe genetic disease is usually constructed as the entry point for the first clinical applications of HGGE, because here the assumed relationship between risks and opportunities is depicted as being in a particularly favorable balance. I have tried to show that this construction is based on a (often tacit) preconceived normative weighting of parental wishes for a genetically own child and the hiding of alternative options (such as IVF&PGT or donor sperm), which, under the guise of empowering affected couples in their reproductive autonomy, tends to bring with it the danger of creating new vulnerabilities: On the side of the future child, whose moral claim to emergence with minimal risks tends to be ignored, and on the side of the parents, whose situation threatens to become a means to the end of establishing HGGE. Both would be consequences that threaten to compromise the moral integrity and dignity of both the future parents and the future child.

Looking at HGGE from a vulnerability perspective could thus demonstrate that the question of possible approval should not only be based on the technical criteria of safety and effectiveness. I discussed several implications of HGGE for the affected parents, children, the relationship between parents and children, intergenerational relationships in general, and for society in light of (some of) the involved vulnerabilities. In doing so, I have supported the view that HGGE would entail a fundamental change in intergenerational

⁸² Fineman, 'The Vulnerable Subject', p. 12.

responsibilities, but at the same time rejected that this can only fail. In addition, the discussion of a new technological development has led us to focus on another dimension of vulnerability: Hermeneutic vulnerability, which in a sense forms the subjective correlate to decisions under uncertainty.

I hope that it has become clear from these considerations that a sufficiently nuanced vulnerability perspective can offer a conceptual tool that is suitable for analyzing the ethical challenges posed by the possibility of germline modifications and – in some questions – also for making an evaluative judgment. Given the uncertainty as to the direction in which developments will proceed, however, uncertainties remain in the ethical judgment even in this perspective, which can probably only be dealt with appropriately in the context of a more intensive, open, and participatory society-wide debate.

It should, however, have become clear that actions aimed at preventing harm and remediating vulnerability may be associated with the risk to "exacerbate existing vulnerabilities or generate new vulnerabilities" and generate "pathogenic vulnerabilities"⁸³. As we move forward in exploring the possibilities by manipulating the genome and developing new applications, we should be concerned that our pursuit is not guided by the fiction that it is a goal in itself to erase vulnerability. "Vulnerability can never be eliminated since otherwise humanity itself would be erased."⁸⁴ And this should never be neither the aim nor a side effect of any technical innovation.

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⁸³ Ibid.

⁸⁴ ten Have, *Vulnerability*, p. 129.

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