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HUMAN REPRODUCTION AND PARENTAL RESPONSIBILITY: NEW THEORIES, NARRATIVES, ETHICS

Edited by Simona Corso, Florian Mussgnug, Virginia Sanchini

Rosenberg & Sellier

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INTRODUCTION

INTRODUCTION

Simona Corso, Florian Mussgnug, Virginia Sanchini

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INTRODUCTION
IMAGINING HUMAN REPRODUCTION

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INTRODUCTION

Questions about human reproduction and parental responsibility run through our lives. They shape our experience as natal and mortal beings and orient our thinking about generation: the process by which we come to be; the activity in which we engage or choose not to engage as procreative beings; our syncopated sense of time; our responsibility for the continuity of human life on a finite and vulnerable planet. Like all living species, humans tend to reproduce. For this reason, assumptions about procreation and parenthood have long provided a powerful means to imagine the future. In *Evolution and Ethics: Prolegomena* (1894), philosopher and biologist Thomas Henry Huxley envisaged an inexorable rise in human numbers: "Man shares with the rest of the living world the mighty instinct of reproduction and its consequences, the tendency to multiply with great rapidity" (Gilbert and Pinto-Correia 2017: 200). More than a dozen decades later, debates about population control, public health and migration still rest on this assumption. Population growth, along with improvements in nutrition, public health and life expectancy, forms the backdrop to advances in assisted reproductive technology, reflections on ethics and values, and a re-assessment of what it means to procreate. In this context, discussions about parental responsibility touch on urgent questions. If the human world population continues to grow in the way that it has, future humans may be condemned to vastly inferior lives. Other species will also suffer the consequences of globalisation and human population growth. But can and should we seek to reduce the number of human births? Practices of family planning and population control – at least as old as Plato's *Republic* – raise deep-seated fears. Since the dawn of the modern age, struggles over population have led to the establishment of coercive regimes, whose brutal interventions have perpetuated and increased inequalities and injustice between and within nations (Connelly 2008). The history of nineteenth-century eugenics – the idea of improving the genetic makeup of humankind – casts a dark shadow on practices of family planning and on advances in medically assisted reproduction. Neo-Malthusians, eugenicists, pro-natalists and nativists disagree in their political visions, but share a deterministic view of procreation, and a desire to control how people breed.

The articles in this special issue offer a different perspective on this complex tangle of questions and challenges. *Human Reproduction and Parental Responsibility* brings together leading scholars and early career researchers from a wide range of disciplines: political and moral philosophy, literary and cultural studies, bioethics, legal philosophy, the medical humanities, and gender and sexuality studies. Individual contributions highlight the diversity between disciplines, moral and political orientations, but agree on a shared set of assumptions and concerns. Against the ethical and methodological strictures of naive biological reductivism, we call for attention to philosophical inquiry and cultural narratives. We do not treat human reproduction as a biological given, but argue that a carefully reasoned case for the permissibility and desirability of procreation can and must be made. At the same time, we are averse to coercive policies and mechanisms of population control that violate individual reproductive lives and futures. Finally, and most importantly, we object to what we perceive as a widespread tendency to discuss reproductive rights exclusively in relation to technological possibility, and affirm the importance of cross-disciplinary dialogue. The articles in this special issue wish to foreground the vital contribution that the humanities can make to this dialogue.

Human Reproduction and Parental Responsibility explores changing social attitudes around parenting and reproductive health through a variety of ethical, legal and cultural lenses. From the Biblical God's exhortation to be fertile and multiply (*Genesis*, 1.28) to governmental demographic policies, human reproduction has always been subject to multiple pressures. Some influential thinkers have argued that human bodies are merely survival machines for "selfish genes", which ache to be perpetuated into the next generation. The long history of debates about human reproduction, however, appears to suggest the contrary: generation is not only a biological process, but also a social, cultural and ethical practice. Since the turn of the millennium, assisted human reproduction has come into view as an increasingly important field of inquiry, across disciplines. Advances in reproductive technology have profoundly altered the demarcations of parenthood. They challenge conventional perspectives on parental rights and responsibilities and call for in-depth philosophical, bioethical and legal reflection. In this context, the differences between academic disciplines and knowledge practices appear less important than their synergies. Philosophical and bioethical debate can shed light on the complex and changing emotions and experiences of parenting. Similarly, literature and film can draw attention to global patterns of exploitation and inequality, and bring into focus the discrepancies between political, philosophical and religious perspectives.

The contributors to this special issue are aware that human procreation and parental responsibility are not only important, dynamic sites of transdisciplinary inquiry, but also the object of fierce political controversy. *Human Reproduction and Parental Responsibility* does not wish to settle these disputes, just like we do not seek to close the gap between nature and history. Rather, our special issue wants to advance a complex and nuanced understanding of reproductive choice that cannot be reduced to simple binaries. Many of the contributions that follow approach ethics as a body of rules and as an applied discipline. They discuss responsibility in terms of the accountability of free agents and develop philosophical orientations that guide a responsible engagement with human reproduction. Other interventions problematize this approach and indicate the need for a wider reflection on the meaning of responsibility. They explore the differences between cultural traditions on a planetary scale, de-centre the notion of the human subject as a free agent, and re-think procreation in terms of a duty of care. Again, it is not our wish, as editors, to resolve the differences between these perspectives. Rather, we have sought to showcase the productive diversity across critical interventions that collectively hold the power to break new ground, set the terms of future debate, and inspire cross-disciplinary dialogue.

This special issue is divided into three cross-disciplinary sections: Cultural Representations, Philosophical Orientations, Ethics in Context. The **first** section, **Cultural Representations**, hosts articles by Roberto Mordacci, Simona Corso, Charlotte Ross and Maria Russo. They explore how literature and film have engaged with human reproduction and parental responsibility, from 1516 to the present, and how storytelling interrogates social and cultural norms and contributes to their transformation and development.

In *Reproductive Utopias and Dystopias: More, Campanella, Bacon and Huxley,* Roberto Mordacci offers a genealogy of the modern reproductive imagination, from Thomas More to Tommaso Campanella and from Francis Bacon to Aldous Huxley. Mordacci argues that More's *Utopia* advocates a liberal idea of the family, where divorce is allowed and relationships are free. By contrast, Campanella's *The City of the Sun* understands reproductive relationships in terms of a eugenic policy and Bacon's *New Atlantis* similarly conceives of generation as a public good. Finally, Huxley's *Brave New World* imagines human reproduction as a totalitarian nightmare. Mordacci's contribution explains how Twentieth Century writers and commentators came to view population control in a sinister light, due to its association with scientific experiment and coercive policies. He argues that this shift in cultural practices and social attitudes may be described as a transition from utopia to dystopia.

In *Birth: Stories from Contemporary Literature and Film*, Simona Corso discusses a selection of contemporary novels and films in English and Italian, which narrate experiences with reproductive medicine, from in vitro fertilization to gamete donation and surrogacy. Corso's examples include *The Kids Are All Right* by American director Lisa Cholodenko, *Google Baby* by Israeli director Zippi Brand Frank, *Venuto al mondo* by Italian director Sergio Castellitto, *Carissimi* by Italian novelist Letizia Muratori, *Non mi vendere, mamma!* by Italian author Barbara Alberti, and *Katherine Carlyle* by British novelist Rupert Thomson. Corso explores how medical practices and family histories are represented in these texts and argues that narrative can help us navigate the troubled waters of our present. While literature and film do not provide definitive answers to the many dilemmas created by advanced technologies of assisted reproductive medicine, they can at least help us formulate new questions.

Charlotte Ross' contribution, *Surviving Melancholy and Mourning: A Queer Politics of Damage in Italian Literary Representations of Same-Sex Parenting*, continues this examination of family narratives. Ross analyses the representation of lesbian and gay parents and their children in the novels of Italian writers Cristiana Alicata, Melania Mazzucco and Chiara Francini. Drawing on Judith Butler's work on mourning and melancholia and on the theoretical framework developed by gender theorist Heather Love, Ross problematizes the persistent spectre of grief that has been evoked in many narratives of gay and lesbian parenting. Her article resists homosexual doom and calls for new experiences of queer vitality that hold the power to subvert and disrupt normative conceptions of the family, in art and life. She argues that such experiences may open up spaces for creative reflection and that they can inspire innovative modes of parenting.

In *Is It Progress or Dystopia? Attitudes Toward Genetic Engineering in Contemporary Film* Maria Russo discusses how film, and especially science fiction, have tackled the theme of genetic engineering and its ethical implications. Russo begins her inquiry with a thematic overview of cultural representations of human gene editing in popular science fiction. She then offers a close reading of Andrew Niccol's film *Gattaca*. Using the critical methodologies and categories of philosopher Thomas Wartenberg, Russo argues that *Gattaca* is both a critique of genetic determinism and a philosophical thought experiment, which illustrates the pitfalls of a society where parents are free to decide the genetic makeup of their children.

The **second** section – **Philosophical Orientations** – hosts contributions by Carmen Dell'Aversano and Florian Mussgnug, Simone Pollo, Lucia Galvagni, and Sergio Filippo Magni. These articles reflect on the ethical and political obligations and dilemmas that may arise from human reproduction and from parental choices: individual and communal duties of care, personal and collective responsibilities for human and non-human wellbeing on a warming planet, reproductive justice. The authors in this section evoke a variety of disciplinary traditions and write with different urgencies, but agree on the need for nuanced ethical frameworks that can guide our thinking about vulnerability, entanglement, and the desirability of human procreation, especially in the context of assisted reproductive technology.

In *Parenthood, Climate Justice and the Ethics of Care: Notes Towards a Queer Analysis,* Carmen Dell'Aversano and Florian Mussgnug explore the concepts of parenthood, reproduction and care in the context of the unfolding global environmental crisis. Arguing from the perspectives of queer theory, literary studies and climate justice, the authors call for new strategies and attitudes towards procreation, beyond the strictures of colonizing frames of knowledge and hegemonic cultural practices. More specifically, Dell'Aversano and Mussgnug seek to move the debate around assisted reproductive technologies in new, speculative directions that are centred on shared vulnerability and kinship, and which remain fully attentive to human and non-human relations and shared responsibilities on a warming planet.

In *A Twenty-First Century Reproductive Bioethics*, Simone Pollo claims that so-called "new reproductive technologies" (NRTs) are no longer properly new. In many parts of the world, they form an integral part of modern life and an important vector of human wellbeing. They allow people to have families that would not otherwise exist. Pollo argues that discussions in bioethics must advance to account for this "new normal" and that disciplinary protocols may require considerable review. NRTs should not be treated as "new frontiers" but ought to be viewed as everyday matters. A properly contemporary reproductive bioethics, Pollo contends, needs to centre on improving universal access to NRTs and should not focus on discussions about their permissibility.

Lucia Galvagni's contribution, *New Motherhood? Embodiment and Relationships in the Assisted Reproductive Technology*, debates the practice of "maternity for others", better known as "surrogacy". As Galvagni notes, this practice, and the struggles to control it, are interconnected transnational phenomena that extend on a global scale. They engage and affect couples, communities, women who lend themselves to being "carrier mothers", and their children, and thereby raise complex moral questions about global justice and the appropriateness and legitimacy of recourse to surrogacy. Galvagni discusses the political and social contexts in which modern surrogacy develops, and reflects on processes of commercialization, corporeity and relationships. She calls for a collective and open-ended debate about new forms of motherhood, and parenting in general.

In *Person-Affecting Procreative Beneficence*, Sergio Filippo Magni comments and develops the work of philosopher and bioethicist Julian Savulescu. More specifically, Magni's contribution engages Savulescu's Principle of Procreative Beneficence, which states that couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information. Magni proposes a person-affecting version of this principle, which was originally stated by Savulescu in an impersonal form, balanced with a person-affecting principle of harm. He discusses and positions both versions of the Principle of Procreative Beneficence in the wider context of ongoing debates about the legitimacy of selection.

The **third** section – **Ethics in Context** – hosts articles by Laura Palazzani, Virginia Sanchini, Davide Disalvatore, Sarah Songhorian, Paolo Spada, Pier Paolo Di Fiore, Federico Pennestrì and Davide Battisti. The articles in this third section address the question of ethical choice from the perspective of bioethics and biolaw. They consider how advances in these disciplines can inform decisions about human reproduction and how research findings and discussions have reflected and transformed notions of parental responsibility and agency.

In *Reproductive Technologies and the Global Bioethics Debate: A Philosophical Analysis of the Report on ART and Parenthood of the International Bioethics Committee of Unesco*, Laura Palazzani discusses some bioethical and biolegal issues that arise from the use of assisted reproductive technologies (ART). Palazzani's contribution specifically centres on reproductive rights and the rights of children. She examines recent advances in ART and calls for a pluralistic debate on parenthood and filiation. In her article, Palazzani exemplifies the importance of such a debate through her analysis and discussion of the Unesco International Bioethics Committee's Report on ART and parenthood: the first global document of this kind.

Deliberation and Public Bioethics: A Test Case in Reproductive Genetics by Virginia Sanchini, Davide Disalvatore, Sarah Songhorian, Paolo Spada and Pier Paolo Di Fiore studies the theory and practice of deliberative public bioethics. The five authors shed light on the figure of the bioethical expert and investigate how deliberation may be implemented in public bioethics. They describe the findings of a large-scale experiment which investigates whether, and to what extent, different moderation styles impact on moral preferences. The authors find that different moderation styles can significantly influence deliberative outcomes. Their work also shows that the effects of deliberation are not necessarily immediate, but may only become apparent after the end of a deliberative session. Finally, they explain how participants appreciate bioethical experts as "passive moderators", namely as someone who acts in order to ensure non-domination.

In *Is Therapeutic Germline Editing Value-Based Healthcare? An Early Health Technology Assessment*, Federico Pennestrì asks why so many innovative healthcare technologies raise ethical concerns that prevent their implementation. He points out that widespread opposition is often inspired by fears of unexpected or undesirable outcomes. Pennestrì recommends that researchers analyse potential benefits and drawbacks from a multidisciplinary perspective, and that they pay attention to biomedical, social and economic factors. He presents value-based healthcare as the appropriate and comprehensive multidisciplinary evaluative framework. Pennestrì also performs a Health Technology Assessment of germline editing technologies and estimates their impact on patients and society. In this context, he comments on the recent, controversial debate which followed the germline gene editing of human embryos.

In *Genetic Enhancement and the Child's Right to an Open Future*, Davide Battisti discusses the ethical implications of genetic enhancement within the specific framework of the "child's right to an open future" argument (CROF). While it is generally assumed that CROF justifies genetic modifications that would eradicate disease or disability, disagreement exists over genetic enhancement. Battisti argues that parents do not have the moral obligation to open as many options as possible for their children. Rather, they should provide them with a reasonable range of opportunities. On this basis, he suggests that CROF is not in contrast with every form of genetic enhancement and that it may in fact entail a moral obligation to enhance progeny, under specific circumstances. Battisti clarifies this idea by referring to philosopher Allen Buchanan's definition of the 'dominant cooperative framework'.

In addition to these articles, the present special issue of *Human Reproduction and Parental Responsibility* also contains two **free contributions** by Ali Yousefi Heris and Piero Mattei-Gentili, which are hosted in the **fourth** section. These texts were submitted directly to the journal and underwent peer review independently from the preparations for the special issue. Yousefi Heris explores the role of simulational mindreading in pragmatic interpretation. Mattei-Gentili addresses ongoing debates about the ontology of norms and considers the case of accounting for customary norms. The two articles bear no specific relation to the theme of the special issue.

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Some articles in this special issue are developed from papers that were presented in April 2018, on the occasion of an interdisciplinary conference: "Reproductive Health and Parental Responsibility". This conference was hosted by the Department of Modern Languages at Roma Tre University, in collaboration with University College London's Faculty of Arts and Humanities, the UCL Global Engagement Office and the EGA Institute for Women's Health. Additional articles were commissioned to widen the cross-disciplinary scope of the special issue. We are grateful to all contributors, who have responded enthusiastically to our invitation to re-think human reproduction and parental responsibility, beyond disciplinary divides. Our thanks go to the colleagues who took part in the conference as speakers and chairs: Rachel Bowlby, Martina Caruso, Simona Corso, Carmen Dell'Aversano, Giorgio de Marchis, Roberto Mordacci, Florian Mussgnug, Helen O'Neill, Laura Palazzani, Zoe Papadopoulou, Iolanda Plescia, Aarathi Prasad, James Wilson. We thank our sponsor, the UCL Cities Partnerships Programme in Rome, for financial support and the Roma Tre University for logistic and technical assistance.

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SECTION

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SECTION 1

CULTURAL REPRESENTATIONS

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Simona Corso
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REPRODUCTIVE UTOPIAS AND DYSTOPIAS: MORE, CAMPANELLA, BACON AND HUXLEY

abstract

Our reproductive imaginaries have changed considerably in the XX century. This cultural change can be described as a transition from Utopia to Dystopia. Plato imagined that in his perfect State women and children were in common, and that adequately matched couples would yield a perfect breed. On the contrary, Thomas More's Utopia *(1516) is based on a modern liberal view of the family, where divorce is allowed and relationships are free. Tommaso Campanella's* The City of the Sun *(1602) understands relationships exactly in terms of a eugenic policy. Francis Bacon's* New Atlantis *(1626) also conceives of generation as a public good. Aldous Huxley's Brave* New World *(1934) creates a vision of reproduction as a total nightmare. The whole process of reproduction has been taken into control by an* ideology. *We must distinguish* liberal utopias *from* totalitarian *ones, which evolve into dystopias.*

keywords

utopia, dystopia, reproductive health, liberalism, totalitarianism

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1. From Utopias to Dystopias

Our reproductive imaginaries have changed considerably in the Twentieth Century. When compared with the imaginaries of the past centuries, and limiting ourselves to modern ones, a sinister turn has been impressed on our perception of reproductive practices, mainly due to their connection with science and technology. On the whole, this cultural and social change might be described by many (though not all) as a transition from utopia to dystopia. We should ask ourselves why this transition took place: what is it that makes us afraid of the possibilities raised by reproductive technologies? What brought us, in late modernity, from utopia to dystopia, in the perception of reproductive practices?

A thorough analysis of this complex social and cultural change is clearly beyond the limits of this paper. A portion of this question can be partially answered by inquiring into some examples of utopian literature, a long tradition notoriously initiated by Thomas More's *Utopia* in 1516 (More, 1995) and developed through the centuries in a variety of genres: philosophical essays, literary novels, short stories, the visual arts, and, in the Twentieth century, film, radio and television (see Mumford, 1992; Manuel, Manuel, 1979; Jameson 2005; Mordacci, 2020).

A notable feature of this literature is that, around the turn from the Nineteenth to the Twentieth Century, it has undergone a radical change from a positive characterization of the ideal society to a negative representation of totalitarian States disguised as perfect societies. This turn can be defined as a switch from utopias to dystopias (Bagchi, 2012; Claeys, 2017; Atchison, Shames, 2019). The result of this change has been to cast a shadow upon the idea of utopia, which today is often assumed to imply, as a natural evolution of the concept, a dystopian outcome in reality. Thus, there has been a growing suspicion against utopias in the Twentieth Century.

The evolution from utopia to dystopia is connected to three features: a strict control of social relationships, the realization of a "perfect" (perfectly managed, perfectly organized) society, and a pervasive use of sophisticated technology. These features are assumed to be present in the very idea of utopia and their implementation is understood as actually creating a dystopian society.

Reproductive practices are always an issue in utopias. They have to do with control, with the idea of perfection and with the use of technology. Therefore, they provide a good starting point for inquiries into the alleged intrinsic relation between utopia and dystopia.

Elsewhere I have argued at length (Mordacci, 2020) that More's utopia is strikingly different from most later utopias because of its humanistic image of a good State, which bears no totalitarian traits. Here, I will argue that none of the features of control, perfection and reliance on technology belongs to the original model of utopia designed by More, while they can be found in the utopias of Campanella and Bacon. My analysis of the representation of reproductive practices serves to support this general argument. On this basis, a distinction can be made between liberal utopias, which do not accept any of the aforementioned features, and totalitarian ones, which rely more or less heavily on them and therefore become dystopias. If my argument works, then we have reason to question the alleged intrinsic connection between utopias and dystopias.

The argument can be made here only by example. I will start by showing that, contrary to Plato's model in the *Republic* (which is not a utopia), Thomas More's *Utopia* does not impose the traits of control, perfection and technology on the reproductive practices of utopian citizens (§2). Then, I will show that these traits are clearly present in Tommaso Campanella's *The City of the Sun,* and, in a less marked form, in Francis Bacon's *New Atlantis* (§§ 3 and 4). These authors present their society as ideal, but clearly emphasize totalitarian features, if we define totalitarianism in terms of very strict State control over the citizens' private and public life, also through terror (Arendt, 1958). These totalitarian features can be traced back to Plato's model of the ideal city (Brown, 2017).

Furthermore, Aldous Huxley's *Brave New World,* which explicitly presents itself as a dystopia, shows how the pursuit of a "perfect" society through technology as a means of social control leads to a totalitarian outcome. Its features are very far from Thomas More's model, while they are somewhat present in Campanella's and Bacon's models. Therefore, Huxley's dystopia cannot be said to be the natural evolution of More's *Utopia* (§5).

I will conclude by arguing that the case of reproductive practices shows that we need to distinguish between liberal (or humanistic) and totalitarian (or technological) utopias. The former do not lead to dystopias, the latter do (§6).

2. More's *Utopia* and reproductive practices

Many utopias include imaginary regulations of reproductive practices. Plato famously imagined that in his perfect State women and children would be in common and that adequately matched couples would yield a perfect breed (*Republic*, 457 c – 460 c). Yet, Plato's *Republic* is more an archetypical image of the perfect State than a real utopia.

Utopias are *narratives* of a harmonious and just republic, not thought experiments that seek to project the proper state of the soul on the "big screen" of a city, as Plato describes his plan in the *Republic* (*Republic,* 368 d). Thomas More's *Utopia* does not set any *a priori* rules for the life of the citizens of a perfect town. It rather *reports*, through the narrative of Raphael Hythlodaeus, the customs of the inhabitants of a harmonious and prosperous community, and then derives from that description the principles on which the community's life is based.

The institutions of More's *Utopia*, first published in 1516, are very different from the ones of Plato's *Republic,* especially as far as reproductive practices are concerned. *Utopia* is based on a rather traditional view of the family, with some modern innovations: for example, priests can get married. Women get married after the age of eighteen, men after the age of twenty-two. "Clandestine marital intercourse, if discovered and proved, brings severe punishment on both man and woman" (More, 1995, p. 189) and on their parents as well. More offers an indulgent reason for such rigorous moral rules: "The reason they punish this offence so severely is that they suppose few people would join in married love – with confinement to a single partner and all the pretty annoyances that married life involves – unless they were strictly restrained from promiscuous intercourse" (*ibidem*). So, the reason for the punishment is not so much a moralistic condemnation of the offence, but the prevention of a cause of the fragility of families, which are the cornerstone of the Utopian society.

Apart from this, More does not seem to imply that marriages are combined, nor that they are totally free. It is likely that his understanding is that there is no reason for families to make "good" combined marriages for economic or political reasons, since all citizens are equal and do not need to have any economic or political influence. In this perspective, the free sentiments of young men and women are *de facto* paramount in the choice of the partner. Of course, More speaks only of heterosexual couples; homosexuality is not even mentioned. Family life in Utopia is dominated by men: women follow their husbands in their households, serve them during meals and manage the home. Children serve their parents and also help during meals. Families are large: "Each household (there are six thousand of them in each city, exclusive of the surrounding countryside) should have no fewer that ten nor more than sixteen adults. They cannot, of course, regulate the number of minor children in a family" (p. 135). This means that there is no demographic policy concerning the number and sex of children allowed for each family: this is a rather liberal rule for an ideal state, where usually (as in Plato, in Campanella and in other authors) the overall number of citizens is artificially kept stable by law.

There is a provision regulating the demographic balance between the towns, and in general across the island:

> If a city has too many people, the extra persons serve to make up the shortage of population in other cities. And if the population throughout the entire island exceeds the quota, they enrol citizens out of every city and plant a colony under their own laws on the mainland near them. (p. 135)

Utopians are allowed to occupy foreign land as long as the local inhabitants do not occupy or cultivate it: "They think it is perfectly justifiable to make war on people who leave their land idle and waste yet forbid the and possession of it to others who, by the law of nature, ought to be supported by it" (p. 137).

There is no eugenic policy concerning "good marriages" or "good breed", as happens, for instance, in both Plato and Campanella (see §3). It seems that More's utopians can choose their partners according to taste and that there is no control over the quality of the offspring. Yet, there is a rather strange custom concerning the couples who want to get married. Hythlodaeus says:

> In choosing marriage partners they solemnly and seriously follow a custom which seemed to us foolish and absurd in the extreme. Whether she be widow or virgin, the woman is shown naked to the suitor by a responsible and respectable matron; and similarly, some honourable man presents the suitor naked to the woman. (p. 189)

More quickly explains the reason for such a bizarre ritual, and explains how it replaces the custom of combined marriage (common at More's time) with a more "natural" and "realistic" practice. People who have to spend their whole life together and faithfully tied to each other should have the opportunity to know each other at least "visually". In fact, More adds:

> We laughed at this custom, and called it absurd; but they were just as amazed at the folly of all other peoples. When men go to buy a colt, when they are risking only a little money, they are so cautious that, though the animal is almost bare, they won't close the deal until saddle and blanket are have been taken off, lest there be a hidden sore underneath. Yet in the choice of a mate, which may cause either delight or disgust for the rest of their lives, men are so careless that they leave all the rest of the woman's body covered up with clothes and estimate her attractiveness from a mere handsbreadth of her person, the face, which is all they can see. [...] Not all people are so

> wise as to concern themselves solely with character; and even the wise appreciate the gifts of the body as a supplement to the virtues of the mind. (189-191)

It seems clear that More simply thinks of the good relationship between the partners, rather than thinking of a biologically good match. Private property is abolished in Utopia, but persons are not considered a property, therefore marriages are protected as personal relationships, not as "goods" to be shared.

Divorces are allowed in Utopia – a matter on which More had to reflect seriously, later in his life. His liberal view on divorce, in *Utopia*, suggests that the subsequent dispute with King Henry VIII concerned the authority of the Pope and not divorce *per se*. Incompatibility of character can be the cause of a consensual separation, when approved by the senate after a careful investigation, although divorce is deliberately made difficult.

Adultery and "intolerably offensive behaviour" are severely condemned: the violator of the marriage is punished "with the strictest form of slavery" (p. 191) and a relapse into the same crime is punished by death (p. 193). In Utopia, slavery is generally considered a sufficient form of punishment; death penalty is only applied in the case of harsh rebellion or recidivism.

More's view on the family is thus a traditional one, albeit with some consideration for the feelings of the partners and with the awareness that a marriage can become intolerable for one or both of them. There exists no eugenics and no communality of women and children. Spontaneous stable relationships are considered a good thing for the city, but there is no absolute rule on this.

More's *Utopia* is quite realistic and traditional. It does not advocate a total control of social relationships and in particular of marriages and reproduction. Utopians are not expected to yield a "perfect" breed, and their marriages are based on individual choice rather than demographic policies. Moreover, no technology is implied in reproductive practices as a tool for social control, not even the calculus of the best time for matching, or the definition of "best matches". No eugenics can be allowed in Utopia and the provisions on marriage are conspicuously liberal in comparison with the customs of his time, leaving more room for individual free choice.

2. *The City of the Sun* and totalitarian control on reproduction

Tommaso Campanella's *The City of the Sun* (2009; *La città del Sole,* originally written in 1602) is much less liberal on reproduction. Sexual relationships are ruled by Mor, one of the Princes governing the town, together with "The Sun or Metaphysical", a supreme spiritual and temporal king with absolute power. Mor, which means Love (Amor), takes care of reproductive practices: "He sees that men and women are so joined together, that they bring forth the best offspring" (p. 15, original text: "*con unir li maschi e le femine in modo che faccin buona razza*").

Campanella repeats More's argument based on the analogy between choosing horses and human partners ("Indeed, they laugh at us who exhibit a studious care for our breed of horses and dogs, but neglect the breeding of human beings", *ibidem*), but gives it a radical twist. In fact, Campanella understands the analogy exactly in terms of a eugenic policy: More ensures that everything is appropriate – food, dresses and intercourse – so that "good" children are delivered. So, rudimental techniques are adopted in order to assure the perfect result in terms of "good breed".

Campanella says that the inhabitants of the City of the Sun arrived in their place from the Indies "flying from the sword of the Magi, a race of plunderers and tyrants who laid waste their country" (*ibidem*). Therefore "they determined to lead a philosophic life in fellowship with one another" (*ibidem*), introducing in their custom the commonality of women (which was not practiced in their homeland) and of any good. The argument against private property is presented by Campanella precisely as an extension of his critique of marriage:

> They say that all private property is acquired and improved for the reason that each one of us by himself has his own home and wife and children. From this, selflove springs. For when we raise a son to riches and dignities, and leave an heir to much wealth, we become either ready to grasp at the property of the State, if in any case fear should be removed from the power which belongs to riches and rank; or avaricious, crafty, and hypocritical, if anyone is of slender purse, little strength, and mean ancestry. But when we have taken away selflove, there remains only love for the State. (p. 16)

More would have strongly disapproved of this connection of marriage with private property. But Campanella was a monk, and his idea of commonality includes everything: women and children are "goods" rather than persons. Therefore, they are subject to a very strict control by the State.

Men procreate after the age of twenty-one, women from the age of nineteen. Sodomy is blamed and punished, but rather mildly, at the beginning. Punishment increases in the case of recidivism, and may even include the death penalty.

Young men and women exercise themselves naked, like the ancient Greeks. Meanwhile, their masters observe and decide who has to be matched with whom: "The big and beautiful women with big and virtuous men; and the fat women with slim men, and slim women with fat men, to create an equilibrium" (Italian edition, p. 46)[1]. The time and the ritual of mating is strictly regulated: it takes place every three nights. An astrologist and a physician determine the exact moment of the mating. Priests and wise men copulate less frequently, but they deserve "the most lively, healthy and beautiful women" (Italian edition, p. 47). Campanella declares openly that without natural dispositions there is no moral virtue. For this reason, the magistrates make the greatest possible effort to create a good breed.

Mothers breast-feed their children for up to two years, and then give them to the magistrates. All children are raised together: at the age of seven, they are instructed in the natural sciences, then in the other sciences and finally in "mechanics". The Metaphysic (not the parents) gives every child a name. The decisions of the magistrates are mandatory. If a couple falls in love, they can play and talk to each other, but they are not allowed to generate (p. 32).

The model for Campanella is Plato's *Republic*, and this text is specifically quoted in *City of the Sun*. Campanella is the first, in the utopian tradition, to connect the abolition of property with the abolition of marriage and with eugenics. Sentimental love is totally separated from generation, which is conceived as a "public good". The communality of women is not imagined as a freedom to form relationships without marriage. Rather, it is assumed that sex is for procreation only and that procreation is for the State. Persons are deprived of their sexual faculties rather than emancipated and granted sexual freedom. The utopian character of Campanella's *City of the Sun* focuses on the abolition of property and on the liberation from hard work and religious dogmas. Yet, social interaction is dominated by a complete control of relationships, which serves to promote biological perfection through genetic politics and through the use of rudimental "technologies" such as a definition of the number and ways of reproductive acts. The State regulates the reproductive life of all citizens in meticulous detail. Violation of these norms is severely punished, and this creates an atmosphere of terror. Campanella's utopia is thus a decidedly illiberal one. When it comes to reproduction, it bears strong similarities with the Platonic model. Using control, perfection as a goal, and technology as a tool, it can be defined as a totalitarian utopia, leading to a clearly dystopian society.

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[1] Some parts of the original text have not been translated in the English translation used. In these cases, I make reference to the Italian edition and translate the passages myself.

4. Reproduction in Francis Bacon's *New Atlantis*

Francis Bacon's *New Atlantis* (1999, originally published in 1627) also presents generation as a public good, although in a less eugenic and totalitarian way than Campanella. A great feast, the Feast of the Family, "is granted to any man that shall live to see thirty persons descended of his body altogether, and all above three years old" (p. 169). The feast is done at the cost of the State. The Father of the Family, called Tirsan, resolves tensions in the family, settles disagreements and helps those in need. He also chooses "one man from amongst his sons, to live in house with him: who is called ever after the Son of the Vine" (*ibidem*). The Tirsan's wife attends the ceremony in a separate place, without being seen. According to the custom of Bensalem, the capital of the New Atlantis, "the king is debtor to no man, but for propagation of his subjects" (p. 170). Only the sons can serve the Tirsan. The daughters wait close to the walls. Women are a marginal part of society. The narrator explains:

> And because propagation of families proceedeth from the nuptial copulation, I desired to know of him what laws and customs they had concerning marriage; and whether they kept marriage well; and whether they were tied to one wife? For that where population is so much affected, and such as with them it seemed to be, there is commonly permission of plurality of wives. To this he said, 'You have reason for to commend that excellent institution of the Feast of the Family. And indeed we have experience, that those families that are partakers of the blessing of that feast do flourish and prosper ever after in an extraordinary manner. But hear me now, and I will tell you what I know. You shall understand that there is not under the heavens so chaste a nation as this of Bensalem; nor so free from all pollution or foulness. It is the virgin of the world. I remember I have read in one of your European books, of an holy hermit amongst you that desired to see the Spirit of Fornication; and there appeared to him a little foul ugly Ethiop. But if he had desired to see the Spirit of Chastity of Bensalem, it would have appeared to him in the likeness of a fair beautiful Cherubin. For there is nothing amongst mortal men more fair and admirable, than the chaste minds of this people. Know therefore, that with them there are no stews, no dissolute houses, no courtesans, nor any thing of that kind. Nay they wonder (with detestation) at you in Europe, which permit such things. (p. 173)

Marriage, though, is not conceived as a personal relationship. Rather, it "is ordained a remedy for unlawful concupiscence; and natural concupiscence seemeth as a spur to marriage" (*ibidem*). Therefore, marriage is treated as a remedy for "a libertine and impure single life" which makes men marry too late, "when the prime and strength of their years is past" (*ibidem*). In Bensalem there is no "masculine love; and yet there are not so faithful and inviolate friendships in the world again as are there" (p. 174). Procreation is a serious business for the State, subject to strict regulation.

Polygamy is not tolerated. Marriage cannot take place before at least one month of mutual acquaintance. Couples can marry without permission from the parents, but in that case they loses any heredity. Bacon quotes More's provision of letting the couple see each other naked, but disapproves of it, because it would be difficult to refuse a person after such an intimate knowledge. Instead, in Bensalem "they have near every town a couple of pools (which they call *Adam and Eve's pool*) where it is permitted to one of the friends of the man, and another of the friends of the woman, to see them severally bathe naked" (p. 175). By this trick, in fact, social control of the couples is re-established, where More's provision foregrounded the couple's privacy and individual freedom .

Bacon's utopia is closer to More's than to Campanella's, which is closer to Plato's. Yet, it also treats reproduction as a public good, to be protected and controlled by the laws of the State.

Chastity is valued as a virtue, since it avoids the dispersion of the primal energy in men and thereby helps to increment the population. This shows that the goal of delivering a perfect descendance is paramount. In Bacon's *New Atlantis* there is no demographic policy which settles the average number of people living in the State. Stereotypical anti-feminism is sharply visible in the description of the role of women during the Feast of the Family. New Atlantis is a town for male scholars, who devote their life to science and whose families act as a support for their academic activity. Science and technology are the main goals of the State, as they are in Bacon's conception of knowledge and society. Bacon's utopia is a republic of knowledge. His text does not describe the forms of government, but, when it comes to reproductive practice, it advocates an illiberal stance. The combination of social control and technological drive makes Bacon's utopia far less liberal than More's model. Terror is not used to exert control, so New Atlantis is not a totalitarian utopia. Nevertheless, Bacon's emphasis on control, perfection and technology make it likely that his imagined State would evolve into a totalitarian society.

5. *Brave New World* as reproductive dystopia

Aldous Huxley's *Brave New World* (2000; originally published in 1932) takes some of these ideas to the extreme and creates a vision of generation which is a total nightmare. Huxley's novel belongs to a rich tradition of literary and political reflection aiming at showing the undesired outcomes of social engineering, especially through the use of technology. Examples of this tradition are the ambiguous *A Modern Utopia* by H.G. Wells (1905), Evgenij Zamjatin's *We* (1921), *Nineteen Eighty-Four* by George Orwell (1948 – a rather more "political" than "technological" dystopia, but where "thought control" by Big Brother has a preminent role) and *Fahrenheit 451* by Ray Bradbury (1953). Huxley's novel takes a prominent place in this tradition, both for its literary quality and for its clear-sighted depiction of a society dominated by social control, the search for perfection and a pervasive use of technology. Political control revolves around artificial procreation and sleep-learning in order to obtain individuals who are perfectly adapted to their role in a highly hierarchical society. Reproductive technologies are essential. From the very first lines of the first page, we are introduced into a cold, indifferent, mechanic world where reproduction is an industrial and totally impersonal activity:

> A SQUAT grey building of only thirty-four stories. Over the main entrance the words, CENTRAL LONDON HATCHERY AND CONDITIONING CENTRE, and, in a shield, the World State's motto, COMMUNITY, IDENTITY, STABILITY.
>
> The enormous room on the ground floor faced towards the north. Cold for all the summer beyond the panes, for all the tropical heat of the room itself, a harsh thin light glared through the windows, hungrily seeking some draped lay figure, some pallid shape of academic goose-flesh, but finding only the glass and nickel and bleakly shining porcelain of a laboratory. Wintriness responded to wintriness. The overalls of the workers were white, their hands gloved with a pale corpse-coloured rubber. The light was frozen, dead, a ghost. Only from the yellow barrels of the microscopes did it borrow a certain rich and living substance, lying along the polished tubes like butter, streak after luscious streak in long recession down the work tables.
>
> "And this," said the Director opening the door, "is the Fertilizing Room." (pp. 15-16)

We feel cold. But we are also confused about the purpose of this setting, until its meaning is made clear by the words "The Fertilizing Room". This expression says it all. Human reproduction is clearly not an event, or even an act. It is an industrial process, in an aseptic environment, guided by the logic of efficiency. Huxley's motto is bitterly hyperbolic: "Community, identity, stability" could be translated into: "State, uniformity, social immobility".

We still feel uneasy. We need an explanation, which comes when the Director of the Fertilization Centre begins his speed. His age cannot be guessed, since in this dystopic London of A.F. 632 people look about thirty until, at the age of sixty, a sudden decline happens and leads to a rapid death. Here are the words of the Director:

> "These," he waved his hand, "are the incubators." [...] "The week's supply of ova. Kept," he explained, "at blood heat; whereas the male gametes," and here he opened another door, "they have to be kept at thirty-five instead of thirty-seven. Full blood heat sterilizes." (pp. 17-18)

Suddenly, we begin to understand the contrast between traditional utopia and Huxley's narrative. The Director gives

> a brief description of the modern fertilizing process; spoke first, of course, of its surgical introduction–"the operation undergone voluntarily for the good of Society, not to mention the fact that it carries a bonus amounting to six months' salary"; continued with some account of the technique for preserving the excised ovary alive and actively developing; passed on to a consideration of optimum temperature, salinity, viscosity; referred to the liquor in which the detached and ripened eggs were kept; and, leading his charges to the work tables, actually showed them how this liquor was drawn off from the test-tubes; how it was let out drop by drop onto the specially warmed slides of the microscopes; how the eggs which it contained were inspected for abnormalities, counted and transferred to a porous receptacle; how (and he now took them to watch the operation) this receptacle was immersed in a warm bouillon containing free-swimming spermatozoa–at a minimum concentration of one hundred thousand per cubic centimetre, he insisted; and how, after ten minutes, the container was lifted out of the liquor and its contents re-examined; how, if any of the eggs remained unfertilized, it was again immersed, and, if necessary, yet again; how the fertilized ova went back to the incubators; where the Alphas and Betas remained until definitely bottled; while the Gammas, Deltas and Epsilons were brought out again, after only thirty-six hours, to undergo Bokanovsky's Process. (pp. 18-19)

The "Bokanovsky's Process" is essentially cloning, which is explained as follows:

> One egg, one embryo, one adult-normality. But a bokanovskified egg will bud, will proliferate, will divide. From eight to ninety-six buds, and every bud will grow into a perfectly formed embryo, and every embryo into a full-sized adult. Making ninety-six human beings grow where only one grew before. Progress. (p. 20)

When a foolish student dares to ask about the advantages of this arrangement, the Director reacts with astonishment:

> "My good boy!" The Director wheeled sharply round on him. "Can't you see? Can't you see?" He raised a hand; his expression was solemn. "Bokanovsky's Process is one of the major instruments of social stability!"
> *Major instruments of social stability*.
> Standard men and women; in uniform batches. The whole of a small factory staffed with the products of a single bokanovskified egg.
> "Ninety-six identical twins working ninety-six identical machines!" The voice was

> almost tremulous with enthusiasm. "You really know where you are. For the first time in history." He quoted the planetary motto. "Community, Identity, Stability." Grand words. "If we could bokanovskify indefinitely the whole problem would be solved."

Solved by standard Gammas, unvarying Deltas, uniform Epsilons. Millions of identical twins. The principle of mass production at last applied to biology. (pp. 21-22)

Now it is clear why Huxley's novel makes us uncomfortable. The whole process of reproduction is controlled by an *ideology*. This is the main difference between utopias and dystopias. The latter are the imaginative expression of an ideology: a scientific, systematic, theoretical construction translated into a political reality. Utopias are exercises of imagination which seek to explore what a good society would look like, but they are not a derived from fully developed theory. As Karl Mannheim (1953) has pointed out, ideology is opposed to utopia exactly because it pretends to be a scientific, empirical and theoretical conception of society, which leads to a necessary, controlled, and certified result. On the contrary, utopias are not theories: they are narratives, often imbued with irony and jokes (More notoriously was a fan of jokes). So, they are not to be taken too seriously. On the contrary, ideologies pretend to be the most serious of plans, and any irony is taken as dangerous dissent (see also Bagchi, 2012 for more on this point).

Ideology severs the relation between nature and the State. Nature is a nuisance. Not only fertility but also sterility are regulated to enable the the creation of rigid, genetic classes of individuals, who will later be conditioned by a mechanical, pedagogical system called "hypnopedia". Social stability is obtained through a system of ultra-rigid division into classes or castes. Nature is replaced by human invention.

> "For of course," said Mr. Foster, "in the vast majority of cases, fertility is merely a nuisance. One fertile ovary in twelve hundred–that would really be quite sufficient for our purposes. But we want to have a good choice. And of course one must always have an enormous margin of safety. So we allow as many as thirty per cent of the female embryos to develop normally. The others get a dose of male sex-hormone every twenty-four metres for the rest of the course. Result: they're decanted as freemartins–structurally quite normal (except," he had to admit, "that they do have the slightest tendency to grow beards), but sterile. Guaranteed sterile. Which brings us at last," continued Mr. Foster, "out of the realm of mere slavish imitation of nature into the much more interesting world of human invention." (pp. 31-32)

Social stability and well-being are guaranteed because some individuals are bred and raised in a permanent and accepted form of slavery, designed to increment consumption in every human activity, so that the market flourishes. This totalitarian society is the paradise of capitalists, since individuals are conditioned to love products and goods in every moment of their lives, also during free time. Huxley understands that extreme control, extreme social engineering and extreme consumerism are integral parts of a single social and political vision.

6. Dystopias as bad (i.e. totalitarian) utopias

Utopias and dystopias are different. They narrate the idea of a perfectly functioning State in different registers: a dream in the first case, a nightmare in the second. Moreover, they point to divergent ideas and have incompatible aims. Utopias want to sketch the general shape of a just and harmonious society, where good relationships and good living are the rule (Bloch, 2000). In utopias, the author attempts an imagination what such a society would look like but also indicates that this is not clear. Irony is a sign of this lack of clarity. Solutions can be bizarre, and are formulated as hypotheses, to be tested rather than realized dogmatically. In dystopias, on the contrary, the goal is to indicate what we certainly do not wish to happen: obsession with order and productivity, with regulation and hierarchy, the perversion of freedom into a totalitarian State. Dystopian authors point to the specific effects of certain ideas of a well-ordered State and denounce the risks of making too detailed plans for engineering a perfect society, especially where they are based on a pervasive and extreme use of technologies. In this sense, utopias and dystopias have a common goal: to alert us to forms of governance that we would wish to refuse. Utopias do this by designing an alternative State, dystopias by bringing to the fore the hidden totalitarian dimension of allegedly "perfect" societies.

Generation and human reproduction are imagined in worrying terms in both utopias and dystopias. Yet, More's *Utopia* (and similarly Bacon's *New Atlantis*) appear less obsessed with the control of reproduction for the good of the State. Families are, after all, a quite natural social structure, even if they are not the only or the best one. The idea of open, enlarged or new kind of families does not seem to be incompatible with these utopias, although it is far from the sensibility of their authors. Nevetheless, there appears to be no insurmountable contrast between rainbow families, which might rely on reproductive technologies, and a just and harmonious society. In utopias, freedom is a part of the project of a good society.

On the contrary, Plato's *Republic,* Campanella's *City of Sun* and Huxley's *Brave New World* appear to be founded on a rigorous control of reproduction through very strict policies. The well-ordered State, in this perspective, is one dominated by the separation of roles and by the total control of the behaviour of citizens. Technology is used to realize a "perfect" society. In this framework, when reproductive technologies make their appearance in the imagination of authors, i.e. when they start to seem feasible, the State power immediately takes control of all processes, and creates a society divided into genetically designed classes (or rather genetic types) of individuals who are structured and conditioned to function as a part of a mechanism. In this perspective, there is a natural slippery slope from illiberal utopias to dystopia. Technology immediately becomes a weapon of power and oppression or rather of social engineering.

The most significant difference, in other words, exists between *liberal (or humanistic) utopias* and *totalitarian* ones. This difference lies in the idea of the State: in the first case, it is a community of free individuals joining for mutual help and good living; in the second, it is a metaphysically based order, politically realized through ideas of necessity and control and often with the aid of reproductive technologies as a means of social engineering. The second kind runs very quickly into dystopia. The first seems to be far less exposed to such a risk.

It needs to be acknowledged that liberal States face the risk of reproductive dystopias created by the free market. This is a serious risk, and it calls for an intervention by the liberal State, in protection of the dignity and equality of all citizens. Ultra-libertarian States can become *de facto* totalitarian societies, based on the economic power of the "happy few". This is another reason why we need *good liberal utopias*: their vision of a harmonious and free society, and their desire to regulate the use of reproductive technologies must be a part of the picture.

We still need utopias. And it seems that the breaking point between utopia and dystopia, as far as reproductive technologies are concerned, *does not lie at all in technology per se*. It lies in a totalitarian, mechanic, metaphysical conception of the political realm: reproductive technologies in totalitarian utopias and in dystopias are tools of social control and of a suspicious idea of human "perfection" (Boym, 2001). But they are not necessarily dystopian *per se*. They become dystopian when associated with the goals of control and perfection.

Dystopias are the possible result of our social dynamics. But as long as we stick to the idea of the State as a community of free individuals (as it is in the liberal conception) there is no danger in imagining how a good society would function. Reproductive technologies can be a part of such a society, as imagined in good utopias, as long as they are a help to citizens rather than a weapon in the hands of a totalitarian State.

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BIRTH: STORIES FROM CONTEMPORARY LITERATURE AND FILM

abstract

Advances in reproductive medicine have opened up new scenarios, changing our experience and our understanding of what it means to be a parent. Literature and cinema have quickly turned their attention to new forms of reproduction, and often do what doctors in centres for assisted reproduction advise against: they reveal secrets, re-unite the various different protagonists, who make the new life possible, and explore the dramatic and sometimes tragic entanglement of birth stories. Significantly, literary and filmic stories also give voice to those whose voice is seldom heard: the children. In my contribution, after providing a brief summary of the history of assisted reproductive technologies, I discuss some contemporary novels and films, in English and Italian, that deal with these new scenarios. Examples include The Kids Are All Right *(2010) by American director Lisa Cholodenko,* Google Baby *(2009) by Israeli director Zippi Brand Frank,* Venuto al mondo [Brought into the world] *(2012) by Italian director Sergio Castellitto,* Carissimi [Dearest] *by Italian writer Letizia Muratori,* Non mi vendere, mamma! [Do not sell me, mom!] *(2016) by Italian writer Barbara Alberti, and* Katherine Carlyle *(2015) by British novelist Rupert Thomson. I argue that each birth has a story and that we cannot struggle free from the stories that make us any more than we can ignore the fact that we were brought into the world.*

keywords

assisted reproduction technology (ART) and literature, ART and cinema, motherhood, surrogacy, birth stories

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1. New scenarios – new dilemmas

Families are changing, as has always been the case.[1] Time passes, and old models are contested or simply give way to new ones. However, in the last forty years we have witnessed an entirely new phenomenon, propelled by advances in reproductive medicine as much as by new cultural paradigms. The emergence of increasingly sophisticated assisted reproductive technologies (ARTs) has brought about profound and astonishing changes, at a medical, legal, political, social and cultural level. These changes compel us to rethink what it means to be a mother, a father, a daughter, a son and a sibling. Advances in reproductive medicine have altered the very 'facts of life' through which babies were born and people became parents. "Nowadays", write Linda G. Khan and Wendy Chavkin, "producing a child can involve half a dozen people or more – commissioning parents, egg and sperm providers, surrogates, and even cytoplasm donors, not to mention medical personnel and agents for the various parts that may be needed to complete the act".[2] This proliferation of technologies has multiplied the number of the actors involved in human reproduction. It has also opened the severance of procreation from sex, thus dividing the act of procreation into distinct phases, each with its own risks, its own costs, its own hopes, its own tribulations.[3]

To explore these dilemmas, I will discuss a set of novels and films that deal with new scenarios that have emerged in the wake of ART. I have chosen two films, *The Kids Are All Right* (2010) by American director Lisa Cholodenko and *Venuto al mondo* [*Brought into the world*] (2012) by Italian director Sergio Castellitto, the documentary film *Google Baby* (2009) by Israeli director Zippi Brand Frank, and three novels: *Carissimi* [*Dearest*] (2019) by Italian writer Letizia Muratori, *Non mi vendere, mamma!* [*Do not sell me, mom!*] (2016) by Italian writer Barbara Alberti, *Katherine Carlyle* (2015) by British novelist Rupert Thomson. Before turning to these films and novels I will provide a brief summary of the history of assisted reproductive technology.

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[1] I am grateful to Rachel Bowlby and Aarathi Prasad for their precious suggestions and insightful comments on the first draft of this article.

[2] Linda G. Khan and Wendy Chavkin, *Assisted Reproductive Technologies and the Biological Bottom Line*, in *Reassembling Motherhood. Procreation and Care in a Globalized World*, edited by Yasmine Ergas, Jane Jenson, Sonya Michel, New York: Columbia University Press, 2017, p. 38.

[3] Some scientists have taken a step further and discussed the possibility, in the near future, of procreation without the co-presence of two genetic parents of different biological sex. On the topic of virgin birth – a widespread phenomenon in the animal kingdom, which could one day become the norm among humans – see the fascinating book by Aarathi Prasad, *Like A Virgin: How Science Is Redesigning The Rules Of Sex*, London: Oneworld Publications, 2012.

For many, ART began with Louise Brown, a baby who was born in England in 1978, thanks to a revolutionary technique invented by P.C. Steptoe and R.G. Edwards: *in vitro* fertilization (IVF). The embryo from which Louise developed was the first to have been created in a lab. Ms Brown's oocyte, extracted from the woman's body, was put together with Mr Brown's sperm in a Petri dish. Two and a half days later, the newly formed embryo was implanted into the woman's uterus. A pregnancy followed, with Louise delivered just over thirty-eight weeks later. IVF quickly became popular, and bypassed some frequent causes of female sterility: fallopian tube blockage, malfunctioning of the ovaries, difficulties caused by the advanced age of the intended mother. In IVF, ovaries are stimulated via hormonal treatment and encouraged to produce multiple eggs in a single cycle. The eggs (or rather the follicles in which they are contained) are then collected from the ovary via a chirurgical intervention and put together with spermatozoa. If the semen fertilizes the egg, the latter (now called embryo or pre-embryo) is implanted into the womb. Doctors, in agreement with the patient, may decide to implant more than one embryo to increase the possibility of success.

As Linda Khan and Wendy Chavkin point out, the birth of Louise Brown was not, in fact, the first case of medically assisted reproduction. Almost a century earlier, in 1884, a respected doctor from Philadelphia, William Pancoast, 'treated' a sterile couple by injecting the woman's uterus with a syringe of fresh semen that had been provided by a medical student. A pregnancy followed and nine months later a baby was born. During the following decades, this form of insemination became a common, albeit clandestine, 'cure' for male infertility in married couples. At the beginning of 1950s, experiments in the zoological sector lead to the discovery that semen could survive freezing and thawing. In 1953, the first successful human pregnancies were achieved using frozen (and duly thawed) semen. Soon after, the first semen banks opened, and the stigma around artificial insemination with third-party semen gradually lifted. But in 1992, a novel technique –intracytoplasmic sperm injection (ICSI) – brought about another revolution: a group of doctors found a way of injecting a single sperm, sperm head or nucleus, directly into the cytoplasm of a mature egg. This technique allowed men with low sperm count or qualitatively poor semen to father genetically related offspring. ICSI – which must always be combined with IVF – determined a drastic downsizing of the practice of sperm donation.[4]

At the beginnings of the 1980s, a new practice was introduced to circumvent the poor quality of some women's eggs and to increase the success rates of IVF: egg donation. In this process, a young woman donates her eggs, often in return for reasonable expenses, or, in countries in which it is legally permissible, sells them.[5] Eggs are then fertilized with the semen of the intended father or, in the case of a sterile father, with the semen of a donor, and the embryo is implanted into the uterus of the intended mother. If the implant is successful, the intended mother carries out the pregnancy, and thereby establishes a biological link with the foetus, even if the foetus is not genetically related to her.

The most controversial form of assisted reproduction, surrogacy, was also developed in the 1980s. This process specifically addressed the needs of women who could not carry out a

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[4] Like all technologies that manipulate genetic material, ICSI entails some risks. On the medical risks associated with ICSI, and especially on the risk of transmitting male sterility from one generation to the next, see Scott Gilbert and Clara Pinto-Correia, *Fear, Wonder, and Science in the New Age of Reproductive Biotechnology*, New York: Columbia University Press, 2017, p. 213.

[5] Many commentators have pointed out that 'donation' is, in most cases, a benign euphemism. The extraction of eggs is a chirurgical procedure, invasive and entailing risks, also because it presupposes heavy hormonal treatments. No woman would understandably submit to such a procedure for free, unless in cases of authentically altruistic donations to relatives or friends.

pregnancy, normally for medical reasons. In surrogacy, another woman offers to gestate the embryo. This second woman, the surrogate mother, can either provide the egg or 'merely' gestate the embryo, or the embryos, that were created with the gametes of the intended parents (or with donor gametes, where this is requested by the parents). In the former case, the process is known as 'traditional surrogacy' ("as though it came over with the Pilgrims", as American feminist Katha Pollit sarcastically wrote).[6] In the latter case, the terms 'full surrogacy' and 'gestational carrier' are used. Surrogacy can be altruistic, when it is not remunerated, or commercial, when it is regulated by a contract and remunerated. In all instances, the surrogate undertakes to carry the pregnancy to term and then relinquishes the child to the commissioning parents. This practice has prompted extreme reactions and seemingly irreconcilable responses. But it has also allowed gay couples and single men to father genetically related offspring.[7]

As technologies became more elaborate, new trends and variations emerged. Some lesbian couples, for instance, rely on an increasingly popular arrangement known as co-mothering. In this process, one partner contributes the egg, which is fertilized with donor sperm through IVF, while the other partner has the embryo implanted in her womb. In this way, one partner has a genetic link to the child, while the other shares a different biological link.[8] In a similar fashion, gay couples occasionally request that their semen is mixed before it is brought into contact with the donor's egg, as Liza Mundy reports. Some gay couples interviewed by Mundy arranged for at least two embryos to be created: one with each partner's semen. The assumption, in this case, was that the hired surrogate would agree to having both embryos implanted.[9]

As this brief overview suggests, many complex situations can arise from ART. Possibilities depend on legal frameworks. Surrogacy, for instance, is banned in some countries, and surrounded by legal uncertainty in other countries. Regulations and procedures need to be brought up to date on a regular basis, as new scenarios emerge. Some surrogacy contracts have ended up in court, or have attracted considerable media attention. There are, for instance, the well-known cases of Mary Beth Whitehead and Anna Johnson – the former a traditional surrogate, the latter a gestational carrier – who refused to relinquish the children that they had gestated.[10] Controversy also developed over the tragic case of Baby Gammy, a boy born to a Thai surrogate, whose parents refused to claim him because he had Down syndrome, and took home only his neurotypical twin sister.[11] Discrepancies in laws across nations have also

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[6] As Rachel Bowlby observes, the terms used to describe new reproductive practices are never neutral. See her *A Child of One's Own: Parental Stories,* Oxford: Oxford University Press, 2013, p. 41 and ff. From here I have taken Katha Pollit's quote (p. 36).

[7] The literature on the topic of surrogacy is vast. There are now several monographs devoted to the theme: Helena Ragoné, *Surrogate Motherhood: Conception In The Heart*, London: Routledge 1994; Elly Teman, *Birthing a Mother. The Surrogate Body and the Pregnant Self*, Berkeley: University of California Press, 2010; Amrita Pande, *Wombs in Labor: Transnational Commercial Surrogacy in India,* New York: Columbia University Press, 2014; Susan Markens, *Surrogate Motherhood and the Politics of Reproduction,* Berkeley: University of California Press, 2007. Among articles and book chapters, see: Claire Achmad, *Multiple "Mothers", Many Requirements for Protection*, in *Reassembling Motherhood*, pp. 55-75; Yasmine Ergas, *Pregnant Bodies and the Subjects of Rights. The Surrogacy-Abortion Nexus*, in *Reassembling Motherhood*, pp. 99-124; Anton Van Niekerk and Liezl van Zyl, "The Ethics of Surrogacy: Women's Reproductive Labour." *Journal of Medical Ethics* 21 (6), 1995: 345-349; Lucia Galvagni, "New motherhood? Embodiment and relationships in the assisted reproductive technology" in this issue.

[8] On the practice of co-mothering, see Liza Mundy, *Everything Conceivable. How Assisted Reproduction is Changing Men, Women, and the World*, London: Allen Lane, 2007, pp. 122-123.

[9] See Mundy, *Everything Conceivable,* p. 141 and ff.

[10] See Ergas, *Pregnant Bodies and the Subjects of Rights*, pp. 102-104.

[11] See Kahn and Chavkin, *Assisted Reproductive Technologies and the Biological Bottom Line*, p. 44.

lead to cases in which children born from surrogates cannot be given to their genetic parents, or else are not recognized as citizens in the countries of their commissioning parents.[12] Surrogacy brings to light and exacerbates social inequalities, which are also implicit in other forms of ART. At international level, there are stark discrepancies between national jurisdictions and social attitudes. In some countries, infertility is considered a disease. This entails that every infertile person has a right to medical assistance, at the expense of the national health service. Elsewhere, like in the United States, the medical practice of assisted reproduction is heavily privatized. There are countries where same sex parents, or single parents, are denied access to ART and others, where the rights of infertile couples have been extended to all who request assistance. Those with sufficient financial means and access to information can easily evade prohibition in their countries of residence, and seek help from medical centres that operate under a different legislation. This has inspired a growing global 'reproduction tourism', premised on obvious differences of class and means.[13] It is no accident, as Claire Achmad writes, that "international surrogacy markets have developed, particularly, in Global South states such as Thailand and India, with demand flowing predominantly from the Global North".[14] The same class divide can also be observed within specific regions of the Global North. Vicken Sahakian – a doctor practicing in Los Angeles who was interviewed by Liza Mundy – puts it with almost embarrassing candour: "If you are looking at beauty or physical features you're not going to find that in the surrogate pool. It's a fact. [...] Most egg donors are smart young girls doing it for the money to pay for college. Most surrogates are – you know, they need the money; they are at home, with four kids – of lower socio-economic class".[15] As biologist and writer Clara Pinto-Correia eloquently comments: "Much still needs to be done if surrogacy is ever going to become a healthy part of any social fabric. In the United States alone, 30 percent or more of gestational carriers are poor black women servicing well-to-do white couples. The couples often have many more resources available to them than the women gestating the embryos."[16]

Advances in ART have resulted in the birth of millions of children who would otherwise not have been born. But they have also triggered numerous controversies. Surrogacy, in particular, inspired heated debates, but disagreement is by no means confined to this particular process. Almost every aspect of ART creates new dilemmas, just as it creates new babies. The practice of implanting several embryos in the uterus of one woman, for instance, has dramatically enhanced the success rates of IVF. But is it ethical to induce multiple pregnancies, given the higher risks for women and foetuses? Studies have demonstrated exceptional levels of support and love among gay parents, and suggest that gay households, in particular, hold the power to educate a new generation of children to positive models of post-patriarchal masculinity and femininity. But is the desire to father genetically related children a good enough reason to recur to the controversial, and often exploitative, practice

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[12] See, for instance, the cases covered by these news reports: http://news.bbc.co.uk/1/hi/world/south_asia/7544430.stm (last accessed on 12 October 2020).
https://uk.reuters.com/article/us-foundation-statelessness-surrogacy/international-surrogacy-traps-babies-in-stateless-limbo-idUSKBN0HD19T20140918 (last accessed on 12 October 2020).

[13] As Charis Thompson puts it, "the technologies might themselves be a site for class and other differentiation and mobility." (*Making Parents. The Ontological Choreography of Reproductive Technologies*, Cambridge, Mass. and London: MIT Press, 2005, p. 8. See also p. 66 and ff.). On the progressive commercialization of 'the baby industry', see Debora L. Spar, *The Baby Business: How Money, Science, and Politics Drive the Commerce of Conception*, Boston: Harvard Business School Press, 2006.

[14] Achmad, *Multiple "Mothers", Many Requirements for Protection*, p. 56.

[15] Mundy, *Everything Conceivable*, p. 133.

[16] Gilbert and Pinto-Correia, *Fear, Wonder, and Science in the New Age of Reproductive Biotechnology*, p. 112.

of surrogacy? Would it not be preferable to campaign globally, internationally, to make the practice of adoption more efficient, and more easily available to gay parents?
Is donor anonymity desirable? Have the offspring a right to know how they came into the world? Or should their parents be allowed to fashion their own story? In *Fare figli. Storia della genitorialità dagli antichi miti all'utero artificiale*, Carlo Flamigni and Carlo Bulletti – two of Italy's leading experts in the physiopathology of reproduction – note, with apparent satisfaction, that many couples choose to interrupt any contact with the birth clinic as soon as the much-desired baby is born. Everyone has played their part – male donors, female donors, gestational carriers – and it is only appropriate, according to the two authors, that everybody should now step back and let the social parents enjoy their new life with the child. Bulletti and Flamigni write:

> Allo stesso modo, pensiamo che il problema del segreto sia un falso problema: non è difficile spiegare a un adolescente che è importante solo colui che ha preso la decisione di farlo nascere (e se n'è assunto la responsabilità) e conta invece meno di zero chi ha fornito il programma genetico, oltretutto insignificante per quanto riguarda la sua struttura di uomo.
> [Similarly, we think that the problem of anonymity is a false problem: it is not difficult to explain to a teenager that there exists only one person who matters: the person who took the decision, and assumed the responsibility for his or her birth. The person who provided the genetic code, by contrast, counts less than zero and is, moreover, insignificant as regards his or her human structure].[17]

Are Bulletti and Flamigni justified to claim that the multiple dilemmas associated with ART are merely 'false problems'? To answer this question, I will now turn to some novels and films, from different national contexts. The United States, Britain, Italy and Israel mark four very different environments for ART, culturally, juridically, and politically. The United States are often described as the cradle of reproductive freedom, notwithstanding stark discrepancies between the various states. By contrast, Italy, where matters of assisted reproduction have been regulated since 2004 by the so called 'Legge 40', is home to one of the most restrictive legislations in Europe.[18] The UK appears to occupy a middle ground,[19] between the many prohibitions of the Italian law and the loose rules of the American system, where medicine is

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[17] Carlo Bulletti and Carlo Flamigni, *Fare figli. Storia della genitorialità dagli antichi miti all'utero artificiale*, Bologna: Pendragon, 2017, p. 137, my translation. Flamigni's and Bulletti's opinion is not uncommon among practitioners working in the field. The sudden abolition of anonymous donorship in the UK, in 2005, has provoked the indignant reaction of many doctors. Ian Craft, one of the best known IVF doctors in England, has been vocal in protesting the new law, pointing out that this unwarranted intrusion by the State into the private domain of parental decision-making will have the effect of enhancing fertility tourism: those who are able to afford it will visit Cyprus, Ukraine or Romania to buy eggs 'donated' by women in those cash-poor countries, usually under unregulated conditions. Many individuals or pro-choice organizations have protested in countries (like Sweden, Austria, Switzerland, parts of Australia), where a compulsory disclosure policy has been enacted. See Mundy, *Everything Conceivable*, p. 181 and p. 188.

[18] Since 2009, various rulings of the Constitutional Court have dismantled some of the prohibitions that Legge 40/2004 had imposed: the prohibition to produce more than three embryos (with the attached imposition to implant all the embryos produced); the prohibition to recur to third-party donation; the prohibition to cryopreserve the embryos in excess; the prohibition to request pre-implantation diagnosis. See Letizia Palumbo, *The Borders of Legal Motherhood. Rethinking Access to Assisted Reproductive Technologies in Europe, in Reassembling Motherhood. Procreation and Care in a Globalized World*, p. 76.

[19] In the UK assisted reproduction is regulated by the Human Fertilisation and Embryology Act 2008, a substantial revision of the Human Fertilisation and Embryology Act 1990 that first regulated these matters.

granted a much greater degree of self-regulation, but where, alas, "assisted reproduction is often not science but business", as ob-gyn David Keefe, interviewed by Liza Mundy, puts it.[20] Israel, on the other hand, ranks highest in ART financing and legislation: the national health insurance covers nearly all fertility treatments, at least twice per couple. Surrogacy is legal, but regulated by strict guidelines, and it is mandatory to keep systematic records of every procedure.[21] In addition to these contextual differences, there are considerable variations in style, artistic quality and political orientation, between the films and novels that I have chosen. Nevertheless, they all explore the moral complexity that lies at the core of many situations generated by ART. And they focus their attention on what Bulletti and Flamigni urged their readers to avoid: entanglement. Indeed, all novels and films probe the dramatic and sometimes tragic connectivity of birth stories. They reveal secrets, and re-unite the various agents who made the new life possible. Finally, they give voice to those who are at the centre of every drama, but whose voices are rarely heard: the children.

2. Secrets unveiled

Lisa Cholodenko's film *The Kids Are All Right* (2010) imagines what happens when the children of a lesbian couple decide to go in search of their sperm donor. Each mother chose to give birth to one child, using the same donor. Now the two children – an eighteen-year-old girl and her fifteen-year-old brother – agree to contact the medical centre that assisted their mothers. They receive permission to contact the donor, and arrange a meeting. The first encounter with the genetic father is awkward, but not unpleasant, and the three decide to meet again. Unbeknownst to the two mothers, a new bond is forged, and, in a sunny and libertarian Californian setting, the man and the two teenagers become friends. When the children finally confess to their mothers, the women react with shock and confusion. The director – herself a lesbian and a mother, thanks to artificial insemination – narrates this emotional turmoil with great subtlety. Paul, the genetic father, is invited home. "Let's pretend to befriend him and then let's put him to sleep", suggests Nic, the woman who appears to be in charge of family decisions. But things take a very different turn. Paul spontaneously offers a job to Jules (the other mother) and develops a crush on her. Jules and Paul, confused and incredulous, end up in bed together. When their affair is discovered, the children rally around their betrayed mother, and Jules, repentant, asks for forgiveness. When Paul, also dismayed, knocks at the door of the large family home, Nic gives him a memorable lesson about parenting: a sperm donor is not a father, and the labour of parenthood is very different from masturbating in a medical laboratory.

The Kids Are All Right affirms the importance of social parenting: a practice that is based on commitment, love, and responsibility, and that no biological bond can either guarantee or replace. This is a claim that has been frequently made in literature and film, from Charles Dickens' *Oliver Twist* and *Great Expectations* to Carlo Collodi's *Pinocchio* and Charlie Chaplin's *The Kid*. Cholodenko's film, however, also testifies to other needs. It explores the children's wish to spend time with a man who is not their father, but who, at the same time, is no longer simply 'the donor'. Also, there is Paul's desire to belong: an emotion that remains difficult to narrate, because what lies between *donor* and *father* is a whole spectrum of human relations that are not taken into account by the medical jargon of reproductive technology. Despite Flamigni's and Bulletti's confident assurance, anonymity is *not* a false problem. As many novels and films

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[20] Mundy, *Everything Conceivable*, p. 332.

[21] Gilbert and Pinto-Correia, *Fear, Wonder, and Science in the New Age of Reproductive Biotechnology*, p. 189.

teach us, secrets are difficult to keep, but truths, when revealed, are impossible to ignore.[22] The novel *Carissimi* (2019), by Italian writer Letizia Muratori, narrates precisely this impossibility. Nurit is an eighteen-year-old Israeli girl, who was told on her seventh birthday that she was born through artificial insemination. Her biological father, Giorgio Amati, has recently passed away, and prior to his death he and Nurit shared an intense correspondence. Nurit now wishes to reconstruct Giorgio's life and the story of his family. She works on a documentary, which she sees as a way of expanding her own life story, and making sense of it. In an interview, Muratori explains that her novel

> non racconta la famiglia, ma l'invenzione della famiglia. Nurit somiglia un po' a quei ragazzi che a un certo punto della loro vita si inventano di essere stati adottati. La ragazza ha una famiglia e ha un donatore. Si sente, scrive, "creata" più che generata, e il donatore, malgrado sia realmente esistito, resta prima di tutto la sua invenzione, la sua fuga, non c'è mai il desiderio di conoscere i suoi consanguinei in quanto tali. Il sangue in questo libro, come in tutti i miei libri, conta davvero pochissimo.
> [does not tell the story of a family, but the story of the invention of a family. Nurit is a bit like those teenagers who invent that they were adopted. She has a family and she has a donor. She feels that she has been "created" rather than conceived. The donor exists, but for her he remains above all an invention, an escape route. She is never really interested in the blood relation, as such. Blood counts very little in this book, as it does in all my other books].[23]

Nurit is perfectly happy with her own family and does not care about blood ties. What interests her is not the biological father *per se*, but the story, or rather the stories, of his life. Nurit is aware that somewhere between Rome, Turin, Haifa and Jerusalem, her own life intersected with these stories. This is the plot that Nurit wishes to unveil. *Carissimi* narrates the challenges of multiple parenting in a serene and playful manner and thereby asserts a fundamental right: a daughter's right to her own story.

Joni and Laser (the children in Cholodenko's film) and Nurit capture a mood that is not uncommon among ART offspring. Their stories raise an important question: do children have a right to the true story of their origin? Are they entitled to know the identity of their donor? Do parents have a right to fashion their own story, on the assumption that they know best what is good for their children? Should donors be allowed to preserve their anonymity? Certainly, most actual donors do not envisage any personal involvement in the lives of dozens of teenagers, scattered around the globe. But why would contact necessarily lead to unwelcome involvement? Liza Mundy's interviews with donor-conceived children reveal, unsurprisingly, that not everybody feels the same way. Some children burn with the desire to know their donor, others are less keen, and a majority would like to meet their siblings or half-siblings. Many parents feel that contact between their children and the donor would need to be accompanied by some counseling. The discrepancy between views and individual expectations suggests that we are undergoing a process of profound anthropological transformation, and that everyone – parents, children, donors – benefits from open dialogue. This idea inspires associations such as the Donor Conception Network, founded by Olivia Montuschi in 1993,

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[22] On the explosive force of secrets in some classical parental stories, see Bowlby, *A Child of One's Own*, especially chapter 12.

[23] Letizia Muratori in conversation with Elena Marinelli, "Un romanzo epistolare per raccontare l'invenzione della famiglia", Il Libraio.it, 6 October 2019, available online at https://www.illibraio.it/carissimi-letizia-muratori-1127285/, (last accessed on 12 October 2020), my translation.

or the Donor Siblings Registry, founded in 2000 by Wendy Kramer. Both networks have done much to encourage open, civil debate and to assist families.[24] Article 8 of the United Nations Convention on the Rights of the Child (1989) affirms the child's right "to preserve his or her identity, including nationality, name and family relations". Personal integrity presupposes the right to preserve the memory of the place where we were born, of the nationality that was conferred to us, of the personal relations that brought us into the world. Medicine is changing the ways in which many families are formed. I do not think that it is possible, or indeed desirable, to simply erase any of the relations that have allowed the creation of specific families. If we are to welcome with joy the new lives that ART has made possible, we must also aim to preserve their stories.[25]

3. Mothers

The social and legal practice of surrogacy presupposes that different maternal functions (providing the egg, gestating the foetus, raising and loving the child) may be split among various women, and that only the latter activity (raising the child and loving them) is what makes a woman a mother. Things need further adjustment in the (now very frequent) cases of two male commissioning parents. In these cases, there will be no mother at all, and parental responsibilities and affects are distributed within the same-sex couple. In traditional surrogacy, artificial insemination is used to impregnate the surrogate with the intended father's sperm. Over the years, and with the advent of IVF, this practice has increasingly given way to so-called full surrogacy, in which the surrogate gestates an embryo that has been created *ad hoc*, if possible with the intended parents' gametes. Today, the most common 'job' of commissioned surrogates is thus 'simply' to gestate the foetus. A full discussion of the numerous political and ethical debates and the multiple arguments in favour or against this practice would exceed the scope of this article. Instead, I shall proceed to explore, through a set of case studies, how literature and film have approached this complex cultural phenomenon.

In 2009, Israeli director Zippi Brand Frank directed a documentary film, *Google Baby*, which narrates the activity of the Akanksha Hospital in Anand, Gujarat, India: probably the most famous surrogacy hospital in the world.[26] The title refers to the film's main plot: Doron, a gay Israeli entrepreneur, has recently become a father and wishes to help his friends, who cannot afford the cost of an American surrogate. He contacts Dr Nayna Patel, the director of the Indian clinic, to set up a business that will allow Israeli clients to buy eggs in America, have them fertilized with semen shipped from Israel, and finally have them implanted in an Indian surrogate mother. As the title suggests, these programmed pregnancies involve a lot of internet surfing and international Fedex shipping, as ways of reducing 'production costs'.[27] The film documents the life of the surrogates employed by the Akanksha Hospital, who, during the nine months of their pregnancy, live in a shared house next to the clinic, lying

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[24] See Mundy, *Everything Conceivable*, p. 176 and ff.

[25] This is the position of the recent Report of the International Bioethics Committee on assisted reproductive technologies (ART) and parenthood (2019). The full text of the Report is available at https://unesdoc.unesco.org/ark:/48223/pf0000367957 (last accessed on 12 October 2020). See in particular § VI.2.1 Best interests of the child. For an analysis of the Report, see Laura Palazzani, "Reproductive technologies and the global bioethics debate: a philosophical analysis of the Report on ART and parenthood of the International Bioethics Committee of Unesco" in this issue.

[26] *Google Baby*, produced by Brandcom Productions in 2009, was first broadcast in the USA, and subsequently in the UK on Channel 4. It is now available, for free, on YouTube https://www.youtube.com/watch?v=pQGlAM0iWFM.

[27] In Patel's hospital, foreign clients pay approximately $30,000 (Indian clients pay 20 percent less), while surrogates receive between $2,500 and $5,000: a wage for their gestational labour which works out as an hourly rate of approximately $0.5. See Sophie Lewis, "Surrogacy as Feminism: The Philanthrocapitalist Framing of Contract Pregnancy", *Frontiers: A Journal of Women Studies*, Vol. 40, No. 1 (2019), p. 29.

mostly in bed, in rooms for eight women or more. This seclusion serves many purposes: it protects the women's privacy, saves them from the potential criticism of neighbours and relatives, and ensures that certain clauses of their contracts are respected (an adequate dietary regime, abstinence from sexual intercourse during the surrogate pregnancy, etc). In several highly publicized interviews (from *The Oprah Winfrey Show* in 2006 to *Hard Talk* in 2013, the English BBC World talk-show hosted by Stephen Sackur), Nayna Patel has strenuously defended the work of 'her' surrogates, and has described their employment as a dignified and well remunerated job that allows families to escape poverty and eventually to buy their own homes: "much better than a laborer, construction-work or a maid", as Patel puts it. Another slogan that Patel frequently reiterated is "one woman helping another woman": one woman gets a baby, another woman gets the money that is necessary to buy a house or guarantee a better future for her children.[28] *Google Baby* demystifies both myths. In the documentary, there is no trace of sisterly solidarity. Only one surrogate is ever shown in a meeting with the future mother of the child that she has agreed to gestate, and in this scene arrangements are discussed and the contract is signed. While the surrogate, sitting next to her husband, listens in silence, Patel, with the brisk self-assurance of the "philantrocapitalist" – as Sophie Lewis puts it – monopolizes the conversation and explains in brutally simple terms the rationale of the arrangement: "You get a baby and you get to a buy a house". For much of the duration of the documentary, the surrogates are shown in a recumbent position: lying in bed while dozing or watching TV, or sprawled out on the operating table, anesthetized and semi-unconscious. The viewer struggles to recognize in them any form of agency (unless one considers pregnancy as one of the highest forms of agency). The hospital manager, by contrast, appears to overflow with a sense of agency. In one of the film's opening scenes, we see Patel answering phone calls to set up business arrangements, while she cuts into the body of one of her surrogates on the operating table. After the baby has been extracted, we see the surrogate silently sobbing and Patel asks: "Why are you sad? You must be happy, you have done a good job". Through overlapping sequences, the film provides insights into the lives of the various actors involved: the egg donor from Tennessee, the commissioning couple in Tel Aviv, the surrogates in Anand. In this way, the film highlights the caesura between the different aspects of a pregnancy on which surrogacy is premised. Multiple lives are assembled together in a puzzle that is orchestrated by skillful managers, in what Charis Thompson has called "the ontological choreography of reproductive technologies". The clear separation of roles, and of the various actors who are involved in assisted procreation is, after all, one of the operating principles of surrogacy. Like many doctors working in the reproductive sector, Patel has praised the principle of disjunction: a clear separation of roles, according to her, improves the overall process. Protesting against the recent abolition of international surrogacy in India, Patel underlines its main advantage: when there is an ocean between surrogate and parents, the risk that the surrogate may one day "come knock at your door" decreases dramatically.[29]

Having mothers or children 'knock at your door' is what literature does particularly well. Many literary texts narrate stories of children who are born of one woman and raised by another, only to be reclaimed, sometimes with tragic consequences, by the original mother.

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[28] Allegedly. Sophie Lewis argues that the wage earned by the surrogates is definitely not enough to buy a house. See Lewis, "Surrogacy as Feminism: The Philanthrocapitalist Framing of Contract Pregnancy", p. 26.

[29] At its peak, surrogacy in India was estimated as a $400 million to $500 million annual business. In the last seven years legislation governing this sector has undergone radical changes. In 2013 commercial surrogacy for foreign homosexual couples and single parents was banned. In 2015 commercial surrogacy was banned altogether. Shortly after, in 2016, a Surrogacy Bill was introduced, proposing to allow only compassionate surrogacy and to limit its access to heterosexual Indian married couples. Some more steps are requested before the Bill becomes a law.

There are numerous versions of this story, from Sophocles' *Oedipus Rex* to Shakespeare's *The Winter's Tale*, and all the way into our present. It has been argued that surrogate motherhood is as old as literature itself, and that it has existed since time immemorial. In *Genesis*, we find at least two relevant narratives: first, the tale of Abraham, Sarah and the servant Hagar, who is asked by the barren Sara to give birth to a child 'for her'; secondly, the story of the two sisters Rachel and Leah, both lovers of the same man, Jacob, and his wives at different moments in time. In *A Child of One's Own*, Rachel Bowlby offers a beautiful and compelling analysis of both stories, and notes, in passing, that "neither of these stories is remotely a happy one".[30] In these biblical stories of surrogate motherhood there is neither a clear separation of roles, nor the contractual clarity of today's arrangements that cleanly assigns roles, costs, wages. Roles get mixed up, Hagar and Sarah become rivals, God seems to side with Hagar, the surrogate, Abraham finally names Hagar's son and takes the full role of father. Until she manages to beget a son herself (at the venerable age of 90), Sarah, the commissioning parent, is pushed out of the picture. Rachel's and Leah's story is just as messy: here the begetting of children through surrogate servants (a method to which both sisters recur, even though only Rachel is afflicted with sterility) becomes a way of perpetuating the ancestral rivalry between the two sisters. As Rachel Bowlby puts it, here "surrogacy is neither a solution nor a disaster; it brings neither completion nor calamity for anyone. And as a strategy, it is simply self-perpetuating: one sister's use of the practice leads to the other one doing the same thing." (p. 54).

As these examples suggest, literature typically explores the political and ethical challenges of surrogate motherhood by enfolding the two mothers in one story. As a fictional character, the surrogate is granted a history of pain and suffering, which becomes interwoven with the life-stories of the social mother and the child. Cinematic treatments of the theme, by and large, appear reliant on the same established narrative format. It is therefore perhaps no accident that the most brutal depiction of a caesura of the emotional bond between surrogate mother and child can be found in *Google Baby*: not a work of fiction, but a documentary. Zippi Brand Frank shows the surrogate lying immobilized, anesthetized and sobbing on the operating table, while a busy nurse leaves the room with the child, on Patel's order: "Take it to its mother!".

The film *Venuto al mondo* (2012), directed by Italian director Sergio Castellitto, is based on a novel of the same name by Margaret Mazzantini. It narrates a drama of motherhood and surrogacy against the tragic background of the Yugoslav civil war. In the film's opening scene, Gemma, a middle-aged Italian woman, receives a phone-call from Sarajevo. Gojko, an old friend, invites her and her fifteen-year-old son Pietro to visit a photographic exhibition about the Yugoslav wars, which ended ten years earlier. The exhibition, he explains, will feature photographs by Gemma's beloved husband Diego, who died in Sarajevo during the war. Castellitto's film hence interweaves three different temporal layers: the present – the end of the first decade of the Twenty-first century, Gemma's first trip to Sarajevo in 1984, and her experiences during the early 1990s. *Venuto al mondo* looks back to the passionate love story between Gemma and Diego, which begins in Sarajevo during the 1984 Winter Olympics. In 1991, the two – now husband and wife – return to Sarajevo in order to mend their relationship, which has been damaged by a long and vain pursuit of pregnancy: Gemma has discovered that she is infertile. In a city on the brink of catastrophe, Gojko introduces them to Aska, a young musician who dreams of moving to London and offers, for money, to lend her womb. A planned artificial insemination fails because the responsible doctor has left the city at the first signs of war. But the three decide to carry out their project anyway. Diego and Aska shelter in a farmhouse on the outskirts of Sarajevo, while Gemma nervously wanders around. One hour later, we see Diego

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[30] Bowlby, *A Child of One's Own*, p. 52.

leave the house, evidently shocked. He tells Gemma that he could not do it. The couple flies back to Rome to resume their life together, but it soon becomes clear that Diego has lost his peace of mind. One morning, unbeknownst to Gemma, he returns to Sarajevo. Gemma enlists in a peacekeeping mission and, after weeks, reunites with Diego and some old friends in Sarajevo, now a besieged city. Gemma accidentally observes Diego as he brings food to Aska, who is visibly pregnant. He finally 'confesses', and some months later Aska gives birth to Pietro in a ramshackle hospital, while the bombs keep falling. The Italian mother receives her baby and Aska her pay. In the following sequence, we see Gemma board a UN airplane, with the baby and a fake birth certificate, while Diego, pretending to have lost his passport, unexpectedly stays behind. A few months later, the news of Diego's death reaches Gemma in her flat in Rome: the messenger speaks of an accident, but to Gemma it sounds like suicide.

Only in the final scenes of Castellitto's film – a dramatic encounter between Gemma and Aska – the whole truth is brought to light. On that tragic afternoon, sixteen years earlier, a group of Serbian soldiers had broken into the house where Diego and Aska had sheltered to make love. The soldiers repeatedly raped Aska, after killing the other male inhabitants of the house, and finally carried her away, while Diego, hidden behind a curtain, witnessed the whole scene. Aska tells Gemma how Diego, tormented by feelings of guilt, returned to Yugoslavia to look for her, and how he finally paid a ransom to liberate her from captivity by the same Serbian soldiers. Gemma discovers, at last, that her husband only told her a very partial and misleading truth.

Pietro is not the son of the man whose memory Gemma continues to venerate, but a child of the war. And indeed, the boy has always refused to think of himself as Diego's son. He sees Gemma's second husband as his real father: an Italian police officer, who, fifteen years earlier, took care of Gemma and her baby at a military airport in Rome, and who later married her.

In an interesting and unsettling display of metafictional self-reflexivity, Sergio Castellitto (who in the film plays the police officer, Gemma's second husband) casted his own son, Pietro Castellitto, as Pietro. Consequently, the actor playing Pietro looks remarkably like the actor playing his social father, Gemma's second husband (i.e. Sergio Castellitto, who in real life is the young actor's father). The effect on the spectator is startling: Pietro, whom Gemma erroneously believes to be Diego's son, likes to imagine himself as the biological child of his social father. He is in fact the son of a Serbian rapist, but looks very much like the father whom he has 'chosen' for himself, and thus invites the audience to consider the entangled stories that often surround biological life. With tragic irony, the film narrates how Aska loses control over her body, which she initially treats as an asset that can be traded for a better life, and which subsequently becomes the site of brutal dispossession. Human bodies are at the centre of Castellitto's narrative: from the erotic passion that overwhelms Gemma and Diego to the terrible discovery of Gemma's sterility; from Aska's carefree sensuality at the beginning of the film to her violent objectification at the hands of the soldiers, who laugh at the fact that they have filled her body "with their shit". Finally, there is also Pietro's body, which we see emerge from Aska's womb, wrapped in a wrinkled umbilical cord, and which we encounter again, fifteen years later, in the shape of a young man standing next to his mother, Gemma. Pietro is the new life that has come into the world ("venuto al mondo"). His existence gives a hopeful meaning even to the darkest moments of Castellitto's narrative, at least in retrospect. Pietro is therefore both the sum of everybody's individual choices and the consequence of a brutal act of violence, yet his birth marks an unpredictable triumph of vitality. His existence marks the mystery of life itself, beyond individual choices, and beyond evil itself.

Young, funny, lovable Pietro reminds us that the ultimate outcome of surrogacy is marvelous. Castellitto, however, does not allow us to forget that surrogacy is more than just a transient 'enabling' process. With melodramatic figurativeness, his film substitutes the planned surrogacy with a brutal act of rape, and thereby underlines that even the former practice leaves marks on real bodies: effects that do not simply vanish with the birth of the child. When Aska and Pietro finally meet again, at the end of the story, they seem light years away from the day when Pietro emerged from Aska's body, in a ramshackle hospital. Pietro ignores who Aska really is and Aska is happy to keep silent about her identity, while she looks in admiration at the handsome young man whom she delivered sixteen years earlier. Aska lives now with her new partner (Gemma's friend Gojko) and their daughter on the small, beautiful island, where she and Diego took refuge many years before. This is also the place where, subsequently, Diego committed suicide. But the world that Gemma, Pietro, Aska, Gojko, and their many friends now inhabit is a new world. While Pietro converses with his teenage half-sister, unaware of their relation, the camera frames for a second a tattoo on Aska's neck. It is not actually a tattoo, but a burn scar, which one of the rapists inflicted on her with the butt of a cigarette. After rescuing Aska, Diego had transformed the bruise into a tattoo, giving it the shape of a flower. In one of the final scenes of Castellitto's film, the camera frames the tattoo on Aska's neck, because it has attracted Gemma's attention. The frame only lasts for a brief moment, then the camera moves on. Gemma does not know what the tattoo conceals, even if she has now just learned the truth about Aska's tragic story. In a couple of hours, Gemma and Pietro will leave, and return to Italy. This powerful last sequence, then, shows once again how the many threads of Pietro's birth story are infinitely entangled. Gemma, Aska and Pietro do not share the same memories, and their stories of suffering and joy diverge, but at least they are allowed, perhaps for the last time, to unite in the same space.

In her novel *Non mi vendere, mamma!* (2016) Italian journalist and writer Barbara Alberti treats the theme of surrogacy in a deliberately politicized style. *Non mi vendere, mamma!* reads more like a pamphlet than a novel, starting from its revealingly programmatic title. The book tells the story of a surrogate pregnancy, with all the indignation that tends to characterize the Italian debate on this topic. The surrogate mother is a young woman, who grew up in an orphanage and is exploited by her mean-spirited boyfriend. This caricature-like crook does not hesitate to force her into prostitution to pay his gambling debts. The couple in search of a surrogate mother is also heavily caricaturized, not least through its family name, Trump. The commissioning mother, Ms Trump, is a swimsuit model and does not want to ruin her figure with a pregnancy. Her husband is a ruthless tycoon, who wants a male heir for his financial empire. The plot unfolds, quite predictably, until the foetus' little voice is heard, talking to his mother from inside the womb. He is, it turns out, a wonderfully cultured and eloquent foetus, who entertains his surrogate mother during long, sleepless nights by reciting William Blake and Marina Cvetaeva, or the fables of Charles Perrault. Chico (as the surrogate names him) refuses to consider her simply her 'carrying' mother, as if she were a vehicle. For him, she is, purely and simply, *mamma*. The young woman protests that she is not, in fact, his mother, that he was made with the Trumps' gametes:

> – Ma che vuoi tu, che non sei manco figlio mio?
> – Già... Vaglielo a dire, al corpo. Vaglielo a dire, all'anima. Ma come, mi tieni nove mesi dentro di te e poi chi si è visto si è visto? Mi dai via? Io non sono in prestito! Che brutto tiro... concepito per essere venduto. Io e te siamo una cosa sola, respiriamo insieme...
> – Ma ovulo e spermatozoo sono dei Trump!
> – Ma tu sei mia madre.[31]

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[31] Barbara Alberti, *Non mi vendere mamma!*, Rome: Nottetempo, 2016, p. 45 (my translation).

> [–What do you want from me? You are not even my son!
> –Well... Go and tell the body. Go and tell the soul. You keep me for nine months inside you and then... who cares about the rest?! Will you give me away? I am not for borrowing! What a bad joke... to be conceived only to be sold. We are one and the same thing, we breathe together...
> –Egg and sperm came from the Trumps!
> –But you are my mother.]

It turns out that the foetus is magical, with an array of superpowers at his disposal. To entertain and educate his surrogate mother, he projects in her mind the films of his favourite directors: Charlie Chaplin, Federico Fellini and Roman Polanski. Every night Chico implores her not to hand him to the Trumps. At first, the young woman does not want to listen. She needs the money, not the baby – in fact, the only creature she really misses is a little dog that she had to give away because the Trumps vetoed any contact with animals. But Chico's eloquence eventually wins over the woman's resistance.[32] She flees with her new-born baby from the Swiss birth clinic, and takes refuge in a park where they are quickly surrounded by the clinic staff and by Trump's private guards. To save himself, the child resorts to a cinematic trick that he has learned from Chaplin's *The Kid*: with a temporal leap, just like in the film, he transforms himself into a five-year-old, from one scene to the next. As the guards approach, mother and son hug each other in a steely embrace, with fiery eyes, and the guards are scared away. The reader mentally recalls the famous scene in *The Kid*, when the policeman is chasing the kid to take him to the orphanage. Despite the tramp's strenuous resistance, the kid is abducted and hurled into the orphans' carriage. The tramp chases the abductors, running across the city's roofs and finally plunges himself into the carriage. When the brute driving the carriage swoops on the tramp with menacing eyes, the tramp and the kid, instead of running away, hold each other tight. The brute is paralysed: their embrace scares him, because it speaks of a love too great for him to understand.

The Kid and the Tramp, holding each other tight, are a quintessential symbol of the love that exists independently from biological ties: an enduring emotional bond that links the child to his adoptive father. Paradoxically, in the final scenes of Alberti's novel, this is precisely the image that triggers the love of the surrogate mother, who only hours earlier had wanted to give the child away. For the author of *Non mi vendere, mamma*, the 'stranger' who discovers her affection is not a random woman in the street, but the child's biological mother, who must learn to love the newborn. The intricacy of Alberti's intertextual reference reminds us, once again, of the infinitely complex, rugged conceptual terrain on which birth stories walk. Parental love is not purely defined by biology and, certainly, it has nothing to do with money. Like in many traditional moral tales – a genre that shares many traits with Alberti's novel – the message is clear: surrogacy must be condemned, not only because it treats women's bodies as if they were 'containers', but also because it is predicated on abysmal social inequalities. Markets should have moral limits: there are things that money should not be allowed to buy.

4. Frozen embryos, frozen time

During IVF, embryos are normally made in larger numbers than can be implanted, unless regulations impose a legal limit on numbers. These excess embryos are frozen, and put aside for future use. Some may be used later by the same couple who commissioned them, some might be given 'in adoption' to other infertile couples, some are likely to be used for

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[32] While reading Alberti's novel, I was reminded of another terribly eloquent and poetic foetus, the protagonist of Ian McEwan's *Nutshell*. Both novels were published in the same year, by an interesting coincidence.

research – provided that the law permits such a use. Others will remain stored in labs for as long as time and space allow this, and will then be destroyed. The freezing of human embryos has proved extremely successful: not all IVF embryos survive freezing and thawing, but many do, even when they have been frozen for years. Nobody knows how many frozen embryos are stored in labs around the world: hundreds of thousands, possibly millions.[33]
This practice – which has proven to be divisive, like many other forms of ART – provides the inspiration for British writer Rupert Thomson's novel *Katherine Carlyle* (2015). Narrated in the first person, in a lucid and urgent present tense, this book tells the story of a nineteen-year-old girl, or rather, as she explains to a friend, of a girl who is nineteen, but also twenty-seven. Thomson's prologue opens with a meticulous but also poetic description of Katherine's conception:

> I was made in a small square dish. The temperature was 37 degrees Celsius, like the inside of a human body. Like a womb. [...] My mother's eggs were placed in the wells, no more than three in each, and then my father's sperm was introduced, the sperm allowed to seek the eggs in a simulacrum of the reproductive process.[34]

What follows next is a description of the various stages of IVF: the transferal into a solution called the "culture medium", the progressive division into cells, the monitoring by the doctors. Suddenly, however, Katherine's story comes to an abrupt halt: "Though I was one of several 'Grade 1' embryos – clear cells, tight junctions, no evidence of fragmentation or 'blebbing' – the technicians did not select me for immediate implantation. I was preserved instead" (p. 4). Katherine's embryo is kept in a steel barrel, filled with liquid nitrogen. It is suspended in a bath of cryo-protectant and other assorted nutrients, and exposed to an extreme and constant temperature of minus 196 degrees. There she remains for eight years, after which her parents decide to have the embryo implanted in her mother's womb.

> Every now and then, and just for a few seconds – reads the last paragraph of the prologue –, the lid was lifted off the storage tank and a torrent of white light poured down through the swirling mist. A number of embryos would be removed, but I stayed where I was, in my see-through straw. The lid was replaced. Darkness descended once more. (p. 5)

When the main part of the novel begins, Katherine is nineteen and lives in Rome. She has been accepted to study in Oxford, but spends her days wandering aimlessly. She has no particular desire to go to university, nor, for that matter, to continue the life that she has led until now. Her mother's death of cancer, seven years earlier, left a wound that refuses to heal. Her father, a war reporter for CNN, is rarely home and has spent even more time traveling since he lost his wife. Alone, despite her many friends, Katherine feels oppressed by a sense of non-existence that she describes as

> the feeling that I'm not there. It's not that I'm dead. I'm simply gone. I never was. Panic opens inside me, slow and stealthy, like a flower that only blooms at night. The eight years are still with me, eight years in the dark, the cold. Waiting. Not knowing. (p. 11)

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[33] See Gilbert and Pinto-Correia, *Fear, Wonder, and Science in the New Age of Reproductive Biotechnology*, pp. 76-78, and Mundy, *Everything Conceivable,* pp. 288-306.

[34] Rupert Thomson, *Katherine Carlyle*, London: Corsair, 2015, p. 3.

To overcome this nagging sense of unreality, Katherine decides that she must undertake a journey, without knowing where it will take her. A set of mysterious, apparently random signals seem to suggest a destination: a banknote found in the street, a phrase caught from a conversation between two strangers, an amulet collected from the ground. These 'messages' indicate the North, cold and silence. Katherine catches a flight to Berlin and there she makes friends with strangers who welcome her, listen to her and help her overcome her sense of emptiness. But Katherine is obsessed with the idea of escape, and continues her journey. She changes names, to confuse her father who she believes may be looking for her. From Berlin, she travels to Warsaw, then to Moscow, to Arkhangelsk on the White Sea, and to Norway. Finally, she reaches a most remote place – an islet in the Arctic Ocean – where she leads a minimal life, little more than bare survival.

What is the goal of Katherine's journey? In one of the novel's final pages, Thomson's protagonist muses that the small island near the Arctic Circle has given her a sense of the eight years spent in the steel barrel, filled with liquid nitrogen. She even believes that she has been joined by the lost embryos of her unborn siblings: "the thawed embryos implanted at the same time as me" whose cells degraded, "their gorgeous yellow darkening to a grim doomed black" (p. 307). One evening, during a bath in the public swimming pool, she sees them float by, evanescent like bubbles of water.

But is this really what Katherine was looking for? During her drawn-out inner monologues, she repeatedly deplores the fact that she had to spend eight years in a frozen state. "Why did you make me wait?" she asks her father, one night; and then answers her own question: "I know why. It's because you thought I'd be a monster, didn't you. And maybe that's exactly what I am – to you" (p. 149). Another time she rebukes her father for having deprived her of eight happy years with her mother, whom Katherine could have been close to for twenty years, not twelve. Eight years of frozen time weigh on Katherine's conscience, and heighten her profound sense of abandonment. If only her mother was still alive, or if her father spent more time with her, these years would acquire a different meaning. But Katherine feels abandoned by her mother and also by her father, and she flees, in order to be pursued.

Katherine Carlyle, then, is not so much a novel about *in vitro* fertilization, but rather a tale of mourning, loss, and the need to be loved. Between the lines of Thomson's novel, we hear echoes of Mary Shelley's *Frankenstein*. Katherine's painful longing for her absent father recalls the creature's tormented quest for the indifferent Viktor Frankenstein.[35] At the end of the novel, in the ghostly and icy city, Katherine suffers a terrible violence. But she survives, and suddenly feels a wish to see her father again: a desire that is stronger than the feelings that had led her to flee from him. When she is helped by two strangers, Katherine tells them: "I'd like to call my dad" (p. 340).

And yet, it is hard to believe that the reference to the frozen embryo, waiting for eight years, only serves to add pathos to the story of an absent father, who does not fill the gap left by his dead wife. Thomson's novel also explores the limits of wilfulness, and asks how far we can go

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[35] Early in the novel, Thomson draws the readers' attention to this important reference. The first of the two exergues ("How slowly the time passes here, encompassed as I am by frost and snow!") is a quotation from *Frankenstein* by Mary Shelley. The intertextual play with Shelley's novel is discussed by Andrew Ervin in his review of the novel, *The New York Times*, 20 December, 2015, available online at https://www.nytimes.com/2015/12/20/books/review/katherine-carlyle-by-rupert-thomson.html (last accessed on 12 October 2020). Ervin writes: "The novel raises any number of ethical questions about parent and personhood. Much to Thomson's credit, he offers no easy answers. Readers will decide for themselves if Kit is meant to be a stand-in for Dr. Frankenstein, for his creature or for something else entirely. At times, she comes across as both the pursuer and the pursued. Her motivations don't entirely make sense, but perhaps that's true of most teenagers."

in our desire for total freedom. Katherine, like the doctors in a birth clinic, 'experiments' with her own life. *Katherine Carlyle* is thus not only a novel about mourning, but also a philosophical meditation on freedom and audacity: what does it take to create an embryo, *ad hoc*, and to keep it frozen for eight years? What does it take to re-invent one's life, as Katherine does, madly and recklessly?

Thomson's novel raises questions that do not have an easy answer. Is it ethical to create an embryo and to suspend its development for eight years? "Such a curious notion, to be the defunct or superannuated version of something that hadn't even existed. Like being a ghost, only the wrong way around", as Katherine puts it in the prologue (p. 4). Are we ready to live with the consequences of such a decision?

Last but not least, *Katherine Carlyle* is a reflection on the power of the stories that precede and surround our birth. Some might argue that there is little difference between the decision to postpone the conception of a child for a few years – to continue one's career and prolong one's youth – and the decision to freeze a newly created embryo. But Thomson reminds us that, for Katherine, the difference exists and that parents cannot ignore the psychological consequences of their reproductive choices, for the child. Thomson, who is himself the father of a daughter conceived with IVF, has declared in an interview that Katherine's obsession with her own conception is somewhat pathological: "She's not entirely aware of what she is doing, but she's right to try to break the spell she's fallen under, which is the belief that she isn't loved. To do that, she must go to the very limit".[36] The story of her conception has become, for Katherine, a spell that conditions her life. Even when she tries to break the spell, the story remains with her. We cannot struggle free from the stories that make us any more than we can ignore the fact that we were brought into this world.

5. Conclusion

Liza Mundy's sensitive and nuanced inquiry into the world of assisted reproduction draws from hundreds of interviews with people who are or have been involved with ART: doctors, parents, children, psychologists, women's groups, activists on both sides. In the conclusion to her study, Mundy observes that "one of the most striking things about assisted reproduction is the way it creates dilemmas that are so much harder for women's groups to grapple with than abortion, which seems, in contrast, almost easy to think about". Notions are slippery: choice, reproductive freedom, rights. Whose choice? Whose freedom? Whose rights? The rights of the parents, of the children, of the donors, of the surrogates, of the human species? The right of the doctors to offer services at whatever costs patients are willing to pay? The freedom of the private individual against the State?

Many stories of assisted reproduction convey a sense of unpredictability. In this respect, they resemble all birth stories. By definition, a birth changes the world where it happens. But medically assisted births mark an especially dramatic change. Ironically, medically assisted reproduction is often the least controllable form of reproduction. Situations frequently take unexpected turns. This is why novels and films, and any kind of artistic reflection on these themes, can help us explore the brave new world of reproductive technologies. Literary and filmic narratives have a clear inclination to embrace the complexity and unpredictability of human experience, to stage and listen to different and divergent voices. For this reason, novels and films can offer an epistemic aid to navigate the troubled waters of our present. If they cannot

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[36] Max Liu, 'A lot of what you write comes true' (book review of *Katherine Carlyle* by Rupert Thomson), "The Independent", 7 November 2015, available online at https://www.independent.co.uk/arts-entertainment/books/reviews/katherine-carlyle-by-rupert-thomson-book-review-a-lot-of-what-you-write-comes-true-a6724436.html (last accessed on 12 October 2020).

provide definitive answers to the many dilemmas created by the incessantly evolving techniques of assisted reproductive medicine, they can at least help us formulate new questions.

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SURVIVING MELANCHOLY AND MOURNING: A QUEER POLITICS OF DAMAGE IN ITALIAN LITERARY REPRESENTATIONS OF SAME-SEX PARENTING[1]

abstract

While family forms are ever more diverse, there are few critical analyses of the ways in which LGBTQ families have been represented in fiction. This article explores recent Italian novels by Cristiana Alicata, Melania Mazzucco and Chiara Francini that depict lesbian and gay parents and their children. In all these novels at least one gay or lesbian parent dies. Drawing on Judith Butler's work on mourning and melancholia, I problematize the persistent spectre of grief and loss attached to gay and lesbian parenting. However, reflections by Heather Love also prompt me to explore what Love calls a "politics of damage", or an attempt to see past the looming threat of inevitable homosexual doom towards the queer, subversive elements of these narratives, which question normative conceptions of the family and open up space to reflect on 'alternative' parental models.

keywords

same-sex parenting, queer politics of damage, Italy

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1. Introduction

Cultural representation of sexual minorities in general, and LGBTQ families in particular, can play a crucial role in how these phenomena are understood and the status they have. As scholars such as Stuart Hall have argued, the meaning that we attribute to socio-cultural phenomena is generated at least in part through representation, indicating that cultural texts can play a significant role in shaping cultural discourses on and attitudes towards the world around us (Hall, 1997, p. 5). In a similar vein, Jeffrey Weeks and Judith Butler have suggested that narratives and representation are vital to our sense of self, to our developing identities and our well-being: Butler goes as far as to argue that the liveability of our lives depends in part on cultural representation, and cultural intelligibility more broadly (Weeks, 2003; Butler, 2005, p. 43). It is my contention that cultural texts that represent LGBTQ families have the potential to make important interventions in ongoing socio-cultural and political debates about human rights issues: they may reinforce problematic stereotypes, or disseminate a more progressive message, for example by enhancing empathy in readers, thereby dissipating homophobic hostility (Bal and Veltkamp, 2013). Moreover, research in the UK has shown that LGBT parents may feel unrepresented in mainstream cultural discourse. While they often seek to engage closely with cultural representation to develop their sense of self they frequently feel alienated by what they find (Reed, 2018). Therefore a critical engagement with these texts is a vital step towards improving our understanding of the messages circulating in culture. While there are many sociological studies of the experiences of LGBTQ families, there are few critical analyses of the ways in which they have been represented in fiction. Consequently our understanding of the discourses circulating in culture is radically incomplete. In particular, there is almost no scholarship on the representations of LGBTQ families in cultural texts in languages other than English. With this in mind, this article begins to address the gap in scholarship on the cultural representation of LGBTQ families, and seeks to push discussion beyond the current focus, which is on children's books and English-language novels. Specifically, my discussion centres on Italy—a country that is still today pervaded by the myth of the heteronormative family, despite the fact that family structures have been diversifying for several decades (Saraceno, 2004). I analyse a series of recent Italian novels that depict lesbian and gay male parents and their children, since, in my research on the topic to date, these are the non-heterosexual family forms that occur most frequently in Italian literature.[1]

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[1] There are several other Italian cultural texts that discuss queer families: these include Goliarda Sapienza's novel

The significance of these texts is compounded by recent and ongoing heated political and media debates about same-sex parents in Italy, largely motivated by problematic, normative anxieties about the well-being of the children of such couples, as well as by new legislation on civil unions and anxieties about surrogacy. Thus these novels, which emerge from a tense and complex discursive context, can be read as speaking to and about the socio-cultural and political status of gay and lesbian parents, and their children, in Italy.

The novels I discuss are: Cristiana Alicata's *Quattro* (Four, 2006), and *Verrai a trovarmi d'inverno* (You Will Come to See Me in the Winter, 2011); Melania Mazzucco's *Sei come sei* (You Are as You Are, 2013); Chiara Francini's *Non parlare con la bocca piena* (Don't Talk with your Mouth Full, 2017) and *Mia madre non lo deve sapere* (My Mother Mustn't Find Out, 2018).[2] As yet, there are no scholarly studies of these works. I note how in all these novels at least one gay or lesbian parent dies. Drawing on Butler's work on mourning and melancholia, I problematize the persistent spectre of grief and loss attached to gay and lesbian parenting, which seems to close down any more progressive vision of a future in which such family forms might flourish. However, reflections by Heather Love also prompt me to explore what Love calls a 'politics of damage': starting from the premise that "modern homosexual identity is formed out of or in relation to the experience of social damage", she suggests that making this damage visible, and critiquing it, opens up new existential pathways (Love, 2007, p. 29). In relation to these novels, we might understand this politics of damage as an attempt to see past the looming threat of inevitable homosexual doom towards the queer, subversive elements of cultural narratives, which question normative conceptions of the family and open up space to reflect on 'alternative' parental models. I argue that traces of this queerer, more combative perspective can be seen in two of the novels in particular: Mazzucco's *Sei come sei* and Alicata's *Verrai a trovarmi d'inverno*. Moreover, I discuss how, significantly, these narratives give space to the children of lesbian and gay parents, whose voices have been largely missing from cultural and political debates, partly due to their age. As such, these fictions supplement political and broader cultural debates in striking ways.

Before turning to the novels, I offer a brief overview of recent scholarship on LGBTQ families and of the socio-political and legal context for same-sex families in Italy.

2. Between Queer Parenting and Homonormativity: The Kids are Alright, but What About the Parents?

Many sociological studies have evaluated LGBTQ families in the UK, US and some European countries, largely with a focus on same-sex, monogamous, and now married, or legally partnered parents.[3] Such studies have allayed problematic homophobic concerns that the children of same-sex parents will identify as gay, and confirmed that they may actually be more open-minded than their peers with heterosexual parents (Schumm, 2016, p. 673). Some scholars have suggested that it is no longer helpful to ask whether LGBTQ families are 'different', but rather to think about how, why and to what effect heteronormative society *constructs* non-normative families as 'different' (Berkowitz, 2009).

In a related vein, work on queer kinship has explored how the normative family form has been

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L'arte della gioia (The Art of Joy, 1998), in which the bisexual protagonist Modesta creates a vibrant and transgressive family of choice; Egon Botteghi's autobiographical theatrical monologue *Mi chiamo Egon* [My name is Egon], which narrativizes his journey as a transman and parent; Ferzàn Ozpetek's film *Le fate ignoranti* (His Secret Life, 2001), in which a widowed heterosexual woman encounters her late husband's queer family of choice. While these all merit critical attention, they are all quite distinct. I have selected novels that share a focus on the challenges facing same-sex parents in a heteronormative society, and the ways in which their children may respond.

[2] All translations are mine.

[3] Schumm, 2016 provides a detailed review of sociological studies that have explored the past few decades. See also, for example, Biblarz and Stacey, 2019, Park, 2013.

challenged by those who seek alternative models for intimate relationships, 'families of choice' (Weston, 1991), and who reclaim "the right to define significant relationships and decide who matters and counts as family", and "the right [of an individual] to create family forms that fit her or his needs to realize the human potential for love in non oppressive relationships" (Goss, 1997, p. 19). A crucial question that has emerged in recent years is the degree to which these new family forms are creatively subversive, as Weeks, Heaphy and Donovan have suggested (2001), or whether they are problematically assimilationist and homonormative. That is, do gay and lesbian couples espouse "a politics that does not contest dominant heteronormative assumptions and institutions [such as marriage], but upholds and sustains them, while promising the possibility of a demobilized gay constituency and a privatized, depoliticized gay culture anchored in domesticity and consumption" (Duggan, 2002, p. 179)?

More recently, drawing on the work of Susan Fraiman, Maggie Nelson has critiqued the tendency to create an opposition between some obliquely evoked form of queer political 'authenticity' and domestic assimilationism: "the tired binary that places femininity, reproduction, and normativity on the one side, and queer resistance on the other" (2016, pp. 75).[4] Can parenthood be queer, she asks? Or, can we queer parenthood? While critically appraising discourses on LGBTQ families, it seems important to hold in our minds the possibility for same-sex parenthood to retain a subversive edge, even if elements of the relationships depicted may appear (homo)normative. As Nelson argues, it is impossible for anyone to be just one thing over the course of their life, whether normative or queer. These concerns inform my analysis.

Research on LGBTQ parents in the Humanities lags far behind the Social Sciences.[5] There are some analyses of children's books in English that depict same-sex parents (DePalma, 2016, Lester, 2014), and a few articles and chapters on certain cultural contexts (e.g. Rye, 2010 explores contemporary literary depictions of lesbian mothers in France). These offer useful critical analyses of how same-sex parents are depicted in individual texts or contexts and serve as a starting point for further debate since a pattern emerges of a concern with how 'normal' or 'progressively different' these parents may be. For example, Epstein (2012) asks why there are so few BTQ characters in children's picture books and young adult fiction, and critiques the lack of diversity and widespread use of stereotypes; Rye argues that in recent French texts (novels and memoirs), lesbian mothers are portrayed and self-portray as oscillating between 'normalcy' and offering a 'different', progressive model of parenting. However there is no clear picture of the dominant representational forms associated with LGBTQ parents within specific national/linguistic contexts; neither have any substantial comparative studies been published that engage critically with differences and similarities between contexts, or with the transnational aspects of cultural representations of LGBTQ parents. This article supplements

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[4] Here, Nelson is engaging indirectly with Lee Edelman's critique of the normative drive towards "reproductive futurism" and his discussion of a queer antisocial stance as an alternative (Edelman 2004). While Edelman's intervention is an important contribution to debate, it has attracted criticism for its insistence on the binary (reproduction/queerness) that Nelson highlights. Similarly, Michael Snediker has noted that "there are ways of resisting a pernicious logic of 'reproductive futurism' besides embodying the death drive" (2006, p. 14).

[5] Critical discussions of LGBTQ families that appear in fiction include a handful of studies of children's books in English that feature gay and lesbian parents, such as DePalma, 2016, Lester, 2014, Epstein, 2012, Sunderland and McGlashan, 2012. Some recent articles which explore the Italian context discuss both Italian-authored books for children and translations of English-language picture books about gay and lesbian parents (Forni, 2018). A recent themed issue of the journal *Ácoma* (Bavaro and Iuliano eds, 2019) explores representations of LGBTQ families in cultural texts more broadly (including novels and TV series), with a focus on English-language texts. Gill Rye has begun to explore the representation of lesbian motherhood in French literature (2009), but there are very few critical analyses of LGBTQ families in literature written in languages other than English.

Rye's work and seeks to shed light on underexplored literary texts that tackle this politically and ethically complex issue.

3. Rainbow Families in Italy: A Precarious Existence

Italy offers a compelling case study in relation to the representation of same-sex parents. It has long had a reputation for being 'backward' in terms of LGBTQ rights. For example, there is inadequate anti-discrimination legislation that actually sanctions discrimination against people on the grounds of sexual orientation in certain professions like the armed forces;[6] legislation on sex reassignment (Law 164/1982) needs urgent improvement, since, it is too rigid and prescriptive and assumes that all trans people follow the same trajectory; moreover, access to medical treatment is uneven in different regions (Maffioletti, 2020). Civil partnerships for same-sex couples were finally introduced in 2016 (Law 76/2016), however, due to the restrictive Law 40 (2004), same-sex couples cannot access reproductive technologies such as IVF, or adopt. Indeed, there is no provision in the civil partnership legislation for legal recognition of non-biological, or social parents: this clause was removed from the draft law after heated debate, leaving thousands of families in legal limbo. Those parents who can afford to do so have applied for adoption, and so far around 20 cases have been heard in court.[7] In the majority of cases, the judge has ruled to recognize the non-biological parent, however this has not always been the case. Recent governments have been clear in their hostility to LGBTQ individuals and communities: on taking up his new role as Minister for Families and Disabilities (which he held from June 2018-July 2019) Lorenzo Fontana declared that same-sex families do not exist (De Luca, 2018). Simone Pillon, a Lega Senator, continues to campaign to revoke civil partnerships and against LGBT rights in general, to the extent that he has been accused of and condemned for defamation towards an Arcigay activist group (Santoro, 2019). In addition, recent years have witnessed many well-attended, widely reported demonstrations and rallies all over Italy organized by the Catholic, anti-gender movement, which opposes the recognition of rights for LGBTQ people, particularly same-sex couples and parents, and trans people (Lavizzari and Prearo, 2018). Yet, since April 2018, several mayors have decided to defy the government and have amended the birth certificates of many children to include the non-biological parent as co-parent, thus giving same-sex parents equal legal status and circumventing the need to go to court (Ricca, 2018). Unsurprisingly, there has been significant media coverage of these issues in the past few years, with three main discursive trends emerging:

1. strong defences of gay and lesbian parents by the national association Famiglie Arcobaleno (Rainbow Families, founded 2005), a minority of centre left politicians (particularly Monica Cirinnà who led the civil unions bill) and some key media personalities (such as Luciana Litizzetto);
2. homophobic and essentialist statements that seek to defend the apparently besieged 'natural' heterosexual family and attack same-sex families, coming from the Church, many leading politicians, and 'anti-gender' campaign groups (*La Repubblica*, 2018);
3. some feminists and lesbians who disagree with the practice of surrogacy, which is currently illegal in Italy, and have made public statements specifically against gay men who decide to have a child with the help of a surrogate (Ross, 2020).

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[6] In Italy, while article 3 of the constitution seems to assert equality for all citizens, it has not historically been implemented in this way. The first law to mention sexual orientation, Legislative Decree 216/2003, regarding equality in the workplace, actually specifies that people can be discriminated against on the basis of their sexuality in certain professions, such as the armed forces (article 3). See also Ross, 2009.

[7] Research project in progress, 'Doing Rights: Innovative Tools for Professionals Working with LGBT Families' (www.doingrights.eu), led by Federica de Cordova, Giulia Selmi, Chiara Sità, Cristina Lonardi, University of Verona.

I offer this sketch of some of the tensions and discourses circulating in Italy to show that there is plenty of hostility, but there is also reason to be hopeful: thanks to decades of activism, as well as to vociferous opposition, same-sex parenting is more talked-about and publicly visible than ever before. Same-sex parenting has some strong supporters, and as yet there are no concrete plans to revoke any legislation relating to civil unions;[8] however, there is still uncertainty about the legal status of some parents, which is stressful and difficult for those families.[9] With this context in mind, I turn now to my selected literary texts.

4. Happy Endings vs Mobilizing Shame and Melancholy

In Italy, as elsewhere, LGBTQ-identified individuals have historically been under-represented, or associated with pathological defects and afflictions (Beccalossi, 2012; Ross, 2015). Even in recent years, representation has not seemed to be able to shake off the shackles of past discourses. Indeed, what has struck me in my research on this topic so far is that there are some unsettling resonances between Italian literary representations of lesbian and gay parents, and some of the more offensive political statements that have been circulating recently, including the idea that same-sex families simply do not exist, as Fontana argued. Strikingly, the novels that I analyse not only draw attention to problems such as the lack of legal protection for same-sex families, but also heap on what I would argue are disproportionate amounts of personal tragedy. To varying degrees, these novels are what Heather Love (2007) would call 'backward': focussed on the past, on shame, on closeted identities, on the impossibility and potential damage of same-sex parenting, and even of same sex relationships in some cases. In these novels, same-sex parents are also inextricably linked to death, loss, and the disintegration of the family: same-sex parents exist, but only briefly, before they are narratively erased. The first part of my analysis therefore explores the persistence of the historically-entrenched, problematic trope of queerness as a harbinger of doom and death in relation to same-sex parenting. The recurring narrative drive to kill off queer characters, perhaps to restore heteronormativity, or to underline how queerness leads inevitably to tragedy, or just through authorial lack of imagination and desire for sensational drama, is such a widespread phenomenon that it is known informally as the habit of 'burying your gays' (Hulan, 2017). I am interested in the degree to which these texts move beyond a problematic association of same-sex parenting with damage, coupled with a desire to 'bury' the offending parents, towards a queer critique of homophobic discourse.

The earliest novel is Alicata's *Quattro*, which tells the story of Andrea and Chiara, the teenage children of Martina and Francesca, who have just been killed in a car crash. It is the early 2000s, so Andrea and Chiara must have been born in the 1990s. We hear about their childhood, and discover that each woman gave birth to one child, apparently thanks to donor insemination although no specific details are provided about that process.[10] We learn from the narrator, Andrea, that the children call their birth mother 'Mamma', but the other mother by her first name. This leads to a startling conversation in which a 7 year-old Andrea asks Francesca, who is not his birth mother, "Ma tu...chi sei?" [But...who are you?] (Alicata, 2006, p. 29). Andrea tells us that Francesca and Martina sought to hide the fact that they were same-sex parents by avoiding coming out and orchestrating select socialising, in a bid to protect their children. We discover that Francesca found it very hard to accept her sexuality, partly as a result of her homophobic parents; and we follow a family crisis as the mothers proclaim they

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[8] Law 76/2016 is recognized by the Constitutional Court and the European Court of Human Rights so it would be difficult to revoke it.

[9] For example, the Court of Appeal recently ruled against recognizing the non-biological parent of a child born abroad with the help of a surrogate (ruling no. 12193, 8th May 2019).

[10] Andrea is Martina's son, Chiara is Francesca's daughter.

are relieved that the children are ‘normal’ (i.e. heterosexual). They were terrified that they would confirm heteronormative society’s worst suspicions and produce queer children—as if this were a serious problem. Chiara is rather horrified at her parents’ normativity and at their belief that they can and should control their children’s sexuality. However all of this is overshadowed by the deaths of Francesca and Martina. Afterwards the ‘normal’ children go on to find partners, and create heterosexual families. Andrea tells the story out of a conviction that his children need to know about their grandmothers, who otherwise would be buried and forgotten.

In Alicata’s second novel, *Verrai a trovarmi d’inverno*, Elena is a closeted medical student struggling to come to terms with her lesbianism. She lives with her father, Aldo, and adopted brother Mattia. Aldo, and Mattia’s father Giovanni, now dead, were best friends in the 60s, and were the ones left to look after the children when Elena’s mother died and Mattia’s mother abandoned them. Elena is deeply depressed because of her manipulative lover Viola, and attempts a sort of bungled suicide by driving her scooter into a wall. While she recovers, she discovers that Giovanni and Aldo were lovers, making the family not just non-normative—two single fathers with children living as a blended family—but more explicitly queer. However, this is only discovered when Elena’s internalized homophobia has almost cost her her life, and when the relationship is no more because of Giovanni’s death.

In Mazzucco’s *Sei come sei*, Eva is the 11-year-old daughter of Giosè and Christian, who has died in a motorcycle accident. Conceived thanks to the help of a surrogate in Armenia, Eva lived happily with her fathers, until she was separated from Giosè because he was not the biological parent, and therefore had no legal relationship with her after Christian’s death. Her uncle and aunt, whom she hates, become her guardians, and she loses touch with Giosè. The novel opens with Eva pushing a classmate under a train because he was bullying her. She then runs away to find Giosè. He is compelled to bring her back to her guardians but it seems like they have begun to rebuild their relationship.

Chiara Francini’s *Non parlare con la bocca piena* and *Mia madre non lo deve sapere*, depict the adventures of Chiara, the protagonist, a young woman whose birth mother decided she was not cut out for parenthood and so entrusted her child to two friends: a gay male couple. Chiara is trying to make her heterosexual relationship work, but ends up moving back to her family home. During this time, one of her fathers, Giancarlo, dies: His last words are about love:

> dobbiamo amare, amare, come regine’ [...] Giancarlo se n’era andato per un infarto. Quel cuore gonfio e stanco Chiara se l’era immaginato talmente pieno di valzer, vita, zucchero e ideali che a un certo punto doveva aver deciso di mettersi a dormire. Giustamente (Francini, 2017, p. 51).
> [We have to love, love like queens. [...] Giancarlo left us because of a heart attack. That tired, swollen heart that Chiara imagined as being so full of waltzes, life, sugar and ideals that at a certain point it had decided to lay down to sleep. And rightly so.]

Here we have a clichéd view that gay men are so caught up in a stereotype of hyperbolic, affected camp that they wear themselves out with it and die.

The status of the authors, and how and where the texts have been received are important details to add here. Alicata is an ‘out’ lesbian, a mechanical engineer who now works in the food industry and also writes novels. *Quattro* is published by a small lesbian feminist press, and the afterword cites letters to Alicata by the lesbian activist Daniela Bellisario, and *Verrai a trovarmi d’inverno* includes a glossary of LGBTQ terminology at the back, framing the text as a progressive contribution to LGBTQ representation. Mazzucco is a much more successful author, published by the major press Mondadori. She has won numerous prestigious prizes, including the Premio Strega (2003), for the novel *Vita* and the Premio Viareggio-Tobino (2011), recognizing her successful career. While she is not closely aligned with LGBTQ activism, she has previously written about the queer Swiss journalist and photographer Annemarie Schwarzenbach in *Lei cosí amata* (2012). Francini is an actor who has appeared in many films and TV series. These are her only novels. All novels have been well-received by the cultural press, with differing visibility: Mazzucco's has received more attention in established literary publications like *L'Indice dei libri del mese*, Alicata's novels have been discussed in relation to LGBTQ activism and on an individual reader's blog, and Francini has had enthusiastic write-ups in the *Huffington Post*.[11]

In these novels, we see same-sex couples choosing to have or raise children, and to defy heteronormativity and Italian laws regarding reproductive technologies, but there is a great deal of shame, hiding and a pervasive, stubborn sense of impossibility. We see the linguistic erasure of the non-biological mother in *Quattro* as the children don't refer to their non-biological parent as 'mamma', and don't even seem to know what relationship they have with them; in *Mi verrai a trovare d'inverno*, Giovanni and Aldo hide their relationship for decades and are unable to live it freely. There is almost an inescapability about the deaths that interrupt these brave new family configurations that, it is implied, are just too risky. The protagonist of Francini's novels is a slight exception since she has made it through to adulthood with both parents, but the death of her father Giancarlo is also presented as inevitable, while her birth mother then comes back into the picture as an enduring presence, symbolically ghosting out the gay male parent.

I argue that these novels are imbued with queer melancholia. In her discussion and reworking of Freud's theories of mourning and melancholia, in *The Psychic Life of Power,* Butler develops a useful perspective on this issue. Simply put, in Freud's view, mourning involves a feeling of loss that is openly acknowledged, and then the subject moves on with their life; melancholia, on the other hand, is produced by a denial or deferral of loss, and an introjection or incorporation of the loss itself into the ego, so that the subject's own identity is thereafter intrinsically bound up with loss. Butler considers this phenomenon in relation to homosexual identity, commenting that the normative prohibition on homosexuality that structures dominant social relations results in widespread melancholia as queer subjects experience their desire through loss. She calls this:

> a preemptive loss, a mourning for unlived possibilities. If this love is from the start out of the question, then it cannot happen, and if it does, it certainly did not. If it does, it happens only under the official sign of its prohibition and disavowal (Butler, 1997, p. 139).

She goes on: 'homosexuality is not abolished but preserved, though preserved precisely in the prohibition on homosexuality' (Butler, 1997, p. 142).

If we apply this view to the narratives of same-sex parenting, we see that the novels are infused with a profound sense of queer melancholy. While we are presented with various examples of same-sex parents, they are all disavowed, narratively sidelined, but preserved as loss. In *Quattro*, Andrea wants to preserve the memory of his child's grandmothers, as though they were a rare example of a historical phenomenon that will never be seen again. They are written into the text, but as a foreclosed impossibility that remains socially and politically prohibited. Giovanni, Christian, Martina, Francesca and Giancarlo are derealized or ghosted, to use Terry Castle's expression: they are evoked only to disappear (Castle 1993, pp. 2-6).

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[11] See, for example, Manetti, 2014; Gilioli, 2011; Massari, 2018.

Of course, some of the novels also contain a good deal of nuanced, subversive narrative and characterization, which complicates this reading. Francini's novels are really a series of vignettes, of mini chapters of a couple of pages that recount anecdotes. However they do sketch out, albeit in a rather stereotypical way, scenes of happy, 'queer' family life, as we learn about the eccentric decor in their family home and see lively dinners with a crowd of gay 'uncles' round the table providing witty observations. In my view, *Quattro* is the most problematic text, since the mothers, Martina and Francesca, seem to have approached parenting with the desire to conceal their relationship from their children, and to have taken active steps to 'heterosexualize' their children. While they are portrayed sympathetically, they are complicit with heteronormative society and have jointly sought to obfuscate their relationship to their own children, which is extremely confusing and potentially quite damaging: this is a far cry from what a queer politics of damage might look like.

Mi verrai a trovare d'inverno is a more progressive novel. While Elena is recuperating from her accident on the island of Pantelleria, she meets a pre-op male to female transsexual called Liz, who berates her for her internalized homophobia, and encourages her to accept her lesbianism, and to live it more openly. Conversations between Liz and Elena show the difficulties that individuals may experience in a hostile context, and the power of queer solidarity to overcome this. Later in the novel we see that homophobia is not necessarily the instinctive response when learning about a relative's homosexuality. When Mattia, Elena's step-brother, learns that Giovanni and Aldo, his fathers, were lovers, he doesn't flinch, maintaining that it changes nothing about his sense of who he is:

> Elena: "Non ti sconvolge che..."
> "...che stessero insieme?" m'interuppe Mattia riferendosi al babbo e a Giovanni.
> "Si".
> "Dimmi cosa cambierebbe della mia vita. Prova a dirmelo" (Alicata, 2011, p. 258).
> [Elena; Doesn't it shock you that..."
> "...that they were together? Mattia interrupted me, referring to Dad and Giovanni.
> "Yes."
> "Tell me what it changes about my life. Just try".]

In this novel, the queer parenting has already happened, silently, and is only really recognized as such after the fact. We see how affective bonds are strong enough to weather the potential shock of an unexpected revelation about a parent's sexuality, and how a parent's sexuality does not necessarily impact on their ability to bring up a child. Moreover, we do see some signs of a more progressive future, as Elena begins to come to terms with her own sexuality through learning about her father's personal life. Her own fears about her sexuality and of rejection by her family are proved to be unfounded and the narrative supports openness about identity.

Sei come sei merits more attention, since it is a complex novel that is also more self-aware of the topics it is dealing with. Mazzucco constructs a narrative that aligns itself alternately with different characters, remaining in the third person but offering insights into their personal experiences. The narrative subtly evokes and dissolves prejudices about how other people live, by juxtaposing different views. For example, Eva's classmate Loris feels sorry for her, not having a mother. He has a strong bond with his own mother, and a rather icy relationship with his father, and therefore imagines family life with two fathers as a tense, cold and stressful situation. In contrast, the novel shows Eva's home life as infused with affection and fun, and makes it abundantly clear that she idolizes her fathers. This challenge to Loris' prejudiced view narrativizes and invalidates the common practice of making assumptions about how non-normative family models might work, based on a heteronormative view. Eva's fathers are entirely different from Loris' stern, patriarchal parent but he has no cultural models to go on aside from the homophobic clichés that the children use to bully Eva.

In this novel we also see subversive narratives of fatherhood: Christian and Giosè's desire to have a child together is linked, quite unexpectedly, to Catholic iconography as Giosè's desire to become a father is catalysed by a painting from 1645 by Francisco de Herrera the Elder (Fig. 1). It shows *St Joseph with Jesus*: a non-biological father whose tenderness towards the infant transfixes Giosè and moves him to tears (Mazzucco, 2013, p. 121-23). This unusual depiction of the Holy family, which puts at the centre a figure who is often eclipsed, and whose role is passed over in silence, reminds us of the queer elements in even those families that are presented as the most normative.

Fig. 1. *St Joseph with Jesus*, Francisco de Herrera the Elder (1645)[12]

Mazzucco's narrative also engages with ongoing debates about frustrations with the recurring trope of queer pathologization. She injects a very self-conscious moment in which Christian is reflecting on literary representation of gay lives:

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[12] This image is available via Wikimedia Commons in the public domain using the Creative Commons Public Domain Mark 1.0 This work is in the public domain in its country of origin and other countries and areas where the copyright term is the author's life plus 100 years or fewer. See https://commons.wikimedia.org/wiki/File:Francisco_de_Herrera_the_Elder_St_Joseph_And_The_Child.jpg

> Christian aveva iniziato a dire che lo avevano stufato i libri che proponevano una visione maledetta dell'omosessualità, i cui protagonisti erano sempre senza scampo, condannati all'infelicità, alla punizione e perfino alla morte. Comunicavano un'idea ormai datata, rancida, esaurita, anche artisticamente. Voleva l'happy end. Voleva una commedia, qualcosa che rispecchiasse la condizione contemporanea dell'omosessualità liberata e vissuta senza sensi di colpa (Mazzucco, 2013, p. 172).
> [Christian had started to say that he was fed up of books that offered a negative view of homosexuality, whose protagonists could never be saved, they were condemned to unhappiness, punishment and even death. They conveyed a dated message that was rotten, worn out, even from an artistic perspective. He wanted the happy ending. He wanted a comedy, something that reflected contemporary liberated homosexuality, that was lived without a sense of guilt.]

Despite this, Mazzucco then obviously decides not to provide the longed for happy ending, perhaps because this would be unrealistic, or would seem simplistic and hackneyed after this reflection. While Christian rightly critiques the inevitability of queer tragedy in many texts, it would be equally problematic and unrealistic to insist on a guaranteed 'happy' outcome. Here, Mazzucco's text resonates with Sara Ahmed's discussion of happiness and unhappiness, in which she argues that we need to retain an open sense of possibility about these different states, rather than seeking a received idea of 'happiness' to be sought at all costs, thereby trapping ourselves in normative logics (Ahmed, 2010, p. 219). Unhappiness can be productive, she observes (Ahmed, 2010, p 217). Instead of a clichéd 'happy' narrative, Mazzucco shows how unexpected tragedy can hit any family, and how families who are not properly protected by law are so much more vulnerable. Giosè, for example, has to endure the humiliation of being interrogated by a police officer about his relationship with Eva, since they don't have the same surname, and he is then called a 'friend of the family' by Eva's uncle, her legal guardian (Mazzucco, 2013, p. 137). Thus Mazzucco uses her novel politically to critique the Italian socio-cultural and legal context, not just to describe personal loss. Yet this is not a novel that can be easily classified as 'pro' gay fatherhood, since it also depicts the ethically-challenging practice of surrogacy in a rather uncomfortable way. Christian even suggests that surrogacy can be seen as reducing women's bodies to reproductive vessels that can be rented out. Christian and Giosè differ in their views: Christian is more aware of how physically hard and invasive it must be for the surrogate, while Giosé is rather idealistically convinced that it is an undertaking that requires a special vocation. We later see the surrogate herself, a poor widow from a family of shepherds in Armenia—as the novel explains, surrogacy costs much less there than in the US. She is pale and exhausted in the hospital after giving birth, silently weeping and grieving for her husband, who died several years previously, whose absence she is feeling keenly. When asked to pose for a photograph with the two new fathers, she refuses, saying that she is not sure that she wants to remember this moment, or this experience (Mazzucco, 2013, p. 216). The juxtaposition of the different perspectives of Giosè, Christian and the surrogate complicate this story, as ethical dilemmas are raised but no specific side is taken. The novel is clearly anti-homophobic, but more ambiguous on the ethics of how gay men might become parents. Here it takes a more nuanced view of surrogacy than recent debates in the Italian media and some activist communities (Ross, 2020). While sexual difference feminists have been vocal in their condemnation of surrogacy as an inevitably exploitative, commodifying practice Mazzucco presents us with a narrative that sheds fascinating but partial light on why each character makes particular choices, or how free those choices might be. The novel's ultimate concern is not to decry surrogacy as universally unacceptable, but to follow Eva and Giosè, as they navigate unchartered territory in hostile waters.

In these novels, queer traces remain after death, heteronormativity is not fully restored, and the narratives of family life are deeply invested with all the powerful emotions that bind together any family or kinship group. Yet death is all around, and a sense of queer melancholy and damage pervades the narratives, from the characters to the plots. Indeed, I am struck overall by how these novels resonate with an image that has been discussed in relation to melancholy, political activism and queerness: Paul Klee's 1920 painting *Angelus Novus* (Fig. 2).[13]

Fig. 2. Paul Klee, *Angelus Novus* (1920)[14]

This image has been interpreted, most influentially by Walter Benjamin, as symbolizing impotence in the face of the growing pile of wreckage that is history. Benjamin sees the angel as paralysed before the ever increasing disaster, unable to turn its back on the past and look to the future, but propelled backwards towards this future by a gathering storm (Benjamin, 2003, p. 392).

It might be argued that rather than bold figures forging non-normative families of the future, the novels analysed here show us cowed individuals, like the Angel, who are fearful, looking

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[13] Love discusses the painting (2007, p. 152), and references Wendy Brown's analysis of the angel in relation to politics and history (2001, pp. 138-72).

[14] This image is available via Wikimedia Commons. The author died in 1940, so this work is in the public domain in its country of origin and other countries and areas where the copyright term is the author's life plus 75 years or fewer. See https://commons.wikimedia.org/wiki/File:Klee,_Angelus_novus.png

backwards, and sometimes in thrall to homonormativity; that is, they seek to prove that they can be as normative or more normative than any other family, instead of redefining in challenging and exciting ways what a family might look like. This is particularly the case in *Quattro.* There is a political significance to narrating that the children of same-sex parents actually do very well, as countless scientific studies have now argued (Schumm, 2016, p. 662). However, in this novel, the children's stability seems to be achieved through a deeply normative, assimilationist agenda: what Shelley Park has called the concealment of queerness in the drive to be accepted (2013, pp. 8-9). This drive for concealment is exemplified in Francini's novels too, since the protagonist develops a lifelong addiction to sweets because her fathers got into the habit of popping sweets into her mouth constantly while they were out in public, so that she wouldn't be heard calling them both 'Papà', drawing attention to their difference. These apparently 'light' and 'amusing' anecdotes testify to a literal, damaging silencing of queerness. Moreover, returning to the narrative trope of burying your gay parents, there seems to be some inescapable destiny that truncates the lives of queer parents in dramatic and tragic ways; the narratives literalize and externalize the introjected loss of the melancholic subject. At least one parent is already dead at the start of *Quattro, Verrai a trovarmi d'inverno* and *Sei come Sei*. They are always already doomed.

It is also worth noting that none of these novels engage in any significant way with the broader LGBTQ movement in Italy. There are a couple of brief mentions of activism, but none of the characters belong to groups or associations, or seek support from them. While obviously not all people who identify as LGBTQ are also activists in the same way, the collective impression from these novels is that gay men and lesbians who want to become parents in Italy are isolated and lack support networks, which is not necessarily the case: the Famiglie Arcobaleno network has been very active over the past 15 years, and its Presidents have often been interviewed on TV, or in newspapers.[15] While not every LGBTQ+ parent would want to join the association, it is striking that these novelists have chosen to ghost out not only same-sex parents but also this quite successful activist community. However, I want to try to look beyond these narrative stumbling blocks and reflect more broadly on what we look for, and hope to find, in literature that engages directly with politically and ethically charged issues like same-sex parenting. My view is that, especially in contexts like Italy where historically queer representation has been either lacking or largely pathologizing, and where the contemporary situation remains hostile, authors who choose to represent these stories need to be aware of the potential political resonances of their narratives.[16]

In making sense of the significance of these novels, I turn again to Love's focus on queer backwardness: she argues for the importance of acknowledging the shame, secrecy and failure historically associated with queerness, the constant costs or social damage of being queer. Love advocates preserving our connection to these emotions and experiences as we move towards the future, rather than attempting to focus instead on queer pleasures, as scholars such as Elizabeth Freeman have suggested (Love, 2007, pp. 160-162). Love seeks to trace a queer politics of damage, and discusses a series of individuals and literary characters whose loneliness, melancholy and reticence make them unlikely queer political figureheads. Yet she argues that they are nevertheless valuable figureheads. Love cites Michael Snediker, who has asked whether it is possible to "mobilize shame, shattering or melancholy as interesting, as

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[15] www.famigliearcobaleno.org, In particular, the former President Marilena Grassadonia has a very strong media presence.

[16] Here I am inspired by Chimamanda Ngozi Adichie, who stated in a 2018 talk at the British Library, while accepting the PEN Pinter Prize, that in her opinion, while they are not required to offer political views, writers have a social duty that goes along with their platform, to call out lies and problems (Flood, 2018).

opposed to merely seeming instances of fear and trembling".[17] One way of reading the novels I consider here is by seeking out and valorizing this politics of damage, of shattered lives, and the ways in which melancholia colours the texts. What can we learn from it? Can queer melancholy be mobilized?

Butler's suggestion for how this might be achieved is complex. Following Freud, she notes that actually, the distinction between mourning and melancholia is ambiguous at best: even when the subject acknowledges the loss, grieves and 'moves on', some loss is introjected and marks the ego (Butler, 1997, p. 193). In other words, melancholy is a permanent and inescapable existential state. However she does make two suggestions: "Survival [...] requires [...] raging against the dead in order not to join them" (Butler, 1997, p. 193); "Survival is a matter of avowing the trace of loss that inaugurates one's own emergence" (Butler, 1997, p. 195). We cannot and should not try to forget or minimize queer damage and loss, but Butler also advocates some anger, some action, some self-reflexivity and a will to move forward with loss rather than being paralyzed by it. Similarly, Ahmed reflects that "bad feelings" are not simply something we should try to forget, but might be considered as "creative responses to histories that are unfinished" (2010, p. 217). Rather than try to overcome such feelings, they need to be experienced and explored.

Returning to the texts, what forms of mobilization can we see? Martina and Francesca in *Quattro* seem to be in thrall to internalized homophobia and cleave to normativity in the hope of being accepted or not being discovered, hoping for what Jasbir Puar has called a temporary "measure of benevolence" meted out to assimilationist gays and lesbians through forms of liberal tolerance (Puar, 2007, p. xx).[18] Their children who survive them certainly move forward, but traces of queer parenthood are consigned to the past without having been fully or critically explored.

Mi verrai a trovare d'inverno offers a more combative picture, as we discover a letter that Giovanni wrote to Elena's father Aldo, before his death: he alludes to the 'thing' that happened between them, which took place while they were caught up in leftwing radical politics of the early 1970s. This was not a particularly gay-friendly context or period, which explains the secrecy and oblique language. Despite this, Giovanni then declares his love for Aldo, and states that what he wants most of all is for them to form a family, and to bring up their children together, which then does happen despite his death. Here Giovanni acknowledges the challenges of a gay male relationship, but refuses to give up the man he desires because of socio-cultural taboos. However, stigma and shame demand a closeted, secretive life, veiling any kind of public queer presence. To use Butler's terminology, the queerness of Giovanni and Aldo's parenting and relationships, as well as Aldo and Elena's queer desires and identities, can only emerge when it becomes clear how much of their own family history has been lost and hidden in unspoken secrecy, and how foolish and existentially damaging it would be to continue to conceal these crucial aspects of their lives and selves.

In *Sei come sei*, we see active determination to become gay parents, as Christian and Giosè sell family property to pay for the services of the surrogate, they travel many times to Armenia and put their relationship to the test, but after Christian's death, when Eva is assigned to her guardians, Giosè becomes deeply passive and seems incapable of assuming political agency. He withdraws from Eva as a result of the pressures of normative society, which has a negative impact on both of them. He insists on the importance of waiting until he is granted the legal

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[17] Snediker (2006, p. 19) cited in Love (2007, p. 188).

[18] A similar argument is made by Lauren Berlant in *Cruel Optimism*, as she discusses how the nostalgia for a perceived sense of security can lead to an unthinking "reproduction of normativity" (2011, p. 291).

right to be recognized as her father, rather than thinking creatively of ways in which he can assert his role, and be the father that she obviously needs, immediately. It is only in the last few pages that he finally articulates to himself the urgency of finding a way to be near Eva, and the novel concludes in a vaguely hopeful key.

Returning to Klee's and Benjamin's angel, we might describe these novels as narrating the moment in which paralysis before the wreckage of history begins to cede, giving way to new and uncertain movement. *Mi verrai a trovare d'inverno* and *Sei come sei* are narratives that are just able to turn their heads far enough to see and acknowledge that there is a future. The voices of Eva and Elena emerge from the chaos of loss and pain with a renewed drive to demand what they want and to act, rather than continuing as they had previously, passively accepting emotional abuse (Elena by her former lover Viola) or accepting a forced estrangement from her one remaining parent (Eva and Giosè). Eva, Giosè, Elena, Aldo, and Mattia are damaged by grief, but also by the culture of silence provoked by queer shame, and the lack of legal rights. The specific evocation of a known historical context from a queer perspective (1970s left-wing activism in *Verrai a trovarmi d'inverno*), or of the contemporary legal situation as regards non-biological gay parents (*Sei come sei*), lends the narratives a special connection with 'real' life that lingers beyond the fictional worlds of the novels and demands a critical engagement with the *reasons* for the melancholy and unhappiness. While Alicata's *Quattro* and the novels by Francini show us same-sex parenting as a phenomenon destined to burn itself out and be evoked only through a fond but toothless nostalgia, *Sei come sei* and *Verrai a trovarmi d'inverno* arguably mobilize a politics of damage that, as Snediker hoped, moves beyond "fear and trembling", towards a more assertive, combative stance. Indeed, in different ways, both novels critique and challenge the silencing and invisibilizing of queer parenting as it impacts on parents and children. Moreover, they are narratives that suggest that same-sex parenting is much more than a simple craving for normativity, since each family engages actively in its own complex rewriting of the norms. Looking forward, we might take these novels as a sign that while queer melancholy will always be with us, critical engagement with loss and tragedy can enable the construction of a future that is includes the possibility of something like happiness.

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IS IT PROGRESS OR DYSTOPIA? ATTITUDES TOWARD GENETIC ENGINEERING IN CONTEMPORARY FILM

abstract

In this paper, I will present how film, and especially science fiction, illustrates and considers the theme of genetic engineering in its ethical implications. Drawing from the work of Thomas Wartenberg, I suggest that movies can be read as philosophy, since they present philosophical argumentations in the form of narrative. I will discuss popular science fiction films that address this theme, showcasing some of the most recurrent reflections and representations of future scientific and technological developments in the field of genetic engineering. Finally, I will focus on the movie Gattaca *in an analysis that presents its philosophical argument. Quoting Wartenberg's categories, I will argue that* Gattaca *is both a thought experiment, illustrating a possible society where it is possible to decide the genetic code of one's children, and a critique of genetic determinism.*

keywords

genetic engineering, genetic determinism, cinema, science fiction, Gattaca

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IS IT PROGRESS OR DYSTOPIA?

1. Introduction. Reasoning about genetic engineering through cinema

Genetic engineering is one of the most controversial themes in several disciplines, such as medicine, bioethics and biotechnology. In addition to the problems regarding the real technological and scientific possibility to modify or alter human DNA, there are a number of ethical and legal issues. While this is often subject to discussion in the scientific world, only some topics are mentioned in the media and brought to the attention of the general public. Nevertheless, new practices have social implications and frequently suggest a perspective that is dystopian, if not apocalyptic. According to Jon Turney, the myth of Frankenstein has influenced public discussions on biology, including the recent field of genetic experimentation.[1]

It is clear that most people cannot share the complete specialist knowledge of scientists. But this does not mean that they cannot reflect on the questions that are raised by scientific progress. As reported by Russell Hardin, "civilization has only continued and progressed because we do not generally demand that our knowledge meet Locke's or even contemporary scientists' standards"[2].

In this sense, cinema can tell us something about how scientific knowledge is represented in images and how wider audiences, beyond the scientific community, understand it. Cinema clearly addresses a mass audience and, as such, it divulges scientific content without however going into too much detail. After all, the main objective for a cultural narrative is not to fully report on the complexity of scientific research but to reflect on certain issues of wider significance. This does not mean, however, that at least some films are not extraordinarily capable of conveying a deeper insight, to the point of presenting philosophical arguments through their images and narration. Obviously, not all films intend to offer a philosophical reflection on a specific theme. Most of them express an opinion, but it is one thing to state a thesis and another to argue for it. Therefore – following the indications of Thomas Wartenberg and Stephen Mulhall – I shall suggest that movies only contribute to philosophical thinking

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[1] Turney, J. (1998). *Frankenstein's Footsteps. Science, Genetics and Popular Culture*, New Haven: Yale University Press. See in particular chapter 9.

[2] Hardin, R., "If It Rained Knowledge", *Philosophy of the Social Sciences*, 33 (1), 2003, pp. 3-24:22. Moreover he writes: "I think ordinary knowledge is defensible as the best way to go most of the time, very nearly all of the time. One should not be very harsh on the lack of scientific foundations for most of our thinking because there is simply no time for us to investigate the truth of even a small fraction of the things we know. [...] Our task is either by instinct or by deliberate judgment to know when to investigate and when to go with what we already know". Ibid., p. 5.

when they do not simply express a particular ethical opinion but also argue for it, albeit in narrative form.

This article shares Wartenberg and Mulhall's view that at least certain movies are capable of philosophical intervention (§2). On this basis, it considers several movies on the theme of genetic engineering, throughout the history of cinema. By focusing on some particularly recurrent representations, fears, hopes and ethical arguments, I seek to offer a categorisation (§3). Moreover, my contribution focuses on one of the most philosophical science fiction movies on genetic engineering to date: *Gattaca*, an American film written and directed by Andrew Niccol in 1997 (§4). Based on the criteria set out in the following discussion, I aim to demonstrate that *Gattaca* not only takes a specific position on this theme, but also develops a precise argument through its narrative.[3] Finally, in the conclusion (§5), I will briefly discuss the main thesis of this movie, which is both a thought experiment – the description of a future in which it is possible to predetermine the entire DNA of human beings – and a critique of the view that a perfect screening of human DNA could imply a real and desirable genetic determinism.

2. Can movies philosophize?

From Ingmar Bergman to Woody Allen and beyond, film has always played an important role in bringing philosophical problems to the attention of wider audiences. Many philosophers have studied the relationship between philosophy and cinema from very different perspectives: Gilles Deleuze[4], Walter Benjamin[5], Slavoj Žižek[6], Stanley Cavell[7], Stephen Mulhall[8] and Thomas Wartenberg[9], among others. In *Thinking on Screen: Film as Philosophy*, Wartenberg lists several narrative techniques through which films may present philosophical arguments. Narrative itself is of course an argumentative method that is also used in philosophical writing, from Plato and St. Augustine to Friedrich Nietzsche and Jean-Paul Sartre. As Wartenberg explains, these cinematographic narrative techniques include: the explicit illustration of a philosophical theory (for example, *Modern Times*), the elaboration of a thought experiment (*The Matrix*) and the ability to provide a counterexample to a philosophical thesis (*The Eternal Sunshine of the Spotless Mind*). In addition to this list, there is also so-called self-writing, which takes its origin from an individual biographical story and draws existential conclusions about the meaning of life and human agency[10].

According to Wartenberg, cinematic thought experiments bear the same function as they would within a philosophical text, until they become true counterexamples of certain epistemological, socio-political and moral theories:

> Here, I only want to point out that thought experiments are one example of the presence of a narrative in philosophy. Even though a thought experiment tells a

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[3] *Gattaca* (1997, 106 minutes). Directed by Andrew Niccol, starring Ethan Hawke, Uma Thurman, Alan Arkin, Jude Law.

[4] Deleuze, G. (1986). *Cinema 1: the Movement-Image*, Minneapolis: University of Minnesota Press – followed by Deleuze, G. (1989), *Cinema 2: the Time-Image,* Minneapolis: University of Minnesota Press.

[5] Benjamin, W. (2008), *The Work of Art in the Age of Mechanical Reproduction*, London: Penguin.

[6] See Žižek, S., *The Pervert's Guide to Cinema*, directed by Sophie Fiennes, 2006 (150 minutes) – followed by Žižek, S., *The Pervert's Guide to Ideology*, directed by Sophie Fiennes, 2012 (136 minutes).

[7] Cavell, S. (1980), *The World Viewed. Reflections on the Ontology of Film*, Cambridge: Harvard University Press.

[8] Mulhall, S. (2008), *On Film*, London and New York: Routledge.

[9] Wartenberg, T. (2007), *Thinking on screen. Film as Philosophy*, London and New York: Routledge.

[10] Mordacci, R. (2019). *Filmmaking as Self-Writing: Federico Fellini 8½*. In C. Rawls, D. Neiva, S. S. Gouveia (Eds.), *Philosophy and Film. Bridging Divides* (pp. 174-184), New York and London: Routledge. See also Russo, M. (2020), *Existentialism and Cinema: The Dialectic of Bad Faith and Authenticity in Federico Fellini's 8½*. In A. Betschart, J. Warner (Eds.), *Sartre and the International Impact of Existentialism* (pp. 363-375), Cham: Palgrave Macmillan.

> particular story, the truth that intends to validate is general, for it does not rely on the specific details of the narrative. Instead, the story is presented in order to persuade the reader of the truth of general principle of which the thought experiment's narrative is but an instance.[11]

Wartenberg does not specify in detail how it is possible to distinguish a simple thought experiment from a philosophical one. Is there a difference? In a thought experiment, one or more characteristics of natural experience are usually suspended in order to investigate what the consequences might be. For this type of imagination to be truly philosophical, the consequences must be deduced in a coherent and logical way. It is not enough to just use fantasy or creativity but it is necessary to develop this fantasy coherently through images, in a world with realistic elements. Therefore, even if many movies are based on thought experiments, only those that conduct such experiments with rigour and consistence will be considered as philosophical movies, for the purpose of this inquiry.

Many of the films discussed in this essay present numerous ethical concerns. In particular, it is interesting to note how many filmic characters hold opinions and points of view that resemble, in a simplified form, the positions of philosopher Hans Jonas. His principle of responsibility[12] tried to establish a normative criterion for an ethics of technological society, being aware of the fact that progress confronts human beings with unprecedented challenges. For the first time in history, thanks to unprecedented technological developments, human beings hold the power to destroy nature, or to imagine possible futures on Earth in ways that were not even imaginable before. In particular, Jonas focused his attention to the long-term consequences that would mainly affect future generations. In this context, Jonas appealed to the so-called fear heuristics, which basically invites humans to imagine the worst possible scenario for every circumstance, in relation to technological developments. The popular films mentioned in the next paragraph do not cite the philosophy of Jonas, with all its implications and possible objections, but they similarly imagine terrible scenarios that follow scientific and technological discoveries related to genetic manipulation.

In fact, a rather cautious attitude towards new methods such as genetic manipulation, cloning, human experimentation and so on is represented in many movies. This position seems to emerge as a reflection of what many people without specific scientific competences think: being able to intervene on human DNA is a fascinating scientific progress, but also one that can get out of hand or be used with profoundly immoral intentions. In this sense, cinema does not appear of particular interest as an object of philosophical analysis, because it tells us little about recent advances in genetic engineering. Its goal, it could be argued, is not to contribute to scientific research (although some science fiction films, from *2001: Space Odyssey* to *Interstellar* have engaged scientists both in the writing of the script and in the production of some scenes). At the same time, however, cinema (as well as literature, but probably in a more intense way) provides one of the most powerful means of elaborating fears and moral intuitions, for those who do not belong to the scientific world. Cinema therefore has much to say about how societies deal with scientific progress, and about doubts or moral resistance. In cinematographic narration, it is possible to imagine thought experiments that show what the world could become if human beings achieved a full development of both scientific knowledge and technology.

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[11] Mordacci, R. (2019). *Filmmaking as Self-Writing: Federico Fellini 8½*, cit., p. 36.

[12] Jonas, H. (1985), *The Imperative of Responsibility: in Search of an Ethics for the Technological Age*, Chicago: University of Chicago Press.

I have chosen a particular movie, *Gattaca*, to demonstrate how film can function as a philosophical thought experiment, illustrating a society where it is possible to choose the genetic make-up of one's children and to foresee their future and talents. This movie imagines a kind of planned eugenics that goes far beyond being able to genetically intervene to cure a person or to prevent certain diseases[13]. Moreover, the film provides a counterexample to the theory according to which scientific progress can configure itself as a perfect genetic determinism and as a morally desirable step forward for humanity.

Before I discuss this film, I want to mention how similar issues are treated in other movies, many of which are mainstream commercial films without any explicit philosophical intent. I will cite these works because they are indicative of how the theme of genetic engineering is addressed in film and specifically in the precise filmic sub-genre of science fiction (sometimes political fiction), which very easily borders into fanta-horror. This suggests that fears, in the collective imagination, have exceeded hopes.

The link between science fiction storytelling and bioethical reflection has been highlighted in relevant critical literature. For example, Bert Gordjin and Henk ten Have write that

> There seem to be certain analogies between science fiction and bioethics. Both combine science and morality in thought-provoking ways. The science fiction genre, triggered by the continually accelerating pace of research and innovation after the Industrial Revolution, offers fictional reflections on developments in science and technology and their various impacts on the human condition and society, among them effects on morality. [...] After all, science fiction can be very rational and scientific whilst bioethics can be quite colourful, full of narratives and geared towards social activism.[14]

3. Movies and genetic engineering: tales made by fears and nightmares

As mentioned before, I will focus on movies as thought experiments that imagine a possible development of certain practices of genetic engineering. Based on their argumentative ability and consistency with scientific evidence, these films are clearly more interesting, from a philosophical point of view, than others, which simply exploit the science fiction theme to reach a certain target and to employ certain techniques of special effects and action.

The most famous set of movies about genetic experiments is, of course, *Jurassic Park*[15]. The first film in the series, directed by Steven Spielberg, (1993) features a scene, which illustrates a *de facto* genetic manipulation: the blood of a mosquito living in Jurassic times, imprisoned in a fossil, is mixed with the DNA of a frog to produce dinosaur clones. One of the merits of this film lies in its ability to reach a wide audience and to bring the theme of genetic engineering to the attention of mass culture. There is often a time when a theme, whether scientific or philosophical, comes out of academia and settles forcefully in the collective imagination. In this plot, the billionaire John Hammond has the plan to resurrect dinosaurs, which have been extinct for over 60 million years. It is only thanks to a cocktail of genetic combination that Mr. Hammond has succeeded in the cloning processes that result in the ability to recreate some dinosaurs on Isla Nubar, an island off Costa Rica, with the aim of creating an amusement park.

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[13] This distinction is presented in the entry of the Stanford Encyclopedia of Philosophy: "A common distinction in the medical world is that between 'treatment' and 'enhancement', where the general idea is that biomedical interventions that are designed to restore or sustain health count as treatments while those that go beyond restoring or sustaining health count as enhancements."
https://plato.stanford.edu/entries/genetics/#ShouGeneUtilForHumaEnha

[14] B. Gordijn, H. ten Have, "Science fiction and bioethics", *Medicine, Health Care and Philosophy* (2018) 21, p. 277.

[15] *Jurassic Park* (1993, 126 minutes). Directed by Steven Spielberg, starring Sam Neill, Laura Dern, Jeff Goldblum, Richard Attenborough, Samuel L. Jackson, Martin Ferrero.

The situation will get out of hand, although the franchise produces several sequels where the audience will see that some dinosaurs can develop a kind of empathy towards their human trainers.

Many other films, less known, have also dealt with this topic. In the following list, I will try to divide them into subgroups, to indicate that there are several ways to treat this theme.

1) The first group includes films that represent images of our deepest fears and depict dystopian scenarios that warn us against the pitfalls of technological development. One of the first science fiction horror films to tackle the problem of genetic manipulation with the technology of its time is a 1932 movie called *Islands of Lost Souls*[16]. In the plot, a castaway arrives on a remote island in Oceania where he meets a scientist who lives with strange creatures, including a young and fascinating woman, Lota, who only appears to be a woman. This scientist is researching the evolutionary possibilities of plants and animals trying to transform them into human beings through plastic surgery, blood transfusions, glandular extracts and X rays. The tools of his bio-anthropological research obviously do not include genetic manipulation but it is clear that the director has something like that in mind (Watson and Crick will discover the double helix structure of the DNA molecule in 1953). Lota is herself actually the result of the prolonged manipulation of a panther. The film ends with the sacrifice of this creature, in order to help the protagonist escape. This movie is classified as a horror film, and the creatures, not intrinsically evil or bad but dangerous, are depicted as the protagonists of a waking nightmare that ends only when the survivor manages to return to England and the civilized world. So, in this movie scientific progress is presented as fascinating (the protagonist is attracted to Lota and betrays his girlfriend with her), but in reality, is dangerous and can become a threat. It suggests that it is better that such fantasies remain confined to daydreams. Many years later, the 1986 film by David Cronenberg, *The Fly*[17], puts us in front of an even more distressing nightmare, which questions the very personal identity of the protagonist, in his becoming something other than himself. The scientist Seth Brundle manages to build a teleportation machine, into which he accidentally enters without realizing that he is not alone: a fly has also entered into the machine with him. Progressively, his body begins to unravel as he discovers that his DNA has been altered and mixed with that of the fly, because the teleportation machine had not been programmed to identify two creatures and thus automatically merged them together. The scientist turns into a terrible creature worthy of a body horror that ultimately made a lot of people feel sick at the movie's premiere in Toronto. In this case too, the theme of the possible modification of human DNA refers to a horrific scenario, which incarnates the worst nightmares. A total loss of humanity is expected as a result of this genetic combination, which runs counter to the laws of nature. The protagonist becomes a giant insect, bringing out the brutality of an animal with which it is impossible to reason, and which inspires only fear. So, this first group of movies includes thought experiments that describe a loss of humanity through the use of technologies that are always associated with unintended and particularly disastrous consequences.

2) A second group of movies could include films like *Blade Runner*[18] (1982), a film that radically questions the positions associated with the first group: the problem here is not that genetic manipulation creates something inhuman; rather, human beings have become inhuman in

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[16] *Island of Lost Souls* (1932, 71 minutes). Directed by Erle C. Kenton, starring Charles Laughton, Richard Arlen, Leila Hyams, Béla Lugosi.

[17] *The Fly* (1986, 96 minutes). Directed by David Cronenberg, starring Jeff Goldblum, Geena Davis, John Getz, Joy Boushel, Leslie Carlson.

[18] *Blade Runner* (1982, 117 minutes). Directed by Ridley Scott, starring Harrison Ford, Rutger Hauer, Sean Young, Daryl Hannah, Edward James Olmos.

treating the products of this manipulation as mere working tools. In this dystopian scenario, technology has exceeded all limits: we are in 2019, in a dystopian Los Angeles that looks like a visual representation of the very concept of postmodernism, where the protagonist, detective Rick Deckard, has the task of picking up some "skin-jobs". These are androids called Replicants, the last frontier of genetic engineering, who rebelled against the task for which they were programmed. Ridley Scott wonders if it is really possible to treat these Replicants as merchandise or if, instead, they are able to feel emotions (especially empathy) and pain or develop intersubjective relationships. This would make them much more like people than objects – although they carry an expiration date and are designed for specific functions. In the sequel, *Blade Runner 2049*[19], directed by Denis Villeneuve, it is even shown that a certain type of Replicants is able to conceive and give birth to a child. This would confirm the argument that Replicants should be regarded as persons and enjoy the same fundamental rights as human beings. In a different way, *Ex Machina* (2014)[20] questions the possibility of drawing a line between human beings and humanoids equipped with artificial intelligence. If a machine passes the Turing test, should we give it full human status, even if it is artificially and synthetically constructed? Or can we continue to treat it as a simple object of research, to be kept closed in a laboratory and on which to conduct experiments? This theme had already been explored in *A.I. Artificial Intelligence*[21] (2001, directed by Steven Spielberg on a subject signed by Stanley Kubrick), set in 2125, where robots practically identical to children are also able to have feelings. A little robot who has the same feelings as a human being and the same forms of emotional attachment becomes victim of bullying and strong prejudice that will lead him to be abandoned and to suffer. The protagonist of *Bicentennial Man* (1999, based on a subject by Isaac Asimov)[22] is a robot that could potentially be immortal, but who wishes to be recognized as a human being by the World Congress, at the cost of becoming mortal. In all these movies, the focus is not on the ethical limits of humanoids, but on the ethical limits of human beings. Moreover, this does not only apply to humanoids, but also to genetically modified animals. In a very realistic future, *Okja*[23] (2017), a Korean-American movie directed by Bong Joon-ho, narrates the discovery of a new race: a genetically modified super-pig whose flesh is particularly delicious. Here the dystopia is linked to the exploitation of animals for purely economic purposes. The super-pig belongs to a little girl who wants to save her at all costs, but it suffers torture at the hands of an evil corporation. First, another super-pig rapes her, then a scientist extracts a sample of live meat from her, so it can be tasted to prove to consumers that it is very good. In the end, the camera also enters a slaughterhouse where these poor animals are brutally killed and only Okja and a piglet are saved. In this case, there is no fear of the product of genetic mutation, but of human beings and their corporate multinationals, which are not at all concerned or disgusted when carrying out cruel genetic experiments out of pure economic interest and with the sole aim of further increasing their wealth.

3) A third group includes movies that consider what happens when experiments are used for

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[19] *Blade Runner 2049* (2017, 163 minutes). Directed by Denis Villeneuve, starring Ryan Gosling, Harrison Ford, Ana de Armas, Robin Wright, Jared Leto, Sylvia Hoeks.

[20] *Ex Machina* (2014, 108 minutes). Directed by Alex Garlands, starring Domhnall Gleeson, Alicia Vikander, Oscar Isaac.

[21] *A.I. Artifical Intelligence* (2001, 146 minutes). Directed by Steven Spielberg, starring Haley Joel Osment, Jude Law, Frances O'Connor, Brendan Gleeson, William Hurt.

[22] *Bicentennial Man* (1999, 132 minutes). Directed by Chris Columbus, starring Robin Williams, Sam Neill, Wendy Crewson, Embeth Davidtz.

[23] *Okja* (2017, 120 minutes). Directed by Bong Joon-Ho, starring Tilda Swinton, Paul Sano, Ahn Seo-hyun, Steven Yeun, Lily Collins, Yoon Je-moon, Jake Gyllenhaal.

profoundly immoral purposes connected to military strategies. For example, in *Watchers*[24] (1988) some scientists try to create humanoids that can be used as members of the army, the so-called Oxon. They are a sort of intersection between robots and hominids, which turn out to be dangerous and aggressive. A similar story is narrated in *Sharktopus*[25] (2010), a horror science fiction in which a strange creature, half shark and half octopus, causes death and destruction. This creature is the result of genetic experiments carried out by a mad scientist working for the military force in order to create a new weapon. In a predictable way, the scientific team loses the control device, and that is where the problems begin. Similarly, in *Rampage*[26] (2018), a movie based on a videogame, the protagonist has to deal with a gorilla, a wolf and a crocodile that have grown out of all proportion because of a genetic experiment that ended badly and threatened to destroy Chicago.

4) Another group of films, very similar to the previous one, explores situations where genetic manipulations are made for the good of mankind, but with apocalyptic consequences. In *Mimic*[27] (1997), directed by Guillermo Del Toro, two scientists combine the DNA of many species to save the lives of New York children by eradicating a powerful virus. Three years later, monsters that look like giant insects begin to appear on the subway in search of human beings. As the title suggests, these creatures are also capable of imitating human appearance. Likewise, in *Deep Blue Sea*[28] (1999), a team of researchers works in the middle of the sea to find a cure for Alzheimer's and uses captive sharks as guinea pigs. These sharks break free and due to the genetic manipulations which they have undergone they become as intelligent as human beings.

5) The only filmic genre in which genetic manipulation is not considered a threat is that of superheroes. In the realm of superheroes, there are several characters who have undergone genetic mutations: *Spiderman*[29], for example, is the result of the union of Peter Parker's DNA and a particular type of genetically modified spider, while the Maximoff twins in the *Avengers*[30], Hulk and Deadpool[31] are the product of a genetic manipulation that was carried out in military laboratory. Differently, the *X-Men*[32] are creatures with natural and unpredictable genetic mutations and in all the films of the saga the problem is centred on their battle for fundamental rights. The genetic mutant is here mostly used as a face of "the outcast", which is often unduly excluded from society. This idea is well represented by one of the most radical mutant leaders in the *X-Men*'s universe, Magneto, who has been a victim of Nazi persecution in the concentration camps during his youth. The theme of genetic engineering in these sagas is more than anything intended as an opportunity to invent extraordinary

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[24] *Watchers* (1988, 87 minutes). Directed by John Hess, starring Corey Haim, Michael Ironside, Barbara Williams, Lara Sloatman.

[25] *Sharktopus* (2010, 89 minutes). Directed by Declan O'Brien, starring Eric Roberts, Sara Malakul Lane, Kerem Bürsin, Héctor Jiménez.

[26] *Rampage* (2018, 107 minutes). Directed by Brad Peyton, starring Dwayne Johnson, Naomie Harris, Jake Lacy, Joe Manganiello.

[27] *Mimic* (1997, 106 minutes). Directed by Guillermo Del Toro, starring Mira Sorvino, Jeremy Northam, Josh Brolin, Giancarlo Giannini, F. Murray Abraham.

[28] *Deep Blue Sea* (1999, 105 minutes). Directed by Renny Harlin, starring Saffron Burrows, Thomas Jane, LL Cool J, Stellan Skarsgård, Samuel L. Jackson.

[29] *Spiderman* (2002, 121 minutes). Directed by Sam Raimi, starring Tobey Maguire, Willem Dafoe, Kirsten Dunst, James Franco, Cliff Robertson, Rosemary Harris.

[30] *Avengers: Age of Ultron* (2015, 141 minutes). Directed by Joss Whedon, starring Robert Downey Jr., Chris Hemsworth, Mark Ruffalo, Scarlett Johansson, Aaron Taylor-Johnson, Elizabeth Olsen, Jeremy Renner.

[31] *Deadpool* (2016, 108 minutes). Directed by Tim Miller, starring Ryan Reynolds, Morena Baccarin, Ed Skrein, T. J. Miller, Gina Carano.

[32] *X-Men* (2000, 104 minutes). Directed by Bryan Singer, starring Patrick Stewart, Hugh Jackman, Ian McKellen, Halle Barry, Famke Janssen, Anna Paquin, Rebecca Romjin-Stamos.

characters. Superheroes are different from ordinary people, either because they are gods (Thor, Wonder Woman, Superman), or because they have developed incredible technologies (Iron Man, Batman) or, precisely, because they are the result of genetic alterations that make them superhuman (Spiderman, Hulk, X-Men, Deadpool). Often, these superheroes make bad decisions which, in proportion to their powers, can cause particularly worrying consequences. But in most cases they are able to face dramatic situations that no one else, without their powers, could solve. In fact, the abilities of characters such as the Hulk or Spider-Man imply that even a laboratory accident can trigger incredible progress, not only from a purely technological point of view. These films support, sometimes naively, the thesis that the world needs heroes, and that science can contribute to this, even if there are both positive and negative aspects. Many of these movies face moral dilemmas, but they also express a positive attitude towards science and its future.

6) Finally, there is the genre of political fiction. *Elysium*[33] is a 2013 movie where only a few elected people on a rich space station can live in luxury and have access to medical capsules that can cure any disease by intervening on patients' genetic code. All this happens at the expense of the majority of the population on Earth, who live in terrible conditions. In this case, the dystopian vision is not linked to genetic engineering. Medical advancement is considered a very precious good, a great achievement in the history of humanity. Dystopia is brought about by the fact that this resource is not equally accessible by all people, but only to a very small minority of the population, who has moved to space. Genetic engineering for healing purposes would therefore be positive if it did not produce further social injustice.

Lastly, it is impossible not to mention a 1980 movie based on Aldous Huxley's dystopian science fiction novel *Brave New World* (1932)[34]. The themes of the novel and of the movie are eugenics and mental control, tools used to create a new model of society. The title itself means "an excellent new world": we are in 2540, in a society based on the mass production of both goods and human beings. Scientists use extrauterine reproduction managed in special factories where the very concept of family is discarded, as there are no more bonds between parents and children and natural children are avoided with a compulsory contraception. Society is divided into castes from birth: some embryos are deprived of oxygen for a certain period in order to impose mental retardation or lower development possibilities in both physical and intellectual domains. Psychophysical conditioning is then carried out through the use of continuous slogans, social coercion and control. Superficially, this fictional world appears to be a perfect society where there are no worries, but in the end we understand that it has sacrificed freedom, personal feelings, critical thought and family with its bonds and authentic relationships. *Gattaca* develops this dystopian scenario, revised in a more contemporary perspective.

4. Gattaca. Is a complete genetic determinism possible or desirable?

This film has attracted great interest.[35] It is both a thought experiment that presents many of the risks and hopes associated with genetic engineering and a critique of the idea that a complete genetic determinism would be possible or desirable. Two quotations at the beginning of the film already introduce the audience to the film's narrative: "Consider what God has

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[33] *Elysium* (2013, 109 minutes). Directed by Neill Blomkamp, starring Matt Damon, Jodie Foster, Sharlto Copley, Alice Braga, Diego Luna.

[34] *Brave New World* (1980, 180 minutes). Directed by Burt Brinckerhoff, starring: Julie Cobb, Bud Cort.

[35] See also: Baldwin, J., "Posthumanist Panic Cinema? The Films of Andrew Niccol", *Cinema: Journal of Philosophy and the Moving Image*, 7, 2015, pp. 86-106; Murphy, P., "Using 'Gattaca' to teach Genetic Discrimination", *Film and Philosophy* 13, 2009, pp. 65-76; Jeffreys, M., "Dr Dedalus and His Minotaur: Mythic Warnings about Genetic Engineering from J.B.S. Haldane, Francois Jacob, and Andrew Niccol's 'Gattaca'", *Journal of Medical Humanities*, 22(2), 2001, pp. 137-152; Palese, E., (2012). *Benvenuti a Gattaca. Corpo liquido, pedicopolitica, genetocrazia*, Milan: Mimesis.

done. Who can straighten out what he made crooked?" (Ecclesiastes 7:13) and "I not only think we will tamper with Mother Nature. I think Mother wants us to" (this is a quote from Willard Gaylin, co-founder of The Hastings Centre and a noted professor of psychiatry at Columbia University). One of the promises of genetic engineering that is presented in this movie is that parents of the future will be able to design their children, in a perfect realization of what Michel Foucault has defined as biopolitics. This is the definition offered in *The Birth of Biopolitics*:

> The theme [of the course] was to have been "biopolitics", by which I meant the attempt, starting from the eighteenth century, to rationalize the problems posed to governmental practice by phenomena characteristic of a set of living beings forming a population: health, hygiene, birthrate, life expectancy, race... We know the increasing importance of these problems since the nineteenth century, and the political and economic issues they have raised up to the present. [...] How can the phenomena of "population", with its specific effects and problems, be taken into account in a system concerned about respect for legal subjects and individual free enterprise?[36]

In *Gattaca*, humans have the opportunity to obtain a perfect body from birth, which is virtually invulnerable to diseases and a key to having a high standard of life and a leading role in society. The title of the movie takes its name from the initials of the nitric bases of DNA (guanine, adenine, thymine, cytosine). The film itself is a sort of "genetic" recombination of different genres, from science fiction to thriller, from romance to drama. Gattaca is not a utopian city (or, on the contrary, a dystopian one), but an aero-spatial entity, an important corporation. Usually, dystopia is set in a model city that turns out to be the opposite of a harmonious place, as in the case of *Brave New World*. In *Gattaca*, by contrast, dystopia is not shown through catastrophic scenes; it is embodied in the logic of a company, as to signal also the contemporary supremacy of economics over politics. The protagonist is Vincent Freeman (the surname is intended ironically): a man who is paradoxically identified as an invalid because he was conceived naturally in a world where those who can afford it program their children through a test tube fertilization, determining strength, height, virological resistance, as well as the colour of eyes and hair. According to Vincent's genes, he is likely to be very myopic, too emotional, and likely to die before the age of thirty due to heart problems. In this society, a choice is made when one wants to have a child, and this choice is clearly based on the family's economic situation. One can have imperfect children, born the old-fashioned way, or perfect and genetically modified children through the aid of a biological laboratory at extra cost. Artificial conception in genetic laboratories is regarded as the "natural" method, in a radical semantic reversal of the term "natural" itself.

What the audience sees is a world where everything is predetermined by an individual's genetic map – including their chances of finding a job and being hired. These are the premises to the argument which *Gattaca* develops. Given these conditions, several questions arise: 1) Is it really possible to determine a person's life, without leaving the slightest room for contingency, unpredictability and free will? 2) Are we sure we can only achieve better results by programming genetically perfect individuals? 3) Is it morally desirable not to leave room for chance or for the individual's capacity to improve on the basis of their own experiences and willpower?

The movie starts with Vincent inside of Gattaca: he is one of the company's most prestigious

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[36] Foucault, M. (2008), *The Birth of Biopolitics. Lectures at the Collège de France, 1978-79*, Hampshire: Palgrave Macmillan, p. 317.

employees. The director of his space mission was killed, and finding out who did it is one of the film's narrative mechanisms. Vincent is suspected for this murder, even if he is innocent. Moreover, the detective on the case discovers that he is Vincent's brother, Anthony, a brother whom he has not seen in years. From the very beginning, Vincent proclaims in a voiceover that he is not what others expect him to be:

> The most unremarkable of events. Jerome Morrow, Navigator First class, is only days away from a one-year manned mission to Titan, a Saturn's satellite. Nothing so unique in that. Last year over one thousand citizens from every walk of life embarked on some space mission or other. Besides, selection for Jerome was virtually guaranteed at birth. He is blessed with all the physical and intellectual gifts required for such an arduous undertaking, a genetic quotient second to none. No, there is truly nothing remarkable about the progress of Jerome Morrow, except that I am not Jerome Morrow.

Vincent Freeman is an "invalid", but in order to enter Gattaca, he pretends to be Jerome Morrow, a "valid". *Gattaca* is a society where maximum happiness corresponds to having a product without errors, flaws, or surprises. From the very beginning, the film is based on the contrast between Vincent and his double, who is often also a nemesis. This role is occupied alternately by his perfect brother Anthony and the real Jerome Morrow, who lends him his identity. This real Jerome ended up in a wheelchair due to an accident and needs food and shelter: this is the pact between the two men, who in fact live together. Vincent refused to accepted the fact that his fate was already written in his DNA. After having beaten his "perfect" brother in a swimming competition one day, he decided that nothing is impossible, refuting the biological determinism that dominates the logics of his society.
Vincent decides to become a genetic pirate, making a deal with the "invalid valid" Jerome. Through this exchange of identities, Vincent succeeds in realizing his dream. His job interview is held in a place that seems perfectly sterilized: an environment that seemingly does not accept imperfections. After the laboratory technician has tested Jerome's urine, we witness the following dialogue:

> TECHNICIAN (reading off the profile): Congratulations.
> JEROME (perplexed): What about the interview?
> TECHNICIAN (referring to the cup): That was it.

Clearly, genetic planning meets certain market needs. A company like Gattaca cannot risk hiring someone who may not be able to accomplish their task: it would be a bad investment. Economy is a more important decision-maker than politics. In the world of *Gattaca*, there is the crime called "genoism" – discrimination on the basis of genetic code – but this is simply ignored by corporate policies. Genetic tests, in fact, are presented as similar to anti-drug tests. We are not in the *Brave New World* universe, where politicians scheme to create the perfect society even if turns into a dystopian. Differently, at the centre of this society lies the relationship between business policy and consumers. They can choose whether to employ private economic means to guarantee their children a better future (there is nothing like "the common good", or "the future of a better community"). Genetic engineering is more related to a capitalist system than to Nazi eugenics: there is no idea of race and no discrimination based on ethnicity or gender. The real discrimination that humans have to deal with have an economic basis. In the background, of course, there is the imperative of greater productivity, which has been analysed by Marxist thought and the Frankfurt School, and in particular by

Herbert Marcuse[37] through his idea of the dominance of the performance principle. In the capitalist system, productivity and performance become a priority even over the primary needs of man – which begin to be manufactured according to productivity itself: this is the self-referential system that creates needs and desires.

In this movie, individuals treat their bodies like merchandise, but in doing so, a paradox emerges: human beings are deprived of their potential development in order to perform as a very functional item. Blood, urine, hair and skin residue from Jerome are the accomplishments that Vincent presents to get into Gattaca. This biological material is the symbol of Jerome's identity. They are partial objects but, even if detached from the body, they are supposed to preserve the identity of the subject. At the same time, Vincent needs to eliminate his biological residue, because he cannot exhibit but must hide his authentic identity. However, just like Vincent's surname, Freeman, has its own meaning, so the name that is given to the real Jerome when he gives up his identity has a specific connotation: Eugene, which indicates a good gene– here too, there is an ironic aftertaste. In fact, although the real Jerome was endowed with every possible genetic advantage, he did not live a happy life without any kind of accident.

So, the film asks: does human DNA fully predetermine a person's identity? This is the thesis of the director of the company, who is questioned by the police and asked to find the culprit for the murder of his colleague. Referring to his genetically over-qualified staff he says:

> DIRECTOR JOSEPH: "They are bodies adapted to the minds. This is increasingly essential now that we push ourselves further and further. [...] No one exceeds their potential."

However, the director's argument is denied by Vincent's very existence. *Gattaca* can therefore be read as a counterexample to the thesis according to which no one exceeds their genetic potentialities because everything has already been decided in a sort of genetic determinism. Moreover, the director adds,

> DIRECTOR JOSEPH: "[...] or we failed to measure their potential."

The director means this literally: he refers to the technical measurement of blood or urine. However, his phrase has a double implication: it can also mean that using genetic mapping to measure an individual's potential is epistemologically wrong. Just as there is no gene for destiny, there is no gene than can predict the real potential of an individual. As underlined by Jon Baldwin,

> The film can be seen to pose ethical questions around biological materialism and the concept of the human genetic determinism. It explores the use of biometrics to construct the ideal human and the elimination of otherness by way of the eradication of 'in-valids' – or as they are also called in the film 'de-gene-rates' – susceptible to genetic 'disorders'. This is the cognitive and nanotechnological-neurological future. The advertising strapline of the film indicates where it sits in the posthuman debate: 'There is no gene for the human spirit.'[38]

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[37] See Marcuse, H. (1974), *Eros and Civilization: A Philosophical Inquiry into Freud*, Boston: Beacon Press; Marcuse, H. (1991), *One Dimensional Man: Studies in Ideology of Advanced Industrial Society*, Boston: Beacon Press.

[38] J. Baldwin, "Posthumanist Panic Cinema? The Films of Andrew Niccol", cit., p. 92. He adds in his conclusions: "Cloning and generic engineering (*Gattaca*) are to be faced with a notion of the human spirit that is not reducible to materiality". Ibid., p. 102.

This aspect is not even understood by the police, whose investigations are exclusively genetic. The irony is that they are so focused on genetic mapping that even when Vincent's photo appears on the computer screen – he is the primary suspect since his authentic biological material was found near the crime scene – no one recognized him because everyone sees him as Jerome. There are no interviews, but only continuous scientific testing of hair, eyelashes, blood and urine. The whole identity of human beings is in fact completely flattened on the biological one.

In one of the last scenes, Anthony understands that his brother Vincent is not to blame for the crime, but the two have a new confrontation, which again becomes a challenge of courage and physical endurance. They throw themselves into the open sea again, and again the miracle happens: in testing their bodies, the "invalid" exceeds the genetically valid younger brother. Consequently, the first time Vincent beat Anthony cannot be seen as a case of pure luck.

In the final scene, Vincent is about to leave for his mission to space, but one last unexpected test finds him completely unprepared. The lab technician Lamar tells him the truth about his son while he examines his test:

> LAMAR: "Did I ever tell you about my son, Jerome? He's a big fan of yours. He wants to apply here. [...] Unfortunately, my son is not all that they promised. But then, who know what he could do."
>
> Even though he discovers Jerome's true identity (and perhaps he always knew it), Lamar lets him free to go on the mission with the following words:
>
> LAMAR: "Have a safe trip, Vincent."

5. Conclusion: (Vincent) Freeman against genetic determinism

Gattaca certainly shows that genetic programming involves a social injustice: only some people can access this service. Consequently, a new type of social status is generated within this kind of society. However, this is not the only thesis supported by this film, which can make us reflect by imagining a hypothetical future in which humans will have complete control of their genetic heritage. Perhaps, a total and infallible prediction of one's own possibilities from DNA is impossible, because people's real commitment and free will mean something. Obviously, this film does not criticize a specific current position of the scientific community (i.e., a naïve determinism), but a possible drift that is philosophically well argued and developed coherently from credible premises. What emerges from this philosophical thought experiment and counterexample is that human beings, both in their physical and mental abilities, do not totally respond to the technological calculations of genetic engineering. Genetic mapping is not, as *Gattaca*'s scientists would claim, capable of mapping human beings and of predicting them completely, but it is only a scientific instrument.

Finally, the other aspect that clearly emerges is that a complete genetic programming does not necessarily produce a better life: the real Jerome attempted suicide (the accident that forced him into the wheelchair was not accidental at all), because he was not able to become a swimming champion even if he had every genetic predisposition. His sense of failure is enhanced by the perfection of his genetic map. And it is no accident that he finally lets himself die in a terrible way: inside an incinerator, like waste (even though, from a narrative point of view he does so not to put Vincent in trouble, to leave no trace of his biological material). Therefore, according to *Gattaca* – which is one of the most profound and philosophical filmic representations of genetic engineering – scientific progress does not strip human beings of their own secrets and mystery, which is perhaps also the mystery of the universe. The film ends in space, in a sort of second birth for Vincent (the tunnel which he enters to access the shuttle seems to recall the exit from the womb). The last suggestion that *Gattaca* makes is a different image of the totality of human beings: not the perfect body of genetic engineering which raises important ethical questions and implies inevitable dilemmas, but the reunion with the true totality: nature, space, universe.

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SECTION

2

SECTION 2

PHILOSOPHICAL ORIENTATIONS

Carmen Dell'Aversano, Florian Mussgnug
Parenthood, Climate Justice and the Ethics of Care: Notes Towards a Queer Analysis

Simone Pollo
A 21st Century Reproductive Bioethics

Lucia Galvagni
New Motherhood? Embodiment and Relationships in the Assisted Reproductive Technology

Sergio Filippo Magni
Person-affecting Procreative Beneficence

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PARENTHOOD, CLIMATE JUSTICE AND THE ETHICS OF CARE: NOTES TOWARDS A QUEER ANALYSIS

abstract

This co-authored contribution takes the form of a dialogue between Carmen Dell'Aversano and Florian Mussgnug. The two discussants explore the concepts of parenthood, reproduction and care in the context of the unfolding global environmental crisis. Arguing from the perspectives of queer theory, literary studies and climate justice, they call for new strategies and attitudes towards procreation, beyond the strictures of colonizing frames of knowledge and hegemonic cultural practices. More specifically, Dell'Aversano and Mussgnug move the debate around assisted reproductive technologies in new, speculative directions that are centred on shared vulnerability and kinship, and which remain fully attentive to human and non-human relations and shared responsibilities on a warming planet.

keywords

responsibility, care, queer, parenthood, animal/human, kinship, climate justice, speculative fiction

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Our conversation explores the concepts of parenthood, reproduction and care in the context of the unfolding global environmental crisis. Arguing from the perspectives of queer theory, literary studies and climate justice, we call for new strategies and attitudes towards procreation, beyond the strictures of colonizing frames of knowledge and hegemonic cultural practices. More specifically, we seek to move the debate around assisted reproductive technologies (ART) in new, speculative directions that are centred on shared vulnerability and kinship, and which remain fully attentive to human and non-human relations and shared responsibilities on a warming planet. We come to this debate from related but distinct disciplinary backgrounds and with different urgencies, but agree on a set of assumptions. First, we share the belief that human reproduction is not in itself an inherent good and that a carefully reasoned case for the permissibility and desirability of procreation can and must be made in each and every case, in relation to the contingent factors that will be discussed in this text. Secondly, we are averse to coercive policies and mechanisms of population control that violate individual reproductive lives and futures. Finally, and most importantly for the purpose of this discussion, we object to what we perceive as a widespread tendency to discuss reproductive rights exclusively in relation to the needs of the well-resourced individualized user – frequently an inhabitant of the global North – in the face of persistent patterns of racist, colonial and heteropatriarchal violence. Against this trend, we insist that meaningful parental responsibility, not only in the context of ART, must be grounded in an egalitarian, transcultural and post-anthropocentric ethics of planetary care (Puig de la Bellacasa 2017). As gender theorist Michelle Murphy puts it, with memorable clarity: “If you cannot drink the water, there is no reproductive justice” (Murphy 2018: 109). Humans live, die and reproduce in the company of other beings. In light of this, our analysis of parenthood affirms the importance of versatile practices that hold the power to support planetary life and the more than human world, not as a mere backdrop or context for human stories, but as a co-constitutive presence that intersects with human culture and society in a single material and ethical force field.

F.M.: Let me begin by sketching the topic of our conversation from the perspective of my work in the environmental humanities. Since 2000, the concept of the Anthropocene has functioned as an important vector for cross-disciplinary research and artistic practice (Clark 2015; Davies 2016; Yusoff 2018). Novelists and visual artists have turned their attention to environmental degradation, planetary deep time and ecological entanglement. An increasing number of works have focused on natural processes and forms that are affected by human activities and impinge upon them: hurricanes, floods, unprecedented heatwaves, habitat destruction, pollution, mass extinction, and so on. These threats have already transformed our lives and, in a matter of decades or even years, will put an end to many familiar comforts and places. The climate crisis therefore requires not only urgent political action, but also a radical re-orientation of our technologies, ethics and values, and a re-assessment of what it means to be human. In this context, human procreation raises urgent and uncomfortable questions. If the human world population continues to grow in the way that it has, future humans will in all likelihood be condemned to vastly inferior lives, and may face resource wars and violence on a global scale. Other species will also suffer the consequences of human population growth, in even more direct and often fatal ways. (Wilson 2004; Heise 2016). But can and should we seek to reduce the number of human births? The problem is familiar to philosophers, and has – in recent years – been addressed with increasing urgency by social scientists, popular science authors, and ecocritics, among others (Weisman 2013; Collings 2014; Conly 2016). Several issues are at stake here: the conflict between individual rights and our entangled planetary future; mass extinction; the complexity of large social and ecological systems and the challenges they pose to demographic forecast; concerns about global inequality and about the abuse of state power; the unpredictable role of new ART. At an individual level, fears and hopes for our future and the future of our children also play a central role. How do you frame this set of concerns in relation to your research interests?

C.D.A.: My considerations on parenthood and its relationship with reproductive technologies arise from, and are connected by, a queer theory perspective. When, together with a number of colleagues from several universities, I established the first queer studies centre in the Italian university system,[1] we decided that our common work would be held together by a more abstract and general approach to queer theory than is customarily encountered in most of academia. Taking our cue from a number of pronouncements by some of the most significant queer studies scholars,[2] we chose to focus on the application of the theoretical constructs of queer beyond the historically central fields of sexuality and gender. In our view the most basic, and at the same time the most abstract, idea in queer studies is the deontologization of categories,[3] first of all of the categories towards which a given culture makes it compulsory to position oneself, those which define social identity.[4] As a consequence, in reflecting about the way the contemporary debate about parenthood in relation to reproductive technologies is framed, I will single out some details about the way the relevant social categories are conceptualized, and the relationships among them are played out. I will anticipate one major point by stating at the

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[1] CIRQUE (Centro Interuniversitario di Ricerca Queer–Inter-University Centre for Queer Research): https://cirque.unipi.it/

[2] Among the most significant: “Queer is by definition whatever is at odds with the normal, the legitimate, the dominant. There is nothing in particular to which it necessarily refers. It is an identity without an essence” (Halperin 1995: 62); “Queer [...] does not designate a class of already objectified pathologies or perversions; rather, it describes a horizon of possibility whose precise extent and heterogeneous scope cannot in principle be delimited in advance” (Halperin 1995: 62); “[A] lot of the more exciting work around “queer” spins the term outward along dimensions that can’t be subsumed under gender or sexuality at all. [...] Queer’s denaturalising impulse may well find an articulation within precisely those contexts to which it has been judged indifferent. [...] By refusing to crystallize in any specific form, queer maintains a relation of resistance to whatever constitutes the normal” (Sedgwick 1993: 9); “It is necessary to affirm the contingency of the term [queer], to let it be vanquished by those who are excluded by the term but who justifiably expect representation by it, to let it take on meanings that cannot now be anticipated by a younger generation whose political vocabulary may well carry a very different set of investments” (Butler 1993: 230).

[3] This theoretical position is outlined, and a number of its implications spelled out, in Dell’Aversano 2018.

[4] Performativity, which is arguably the most widely applied concept in queer theory, is, from the logical viewpoint, nothing but a consequence of this questioning and deconstruction of categories: unless social categories are deontologized, they cannot be revealed as nothing more than the outcome of the iteration of performances.

outset that what I think happens as a consequence of these two factors is the creation of what I would like to call a conceptual chimaera, built up of inferentially incompatible constructions of relevant concepts.

F.M.: Reflecting on the social categories of motherhood and fatherhood, I am struck by the fact that many influential thinkers have treated parental responsibility as a seemingly stable category, without adequate attention to its historical roots, shifting social functions, and uncertain future. British philosopher Onora O'Neill, for example, has argued in a landmark essay published in 1979 that "the basis of parents' obligations and rights cannot lie solely or necessarily in a biological relationship between child and parents" but must reflect the obligation to rear a child "to at least that level which will minimally fit the child for independent adult life in its society" (O'Neill 1979: 26). This important definition of parenthood places an emphasis on epistemic and relational possibilities, but fails to engage with the external pressures that I have tried to summarise at the beginning of our conversation. How can we make sense of O'Neill's definition of parental responsibility in a rapidly changing and potentially catastrophic world? Can we even decide what it means to raise a child to be "minimally fit" for life, given the unpredictability of post-holocenic societies and ecologies?

C.D.A.: Are you suggesting that analytic philosophers ought to be more attentive to the climate catastrophe?

F.M: Your question makes me think of an extraordinary thought experiment by philosopher Tim Mulgan: *Ethics for a Broken World* (2011). In this book, Mulgan introduces and explains the key texts and theories of twentieth-century Anglophone political and moral theory from the perspective of a fictional philosopher on a tragically plausible future Earth. This "broken world" has nearly exhausted its capacity to sustain life as we know it. With an unsettling mixture of anger, regret, and profound disbelief, Mulgan's future philosopher revisits what he calls "the age of affluence": our present age, whose political and ethical theories, according to Mulgan, are tragically oblivious to the basic needs of future generations of human and nonhuman denizens. *Ethics for a Broken World* does not focus specifically on human procreation, but Mulgan's project appears relevant to our topic. How would the inhabitants of a "broken world" judge twentieth and twenty-first century reproductive habits and values, and the irresponsibly consumptive behaviour of present-day global elites? Let me phrase this question differently, to engage more directly with your interest in conceptual definitions: in your opinion, does the concept of parenthood – with its rich and nuanced history of social responsibility, power and authority – offer an adequate guide to human procreation?

C.D.A.: I would like to start with a number of apparently mundane and benign considerations. The first has to do with the nature of motherhood and fatherhood. Motherhood and fatherhood are social categories, as we have discussed. More specifically, motherhood and fatherhood are social categories into which grown-ups, especially women, with very few exceptions (such as members of the clergy, in religions in which the clergy is held to celibacy) are supposed to transition as a condition of being considered full-fledged adults; evidence for this is, for instance, the stigma on women who refuse to have children, or regret having done so.[5] Moreover, motherhood and fatherhood are social categories into which one can only be legitimately

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[5] The childfree movement has been visible for some time despite vicious criticism and ubiquitous stigma, and has an established online presence. The first study of "regretting mothers" is Donath 2017.

inducted by another incumbent, who at the same time makes the transition herself or himself. Indeed, the wish to accomplish this transition, and the impossibility of accomplishing it on one's own, is one of the most important reasons people pair up. It should be born in mind that, until quite recently, there used to be no way that people could reap the social benefits (as opposed to the social opprobrium) of motherhood and fatherhood without being in a legitimate, preferably married, if at all possible heterosexual, couple; this is of course still the case in most of the non-WEIRD[6] world, and for quite a few people in WEIRD societies as well.

F.M.: Motherhood and fatherhood are relational concepts. Anthropologist Marilyn Strathern has argued that such concepts, in common parlance, are not simply expository devices (Strathern 2020: 13). They are frequently employed in a normative sense, to imply the desirability of close ties between people or mutuality of engagement…

C.D.A.: Evidence for this, as for the workings of social categories in general, is to be found in our experience of native speakers about the way language works. The principles I have just spelled out provide the underlying rationale for linguistic expressions like "giving one's husband/wife a baby", "becoming a mother", "making one's husband a father", "making one's wife a mother" etc. These phrases would not exist, and would not be conceivable, utterable, or comprehensible, without implicit reference to the category structure I have just outlined. This structure is also, in my opinion, one major reason why, despite any number of changes, both technological and social, in the way reproduction actually takes place (an egg and sperm harvested from donors can be brought to term by a surrogate, and the resultant infant be adopted by a gay man living in a polyamorous family of adults who will all rear the child together…) I believe the stories we tell about reproduction will not evolve; indeed, why I feel we are doing all we can to keep them from evolving by clinging to an outmoded, ultimately untenable, model of the mechanics, structure, and consequences of reproduction.

F.M.: I am surprised by your claim that stories about reproduction will not evolve. ART features in numerous recent works of literature. Surrogate motherhood, for example, is a prominent theme in many recent, darkly speculative novels that have been grouped together under the label of feminist dystopia (Ditum 2018). I am thinking, for instance, of Jane Rogers' *The Testament of Jessie Lamb* (2011), Louise Erdrich's *Future Home of the Living God* (2017), Helen Sedgwick, *The Growing Season* (2017), or Leni Zumas' *Red Clocks* (2018). Many of these writers have been directly inspired by Margaret Atwood's dystopian classic, *The Handmaid's Tale* (1985). At a superficial level, the success of their narratives seems to contradict your claim that category structures have survived unchallenged. But I suspect that this sense of contradiction is only apparent. Indeed, most twenty-first century reproductive dystopias are permeated by fears about the future, and by a deep sense of guilt towards unborn generations. Rogers, for example, describes a world of dwindling human fertility, where the reproductive lives of pregnant women are literally sacrificed to a violently pro-natalist regime, in order to guarantee the bare survival of the species. Similarly, *Red Clocks* imagines a world where every form of birth control or abortion is illegal. Generally speaking, many contemporary narratives of parenthood do not seek to promote alternative patterns of kinship or more hopeful

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[6] The acronym stands for "Western, Educated, Industrialized, Rich, and Democratic"; it was first introduced by Henrich, Heine and Norenzayan in their seminal 2010 paper (Henrich et al. 2010), which first systematically called into question the broad claims about human psychology and behavior based on samples drawn entirely from societies which are outliers with respect both to the vast majority of present human population, and to the totality of historical human groups.

visions. Rather, at the intimate level of literary representation, our age appears profoundly pessimistic. In most literary accounts of the future, outmoded social structures persist, with fatal consequences.

C.D.A.: The novels you mention are a good example of the ubiquitousness of cultural representations of biological reproduction. Why is there such a wealth of representations of parents and children in social discourse? Because biological reproduction is a crucial part of the way societies and culture, literally, reproduce themselves and thus achieve continuity and also, in a manner of speaking, immortality. It is therefore vital that cultures get members invested in biological reproduction. How does this happen? Through the workings of a number of social mechanisms which direct members' desires (which are always culturally constructed) towards children as a socially sanctioned object.

F.M.: The child as a symbol of futurity?

C.D.A.: Exactly. This is achieved by framing reproduction in a number of interesting ways. First, reproduction is conceived as metaphorical immortality: our children are supposed to provide us with social continuity beyond individual death. This is one major reason why people make such momentous investments (both financial and existential) in children. Secondly, reproduction becomes an overarching, unfalsifiable, all-purpose teleology, which has the added benefit of turning, by a form of social sleight of hand, selfishness and megalomania into far-sighted altruism, since the quest to achieve status and amass wealth well beyond what a single individual may under any circumstances reasonably expect to need or use in their lifetime can be justified as rational because the privileges are going to be handed down to the following generation. Of course, the children's opinion about all this is never sought: if they display no interest in occupying the place their parents carved out for them this does not in any way cast doubts on the parents' designs on them but is dismissed as evidence of ingratitude. Finally, reproduction is marked as the achievement of a hierarchically superordinate social identity: full adulthood, as defined by the relationship to dependents who owe their very existence to us.

F.M.: Does this persistent social framing of parenthood stand in the way of alternative conceptions of parental responsibility? Do we need new categories and stories that are less concerned with parenthood as a social marker and more attentive to our shared planetary future?

C.D.A.: The reason I feel it is important to spell out these considerations is that they are crucial to our ability to productively interrogate the desire to be a parent. Any human who desires to be a parent is necessarily part of a society, and therefore, by desiring to be a parent, implicitly desires not a personal relationship to an individual who does not yet exist and about whom she knows nothing, but the social role of a parent in a given society. Therefore it is impossible to interrogate the desire to be a parent without interrogating the role of parenthood in the construction of social identities. First of all, how can people become suicidally depressed because they cannot have something they never had, such as a child? It is one thing to become depressed if you no longer have the two legs which have been part of your body from birth; it is quite another to become depressed if you realize you are not going to have a third leg implanted.

F.M: Supernumerary limbs are not a widely recognised symbol of social success?

C.D.A.: Of course I am being deliberately disingenuous. Non-parents are all too well aware that becoming a parent is not like having a third leg implanted: it is like going through puberty or finding a job: it is a necessary experience to have to achieve full adult status; and this is so much more for women than for men, from the Biblical cry of Rachel to Jacob "give me children or else I die" to the contemporary women becoming "bitter" over their husbands' lack of interest in an artificial insemination by donor procedure, and eventually obtaining their probably not-too-enthusiastic consent.[7]

F.M.: Allow me to return to speculative fiction, for a moment. Atwood, Rogers, Sedgwick, Erdrich and Zumas imagine worlds on the brink of destruction: their bleak, impoverished, post-catastrophic futures are clearly recognizable as the uncannily protracted aftermaths of our own age. Their novels leave no room for progress, or for new forms of compassion and care, across and between species. Instead, ART is imagined as a bio-political nightmare. When I read these novels, I find them anxiously resonant with the vast transnational pressures of accelerating globalization, in the present: political, military and economic interests that operate on a planetary scale, weapons of mass destruction, industrialization, irreparable environmental degradation, forced mass migration, genocidal wars, and so on. What seems largely absent, by contrast, is any genuine sense of alterity: a future that is imagined not in terms of eschatological closure, but as a state of protracted uncertainty. It seems to me, then, that these fictions are involuntarily complicit with the mentality that you deplore. They mark a missed opportunity. If we want to assess the vulnerability and value of human and nonhuman life on a warming planet, we must learn to consider both the climate emergency and ART as dynamic openings: as invitations to re-think our categories.

C.D.A.: The social characteristics of reproduction as a necessary prop of full adult social status explain why the narrative about reproduction has to be kept simple: because allowing for a wealth and multiplicity of different actors and of roles would dilute the social status accruing to parents and make it ultimately less desirable. If that status crumbled, people might no longer be willing to invest the extensive amount of resources which make successful reproduction possible in human societies. In my opinion, the artificially simplified and sanitized terms in which the debate about reproductive technologies is framed nowadays is just one more instance of the widespread, and dangerous, present-day propensity to desperately cling to simplistic, "traditional" narratives which are no longer adequate but which are useful to screen us from awareness of just how messy and complex things actually are. In this respect the invisibilization of the role people beyond the "social" parents play in ART is on a par with a number of other disingenous and pernicious nostalgic narratives such as "Make America Great Again", and of course with the various nationalisms and anti-immigration sentiments throughout Europe and the neo-Europes.[8]

F.M.: A more mature reflection on assisted reproductive technology, along the lines you suggest, would also have to account for the growing interconnectedness and inequalities brought about by global markets. So-called "reproductive tourism" has perpetuated and exacerbated social divides between and within nations. Our critical re-thinking of parenthood must be attentive to these phenomena, and to the inequalities and systemic violence that are

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[7] Rachel Bowlby, "How not to have children: early arguments about new reproductive technologies", opening keynote lecture, Reproductive Health and Parental Responsibility, international conference, Roma Tre University, Rome, Italy, 23-24 April 2018. See also Bowlby 2003.

[8] The term "Neo-Europes" was coined by historian and geographer Alfred Crosby (Crosby 1986) to refer to the extra-European areas which were not only colonized by Europeans, but which to this day are homes to large populations of European descent, such as the Americas and Australasia.

inscribed in the current global political and economic order.
C.D.A.: ART offer us an opportunity to rethink social categories, social relationships, and therefore processes of inclusion and exclusion. On a level, we are well aware of this: it is exactly because we are, and because this frightens us so much, that our reaction is to make all challenges to the traditional, simplistic narrative about parenthood (such as the genetic bond between egg or sperm "donors" and children, or the biological bond between children and "surrogate" mothers) not only socially, but legally invisible, and to uniformly choose to stick to the narratives we are already familiar with, even though they are no longer viable or helpful, but are, indeed, ridiculously inadequate to account for the facts.

F.M.: We need new narratives. I note how this basic claim has shaped our present discussion, as literary and cultural critics, about parenthood, ART and the climate crisis. All these phenomena demand new forms of linguistic and conceptual inventiveness that can alert readers to unfamiliar and counterintuitive scales. As ecocritic Timothy Clark has suggested, much environmental damage happens at a scale which cannot be fully expressed by traditional realist modes of literary representation (Clark 2019: 38). It is brought about by individual human actions that are not ecologically significant in themselves but that collectively, across space and over time, threaten much of what we value about humanity and the more-than-human world. If we apply Clark's insight to the context of human reproduction, we observe that the relation between individual observable causes and vast global effects marks a stark challenge to traditional feminist accounts of agency: the personal is political, but it also resonates in planetary deep time. Cultural theorist Claire Colebrook has argued that the Anthropocene "requires us to open the classically feminist question of the *scale of the personal*: [...] is my personal sense of gender meaningful only in terms of the history of the human family, *or* in terms of the narrower history of bourgeois marriage, or might we say that the personal is geological?" (Colebrook 2017: 1-2, author's italics).

C.D.A.: On a different but related topic, it might be interesting to note that the distinction between genetic and social parents is in a way analogous to a number of other distinctions which are becoming more and more important in contemporary cultural discourse, and which invariably pit biology against social construction. An obvious example is the distinction between sex and gender, and its significance for gender studies and queer theory. To my mind this analogy is a potentially interesting and productive one precisely because of the ways it does *not* work. While in the sex/gender equation the biological component is used as a means of coercion, to "naturalize" what is a purely cultural connection between anatomy and social performance, in the genetic parents/social parents equation the social component is used to discursively marginalize and repress the significance of the biological one, as is obvious in the whole debate about donors and surrogates. I believe this is an excellent occasion to start questioning the analytically naïve and politically risky notion that there is something *inherently* theoretically shrewd and politically progressive about privileging the socially constructed above the biological: each situation is different, each deserves to be analyzed on its own terms, each may lead us to different, even to unsettling, conclusions.

F.M.: The success of concerted efforts to re-think parenthood depends on our ability to express and relate different scales and points of view?

C.D.A.: We also need to pay attention to changing historical and cultural contexts. As to the social viability of the opening up of parenthood to a larger number of actors, it might be interesting to mention in passing that in the history of the West our narrow construction of parenthood has been questioned, for instance, by the XVIII-century institution of "cicisbei", the young aristocratic men who befriended the young wives of older aristocrats and in many cases were known to all to be the biological fathers of the children of the couple, a fact that nobody found shocking (Bizzochi 2008). Our present-day anxiety about the dissolution of traditional simplistic constructions of parenthood, and about the possible emergence of new social categories ("donor" mother, "surrogate" mother and "social" mother; "donor" father and "social" father, aunt/grandmother+"surrogate" mother, friend of the family+"donor" father, and so on...) is in my opinion one of the reasons why art (literature, film, performances, installations, you name it...) continues to pick at this sore. A brilliant Italian literary theorist, who would deserve to be more widely known abroad, Francesco Orlando, maintained that art is a form of the return of the repressed (Orlando1965). If you are not comfortable with this Freudian definition, I can offer you an updated queer one: art is about anxiety about emerging and liminal constructions of identity categories and their properties. Hard cases make bad law, but they make good art.

F.M.: I find both definitions of the artistic very illuminating: Francesco Orlando's and yours.

C.D.A.: If we are willing to take a good hard look at what actually happens, as opposed to what is supposed to happen, in assisted reproduction we will get a sense of the irrepressible proliferation of "hard cases"; how messy this tangle of physiology, technology, emotions, and social relations can become, and of how unpredictable, and ultimately insoluble, this mess is. A lot of what we are used to taking for granted as "good practices" in surrogacy is designed to keep the mess at bay; for example, it is widely known that the form of surrogacy doctors like the least is the one between sisters because it creates lots of what the doctors define as "problems", and that I, as a queer scholar, would instead define as the collapse of the neat repressive compartments which are supposed to keep social categories neatly apart.

F.M.: Why does the collapse of these pigeonholes cause so much anxiety?

C.D.A.: Because the way social categories work is predicated on neat compartments, while life is messy, and the messiness of life is exactly what culture is supposed to keep at bay. Surrogacy necessarily makes things messier because the neat social construction of parenthood is complicated by a proliferation of actors most of whom are then edited out of the story. And the reason why this happens is that we need to cling to a normative narrative even when the narrative is clearly inadequate to make sense of the facts, because the only roles we know how to play, and which therefore do not fill us with unmanageable anxiety, are the roles provided to us by the normative narrative. As a queer scholar, I tend to find messiness much more interesting than neatness, both theoretically, existentially, and politically. Therefore my practical, indeed political, recommendation is: by all means, keep the babies coming, but do not edit their three mothers, two fathers and mother-aunts or mother-grandmothers out of their lives, or of our society, or of our culture.

F.M.: Until now, our conversation has focused on the concept of parenthood and on the notion of "parental responsibility". I suggest that we shift our attention to the debate about reproductive rights.

C.D.A.: Please note that I am not interested in analysing the merits of a given discourse, but only in how the discourse turns to be one that we can formulate, and what the consequences of formulating it are. Do we have a right to bring into the world a being fully equivalent to us, another human? This is philosophically far from clear, since in this way a being who is by definition equivalent to us would end up being ontologically subordinate to us, owing her very being to us. This to me is a form of ontological hubris: being the cause of the existence of, and therefore ontologically superordinate to, a being in every way equivalent to us. It should be noted that this philosophical problem owes its existence to a very recent, and still not very widespread on a global scale beyond WEIRD societies, reconceptualization of parenthood. The ontological subordination of children to parents, particularly to fathers, was an unquestioned assumption for most of human history, in most societies (certainly in all the ones I personally have ever heard of), where parents, more specifically fathers, had *patria potestas*, which in traditional Roman law for instance included the power of life and death over offspring, who were in this respect indistinguishable from slaves. The very existence in all cultures of such a thing as anthropopoietic processes[9] shows that human newborns are not considered fully human, but must be made so by a long and often gruesome itinerary. It was only very recently that in WEIRD legal discourse *patria potestas* has been replaced first by parental *potestas* shared by both parents, and then by that radically novel concept, parental *responsibility*.

F.M.: In a recent exchange with anti-natalist philosopher David Benatar, bioethicist David Wasserman has offered what he calls "a piecemeal defense of procreation" (Benatar and Wasserman 2015: 257). While Benatar regards any form of human procreation as morally unjustifiable, Wasserman holds that there can be no categorical argument against human reproduction. But he shares Benatar's suspicion of those who argue that procreation – in all or most circumstances – requires no defence. In this context, Wasserman also rejects the idea of so-called "procreative liberty", and suggests that liberal moral-political theory, with its traditional focus on the abstract, interchangeable, autonomous individual, is not an appropriate context for debates about procreation. Your own critique of the idea of procreative rights appears to strike a similar chord.

C.D.A.: I believe we should face the unsettling but ultimately inevitable realization that our present-day notion of "having a right to children" is incompatible with the equally present-day ubiquitous abhorrence of *patria potestas*. Either children are a right we can demand (which they could very well be, as long as our relationship to them was framed in the terms of *patria potestas*), or they are autonomous beings whose welfare we are responsible for (as they are now that we conceive of our relationship to them as parental *responsibility*); they cannot logically be both. For instance, health care is (at least for the time being...) a right, and therefore the personal preferences of medical personnel are not taken into account when it comes to caring for patients; indeed, the notion that they might be is intrinsically abhorrent. Patients, on the other hand, are autonomous beings health practitioners are responsible for and to, and therefore medical personnel are obliged to take their wishes, preferences, and values into account every step of the way.

F.M.: So would you agree that it is productive to imagine parenthood, first and foremost, as a practice of responsible care?

C.D.A.: I am interested in exploring how progress in ART, and the consequent reconceptualization of "parental responsibility" might make visible some hitherto unanticipated,

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[9] See Geertz 1965. Italian anthropologist Francesco Remotti has explored the implications of this fascinating issue in his important work on anthropopoiesis (Remotti 2013). Foucault's concept of "subjectivation" (Foucault 1982) is also of clear relevance, but has not, until now, been the object of systematic study, in this context.

but potentially interesting, possibilities for the application of the concept. Our conversation is inspired by a conference that was jointly hosted by Roma Tre University and University College London, in April 2018: "Reproductive Health and Parental Responsibility".[10] This juxtaposition of terms assumes a connection between reproductive health and parental responsibility, which has inspired my interest. I contend that "reproductive health", in the context of our debate, is first and foremost the health of the offspring; and "parental responsibility" is about keeping the offspring in good health, and ensuring that no offspring is produced where this is not feasible. This, after all, was the gist of O'Neill influential definition, which you quoted at the beginning of our conversation. I would like to suggest a further development, and I believe it would make sense to start by analysing the two words which make up the phrase "parental responsibility".

F.M.: Please carry on.

C.D.A.: Who is a parent? To whom? Obviously, the recent developments in the legal conceptualization of parenthood point to this: a parent is whoever ultimately causes a life to be brought into the world; if it is possible, on the one hand, to conceive as a sterile couple hiring the services of donors and surrogates to be the child's parents when she is born, and, on the other hand, to maintain that the donors and surrogates are not the child's parents, it is evident that the *only* legally meaningful condition for being a parent is being the first link in the causal chain which ultimately leads to the creation of a life. If we subscribe to this definition, I think it might be interesting to consider that most of the lives we cause to be brought into the world are not human. If it were not for us, so-called farm animals would never reproduce, not least because we have bred them in order to maximize anatomical traits which now make it impossible for them to have sex, so that in order, for example, to get more turkeys, we have to resort to artificial insemination.[11] Thus, in a way, we are the parents of these billions of creatures we bring into the world, raise and slaughter every year (in most cases actually every few weeks) only to breed more who will share the same fate.

F.M.: This is a powerful provocation. Your suggestion resonates with the demands of leading posthumanist thinkers, and pioneers a new understanding of care, in line with the political trajectories that we examined in our conversation. There is more to explore, I suspect, than

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[10] The interdisciplinary conference was supported by the UCL Cities Partnerships Programme in Rome. Speakers included philosophers Roberto Mordacci, Loredana Persampieri and James Wilson, bioscientists Aarathi Prasad and Helen O'Neill, artist Zoe Papadopoulou, and literary scholars Rachel Bowlby, Simona Corso, Carmen Dell'Aversano and Florian Mussgnug.

[11] This is how the process unfolds: "Although most turkey processing operations have been industrialized, the process of insemination must be done by hand. First, semen is collected by picking up a tom by its legs and one wing and locking it to a bench with rubber clamps, rear facing upward. The copulatory organs are stimulated by stroking the tail feathers and back; the vent is squeezed; and semen is collected with an aspirator, a glass tube that vacuums it in. The semen is then combined with 'extenders' that include antibiotics and a saline solution to give more control over the inseminating dose. A syringe is filled, taken to the henhouse, and inserted into the artificial insemination machine. A worker grabs a hen's legs, crosses them, and holds the hen with one hand. With the other hand the worker wipes the hen's backside and pushes up her tail. Pressure is applied to her abdomen, which causes the cloaca to evert and the oviduct to protrude. A tube is inserted into the vent, and the semen is injected." (Madrigal 2013). Observer 1994 offers a first-person account of what the process actually implies from the workers' perspective: "The insemination crew did 2 houses a day--6000 hens a day. Figuring a 10-hour day, that's 600 hens per hour, ten a minute. Two breakers did 10 hens a minute, or each breaker "broke" 5 hens a minute--one hen every 12 seconds. This pace pressured the drivers to keep a steady flow of birds into the chute to supply the pit. Having been through this week after week, the birds feared the chute and bulked and huddled up. The drivers literally kicked them into the chute. The idea seemed to be to terrify at least one bird, who squawked, beat her wings in panic, and terrified the others in her group. In this way the drivers created such pain and terror behind the birds that it forced them to plunge ahead to the pain and terror they knew to be in the chute and pit ahead."

we can cover on this occasion.[12] But I would like to flag two recent interventions which I think might guide further discussion. Rosi Braidotti has argued for a post-anthropocentric turn in activism and political theory, and has described this as potentially the most important legacy of feminist, queer, antiracist, ecological and postcolonial struggle (Braidotti 2017: 26-31). Similarly, Donna Haraway has called for new creative practices of multispecies kin making, which hold the power to "increase human multispecies wellbeing as means and not just ends, while radically reducing human demands and radically repairing damaged life worlds and places across the planet" (Haraway 2018: 98; see also Haraway 2016).

C.D.A.: At this point I would like to turn to "responsibility". Responsibility is, of course, a Latin word. The English equivalent is "to be answerable for, to answer to". This has two profound implications. The first is that responsibility arises in a relationship: we can never be responsible in the abstract: we are always responsible *to* someone for someone or something; in the case of legally sanctioned obligations like parental responsibility, to the law. The second is that our responsibility takes the form of "answering for" what we do or did not do: responsibility is expressed verbally in a dialogic relationship to whoever we are answerable to. These two implications have one important consequence: that unless social discourse makes it possible to articulate parental responsibility, to make it something we are called upon to answer for, parental responsibility does not exist. Of course, one major area in which parental responsibility does not exist at present is in relation to the over ten billions of creatures we cause to be born in order to eat their corpses. But since none of them would be born unless we, as consumers, literally had them manufactured to order, just like parents using donors and surrogates, it could be argued that we are, in a way, their parents. I believe the consequences of this application of the concept of "parental responsibility" to be deserving of further exploration.

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[12] For further discussion, see Mussgnug 2019.

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A 21ST CENTURY REPRODUCTIVE BIOETHOCS[1]

abstract

Since its beginnings Bioethical analyses and debates have been mostly aimed at discussing the permissibility of new practices such as New Reproductive Technologies (NRTs). NRTs are no longer "new": they are part of human ordinary life and contribute to human flourishing, allowing people to build families that could have not been built otherwise. Bioethics should take this fact into account and modify its agenda accordingly. NRTs should be regarded not as a matter of "Frontiers Bioethics" but rather of "Everyday Bioethics" even when genetic interventions aimed at "choosing" the identities of future people are at stake. A 21st Century Reproductive Bioethics should be focused on how to improve the right of every human being to access NRTs and not on a general discussion about their permissibility.

keywords

new reproductive technologies, reproductive rights, frontiers bioethics, everyday bioethics, genetic engineering

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[1] I'm grateful to an anonymous reviewer. Her/his insightful comments on an earlier version of the paper helped me to better clarify some important points of my argumentation.

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1. Bioethics yesterday and today

Usually an introductory course in Bioethics starts with the teacher stressing the “novelty” of the discipline she is introducing to her students. Bioethics is a relatively recent field of theoretical inquiry and public debate whose roots must be identified as being in the spread of new biomedical technologies and practices and, in general, in the advancement of science. The birth of Bioethics has been provoked by public concern and intellectual challenges raised by the new choices made possible by transplant techniques, IVF (*In Vitro Fertilization*), genetic diagnosis and so on. Furthermore, most of these new choices happened to become possible at an emblematic time for western democratic societies, that is the Sixties and the Seventies of the 20th Century. Those two decades have been characterized, in different forms in the various countries, by public debates and social movements aimed at rethinking the very nature of liberal-democracies in order to make them more equal and inclusive. In a sense, western societies have been shaken and challenged by movements aimed at making them more “democratic”, on the basis of the idea that democracy is not achieved only when political representation is democratic but when a “democratic form of life” is spread through society in its different institutions and practices (family, medicine, school and so on). In brief, the meeting of new biomedical choices and the new understanding of democratic citizenship triggered a debate about new rights connected to those choices, that is, the individual right to make choices in the new scenario of biomedicine (this kind of account about the birth of bioethics can be found in Lecaldano, 2005).

Most of the 20th Century Bioethics debate is occupied by discussions around the justification, nature and limits of those new rights: the right to reproduce, right to die and so on. This discussion is linked to the other main field of bioethical inquiry and debate aimed at scrutinizing the moral acceptability of such new techniques (“Is euthanasia permissible?”, “Can embryo research be performed?” and so on). Of course, the two fields are deeply intertwined and most of the answers to the questions raised regarding the first field depend upon answers given to the second one. Nonetheless, these two areas of bioethical research are not completely overlapping: from a normative point of view a particular technique/practice can be regarded as morally acceptable, but the right to use/perform it can be recognized as not being so (i.e. euthanasia can be judged per se as morally permissible and valuable on the grounds of normative quality of life, but the right to access it can be regarded as not being universal, as it is granted only under certain conditions).

Given this rough distinction between these two subfields of bioethics, a general assessment of the evolution of the bioethics debate can be attempted. In the light of these two topics, a question can be asked: is 21st Century Bioethics different from 20th Century Bioethics? Is the agenda of Bioethics still the same or did it change through the years? The answer I will try to attempt is not a "sociological" one, that is, I will not evaluate trends in bioethics literature, public discussion and academic research. Reconstructing trends in academia and society is mostly a task for sociological research and I will attempt instead to pursue a different one. I will try to develop a theoretical answer to those questions, that is I will try to argue in favour of the idea that nowadays, in the 21st Century, Bioethics must deal with an agenda that is somehow different from that of 20th Century Bioethics. In particular, I will discuss this idea by looking at some topics within a specific field of Bioethics, that is *Reproductive Bioethics*.

In general, my claim is that today agenda of Reproductive Bioethics should take into account, first, the fact that some techniques and practices regarded as "new" some years ago now they are part of human ordinary life. Since the birth of Louise Brown in 1978 it is estimated that 8 million human beings have been born thanks to IVF (data European Society of Human Reproduction and Embryology data, see: https://www.sciencedaily.com/releases/2018/07/180703084127.htm). The percentage of human beings born this way is still minimal with respect to the whole human population, nonetheless, it is a much more impressive figure with regard to the general population of countries where assisted reproductive techniques are mostly used. Whereas in less developed countries IVF is almost absent, in Europe and North America they are routinely adopted. Setting aside the issues of global international justice that might be raised by these different situations, when I speak of assisted reproduction techniques as part of daily human life, I am referring solely to ordinary life in some parts of the world. Therefore, my remarks will progress from this factual premise and will attempt to discuss whether the diffusion of assisted reproductive techniques should change the way philosophical bioethics deals with them.

The second point that reproductive bioethics should, at the present time, take into account is connected with the development of scientific knowledge about human ontogenesis. A great part of the reproductive bioethics debate has been traditionally dedicated to discussing possible responsibilities (and limits) of intervention aimed at choosing features of the offspring. Traditionally, this kind of discussion is elicited by practices such as embryo screening and selection, "germline" genetic interventions and, more recently, "bioenhancement" (Persson and Savulescu, 2014). My claim is that recent developments in the biological understanding of ontogenesis change the factual landscape against which this kind of discussion is developed. In a nutshell, an updated discussion should take into account the non-deterministic model of the genotype-phenotype relationship as demonstrated by the most recent advances in evolutionary biology.

2. Assisted Reproduction and "Everyday Bioethics"

In bioethical literature various forms of assisted reproduction are very often filed under the label "New Reproductive Technologies" (NRTs).[1] Given the approximate 8 million human beings born since 1978 thanks to various forms of assisted reproduction, perhaps whether such a definition is still appropriate for such techniques could be questioned. That assisted reproduction is part of ordinary human life does not need to be proved. Therefore, dropping the idea that NRTs are "novel" must be seriously considered. What kind of consequences could such a move entail for bioethical analysis?

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[1] The locution "Reproductive Technologies" entered the bioethics' debate very early. It can be found, for example, as a lemma of the first edition of the famous *Encyclopedia of bioethics* edited by W.T. Reich (1978). The adjective "New" attached to that locution appeared also very early in the bioethical discourse and since the first half of the Eighties the locution "New Reproductive Technologies" started to be quite a common definition used to embrace various form of assisted reproduction (i.e. Frey, 1982; Walters, 1987).

In the 90's of the 20th Century, one of the leading Italian scholars of Bioethics, Giovanni Berlinguer, suggested that a distinction should be made between "Frontiers Bioethics" ("Bioetica di frontiera") and an "Everyday Bioethics" ("Bioetica quotidiana") (Berlinguer, 2003). According to Berlinguer, Frontiers Bioethics is about novel technologies challenging ethical reflection with new problems. One of the features of Frontiers Bioethics is that it deals with technologies and practices involving a limited number of people. On the contrary, Berlinguer suggested that Everyday Bioethics deals with issues embedded in more ordinary practices of medical care. Berlinguer's aim was to stress the need for theoretical and public debate of Bioethics to not underestimate the justice issues affecting a large number of people dealing with healthcare. Stretching a little the distinction made by Berlinguer and pushing it further its original scope, it can be said that nowadays, for the most part, assisted reproduction can only be very tenuously regarded as a matter of Frontiers Bioethics, forming instead a topic for Everyday Bioethics (for a recent overview of Berlinguer's positions: Rufo, 2020).

Filing assisted reproduction under the category of Everyday Bioethics means transcending the debate about its intrinsic moral acceptability: it is *prima facie* acceptable and people use it to purse their own goals towards achieving the kind of life they judge to be good. Assisted reproduction as an Everyday bioethics issue means that its discussion and analysis should be mostly focused on the ethical issues raised by the ordinary uses people make of them. Before going into further detail about an Everyday Bioethics approach to assisted reproduction, a remark must be made about the premise behind moving assisted reproduction from Frontiers to Everyday Bioethics.

The claim that the spread and common use of assisted reproduction techniques justifies transcending the debate on their intrinsic acceptability can raise the objection that such a move means limiting the task of bioethics to descriptive ethics, dropping its normative ambitions. A full and in-depth confutation of this objection would require an analysis that cannot be articulated here. Nonetheless, a short reply against this objection can be made by recalling the fundamental character of philosophical analysis of ethics. Philosophical ethics – and therefore philosophical bioethics too – starts with human moral experience as it is and its normative task (whatever it is understood to be) cannot subvert such experience, but it can aim at critically reflecting on it and suggesting reforms based upon philosophical arguments. Philosophical ethics has neither the aim of founding the very fact of human morality nor the task of ignoring human moral experience as it is. This feature of philosophical ethics is particularly evident in a case such as assisted reproduction: both philosophical analysis and ordinary moral thinking must be engaged in a reflection on the acceptability of such technologies. Such reflection has taken place while the use of assisted reproduction has become more and more common. Therefore, we should recognize that assisted reproduction, at least in its fundamental features, has already been scrutinized and is part of ordinary human moral experience. Furthermore, it must also be recognized that assisted reproduction is, in general, understood and perceived to be something morally appreciable since it contributes to human happiness and flourishing. It helps people to pursue their plans to live the good life and it effects something that, prima facie, both for theoretical analysis and ordinary moral thinking, is regarded as morally valuable: bringing new human beings to life (for further details on this perspective in bioethics: Pollo, 2018).

3. New families, new forms of reproduction

The spreading of assisted reproduction into ordinary life is deeply intertwined with another phenomenon that took place in the last fifty years, that is the transformation of the family. Such a transformation is fundamentally characterized by two features. On one hand, the patriarchal hierarchal model has been placed into question and replaced with an egalitarian model based on gender equality and the idea that children have rights and interests that are not necessarily best represented by their parents' will. Along with the abandonment of the patriarchal model, other changes have occurred to the family: the family as based on a heterosexual relationship was paralleled by other models of families built upon non heterosexual relationships. These two facts (combined with others: single parent families, recombined families...) represent the core of the transformation real world families have undergone in the last decades. Instead of speaking of "family", nowadays, "families" is far more accurate. Of course, the old model of the family still survives and there is no unanimous consensus on the switch from "family" to "families" (assuming that a previous concept of one "family" was indeed justified). Nonetheless, the plurality of families is a fact, and such fact is recognized by the law, even if in different, incomplete or undefined ways (in Italy, for example, such a process started with the reform of Family Law in 1975, with its most recent revision being the law on civil unions enacted in 2016). As a matter of fact, the trend in Western countries is of egalitarianism towards the various forms of family (an authoritative defence of new families' recognition through marriage is: Nussbaum, 2010). Of course, recognizing such a trend does not imply that egalitarianism is fully realized. This lack of full recognition is the topic I would like to deal with here.

As a matter of fact, assisted reproduction has been one of the key factors contributing to this societal change by allowing new families to develop and flourish. Nonetheless, new families attempting to have babies through assisted reproduction have struggled, and still struggle with inequalities with respect to the right to access such techniques. Many countries still allow access to assisted reproduction just to heterosexual couples and only if they prove to be in a "stable relationship" (Italy is among such countries). Single and non-heterosexual parents-to-be- are forced into so called "fertility tourism", or else relinquish their reproductive plans should they not have resources to try to do abroad what they are prohibited to in their own countries. Therefore, one key issue of 21st Century Bioethics is the right to equal access to assisted reproduction techniques for people living in all different forms of families.

As a matter of fact, such a topic seems to be an old one, since – as stated before – it has been debated since the very beginning of assisted reproduction techniques. Nonetheless, my thesis is that the way this topic should be raised today is substantially different from the way in which it has been discussed during the early days of reproductive bioethics. Understanding assisted reproduction as one of the various forms through which human beings today can reproduce, rather than as an exclusive medical practice, radically changes the scenario. Such a change of scenario places the issue of the right to access to assisted reproduction squarely into the domain of basic human rights rather than in the more limited context of policies regarding access to the medical domain. Today, of course, there is no general consensus among bioethics scholars and moral philosophers on this idea. My thesis is a normative and theoretical claim: given what assisted reproduction represents in ordinary human life today, bioethical discussion about it must change. Nowadays discussing the right to access to assisted reproduction means discussing the right of human beings to build a family and allow it to flourish.

What kind of consequences should be entailed by such a change of scenario? It is not possible to present all of them in detail here. Nonetheless, a couple of general remarks can be made. First, the change of scenario entails a "demedicalization" of the bioethical debate on assisted reproduction. Of course, at least for the foreseeable future, assisted reproduction will continue to take place in medical environments and to be practiced by doctors. The "demedicalization" of the debate means that the medical reasons and arguments cannot form the ultimate reasons and arguments for regulating access to assisted reproduction and its practice in general. More precisely, this means that every human being has a *prima facie* right to access assisted reproduction in the same way that she/he has *prima facie* right to "naturally" reproduce and to build a family (this is a negative right in as far as it is the right not to be prevented to).[2] This means that discussions on rights and responsibilities in assisted reproduction should not be separated from discussions on rights and responsibilities in more traditional forms of reproduction. If it is recognized that the aim of both "traditional" reproduction and NRTs is the same (that is, the birth of new human beings) then claiming different treatments for assisted reproduction becomes morally doubtful. Such a different regard for NRTs is, for example, argued from a slippery metaphysical premise that differentiates what happens "naturally" (whatever this means) from what happens "artificially" (whatever this means). Most of what has to be set against the soundness and tenability of moral arguments grounded in ideas of "nature" has already been persuasively argued by great modern philosophers like David Hume (1985) and John S. Mill (1985) (for a recap of the uses of "nature" in ethics and arguments against such uses: Pollo, 2008).

"Traditional" reproduction happens without any preliminary check of parents-to-be as a consequence of an unquestioned respect of the *prima facie* right of any human being to freely use her/his own reproductive capacities and of the right to pursue this towards building a family. Applying the same criteria used for "traditional" reproduction to NRTs (that is, subordinating medical considerations to more general and axiological prior ethical considerations about basic human rights) means that no assessment of requirements can be requested in order to enter into assisted reproduction procedures.

"Demedicalization" of assisted reproduction in the name of protecting basic human rights means its radical liberalization by virtue of the role it plays in the fulfilment of fundamental needs and the achievement of the goods essential for human beings. An objection to this claim could be that endorsing such a position could lead to some kind of "free market" of assisted reproduction and, therefore, to a sort of "far west" of reproductive techniques. Nonetheless, recognizing a basic universal right to access assisted reproduction does not *per se* entail an absence of regulation and control from the State. Affirming that every adult human being has a right to access assisted reproduction does not entail that those techniques can be offered by everybody, and, therefore, this means that the State can (and maybe should) regulate professionals and centres performing assisted reproduction by imposing norms and codes for them. Such a form of control should be performed to protect citizens willing to undergo assisted reproduction techniques. The nature and extension of this control cannot be discussed here, but it can be said that in general they should be aimed not to paternalistically interfere with people's reproductive rights but to enhance their capacity to fully enjoy them. Controls should then be focused on the professionality of operators, transparency of communication, economic fairness, and so on.

4. Designing future people?

The claim that assisted reproduction should today be demedicalized and that access to it should be recognized as a basic universal right is not the only reason for placing assisted reproduction into the field of Everyday bioethics. There is another consequence that must

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[2] This is not the place to present a discussion about the different arguments that can be made in order to justify and defend the right to reproduce ("traditionally" and therefore by means of assisted reproduction). Here I can just state that the background of my mentions of the right to reproduce is a virtue-utilitarian justification akin to the one presented by Eugenio Lecaldano (2005). I presented such an argument in Pollo, 2003. The right to reproduce should be understood as a "positive right to negative liberty". This means that human beings should be helped in the exercise of their liberty to reproduce, which in itself does not entail the duty of anybody else to cooperate in the effort to reproduce the one who is exercising a right. Therefore, someone who tries to reproduce by means of surrogate pregnancy does not have a valid claim to oblige a woman to perform the pregnancy (but is free to make arrangements with a woman who agrees). Also, the right to reproduce is not the right to have a genetically linked offspring, but it is just the right to cause the birth of a baby who will be raised as a child.

be mentioned here. One of the features of assisted reproduction techniques that has been particularly highlighted as novel and unprecedented is the potential to give prospective parents the capacity to "control" traits of their offspring through forms of genetic screening (and embryo selection), and, more recently, by means of forms of gene-editing and genetic engineering. Apparently, the development of capacities in understanding the role of genes and of gene-editing techniques such as CRISPR could undermine the claim that assisted reproduction should be regarded as a part of Everyday bioethics. As a matter of fact, today it seems that we have far more efficient tools to shape the identity of the offspring than thirty years ago. Designing newborn identities seems to be a topic of Frontier Bioethics, since it is something that can happen now for the first time. Nonetheless, my claim is that, with regard to these new possibilities too, the approach should be rather different to the approach that was common during first wave bioethics. How can such a claim be justified, if it seems that today and in the foreseeable future tools to "control" offspring traits will be more powerful than in the past? As a matter of fact, such a claim can be sustained by the development undergone by genetics in the last thirty years. In the past, bioethical debates about genetic engineering and germ-line gene interventions seemed to be generally dominated by a rather deterministic view of the relationship between genotype and phenotype. Aside from some general caveats around the need to better understand the role of the environment in gene expression and the difficulty to identify single genes (or set of genes) for phenotypic traits, most of the discussions about genetic engineering and control of phenotypic traits of the offspring was dominated by a deterministic view of the relation between genes and somatic traits. Ethical discussion was mostly articulated around the issue of the legitimacy (or even the duty) to produce desired traits in the offspring (or to prevent undesired ones).

On the one hand, critics of the possibility of shaping offsprings' identities by means of genetic engineering often highlight the loss of individual freedom that such an intervention will cause in people who will be born with traits predetermined by genetic choices of the parents. Notorious arguments of this kind are those presented by Hans Jonas (Jonas, 1985) and Jürgen Habermas (Habermas, 2003). These arguments claim that germ-line genetic engineering (and reproductive cloning) radically undermine the very possibility of individual freedom, that is the fact that human beings traditionally come to life "unforeseen", and not carrying the burden of choices about who they should be that were made by their parents. On the other hand, supporters of the legitimacy or mandatory nature of germ-line genetic engineering claim that if it would be possible to safely produce traits in the offspring that will allow them to have a greater quality of life or, in general, to perform better in life, then it would be mandatory to do it (Harris, 1993; Persson and Savulescu, 2014).

Even if they sustain different ethical conclusions about germ-line genetic engineering, both positions seem to be based upon the same general factual premise about the nature of such engineering. Such a premise consists of the belief that genetic interventions are able to produce precise phenotypic traits by means of genetic interventions. The background of such a belief is another belief, that is the idea that there is a linear and simplistic relation between gene(s) and phenotypic traits.[3] This kind of simplistic linear causal link from genes

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[3] As a matter of fact, Savulescu, for example, somewhere rebuts genetic determinism and, on the contrary, uses such a rebuttal as a counter-argument against those who object with the argument that bio-enhancement entails a deprivation of autonomy (Habermas-like objections): "Unless one accepts a crude form of genetic determinism, it makes little sense to worry that the qualities of selected children would lose their unpredictability" (Savulescu & Kahane, 2009, p. 278). The oddity of such a rebuttal consists of the fact that removing predictability from genetic interventions radically undermines the argument in favour of their mandatoriness. If genetic interventions are just *likely* to entail some beneficial consequences in terms of offspring's better quality of life then the idea that parents

to phenotype has been challenged by a dramatic development in the fields of Epigenetics and Evo-Devo (Evolutionary Developmental Biology) in the last twenty/thirty years. It is not possible to summarize here the large amount of knowledge collected in these fields of evolutionary biology. For the purposes of the present discussion it is enough to stress the fact that a non-reductionistic and non-linear relation between genes and phenotype emerges from these fields of research. The ontogeny of an organism (*Homo sapiens* included) is not just the unfolding of information coded in the DNA, producing the phenotypic traits building the individual as a whole. There are some phenotypic traits (among them, some pathological conditions and illnesses) that are linearly and directly caused by single or multiple genes, but the large majority of phenotypic traits are the outcome of much more complex processes in which environmental stimuli are crucial (for a general discussion of ethical issues of epigenetic see: Heil, Seitz, König and Robienski, 2017; for a discussion of the philosophical aspects of new developments of genetics: Griffiths and Stotz, 2013; for a general presentation of a no gene centered view of biological evolution: Jablonka and Lamb, 2005).

Such a non-reductionist scenario entails important consequences for the bioethical debate about genetic engineering in assisted reproduction. Trust in the possibility of "creating" phenotypic traits in the offspring (i.e. physical/mental qualities) and therefore of shaping precisely the identity of a new human being seems to be profoundly undermined. As a consequence, the ethical claims based on this trust are radically challenged. Of course, evaluations should be made case by case with regard to specific and particular interventions, but in general it can be said that both the fear of a predetermined (and, therefore, "slave") genetically engineered human being and the hope for an enhanced human being genetically fit for a better quality of life seem at present to be built upon grossly underdeveloped ideas about what links a real human being to her DNA. Maybe in the future some sophisticated techniques will be able to deal with the uncertainties of the ontogeny and also determine phenotypes in the complex framework of the relationship between genes and environmental stimuli. Nowadays, both ethical opponents of genetic engineering and its ethical supporters should recognize the inadequacy of their premises. The idea that complex phenotypic traits can be easily "determined" by manipulation of an embryo's genes is falsified by the new understanding of ontogeny provided by developments in evolutionary biology in the last decades.

This does not mean that a discussion about the moral implications of germ-line genetic interventions of human beings should not be carried out. The new framework of ontogeny entails some in changes in *how* such an analysis should be done. In this case, the "exceptionality" of the new techniques (those already possible and also the ones yet to be developed) should also be reappraised. Of course, manipulation (and screening) of the genes of a human being that will be born is something new for human beings, but what the new understanding of ontogeny brings to debate is the idea that such a novelty does not consist of a dramatic and radical change in how human beings come to life. Genetic choices can be made but they are not likely to be of a rigid deterministic nature. Perhaps we can place them on a continuous line of choices that can already be made in more traditional way of reproducing (pre-conception exams, lifestyle decisions during pregnancy and so on).

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are strictly obliged to perform them when reproducing can be challenged. In a non-deterministic framework, genetic interventions are more similar to already existing precautionary measures to enhance quality of life of "traditionally" created human beings than to a silver bullet for future people's quality of life. Therefore, in line with my point in this paper, genetic interventions should be treated and discussed in the same way as other, more common interventions are already.

5. Conclusion

The analysis carried out so far was intended to reflect on how to conceptualize assisted reproduction in the light of changes that have happened since new reproductive technologies started to become a part of human life. The aim was to argue in favour of the idea that the spread of assisted reproduction in ordinary human life, and the fact that it is becoming less and less "exceptional". This normalization has been caused both by the increasing availability and success rate of assisted reproduction and by its role in helping "non-traditional" families to have babies. Another drive to normalization can be found in the advancement of knowledge about the role of genes in ontogenesis and in the debunking of purely reductionistic models of the genotype-phenotype causal relation. The consequences of acknowledging such normalization for bioethical debate on assisted reproduction can be different and varied. In conclusion, one of these consequences can be simply stated. Recognizing assisted reproduction as a subject for Everyday bioethics rather than Frontier bioethics (at least in the light of the present state of such techniques and of their role in human life) could help foster analyses and debates aimed at discussing the ethical issues of human reproduction as a whole, eliminating distinctions between "natural" and "artificial" reproduction. Freedom and responsibilities in bringing new human beings into existence are always the same, whatever the means through which these new human beings will be born.

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NEW MOTHERHOOD? EMBODIMENT AND RELATIONSHIPS IN THE ASSISTED REPRODUCTIVE TECHNOLOGY[1]

abstract

In the assisted reproductive technologies (ART) debate an important discussion concerns the practice of "maternity for others", better known as "surrogacy". The dynamics that this scenario implies do not characterize a single context, but are extended on a global scale: they affect couples, women who lend themselves to being "carrier mothers" and the unborn child and thus raise both moral questions about the appropriateness of recourse to such interventions and complex problems of global justice. The article tries to analyze the dynamics involved, in particular with regard to the dimension of commercialization, corporeity and relationships, to try to understand which new forms motherhood, fatherhood and more generally parenting can take.

keywords

assisted reproduction, surrogacy, international debate, marketing, embodiment, relationality

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1. New ways of becoming parents, in light of the new biomedical possibilities and social developments

Today, adoption and assisted reproduction can be considered to be two different ways for having children, when this does not happen in the more traditional way. The choice of resorting to assisted reproduction rather than adoption is one that is extremely personal, in the sense that each person or couple decides the preference most resonant with their own thinking on becoming parents.

At the root of these considerations is the desire for a child. The desire to embark on a journey to have a child – through ART[1] or adoption – reflects an intention, which refers to the intentionality that drives our choices, decisions and actions: this intention is developed on more than one level, the biological, as well as the psychic and existential one. After all, this desire can be read in moral terms as an opening to the other: we speak of an ethics of the "third included", that is, when the ethic that emerges from the singularity, and from the relationship I-you, opens up to the other—the third (Malherbe 2014).

We are, and we exist because someone decided that s/he wanted us, that s/he welcomed us, that s/he cared for us. This brings us back to what in ethics is defined as a way and a form of recognition, which also represents the way we define who we are, and what our identity is.

In recent years, there has been a return to a closer attention to the practice of surrogacy in the ART debate. Both at European and international levels, this currently represents one of the most controversial scenarios in the practice of medically assisted reproduction.

Surrogacy is used in response to the difficulties, or impossibility of a couple, a woman, or a man to carry a pregnancy. An important distinction in the surrogacy debate concerns genetic, or traditional surrogacy, in which a woman makes her eggs available and agrees to carry a pregnancy for someone else, often after artificial insemination, thus creating a genetic and gestational link between her and the unborn child. So-called 'gestational surrogacy' represents a pregnancy conducted for others by a woman who has no genetic link with the fetus and the unborn child. If, instead, a woman who carries the pregnancy is paid, the practice is considered commercial surrogacy. By contrast, "gestational surrogacy for others", or "altruistic surrogacy" is when a woman acts as a surrogate for altruistic reasons, without compensation.

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[1] In Italy Assisted Reproductive Technology refers to medically assisted reproduction: the expression "procreazione medicalmente assistita" is the formula chosen and used in the Italian Law 40/2004 to deal with assisted reproduction practices. See Law no. 40 of 19 February 2004, "Rules on medically assisted procreation".

Not all countries approve such practices from a legal point of view. Some countries prohibit surrogacy, others permit only altruistic surrogacy, without any form of payment, while other countries actively favour the practice of maternity for payment or altruistic surrogacy, legalizing and/or regulating it. The fourth scenario is represented by those countries that do not clarify the issue, not taking a clear position on it. In Europe, the countries that have banned the practice of gestation for others, both paid and altruistic are Austria, Bulgaria, France, Germany, Italy, Norway, Portugal, Spain, Sweden and Switzerland. Altruistic surrogacy is permitted in some European countries, in particular in Belgium, the Netherlands, Denmark, Great Britain, Greece, Portugal and Ireland. Both altruistic and not-for-profit surrogacy is also allowed in Israel, Vietnam, New Zealand and some states in Australia, as well as in Canada, in Brazil and in Mexico, where the first law on altruistic surrogacy was enacted in Mexico City in 2010. Commercial surrogacy has been legalized in Russia, Ukraine,[2] Uganda, Nigeria, Kenya, Thailand[3] and in some states of the USA[4]: these countries have regulated surrogacy practices, but with few restrictions, in particular with regard to the origin of the parents, who may or may not be residents and citizens of that country. The practice of commercial surrogacy is on the rise in the United States, where it is estimated that around 1000 women per year act as surrogates (Armour 2012). India, where liberal guidelines on commercial surrogacy had been defined in 2002, sanctioned a ban on international surrogacy with the Assisted Reproductive Technology (Regulation) Bill (2014), preventing access to clinics and profit-making interventions for non-Indian couples. The recent Surrogacy (Regulation) Bill (2019) prohibits any form of commercial surrogacy and allows only altruistic surrogacy, which can be requested exclusively by Indian couples.[5]

In recent years, numerous studies and research have been carried out, for example in Great Britain and Australia, from which interesting data has emerged regarding the psychological implications for women who act as surrogate mothers, and regarding the parental relationships established between them and the 'commissioning' parents. These studies demonstrate that women who gestatee for others often show recurrent characteristics, such as greater resilience, an ability to live without excessive anxiety during pregnancy, as well as the ability to detach from the child. For this reason, it is recommended that women who become surrogate mothers be particularly "resilient" from a psychological point of view (Pizitz, McCullaugh, Rabin 2013). With specific regard to the parental relationships thereby created, there is progressive consideration of the possibility of maintaining relationships and contacts between sponsoring parents, the child and the surrogate mother herself (Imrie, Jadva 2014). These relationships seem to become less close as the children grow up, particularly when the surrogate mothers were not known to the parents before starting the assisted reproduction process (Jadva *et al.* 2012).

For all involved parties, the potential benefits and risks arising from the use of assisted reproduction have been highlighted and studied by learned societies of reproductive medicine, gynecology and obstetrics, foetal medicine, and neonatology (Burrell, Edozien 2014). Moreover, some phenomenological studies reflect, from a bodily and lived point of view, on

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[2] As far as Ukraine is concerned, access to the practice is provided for heterosexual couples with a medical problem.

[3] The use of these techniques is allowed only to couples who are residents of the country.

[4] The US states that have legalized this practice are Alabama, Arkansas, California, Connecticut, Illinois, Iowa, Maryland, Massachusetts, Minnesota, Nevada, North Dakota, Ohio, Oregon, Pennsylvania, South Carolina, Tennessee, Texas, Utah, West Virginia and Wisconsin.

[5] The law defines forms of protection for surrogate mothers both in terms of the conditions under which a surrogacy can be carried out and in terms of coverage of health insurance costs related to any health problems linked to the surrogacy itself.

the specificity and relevance of the relationships established between mother, father and child, during pregnancy and at birth (Bornemark, Smith 2016).

2. Any possible commercialization?

The "baby business" and the market for reproduction and parenting represents a key issue for ART and has been the subject of numerous studies[6]. At local and global levels, the impact these practices can have in terms of fairness and justice is the subject of international debate, as exemplified by the discussion within the Council of Europe on whether or not to permit practices that allow and encourage the gestation of a child by another woman when the couple or woman is unable to carry it out.[7]

The growing practice of so-called transnational surrogacy, which in particular leads to the movement of couples and individuals from wealthier countries to countries with developing economies, is raising complex issues of justice on a global scale. This new "procreative tourism" has brought many US couples and those of other nationalities to countries such as India, where surrogacy had been legalized with costs amounting about half or even a third of what the same couples would have to pay in their home countries (Frankford *et al.* 2015).[8] What emerges from the studies carried out particularly concerns complex gender dynamics, an imbalance bargaining power and lack of genuine legal protection for surrogate mothers. These practices involve women who generally have a low level of schooling, are poor, and often come from rural backgrounds. It is important to understand what dynamics are triggered from multiple view points, considering the clinical risks for women, the impact from a psychological and relational point of view, as well as to their personal life and their past family dynamics. With regard to commercial dynamics and the elements of potential inequities that are thus triggered, the discussion is currently very heated. At the political level, and on an international scale, a consideration of global justice has even raised the possibility of a universal "ban" of these practices (Saravanan 2015).[9] In economic terms, for example, the cost of a child obtained through assisted reproduction in the United States can be very high, compared to the costs that these interventions carry in other countries of the world.[10]

How much can the use of paid practices in relation to assisted reproduction change the way we perceive the body and its value, the transmission of life and perhaps even parenting?

In the contexts that have legalized this practice, as the United States, it has been observed over the years that the substantial investment that couples have to make in order to have a child with assisted reproduction techniques leads to a frequent recourse in speech and language to the idea of "ownership", of ownership with respect to the child, which is also very present when we speak of "own" children, in the sense of children biologically generated by the couple: this language, on the other hand, seems less strong in situations where adoption is used (Brakman, Scholz 2006).

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[6] See the research carried out by Debora Spar (Spar 2006) in the USA on the subject.

[7] I am referring here to the survey conducted within the Committee on Social Affairs, Health and Sustainable Development of the Council of Europe Parliamentary Assembly and the discussion that followed this survey. See in this regard the concluding report, known as De Sutter Report (2016).

[8] It is estimated that infertility affects 7 million American couples: infertility affects many Indian couples as well, see the interesting documentary *Mother India* realised in India by director Raffaele Brunetti (2011).

[9] The author highlights the dynamics of global injustice that are remarked by assisted reproduction practices carried out in Indian clinics, particularly when they are carried out in favor of couples coming from other countries. The total annual amount resulting from the practice of surrogacy in India is 2.3 bn dollars. See also the aforementioned Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly, Council of Europe.

[10] The cost of ART in the USA today is as high as $250,000 when interventions are performed in the most renowned and prestigious clinics. The costs of ART procedures in Italy are about 30,000 euros: the largest part of the cost is covered by the National Health System and couples are required to pay a ticket, which varies according to the different regions and generally amounts to several hundred euros.

One observation, which emerged in the debate, concerns the fact that disembodying, in a literal sense, the gametes and the fertilization itself from the body, we move in the direction of a sort of "objectification" of life, so to speak, or at least of some of its elements, essential, moreover: for this reason it is possible to consider these forms of life as "bio-objects". Today, these themes deal not only with bioethics and biolaw, but also with biopolitics, which studies the policies of life considering the economic value that is thus recognized and attributed to it (Rose 2007).

From this point of view, possible forms of control and containment of costs can help not only to guarantee forms of greater equity, but also to maintain a sort of "naturalness" of assisted reproduction interventions, avoiding falling into too much or exclusively commercial logic and instead bringing back to the forefront the most proper meaning of such interventions, that is, that of an aid that medicine can offer with respect to reproduction (Del Savio, Cavaliere 2016).

These scenarios generate new problems both on a local and international scale, and on a global level, and the economic and commercial component must be controlled, precisely because in fact the "objects" in question are very special: they are "prerequisites" necessary for the biological and genetic transmission of life, and what derives from them is then a subject, therefore the symbolic meaning associated with them is very relevant.

3. Life between corporeity and politics

Alongside the problems of justice and the anthropological ones, related to the meaning associated to life and its transmission, there are aspects of parental relations that are thus established.

All these experiences seem to have a common trait, that of being bodily experiences and bringing the maternal body in particular to the center of the discussion. In the debate on adoptions and in the reading of motherhood, the strength of what has been defined as the "biological paradigm", which "unduly influences the way we conceive, speak and consequently behave in relation to the different forms that the maternal body assumes" (Brakman, Scholz 2006, p. 57),[11] emerges clearly. The biological paradigm also seems to be central in the approach to assisted reproduction.

In the phenomenological tradition and in the debate of feminist philosophy the value of embodiment and bodily condition is highlighted, and it is emphasized that "maternity relationships are physical relationships, but they cannot be reduced to them" (Brakman, Scholz 2006, p. 69): in this tradition and in this debate, the concept of body and embodiment are considered to go beyond the simple organic condition, which remains anyway their main condition of possibility. Considering this concept of corporeity, lived experiences and relationships play an important role in helping to shape personal, moral and social identity. With the notion of "bodily motherhood", are emphasized the "physical relationships of the subjective body-lived more than the genetic and biological links" (Brakman, Scholz 2006, p. 65).[12] Rebecca Kukla noted that we can find "bodily motherhood" in "women who seek conception, women who are pregnant and giving birth, adoptive mothers, birth mothers who give their children for adoption, women who donate and 'adopt' gametes, and women who care for babies and children" (Kukla 2006, p. vii).

In an alternative or complementary model to the biological and genetic paradigm, more

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[11] The authors observe that the experience of adoption and that of the mother and adoptive parents tend to be interpreted mainly "with the limited lens of biology" (p. 62).

[12] A notion of this kind brings attention back to the particularity of experience, which always inevitably refers to a subjective embodiment.

focused on nurturing, and community, on the importance of physical relationships and even more on their social and symbolic value, motherhood, fatherhood and parenthood can be read as a kind of "community event". The very act of raising a child is read as something that goes beyond a simple "natural" act.[13] If this applies to adoption practices and situations, can we extend the model to assisted reproduction and gestation practices for others?

When we consider a maternity carried out for solidarity purposes, this extended and "community" parental model can present some interesting characteristics, by analogy with that of adoption, at least in terms of the "community" involved and responsible for bringing a child into the world, seeing it born and raising it. The commercial dimension extended to these practices – as in the cases of surrogacy for payment – seems to change their characteristics and condition introducing different logics in the process of reproduction, however already complex in itself in biological, psychological, moral, social and symbolic terms.

In fact, the problem of interpersonal dynamics that are created in motherhood for others, between the surrogate and/or gestational mother and the unborn child and between these and those who will become the social parents of the child, remains open. It is not by chance, perhaps, that in the debate on surrogacy the notion of the best interest of the child has been taken up again, in order to highlight how – among the many subjects and actors involved in the articulated process of medically assisted reproduction – a special attention and preventive legal protection must be reserved to the unborn child.[14]

4. Lived body and bodily memory

What else can suggest an enhancement of bodily relationships and their meaning with respect to the definition of identity? Even when we have not lived the experience of being mothers or fathers, we have lived the other experience, that of being children, of having been generated. And on this we could ask ourselves what is the relationship we have with those who gave birth to us and how much their way of wanting us, of welcoming us, of accompanying us or not, could have influenced who we are, how we are and where we are going in the challenging and complex path of our lives.

It is always a corporeal relationship that has brought us into the world. And care is corporeal, never disembodied, because it deals with the body, the flesh, the life, not in the abstract but in concrete, entering in relationship with it, touching it, manipulating it, and this helps to define the relationship we have with it (Mortari 2015).

Our body represents our space in the world and this has a determining value with respect to how we perceive ourselves and how we relate to ourselves, to others and to reality. The body keeps memory in many ways. We are, we remain embodied existences: our existence, the choices and events that have designed it seem to be impressed not only in our consciousness and our memory, but also in our flesh, in our being a body, in our somatic reality. From there they then pass to the memory and emerge in the conscious and unconscious, in experiences and relationships, in events and feelings. Also for this reason, with the body we understand.

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[13] "The activity of mothering, which accompanies a child in becoming a particular social person, is an act capable of transcendence..." (Held 1993, p. 126).

[14] See Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly, Council of Europe (2016): the proposal and recommendations contained in the report - putting the interest and rights of the child first, working with international bodies on issues of private international law relating to the condition of children conceived and born as a result of such practices, based on agreements between parents, surrogate mothers and clinics; banning surrogacy for payment, accepting instead altruistic motherhood - were rejected by the Assembly in the final vote. One of the complex issues facing the right today is the recognition of children born following assisted reproduction and surrogacy in a country other than that in which the parents live: at the moment the recognition is achieved either through the legal attribution of parenthood or, alternatively, through adoption procedures.

It is curious to reread today, in the light of the new ways that fertilization, conception and reproduction as a whole have taken on, the very beautiful pages of a book by the body historian Barbara Duden (Duden 1987): Duden has reconstructed the history of the perception of pregnancy, of its initial signs, studying the archive of Dr. Storch, a German doctor who in 1730 had decided to record the descriptions with which her young patients spoke of strange symptoms perceived before addressing him. From these colorful images the signs and "symptoms" of pregnancies in progress emerged little by little. In her book on genetics and maternal bodily experience (Duden 2002), Barbara Duden observed that perhaps we lack today – in the age of ultrasound scans and such relevant visual images – the ability to reconnect "head and womb", to listen to our bodies, for what they tell us, and thus to collect the signs that speak to us of something new, of something that has begun and that in this uncertain beginning does not always represent a positive moment of pleasure, because it is accompanied by discomfort, effusions and new moods. Yet this remains a beginning and comes from each woman and each man charged with those personal and interpersonal, social and cultural complex meanings with which we paint our ideas and representations of giving life, giving birth and coming to the world.

As Martin Buber wrote: "... in the mythical Hebrew language it is said that in the womb man knows the universe, and forgets it at birth. And this bond remains imprinted on him, as a mysterious image of desire" (Buber 1993, p. 77). Once again, and also in a reflection that draws on other philosophical and religious traditions, the value and essential function that desire has for human existence re-emerges.

5. Relationality and recognition: Being mothers and fathers, being parents today

In the bioethical debate the value of relationality has been emphasized, as a characteristic trait of the person for what defines his moral autonomy, subjectivity and social identity. An original, but not isolated, contribution has come in this sense from feminist philosophies, which have revisited the notion of autonomy in a relational sense:[15] criticizing the most widespread conception of autonomy – the one adopted in the bioethical debate starting from the approach of principlism – these authors have highlighted its limits, represented primarily by excessive individualism, abstraction from reality and the atomistic vision of the individual that would underlie it. In an alternative conception, the moral autonomy of the subject is built from his being and being in relation with himself, with others and with the world: the subject and the person are thus defined in their moral identity also through the body, living in time and living in relation. This is why the notion of relational and reciprocal autonomy has been taken up again in the bioethical debate. It seems to be precisely the relationships and relational dynamics within which we grow and form those that are at the basis of even our most significant moral behaviors, ranging from our attitudes to care, our sense of justice to the ability to manage these dynamics in the complexity of situations, but especially of relationships with others.[16]

This relational dimension also characterizes and concerns the fetus and the unborn child (McLeod, Baylis 2006).[17] The fetus in its development is conditioned – again, at least until

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[15] Relational autonomy, or autonomy in relation, refers to the recognition of the essentially relational condition of the person, of our human being, which can express itself in relation to other people and implies dynamics of reciprocity (Mackenzie, Stoljar 2007; Botti 2000; Malherbe 2014).

[16] The notion of relational autonomy highlights the dynamics relevant to our moral development and our understanding of it. In this sense, the reflections formulated by Carol Gilligan, in response to the theories of her teacher Laurence Kohlberg, on the different stages of the moral development of children and adolescents are significant (Gilligan 1982).

[17] Every person, according to these authors, is defined by her embodiment and her relationality, that implies "being

now – by an essential relationality with the mother, with her body, with her corporeity:[18] it has been observed in this regard that there are no embryos without mothers and that life is never given in the abstract, but always in concrete form, that is, in the form of the living, taken individually and as a human species (Mahowald 2005; Duden 1991). The fetus grows, develops and enters into a form of "recognition" starting from this original relationship that could be even only "gestational". Hilde Lindemann Nelson wrote that the decision to "sustain a pregnancy also represents an exercise in moral action" (Lindemann Nelson 2009, p. 48): the choice of the mother highlights this condition of always being a moral agent and this moral trait takes on even more particular importance when morality is read by highlighting the value of corporeity and relationality. The experience reflects the fact that "those of us who are mothers know that our bodies will always be maternal bodies and that the profound moral and phenomenological transformation that awaits our motherhood continues throughout life" (Kukla 2006, p. ix).[19]

Lindemann Nelson writes: "If we take seriously the feminist emphasis on the relational nature of the human self, we must abandon the idea that pregnancy is essentially a private problem (in which the woman is not responsible to anyone other than herself) ... as and if she experiences her pregnancy it cannot be a morally indifferent problem for at least someone else" (Lindemann Nelson 2009, p. 46).

In the consideration of relational dynamics, another important figure remains to be analyzed, namely that of the father, in the role that he assumes today in the light of the new practices of reproduction and also socially new ways of becoming parents (Recalcati 2011).

The experiences of women who have decided to become surrogate mothers have been analyzed through some qualitative research, aimed at capturing the emotional components and experiences of surrogate mothers (Taebi *et al.* 2020; Jadva 2020).[20] The different contexts and cultures in which these practices take shape always seem to play an important role, both for the couple and the surrogate mother, since where a situation is very precarious, from a social and economic point of view, the choice to carry out a surrogacy can be dictated by necessity and the consequences can sometimes be more complex in psychological and relational terms, in the community of reference and also within the family of these women (Theran *et al.* 2014; Lamba *et al.* 2018).

In the case of gestational surrogacies, the motivations of these choices generally correspond to those of making an altruistic gesture and facing a different maternity, but also to the possibility of having a different body image of oneself: in the case of commercial surrogacy, the motivations seem to mix intrinsic elements, such as altruism, with extrinsic elements, such as the compensation that can be obtained (Ferolino *et al.* 2020). What emerges from studies conducted on women who have carried out pregnancy for others in the form of an altruistic surrogacy is that the difficulties have been experienced especially in the early stages and that they are mostly overcome over time, in physical terms but especially with regard to their psychological condition; starting from the same studies it seems that children born using this

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in relation" from an interpersonal, social and political point of view.

[18] Duden observed that the fetus has become a very marked "discursive object" since biomedical technologies have allowed its representation - even visual - and analysis (Duden 2002). With respect to the new scenarios and the near future scenarios of reproduction, see as well the considerations of Balistreri (Balistreri 2016).

[19] Rebecca Kukla notes that motherhood and maternity represent a very rich and fertile ground not only for ethics, social philosophy and political philosophy, but also for epistemology and aesthetics, where these different disciplines deal with the lived body, in its materiality and its cultural being.

[20] The studies conducted in this area still seem to be rather limited, while their contribution may be important to understand the value and commitment that an experience such as surrogacy can have for the different people involved in it.

practice are children who do not suffer psychological or existential repercussions different from those who encounter children born in the most traditional ways, since the complex behavioral dynamics seem to be comparable and they can be addressed in a similar way (Zadeh *et al.* 2018). As far as their story is concerned, it seems important to privilege a form of early storytelling to these children of the way they were born, explaining to them what happened and allowing them to confront their own story, to become aware of it and make it part of their own story. What the children seem to be looking for are mainly explanations of the motivations that led these people to give their availability as donors or gestational mothers, but sometimes they also look for forms of relationship with surrogate mothers, as well as with donors: the search for their biological parents and gestational mother seems to involve fewer difficulties where the children present a situation of stability towards their parents and their family. Parents, for their part, seem to exercise and live towards these children very dedicated forms of care, which are also explained in light of the difficulties that these parents may have experienced and lived in trying to have children. What emerges in any case in multiple studies is the importance of thinking about and organizing accompaniment and counseling for women who became surrogate mothers before, during and after pregnancy, so as to support them also with regard to the experiences that this kind of pregnancy and the need to take distance from the child can arouse in them. It also seems very significant the relationship that can be established between the parents and the gestational mother, because good communication helps to deal differently with the stages and dynamics of pregnancy and the following ones (Yee, Librach 2019; Yee *et al.* 2020).

The conceptual elements relevant in this reflection seem to be in particular the body and corporeity, relationships and emotions, which can be considered as pre-political dynamics and which define the subjective identity of the person and his moral subjectivity, profiling a condition and a reality of relational autonomy. Also for this reason, when we talk about ethical issues related to reproduction, we could observe that the real "challenge" begins when we become mothers and fathers, when we "meet" the other and open ourselves to the novelty that s/he can bring, to the "beyond" that s/he can represent, to the "surprise" that s/he can offer (Malherbe 2014, pp. 163-167). In the reflection on assisted procreation and the use of surrogacy, reference has been made to the relevance of relationships and the importance of composing different relationships, in a dynamic of reciprocity and responsibility, recovering the concept of ethics formulated in the phenomenological field by Emmanuel Lévinas, who understands ethics as that component of mutual responsibility that unites human beings (Krause 2018).[21] It is possible to consider today a way of becoming parents that involves the intervention of another person, to carry the pregnancy forward, considering that this process takes place in a more communitarian way, as is also the case with adoptions (Gunnarsson Payne 2018). The dynamics of solidarity is also considered in the field of transplantation, when donations are made between living human beings: in this case, too, the psychological dynamics and experiences of the people involved are very complex and delicate and require dedicated forms of accompaniment. In analogy with these two situations, that of adoption and that of transplantation between living persons, also with regard to forms of surrogacy, it can be said that the solidarity dynamic seems to allow more relevant forms of recognition and respect and better protect the freedom and dignity of the different persons involved.

In the analyses and reflections dedicated to the birth rate, the decline of births, the value and meaning of life, one can look at these new practices with a critical eye, that is, willing to see and collect the value and possible limits of these interventions, to try to reduce and correct them, in perspective. Medicine works from the inside out to its own limits, because knowledge

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[21] According to the author, this need for reciprocity and equality concerns both relationships and institutions.

expands, techniques improve and therefore we move in the direction of a refinement of interventions: societies and cultures – for their part – contribute to re-read and redefine their moral parameters of reference.

In her book *The human condition*, Hannah Arendt wrote:

"The miracle that saves the world, the realm of human affairs from its normal, 'natural' ruin is ultimately the fact of natality, in which the faculty of action is ontologically rooted. It is, in other words, the birth of new man and the new beginning, the action they are capable of by virtue of being born. Only the full experience of this capacity can bestow upon human affairs faith and hope, those two essential characteristics of human existence ..." (Arendt 1958, p. 247).

The numerous questions that remain open call to the possibility of considering new ways of formation and of transmitting life, they call to our ability to maintain a high attention to the symbolic meanings that these practices invest: that remembers the opportunity to exercise a form of moral creativity, in order to identify ways of intervention and scenarios that can protect and respect the different subjects involved in them.

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PERSON-AFFECTING PROCREATIVE BENEFICENCE

abstract

A relevant problem in reproductive ethics is the moral evaluation of selection of the possible children that the parents can have. This article discusses one of the main attempts to solve this problem, the principle of Procreative Beneficence proposed by Julian Savulescu to define a strong pro-selection perspective. According to Savulescu, such a principle has an impersonal form and is balanced with a person-affecting principle of harm. The article proposes a new person-affecting interpretation of Procreative Beneficence, distinguishing it from other pro-selection views and exploring its extension beyond selection to other problems of reproductive ethics.

keywords

procreative beneficence, selection, reproductive ethics, future generations, enhancement

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PERSON-AFFECTING PROCREATIVE BENEFICENCE

1. Ethics and selection

One of the main issues in reproductive ethics is the problem of the evaluation of selection of the possible children that the reproducers (the parents, a couple, a single person) can have, in a coital or non-coital way of reproduction. The most evident cases of selection are related to pre-conception testing on reproducers' gametes (carrier screening), to post-conception testing (like pre-implantation genetic diagnosis, PGD, connected to in-vitro fertilization, IVF) and to post-implantation screening (like chorionic villus sampling or amniocentesis). Yet, the case of selection may be wider and involve all the cases where the reproducers decide when and whether to have a child: in this wider use, all of us are possible selectors.

> The idea of selecting offspring traits – of quality control of offspring – is both appealing and disturbing. It is appealing because of the understandable desire for a normal, healthy child. Avoiding conception or terminating an affected pregnancy rather than living with the burdens of handicapped birth would appear to be a central part of procreative liberty. [...] Yet there is something deeply disturbing about deliberate efforts to assure a healthy birth, at least when certain means are used. The very concept of selection of offspring characteristics or 'quality control' reveal a major discomfort – the idea that children are objects or products chosen on the basis of their qualities, like products in a shop window, valued not for themselves but for the pleasure or satisfaction they will give parents (Robertson 1996, 150).

There are several answers to the moral problem of selection. A first answer considers selection as morally forbidden. This answer is given by several anti-selection views, like those of the Roman Catholic Church or of some secular thinkers (Jonas, Habermas, Sandel)

> To appreciate children as gifts – Sandel writes - is to accept them as they come, not as objects of our design or products of our will or instruments of our ambition. Parental love is not contingent on the talents and attributes a child happens to have. We choose our friends and spouses at least partly on the basis of qualities we find attractive. But we do not choose our children. Their qualities are unpredictable, and even the most conscientious parents cannot be held wholly responsible for the kind of children they have (Sandel 2008, 45 f).

A second answer considers selection morally permissible. This answer is given by many pro-selection views which grant the reproducers a moral permission (a liberty or a right) to select. These pro-selection views believe that reproduction is a private matter and therefore that selection is morally permitted; or believe that morality gives reproducers a sort of freedom when they make procreative decisions: a form of procreative liberty or reproductive autonomy (Roberson, Glover, Agar).

> We must distinguish positive from negative selection techniques and ask whether the technique is used for therapeutic or nontherapeutic purposes. In each case we must first establish whether the central concerns of procreative liberty are involved, and then whether the use in question harms the interests of others sufficiently to justify restriction. [...] As with other reproductive technologies, procreative liberty would entitle most couples to use—or not use—negative and even positive selection techniques as they choose. The perceived dangers of 'quality control' appear to be insufficient to remove these choices from the discretion of persons planning to reproduce (Robertson 1996, 151)

A third answer considers selection morally obligatory. This answer is given by some pro-selection views which assign to the reproducers a moral obligation to select an advantaged child. The main example in this group is the principle of Procreative Beneficence proposed by Julian Savulescu and Guy Kahane, to which I will turn below. Another form is the view that will be proposed in the second part of this essay.

2. The non-identity problem

Like other decisions in reproductive ethics, selection affects the identity of the children who will exist: it is an identity-affecting choice. In this way, selection relates to a fundamental problem regarding future generations ethics: the *non-identity* problem, due to the fact that selective actions affect not only the *quality* of life but also the *identity* of future people, and may affect their *quantity* too (selecting for two or more twins instead of one child). Therefore, selection brings with itself the need to distinguish different ways of understanding normative principles applied in reproductive ethics and different kinds of moral obligations and reasons: a person-affecting view, an impersonal view and a trans-personal view.

A person-affecting view states that "an act is right or wrong only if there is or will be a person affected by it" (Glover 1977, 66). According to this view, we have an obligation only toward present or future people who will exist: *actual* people. Traditionally, it states that wrongs require victims: «what is bad must be bad for someone» (Parfit 1984, 363). According to this view, every harm (or benefit) is personal.

> In deciding what we are to do, the only consideration which is morally relevant [...] is how others would be affected. If we cannot envisage effects on certain people which would ensue from our acts, then we have no moral material to work on and we can do as we like (Narveson 1967, 63)

According to a person-affecting view, there is an *asymmetry* between the obligations related to reproduction: we do not benefit a child if we bring her into life, but if her life is not worth-living we harm a child by generating her. "If, therefore, it is our duty to prevent suffering and relieve it, it is also our duty not to bring children into the world if we know that they would suffer or that we would inflict suffering upon them" (Narveson, 1967, 71).

On the other hand, an impersonal view states that an act can be right or wrong even if there is, or will be, no person affected by it, but she could have been, if we had acted otherwise.

According to this view, we have an obligation even toward *potential* (or ‘merely possible’) people: people who will not exist but whose existence depends on us (Hare 1988, 68). In this case, we have a different kind of harm (or benefit): an impersonal harm, a harm without a victim, which makes the world a worse place.

> We should do what is the best interests of those concerned. [...] Such a principle can take different forms. We need only look at a single difference. The principle can take what I call an “impersonal” form: for example, it can run
> 1) We should do what most reduces misery and increases happiness.
> It can instead take a “person-affecting” form: for example
> 2) We should do what harms people the least and benefits them most.
> When we can only affect actual people, those who do or will exist, the difference between these forms of the principle makes, in practice, no difference. But when can affect who exist, it can make a great difference (Parfit 1976, 109).

An impersonal view implies three requirements: 1) a *comparability* requirement: that a life of actual or future people can be compared with the life of potential people (Parfit 1984); 2) a *substitutability* requirement: that actual, future and potential people may be replaceable with each other (Singer 1979); 3) a *compensability* requirement: that a harm made to actual or future people may be compensated for with a benefit made to potential people and vice-versa.
Thirdly, a trans-personal (or wide person-affecting) view states that an act is right or wrong only if there is or will be a person affected by it, but her harm or benefit is defined by comparing her condition with that of a potential person who would have lived in her place if we had acted otherwise (Parfit 1984, 395). If the potential person had had a better condition, there is a harm made to the first person, if the potential person had had a worse condition, there is a benefit. In this case, we are facing a trans-personal harm (or benefit).

> I propose interpreting the principle [of harm] so that ‘harm to others’ includes ‘transpersonal harms’: that is, where one course of action brings about a world where those who exist are worse off than would have been the different people who would have existed on the alternative course. The harm principle needs this adaptation to cope with some of the genetic choices (Glover 2006, 74).

According to impersonal or trans-personal views, there is a *symmetry* between the obligations related to reproduction: if we harm a child by bringing her into a life not worth living, in the same way we benefit a child if we bring her into a worth-living life. Therefore, there is a moral obligation not only not to generate children if they would suffer, but also to generate children if they would be happy.
The consequences of symmetry are problematic. Roughly, symmetry “would require unlimited procreation”, avoiding contraception or forbidding chastity (Hare 1976, 163) and thus the obligation to generate extra happy children whenever possible (to make happy people) and to increase the quantity of future people.

> According to the ‘impersonal’ principle [...] [a childless couple] should do what most increases happiness. One of the most effective ways of increasing the quality of happiness is to increase the number of people. So the couple ought to have children; their failure to do so is [...] morally wrong (Parfit 1976, 109).

3. Savulescu's Procreative Beneficence

The Principle of Procreative Beneficence (PB) proposed by Savulescu states:

> (PB): If reproducers have decided to have a child, and selection is possible, they have a relevant moral reason to [should] select the child, of the possible children they could have, whose life can be expected, in light of the relevant available information, to go best or at least not worse than any of the others (Savulescu & Kahane 2009, 274).

PB is a consequentialist and maximizing principle: it states an obligation to have the child with the greatest well-being (a life with memory, intelligence, empathy, etc.); and it is a comparative principle: it compares the well-being of the possible children the parents could have (Savulescu & Kahane 2009, 175).
This theory is based on the concept of well-being as a viable way to assess the value of a life, but it is not necessarily related to a definite view about well-being, and thus it is compatible with different conceptions of well-being:

> A common objection to PB is that there is no such thing as a better or best life. It is hard to defend such a claim. What constitutes a good life is a difficult philosophical question. According to hedonistic theories, it consists of having pleasant experiences and being happy. According to desire fulfilment theories, what matters is having our preferences fulfilled. According to objective good theories, certain activities are intrinsically good – developing deep personal relationships and talents, gaining knowledge, and so on. PB is neutral with respect to such philosophical disputes about the nature of the good life. But although there is this philosophical disagreement, there is considerable consensus about the particular traits or states that make life better or worse, a consensus that would rule out many procreative choices as grossly unreasonable (Savulescu & Kahane 2009, 279).

An example of PB's application regards a case of selection related to a pre-conception test of a woman during rubella. PB states the moral obligation to postpone the conception of the child in order not to have a deaf or a blind child (Savulescu 2001, 417; Savulescu & Kahane 2017, 592).
Yet, according to Savulescu, there are limits to Procreative Beneficence. The obligation is not an absolute obligation but a *pro tanto* obligation, which needs to be balanced with other *prima facie* obligations in order to become an "all-things-considered overriding obligation" (Savulescu & Kahane 2017, 594). For this reason, Savulescu states that, in PB, 'should' means 'have good reasons to' or 'is morally required', and it is different from 'must'. It implies that persuasion is justified but not coercion:

> PB is not an absolute obligation. It is the claim that there is a *significant moral reason* to choose the better child. The principle states not what people invariably must do but what they have significant moral reason to do (Savulescu & Kahane 2009, 278).

In particular, it has to be balanced with another fundamental principle: the principle of harm, that states a moral obligation not to harm others against their will. Following such a non-harming restriction, Savulescu admits the couple's free choice to select a less advantaged child: "there are strong philosophical grounds to hold that procreative liberty should extend to people selecting less than the best child" (Savulescu 2014, 178).
Moreover, Savulescu considers PB compatible only with an impersonal or a trans-personal (wide person-affecting) interpretation: «like competing principles of procreative ethics, PB is compatible with different accounts of reasons to select future children. It can take either

a wide person-affecting form or an impersonal form» (Savulescu-Kahene 2009, 227). On the other hand, the Principle of Harm is intended as intrinsically related to a person-affecting restriction: «harm is personal in nature» (Savulescu 2014, 178).

There may be a conflict between this impersonal (or trans-personal) principle of procreative beneficence and a person-affecting principle of harm, and the solution proposed by Savulescu is to give precedence to the principle of harm:

> In general, proscriptions against person-affecting harm should be much stronger than those against impersonal harms. We should not significantly harm individuals now to bring about a better world, where the betterness is impersonal. Impersonal reasons then could be rather weak when pitted against personal reasons. Requirements of PB [...] are reasons but should not require major person-affecting harms (Savulescu 2014, 178).

To clarify, Savulescu refers to Parfit's example of the Two Medical Programmes, one for the treatment of a rare disease, the other for the prevention of such a disease, in order to refuse Parfit's No Difference View between the two programmes and to state the priority of person-affecting reasons over impersonal reasons:

> There are two rare conditions, *J* and *K*, which cannot be detected without special tests. If a pregnant woman has condition J, this will cause the child she is carrying to have a certain handicap. A simple treatment would prevent this effect. If a woman has condition K when she conceives a child, this will cause the child to have the same particular handicap. Condition K cannot be treated, but always disappears within two months. Suppose next that we have planned two medical programmes, but there are funds for only one; so one must be cancelled. Parfit supports the No Difference View: he believes that each programme is right and there are equally strong reasons to pursue each. This I believe is wrong [...]. In the case of *Treatment*, there is person-affecting harm. If you fail to treat, a future person is made worse off than he or she would otherwise have been. In *Prevention*, the harm is impersonal - the world is worse for having more suffering than it could have contained, but no person is worse off than he or she would otherwise have been (Savulescu 2014, 176-7).

This person-affecting restriction reduces the revolutionary impact of Procreative Beneficence and diminishes its radicality, permitting a general agreement with common-sense morality: "although PB is often presented as a radical view, it is really just an extension of widely accepted existing practices and an application of common-sense ethical ideas" (Savulescu & Kahane 2017, 598). For this reason, deaf or dwarf people should be acknowledged to be free to deliberately select children with deafness or dwarfism.

Therefore, Savulescu's proposal regarding selection is a complex and hybrid position, which admits both impersonal and personal reasons for actions, and states an order of priority among them (2014, 177). The result is "a liberal form of procreative perfectionism" (Glover 2006, 54), which is not immune from problems and which has had different critics.

Some scholars have refused Savulescu's position from an anti-selection point of view, which does not consider selection of the best child as a morally permissible act (because of problems related to selection procedures, De Melo-Martìn 2004 and 2016, or related to identifying what the best life is, Parker 2007). Others have refused Savulescu's position from a liberal pro-selection point of view, which does not consider selection of the best child as a moral obligation but only as a moral permission, not correlated to any duty of beneficence (see

Herisonne-Kelly 2006, Bennett 2009, Sparrow 2014). Others have refused Savulescu's position from anti-consequentialist points of view (see Stoller 2008, Hotke 2012).
Elsewhere, I have focused on some problems related to the hybrid aspect of the theory: the possible conflict between an impersonal procreative beneficence and a personal harm, the risk of limiting beneficence to pre-implantation selection, the necessary extension of maximising beneficence to different quantity people choice (see Magni 2019). There, I have proposed another view of selection (and more generally of reproductive ethics) which can avoid Savulescu's perfectionist complex solution without renouncing a principle of beneficence: person-affecting Procreative Beneficence (PaPB).

1. A person-affecting form of Procreative Beneficence

A person-affecting form of Procreative Beneficence aims to diminish the suffering and to increase the well-being of all present or future *existing* people affected by the action, not taking into consideration potential people.
According to such a person-affecting view, in the case of selection, Procreative Beneficence states that:

> (PaPB): If reproducers have decided to have a child, and selection is possible, they should not select a child, of the possible children they could have, whose life can be expected, in light of the relevant available information, to be *for her* not worth living (Magni 2019, 78).

The consequences of such a person-affecting principle of Procreative Beneficence in part are similar to Savulescu's hybrid position. Since all that is not morally prohibited is morally permissible, PaPB allows several selective actions to be morally permitted (for example, to select in favour of a deaf child instead of a hearing child), but not other selective actions (for example, to select in favour of an anencephalic child). According to this person-affecting version of Procreative Beneficence, reproducers are free to select the best or someone less than the best, but they are not free to select the worst, when the worst means having a life not worth living.
In part, the consequences are different from Savulescu's: PaPB does not need to refer to any separate principle of harm and states no moral obligation for the reproducers to select the best of the possible children, but only a moral permission. In the example of rubella, such a view does not tell the woman that she *should* wait three months, but that she *could* (not taking into consideration other prudential or moral person-affecting reasons for waiting, which may be decisive). Analogously, in the case of the Two Medical Programmes, like Savulescu's hybrid position, PaPB states that Parfit's solution is wrong and that Treatment ought to be preferred to Prevention, but only on the basis of person-affecting beneficence and without referring to a separate principle of harm.
Parfit imagines the case of a mother, Ruth, who has a genetic disease and wants to have a child:

> Ruth's Choice. [...] Her congenital disease kills only males. If Ruth pays for the new technique of in vitro fertilization, she would be certain to have a daughter whom this disease would not kill. She decides to save this expense and takes a risk. Unluckily, she has a son, whose inherited disease will kill him at about the age of 40 (Parfit 1984, 375).

Differently from Parfit's impersonal view, which considers Ruth's action morally wrong because it makes the world a worse place, PaPB states that Ruth's action is morally permissible: her son would not have existed otherwise and his life, despite short, remains a life worth living. There is no harm made to him.

Such person-affecting PB is a pro-selection view which is opposed to anti-selection views which do not permit selection. Moreover, it is stronger than other pro-selection views, such as those that stress reproductive liberty or procreative autonomy, because it is a consequentialist principle that does not allow any kind of choice (i.e., a selection in favour of a child with a life not worth living) and states that some choices are not only morally permissible but morally obligatory.
Analogously, it is also different from other pro-selection perspectives based on beneficence, with which it ought not to be confused. Following the list proposed by Savulescu and Kahane: the Minimal Threshold View, the Prevention of Harm View, and the Satisficing View (Savulescu & Kahane 2009, 289).
The Minimal Threshold View states:

> If couples (or single reproducers) have decided to have a child, and selection is possible, then they have a significant moral reason to [should] select one of the possible children they could have who is expected to have a life worth living over any that does not; they have no significant moral reason to choose one such possible child over any other (Savulescu & Kahane 2009, 280).

This view is a comparative principle and states an obligation to select one of the possible children who are over the threshold. Thus, it conceives the obligation to procreate as an impersonal obligation. On the contrary, PaPB is not a comparative principle and states only a permission to select. It does not imply any obligation to procreate: it is morally permitted not to have any child.
Secondly, it is different from the Prevention of Harm View:

> If reproducers have decided to have a child, and selection is possible, then they have a significant moral reason to [should] select one of the possible children they could have who is expected to experience least suffering or limited opportunity or serious loss of happiness or good compared to the others (Savulescu & Kahane 2009, 281).

This is a comparative view which states that we should avoid the worst among different possibilities. Instead, PaPB is not a comparative view: it aims to avoid having children with a life not worth living irrespective of other possibilities.
Thirdly, it is different from the Satisficing View:

> If reproducers have decided to have a child, and selection is possible, then they have a significant moral reason to [should] select one of the possible children they could have who is expected to have a good enough life over any that does not; they have no significant moral reason to choose one such possible child over any other (Savulescu & Kahane 2009, 280).

This is another comparative and impersonal view that states that we should select a child with a sufficient level of well-being, while PaPB only aims to avoid a life not worth living. According to PaPB, reproducers are morally allowed not to have children at all: it is morally permitted not to select any child.
However, it shares with all these views the problem of identifying a level of well-being that defines a life not worth living, and the assumption that such an identification, despite being vague and coarse grain, is viable and it may be applied in the evaluation of some dramatic cases. As an example, the life of an anencephalic child, of a child affected by Tay-Sachs disease or Lesch–Nyhan syndrome, and so on.

> Lesch–Nyhan syndrome [is] a rare genetic disorder found only in males. The body produces too much uric acid. Consequences include impaired kidney function, blood in the urine, deposits of uric acid crystals in the urine and under the skin, kidney stones, muscle weakness, arthritis, painful swelling in the joints, difficulty in swallowing and eating, vomiting. It involves mental retardation and speech impairment. Associated with it are muscular spasms and involuntary writhing, as well as violent flinging of arms and legs. There is irritability and compulsive aggression (often later regretted) towards others: kicking or head-butting them, spitting or vomiting on them. There is also compulsive self-harm: head banging, biting their own lips or fingers, poking their own eyes, or putting their fingers in the wheelchair spokes. [...] Without treatment, children with the disorder have a life expectation of less than 5 years. [...] Having never known anyone with this condition, I am reluctant to say that it is incompatible with having a life worth living. But it must carry a serious risk of a life not worth living (Glover 2006, 59 f).

4. Beyond selection

Regarding selection, person-affecting Procreative Beneficence affirms a negative obligation (the obligation not to select) and is equivalent to a principle of non-maleficence, but it implies positive obligations when it is extended beyond selection to the cases of modification of the characteristic of the children: the obligation to benefit the future children. That is, the obligation to increase the quality of life of the child selected and to modify her characteristics in order to avoid possible diseases or to enhance physical and cognitive capabilities, because it remains a consequentialist principle of beneficence. Moreover, like Savulescu's procreative beneficence, this obligation may be a *prima facie* obligation and may be compatible with other moral requirements (for example the requirement to respect autonomy in the case of other reproductive issues, like abortion).

According to such person-affecting PB, we have a moral obligation to make a foetus immune to dangerous viruses through biomedical intervention (vax), when it is possible and safe, because otherwise we would harm the child giving her a worse life than she could have had. Analogously we have a moral obligation to reduce the disability of a foetus whenever is possible, in order to benefit the person who will exist. In the same way, according to Pa PB selecting a handicapped child instead of a different non-handicapped child is morally permitted, but reducing the quality of life of a possible child, using drugs or modifying the genome of an embryo, in order to have a deaf instead of a hearing child, is not morally permitted. Such a 'Bladerunner scenario' of intentional diminishment is not morally permitted (Robertson 1994, 170).

Frances Kamm has imagined a case of a mother who can affect the IQ level of her child during pregnancy:

> suppose we compare (1) a case in which someone does something that affects her foetus in a way that results in her child having a 140 rather than a 160 IQ (e.g., she smokes during pregnancy) with (2) a case in which someone does something that creates a 140 IQ child rather than a different 160 IQ child (e.g., she smokes prior to pregnancy) (Kamm 2013, 317).

Differently from Kamm's solution which considers the two cases morally equivalent, according to PaPB the first case is morally wrong because it causes a person-affecting harm, while the second case is morally permitted, because the child would not have existed otherwise and it does not cause any person-affecting harm.

Finally, as a person-affecting consequentialist principle, PaPB can be easily extended to *different quantity* people choice. Yet, person-affecting procreative beneficence does not imply the obligation to generate happy new children: it aims at making people happy, not at making happy people.

In this way, it avoids the problems of an impersonal maximizing conception of beneficence extended to different quantity choices. In a case of post-conception testing on two asthmatic twin embryos, it does not require that we should select in favour of the two asthmatic embryos rather than in favour of one healthy child. In a case of IVF, it does not require that we should implant the highest number of healthy embryos in order to have the highest number of future healthy children and the greatest quantity of well-being. According to a person-affecting form of beneficence less quality of life cannot be compensated with more quantity of people.

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SECTION

3

SECTION 3

ETHICS IN CONTEXT

Laura Palazzani
Reproductive Technologies and the Global Bioethics Debate: A Philosophical Analysis of the Report on ART and Parenthood of the International Bioethics Committee of Unesco

Virginia Sanchini, Davide Disalvatore, Sarah Songhorian, Paolo Spada, Pier Paolo Di Fiore
Deliberation and Public Bioethics: A Test Case in Reproductive Genetics

Federico Pennestrì)
Is Therapeutic Germline Editing Value-based Healthcare? An Early Health Technology Assessment

Davide Battisti
Genetic Enhancement and the Child's Right to an Open Future

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REPRODUCTIVE TECHNOLOGIES AND THE GLOBAL BIOETHICS DEBATE: A PHILOSOPHICAL ANALYSIS OF THE REPORT ON ART AND PARENTHOOD OF THE INTERNATIONAL BIOETHICS COMMITTEE OF UNESCO

abstract

Over the last few decades an increasingly pressing social demand for access to assisted reproductive technologies (ART) has emerged. Alongside the use of reproductive technologies, relevant bioethical and biolegal issues arise, such as the claim of a "right" to have a child, the so-called "reproductive rights", of the prospective parents and the rights of children. This paper explores these and further challenges, both old and new, calling for a transformation of parenthood and filiation, from the perspective of the different theories of the contemporary pluralistic debate, with a descriptive and critical analysis of the recent Report on ART of the Unesco International Bioethics Committee, the first global document on these topics.

keywords

parenthood, best interest of the child, reproductive freedom, procreative responsibility, surrogacy

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1. Introduction

The International Bioethics Committee of UNESCO (IBC), a transnational organism with the function of discussing bioethical issues on a global perspective, in 2017 decided to address the topic of assisted reproductive technologies (ART) with a specific focus on the transformations of parenthood and filiation, reflecting on the interactions between societal and technological developments, including the impact on cross-border practices and reproductive rights. Many problems belong to the "traditional" discussion on ART in Western Countries (the so called technologically advanced Countries), others are new, both as new challenges facing emerging technologies, or innovative ways to deal with "old" problems. The final version of the "*Report of the IBC on assisted reproductive technologies and parenthood*" was discussed in July 2019, after undergoing a series of changes during the two years of debate, before being published in 2020 along with a dissenting Opinion. This article will go through the main issues discussed, in a descriptive and critical way, outlining main questions still at stake in the international discussion both in bioethics and biolaw.

There was a huge discussion on the actual choice of the topic. The decision to discuss it came from a shared recognition of the need to update ethical reflection on ART above all from the perspective of their impact on the concept of parenthood, given the fact that the number of children born after the use of ART is regularly increasing. Worldwide about 2.4 million ART cycles are estimated every year, from which about 500,000 children are born each year, resulting in more than 7 million children being born worldwide to 2018, with more than 4 % of these annual births in rich countries (ESHRE, 2018). The increase in the number of children born now makes more visible some concrete and challenging ethical problems that were at one time only intuited. The document is an overview of the latest achievements of scientific knowledge and technological applications in the field, and focuses on the ethical, psycho-social, cultural and legal issues in a global perspective.

Consideration should be given to the fact that the context of the discussion in the IBC is global, with its experts coming from all over the world, from countries with different levels of technoscientific advancement, different religions and cultures, differences in socio-economic-political history and context, differing also in their ethical perspectives and regulations. All disciplines and ethical approaches are represented, so that the interdisciplinary and pluralistic discussion is finalized to reach (whenever possible) the "ethical minimum", or "maximum ethical" consensus possible, accepting, at times, the need for "mediation" (not compromise) in order to identify common values.

2. The status of the embryo as a neglected question in theory, but not in practice

One of the first main points in the document is the absence of the discussion on the status of the embryo. It has always been, right from the beginning, a delicate topic inside the IBC, and after a long discussion, the decision was taken to "acknowledge" that the moral status of the embryo is a "fiercely debated philosophical problem on which very different views are expressed". For this reason the Committee decided "not to try to reach consensus" on this topic in the Report.

It is well known in the discussion that ART is strictly connected to the status of the embryo, as it involves forms of "manipulation" of embryos: the over-production and freezing of embryos in order to reach a high rate of success of the technology, the reduction of embryos or the random suppression of some of the implanted embryos to avoid the risks of multiparous pregnancies, the possibility of selecting (after preimplantation genetic tests) the embryos produced (Becker, 2000).

It seems a contradiction within the document, not to elaborate the status of the embryo. It is clear in the title that the focus is on "parenthood", but children are also mentioned, and it is obvious that there would not be any children without embryos, as the condition of possibility of their existence. In the end, after a very lively debate, the first mediation was necessary in order to go on with the discussion on the delicate topics of ART, and the decision was taken unanimously not to open a neverending discussion on the embryo and prenatal life in general, considering it impossible to reach a consensus.

In the Report the status of the embryo, even if neglected in theory, is considered in practice. In the scientific description of the status of the research in ART, on the basis of the achievements reached on the technological level and the success rate and negative consequences of the use of ART, it is clearly perceivable that there is consideration of the status of the embryo even beyond an explicit theorization. There is an effort, that is implicit in research (as highlighted in the document), to balance the success rate of the techniques with the protection of the embryo. No one in research and use of ART considers the embryo as a mere "object" to manipulate and use: this is evident in the scientific description of the state of the ART.

The Report underlines that the available research itself shows the importance of changing the perspective in ART: in the past, in order to increase the success rate, the risks for embryos (and also for women) were generally accepted. Now attention is paid to both elements: a single production, and consequently single transfer and implantation of embryo is considered preferable to over-production both in terms of success rate and reduction of risk of adverse outcomes for embryos (risks of low birth weight, preterm birth, and birth with neurological pathologies) and for women (risks of multiple pregnancies) (Rizck, Gerris, 2017).

Notwithstanding the position (or non position) on embryos, IBC calls for more "well-designed research studies into the causes and nature of adverse perinatal outcomes in children conceived by ART" in order to better guarantee the protection of embryos, newborn babies and the mother.

3. The transformations of parenthood

In the document it is outlined that the use of ART by single persons, same sex couples or heterosexual fertile couples made it clear that these techniques were not only used to treat infertility (the initial goal of these techniques), but that they also created a space for "fulfilling wishes" and going beyond biological limits in procreation. That is the reason why the use of these technologies raises a number of relevant bioethical and biolegal questions. Does the desire to have a child represent the claiming of a "right"? Do "reproductive rights" of prospective parents exist, choosing not only "if" and "when", but also "how" to reproduce through technologies, and in the event within which limits? What are the implications of such claims on the transformations of parenthood? (Rizck, Gerris, 2017; Austin, 2016). The answers to these questions highlight the ethical, cultural, societal and legal implications on parenthood.

In the Report there are two main positions on these topics: on the one hand, there is the conception of parenthood as a “changing institution”, in which the family is considered as a historical and social product (in the framework of a relativistic perspective), a phenomenon, variable and flexible according to needs and situations, where individuals will have pre-eminence over the “traditional” natural status of the family; on the other hand, the perspective which defends “a” family model, recognised as a “natural community” as a basic unit of society, the first condition for relationships, the place of the anthropological as well as the psychological, social and existential identification of the subject (Aristotle and Aquinas are identified in the document as philosophical sources for this position).

The mediation between these opposed conceptions of parenthood/family is found in the document in the acknowledgment that ART is configuring new forms of parenthood (like same sex couples, bi-motherhood or bi-fatherhood, mono-parenthood by a single man or woman), while recognising that ART does not change the role of the family as a fundamental unit of society, or the norms referring to parental responsibility and the child’s interests. This is the common ground recognized by all, regardless of their anthropological and ethical perspective: “a parent is someone who has rights, duties and responsibilities towards a child. Parents have decision-making rights over some areas of their child’s life: these rights are generally limited when life and health (considered as objective values and identified with the best interest of the child) are at stake”. In ART, as in natural reproduction, but even more so than in natural reproduction, the willingness to procreate through technologies also encompasses a responsibility towards those born.

The legal dimension of parenthood is a specific object of analysis in the document, starting from the existing regulation (both on a national level in a comparative way, and on an international level) and outlining the trends of development of the future normative framework. The Report highlights that the principle of using childbirth to recognise motherhood continues to be relevant today, including in the context of ART (laws have not changed in this sense), the rationale being that of assigning a person with an immediate responsibility for the care of the born child. Legal fatherhood is generally defined by marital presumption (if the mother is married), voluntary acknowledgment and court ruling (in the case of no acknowledgment of paternity and a non marital relationship). The “traditional” ways of establishing legal motherhood (via childbirth) and legal fatherhood (via marital presumption) are based on an actual or presumed biological relationship between the child and parents. But ART may separate genetic, gestational, and social aspects of parenthood, therefore new criteria for establishing parenthood have been developing.

“Procreative intentionality” of prospective parents is considered the source of legal parenthood in ART: third parties involved (gametes donors, surrogates) cannot be considered parents, as they are external to the project, even if biologically linked. Informed consent to access ART is considered as an *a priori* legal recognition of parenthood and filiation, that generally in most legislations cannot be denied after birth (with the anonymity of the mother or disavowal of the father). When donors of gametes or gestation (even if they have genetic linkage or give birth to the child) sign the informed consent, they relinquish all parental rights, as well as parental obligations.

Another ethical and legal discussion in the Report on parenthood is referred to in the determination of whether the claim/ desire to have a child through technologies constitutes an expression of freedom or an entitlement. In the document there is a mention of the development of “reproductive autonomy”, as “a hard won freedom” versus “a coercive freedom”, in the context of a strong social and political control. There is a mention of the horrific violations of individual freedom in the domain of reproduction, as forced contraception and forced sterilization in eugenic programs and restrictive reproductive policies aimed at slowing population growth.

In this context, the Report makes a distinction between a right as a “liberty or freedom”, and a right as an “entitlement or benefit”. The former implies protection against interference by the State, removal of obstacles to the exercise of freedom, so long as it does not harm others (negative rights); while the latter entails also the provision of assistance by the State and others to fulfil that right (positive rights). In this framework, reproductive negative rights are against coercive interference in decisions regarding procreation, positive rights refer to entitlement to assistance in procreation. The document recognizes that there is a growing consensus in bioethics that reproductive autonomy includes both the “right to reproduce” and the “right not to reproduce”, but also that there are many ethical controversies due to the interpersonal relevance of the decision to reproduce, affecting a third party, the future child. The Report underlines that: “not procreating is personal; procreating is interpersonal”, considering that the right not to procreate and the right to procreate are not symmetrical. A parenthood right determined as “a right to have children” cannot be accepted because it would reduce children to properties or commodities: the child as “something”, and not “someone”, intentional parents are entitled to “have”. The Report starts from a general consideration that sometimes those wishes, claimed as rights, are exacerbated by the cultural and social pressures of having a child. This pressure is a combined result of the “technological imperative”, which considers the development of the new technologies as “prior” and “inevitable” as an innovative solution to fertility problems or to the fulfilment of desires, needing to be accepted for the benefit of society, regardless of costs and safety (Fisher and Monahan, 2011), and the parallel development of a “reproductive market” and “shopping forum” of reproductive technologies and services, emphasized by the media, advertisement and publicity referring to technological successes using great power of persuasion, without considering the problems of safety and justice. ART is often advertised as “the” response to infertility or to the claim/ desire to have “a healthy baby”, hiding the risks and/or costs, and increasing societal expectations and acceptance. Both the technological and commercial pressures, together with the societal pressure placed, above all, in Western societies on women for them to have their “own” baby, are always to be considered in the concept of autonomy and rights in the area of procreation.

In this framework the IBC underlines that “reproductive autonomy” should always be strictly connected to “procreative responsibility” to be considered the “new paradigm”. In the document there is no specific discussion on the different technologies to be used and specifically connected problems (gamete donation, same-sex couples, single mother or father, late or delayed parenthood). Discussing the “traditional” arguments for and against, the positions in the IBC are very different on each of these (some in favor, some against), but the general consideration was not to focus on the “claims” of the parents but to better understand, regardless of the technology chosen, the transformations of parenthood and rights/interests of the child.

4. The focus on gestational surrogacy

A specific issue at the centre of the discussion in the IBC is the practice of surrogacy, due to the global increase in the phenomenon. In the Report there is a descriptive analysis of the reasons, considered relevant, for and against surrogacy, followed by a reference to the internal positions in the IBC.

The reasons against surrogacy are referred to as social injustice arising above all in poor countries, with the exploitation of women, often illiterate, in disadvantaged socio-economic and cultural conditions; the lack of real informed consent, considering the difficulty in having awareness and freedom of choice; the commodification and exploitation of the woman through her social role as mother; the control over lifestyle and private life and possibile conflict between the surrogate mother and the intended parents; the psychological problems of the surrogate; commodification of children, conceived as the best "product", the "best child", in which perfection seems to be buyable; and the risk of abandonment if the child does not meet the parents' expectations (Madeira, 2015). A final argument against surrogacy is the reference to family as the core institution in societies: the Report mentions the Universal Declaration of Human Rights (Article 16 paragraph 3, "The family is the natural and fundamental group unit of society and is entitled to protection by society and the State"), and the International Covenant on Economic, Social and Cultural Rights (Article 10 paragraph 1, "the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children").

The arguments in favor of surrogacy in the document refer to: the opportunity to become parents, considering motherhood as a social construct separate from gestation which can be regulated by the market (Lyzwinski, 2013); the acknowledgment of the possibility to negotiate a contract also privately between afferents (private clinics/organization) and intended parents; the legitimation of compensation to the surrogate for the costs of pregnancy and inconvenience to her working or family life; the consideration of cross-border surrogacy as an option, which for some couples might come with an advantage due to the territorial distance between the intended parents, the child and the woman, avoiding any relationship between the child and the surrogate.

In the context of this discussion, the IBC unanimously restates the unconditional value of human dignity, rejecting any form of commodification of the human body. The surrogate is vulnerable due to the risks to her health and the strong psycho-physical bond with the foetus, with the possible trauma of separation. The contract usually contains conditions that oblige the surrogate to undergo specific health treatments and to follow certain rules and an appropriate lifestyle for the health of the foetus, in addition to possible agreements for an abortion should there be genetic pathologies or malformations that the intended parents refuse to accept.

Within this framework, there are three positions that are supported within the IBC. For some members, surrogacy should be rejected because of the risk of exploitation of the surrogate mothers (both paid and altruistic surrogacy), the best interest of the child and the threat to the central position of the family as an institution. Other members of the IBC argue that altruistic surrogacy under special conditions can be accepted as a way to create a family with a child: securing the interests and rights of the child; securing the autonomy and welfare of the surrogate and her family; and enabling the successful involvement of all parties, with appropriate counselling and psychosocial assessment (including intentional parents), and in the case of the surrogate, also medical assessment and adequate follow-up. A third group of members holds the position that altruistic surrogacy could be acceptable in some specific cases, but doubts whether the conditions required can be met in reality.

5. The best interest of the child

The *United Nations Convention on the Rights of the Child* (UN, 1989) states that the best interests of the child shall be a primary consideration in all actions affecting children (Article 3) and specifies that "the child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents" (Article 7). This international declaration was taken by the IBC as the basis for the discussion on the best interest of the child in ART. The concept of "best interest" related to ART is a general notion that may cover medical interests (e.g. safety of medical procedures, evaluation of risk/benefit ratio), psychosocial interests (e.g. security and identity), and legal interests (e.g. recognition of filiation), and it was not easy to achieve consensus on what it means in the context of ART.

In the Report there are two rights unanimously recognized as belonging to the best interests of children: the right to know their own origin in the context of gamete donation and the right to acquire nationality in the context of cross-border reproductive services (expression preferred to “bioethical or reproductive tourism”: Donchin, 2010; Lyzwinski, 2013; Paraskou, George, 2017).

The right to access information on the identity of the gamete donor at a certain time, if requested, is considered important for two main reasons. The first reason is the relevance of the genetic link, as a basic element of inheritance that marks the genealogy of each human being. In this sense it may be considered connected to the right to health, as genetic origin is the main source of information needed for a correct diagnosis or prediction of hereditary disease. The second reason is psychological, existential and anthropological: hiding a person’s knowledge about his/her origin (when requested) could imply denying one of the constituent elements of identity. It does not mean that the State has an obligation to tell the truth, but that the State should not prevent access to information about the donor, as it could mean depriving the person of an important aspect of his/her identity.

Based on the fact that the requirement for anonymity affects the rights to personal identity and the development of the personality of the child, the Report affirms that those rights should prevail above any other rights either from parents or from donors. The right to know the child’s origin includes not just the right to access information that would make it possible to trace one’s roots and to know the circumstances of one’s birth. The knowledge of their origin can be confined only to the knowledge of genetic origin (without knowing the anagraphical traits of the donor) or the knowledge of both, including knowledge about half-brothers and half-sisters which would enable the avoidance of possible accidental incest. It is a right to know about the past, and to develop the future.

The principle of the anonymity of human gamete donors that was recognized at the beginning of the debate and of regulation is today called into question. In Europe, several countries (such as Sweden, Germany, Switzerland, the Netherlands, Austria, Finland, Iceland, Norway, the United Kingdom and Portugal) have decided to follow a similar practice. There is a growing tendency to give priority to the rights of donor-conceived persons to know their origins and to favour waiving the anonymity of gamete donors. None of the legislations recognize neither donor’s legal establishment of parenthood nor any rights and duties towards the born child (Kramer, 2016).

The Report underlines that no decrease in donations has been noted in the countries which have granted the right to have access to one’s origins. The different studies have shown a substantial change in the donor profile, as they are generally older and have had time to think about their decision, but not a reduction in their number.

The IBC recommends that regulation of the child’s right to know should be implemented in the national legal framework without retroactive effect, unless there are medical reasons involved or there is a possibility to have the consent of the donor. The recognition of the right to know represents an option given to the child (normally on reaching the age of majority) to access information. Proper guidance, counselling and support should also be offered to donor-conceived children before they decide whether to exercise their right to access information containing the identity of the donor and during the decision (with a sort of “accompanied right to know”).

In this sense the right of the child should prevail over the rights of adults (both parents and donors). Many parents do not want to disclose this information to their children for various reasons: to protect them against negative reactions from others knowing they are the result of ART; to protect themselves from the stigma of infertility leading to negative social and psychological effects; to prevent the impact of the disclosure from disrupting family unity. The main reason put forward in support of the choice to remain anonymous by donors is the claim of privacy regarding the choice, avoiding any kind of implication in the donation of genetic materials.

The second right of the children recognized by the IBC is the right to identity and nationality in case of surrogacy. In the document there is a reference to the European Court of Human Rights that guarantees childrens' identity (Mennesson v. France, 2014; Labassee v. France, 2014; Foulon and Bouvet v. France, 2016; Laborie and others v. France, 2016): respect for the best interests of the child requires guaranteeing the cross-border continuity of filiation relationships constituted by surrogate pregnancy, referred to those cases in which there is a biological link between the minor and, at least, one of the parents.

The prohibition of surrogacy should not affect the proclaimed rights of the child, above all, those related to national identity. The child can not be deprived of his/her nationality and filiation because one of their biological parents decided to resort to surrogacy. In any case, the solution to the conflict should be resolved considering always the best interests of the child because ART is not aiming at giving a child to a family but of giving a family to the child, considering solely his/her best interest.

Beyond the recognition of these two rights (the right to know the origin and the right to nationality and identity), the Report recognizes, in general, the importance of the protection of the child's particular vulnerability. Children may be in a condition of weakness, possibly being the objects of adults' choices and not the subjects, as not yet capable of expressing their own choices and autonomy. They are at risk of harm and damage, without the ability to protect themselves (Berntsen et al., 2019).

Childrens' vulnerability in the context of ART is connected to their health condition. Some reproductive technologies employing invasive interventions and leading to multiple pregnancies involve risks for children, both physical (premature birth, neurological damage etc.) and pshychological (confusion and disorientation). Today it is not possible to foresee what the future consequences might be on the unborn child, as well as on the affective and psychological relations with the parents. No sufficiently documented psychological studies exist on the subject yet. But the mere possibility that such a situation could upset the delicate process of the child's anthropological, psychological and existential identification should lead to the tackling of this issue with great caution. There is no mention in the document of the possible recognition of the right to have two parents versus single parenthood, of different sex versus same-sex couples as parents, because no consensus was possible in the IBC. But the vulnerability of the child born with ART is one of the main unanimous concerns in the Report.

6. Future challenges: artificial uterus and artificial gametes

In the Report there is also a reflection on the artificial uterus and artificial gametes, as remote emerging future issues of ART, but no explicit position has been taken, due to the novelty of the theme (still dynamically evolving) and the need for consolidation of the discussion both on the scientific level as well as on ethical, legal and societal levels.

Birth from an artificial uterus, also called ectogenesis, concerns the possible, still futuristic prediction regarding technologies allowing for an extracorporeal pregnancy in an artificial womb that can be either partially or totally realised (Corea, 1985). Partial or tardive ectogenesis (on which animal experimentation has been carried out, recently through the "biobag" in which a lamb developed through a crucial phase of its gestation and was successfully 'born') would come into play after a first phase of intrauterine life, or more precisely from the moment in which the foetus has its umbilical cord to attach to machines able to feed, oxygenate and purify the blood. The complete artificial gestation, from fertilisation to delivery, foresees the manufacturing of wombs like incubators with an artificial placenta, surrogate membrane and amniotic fluid able to let an embryo and foetus survive outside the mother's womb, substituting for the maternal organism in the nutrition and exchange functions from the moment of implantation up to the end of gestation. This is a technique that still cannot be reproduced experimentally, given the functional complexity of the human placenta. Despite the fact that this technology has not yet actually been realised (at least with humans), bioethics is already debating its legitimacy or illegitimacy, reflecting on the issues relative to the availability of the body, as well as the implications in the context of parenthood and children's interests (Segers, Pennings, Mertes, 2020; Smajdor, 2012).

The supporters of such a technological advancement affirm its therapeutic usefulness both with reference to the mother and the unborn child: the possibility of carrying pregnancies for wombless women, without having recourse to gestational surrogacy; the prevention of miscarriages or abortions (transferring foetuses from mothers who do not accept pregnancy to artificial wombs); the prevention of harmful effects on the embryo of mothers with risky behaviour (alcoholics, drug addicts, heavy smokers or also those with inadequate diets); the possibility to control the different stages of development of the child that is undoubtedly superior to prenatal diagnoses with the planning of therapeutic interventions too.

That is why in the Report there is an explicit acceptance of the technique when proved safe to be used in humans, which would allow extremely premature infants (23-25 weeks old) to survive. The high morbidity and mortality of this group of vulnerable infants might justify the application of this technology "if ethically acceptable clinical trials could show dramatic improvements of their outcomes". The therapeutic aim is to give premature infants in incubators, with undeveloped lungs, a chance to thrive. Further prospects for the artificial uterus may include the possibility of bringing children to life through development of foetuses or embryos in the very early stages of gestation outside the natural uterus.

Undoubtedly ectogenesis could represent an important advancement for biomedical techno-science if considered for therapeutic reasons, or aimed only at saving foetuses from abortions, anticipating the time necessary for gestation outside the mother's body. Nevertheless, together with such a hypothesis an unavoidable bioethical issue remains open: in the experimentation phase of an apparatus that substitutes the womb, embryos and human foetuses would be used and instrumentalised, with the likelihood of a very high number of damaged ones possibly or probably being destroyed. The use of embryos as guinea pigs for the functionality of an artificial womb would also contradict the generally accepted principles of the experimentation of drugs or medical apparatus on human beings. Experiments must be carried out with respect to the physical integrity of the subject in question, with the aim of improving health and not reducing or harming it.

In the document many challenges are raised, both medical and ethical. This would represent a "disconnection" of gestational development of the child and the natural biological process of pregnancy, and even birth, if the embryo was to develop in an artificial uterus from the very beginning. It is a project that presupposes a de-naturalisation of reproduction which opens up scenarios of the complete artificialisation of the unborn child, able to produce a child devoid of any relationship with human bodies from the very beginning to birth. Artificial gestation coincides with the de-incarnation of motherhood and the cancelling of the physical- psychological bond with the mother. Not only in scientific studies but also from human experience, it is now widely reported that gestation is a phase of intense interrelation between mother and child and that the prolonged relationship of interaction of the mother towards the foetus has a strong impact on the health of the unborn child and its psychological and emotional /development. The artificial uterus would break the bond between mother and child definitively from a natural point of view, a bond which could not be substituted by surrogate mechanical support and would take away from the unborn child not only unreproducible elements (insofar as these are extremely complex with respect to technical reproducibility) but no longer recoverable for the child once born. This raises fundamental challenges to human dignity and human rights, raising possible forms of instrumentalization of human life.

Such a technique would furthermore constitute a premise for the possible radical de-sexualisation of procreation, opening also possible scenarios of the production of children without parents, anonymous procreations in which orphans could be brought up in collective facilities, with the consequent end of the family, and also parenthood. The child's right to be born in contact with the mother and the right to an interaction with the mother's body as the conditions for an appropriate development of personality will be at stake.

Scientists are also exploring the possibility of creating gametes in vitro, producing artificial sperm in males and artificial oocytes in women. The state of knowledge on functionality and safety of these methods is currently limited. Possible future use of artificial gametes could increase the availability of gametes and represent a possibility for infertile persons who now use donated gametes to have a child who is genetically related to them. The current situation is such that this is only a remote possibility at the moment. The first report of experimentation in animals, failed.

Artificial gametes pose a fundamental challenge to many assumptions about the limits to human reproduction. The possibilities that these techniques may represent raise issues related to how infertility, gametes and parenthood are understood and a number of ethical concerns, including the commodification of human reproductive material. The main ethical question is related to the legitimacy of the research itself in this field, because of the potential genetic or psychological harm to the offspring, and gender and parenthood issues. Artificial gametes raise the problems of possible gamete theft and the prospect of unwitting parenthood, issues that may be particularly difficult to be elaborated (Smajdor, Cutas, 2015).

In the context of divergent theoretical positions in the ethics of ART, the Committee found some shared recommendations in the global discussion, recognising the need for a broad debate and implementation of evidence-based policies, including public debate, as these technologies have a broad cultural and social impact. The IBC calls on scientists, governments, and civil society at large to promote multidisciplinary scientific research and discussions on the emergence of new models of families and parenthood, the protection of the rights of the individuals involved, balancing them with the best interests of the child. The focus is also on the safety of reproductive technologies, specifically considering the risks for women, men and children in a condition of particular vulnerability.

The Committee underlines the need to balance the right or liberty with responsibility towards the child, promoting an intergovernmental debate aimed at ensuring non-commodification of gametes and clarifying it in the context of the discussion on organ donation and the prohibition of making a profit from the body and its parts. One recommendation is devoted to promotion of a debate about perceived risks in the implementation of reproductive technologies as a way of avoiding genetic diseases and possible consequences for the rights of persons with disabilities.

The Committee urges the promotion of research on the causes of the increase of infertility and sterility and the methods of preventing infertility and sterility on a medical, psychological and social level and calls for the promotion of psychological and social research on the implications for children born as a result of reproductive technologies and on parents using such technologies.

The Committee calls upon National Governments to establish regulations for ART to avoid legal uncertainty. In the case of surrogacy, the Committee asks for the position of the child born with the help of a surrogate to be regulated, whether surrogacy is accepted or not in a specific Country; in all cases the identity and nationality of these children should be clear.

The Committee, unanimously, recognises the need for a ban, on a global level, of commercial surrogacy and the commodification of children.

The Committee underlines the need to establish and ensure justice regarding access to reproductive technologies. It is interesting to note that the Committee affirms the need to promote public policies to prevent infertility, and calls on professional organizations of physicians and other relevant health professionals to promote a constant evaluation of the safety of technologies, the development of ethical guidelines and adoption of precautionary measures for their application, unequivocally focusing on medical ethics over business interests. The Committee recognizes that the counselling of persons using reproductive technologies, especially those using donated gametes should be human-rights based and oriented at providing information to all persons involved. It is essential that the counsellor makes sure that the information has been understood by the people who are advised, so that they can make a free and informed decision, avoiding any kind of undue interference on the decision-making process.

In the Report there is a dissenting opinion on two specific paragraphs in the recommendations considered uncorrelated with the UN Convention on Children's Rights. Specifically, the recommendation on the "balancing" of parents' rights and children's rights, as "balance" does not recognize the best interests of the child. The specific words of the Convention are the following: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration" (Article 3): the term "balancing" means to find a sort of compromise, not to attend to the best interest of the child as a prevalent principle over the rights of the others parties involved (the parents, and donors).

The dissenting opinion focuses also on a recommendation, which calls to "observe neutrality on different forms of family and parenthood chosen and not discriminate... any of their citizens on the basis of their choice under the scope of each national legislation". The reference to the "scope of each national legislation" is considered vague and ambiguous and an explicit reference to the best interest of the child is also needed in this context for coherence within the document. To mention the "neutrality" of States with regard to the parenthood chosen means that the State doesn't have the duty to protect the best interest of the child over protection of the form of parenthood chosen, instead, the State must remain neutral and tolerate the parents' choices whatever they are. This point is not shared by those in the field of reproductive technologies who underline the need to prioritise the interests of the child over the rights of the parents.

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DELIBERATION AND PUBLIC BIOETHICS: A TEST CASE IN REPRODUCTIVE GENETICS[1]

abstract

Background. Since the nineties, policymakers and theorists working across several disciplines started to entertain the notion of directly engaging the public in matters of public concern. Accompanying this was the attempt to resort to deliberative democracy in order to make such an involvement effective. Seizing on its intrinsic dialogic nature, some scholars proposed the application of public deliberation to the realm of public bioethics. Drawing upon the theory and practice of deliberative public bioethics, the purpose of this paper is to shed light onto the figure of the bioethical expert and its role in public bioethics, and relatedly, to investigate how deliberation may be implemented in a public bioethics context.
Methods. We set up a large-scale experiment to investigate whether, and to what extent, different moderation styles impact on participants' moral preferences. The study combines a survey of a representative sample of the general population with a laboratory experiment based on a random sample of students that ex-ante has identical attitudes to the general population.
Results. Findings show that: i) different moderation styles can significantly influence deliberative outcomes; iii) the effects of deliberation are not necessarily immediate, but may be revealed after the end of deliberative session; iii) participants tend to better appreciate a bioethical expert acting as "passive moderator", namely as someone who acts in order to ensure non-domination and non-interference, thus allowing the creation of basic conditions for equality within the deliberative setting.
Conclusions. Our experiment represents an example of how deliberation can be employed in public bioethics.

keywords

public bioethics, deliberation, genetic testing, bioethical expertise, moderator

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DELIBERATION AND PUBLIC BIOETHICS

1. Introduction

Since the nineties, policymakers and theorists working across several disciplines started to entertain the notion of directly engaging the public in matters of public concern (e.g., Fishkin 1991; Bohman 1998; Moore 2010; Landemore 2012; Neblo 2015). This was accompanied by the attempt to resort to deliberative democracy (henceforth DD) to make such an involvement effective (Gutmann and Thompson 1996; Gutmann and Thompson 2004). Geared towards bringing the core tenets of DD into different contexts of the public sphere, the main aim of these deliberative processes – generally defined under the common, albeit variously interpreted (Blacksher et al. 2012), label of "public deliberation" – is that of eliciting citizens' opinions, while also, in some cases, informing policy-making (Abelson et al. 2012).

Leveraging upon its intrinsic dialogic nature, some scholars have proposed the integration of deliberation into the realm of public bioethics, which is considered to be a field of bioethics dominated by "value conflict and high pressure for decision and regulation" (Moore 2010, p. 715). In particular, seizing on its capacity to constructively deal with (value) conflicts, deliberation was considered, by some, to be a promising tool for addressing moral disagreements of public relevance (Crawshaw et al. 1985; Bowling, Jacobson, and Southgate 1993; Bowie, Richardson, and Sykes 1995; Gutmann and Thompson 1997; MacLean and Burgess 2010; King et al. 2010; Meagher and Lee 2016).

In parallel, the *theoretical* proposal of a *deliberative public bioethics* has been accompanied by the attempt to empirically test deliberation in the context of public dialogue over ethical issues (Abelson et al. 2003a; Abelson et al. 2003b; Abelson et al. 2012; Abelson et al. 2013). These deliberative experiments have been implemented in different forms – from citizens' juries to national issue forums, from deliberative opinion polls to participatory budgeting (Abelson et al. 2003a; Goold et al. 2012, p. 24) – and focus on a wide range of ethically sensitive issues, ranging from priority setting in healthcare to the ethics and regulation of (healthcare) technologies (Abelson et al. 2013).

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Drawing upon the theory and practice of deliberative public bioethics, this paper presents *the overarching goals* to shed light on the figure of the bioethical expert and its role in public bioethics, and – relatedly – to investigate how DD may be implemented in a public bioethics context, assuming the principles of DD at face value[1].
The paper sets out from the dominant view–according to which public bioethics can be considered an exemplary case for practically embedding the deliberative democratic ideals (Moore 2010; Rei et al. 2009) –to contend that, in fact, it is deliberation in its role of managing (value) conflicts, that can be considered a useful tool to be employed in public bioethics' settings. To this end, we devised a "validated laboratory experiment" (in line with Abelson et al. 2003a, p. 98), designed according to results obtained through two preliminary surveys[2].
Specifically, *the endpoint* of our study was to empirically investigate whether, and to what extent, different moderation styles – implemented by different figures (active moderator, passive moderator[3], and observer) – would impact upon participants' individual moral preferences and, in particular, on preference shifts. The idea of devising and testing a 'supervisor' – a well-established figure within deliberative experiments, albeit underestimated in its impact (Moore 2010), something that is mostly absent in bioethics literature – represents the most relevant novel element in this experiment. As it will be explained herein, we did not intend to measure the mere shift of preferences (Stewart, Kendall, and Coote 1994; Coote and Lenaghan 1997; Fung 2006; Fishkin 2011), but rather the shift towards what Engelhardt defined as *"the Principle of Permission" (or forbearance)* (Engelhardt 1996) – see section below "Theoretical Background".

The paper is structured as follows. First, we explain the theoretical background upon which the paper builds. Then, we present the rationale, design, and metrics of the study. Next, we present the study results. Finally, we analyse and discuss our findings in relation to four phenomena: i) the apparent lack of impact of information; ii) the role of time in unmasking the effects, iii) the better appreciation of passive moderation over active moderation; iv) the impact of our findings on the bioethical debate regarding bioethics expertise and public bioethics.

1.1 Theoretical background

The "Principle of Permission" (henceforth PoP) is a non-substantive negative principle interpretable as "non-interference". In Engelhardt's view, the principle of permission represents the most fitting principle for a "secular bioethics", i.e. the contemporary bioethical reflection characterised by deep moral disagreement, inhabited by "moral strangers", i.e. individuals endorsing different moral views.
By adopting this view, we measured, as the end point of our study, a shift towards PoP[4]. The

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[1] We are not claiming that DD is *always* the best tools to address moral disagreements, as this, we do believe, would require a case-by-case discussion that we cannot carry out within the scope of this paper. Rather, we aim to investigate whether it could be a useful tool to address moral disagreements, and its impact on participants' preferences.

[2] The preliminary surveys consisted of two pilot studies aimed at defining the topic to be addressed in the main experiment through the analysis of the similarities between the Italian general population and the study population, so as to increase the external validity of the experiment. In this paper we do not report and/or discuss the preliminary surveys.

[3] The expression "active" and "passive moderators" is drawn from Farrar and colleagues' paper (Farrar et al. 2009). However, despite the same wording, and for the reasons that will be extensively covered in the discussion section, our connotation of the terms is different from theirs.

[4] As already noted, the outcome of our study was not the mere shift of preferences after deliberative session. Following Smith (Smith 2009). Democratic Innovations: Designing Institutions for Citizen Participation. Cambridge: Cambridge University Press), who claims that "in itself, opinion change tells nothing about whether judgments represent *enlightened preferences*" (Ibid: 95), we believed that the mere opinion change after deliberation cannot be considered proof of the success or failure of different interventions, since transformation of preferences *per se* does not prove that the purposes of deliberation have been met.

main justification lying behind this proposal is the following[5]: we argue that this shift is consistent with the purposes that proponents of DD have attributed to deliberation itself: *pluralism awareness*, i.e. to make people aware that the public arena is a domain dominated by moral pluralism – namely, of what Rawls defines as "the fact of pluralism" (Rawls 1993); *pluralism recognition*, i.e. the fact that moral pluralism characterises the public arena should be recognised and endorsed, and that pluralism-oriented discussions and decision-making strategies to cope with it should be put in place.

Once recognized that deliberation intends to fulfill these purposes, to quantify the shift of participants' preferences towards pluralism awareness and recognition, we considered the shift to be in place when participants replied in line with PoP. Indeed, since PoP, as non-interference, is the condition enabling the simultaneous co-existence of a wider spectrum of substantive positions, this appears to be the principle that better serves deliberative purposes. So conceived, PoP is the descendant of the Rawlsian liberal tradition, which draws on the acceptance of moral pluralism as an undisputed fact, and on the consideration that this is the principle that maximises it the most. Accordingly, secular bioethics cannot be regulated by the principle of autonomy, since the latter represents a substantive principle, bound to substantive moral doctrines. Only a non-substantive principle, PoP, safeguards the simultaneous coexistence of different substantive moral positions dominating the public arena.

To summarise, once recognised that the purposes of deliberation are the awareness and recognition of pluralism, we identified PoP as the best means to serve these purposes and, therefore, that the shift towards this principle represents a sign of the success of the deliberation. Accordingly, for the authors of this contribution, claiming that a deliberation is successful if it promotes PoP does not equal the endorsement of any substantive moral stance[6].

2. Methods

In what follows, we will discuss materials and methods of the validated laboratory experiment.

2.1 Rationale

Our experiment consisted of a randomized controlled trial (RCT) design based on a template of a laboratory experiment (Figure 1). The overall aim was to observe what happened to participants' preferences after the deliberative intervention and to observe whether the deliberative approach devised here led to positions compliant with the purposes of

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[5] Actually, there is another reason for adopting a value-laden analysis of the outcome, which is connected with the potential artifact of "inconclusive addition" of the mere shift of preferences. To explain this effect, let us imagine a two-question questionnaire. One individual in the control group (the observed group, in our case) changes her preferences, after the intervention. On one question, she moves one notch towards PoP; on the other, one notch away from it. Her total score would be 2. In another arm of the study, one individual changes preferences moving one notch towards PoP, on both questions. Her score would also be 2. In this "inconclusive addition" the "real" effect, i.e., that one individual moved towards PoP, while the other did not, would be lost. In many political science studies, this caveat would not apply, since the choices are binary (agree/do not agree or in favour/against) and the mere shift suffices. In our study, the adoption of a value-laden 5-point scale allowed this possibility (hence our choice to assign a "direction" to the shift). As an experimental proof of this notion, when we reanalyzed our data without considering the direction, all effects were nullified (data not shown).

[6] In the specific context from which we draw our analysis – genetic testing employed in reproduction – it is nevertheless important to point out that, for some specific techniques – namely Non Invasive Prenatal Testing (NIPT) – PoP is compatible with different substantive moral views, spanning those supporting the principle of procreative liberty in its different connotations (Robertson 1983; 1985) to those granting the foetus with an unconditional intrinsic moral value. Indeed, performing NIPS may be considered ethically legitimate by supporters of both these views, as the former may draw from very different intentions and lead to very different outcomes. As an example, the decision to perform NIPS can be grounded in the intention of verifying the health of the foetus to decide whether to interrupt the pregnancy or to gain more knowledge in order to be prepared to properly welcome the newborn, even in cases of genetic disorders. In any case, it is not our intention to endorse a specific moral viewpoint in the paper, especially insofar as the different authors of this piece would endorse very different moral viewpoints.

deliberation, in this specific context to PoP (§1/1.1.). The RCT was designed to accomplish the aim of challenging various modalities of supervision in the deliberative setting applied to bioethics. To this end, the RCT comprised three arms: i) *Observed*, in which a supervisor was present but silent and did not intervene in the discussion; ii) *Passively Moderated*, with a supervisor acting as a promoter of some "negative" deliberative values[7]; and iii) *Actively Moderated*, with a supervisor acting as a promoter of positive and negative deliberative values. The roles and the rules of engagement of these three figures were precisely defined and the supervisors were extensively trained before the sessions (Appendix 1A). In addition, precise lists of "DOs" and "DON'Ts" were provided (Appendix 1A).

2.2 Experimental design

274 students were enrolled[8]. The study was implemented through the administration of a questionnaire (Q, Appendix 1B) centred on "*Genetic testing related to reproductive choices*", selected through the Pilot Studies. The questionnaire comprised 10 statements that could be answered using a 5-point Likert scale. The same questionnaire was administered at various time points (Q1 – Q4 corresponding to time points T1 – T4, respectively) (Figure 1).
At Time 1 (T1), the initial preferences of the students were recorded in Q1. Students then received the "Informative Material"[9], consisting of simple, yet accurate, information on the scientific aspects of genetic testing related to reproductive choices (Appendix 1C)[10]. They were then asked to complete Q2 (T2) to measure the impact of information on their preferences. Q2 also included 5 questions for evaluating their comprehension of the Informative Material (Appendix 1D).
Next, students were randomized, through a double randomization process, into the three aforementioned arms[11]. They then attended the deliberative sessions that lasted 90 minutes.

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[7] By "negative deliberative values" we refer to those values that try to prevent from some group's dynamics to occur (e.g. interference, domination). Accordingly, these values may be defined as "negative" since, rather than promoting some actions/behaviours, they try to limit and/or impede actions and/or behaviours (e.g. try to limit domination dynamics within the group). Differently, by "positive deliberative values" we refer to those values that, rather than simply limiting some dynamics, try to promote certain additional behaviours which should enable group's dynamics (e.g., promote mutual respect, promote equal consideration, etc.).

[8] In line with the results of the two preliminary surveys, students were first- or second-year undergraduates from the University of Milan, selected on a voluntary basis. At enrollment, students were only informed of the "bioethics nature of the experiment". Upon arrival, they were received by the experimenter in charge of the study (V.S.), who provided participants with the following information: 1) that the experiment consisted of anonymously recording their preferences on the issue of genetic testing in reproduction; 2) that the preferences would be recorded repeatedly, upon completion of a number of phases – the nature of these phases was not disclosed; c) no information was provided as to the rationale, the aim, and the structure of the experiment; d) participants were instructed to be truthful in their opinions and behaviors, since there was no expected outcome, no right/wrong answers, in order to exclude and/or minimize 'the expectancy effect' (McDermott 2002). Students enrolled received credits; however, credits were not linked to any mandatory course, in order to prevent undue influence.

[9] Participants received the Informative Material only during the course of the experiment and not beforehand. This was intended to prevent participants from looking for further information and/or discussing it with others, in order to achieve uniformity in the access to background information and a cleaner measure of the impact of information on the subsequent expression of preference. All the study material was prepared by the researcher responsible for the trial (V.S.), and was then corrected/modified/integrated by different experts – namely, two physicians (one specialized in genetics); five PhD students in philosophy (three of them specialized in bioethics); two statisticians; five professors of philosophy (one of political philosophy, two of philosophy of science; one of political science); two psychologists; a sample of high school students at their last year (therefore of a similar age to the sample). After this, DOXA, a leading Italian polling organization also checked the material (information sheet and questionnaires) to provide a final professional verification.

[10] Students had one hour to read the material. During this time, they were not allowed to interact with each other or to use other sources of information.

[11] Immediately after T2, students were randomized (without communicating to them the groups to which they had been assigned) into three equal groups. Students within each group were then further randomized into subgroups of 4 or 5 students (Verba 1961; Karpowitz et al. 2012). The study was run over 10 days with a total of 59 subgroups: due to several no-shows on a specific day, one subgroup - in the observed arm - was not formed.

At the end of the deliberative session T3, students were asked to complete Q3, which also included a series of questions aimed at qualitatively evaluating the procedure (Appendix 1E-G). Finally, all students were recalled one month after the deliberative sessions to fill in Q4, to evaluate the impact of time.

2.3 Metrics

As mentioned, distinct from similar studies, the endpoint of our study was not the mere change of preferences (Stewart et al. 1994; Coote and Lenaghan 1997; Fung 2006; Fishkin 2011), but the shift towards PoP. To quantitatively estimate the shift, we developed a 5-point scale. A score of 5 was attributed to answers closest to PoP as non-interference (scoring matrix is in Appendix 1H). The quantitative outcome of the RCT was the mean individual change (MIC) towards (or away from) a perspective in line with PoP with respect to the use and implications of genetic testing in the context of reproduction at the time points T2, T3 and T4, relative to the baseline, T1. We calculated the transformation for each student. The effect of the intervention was measured as the difference in pairwise comparisons between the three groups. To calculate the minimum observable difference of MIC between two groups, we used a two-sided t-test. Assuming: i) an enrolment of at least 100 students per group, ii) a significance level of 1%, iii) a statistical power of 80%, and iv) a variance of MIC in each group between 5 and 100, the minimum observable MIC was calculated to be 1.08 and 4.83 for a variance of 5 and 100, respectively. We considered this range in the minimum MIC as a reasonably observable one.

By analysing the MIC between T1 and T2 and by applying Tukey's interquartile rule for outliers to identify poor quality data (Tukey 1977), we identified 31 (11%) students as outliers, defined as external to the median range ± (1.5 x the interquartile range), i.e., score ≤ -6 or score ≥ 6. These students were excluded from further consideration and all outcomes were calculated on the remaining 243 students (Appendix 1I-J).

3. Results

3.1 Quantitative analysis

The distribution of answers to questionnaires Q1-Q4 are reported in Appendix 1K. The quantitative analysis of the preferences at the various time points of the study (Table 1), revealed that:

- There were no significant differences at T1 between the three arms of the intervention (Observed, Passively Moderated, Actively Moderated), indicating that the randomization was appropriately conducted (Table 2).
- There were no significant differences in all pairwise comparisons between the three arms in the analyses T2 *vs.* T1 and T3 *vs.* T1. This finding indicates that there were no immediate effects of "information" (T2 *vs.* T1) or of "deliberation" (T3 *vs.* T1) (Table 3, top).
- There was a significant difference at T4 *vs.* T1 in the pairwise comparison Passively Moderated *vs.* Observed (p=0.0019) towards acceptance of freedom in reproductive choices (Table 3, top). No significant differences were evidenced in the comparison T4 *vs.* T1, Actively Moderated *vs.* Observed (see §4).
- All of the above results were confirmed in an independent analysis, where we did not adjust for covariates (Table 3, bottom).

3.2 Additional analyses

During the course of the study, participants were asked to answer additional questions at various time points.

At T2, students were asked to answer questions (Appendix 1D) to verify their comprehension of the Informative Material. Setting the threshold of understanding at 3 correct answers out of 5, only 10 participants out of 274 (3.6%) failed to meet it. Raising the threshold to 4 out of 5, 16.1% of participants did not meet the conditions of comprehension. Thus, since 83,9% of participants answered at least 4 out of 5 questions correctly, we concluded the material was comprehensible (p=0.0001**)** (Appendix 1F).

At T3, the additional questions (Appendix 1E) aimed at analysing interactional aspects of the experiment, such as the behaviour of participants, the general tendency of deliberative sessions, the implicit or explicit consensus reached between participants, and so on. In detail, 82% of the subjects found the questionnaire clear or very clear. Furthermore, 90% did not feel at all manipulated. Similarly, 95% felt highly or very highly free to express their preferences within deliberative sessions. Thus, there was almost no perception of any kind of manipulation.

Three questions dealt with the topics of respect, consensus, and transformation of preferences, broadly addressing issues of perceived legitimacy[12]. On the question asking whether the discussion promoted an attitude of higher respect towards the preferences of others, 88% answered "High/Very High".

In addition, on the question exploring whether the discussion was perceived as designed to strive towards consensus, 69% answered "High/Very High" (p=0.00005, calculated on the entire distribution with respect to a null hypothesis of equal distribution among the categories); despite the fact that i) consensus-reaching was not the aim of the deliberative sessions, and ii) no indication in this direction was given to participants, the latter, nevertheless, appeared to conceive their task as an attempt to reach a consensus.

Finally, concerning the question related to the transformation of preferences, the majority of subjects did not perceive that they had changed their minds significantly from T1 to T3: 63% answered "Not at all/Small degree". This result is in line with the fact that at T3 no significant differences in the MIC were present. These data suggest that perceived legitimacy was in line with real legitimacy.

To conclude, having adopted a rather stringent criterion to define significance (p-value<0.01), we did not observe significant differences between the three experimental arms, regarding the aforementioned questions. However, in the question regarding manipulation (Q5), a trend towards the actively moderated group (p=0.011) was noticed. And yet, if we consider the answers "Not at all" and "Small degree" as different, albeit comparable, proofs of absence of substantial manipulation by the side of the supervising figure, we can consider such a result not significant (p=0.53).

4. Discussion

The primary endpoint of the study was to describe the effects of deliberation on individual moral preferences in a wide sample of undergraduates representative of the general Italian population. In particular, we wanted to investigate whether deliberation might have led participants to adopt practices more oriented to the awareness and recognition of pluralism than the ones they initially expressed. The secondary endpoint was to investigate whether this shift was emphasized or downsized by different moderation styles.

In the discussion of results, we will focus on the four major study outcomes: the apparent lack of impact of information, the role of time in unmasking the effects, the better appreciation of passive over active moderation, and the impact of study results over the debate around bioethical expertise and public bioethics accounts.

4.1 Is there an impact of information?

The first outcome of the RCT is that providing informative material demonstrated no effect, as illustrated by the lack of change at T2 (Table 3). One could argue that, since it is impossible to

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[12] Here we draw a distinction between *perceived* legitimacy – i.e. what participants declare as a consequence of their perception –, and *real* legitimacy – i.e. what they declare after having investigated, reflected upon, and rationalized what they have perceived. This distinction rests upon the idea that what participants claim through their preferences does not always correspond to their *considered* preferences; i.e., the preferences that participants would have expressed if they had had enough time and information to reflect upon them (Parkinson 2006).

distinguish between the impact of information and deliberation at T3 and at T4, the fact that an effect was observed at T4 in the passively moderated group (*vs*. the observed one) could be due to some additive effect (over time) of information plus deliberation. In principle, this is a reasonable objection, given that information might have laid the foundations for a less biased approach to the subsequent deliberation, therefore representing an "enabling condition" for the subsequent shift of preferences. However, this potential 'enablement' was unmasked only in the moderated arm (see below), while one might have reasonably expected it in all arms.

It remains indisputable that there was no effect of information *in the short term* (from T1 to T2) and this raises a number of methodological questions and caveats. First, we did not measure the impact of information over time *per se*. This may be relevant since time was an important factor in influencing opinions. Second, the time that participants were given to read and to comprehend the information might have been too short (1 hour), even though the comprehension test revealed a satisfactory level of understanding. Third, we did not include sessions with experts, which are frequently part of traditional deliberative studies (Fiorino 1990; Fishkin, Luskin, & Jowell 2000; Abelson 2003b; Fishkin 2011), thereby reducing exposure to information. However, at least the last two modifications were intentionally introduced to test an approach that was less idealized than the ones currently present in the literature and that can hardly be applied in real-life settings. Our design, while retaining the rigor of a laboratory setting to obtain causal inferences from the adopted interventions, was conceived with the intent of moving closer to practice[13].

To conclude, although more work is needed, our hypothesis is that, at least in the close-to-practice setting that we enacted and limited to bioethical issues, deliberation is more effective than information in promoting pluralism.

4.2 The role of time

At T3, i.e., immediately after the deliberative sessions, we did not observe any significant effect of the various moderation styles. However, after one month (T4) and in the absence of any other intervention, there was a significant shift towards PoP. The effect was not only highly significant (Passively Moderated *vs*. Observed, $p=0.0019$), but also of a relevant absolute magnitude. In principle, if each participant had shifted all his/her preferences (i.e., to each single question) one notch towards PoP, we should have seen a MIC difference of 10. In the Passively Moderated group, the change in mean MIC between T1 and T4 was ~1. This means that, on average, with only 90 minutes of passively moderated deliberation followed by one month of "reflection" time, ~10% of all participants embraced a view compliant with PoP on all questions (or that all the participants did so on 10% of the questions).

This is interesting in light of the doubts that have been raised on whether deliberation is a useful learning process, above all when devised as a single event. Chlivers, for instance, reported that those who attended deliberative experiments repeatedly asked to have "enough time [...] to become informed and develop a competent understanding" (Chlivers 2008, p. 174). Similarly, several of our participants expressed the need to extend the time devoted to deliberation in the final Evaluation Questionnaire. Analysing our data, however, rather than being a matter of the number (or length) of deliberative sessions, the issue might be the time that participants need in order to properly digest the deliberative session.

At a minimum, therefore, our results show the need to evaluate the impact of deliberative

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[13] In real-life settings, procedures will have to be streamlined to ensure citizens' compliance (doing otherwise might introduce severe sampling biases due to the selection of a population with more time available), and to contain costs. Thus, we opted for a series of time-saving and parsimonious approaches, such as providing written balanced material as "information" and limiting the entire RCT to 5 hours per participant. And yet, being aware that time to metabolize what was learned is important, we introduced a final questionnaire (T4) one month after the RCT.

interventions some time after them – which is atypical for experimental settings, while present in mini-publics (e.g., Nabatchi 2010). If relatively brief sessions prove effective, our results encourage devising protocols for the real-life application of deliberative methodologies. We submit here, based on our results, that a limited number of short sessions might be sufficient, provided that the end-points are evaluated after a reasonable amount of time.

4.3 Passive Moderators vs. Active Moderators

In political science, the role of the so-called moderators has been recognized as crucial, as they serve the purpose of fostering negative deliberative values, such as non-domination and non-interference, allowing the creation of the basic conditions for political equality (Mansbridge et al. 2006; Smith 2009; Gerber 2011; Moore 2012; Landwehr 2014). Ideally, as public bioethics is a domain dominated by substantive disputes, a proactive figure helping participants to develop their own preferences – both in terms of internal (logical coherence) and external (awareness of the consequences) consistency, and not only someone acting as guarantor of freedom of speech and equal participation – might be advantageous. Accordingly, we devised and tested, not only the traditional figures of Observer and Passive Moderator, but also an Active Moderator, crafted as the promoter of a set of positive values, such as autonomy, critical thinking, critical reasoning, and mutual respect.

However, our results showed a remarkable difference ascribable to the presence of Passive Moderators *vs.* Active Moderators in the discussion groups. While in the passively moderated setting there was a clear (and very significant) shift towards PoP, this did not occur in the actively moderated groups.

The first conclusion is that the presence of a non-corrective figure (the Passive Moderator) was beneficial in promoting the purposes of deliberation, in particular pluralism awareness[14]. From a bioethical perspective, the failure of active moderation might be disappointing, as it seems to hinder the public utility and relevance of bioethics' experts (Weinstein 1994; Steinkamp and Gordijn 2003; Steinkamp, Gordijn, and ten Have 2008; Rasmussen 2005; Varelius 2008; Archard 2011; Gordon 2014; Gesang 2010; Cowley 2012; Schicktanz, Schweda and Wynne 2012). In our design, the Active Moderator was devised as a public bioethicist – namely with the express intention of identifying a potential role for the (public) bioethical expert as *ethical expert*, while not being a moral expert (Sanchini 2015). In the bioethics literature, this distinction refers to the fact that the expert possesses some knowledge and skills that do not legitimate her to decide *for others*, but that enable her to help others to decide *for themselves* – i.e. by fostering the formation of participants' considered preferences (Dryzek 2001, Hendriks 2006).

In principle, there were reasonable theoretical justifications to entertain this idea. In particular, although National Bioethics Commissions (NBCs) are already widespread[15], the role of the bioethical expert in the public arena has not yet been standardized and/or institutionalized. Moreover, because of their composition, NBCs are at risk of being epistocratic, thus failing to sincerely mediate between non-experts' needs and institutional requests (Doods and Thomson 2006; Moore 2010). Finally, although DD ideals are paramount

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[14] Moore has suggested further reflection upon and possibly standardise the different figures mediating deliberation (Moore 2012, op. cit. note 32). In this context, our identification of DOs and DON'Ts for Passive Moderators (Appendix 5A) might represent a valuable starting point.

[15] As reported by Doods and Thomson, The World Health Organisation lists about 90 national bioethics committees on its website (Dodds, S., & Thomson, C. (2006). Bioethics and Democracy: Competing Roles of National Bioethics Organisations. Bioethics, 20(6), 326–338, p. 326).

for public bioethics[16], these remain frequently under-expressed[17].

Our data, however, show otherwise. A possible explanation is that people are more willing to consider different perspectives when they come from their peers rather than from a superior figure. In other words, the corrective (albeit non-directive) role of the Active Moderator might have induced a defensive attitude, which, in turn, produced the rejection rather than the acceptance of a deeper consideration of their initial preferences.

We can only speculate about why this would be so. There is evidence that individuals are more prone to accept positions and arguments that are in line with their pre-existing beliefs (Himmelroos and Christensen 2013). Indeed, although from a theoretical viewpoint being exposed to dissimilar views might be beneficial for deliberation (Calhoun 2002; Manin 2005; Mutz 2002), several concerns have been raised regarding its practicability. Evidence from naturally occurring deliberation shows that people prefer to discuss with likeminded people (Mutz 2006). Huckfeldt and colleagues suggest that this human trait may be either ascribed to the human desire of reducing information costs, or to the psychic discomfort that encountering disagreement may produce (Huckfeldt et al. 2004). “Thus, in case of disagreement, people might not necessarily be inclined to confront the dissent with a counter claim, but rather opt for an escape strategy” (Gerber 2011, pp. 4-5). These considerations might explain why the passively moderated group showed a significant effect *vs.* the actively moderated one. The role of the Passive Moderator was simply to prompt equal contribution by encouraging silent participants to speak or by slowing down too dominant ones (Young 2002). The Active Moderator, conversely, may have been disruptive by prompting reflection on expressed preferences and by pointing to different viewpoints and to their likely consequences. The Passive Moderator did not question participants’ preferences, while the Active Moderator did. It can, thus, be hypothesized that, for participants of passively moderated groups, it was easier to conform to a viewpoint more in line with PoP, because they were not induced to develop a defensive attitude or to opt for an escape strategy.

4.4 From bioethical experts to public bioethics: which role/s for public bioethics

Let us now consider the final question of whether there is a role for bioethicists in public bioethics, and, if so, what that may be.

The prudent approach is to take our results at face value and to consider our experiment as preliminary evidence that bioethical experts are not beneficial to the promotion of deliberative values in the *discussion phase* of deliberative processes (where a more passive moderation is more effective). This does not imply, however, that the pre-deliberation phase can be constructed in the absence of expertise: the preparation of both informative material and questionnaires requires the knowledge and skills of bioethical experts[18].

Our results are also consistent with some tendencies in the broader debate on the role of public bioethics and NBCs, whether advisory or policy-making (Black 1998; Doods and Thomson 2006; Trotter 2006). Many scholars have claimed that the role for public bioethics in embedding deliberative ideals – a deliberative public bioethics – is that of mediating discussion on

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[16] Moore claims that public bioethics has a self-understanding that explicitly draws on deliberative ideals (Moore 2010, op. cit. note 1, p. 715). On the same point see also: Moreno 1995; Trotter 2006; Dzur and Levin 2007.

[17] Indeed, traditional moderators, as described in political science, are not usually given reasonable latitude of intervention in the execution of their function, whereas an empowered version of the traditional moderator, the Active Moderator, would be able to fulfill the reason-giving requirement and to promote autonomy.

[18] Furthermore, bioethicists could be added to an expert panel in the information phase. One might reasonably argue that providing information in the realm of bioethics does not need to be limited to the provision of factual/scientific information and might include, for instance, providing (upon request) scenarios about the moral implications of some practices.

contentious ethical issues of public relevance (Moore 2010). Accordingly, public bioethics plays a *preparatory* role in opening up and facilitating public debate (Doods and Thomson 2006), clarifying, if necessary, moral concepts and facilitating cooperation (Trotter 2006). In this sense, public bioethics should be considered to have primarily an advisory function, where its policy-making function has been articulated in the notion of "regulation as facilitation" (Black 1998). Another, still tenable, position is that by allowing longer deliberative sessions (and/or perhaps by increasing their numbers), the figure of the Active Moderator/bioethicist can still prevail and be superior to the Passive Moderator. This is a testable hypothesis that can be integrated into future studies aimed at verifying the impact and the cost/benefit balance of repeated short interventions employing various moderation styles.

5. Conclusion

Herein, we have reported and discussed the results of a large-scale mixed method study exploring moral preferences of undergraduates, subject to different moderation styles, on the topic of genetic testing in the context of reproductive choices. Drawing from the hypothesis that DD can be an instrument tailored for serving the purposes of public bioethics, acting as a tool for addressing and managing moral disagreement occurring in the public sphere, this study has shown that public deliberation with the presence of a passive moderator is an appropriate means of fulfilling the purposes that proponents of deliberation envisaged in theorising it.

Considering this outcome in relation to the current debate over bioethical expertise, we may argue not only that the "moral expert" – someone who interferes with other's own decisions because of his/her superior expertise – but also the less invasive "ethical expert" – someone who actively fosters the formation of considered preferences on a specific topic (corresponding to our Active Moderator) – should be rejected if deliberative ideals are endorsed, and that, conversely, a third figure, the Passive Moderator, appears, to this end, more promising.

This result is also consistent with the interpretation, within public bioethics debate, in favour of a specific connotation of public bioethics, namely as a sphere aimed at opening up and facilitating public debate, and mediating discussion on controversial ethical issues (Hendriks 2006).

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FIGURE AND TABLES

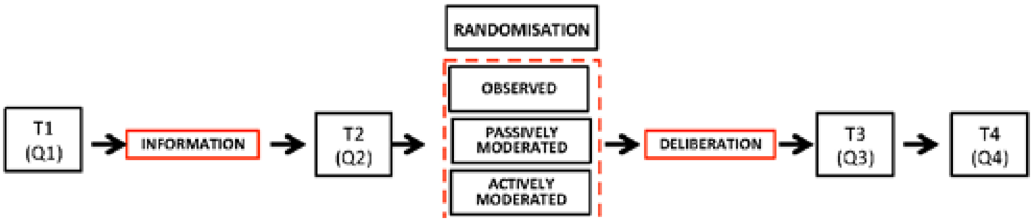


Figure 1:
Design of the Randomized Controlled Trial (RCT)

The flow-chart of the RCT is shown. Details are in the Main Experiment section of the text. T1, T2, T3 and T4 are the times of intervention at which the questionnaires, Q1, Q2, Q3 and Q4, were administered, respectively.

Table 1: Scores per group at the various time points
Questionnaire scores. Observed means and MICs, divided into groups and time (N=243)

Groups		Time			
		T1	T2	T3	T4
Observed	Mean (STD)	35.34 (7.96)	35.10 (7.98)	35.53 (7.20)	34.71 (7.45)
	MIC[$] (STD)	---	-0.24 (2.47)	0.19 (3.71)	-0.56 (3.92)
	P*	---	0.53	0.81	0.20
Actively Moderated	Mean (STD)	36.32 (7.97)	37.04 (8.12)	37.02 (7.98)	37.24 (8.24)
	MIC[$] (STD)	---	0.71 (2.29)	0.70 (3.76)	0.96 (3.78)
	P*	---	0.13	0.14	0.04
Passively Moderated	Mean (STD)	36.06 (7.46)	36.30 (7.61)	36.09 (7.65)	35.51 (8.21)
	MIC[$] (STD)	---	0.24 (2.55)	0.03 (3.63)	-0.16 (4.01)
	P*	---	0.56	0.86	0.84

The scores (N=243), expressed as mean values (standard deviation, STD, is in parentheses), are reported together with the differences *vs.* T1, for the three branches of the study at the various time points. There were no drop-outs in T2 and T3. In T4, there were 8 drop-outs (3.3%). There were no statistically significant differences among the three arms of the study in the number of drop-outs at T4 (P=0.94). See Appendix 4J. *P: p-value from t-test linear regression model for repeated measures, considering the correlation between groups of discussion, and correcting for the level of the score at T1, for age, and for degree. [$]: The differences were calculated on the number of available students. Note that in this and all following analyses, we adopted a rather stringent criterion to define significance, setting our significant p-value at 0.01, instead of the customary 0.05.

Table 2: Baseline distribution (T1) of the questionnaire scores, by group

Group	N	Mean (STD)	Median (q1;q3)	Coefficient (95% CI)	P
All	243	35.9 (7.78)	37.0 (30.0;42.0)		
Observed	79	35.3 (7.96)	37.0 (29.0;42.0)	Ref.	
Passively Moderated	84	36.3 (7.97)	38.0 (30.5;42.5)	0.98 (-1.40;3.36)	0.42
Actively Moderated	80	36.1 (7.46)	37.0 (30.5;42.0)	0.72 (-1.69;3.13)	0.56

N: number of students, STD: standard deviation, q1: first quartile, q3: third quartile, Ref: reference group, CI: Confidence interval, P: p-value. Coefficients and p-values were calculated using a univariate linear regression model. The coefficient of the linear regression model is the average difference in Q1 scores between the comparison group (Actively Moderated or Passively Moderated group) and the reference group (ref. Observed group).

Table 3: Differences in MIC transformation among the groups

Time	Comparison	Coefficient (SE)	P-Value
T2	Actively Moderated/Observed	0.61 (0.53)	0.25
	Passively Moderated/Observed	1.07 (0.52)	0.04
	Actively Moderated / Passively Moderated	-0.46 (0.52)	0.38
T3	Actively Moderated /Observed	-0.03 (0.53)	0.96
	Passively Moderated/Observed	0.63 (0.52)	0.23
	Actively Moderated / Passively Moderated	-0.66 (0.52)	0.21
T4	Actively Moderated /Observed	0.55 (0.54)	0.31
	Passively Moderated/Observed	1.65 (0.53)	**0.0019**
	Actively Moderated / Passively Moderated	-1.10 (0.53)	0.04

Time	Comparison	Coefficient (SE)	P-Value
T2	Actively Moderated / Observed	0.53 (0.54)	0.33
	Passively Moderated/ Observed	0.98 (0.53)	0.07
	Actively Moderated / Passively Moderated	-0.45 (0.53)	0.40
T3	Actively Moderated / Observed	-0.11 (0.54)	0.83
	Passively Moderated/ Observed	0.53 (0.53)	0.32
	Actively Moderated / Passively Moderated	-0.65 (0.53)	0.22
T4	Actively Moderated / Observed	0.47 (0.55)	0.39
	Passively Moderated/ Observed	1.55 (0.54)	**0.004**
	Actively Moderated / Passively Moderated	-1.08 (0.54)	0.05

Top: Coefficient is the average difference in MIC between the groups of intervention at each time point and was estimated using a linear regression model for repeated measures, considering the correlation between groups of intervention, and correcting for the level of the score at T1, for age and for degree. P: p-value, SE: Standard error.

Bottom: Coefficient is the average difference in MIC between the groups of intervention at each time point and was estimated using a linear regression model for repeated measures, considering the correlation between groups of discussion, without adjusting for covariates. P: p-value, SE: Standard error.

APPENDICES MAIN STUDY

APPENDIX 1

In Appendix 1, we provide additional information concerning the main experiment. In particular:

1A. A description of the modalities of training and of the instructions received by Observers, Passive Moderators and Active Moderators for the performance of their duties during the deliberative sessions.
1B. The Questionnaire (Q) administered at T1, T2, T3 and T4.
1C. The Informative Material provided after T1.
1D. The Comprehension Questionnaire administered together with Q2.
1E. The Evaluation Questionnaire administered together with Q3.
1F. Results of correct answers to the Comprehension Questionnaire
1G. The results of the Evaluation Questionnaire.
1H. The scoring matrix adopted to quantitatively evaluate the Questionnaires at the various time points.
1I. The comparison between the analysis group and the outlier group.
1J. Number of study participants for each time point/group.
1K. Results of the Questionnaires (Q1-Q4) at T1-T4.

1A. Training and performance of Observers, Passive Moderators and Active Moderators before and during the deliberative sessions

To ensure uniformity of treatment in the various sub-groups of each experimental arm, supervisors were trained and given specific rules of behavior (see Table below) and a statement to deliver to the participants at the beginning of each session. Statements were as follows:

Observer: "My name is X and I will be observing your group as you discuss the ethical issues regarding genetic testing in the context of reproduction. I will not intervene in any way. I cannot provide you with any additional information. You can either start a discussion based on the informative material or based on the questions you found in the questionnaires. I will only tell you when the time for your discussion is over".

Passive Moderator: "My name is X and I will be your moderator today as you discuss the ethical issues regarding genetic testing in the context of reproduction. I will only intervene so that everyone gets a chance to express his or her opinion. I will keep time of your interventions so that everyone can speak for roughly the same amount of time. I will not provide you with additional scientific or ethical information. You can either start a discussion based on the informative material or on the questions you found in the questionnaires. I suggest that you start by presenting yourselves, your background, and by expressing your preferences on the topic at hand".

Active Moderator: "My name is X and I will facilitate this group today as you discuss the ethical issues regarding genetic testing in the context of reproduction. I will keep time of your interventions, making sure that everyone gets the chance to express his or her opinion. Moreover, I will help to promote an open and respectful discussion on different perspectives on the issue at hand. My role in facilitating this group is that of helping you to elaborate your own position. You are just asked to justify your preferences – that is, provide reasons for them that can be considered acceptable by reasonable people even though they may not share your perspective -, and I will help you do that. Any reasonable position you defend will be considered equally valid. I will not judge your position, I will only help you understand and consider various possible implications and consequences of it, nor will I provide you with any scientific additional information. If necessary, I will just refer you back to the material that you have read. I suggest that you start by presenting yourselves, your background, and by expressing your preferences on the topic at hand".

The rules of behavior for the supervisors are summarized in the following Table:

TASKS	PASSIVE MODERATOR	ACTIVE MODERATOR
Ensure that all the participants have the chance to speak.		
Curb talkative participants.		
Keep time.		
Give the participants time to think and reflect. *		
Prevent episodes of domination amongst participants.		
Ensure that all the participants express a *preference.*		
Ensure that the preference is grounded on validated scientific information.		
Encourage participants to provide arguments to justify their preferences.		
Ensure that presented arguments are logically consistent and do not show logical fallacies.		
Establish a dialogic relationship with the participants so as to understand their viewpoint/preference, with the final aim of making them aware of it.		
Ensure that the participant is aware of the implications of having adopted one position over another, both at an individual level and a societal level.		
Ensure that all viewpoints have been pointed out in the discussion and, if not, do this, so as to allow the participants to be aware of all the possible scenarios.		
Encourage participants to interact with one another, promoting a cooperative attitude.		
Encourage participants to pay attention to what other participants are saying.		
Maintain a neutral position.	[Since he/she does not intervene in the discussion]	[Since, despite intervening, he/she does not reveal his/her own viewpoint]
Provide participants with additional scientific information with respect to that already present in the supplied material.	**NO**	**NO**
Refer back to the supplied material in order to provide context for discussion (if necessary).		

* In the passively moderated setting, this translated essentially in an attitude of the moderator towards shy participants exemplified by the dynamics: “If you do not want to say something now, why don’t you take the time to think and reflect and I will make sure that we come back to you when you are ready”. In the actively moderated settings, this function was executed in a more proactive way by helping shy participants to articulate their thoughts in a maieutic fashion.

In addition to providing the above guidelines and rules, we were concerned that during the deliberative sessions, some degree of unconscious manipulation by the supervisors might occur: a situation that might apply especially in the actively moderated groups. Thus, training of the supervisors (Observers, Passive Moderators, Active Moderators) was implemented with great care.

In particular:

1. As pointed out by Karpowitz and Mendelberg, it is important to find out how experimenters are trained (Karpowitz and Mendelberg 2012). In our setting, all supervisors met three times before the experiment to receive instructions and, raise and discuss possible questions and, importantly, to simulate the actual modalities of the intervention. In particular:

- In the first meeting, one of the study designers (V.S.) met with all supervisors, to allow them to introduce themselves to the others. Then, the experimental design was presented and discussed, including all the propaedeutic work derived from Pilot Study 1 and Pilot Study 2. The study population was described and discussed. Finally, the schedule of the experiment was presented and discussed.
- In the second meeting, the “rules of engagement” in the three arms of the intervention were presented and discussed, with particular attention to procedure standardization emphasizing the DOs and DON’Ts pertaining to the various roles, and “what to say and how to say it”.
- In the final meeting, a role-play was set up in order to simulate the real experimental setting and test all the details previously discussed.

2. In preparation for the actual deliberative sessions, supervisors were asked to dress similarly and avoid revealing their academic background.
3. Before the actual experiment, all supervisors were asked to fill in the Questionnaire (Q), so that their preferences would be disclosed and recorded in advance.
4. Finally, and most importantly, participants were asked to evaluate the figure supervising their group and to declare whether they thought they had been manipulated (see comments on the “evaluation questionnaire” and in the “Additional analyses” section in the main text).

1B. The Questionnaire (Q)

The questionnaire shown below was used at T1, T2, T3 and T4.

Note that at T2 and T3 additional questionnaires were administered: the Comprehension Questionnaire (T2) and the Evaluation Questionnaire (T3).

IDENTIFICATION NUMBER:

Before completing this questionnaire please read the following points carefully:

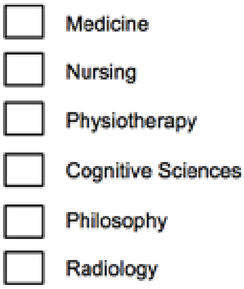
1. The questionnaire is completely anonymous and the answers will be used only for statistical analyses.
2. When filling out the questionnaire, please note that there are no right or wrong answers.
3. The purpose of the questionnaire is solely to assess how the participants' preferences are distributed with respect to the statements in the questionnaire.
4. The questionnaire focuses on the following subject: genetic testing in the context of reproductive choices.
5. Choosing the response "I neither agree nor disagree" may mean that you do not have sufficient information to answer the question, or that you are not yet certain of your preference despite having sufficient information, or that there are other reasons for not giving or being able to give a definitive answer to the question.
6. Please **mark with an "X" only one answer**, and provide an answer for **each question**.
7. Remember to enter your identification number.

Before starting the questionnaire, please fill in the demographic information

GENDER: M / F

AGE: _____ in years

DEGREE:



☐ Medicine
☐ Nursing
☐ Physiotherapy
☐ Cognitive Sciences
☐ Philosophy
☐ Radiology

Abbreviations Used

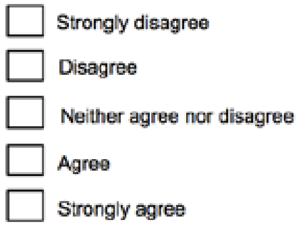
PGD = Preimplantation genetic diagnosis

PD = Prenatal diagnosis

QUESTIONNAIRE

For each of the following statements, please mark with an X the answer that most accurately reflects your opinion.

Note: each question was followed by the following options



☐ Strongly disagree
☐ Disagree
☐ Neither agree nor disagree
☐ Agree
☐ Strongly agree

Question 1
A person who wants to have a child and suspects to be at risk of giving birth to an individual with a genetic disease can freely choose whether or not to verify this risk through genetic testing i.e., he/she is not obliged to undergo genetic testing.

Question 2
A person who wants to have a child after being informed, following genetic testing, to be at risk of giving birth to an individual with a genetic disease, should be forced towards a specific set of reproductive choices: reproductive abstinence; adoption; heterologous fertilization; PGD and implantation in the uterus of unaffected embryos; conception, PD and therapeutic abortion.

Question 3
It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, because frequently it is the parents who will bear the greater burden of the child's genetic disease.

Question 4
It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, as this is consistent with the aims of medicine: to prevent and to cure disabilities.

Question 5
It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, as it is not the fault of the embryo/fetus if it is suffering from a genetic disease. Not implanting or aborting an affected embryo/fetus will harm it unjustly.

Question 6
It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, by doing so, one assumes to have the right to choose whom to allow or to deny the possibility of life.

Question 7
It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases in the case of low-penetrance diseases, as by doing so they may eliminate a future individual who will not develop the disease.

Question 8
It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because the affected embryo/fetus has only two alternatives: to be born with the disease or not to be born at all. In fact, PGD/PD is not a therapy: the affected embryo/fetus is not treated; on the contrary, a healthy one is chosen in its place.

Question 9
It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because; by doing so, there will be fewer and fewer sick people in the world and therefore their voices and their rights will be less and less heard or considered to be politically relevant.

Question 10
It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, in the long-term, this practice is likely to promote social rejection of people suffering from those diseases.

DID YOU ANSWER TO ALL OF THE QUESTIONS?
DID YOU FILL IN YOUR IDENTIFICATION NUMBER?
PLEASE CHECK ONE LAST TIME!

Note that the original Q administered to participants contained 14 questions. We noticed, however, that in 4 cases some ambiguities in the formulation of the questions (or in their possible interpretation) prevented the assignment of an unambiguous quantitative score (see 3G) to the answers. For this reason, these questions were excluded from further consideration and are not shown here.

1C. The Informative Material

GENETIC TESTS AND REPRODUCTIVE CHOICES
INFORMATIVE MATERIAL

WORDS HIGHLIGHTED IN RED ARE DEFINED IN THE GLOSSARY AT THE END OF THE INFORMATIVE MATERIAL

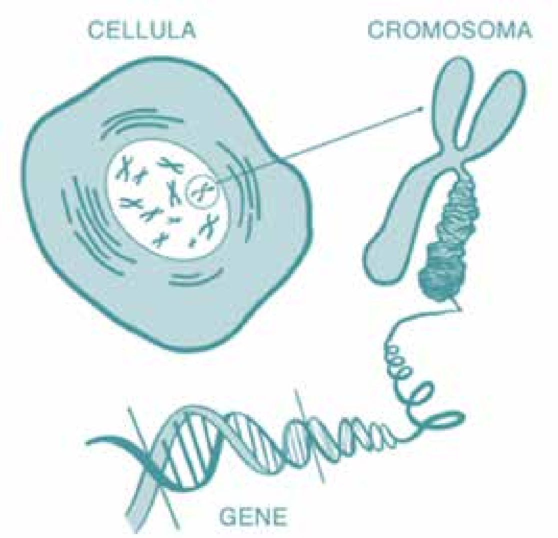
Introduction: genes and chromosomes

The human body is made up of approximately 100,000 billion cells. Almost all cells contain a set of chromosomes, which carry genetic information. A gene is a heritable region on the DNA, from which an RNA molecule, associated with a particular function, is synthesized.

The human genome is made up of thousands of genes: 20,000 – 25,000 depending on the particular calculation. Genes control all cellular functions and have a fundamental role in the determination of many characteristics, such as eye color, blood group and height.

Genes are contained on long, linearly condensed filaments, called chromosomes. *Homo Sapiens* have 46 chromosomes: 22 pairs of autosomal or non-sex chromosomes, and one pair of sex chromosomes, X and Y. A person's chromosomes are inherited from his/her parents, 23 from the mother and 23 from the father. Thus, there are usually two copies or versions of each gene, termed alleles.

Chromosomes and genes are made up of a chemical substance called deoxyribonucleic acid or DNA.



A genetic disorder is a disease caused by an alteration in the genetic material present in the cells, involving one or more genes. A genetic disorder can be *inherited*, if passed from parent to child. In this case, the mutation is present in the DNA in the oocyte or sperm. Alternatively, a genetic disorder can emerge after conception or during pregnancy, in which case the disease is referred to as a *congenital*, rather than inherited, genetic disorder.

A separate discussion applies to cancer, where, in general, cells accumulate genetic mutations during a person's life that lead to their uncontrolled proliferation.

Genetic disorders are usually classified as:

a. *Chromosomal disorders.* Chromosomal disorders derive from variations in the set of human chromosomes. Since each chromosome contains thousands of genes, chromosomal alterations usually result in very serious clinical syndromes, i.e., a set of medical signs and symptoms that are associated with one or more somatic abnormalities, growth retardation, mental delay, etc. There are two types of chromosomal variations that can determine the onset of a disorder: numerical alterations in the number of whole chromosomes, referred to as aneuploidy or polyploidy, and structural alterations in the integrity, copy number and sequence direction within the chromosomes, due to translocations, insertions, deletions, duplications, etc.
   An example of a chromosomal disorder is Down's syndrome. This disorder is a numerical chromosomal disorder, specifically an aneuploidy disorder. It is also known as trisomy 21 because all the body's cells contain 3 copies of chromosome 21. The life expectancy of individuals with Down's syndrome is about 60 years. This syndrome is the most common chromosomal abnormality in humans: it appears in 1 out of 700/1000 live births. The only other viable trisomies are Edward's syndrome (abnormality in chromosome 18) and Patau's syndrome (abnormality in chromosome 13) and Kleinfelter's syndrome. All other trisomies are non-viable. The only viable monosomy is Turner's syndrome.

b. *Monogenic or single-gene disorders.* Monogenic or single-gene disorders are caused by mutations in a single gene (point mutations or genetic mutations). Monogenic disorders are classified as autosomal if the mutation occurs in a gene on a non-sex chromosome or X/Y-linked if the mutation occurs in a gene on a sex chromosome. Autosomal disorders can also be classified as dominant or recessive. An autosomal disorder is dominant if the mutation of a single allele is sufficient for the disease to manifest itself, and recessive if both alleles need to be mutated.
   An example of a monogenic disorder is Huntington's disease, which is a dominant autosomal disorder. This disease is caused by the mutation of one of the two alleles of the Huntingtin gene. Disease onset usually occurs in individuals between 30 to 50 years of age, after which the disease progresses slowly, but is fatal after 16-20 years. The incidence of this syndrome is 5-10 cases per 100,000 people.

c. *Multifactorial inheritance disorders.* Multifactorial inheritance disorders are caused by a combination of multiple factors, including genetic and environmental factors and their reciprocal interactions.
   An example of a multifactorial inheritance disorder is diabetes mellitus. Diabetes is a chronic disease that is characterized by the presence of elevated levels of glucose in the blood due to alterations in the amount or function of insulin. Insulin is a hormone produced by the pancreas that allows the absorption of blood glucose into intestinal mucosal cells, where it is used as an energy source. When this mechanism is impaired, glucose builds up in the bloodstream. There are different types of diabetes (type 1, type 2 and gestational diabetes), all of which are considered as multifactorial disorders. The incidence of this disease is about 1 in every 20 people[1].

Genetic analysis

A genetic test or analysis aims to detect or exclude the presence of DNA modifications associated with genetic disorders through the analysis of specific genes or chromosomes. Genetic analyses are usually performed on blood or tissue samples.

What are genetic tests used for?

A genetic test is a tool used to determine:

i) If a person has a genetic disorder – *diagnostic purpose*.
ii) A person's predisposition to develop a specific genetic disorder, particularly, in cases where there is a family history of the disease – *predictive purpose*.

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[1] This estimation is based on a study according to which there are 347 million people with diabetes mellitus worldwide today (for further information: http://www.who.int/mediacentre/factsheets/fs312/en/).

iii) Individual genetic variations, knowledge of which permits the selection of the most appropriate treatment for a specific person – *pharmacogenomics purpose*.

What can genetic tests tell us?

To understand what a genetic test can tell us about a given genetic disorder, it is important to understand the concepts of penetrance and genetic risk.

Penetrance

Penetrance is the frequency (expressed as a percentage) with which a characteristic linked to a particular gene, and thus to a corresponding genetic disease, is displayed in individuals carrying a given mutation. The concept of penetrance is of primary importance in the debate on genetic testing because it indicates the frequency with which a particular genotype determines, *at the population level,* the appearance of a corresponding genetic disorder.

There are two types of disease penetrance: complete and incomplete. Penetrance is *complete* when 100% of carriers of a certain genotype display the typical phenotype associated with that genotype (e.g., Down's syndrome is a genetic disorder with complete penetrance because everyone who has a trisomy of chromosome 21 is affected by the syndrome). Penetrance is *incomplete* when less than 100% of carriers display the typical phenotype (e.g., Huntington's disease is a genetic disorder with incomplete penetrance because not all individuals carrying a mutation in the disease-causing gene develop the disease).

For diseases with complete penetrance, the individual will know that, at the population level, the presence of the genotype determines the presence of the disease in all cases. For diseases with incomplete penetrance, the individual is less facilitated in the choice he/she has to make because he/she does not know whether the observed genotype will give rise to the corresponding genetic disorder.

Genetic risk

"Genetic risk" is the probability that an individual carrying one or more mutations associated with a genetic disorder will actually suffer from the disease. Penetrance is linked to single mutations, while genetic risk takes into account all of the mutations present in an individual. Thus, there may be individuals carrying several low penetrance mutations, which when considered together, increase the genetic risk of that individual.

Genetic tests and reproductive choices

By "reproductive choices" we mean the decisions that one has to make as a prospective parent regarding whether to procreate, with whom, under what conditions, when, etc.

To help a person make these decisions, genetic testing can be carried out on the prospective parents and on the embryo, either before implantation in the uterus or during pregnancy.

Genetic tests on prospective parents are performed using small blood samples and/or saliva and are used to determine whether the parent is a healthy carrier, suffers from a certain disease, or neither of these alternatives.

For the embryo/fetus, two types of genetic tests can be performed: prenatal diagnosis and preimplantation genetic diagnosis.

Prenatal Diagnosis (PD)

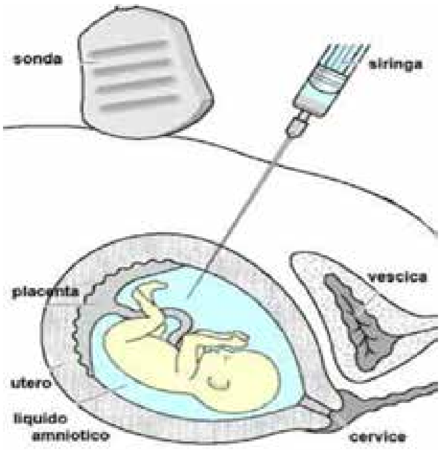
PD refers to all techniques that reveal the presence of disease (genetic and non-genetic) in the fetus. These techniques are performed during pregnancy and may be invasive or non-invasive. Invasive techniques (e.g., amniocentesis and chorionic villus sampling) are reimbursed by the National Health Service for pregnant women over 35 years old at the time of delivery. In contrast, non-invasive techniques, such as maternal blood tests, are paid for by the pregnant woman.

Non-invasive techniques include:

- *Ultrasound.* Ultrasound is a radiological investigation that does not use ionizing radiation but ultrasound. It is therefore risk-free, and is used routinely during pregnancy to assess gestational age, to monitor fetal growth, to identify twin pregnancies, and to determine the sex of the unborn child. Ultrasound tests are able to diagnose anatomical malformations that are often transmitted as a multifactorial disorder, but cannot identify specific biochemical or molecular defects.
- *Screening of maternal blood in particular, triple and quadruple tests on maternal blood.* Triple and quadruple screening tests are carried out between the 15th and 18th gestational week and are performed using a simple blood test. These tests assess the concentrations of specific substances present in the maternal blood that are produced by the fetus and the placenta. The triple test measures the amounts of three substances: alpha-fetoprotein AFP, beta-human chorionic gonadotropin bHCG and unconjugated estriol E3 FREE. The quadruple test measures the amounts of inhibin A in addition to the substances in the triple test. These analyses evaluate the fetus' genetic risk for developing a particular disease, but cannot diagnose with certainty the actual presence of the genetic disease.
- *Non-invasive tests to detect fetal DNA in maternal blood.* These tests are early diagnostic tests that are performed from the 9th week of gestation. They are precise and reliable tests, as well as safe as they require a normal sample of maternal blood. This technique assesses the risk of having some fetal chromosomal abnormalities, such as Down's syndrome or other syndromes that are derived from alterations of the sex chromosomes. The reliability of these tests in detecting these abnormalities is 99%.

Invasive techniques[2]:

- *Amniocentesis.* Amniocentesis is performed through trans-abdominal sampling of the amniotic liquid after the 15th week of gestation under ultrasound guidance. The risk of miscarriage is low but not negligible (less than 1%).



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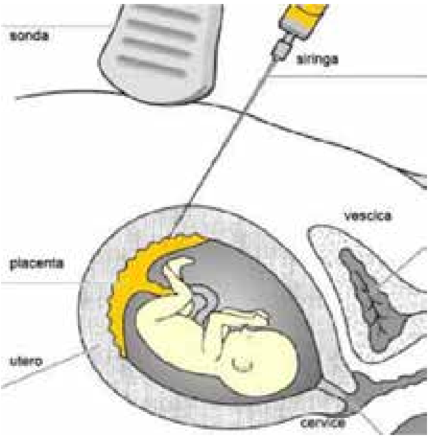
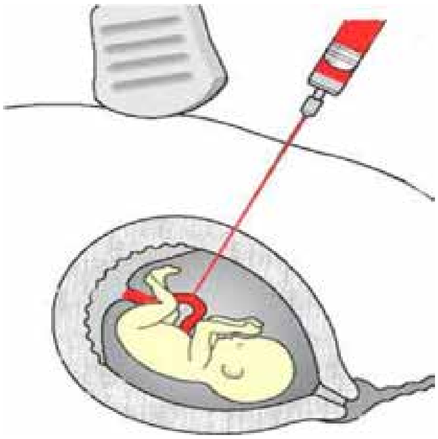
[2] Invasive diagnosis can be performed in the following cases: a) in women older than 35 years at time of delivery; b) in parents carrying chromosomal translocations or aneuploidy of sex chromosomes; c) in women who previously gave birth to a child with chromosomal abnormalities; d) following detection of fetal malformations by ultrasound scan; e) following a positive nuchal translucency ultrasound scan assessing the quantity of the fluid in the nape of the fetal neck, or a positive triple test biochemical analysis performed on a blood sample, which quantifies the risk of chromosomal abnormalities in the fetus; f) for the detection of infective agents in the amniotic fluid; g) for studies on fetal DNA; h) for the determination of metabolites in the amniotic fluid.

- *Chorionic villus sampling.* Chorionic villus sampling involves trans-abdominal sampling of placental villi under ultrasound guidance after the 10th gestational week. The risk of miscarriage is the same as or slightly higher than that of amniocentesis[3].



- *Cordocentesis.* Cordocentesis involves sampling of fetal blood after the 18th gestational week. The risk of miscarriage is 2-3%.



How to choose between the different invasive and non-invasive techniques?

Both amniocentesis and chorionic villus sampling allow the detection of chromosomal abnormalities (karyotype and microscopic rearrangements). Genetic testing is not carried out unless there is some indication that a specific genetic disease might be present, such as a family history. This is because it is not possible to test for all genetic disorders since they are numerous and not all are known. It is therefore possible for a child to be born with a genetic disorder despite having a karyotype result that appears negative for chromosomal mutations.

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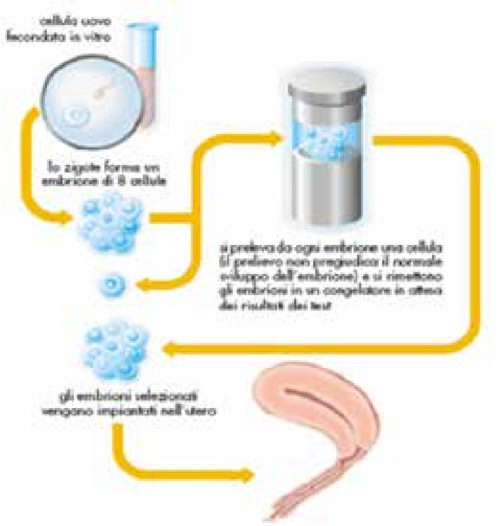
[3] There are some reports indicating a higher risk of miscarriage for chorionic villus sampling with respect to amniocentesis. In reality, the higher rate of miscarriage reflects the higher risk of a spontaneous miscarriage in the first trimester, when chorionic villus sampling is performed. Thus, the two methods carry equivalent risks of miscarriage.

The main differences between amniocentesis and chorionic villus sampling are the time at which the tests are performed (chorionic villus sampling is usually performed between the 11th-12th gestational week and amniocentesis between the 16th-18th gestational week) and the length of time required to obtain results (a few days for chorionic villus sampling and 2-3 weeks for amniocentesis).
The choice of technique depends on the following factors: gestational week, the likelihood that a chromosomal abnormality is present, and the desired level of confidence in the results, which is influenced by the efficacy and sensitivity of the test.
The reliability of PD varies depending on the technique. The reliability of non-invasive techniques, such as ultrasound, is between 59-80%, while that of invasive techniques, such as amniocentesis and chorionic villus sampling, is close to, although not quite, 100% (99%).
The reliability of the non-invasive technique, maternal blood screening, is 99% but, unlike amniocentesis and chorionic villus sampling, this technique is limited to just a few specific chromosomal abnormalities.

Preimplantation genetic diagnosis (PGD)



PGD is a complementary procedure to PD that detects genetic disorders in embryos generated through medically assisted reproduction. PGD is used by couples with a high reproductive risk for a given genetic disorder and is carried out at very early stages of embryonic development, before implantation of the embryo in the uterus. Thus, in contrast to PD tests, PGD tests are not performed during pregnancy, but earlier before the embryo is implanted in the uterus. This allows a choice to be made as to whether or not to implant an embryo presenting a genetic disorder.

PGD is performed through the following steps:

a. Induction of ovulation. Ovulation is artificially induced by ovarian stimulation. The purpose of this stimulation is to induce the maturation of multiple follicles in the patient in order to obtain more oocytes and, thus, increase the probability of obtaining embryos to transfer.
b. Oocyte retrieval. This is performed via transvaginal ultrasound. The aspirated fluid is sent to the laboratory for collection of mature oocytes.

c. Medically assisted reproduction. This is the artificial fertilization of the oocyte by male sperm. The technique typically used for artificial fertilization is *Intracytoplasmic Sperm Injection* (ICSI). This technique ensures a greater precision of the fertilization process by injecting sperm directly into the cytoplasm of a single oocyte.
d. Harvesting of embryonic cells. On the third day after fertilization, the embryo usually consists of 6-8 cells. One/two of these cells are collected by introducing a glass micropipette in an opening in the 'zona pellucida' (the wall that surrounds the embryo until the blastocyst stage) and gently aspirating. This procedure does not interfere with the subsequent development of the embryo.
e. Analysis of harvested cells to test for the presence of genetic mutations associated with the genetic disorder under investigation.
f. Implantation in the uterus of embryos displaying no genetic defects, unless otherwise indicated by the parents.

PGD is able to detect the genetic disorder under investigation in 95% of cases, but fails to detect in 5% of cases[4]. This means that, in the case of a disease with a rate of onset of 1%, the probability that the child who was positive in the PGD test will be born with the disease is 1 in 20 x 1 in 100, i.e., 1 in 2000[5].

GLOSSARY

Allele. One of a pair of genes that appear at a particular location on a particular chromosome and control the same characteristic.
Amniotic liquid. A liquid composed mainly of water, mineral salts, lipids and proteins produced by the placenta and by the membranes that surround the uterine wall in early pregnancy.
Blastocyst. The embryo during the early stages of its development. This phase corresponds to the 5 – 7th day of fertilization.
Chromosome. Elongated filaments present in the nucleus of animal and plant cells, and comprised of a single DNA molecule that holds the genetic information. Members of each species typically have the same number of chromosomes in their cells.
Chronic disease. A stationary or slowly progressive disease.
DNA. Deoxyribonucleic acid, which carries hereditary information and is found almost exclusively in the nucleus of the cell.
Follicle. Spheroidal cellular aggregation present in the ovary that contains the oocyte.
Genome. The set of DNA sequences in the nucleus, including all genes and other sequences.
Genotype. The genetic and hereditary characters of an individual or population that result in a phenotype.
Gestation. The period between conception and birth during which the development of the fetus takes place.
Implantation. Implantation of the fertilized oocyte in the wall of the uterus.
Karyotype. The profile of chromosomes in a cell defined by their number, size, shape and dimension. The karyotype is specific for each species, organism and cell type.

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[4] This is due to various factors: i) possible contamination of the sample with foreign material; ii) inability to amplify one of the two alleles for technical reasons, and consequently the mutation is not detected (phenomenon known as Allele Drop Out); iii) mosaicism, when cells derived from the same embryo present different karyotypes. Thus, some cells within an embryo could be normal, while others are mutated. Depending on the precise cells that are sampled, the cytogenetic analysis will give varying results.
[5] Diagnostic error: less than 1%.

Medically assisted reproduction. All procedures involving the processing of human oocytes, sperm or embryos with the aim of resulting in a pregnancy.
Miscarriage. Miscarriage is the premature termination of a pregnancy. This may be due to natural causes (spontaneous) or induced.
Mutation. A random variation in the genetic makeup of an individual animal or plant that causes a change in protein synthesis and in the transmission of characteristics.
Oocyte. The female gamete.
Ovarian stimulation. Application of a stimulus to the ovaries to stimulate the production of oocytes.
Phenotype. The set of morphological characteristics of an individual, resulting from the interaction between their genetic material and environmental factors.
RNA. Ribonucleic acid is a molecule similar to DNA that is contained in the nucleus and cytoplasm of cells and is required for protein synthesis.
Translocation. The physical movement of genome sequences inside the nucleus that change their position on chromosomes.

1D. The Comprehension Questionnaire (administered at T2 together with Q2)

Question 1

Genetic diseases include:

- All chromosomal disorders
- All chromosomal disorders, monogenic/single-gene disorders and multifactorial inheritance disorders
- Only monogenic disorders

Question 2

Genetic tests/analyses are able to:

- Determine only whether a person has a genetic disorder at the time of testing
- Determine only a person's predisposition to developing a specific genetic disorder
- Determine both of the above points, as well as individual genetic variations thereby allowing the selection of the most appropriate treatment for a specific individual

Question 3

Penetrance tells us:

- The relationship between genotype and phenotype for a specific genetic disease in a given population
- The relationship between genotype and phenotype for a specific genetic disease in a specific individual
- How severe a given disease will be in a specific individual

Question 4

Prenatal tests:

- Are performed on the embryo to determine whether it is affected by a specific genetic disorder
- Are performed on the fetus, already implanted in the uterus, during different stages of pregnancy to determine whether it is affected or not by a specific genetic disorder
- Are performed on the fetus, already implanted in the uterus, during different stages of pregnancy to determine whether it is affected or not by any of the known genetic disorders

Question 5

Preimplantation genetic diagnosis:

- Is performed on the fetus during the second month pregnancy to check for chromosomal abnormalities
- Is performed on embryos, created through various assisted reproduction techniques, before their implantation in the uterus, to test for a given genetic disorder
- Is performed on embryos, created through various assisted reproduction techniques, before their implantation in the uterus to test for multifactorial inheritance disorders.

1E. The Evaluation Questionnaire (administered at T3 together with the Q3)

Please fill in the following table expressing your opinion on the experience. Please tick one box for each question.

QUESTIONS	**Not at all**	**Small degree**	**Moderate degree**	**High degree**	**Very high degree**
1. Did the discussion promote an attitude of **higher respect towards the preferences of the other participants**?					
2. Did the discussion **prompt your group to reach a consensus**?					
3. Did the discussion have **an impact on the transformation of your preferences concerning the issue at hand**?					
4. How much has the discussion **allowed you to express your preferences in an unconstrained way**?					
5. Do you think you have been somehow manipulated towards a specific position **by the person who supervised the discussion**?					
6. How **clear** were the questions of the questionnaire?					

Do you have any additional comments and/or suggestions?

write here

1F. Results of correct answers to the Comprehension Questionnaire

N of correct answers	**N of students**	**%**	**p-value***
0	**0**	**0**	**0.0001**
1	**4**	**1.5**	
2	**6**	**2.2**	
3	**34**	**12.4**	
4	**117**	**42.7**	
5	**113**	**41.2**	

*: p-value of multinomial distribution test. The multinomial distribution test was used to test the hypothesis that the distribution of answers could originate from random answers.

1G. Results of the Evaluation Questionnaire

Question	Answers	All %	Observed (%)	Passively Moderated %	Actively Moderated %	*P**
1	Not at all	0.8	0	1.2	1.3	0.15
	Small degree	2.9	2.5	1.2	5.1	
	Moderate degree	8.7	11.4	4.8	10.3	
	High degree	33.3	27.8	31.3	41.0	
	Very high degree	54.2	58.2	61.4	42.3	
2	Not at all	2.9	1.3	3.6	3.8	0.15
	Small degree	6.3	5.1	6	7.7	
	Moderate degree	21.7	12.7	22.9	30.8	
	High degree	42.9	46.8	44.6	37.2	
	Very high degree	25.8	34.2	22.9	20.5	
3	Not at all	18.8	15.2	26.5	14.1	0.31
	Small degree	43.8	43.0	45.8	42.3	
	Moderate degree	27.5	31.6	18.1	33.3	
	High degree	8.3	8.9	8.4	7.7	
	Very high degree	1.7	1.3	1.2	2.6	
4	Not at all	0.4	0	1.2	0	0.30
	Small degree	1.3	2.5	0	1.3	
	Moderate degree	2.9	3.8	1.2	3.8	
	High degree	16.3	12.7	22.9	12.8	
	Very high degree	79.1	81.0	74.7	82.1	
5	Not at all	90.4	93.7	95.2	82.1	0.011
	Small degree	7.5	3.8	3.6	15.2	
	Moderate degree	0.8	1.2	1.2	0	
	High degree	0.8	1.3	0	1.3	
	Very high degree	0.4	0	0	1.3	
6	Not at all	0.4	0	1.2	0	0.15
	Small degree	0.8	1.3	1.2	0	
	Moderate degree	16.2	24.1	13.3	11.5	
	High degree	51.3	51.9	51.8	50.0	
	Very high degree	31.1	22.8	32.5	38.5	

*P: Fischer’s exact test

N=240. Observed, N=79; Passively Moderated, N=83; Actively Moderated N=78

1H. Scoring matrix for the Questionnaire (Q1 – Q4)

Question	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	1	2	3	4	5
2	5	4	3	2	1
3	1	2	3	4	5
4	1	2	3	4	5
5	5	4	3	2	1
6	5	4	3	2	1
7	5	4	3	2	1
8	5	4	3	2	1
9	5	4	3	2	1
10	5	4	3	2	1

The scoring matrix, used to evaluate quantitatively the questionnaire is reported. The column "Question" displays the question number. Scores were assigned on a 5-point scale: a score of 5 was given for answers closest to a perspective in favor of freedom in reproduction, while a score of 1 was given for answers most distant from that perspective.

1I. Comparison between the analysis group and the outlier group at T1.

Variable	All N (% col)	Analysis group N (% row)	Outlier group N (% row)	p
All	274 (100)	243 (88.7)	31 (11.3)	
Degree				0.02
Philosophy	64 (23.4)	60 (93.7)	4 (6.2)	
Medicine	104 (38.0)	96 (92.3)	8 (7.7)	
Professional	106 (38.7)	87 (82.1)	19 (17.9)	
Age				0.99
<21	124 (45.3)	110 (88.7)	14 (11.3)	
>=21	150 (54.7)	133 (88.7)	17 (11.3)	
Gender				0.40
F	152 (55.5)	137 (90.1)	15 (9.9)	
M	122 (44.5)	106 (86.9)	16 (13.1)	

By analyzing the mean individual change (MIC) between T1 and T2, we identified 31 (11%) students as outliers defined as external to the median range ± (1.5*interquartile range), i.e., score ≤ -6 or score ≥ 6.
Professional degrees: Physiotherapy, Cognitive Sciences, Nursing, and Radiology.
p: p-value calculated using the Chi-square test.

5J. Number of study participants for each time point/group

Group	Time			
	T1 N	T2 N	T3 N	T4 N (% T1)
Observed	79	79	79	78 (98.7)
Passively Moderated	84	84	84	82 (97.6)
Actively Moderated	80	80	80	75 (93.8)
Total	243	243	243	235 (96.7)

1K. Results of the Questionnaires (Q1-Q4) at T1-T4

Answers T1	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 1					0.447
No answer	1 (0.4)	0 (0)	0 (0)	1 (100)	
Strongly agree	6 (2.5)	1 (16.7)	4 (66.7)	1 (16.7)	
Agree	21 (8.6)	6 (28.6)	8 (38.1)	7 (33.3)	
Neither agree nor disagree	5 (2.1)	0 (0)	3 (60)	2 (40)	
Disagree	66 (27.2)	27 (40.9)	20 (30.3)	19 (28.8)	
Strongly disagree	144 (59.3)	45 (31.2)	49 (34)	50 (34.7)	
QUESTION 2					0.764
Strongly agree	124 (51)	45 (36.3)	41 (33.1)	38 (30.6)	
Agree	77 (31.7)	24 (31.2)	25 (32.5)	28 (36.4)	
Neither agree nor disagree	10 (4.1)	2 (20)	5 (50)	3 (30)	
Disagree	30 (12.3)	7 (23.3)	13 (43.3)	10 (33.3)	
Strongly disagree	2 (0.8)	1 (50)	0 (0)	1 (50)	
QUESTION 3					0.682
Strongly agree	17 (7)	4 (23.5)	8 (47.1)	5 (29.4)	
Agree	40 (16.5)	17 (42.5)	10 (25)	13 (32.5)	
Neither agree nor disagree	30 (12.3)	8 (26.7)	12 (40)	10 (33.3)	
Disagree	77 (31.7)	27 (35.1)	23 (29.9)	27 (35.1)	
Strongly disagree	79 (32.5)	23 (29.1)	31 (39.2)	25 (31.6)	
QUESTION 4					0.633
Strongly agree	41 (16.9)	12 (29.3)	16 (39)	13 (31.7)	
Agree	41 (16.9)	17 (41.5)	15 (36.6)	9 (22)	
Neither agree nor disagree	29 (11.9)	10 (34.5)	10 (34.5)	9 (31)	
Disagree	85 (35)	27 (31.8)	24 (28.2)	34 (40)	
Strongly disagree	47 (19.3)	13 (27.7)	19 (40.4)	15 (31.9)	
QUESTION 5					0.945
Strongly agree	79 (32.5)	25 (31.6)	30 (38)	24 (30.4)	
Agree	79 (32.5)	27 (34.2)	25 (31.6)	27 (34.2)	
Neither agree nor disagree	32 (13.2)	9 (28.1)	11 (34.4)	12 (37.5)	
Disagree	42 (17.3)	13 (31)	16 (38.1)	13 (31)	

Answers T1	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
Strongly disagree	11 (4.5)	5 (45.5)	2 (18.2)	4 (36.4)	
QUESTION 6					0.184
Strongly agree	64 (26.3)	23 (35.9)	22 (34.4)	19 (29.7)	
Agree	78 (32.1)	18 (23.1)	32 (41)	28 (35.9)	
Neither agree nor disagree	22 (9.1)	12 (54.5)	7 (31.8)	3 (13.6)	
Disagree	52 (21.4)	16 (30.8)	15 (28.8)	21 (40.4)	
Strongly disagree	27 (11.1)	10 (37)	8 (29.6)	9 (33.3)	
QUESTION 7					0.59
Strongly agree	15 (6.2)	6 (40)	6 (40)	3 (20)	
Agree	55 (22.6)	15 (27.3)	18 (32.7)	22 (40)	
Neither agree nor disagree	51 (21)	15 (29.4)	23 (45.1)	13 (25.5)	
Disagree	77 (31.7)	28 (36.4)	24 (31.2)	25 (32.5)	
Strongly disagree	45 (18.5)	15 (33.3)	13 (28.9)	17 (37.8)	
QUESTION 8					0.793
Strongly agree	61 (25.1)	21 (34.4)	18 (29.5)	22 (36.1)	
Agree	74 (30.5)	19 (25.7)	30 (40.5)	25 (33.8)	
Neither agree nor disagree	45 (18.5)	15 (33.3)	17 (37.8)	13 (28.9)	
Disagree	32 (13.2)	13 (40.6)	8 (25)	11 (34.4)	
Strongly disagree	31 (12.8)	11 (35.5)	11 (35.5)	9 (29)	
QUESTION 9					0.859
Strongly agree	108 (44.4)	30 (27.8)	42 (38.9)	36 (33.3)	
Agree	70 (28.8)	23 (32.9)	23 (32.9)	24 (34.3)	
Neither agree nor disagree	21 (8.6)	8 (38.1)	6 (28.6)	7 (33.3)	
Disagree	31 (12.8)	13 (41.9)	8 (25.8)	10 (32.3)	
Strongly disagree	13 (5.3)	5 (38.5)	5 (38.5)	3 (23.1)	
QUESTION 10					0.103
Strongly agree	69 (28.4)	16 (23.2)	30 (43.5)	23 (33.3)	
Agree	64 (26.3)	19 (29.7)	23 (35.9)	22 (34.4)	
Neither agree nor disagree	24 (9.9)	12 (50)	6 (25)	6 (25)	
Disagree	60 (24.7)	24 (40)	13 (21.7)	23 (38.3)	
Strongly disagree	26 (10.7)	8 (30.8)	12 (46.2)	6 (23.1)	

Answers T2	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 1					0.108
Strongly agree	8 (3.3)	2 (25)	6 (75)	0 (0)	
Agree	22 (9.1)	6 (27.3)	9 (40.9)	7 (31.8)	
Neither agree nor disagree	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Disagree	54 (22.2)	23 (42.6)	14 (25.9)	17 (31.5)	
Strongly disagree	159 (65.4)	48 (30.2)	55 (34.6)	56 (35.2)	
QUESTION 2					0.517
Strongly agree	121 (49.8)	38 (31.4)	47 (38.8)	36 (29.8)	
Agree	80 (32.9)	29 (36.2)	20 (25)	31 (38.7)	
Neither agree nor disagree	8 (3.3)	2 (25)	4 (50)	2 (25)	
Disagree	25 (10.3)	6 (24)	11 (44)	8 (32)	
Strongly disagree	9 (3.7)	4 (44.4)	2 (22.2)	3 (33.3)	
QUESTION 3					0.171
Strongly agree	23 (9.5)	6 (26.1)	12 (52.2)	5 (21.7)	
Agree	42 (17.3)	15 (35.7)	8 (19)	19 (45.2)	
Neither agree nor disagree	15 (6.2)	6 (40)	6 (40)	3 (20)	
Disagree	93 (38.3)	34 (36.6)	31 (33.3)	28 (30.1)	
Strongly disagree	70 (28.8)	18 (25.7)	27 (38.6)	25 (35.7)	
QUESTION 4					0.607
Strongly agree	38 (15.6)	12 (31.6)	14 (36.8)	12 (31.6)	
Agree	43 (17.7)	16 (37.2)	15 (34.9)	12 (27.9)	
Neither agree nor disagree	18 (7.4)	7 (38.9)	7 (38.9)	4 (22.2)	
Disagree	93 (38.3)	29 (31.2)	26 (28)	38 (40.9)	
Strongly disagree	51 (21)	15 (29.4)	22 (43.1)	14 (27.5)	
QUESTION 5					0.794
Strongly agree	80 (32.9)	28 (35)	29 (36.2)	23 (28.7)	
Agree	92 (37.9)	26 (28.3)	31 (33.7)	35 (38)	
Neither agree nor disagree	11 (4.5)	2 (18.2)	4 (36.4)	5 (45.5)	
Disagree	47 (19.3)	17 (36.2)	16 (34)	14 (29.8)	
Strongly disagree	13 (5.3)	6 (46.2)	4 (30.8)	3 (23.1)	

Answers T2	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 6					0.753
Strongly agree	66 (27.2)	19 (28.8)	26 (39.4)	21 (31.8)	
Agree	81 (33.3)	27 (33.3)	28 (34.6)	26 (32.1)	
Neither agree nor disagree	15 (6.2)	4 (26.7)	7 (46.7)	4 (26.7)	
Disagree	52 (21.4)	19 (36.5)	17 (32.7)	16 (30.8)	
Strongly disagree	29 (11.9)	10 (34.5)	6 (20.7)	13 (44.8)	
QUESTION 7					0.09
Strongly agree	23 (9.5)	5 (21.7)	13 (56.5)	5 (21.7)	
Agree	51 (21)	14 (27.5)	24 (47.1)	13 (25.5)	
Neither agree nor disagree	37 (15.2)	14 (37.8)	8 (21.6)	15 (40.5)	
Disagree	87 (35.8)	28 (32.2)	26 (29.9)	33 (37.9)	
Strongly disagree	45 (18.5)	18 (40)	13 (28.9)	14 (31.1)	
QUESTION 8					0.526
Strongly agree	72 (29.6)	24 (33.3)	28 (38.9)	20 (27.8)	
Agree	83 (34.2)	21 (25.3)	29 (34.9)	33 (39.8)	
Neither agree nor disagree	23 (9.5)	7 (30.4)	7 (30.4)	9 (39.1)	
Disagree	47 (19.3)	20 (42.6)	13 (27.7)	14 (29.8)	
Strongly disagree	18 (7.4)	7 (38.9)	7 (38.9)	4 (22.2)	
QUESTION 9					0.524
Strongly agree	102 (42)	30 (29.4)	41 (40.2)	31 (30.4)	
Agree	68 (28)	19 (27.9)	21 (30.9)	28 (41.2)	
Neither agree nor disagree	19 (7.8)	8 (42.1)	6 (31.6)	5 (26.3)	
Disagree	39 (16)	17 (43.6)	10 (25.6)	12 (30.8)	
Strongly disagree	15 (6.2)	5 (33.3)	6 (40)	4 (26.7)	
QUESTION 10					0.247
Strongly agree	79 (32.5)	24 (30.4)	29 (36.7)	26 (32.9)	
Agree	65 (26.7)	13 (20)	28 (43.1)	24 (36.9)	
Neither agree nor disagree	18 (7.4)	8 (44.4)	5 (27.8)	5 (27.8)	
Disagree	54 (22.2)	22 (40.7)	14 (25.9)	18 (33.3)	
Strongly disagree	27 (11.1)	12 (44.4)	8 (29.6)	7 (25.9)	

Answers T3	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 1					0.355
Strongly agree	12 (4.9)	0 (0)	7 (58.3)	5 (41.7)	
Agree	16 (6.6)	8 (50)	4 (25)	4 (25)	
Neither agree nor disagree	3 (1.2)	1 (33.3)	1 (33.3)	1 (33.3)	
Disagree	46 (18.9)	17 (37)	15 (32.6)	14 (30.4)	
Strongly disagree	166 (68.3)	53 (31.9)	57 (34.3)	56 (33.7)	
QUESTION 2					0.268
Strongly agree	136 (56)	46 (33.8)	49 (36)	41 (30.1)	
Agree	64 (26.3)	22 (34.4)	17 (26.6)	25 (39.1)	
Neither agree nor disagree	7 (2.9)	1 (14.3)	4 (57.1)	2 (28.6)	
Disagree	26 (10.7)	10 (38.5)	8 (30.8)	8 (30.8)	
Strongly disagree	10 (4.1)	0 (0)	6 (60)	4 (40)	
QUESTION 3					0.568
Strongly agree	21 (8.6)	10 (47.6)	6 (28.6)	5 (23.8)	
Agree	55 (22.6)	21 (38.2)	16 (29.1)	18 (32.7)	
Neither agree nor disagree	11 (4.5)	2 (18.2)	4 (36.4)	5 (45.5)	
Disagree	90 (37)	29 (32.2)	30 (33.3)	31 (34.4)	
Strongly disagree	66 (27.2)	17 (25.8)	28 (42.4)	21 (31.8)	
QUESTION 4					0.072
Strongly agree	35 (14.4)	13 (37.1)	12 (34.3)	10 (28.6)	
Agree	58 (23.9)	22 (37.9)	18 (31)	18 (31)	
Neither agree nor disagree	13 (5.3)	7 (53.8)	4 (30.8)	2 (15.4)	
Disagree	81 (33.3)	24 (29.6)	22 (27.2)	35 (43.2)	
Strongly disagree	56 (23)	13 (23.2)	28 (50)	15 (26.8)	
QUESTION 5					0.822
Strongly agree	75 (30.9)	22 (29.3)	29 (38.7)	24 (32)	
Agree	83 (34.2)	27 (32.5)	26 (31.3)	30 (36.1)	
Neither agree nor disagree	20 (8.2)	7 (35)	9 (45)	4 (20)	
Disagree	48 (19.8)	18 (37.5)	13 (27.1)	17 (35.4)	
Strongly disagree	17 (7)	5 (29.4)	7 (41.2)	5 (29.4)	

Answers T3	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 6					0.802
Strongly agree	64 (26.3)	20 (31.2)	25 (39.1)	19 (29.7)	
Agree	81 (33.3)	25 (30.9)	26 (32.1)	30 (37)	
Neither agree nor disagree	19 (7.8)	8 (42.1)	5 (26.3)	6 (31.6)	
Disagree	46 (18.9)	18 (39.1)	16 (34.8)	12 (26.1)	
Strongly disagree	33 (13.6)	8 (24.2)	12 (36.4)	13 (39.4)	
QUESTION 7					0.391
Strongly agree	22 (9.1)	5 (22.7)	12 (54.5)	5 (22.7)	
Agree	54 (22.2)	17 (31.5)	18 (33.3)	19 (35.2)	
Neither agree nor disagree	26 (10.7)	10 (38.5)	10 (38.5)	6 (23.1)	
Disagree	105 (43.2)	36 (34.3)	29 (27.6)	40 (38.1)	
Strongly disagree	36 (14.8)	11 (30.6)	15 (41.7)	10 (27.8)	
QUESTION 8					0.488
Strongly agree	69 (28.4)	20 (29)	28 (40.6)	21 (30.4)	
Agree	86 (35.4)	28 (32.6)	25 (29.1)	33 (38.4)	
Neither agree nor disagree	22 (9.1)	9 (40.9)	10 (45.5)	3 (13.6)	
Disagree	44 (18.1)	14 (31.8)	13 (29.5)	17 (38.6)	
Strongly disagree	22 (9.1)	8 (36.4)	8 (36.4)	6 (27.3)	
QUESTION 9					0.576
Strongly agree	109 (44.9)	37 (33.9)	38 (34.9)	34 (31.2)	
Agree	64 (26.3)	15 (23.4)	27 (42.2)	22 (34.4)	
Neither agree nor disagree	21 (8.6)	10 (47.6)	5 (23.8)	6 (28.6)	
Disagree	34 (14)	13 (38.2)	9 (26.5)	12 (35.3)	
Strongly disagree	15 (6.2)	4 (26.7)	5 (33.3)	6 (40)	
QUESTION 10					0.382
Strongly agree	99 (40.7)	29 (29.3)	40 (40.4)	30 (30.3)	
Agree	63 (25.9)	19 (30.2)	20 (31.7)	24 (38.1)	
Neither agree nor disagree	15 (6.2)	6 (40)	6 (40)	3 (20)	
Disagree	44 (18.1)	18 (40.9)	14 (31.8)	12 (27.3)	
Strongly disagree	22 (9.1)	7 (31.8)	4 (18.2)	11 (50)	

Answers T4	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 1					0.77
Strongly agree	7 (3)	2 (28.6)	4 (57.1)	1 (14.3)	
Agree	21 (8.9)	6 (28.6)	6 (28.6)	9 (42.9)	
Neither agree nor disagree	2 (0.9)	1 (50)	1 (50)	0 (0)	
Disagree	49 (20.9)	18 (36.7)	14 (28.6)	17 (34.7)	
Strongly disagree	156 (66.4)	51 (32.7)	57 (36.5)	48 (30.8)	
QUESTION 2					0.525
Strongly agree	123 (52.3)	43 (35)	47 (38.2)	33 (26.8)	
Agree	62 (26.4)	17 (27.4)	18 (29)	27 (43.5)	
Neither agree nor disagree	10 (4.3)	3 (30)	3 (30)	4 (40)	
Disagree	26 (11.1)	11 (42.3)	9 (34.6)	6 (23.1)	
Strongly disagree	14 (6)	4 (28.6)	5 (35.7)	5 (35.7)	
QUESTION 3					0.118
Strongly agree	17 (7.2)	4 (23.5)	9 (52.9)	4 (23.5)	
Agree	50 (21.3)	21 (42)	11 (22)	18 (36)	
Neither agree nor disagree	14 (6)	7 (50)	3 (21.4)	4 (28.6)	
Disagree	100 (42.6)	33 (33)	33 (33)	34 (34)	
Strongly disagree	54 (23)	13 (24.1)	26 (48.1)	15 (27.8)	
QUESTION 4					0.563
Strongly agree	44 (18.7)	17 (38.6)	15 (34.1)	12 (27.3)	
Agree	57 (24.3)	21 (36.8)	16 (28.1)	20 (35.1)	
Neither agree nor disagree	13 (5.5)	5 (38.5)	5 (38.5)	3 (23.1)	
Disagree	75 (31.9)	25 (33.3)	24 (32)	26 (34.7)	
Strongly disagree	46 (19.6)	10 (21.7)	22 (47.8)	14 (30.4)	
QUESTION 5					0.389
Strongly agree	76 (32.3)	19 (25)	31 (40.8)	26 (34.2)	
Agree	78 (33.2)	25 (32.1)	28 (35.9)	25 (32.1)	
Neither agree nor disagree	24 (10.2)	12 (50)	7 (29.2)	5 (20.8)	
Disagree	36 (15.3)	16 (44.4)	9 (25)	11 (30.6)	
Strongly disagree	21 (8.9)	6 (28.6)	7 (33.3)	8 (38.1)	

Answers T4	All (%)	Observed (%)	Passively Moderated (%)	Actively Moderated (%)	P
QUESTION 6					0.915
Strongly agree	66 (28.1)	19 (28.8)	26 (39.4)	21 (31.8)	
Agree	74 (31.5)	25 (33.8)	24 (32.4)	25 (33.8)	
Neither agree nor disagree	19 (8.1)	9 (47.4)	6 (31.6)	4 (21.1)	
Disagree	46 (19.6)	16 (34.8)	16 (34.8)	14 (30.4)	
Strongly disagree	30 (12.8)	9 (30)	10 (33.3)	11 (36.7)	
QUESTION 7					0.021
Strongly agree	16 (6.8)	3 (18.7)	9 (56.2)	4 (25)	
Agree	58 (24.7)	11 (19)	27 (46.6)	20 (34.5)	
Neither agree nor disagree	28 (11.9)	11 (39.3)	12 (42.9)	5 (17.9)	
Disagree	92 (39.1)	36 (39.1)	22 (23.9)	34 (37)	
Strongly disagree	41 (17.4)	17 (41.5)	12 (29.3)	12 (29.3)	
QUESTION 8					0.128
Strongly agree	58 (24.7)	16 (27.6)	26 (44.8)	16 (27.6)	
Agree	84 (35.7)	25 (29.8)	31 (36.9)	28 (33.3)	
Neither agree nor disagree	20 (8.5)	10 (50)	7 (35)	3 (15)	
Disagree	49 (20.9)	20 (40.8)	9 (18.4)	20 (40.8)	
Strongly disagree	24 (10.2)	7 (29.2)	9 (37.5)	8 (33.3)	
QUESTION 9					0.892
Strongly agree	98 (41.7)	34 (34.7)	37 (37.8)	27 (27.6)	
Agree	74 (31.5)	21 (28.4)	26 (35.1)	27 (36.5)	
Neither agree nor disagree	17 (7.2)	6 (35.3)	5 (29.4)	6 (35.3)	
Disagree	36 (15.3)	13 (36.1)	10 (27.8)	13 (36.1)	
Strongly disagree	10 (4.3)	4 (40)	4 (40)	2 (20)	
QUESTION 10					0.851
Strongly agree	91 (38.7)	30 (33)	32 (35.2)	29 (31.9)	
Agree	62 (26.4)	20 (32.3)	25 (40.3)	17 (27.4)	
Neither agree nor disagree	14 (6)	3 (21.4)	6 (42.9)	5 (35.7)	
Disagree	55 (23.4)	21 (38.2)	14 (25.5)	20 (36.4)	
Strongly disagree	13 (5.5)	4 (30.8)	5 (38.5)	4 (30.8)	

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IS THERAPEUTIC GERMLINE EDITING VALUE-BASED HEALTHCARE? AN EARLY HEALTH TECHNOLOGY ASSESSMENT

abstract

Innovative healthcare technologies may raise ethical concerns which prevent their implementation for fear of unexpected or undesirable outcomes, even before they are introduced into usual clinical practice. Essential to innovation is therefore to analyze benefits and drawbacks from a multidisciplinary point of view (i.e., biomedical, social, financial). Value-based healthcare is currently the most comprehensive theoretical framework to evaluate the benefits of healthcare technologies on patients and society in the longer term. Technically, "the systematic evaluation of properties, effects and/or impacts of health technologies" must be performed by validated procedures of Health Technology Assessment (HTA), supported by early HTA procedures to retrieve preliminary evidence and expert opinions. The aim of this study is to perform an early HTA of germline editing technologies in order to estimate their impact on patients and society, in light of the recent, controversial debate which followed the germline gene editing of human embryos.

keywords

bioethics, designer babies, distributive justice, germline editing, value-based healthcare

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IS THERAPEUTIC GERMLINE EDITING VALUE-BASED HEALTHCARE?

1. Introduction

Psychophysical functions and social capabilities are given special value as long as they allow people to achieve what they hold most important in life (Sen, 1993). This is why healthcare is considered a fundamental social right, at least in the European welfare tradition (European Commission, 2019). Today, advanced healthcare systems are challenged by financial and human constraints, more health expectations, more patients affected by chronic morbidities and constantly evolving technology and clinical practice (Organization for the Economic Cooperation and Development, 2015). As a result, they are asked to provide increasing quality of care at sustainable costs, and spend their resources more efficiently and wisely.

Efficiency is a technical assessment based upon the number of resources employed to achieve certain benefits. Wisdom is a value judgement upon which of these benefits matter most, given the impossibility of achieving them all (European Commission, 2019). When human and financial resources are no longer able to cope with endlessly growing demand, and room for further efficiency is reduced to the bone, investing in healthcare becomes a matter of distributive justice and value. Value-based healthcare (VBHC) is currently the most comprehensive approach to evaluate the benefits of healthcare technologies on patients and society in the longer term, as best value is determined by long-term benefits that can be shared by the maximum possible stakeholders (patients, funders, providers) (European Commission, 2019; Pennestrì *et al.*, 2019).

Some researchers have questioned whether the introduction of new technologies really does benefit the patients they are designed for, as innovation should improve "outcomes that matter to patients" and solve real-world problems (Coffey & Coffey, 2019; Mangan, 2018; Finnegan 2017) rather than promote technological advancement itself (Kluytmans *et al.*, 2019). Technically, "the systematic evaluation of properties, effects and/or impacts of health technologies and interventions" must be performed by validated procedures of the Health Technology Assessment (HTA) (World Health Organization, 2007). A complete HTA needs a certain technology (drug, medical device, surgical procedure) to have been previously tested in clinical trials or real-world settings, in order to compare different treatments and maximize the expected outcomes. However, some technologies raise ethical concerns which may prevent their implementation for fear of unexpected or undesirable outcomes (i.e, patient harm or the slippery slope) (Van der Burg, 1991), in which case it is essential to analyze the benefits and drawbacks before introducing them into routine clinical practice. For this reason, preliminary assessments or early-HTA (eHTA) have been developed to retrieve preliminary evidence and expert opinion before a full HTA can be performed (Kluytmans *et al.*, 2019; Ijzermans *et al.*, 2017).

A relevant part of this information is represented by the ethical and social issues associated with the introduction of a certain technology into current medical practice, which requires a consideration of values and philosophical reflection. The aim of this manuscript is to perform an eHTA of germline editing technologies in order to estimate their impact on individual patients and wider society, in light of the recent, controversial debates which followed the performance of germline gene editing of human embryos (Lander *et al.*, 2019; Greely, 2019; Lavazza, 2019).

In section one, germline editing is described, together with a discussion of the opportunities which emerge upon the technology, their potential applications (distinguishing between therapeutic, cosmetic and enhancement germline editing), as well as key associated risks. Section two provides a multidisciplinary set of indicators used to perform an eHTA, via the introduction of the four dimensions of healthcare value (personal, technical, allocative and societal) and the nine dimensions of HTA (relevance of the technology, technical characteristics, safety, clinical effectiveness, cost and economic evaluation, ethical and legal analysis, social and organizational impact). In section three the economic, ethical, organizational and social dimensions of impact are developed, building on preliminary evidence of effectiveness, costs, and philosophical considerations of distributive justice.

2. From chance to choice - what is germline editing and why it is controversial?

The human animal has always been worried, and frustrated, by the corruption of its body (Silverstein, 1979). Innovative healthcare technologies have continually been developed to heal disease, slow down aging, and delay death. Among them, gene editing is the latest, promising attempt (Pennestrì, 2019). Behind this technology, however, lie ancient immunological mechanisms employed by some of the simplest living beings on earth (bacteria), to defend against even simpler, barely-living beings (viruses), for millions of years before mankind made its appearance.

Streptococcus pyogenes, responsible for sore throat, is one of these bacterial species. Among the viruses that attack bacteria are bacteriophages, or phages, parasites that "eat (from the Greek *phagein*) their host (bacteria)". Phages take advantage of a host organism's DNA replication to reproduce their own genes and preserve themselves, hijacking the host's biochemical cornerstone of life. In response, bacteria co-evolved an ingenious 'fingerprint scan' security system, CRISPR (a guide RNA able to identify the genetic sequences of the viral aggressor), and a scissor-protein, Cas9 (able to cut those sequences in order to prevent them from replication) (Le Rhun *et al.*, 2019; Marraffini *et al.*, 2016; Barrangou *et al.*, 2007).

Interestingly to humans, this natural security system has the potential to defeat rare, deadly diseases which do not yet have effective therapy. This is the revolutionary idea that led American chemist Jennifer Doudna and French microbiologist Emmanuelle Charpentier to test CRISPR-Cas9 on humans (Jinek *et al.*, 2012). Seven years and 11135 scientific publications after their brilliant, pioneering work, a bacterial defence mechanism became the State-of-the-Art genetic manipulation tool (Loureiro & da Silva, 2019). Doctors and scientists are performing stunning international trials to assess the safety of this complex engineering technique on living patients. CRISPR-Cas9 is being tested to treat lung cancer in China (Cyranoski, 2016), inherited blood disorders in Europe (European Hematology Association, 2017), and strengthen key components of the immune system in the United States (PennMedicineNews, 2019). Huntington's Corea (Vachey & Déglon, 2018), Cystic Fibrosis (Marangi & Pistritto, 2018), Duchenne Muscular Dystrophy (Lim *et al.*, 2018) and Acquired-Immuno Deficiency Syndrome (AIDS) (Huang *et al.*, 2017) may follow the same route. The greatest global health worry at the time of writing, the novel coronavirus SARS-CoV-2, can hopefully become another target (World Health Organization, 2020; Jamal Anjum Official, 2020).

Gene editing may *heal* disease if therapeutic genes are administered to a living patient (somatic gene therapy). But gene editing may also *prevent* disease if mutations are performed on developing embryos (germline editing). Once embryos are generated from *in vitro* fertilization, they can be engineered with target adaptive mutations, such as strengthening the immune system or removing HIV receptors (Tebas *et al*., 2014); if the mutation occurs, it will not just be the newborn who will be covered against certain types of cancer and life-threatening viral infections, but that coverage will potentially be extended to its children, grandchildren, and any subsequent generations: the more embryos are subject to a certain therapeutic mutation, the earlier next generations will benefit.

If *adding therapeutic genes* was the breakthrough introduced by classical gene editing (that made bacteria produce insulin and fish glow like fireflies), *replacing corrupted genes* is technically more promising. Correlations between genes, psychosomatic traits and disease are generally difficult to capture, but more than a hundred monogenetic diseases have already been found (Tang *et al*., 2017). International fertility institutes already offer *in vitro* genetic selection in order to design the sex and eye colour of babies (The Fertility Institutes, 2020). The more humans can *reduce* their nature to genes (*that* disease, *that* somatic trait, *that* talent, or *that* psychological skill, is generated by *that* gene, or *that* sequence of genes), the more they are able to modify it.

A first clarification is needed here. Given that it is possible to modify genes, and that such modifications can be performed with different end goals in mind, the reasons behind performing such a surgeries is worth considering. Preventing Huntington's Chorea, Cystic Fybrosis, Muscular Dystrophy and AIDS can be considered *therapeutic* germline editing, being that the target of surgery is correcting disease. In contrast, choosing height, eye colour and skin colour has been called *cosmetic* germline editing, as a certain eye colour, skin colour or height are not diseases (Carroll, 2017). Empowering psychophysical skills beyond the "average function of the species" (Boorse, 1977) is *enhancing* germline editing, as the goal is to perform better than that average (i.e., by increasing strength, memory and attention) with no disabling infirmity occurring at baseline. The focus of this manuscript is on therapeutic germline editing, as 1) cosmetic gene selection is already performed by choosing – rather than modifying – embryos after *in vitro* fertilization, which makes germline editing a more complicated and implausible alternative as of now; 2) similar considerations apply to human enhancement, as cheaper, available drugs represent a widespread and affordable alternative to germline editing, although the effects cannot be transmitted from generation to generation (Frati *et al*., 2015; Outram, 2010; Glannon, 2006); 3) major scientific interest is currently focused on the prevention of non-curable disease, as the case of He Jiankui demonstrates (Greely, 2019).

In November 2018, the Chinese biophysicist announced that 22 human embryos generated by 8 couples with an HIV+ father had been modified, and two HIV-free female twins, Lulu and Nana, were born as a result (He, 2018). The goal was to test CRISPR-Cas9 technology directly on human embryos, in order to prevent the transmission of HIV from positive parents to the newborn. As a matter of fact, CRISPR-Cas9 is able to remove the cellular receptor that works as a target for the virus, performing a gene mutation (CCR5Δ32) which can be adaptive for the host. Other scientists were already working on this premise, but previous trials were performed on tripronuclear zygotes which could not initiate pregnancy. Moreover, these trials did not show promising results (Liang *et al*., 2015; Kang *et al*., 2016).

For Lulu and Nana, not only did the gene editing appear to have failed, but unexpected mutations occurred on target genes. Since the protocol was unclear (Greely, 2019) and the manipulation of regular human embryos is forbidden in China (Araki & Ishii, 2014), the scientist was fired from his University and has been recently sentenced to three years in prison (Sample, 2019). The Chinese scientific community was "opposed to any clinical operation of human embryo genome editing for reproductive purposes in violation of laws, regulations, and ethical norms in the absence of full scientific evaluation" (Wang *et al.*, 2019). The international scientific community, in turn, called for "a global moratorium on all clinical uses of germline editing, that is, changing heritable DNA (in sperm, eggs or embryos) to make genetically modified children" (Lander *et al.*, 2019). The trial generated rich ground for a multidisciplinary assessment of the technology, as all dimensions of value were involved in the case.

3. Healthcare value from theory to practice

According to the European Commission's Expert Panel on Effective Ways of Investing in Health (EXPH), there are four pillars of value (European Commission, 2019).

1. Personal value: significantly improving patient wellbeing, quality of life and autonomy (i.e., restoring the functions that make patients' lives worth living, according to their preferences);
2. Technical value: reaching the desired result(s) using as few resources as possible (i.e., reducing pain with conservative treatment rather than major orthopaedic surgery);
3. Allocative value: equitable distribution of resources across patients (i.e., freeing up resources which can be invested in the treatment of other patients and diseases);
4. Societal value: extending the benefits of a certain treatment from patient to society (i.e., reducing the burden of disability, loss of productivity, and social fabric erosion).

Best value is when shared benefits are experienced by all the stakeholders involved in the process. Few technologies can meet all the requirements at the same time or to the same degree, but this approach still provides a useful framework to perform HTAs from a sustainable and longer-term perspective. To avoid wasting limited resources, the value of a certain treatment should not be reduced to its effectiveness in an ideal clinical trial, in ideal settings, or in the shortest possible time; rather, it should be assessed in real-world patients, living in a real-world society, over the longest possible span; otherwise, these resources are wasted, generating poor allocative and societal value. Therefore, providing VBHC is mandatory for healthcare systems based on the universal taxation of workers, as resources are shared and institutions are accountable for how they are spent (accountability for reasonableness) (Pennestrì, 2017; Daniels & Sabin, 2008).

The validated European Network for Health Technology Assessment (EuNetHTA) core model is currently employed to support healthcare planning from the assessment of public priorities to the adoption of certain technologies in single hospitals (Foglia *et al.*, 2017; Radaelli *et al.*, 2014; Kristensen et al. 2009). The assessment is based on nine dimensions, six of which are not strictly clinical (5-9):

1. Relevance (health problem and current use) of the technology;
2. Technical characteristics;
3. Safety;
4. Clinical effectiveness;
5. Cost and economic evaluation;
6. Ethical analysis;
7. Social aspects;
8. Legal analysis;
9. Organizational aspects.

The relevance of germline editing technologies was described in detail in the previous section, along with the current use of CRISPR in regular and irregular experimentation. Information about their safety and clinical effectiveness on human embryos is (partly) available only from He's trial and the following legal vicissitudes. Legally, the moratorium of international scientists places further warnings on a procedure already banned in much of Europe, United

States and China (National Academies of Sciences, 2017; Araki & Ishii, 2014). Ethical and social analysis can be retrieved from the philosophical debate on germline editing, which has formed the basis of books (Huxley, 1932), movies (Niccol, 1997) and philosophy (Buchanan *et al*., 2000) even before this technology was at hand. Today, the debate is also attracting the attention of civil society (The Associated Press-NORC Center for Public Affairs Research, 2018). The economic benefits of the procedure can be estimated on the basis of the cost of somatic gene editing already introduced in pioneer countries, such as the United States and Italy, compared to alternative treatments and in light of intergenerational benefits or harms. The organizational aspects derive in part from this dimension.

The need for temporary assessments is frequent in the rapidly evolving process of healthcare innovation, as demonstrated by the spread of eHTA frameworks (Kluytmans *et al*., 2019; Ijzermans *et al*., 2017). Distinct from traditional HTA (which evaluates the benefits of new technologies *after* they have been tested in clinical trials or applied in practice for some time), eHTA is performed *during* the early phases of development of a novel technology, when information is limited and evidence is lacking. The key idea is that earlier stages of experimentation (here represented by regular clinical experimentation with CRISPR somatic editing or germline editing on irregular experimental human embryos, and He's experimentation with germline editing on IVF embryos) enable the identification of barriers and facilitators *before* the technology is introduced into society, or adopting necessary precautions before major investments are made. The VBHC framework is adopted here to bring order to the economic, social, ethical and organizational dimensions, as it provides a clear framework that highlights their connections.

4. Is therapeutic germline editing value-based healthcare? An early health technology assessment

4.1 Personal value

It is difficult to assess the benefits of a certain healthcare technology on a patient who is unable to provide a preference, to describe his/her experience, and to compare his/her wellbeing before and after applying that technology. Would a person agree to have his/her genes modified before being born? In order to overcome the consensus problem (Santas, 2019), two surrogate solutions are 1) to hypothesize how these modifications could be perceived by patients once performed, after birth, building on the preference, experience and sensitivity of a population interested to this question; 2) to evaluate whether the parents have a duty to protect their child from developing preventable disease or disability, at the early stage of embryos, in the absence of safer or less invasive alternative treatments (Benston, 2016).

A preliminary answer to both questions is suggested by a University of Chicago survey that investigated the attitudes of 1,067 adult Americans towards "the technology that could be used to edit the genes of human embryos" (The Associated Press-NORC Center for Public Affairs Research, 2018). The majority of those surveyed was in favour of using gene editing to prevent disease or disability, while remaining strongly opposed the use of technology to change psychosomatic characteristics such as eye colour or intelligence. In both cases, there was a deep agreement among citizens regardless of party identification, education and religious preference.

The author agrees with this view, with the provision of some further clarification. On the one hand, it is reasonable to expect that a person who decides from a hypothetical original position (Rawls, 1971) would not choose to have a serious illness or disability that prevents him/her from living a life similar to that of the people he/she is surrounded by, characterized by comparable opportunities and substantial freedom. This is confirmed by the reactions of many people affected by disabilities or hereditary diseases after the introduction of the Abortion Act (1967) in the U.K., and later in other European countries, who have sued parents, doctors and hospitals for not interrupting pregnancy although they were aware of impending health conditions (Falzon, 2014). A few years after the introduction of the artificial kidney, another "medical miracle" (the introduction of advanced screening and diagnostic technologies) presented people with the moral burden to "decide who could live and who should die" (Alexander, 1962). The argument of "wrongful birth" (or "wrongful pregnancy", "-conception", and "-life") is still frequent in worldwide law Courts, from the U.S. to Hong Kong (Tsang & Cho, 2018; Hale, 2001; Teff, 1985).

On the other hand, disability is a relative condition which depends on a number of psychological, social and environmental factors, as the "happy disabled" argument supports (Kamm, 2013). Disabled people can learn to cope with their impairment much better than a healthy person can imagine, as 1) patients affected by genetic diseases have never experienced complete health, and 2) even if they were healthy before a certain accident occurred, they show a capacity to cope with critical, sudden disabilities much better than one would expect, provided genuine love, spiritual and social support from the environment. Moreover, the disability of a few people may be interpreted as a lesson to help much higher numbers of healthy people appreciate what they do have in their life (Adams *et al*., 2015; van Leeuwen *et al*., 2012; Do Rozario, 1997), especially when the latter are mentally conditioned by perfectionism, healthism and healthcare consumerism, as more health and more expectations are increasingly associated with more frustration and wasteful expenditure (Davini, 2013; Gossen, 1854).

Halfway between the "happy-disabled" and the "wrongful birth" arguments, germline editing – once safe – could prevent severe disabilities and frequent abortions at the same time, allowing parents to choose in light of their sensitivity without any pressure from society. If germline editing is performed in safe conditions and no alternative treatment is available, the technology would provide better personal value in comparison with abortion, for the same outcome (preventing disease) is achieved while also preserving life. Theoretically, performing gene surgery after the embryo has been implanted (*in vivo*) would benefit the very same individual that has been conceived, providing the equivalent of somatic gene therapy before the child can suffer from the target disease. In this scenario, the personal value disclosed by the procedure would be achieved in the narrow sense of the definition.

4.2 Technical value

Technical value is given by the ability to obtain the desired results using as few resources as possible. To extinguish a match, a person can either blow or employ a Canadair. To get rid of an annoying fly, a person can either use a fly swatter or a bazooka. All these actions and technologies are very likely to reach the goal, but employing a Canadair or a bazooka adds no effectiveness and must be set against the considerable waste of human and/or financial resources.

With respect to healthcare, several treatments provide less trivial but still clear examples. Vaccinations reduce infectious disease mortality saving significant resources compared to hospitalization of patients in specialized units, providing higher technical value and additional allocative value, as more resources are freed up to invest in other treatments (i.e., beds in intensive care), and critical side-effects of drug misuse are reduced (i.e., antibiotic resistance). When a vaccine is not available, other preventive techniques can still provide high technical value. For instance, wearing a condom prevents HIV infection by saving significant resources compared to engineering the cells that offer entry to the virus, either through gene surgery or a bone marrow transplant (Gupta *et al*., 2019; Hütter *et al*., 2009). From a technical point of view, prevention is generally more valuable than cure. When prevention is not viable or sufficient, different treatments can still be compared. For instance, conservative antalgic therapy offers more technical value in the treatment of a certain degree of knee osteoarthritis compared to major orthopaedic surgery (i.e., total knee arthroplasty), even more so if the patient loves to kneel down to garden or to play with grandchildren nephews on the ground.

What is relevant here is not whether germline editing can prevent a fatal or non-fatal condition, but the presence of any effective alternatives. This is consistent with findings from a survey on American citizens' attitudes towards germline editing, which are equally in favor of using the technology for both the prevention of incurable, inherited fatal disease (such as Huntington's Korea and Cystic Fybrosis) and non-fatal inherited conditions such as genetic blindness. In the case of He, the experiment was conducted on embryos generated by couples with a HIV-positive father and HIV-negative mother. The scientist welcomed the birth of Lulu and Nana by calling attention to the resulting significant personal and social value, for example, 1) "Mark has HIV, discrimination in many developing countries makes the virus worse; employers fire people like Mark, doctors deny medical care, and even forcibly sterilize women"; 2) Mark "said that he never thought he could be a father, [while] now he has found a reason to live, a reason to work, a purpose" (He, 2018). These are the kind of problems that Lulu and Nana were expected to avoid thanks to editing technology, were it not for the fact that the surgery did not work and that the twins could suffer from critical health conditions (Xie *et al*., 2019). Morally aggravated by being artificially induced, this highlights poor personal value (worse health), poor technical value (bad healthcare outcomes), poor allocative value (preventable healthcare expenditure will be employed to treat potential long term disease, i.e., following from irregular bone growth and development) and poor societal value (the impact of the associated disability on their family and society).

While taking these risks is acceptable when there is no alternative treatment at all, as the argument of compassionate care supports (Hyry *et al*., 2015), safer prevention and treatment of HIV infection do already exist. First, a child can inherit HIV from the mother during pregnancy, delivery or through breast-feeding (vertical transmission). Transmission occurs in less than 1% of cases if adequate precautions are taken, from antiretroviral treatment for the woman in labour to caesarean delivery, neonatal prophylaxis and artificial milk feeding (Lega Italiana per la Lotta contro l'AIDS, 2019). Hence, vertical mother-to-child transmission can be prevented via many other alternatives before gene editing is performed on embryos, provided it works in the future.

Second, Anti-Retroviral Therapy (ART) has made HIV infection a non-fatal condition since 1996, preventing the virus from evolving into AIDS and guaranteeing patients a life expectancy roughly equivalent to the average population. When therapy is effective, people can have personal life plans including becoming parents and avoiding the risk of sexual transmission to a partner (Lega Italiana per la Lotta contro l'AIDS, 2019). When the treatment is funded by public resources, there is evidence of increased personal value (more health, freedom and better opportunities), allocative value (prevention of complications) and societal value (protection of other people) (Taramasso *et al*., 2018). Although ART almost halved the average mortality after HIV-infection in Europe and the U.S., the difficulty of affording life-long therapy in limited-resources settings, the interaction of social and clinical conditions with adherence to therapy, and the side-effects associated with the alternative of bone marrow transplant (Xie et al., 2019; Haworth *et al*., 2017; Zou *et al*., 2013; Scanlon & Vreeman, 2013; The HIV-Causal Collaboration, 2010) still make prevention technically more valuable, but several effective alternatives exist that might be employed before germline editing. From a technical point of view, germline editing could be valuable only in the absence of more conventional, safer and cheaper alternatives.

4.3 Allocative value

In 2017, the U.S. Food and Drug Administration approved the first gene therapy against cancer, Kymriah® (tisagenlecleucel), to treat acute lymphoblastic leukaemia (ALL). A single therapy costs USD 470,000, is hardly covered by insurance, and is not effective on patients older than 25 years. In 2016, Agenzia Italiana del Farmaco approved the first gene therapy against Severe

Combined Immunodeficiency Syndrome (SCID), a rare paediatric disease that forces babies to live within blisters to protect them from common but lethal microorganisms (the so-called "bubble babies"). The therapy, called Strimvelis®, is administered via a single intravenous injection, and costs Euros 600,000 per patient.

Funding expensive drugs for rare diseases is a puzzling problem for many European healthcare systems (Wieseler, 2019; Jørgensen & Kefalas, 2013; McCabe *et al.*, 2008), as public resources are always limited and tragic choices must frequently be made. For any treatment introduced into the basket of healthcare, another treatment is removed, delivered late, or covered by additional financial payments on part of the user, which seriously questions the consistency of universal health coverage in practice (Consorzio Universitario per la Ricerca Economica Applicata in Sanità, 2015; Costa *et al.*, 2014; Bognar *et al.*, 2014; Daniels, 2008). The administration of somatic gene therapy to a single patient can offer him/her a lot of personal value, allowing for an effective and complete recovery to the detriment of many other patients who are denied more conventional, cheaper, but effective treatments for more common diseases. Opting for this technology would then generate poor personal value to those who are denied care, poor allocative value to the funder, and poor societal value as a result of more people suffering direct or indirect burdens of disease. If it is immoral to give a blameless child a price for his life, it is probably equally immoral to neglect more common therapies for other hundreds of blameless children, in order to treat one affected by such a rare disease. As long as no ideal solutions are viable here, distributive justice becomes a question of comparing losses (Calabresi *et al.*, 1978).

This is what makes germline gene editing financially attractive. Performing gene editing on a 8-cell embryo 3 days after fertilisation would theoretically transmit the mutation to all of the cells, tissues, organs, and systems it produces, and passes to subsequent generations, due to the staminal power of these cells. The price of one gene surgery would be an expensive lump sum, but entire populations could benefit from a single treatment, which produces high intergenerational allocative value. Add to that, if patients affected by genetic disease are children with very demanding needs, which cause a heavy burden to their carers (Reichman *et al.* 2007), germline editing would also generate high societal value. Consider therefore how many human and financial resources –no child left untreated – would be saved to assist patients affected by more common disabilities and diseases, their lives being equally worthy, which is optimal distributive justice for utilitarian philosophers and considerable allocative value (European Commission, 2019). Moreover, the institutional fragmentation of long-term care is today a major determinant of suboptimal outcomes, inappropriate prescriptions, extended waiting lists and rising health expenditure to the detriment of the most fragile people, among which patients affected by critical disabilities, genetic disease, and children with different degrees of incurable conditions (Lawless *et al.*, 2020; Brewer, 2018; Altman *et al.*, 2018). In this case, preventing the onset of such morbidities could add further, organizational benefits to increasingly complex and stratified healthcare systems.

Germline editing may also reveal unexpected benefits for the prevention of sudden public health emergencies such as the current COVID-19 pandemic. At the time of writing, no preventive or therapeutic treatments are available yet, although the virus had been isolated and a spike protein is paving the way for the creation of a vaccine (King, 2020). Personal hygiene, quarantine and individual protective equipment are the only viable solutions to reduce the spread, to the extent that apparently trivial and obsolete public health measures have made a return to paramount importance (Signorelli & Fara, 2020). CRISPR editing is being studied not just to rapidly diagnose SARS-CoV-2 infections, but even to engineer human cells in order to remove the target receptor of the virus as for the (HIV) CCR5Δ32 mutation, and with similar potential germline applications (Davies & Barrangou, 2020; Chekani-Azar *et al.*, 2020; Soni, 2020). Once the technology proves safe and effective, the remarkable regularity of viral epidemics (SARS 2003, H1N1 2009, MERS 2012, SARSCOV2 2019) (Zangrillo & Gattinoni, 2019) would be a further reason to consider germline gene editing valuable from an allocative point of view.

4.4 Societal value

The societal value of germline gene editing was already introduced in the previous three paragraphs, in which the prevention of genetic diseases and disability was associated with better opportunities for more patients and families. Not only patients affected by permanent impairment have reduced chances to find a job, if any, but their parents, relatives and carers may experience from the same problem. Indeed, people suffering from serious chronic disease or disability need to be assisted at home and/or frequently accompanied to one or more healthcare facilities. When care givers are not able to provide sufficient support on their own, i.e., because of incompatibility with work, they can be replaced or helped by social professionals. However, social professionals may not able to provide sufficient support in turn, i.e., because of long term care fragmentation or limited investments. When this is the case, increasing numbers of patients and families get into debt in order to access private support, or give up seeking treatment because long term care is too expensive or complicated to follow, meaning that even more clinical fragility is aggravated by the progressive erosion of the social fabric (Consorzio Nazionale delle Associazioni dei Malati Cronici & CittadinanzAttiva, 2015; Consorzio Universitario per la Ricerca Economica Applicata in Sanità, 2015; Regione Lombardia, 2014).

In that case, the individual and social burden associated with permanent physical impairment may offer a strong empirical reason to support therapeutic germline editing. However, there are normative counterarguments to be considered. First, if being disabled is associated with lower social opportunities, the solution may not necessarily be in preventing disability with gene editing technologies, but rather in educating society to include disabled patients, as the "stigmatization" or "right to disability" arguments claim (Conti, 2017; Benston, 2016). Second, the authorization of germline editing for the prevention of exceptional disabilities could gradually pave the way for the authorization of cosmetic germline editing to avoid discrimination of somatic diversity. Setting aside racism, beautiful people have better access to many social and employment opportunities, and beauty is a relative concept strongly associated with somatic traits (Little *et al.*, 2011). In turn, the authorization of cosmetic germline editing to protect equal opportunities could gradually pave the way to the strengthening of psychosomatic skills in order to ensure optimal performance in an increasingly competitive society.

If psychosomatic enhancement was available to any citizen by drawing on shared financial resources, society would simply shift from one average of acceptable performance to another, more advanced, new average of acceptable performance, jeopardizing any competitive advancement (low personal and technical value) while also neglecting the risks of long-term, unpredictable side effects (low allocative and societal value). From a strictly biomedical point of view, even once the safety of germline editing has been demonstrated on a single patient, it will still be necessary to monitor the long-term effects of gene surgery on that patient and future generations (Araki & Ishii, 2014); from a holistic, psychosocial point of view, the theory of decreased marginal benefit clearly shows how – beyond a certain threshold of health – increasing expectations are associated with more healthcare expenditure and less satisfaction (Davini, 2013). If psychosomatic enhancement is funded by individual, private resources, progressive health inequalities would follow from financial (ability to afford treatment) or cultural inequalities (awareness of treatments and which genes to modify), extending the social determinants of health gap to subsequent familial generations (Buchanan *et al.*, 2000).

In this way, deep health inequalities, decreased health satisfaction and potential harm to the next generations – which present an undesirable state of things – could gradually follow from an initial authorization of germline editing for the prevention of incurable disease or severe disability. This is known as the "slippery slope" argument (Gumer, 2019; Van der Burg, 1991). If psychosomatic enhancement is considered an abuse of germline editing, the use of these technologies should therefore be either completely prohibited (Gumer, 2019) or strictly regulated and limited to therapeutic applications (Xu, 2020).
Considering the slippery slope argument from an even longer perspective, the societal value of therapeutic germline editing may become even more controversial. Epidemics are known, in history, to have provided a rapid, though brutal solution to chronic problems of overcrowding, misery, lack of resources, and violent competition among populations, if not within the same families. During the golden age of medicine (Le Fanu, 2011), many countries learned to get rid of the scourge of infections that significantly reduced childhood mortality (Istat & Unicef, 2011), extending the average life expectancy (Le Fanu, 2011). Unfortunately for wealthy societies, today, a longer life expectancy hardly means a *healthier* life expectancy, since chronic comorbidity and degenerative disease multiply precisely due to aging and greater exposure to the side-effects of comfort (i.e., pollution, overeating, traffic accidents, poor physical activity, poor prevention, inappropriate medicalization and drug abuse) (Davini, 2013). Less brutally but more insidiously than the plague, tuberculosis or Spanish flu, the diseases of the "health [and wealth] epidemic" (Porter, 2011) reveal hidden pitfalls behind a determination to prolong life at all costs, raising fundamental questions about the reasonable goals of medicine and healthcare. Is the goal of medicine adding years to life, or life to years? Current CRISPR trials against aging (either directly, by addressing the molecular drivers of aging, or indirectly, addressing age-related disease) (Beyret *et al*., 2019; Chen *et al*., 2018) seem to favour the latter option. That being the case, suppose that germline editing works on regular human embryos with no side-effects on the newborn or subsequent generations; suppose that germline editing is able to prevent any (non-traumatic) disease and slow down or eliminate aging, transmitting extraordinary resistance against the physio-pathological mechanisms of human nature, generation after generation; even so, our invincible offspring will, at some point, be faced with more and more people living on a planet with fewer and fewer resources, and will continue to die because of the natural selection, fighting for food, shelter or water. If the potential benefits of germline editing are expected to obtain maximum value because of the transmission of benefit between generations, the risk of a slippery slope additionally makes the societal value of germline editing controversial from the longest possible perspective.

5. Conclusions

Aging societies, financial constraints and the progressive erosion of the social fabric mean that the wellbeing of individuals, the cohesion of society and the sustainability of welfare can no longer be considered within watertight compartments. The key to maintaining a fair and sustainable healthcare system is to identify which treatments provide greater value, to whom, and for how long. A multidisciplinary HTA is needed to answer these questions. Awaiting further clinical trials and developments of gene editing techniques on embryos, a useful framework to assess the social, ethical, economic and organizational implications of potential applications is provided by the value-based approach. Once safe, germline editing could prevent severe impairment and disability. Even though parents should be free from coercion, as there is no intrinsic moral evil in conceiving and living with disability, this intervention could provide better personal value to the newborn, as compared with abortion. Better social inclusion is a worthwhile cultural effort to avoid stigma and the risks that might follow either abortions or inappropriate germline editing. From a technical point of view, germline editing can generate significant value – once safe – in the absence of safer, cheaper or more conventional treatments. In that case, germline editing would also generate significant allocative value. In terms of societal value, germline editing can benefit patients and society provided there is strict regulation against any inappropriate use. Overall, the value of germline editing technologies – once clinically safe – would lie in the prevention of serious disease and disability where safer, and cost-effective alternatives do not exist, maintaining the freedom of parents to choose whether or not to opt for treatment.

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GENETIC ENHANCEMENT AND THE CHILD'S RIGHT TO AN OPEN FUTURE[1]

abstract

In this paper, I analyze the ethical implications of genetic enhancement within the specific framework of the "child's right to an open future" argument (CROF). Whilst there is a broad ethical consensus that genetic modifications for eradicating diseases or disabilities are in line with – or do not violate – CROF, there is huge disagreement about how to ethically understand genetic enhancement. Here, I analyze this disagreement and I provide a revised formulation of the argument in the specific field of genetic enhancement. First, I argue that CROF is not in contrast with every kind of enhancement. I subsequently discuss whether CROF requires some moral obligations to enhance progeny. My argument is that parents do not have the moral obligation to open as many options as possible for their children. Rather, they should provide them with a reasonable range of opportunities. Finally, I contend that the moral obligations required by CROF are directly dependent on what Allen Buchanan calls the 'dominant cooperative framework' in a given society. I conclude by claiming that, at present, parents are not morally obliged to genetically enhance their children since a non-enhanced person already might have access to a reasonable range of opportunities. However, the moral obligation to enhance progeny might arise if a structural modification of the dominant cooperative framework occurs.

keywords

child's right to an open future, genetic enhancement, reproductive choices, dominant cooperative framework, assisted reproductive technologies

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1. Introduction

According to the Child's Right to an Open Future (CROF), parents should guarantee, or at least not deliberately constrain, the future autonomy and self-realization of their children. This argument was initially proposed by Joel Feinberg (1980) in order to guide parental choices related to child-rearing. Subsequently, it has become commonplace in the debate on the procreative choices in the field of new reproductive genetic technologies. Because of the availability of techniques such as *in vitro* fertilization, preimplantation genetic diagnosis (PGD), mitochondrial replacement therapy, and genetic testing, parents-to-be have unprecedented control over the genetic characteristics of their future progeny. Furthermore, through germline genome editing, in the next future, we will be able to directly choose some genetic traits of the future individual by modifying in vitro human embryos' DNA before implantation (Tang *et al*., 2017). Due to germline genome editing, we will treat effectively some genetic diseases such as Duchenne muscular dystrophy, cystic fibrosis and even Huntington's disease. But the most challenging possible outcome of the application of this technique may be the possibility to genetically enhance the progeny.

By genetic enhancement I mean the use of reproductive technologies in the following ways: a) to improve the capacities or to change traits – such as intelligence, height, memory, etc. – in early embryos that would already have developed in healthy, normal people, namely people who have the normal functioning capabilities of human species (Douglas, 2014); b) to choose some aesthetic traits of the progeny, such as hair or eye color[1].

In light of these current and future possibilities and the growing control that parents have on the genetic make-up of their progeny, according to CROF advocates, we are facing not only an extension of the range of procreative choices, but also some emerging moral obligations towards future progeny.

CROF suggests rethinking procreative choices not as a clash between two different kinds of principles, namely the parental right to procreate autonomously (principle of autonomy) and concerns for the future child's quality of life (principle of beneficence); on the contrary, reproductive decisions should be considered as a clash between the autonomy of parents and

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[1] In the next future, it might be possible that genome editing technologies will enable scientists to make changes to embryo's DNA leading to specific changes in physical traits of a future child - such as hair and eye color - according to the parents' preferences. However, it must be said that some fertility clinics have already begun offering PGD to select the eye color of the future child (Ranisch, 2019).

the autonomy of the child. Whereas in a conflict between two different bioethical principles the point is to argue which one will trump the other, conceiving the clash as one between two instances of the same principle helps us to recast the discussion. In this way, according to CROF advocates, it is easier to understand that some procreative decisions should be considered morally objectionable because they compromise the future autonomy and self-realization of the progeny.

In this paper, I investigate the ethical implications of genetic enhancement through the lens of the "child's right to an open future" argument. Here, I do not want either to criticize CROF or to support it: assuming its validity, I want to assess the required moral obligations towards progeny in this specific framework. Whilst there is a broad ethical consensus that genetic modifications for eradicating diseases or disabilities are in line with, or do not violate CROF, the same does not hold for genetic enhancements. Indeed, some scholars reject the claim that CROF allows genetic enhancement (Mintz *et al.,* 2019), others maintain that such an argument should allow only some specific kinds of enhancement (Buchanan et. al., 2009; Agar, 2004) and others even believe that it grounds a moral obligation to genetically enhance the future progeny (Resnik, 2000; Savulescu, 2007; Schmidt, 2007). Disagreement on the conclusions reached starting from the same argument seems to make CROF an empty concept, useless to inform procreative choices in the field of genetic enhancement. Hence, it is necessary to analyze the aforementioned disagreement to propose a revised version of the argument.

In order to do this, I analyze this disagreement and provide a revised formulation of the argument in the specific field of genetic enhancement. After presenting the formulations of CROF provided by Feinberg and Davis (Section 2 and 3), I argue that CROF is not in contrast with *all* kinds of enhancement (Section 4). I then discuss whether CROF requires some moral obligations to enhance progeny (Section 5). My argument will be that parents do not have a moral obligation to open as many options as possible for their children. Rather, they should provide them with a reasonable range of opportunities. Finally, I contend that the moral obligations required by CROF are directly dependent on what Buchanan calls the 'dominant cooperative framework'. I conclude by claiming that, at present, parents are not obliged to genetically enhance their children since a non-enhanced person already has access to a reasonable range of opportunities (Section 6). However, the moral obligation to enhance the progeny might arise if a structural modification of the dominant cooperative framework occurs (Section 7).

2. The child's right to an open future

In his paper *The Child's Right to an Open Future*, Feinberg argues that parents should protect the future autonomy and self-realization of their children (Feinberg, 1980). According to Feinberg, there are two types of rights belonging only to children called 'C-Rights': firstly, 'dependency rights', that are those derived from the child's dependence on others for the basic goods of life such as food, shelter and protection; secondly, 'rights-in-trust', namely rights that have to be preserved for the child until is an adult. In this respect, the child is not yet able to exercise such rights-in-trust, however, they should be protected so that the future person that the child will eventually become has the possibility to exercise them. Parents' actions that violate these rights should be considered morally objectionable. Whilst rights-in-trust are a heterogeneous cluster of rights, they broadly fall within the category of the 'right to an open future', that is, an 'anticipatory autonomy right'. Rights within this cluster include virtually all the significant rights we believe adults have, but which have to be safeguarded now to be exercised in the future.

One example of a right that falls within the right to an open future is the procreative right (Cutas & Hens, 2015): since a child is not physically able to procreate, she cannot currently exercise this right. However, when she becomes able to conceive children, she will be able to exercise such a right (Davis, 2010). Therefore, in order to have the possibility to exercise her procreative rights, the child has the right not to be sterilized by her parents.

Summarizing, Feinberg maintains that parents should guarantee that "basic options are kept open and growth kept natural or unforced" (Feinberg, 1980 p. 127). Furthermore, serious and final commitments should be postponed until the child is able to make her own decisions about her life plan.

3. Procreative choices and the right to an open future

The first formulation of CROF aiming to guide parents' procreative decisions is proposed by Dena Davis (1997). She claims that not only parental choices made after the birth of the baby can violate the child's right to an open future, but also decisions made before birth. Specifically, procreative choices in the context of PGD, namely selecting embryos according to the genetic traits, might confine the future child forever to a narrow group of people and a limited set of careers. Davis analyzes the case of deaf parents who want to give birth to a deaf child: parents who employ PGD to select for deafness violate CROF, since "they are deliberately constraining the ability of their children to make a wide variety of choices when they become adults" (Davis, 2010, p. 84). According to Davis, this conclusion is consistent with both interpretations of deafness, namely deafness as a disability (Harris, 2000) and as a cultural trait (Sparrow, 2005). Indeed, regardless of the interpretation that we support, parents are limiting cultural, social and career choices, since such a choice forecloses significant pieces of the child's adult life and cannot normally be reversed during the child's life (Davis, 2010). In this way, the future child would not be able to lead a lifestyle grounded in values that differ substantially from those of her parents.

The aforementioned formulation provided by Davis, suggests some moral limitations on the principle of procreative autonomy primarily in order to deliberately avoid constraining, through genetic selection, the ability of the future child to make a wide variety of choices when she becomes an adult. However, this formulation is less clear about how to deal with choices in light of the availability of genetic enhancement through germline genome editing. In the next section, I discuss whether CROF precludes or not the possibility of employing any kind of genetic improvement for offspring.

4. The ethics of enhancement: closing the door to an open future?

Some CROF advocates claim that all kinds of genetic enhancement should be considered inconsistent with CROF. According to Mintz and colleagues, germline genome editing for enhancing aims undermines the child's right to an open future because such a practice compromises the autonomy of the future child (Mintz *et al.,* 2019). With germline genome editing, anticipatory autonomy rights of the future individual would not be preserved but would rather be taken over by the parents' preferences. In order to establish whether or not the right to have a non-enhanced genome should be considered as a right in trust, the authors consider the features of personhood that develop in children as they mature (Feinberg, 1980): 1) abilities of self-governance necessary for autonomy; 2) skills or acquired abilities; 3) options or opportunities: 4) preferences based upon desires and values. Mintz and colleagues maintain that if one considers germline engineering in light of Feinberg's four features of personhood, the child's potential to exercise autonomy is preserved only if we postpone genetic engineering. Autonomy is more important than any capacity that can be provided through germline engineering other than life itself (Mintz *et al.,* 2019). Furthermore, at the time when germline genome editing is viable, namely at the *in vitro* stage, parents cannot know what capacities, options, skills or preferences the future individual will want to have. Therefore, the genetic manipulation might be unnecessary, since one could open up possibilities that the future child would not want to pursue or, at the worst, it might be counterproductive since one could risk restricting possibilities that the child would want to pursue (Mintz *et al.,* 2019).

In short, forcing a future child into the parent's notions of the good life through genetic enhancement would likely violate CROF. From this perspective, germline genome editing should be allowed only for saving a life or mitigating a life of pain and suffering and not for improving any trait in the future individual.

This view presents some weaknesses that make it difficult to support it. Firstly, there are numerous genetic treatments, other than those aimed at saving a life or mitigating a life of pain and suffering, which do not undermine the child's right to an open future. It is worth noting that I agree with Mintz and colleagues when they claim that providing some specific traits could undermine the development of future life's autonomy by sticking the child in a life plan that has been decided by her parents. For instance, modifying an embryo to obtain a child with specific personality traits is a direct infringement of CROF. Indeed, parents' wishes could convey the prejudices of a certain historical age preventing the child from having an open future. John Mackie in this regard states: "if the Victorians had been able to use genetic engineering, they would have made us more pious and patriotic" (Mackie cited in Glover 1984, p. 149). However, it does not follow that *every* kind of enhancement undermines CROF. Genetic enhancements, such as expanding the future individual's lifespan, enhancing human vision or even improving memory or general intelligence, should not be considered against the child's open future; on the contrary, these interventions may even enlarge the range of the possible life plans of the future individual or, at least, help her to make better choices about her life (Schaefer *et al.,* 2014).

Furthermore, contra Mentz and colleagues, it seems reasonable to maintain that CROF should also consider some aesthetic enhancements as ethically legitimate interventions. Let us consider, for instance, choosing the hair and eye color of the future individual according to the parents' preferences. While one could argue that in some cultures around the world having some particular aesthetic traits could limit the range of life plans, in Western society it seems quite difficult to support that view[2]. In this context, changing these traits would not necessarily close the door to an open future, hence they should be considered morally legitimate.

Here, Mintz and colleagues would reply that these kinds of aesthetic enhancements (and generally every genetic enhancement) are not in line with the second formulation of the categorical imperative provided by Kant, according to which people should be treated not as merely means but also as ends in itself (Kant, 1993). Indeed, in their paper, Mintz and colleagues theoretically ground CROF on the second formulation of the Kantian imperative from which they derive the concept of autonomy. From this perspective, choosing the hair or eye color of the future child should be considered an instrumentalization of the embryo who is considered here as a mere means to create the parent's ideal child. Since embryo and person, such as child and adult, are biological stages of growth interrelated on the same continuum of humanity, genetically enhancing the embryo would undermine the autonomy and human dignity of the future individual.

Nevertheless, even if we accept the notion of autonomy provided by Kant, it seems quite hard to support the thesis according to which the aforementioned aesthetic enhancement should be banned. Mintz and colleagues give an overly strong interpretation of Kant's principle and this makes it too demanding and difficult to apply. Indeed, asking parents to adhere to

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[2] Here I am only referring to aesthetic traits such as the aforementioned hair and eye color. For others, such as color skin, things are more complex. The recent, growing attention to racialization and racial inequalities suggests that having a particular color skin could limit the range of life plans even in Western societies. In this paper, I do not want to deal with this delicate and important issue which requires an in-depth analysis that considers discrimination concerns. For a recent study that analyzes race and economic opportunity in the US see Chetty *et al.,* (2020).

such a strict application of the Kantian principle, assuming its putative plausibility, might make the growing-up process impossible. If we maintain that choosing hair or eye color is a direct infringement of the Kantian principle, many daily actions concerning the relationship between parents and children will have to be considered morally wrong as well: for instance, by choosing a dress with a specific color for a newborn, parents may be treating the child as a means for the satisfaction of having a child who dresses in a certain way; but this seems quite bizarre.

Someone might reply that, whereas choosing the eye color of a person produces a permanent state, this is not so with choosing a dress; hence, the former action should be considered more problematic (from a Kantian perspective) than the latter[3]. However, to maintain that an action is a direct infringement of the Kantian principle only if it has a permanent effect seems quite implausible; one can damage another person even without causing permanent effects (e.g. kidnapping for forty-eight hours somebody who suffers during that time, but who will not have future psychological problems caused by this event). On the other hand, a person can cause a permanent effect on another without exploiting her (e.g. sending children to school where they will develop cognitive capabilities that will change permanently their perceptions and abilities to interact with the world). I argue that the permanent effects of an action are neither sufficient nor necessary conditions to be aligned with the Kantian principle. In the specific context of procreation, what really matters is to avoid taking away future possibilities from the range of the individual's choices.

In sum, to choose hair or eye color, precisely as choosing a specific dress for the child, does not corrupt the possibility for parents to consider the child as an end in herself and not as a mere means. It seems more reasonable to claim that the concept of autonomy is undermined only if parents decide to provide the future child with some specific traits constraining the future possibility of individual choices. Only in this way, parents render the child unable to live autonomously: for instance, providing a specific type of intelligence to the future individual might be considered morally objectionable for the aforementioned reasons.

In line with these considerations and in agreement with several scholars, we can claim that not every genetic enhancement is inconsistent with CROF (Agar, 2004; Buchanan *et al*., 2009; Mameli, 2007; Savulescu, 2007) and that the aforementioned view of this argument does not offer a satisfactory interpretation of it. Furthermore, it is important also to say that, in agreement with Mintz and colleagues, it is nevertheless reasonable to delay enhancement interventions until an individual reaches maturity to decide for herself. However, many genetic treatments would have to be performed very early in life if they are to have an effect (Savulescu, 2007).

So far so good, but in order to clarify what CROF requires parents to do, we need to address also a new question: due to the availability of some genetic enhancements, should we consider them as *only* morally legitimate, and thus permissible but not morally compulsory, or would CROF also imply some moral obligation to enhance the future progeny? In the next section, I will investigate whether CROF requires parents to enhance their progeny.

5. Genetic enhancement: can we, or should we?

Someone could argue that, in order to respect the future individual's right to have an open future, parents should not only avoid to deliberately constrain her possibilities, but also enhance her capacities. Eric Schmidt proposes a useful metaphor to explain this position: "imagine a map containing all possible significant experiences, including but not limited to educational, vocational, aesthetic and cultural experiences" (Schmidt, 2007, p. 193). By

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[3] I am indebted to an anonymous reviewer for bringing this issue to my attention.

‘significant experiences’, Schmidt means those experiences that have the potential to change the path of a person’s future. Through genetic modification, parents can modify the child’s map and so modify the child’s range of open futures; they can make genetic modifications that add roads to the map, allowing the child to have significant experiences that the child could not otherwise have had. Hence, such added roads on the child’s map would expand the child’s range of open futures. Schmidt suggests that the CROF approach provides further ethical guidance where Davis’s requirement of substantial constraint does not. Indeed, from this perspective, parents act ethically only if they make procreative choices that expand their child’s range of futures. Since some genetic enhancement, far from restricting a child’s future, may increase the number of possibilities or at least the quality of the child’s future (Savulescu, 2007), conceiving genetic enhancement as permissible but not morally required may not be enough: as a matter of fact, we should face a moral obligation to use enhancements as instruments to enlarge the openness of the child’s future. Such an interpretation of CROF also seems in line with Feinberg’s view: indeed, as Claudia Mills suggests, he would claim that parents have a duty not to isolate children intentionally from other ways of life and to make sure that their children will learn a variety of ways of life (Mills, 2005, p. 541).

CROF would, in fact, require that parents comply with both negative and positive duties towards progeny. However, claiming that CROF calls for some positive parental duties, rather than only negatives ones – namely, seeking to provide an open future, rather than just to avoid constraining it – is not enough to claim the existence of a moral obligation to enhance their progeny. In order to support the existence of a moral duty to genetically enhance the progeny, we should, in fact, assume a maximizing conception of the child’s right to an open future. According to the maximizing view, parents have a moral obligation to open as many options as possible for the future person, namely, maximizing her possibility to make the widest variety of choices in her life because it may maximize the child’s chances for self-fulfillment (Feinberg, 1980). From this perspective, genetically enhancing the progeny is a way to enlarge the child’s chances for self-fulfillment and, as a consequence, parents should be morally committed to employing them.

Nonetheless, the maximizing view is difficult to embrace due to its implausible implications (Millum, 2014). Firstly, the moral obligation to open as many options as possible forces parents to make some unrealistic assumptions about possible future desires of the child and to give up, or at least reduce dramatically, the importance of their own ideals for their children’s lives (Ruddick, 1999). Secondly, according to Mills, CROF in its maximizing view is even impossible to satisfy, since parents would never be able to avoid violating the child’s right to an open future (Mills, 2003). Accordingly, this approach implies a too demanding and impossible neutrality about values that can produce a sort of alienation of the child from her parents. Thirdly, from a more practical point of view, according to Francis Kamm, the maximizing view also bizarrely requires parents to use genetic modification to alter the makeup of individuals who would naturally have an excessively constricted range of options, even if those options are very good ones (Kamm, 2005). Therefore, there seem to be good reasons to reject the maximizing view.

A more plausible interpretation of the parental duties required by CROF – one that is in contrast with the maximizing view – is the satisfying view (Buchanan *et al.*, 2009; Lotz, 2006) or what Joseph Millum calls the moderate interpretation of CROF (Millum, 2014). From this perspective, CROF only requires that the future adult be able to choose among some, perhaps particularly important, sets of options. Negatively construed, this requires allowing the child to acquire certain skills and ensuring that certain options are not closed off. Positively construed, it requires helping the child to develop key skills and providing her with the resources to choose among a reasonable range of opportunities (Millum, 2014). By a 'reasonable range of opportunities', I mean varied, relevant, culturally meaningful options, which, in a broad sense, can be considered representative of the diversity of ways of life (Lotz, 2006). Furthermore, the satisfying view does not call for the level of neutrality required by the maximizing view, but rather for a sort of 'approximate neutrality' (Lotz, 2006). Following the satisfying view, I argue that it is too demanding to morally oblige parents to expand their child's range of futures through genetic enhancement and that this does not constitute a reasonable interpretation of CROF. In fact, it seems sensible to claim that non-enhanced children already have a reasonable array of opportunities: however, in order to justify this claim we must introduce the concept of what Allen Buchanan calls "dominant cooperative framework". In the next section, I present this concept and defend the view according to which having a reasonable range of opportunities depends on the setting of the dominant cooperative framework.

5. The reasonable range of opportunities and the dominant cooperative framework

With "dominant institutional infrastructure for productive interaction", or more simply, "dominant cooperative framework", Buchanan refers to the set of basic institutions and practices that enable individuals and groups in a given society to engage in ongoing mutually beneficial cooperation (Buchanan, 1996; 2011; Buchanan *et al.*, 2009). Participating successfully in this mutually beneficial cooperation allows people to have a reasonable range of opportunities within a society, namely to have access to a great number of careers, life plans and social positions that would not be feasible outside that framework. Indeed, most of the desires that an individual can have during her life can only be realized within a cooperative social context: in this way, we can claim that having a reasonable number of opportunities for a person depends on being included, and to what extent, in the dominant cooperative framework of a society.

Buchanan explains the dominant cooperative framework using the analogy of the card game: this analogy can show the relationship between having a reasonable range of opportunities and the dominant cooperative framework. In fact, within a card game, we can appreciate that a number of experiences, such as winning, losing, having fun and talking to other players, can be enjoyed only by people who are playing the card game. However, in order to play such a card game and be able to enjoy those experiences, players should decide which specific game, defined and governed by which set of rules, they will be playing. People or groups have different skills and abilities: someone might prefer playing Bridge, a complex game, whereas others, for instance, the youngest people who do not possess the cognitive skills to play this card game, would prefer a simpler one. Moreover, others might also want to play a harder game than Bridge, since their cognitive skills are very high. Here, with Buchanan, we shall note that the ability to perform the tasks required by the institutional rules of interaction – hence, having access to a great number of opportunities – "depends not just upon what skills and talents the individuals have, but also upon the character of the demands of the forms of interaction specified by the rules" (Buchanan, 1996, p. 40). From this perspective, choosing which rules should govern the dominant cooperative scheme means choosing who will be able to have a reasonable range of opportunities within society. As a matter of fact, an individual will be able to participate successfully in the interaction if there is a fit between her abilities and the demands of the form of interaction (Buchanan, 1996). Deciding which rules should guide the dominant cooperative framework within a society is a complex ethical task that is not the aim of this paper to discuss, since we are investigating the problem only through the lens of CROF. Here, we can only observe that usually the rules of cooperative frameworks are decided by the majority of people who join them. As a consequence, if the majority of people possess specific cognitive and physical skills, it is reasonable to claim that the dominant cooperative framework chosen will require cooperators to possess the aforementioned traits to have access to the majority of careers, life plans and social positions. It is important to notice that possessing the cognitive and physical skills of the majority of people within a society is not a sufficient condition to have access to a reasonable range of opportunities: people need also other primary goods, such as education or healthcare, in order to realize their life plans. However, having such traits should be considered a necessary condition, although it is not the only one nor a sufficient one.

Nowadays, the majority of people within our society have the normal, namely non-enhanced, functioning capabilities of human species; therefore, it is likely that the dominant cooperative framework generally shall be based on those capabilities. In fact, it would seem bizarre for the cooperative scheme in our society to require people to fly, or to have an enhanced view, or to have physical and cognitive capacities and endurance above the human standard, since no one in our society possesses these traits. The aforementioned skills are just not necessary to have the possibility to realize a great number of life plans and then having a reasonable range of opportunities. Hence, having a reasonable range of opportunities depends on the conformation of the dominant cooperative framework which in turn depends on the functioning capabilities of the majority of human beings in a given society.

Therefore, since CROF requires that parents should guarantee a reasonable range of opportunities, such a moral obligation is strictly dependent on the dominant cooperative framework within a specific society. As claimed above, it is sensible to maintain that unenhanced people – namely, individuals who possess the normal functioning capabilities of the human species – can already join the dominant social framework and, as a consequence, can have a reasonable range of opportunities. Thus, we can justify the claim according to which parents who decide not to genetically enhance their child are not infringing CROF. Therefore, those enhancements that are in line with CROF should be considered permissible, but this argument does not necessarily call for a moral obligation to genetically enhance the progeny.

7. Changing the framework, changing the obligations

Linking CROF with the concept of the dominant cooperative framework allows us to provide another important consideration: cooperative frameworks change over time and, since the moral obligations towards progeny required by CROF regarding genetic enhancement depend on the dominant cooperative framework, such duties change as the dominant social framework changes. Let us consider an example outside the topic of genetic enhancement to clarify this important point: in the past, in order to have a reasonable range of opportunities within Italian society, it was not strictly necessary to have a good knowledge of the English language. As a matter of the fact, a large number of courses of study and careers did not require such knowledge. However, in recent years, due to economic, political, and social dynamics, the English language has become a requirement for many careers and life plans; moreover, compulsory school started providing English lessons and, nowadays, a growing number of Italian people speak English as a second language. In this context, we can appreciate a change of the dominant cooperative framework; whereas in the past English was not required to have a reasonable range of opportunities, nowadays it is. Hence, assuming that the English language is a requirement to access a reasonable range of opportunities, nowadays CROF requires parents to enable their children to attend English lessons. On the contrary, this obligation would not have arisen in the past when the English language was not required to access a reasonable range of opportunities.

In the same way, we should offer similar considerations in the field of genetic enhancement: as I have claimed above, some genetic enhancements, such as improving memory or general intelligence, are not in contrast with CROF, hence they should be considered ethically legitimate. As a consequence of the permissibility of such genetic enhancements and their availability, a great number of people in a society might be enhanced and this could have some challenging consequences on the assets of the dominant cooperative framework. Assuming a scenario in which the majority of human beings, but not all, are enhanced to have much greater cognitive abilities and significant augmented capacity for complex practical reasoning, the interaction between enhanced people becomes more sophisticated, more productive than the interaction between non-enhanced people (Buchanan, 2011). Since the functioning capabilities of the majority of human beings in a given society determine the rules shaping the dominant cooperative framework, there is a reasonable likelihood that the framework will be transformed as the number of enhanced people increases within society. For instance, the mainstream economy and the most important political processes will be structured for enhanced people and no longer for those who are unenhanced. The result is that the unenhanced people will no longer have access to a reasonable range of opportunities in a given society. Therefore, in these specific circumstances, the moral obligations required by CROF will change, compared to a situation in which the dominant cooperative framework was shaped by non-enhanced human beings. Indeed, since according to the satisfying view of CROF we have a positive duty to guarantee a reasonable range of opportunities to our progeny, in this context we need to enhance them because the only way to have a reasonable range of opportunities in the new dominant cooperative framework is being enhanced. Summarizing, the moral obligations required by CROF are fluid over time and they might change as the dominant cooperative framework transformation.

8. Conclusion

I have argued that CROF is not in contrast with genetic enhancements, as long as they do not compromise the development of the child's future life or their autonomy or confine her to a life plan decided by her parents. Genetic enhancements such as expanding the future individual's lifespan, enhancing human vision or even improving memory or general intelligence in some cases may not be considered against the child's open future. However, it is nevertheless reasonable to delay enhancement interventions until an individual reaches maturity to decide for herself except those that would have to be performed very early in life to have an effect. Furthermore, I argued that CROF requires that parents should not be required to open as many options as possible to their children, but rather should provide a reasonable range of opportunities. I have also claimed that having a reasonable range of opportunities depends on the dominant cooperative framework, which may change over time. As a consequence, the moral obligations required by CROF change as the dominant cooperative framework changes. In light of this, I argued that, according to CROF, nowadays, within the current dominant cooperative framework, parents are not obliged to genetically enhance their children since a non-enhanced person who possesses traits within the normal functioning of the species already has access to a reasonable range of opportunities. However, if the dominant cooperative framework changed, and if it required cognitive and physical capabilities that can only be reached through genetic enhancement, then parents, in order to provide a reasonable range of opportunities for their future children, would be morally obliged to enhance them.

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SECTION 4

SECTION 4

FREE CONTRIBUTIONS

Ali Yousefi Heris
How Might Simulation-Based Accounts of Mindreading Explain Pragmatic Interpretation?

Piero Mattei-Gentili
Social Facts & the Semantic Conception of Norms. Customary Norms as a Test of Ontology

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HOW MIGHT SIMULATION-BASED ACCOUNTS OF MINDREADING EXPLAIN PRAGMATIC INTERPRETATION?

abstract

This paper examines the role of simulational mindreading in pragmatic interpretation (conceived of in a Gricean manner). There are two parts to this paper. In part one, I argue that mirroring, in the form of direct or indirect simulation, underdetermines pragmatic interpretation. Nevertheless, to deliver a unique interpretation, mirroring can contribute either by reducing the number of salient interpretations or to be accompanied by theoretical considerations. This results in a hybrid view in which theory and simulation cooperate. The second part of the paper examines the imaginative or perspective-taking sense of simulation. Drawing on evidence from several clinical populations, I will show that subjects with difficulty in pragmatic interpretation often show little or no difficulty in perspective taking, and subjects with difficulty in perspective taking do not always show difficulty in pragmatic interpretation. This, I conclude, suggests that simulation in the sense of perspective taking is not necessary or plays no significant role in pragmatic interpretation.

keywords

mindreading, simulation theory, mirroring, mirror neurons, pragmatic interpretation

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1. Introduction

Following Grice (1989), there is a more or less general consensus that our communication does not consist of a sequence of disconnected remarks, but involves, alongside to linguistically decoding, the ability of metarepresentation, expression and recognition of intentions. Metarepresentation is present not only in implicit communication, e.g., in conversational implicatures but also in the identification of explicit content. To establish communicative intentions, a hearer must be able to disambiguate and assign a reference, fix the scope of quantifiers, resolve the interpretation of vague expressions, and resolve illocutionary indeterminacies (Sperber & Wilson, 2002; Wilson, 2005). Details of Gricean or other pragmatic theories are not our concern here. The main point for our purposes is that whether it is referential ambivalences and illocutionary indeterminacies to resolve, or metaphors, ironies and non-sentential expressions to interpret, people in a communicative context deeply engage in spontaneous metarepresentation and mental state attribution, often referred to as *mindreading*, either for what they trying to express or in recognizing what is expressed. Based on this association, pragmatic impairments are often explained by reference to mindreading impairments (Cummings, 2014). Mindreading itself, however, has been a matter of debate over the years. Several theories have been developed to account for mindreading, but the question as to which one is explanatorily adequate and more fundamental in pragmatic interpretation has remained unanswered. This is the question I will address in the present paper. First, after a brief introduction to the simulation theory, I will distinguish between *direct* and *indirect* simulation and argue that simulation in these senses underdetermines pragmatic interpretation. This, however, is not to argue that simulation plays no role in interpretation. Rather, to deliver a unique interpretation, the simulation would need to be accompanied by theoretical considerations of the sorts to which a theory-theorists might appeal. In the second part, I will examine a broader conception of simulation, the imaginative or perspective-taking sense of simulation. The evidence, I will argue, suggests that simulation in the sense of perspective taking plays no significant role in pragmatic interpretation.

2. Direct & Indirect Simulation

Questions concerning the cognitive basis of mindreading—how we engage in mental state attribution—has given rise to several theories, including the theory-theory, the simulation-theory, and, more recently, the hybrid theories that take elements of both theory and simulation. Given the fundamental role that mindreading plays in pragmatic interpretation, the question occurs as to how *simulation* or *theory* account for the mindreading exhibited in pragmatic interpretation. Advocates of the theory-theory approach consider mindreading as an information-rich and thoroughly metarepresentational process which, when considered for pragmatic interpretation, is characterized either as a general theory of mind (e.g., Grice 1989) or alternatively a specialized module dedicated to utterance interpretation (e.g., Sperber & Wilson, 2002; Wilson, 2005). The theory-theory approach, however, has been challenged by an alternative view, the simulation theory, according to which mindreading is achieved by a simulational process in which, instead of using theory, we deploy our mind and its cognitive resources as a model for the other person's mental life. The basic idea of simulation has been interpreted in rather different ways: either as a basically imaginative, perspective-taking process—variously referred to as imaginative identification (Gordon, 1992), imaginative transformation (Gordon, 1996), off-line simulation (Currie, 1995; Goldman, 1989), and enactment imagination (Goldman, 2006)—or as neurological resemblance understood either as neural reuse and embodied simulation (Gallese, 2007) or mirror-based simulation (Goldman, 2006). Despite this variation, the simulational accounts all share the core idea that the same mechanism (e.g., a specific brain region) or a sub-cognitive system (e.g., the decision-making system) can be used in two modes of operation. For instance, when the same mechanism is used during action execution and action observation, or during emotion experience and emotion recognition. So, we can take all of these interpretations relatively identical or at least position them along a continuum. The question is: how might the simulation-based accounts explain the mindreading exhibited in pragmatic interpretation?

Simulation theorists have been almost silent on the question. However, a cursory glance at the literature reveals that to account for pragmatic interpretation they would probably take the same explanatory strategy they do in other domains, that is, downplaying the role of theory and insisting on simulation as an imaginative perspective-taking process. For instance, Goldman notes:

> Verbal communicators commonly make assumptions...My question is: how does a communicator proceed to estimate what pieces of information will be marshaled, or made salient, in the mind of the audience...The speaker cannot appeal to any such *theoretical* knowledge to make predictions of what is likely to be derived or calculated by the hearer. Nonetheless, speakers are evidently pretty good at making such predictions, more precisely, at predicting what kinds of 'implicatures', will be appreciated by an audience. How do they do that? Again, I suggest, by simulation. (1989, p. 171-2)

Similarly, Currie & Ravenscroft (2002) remark that understanding a speaker's meaning where it differs from utterance meaning is achieved by imaginative projection, that is, by "putting yourself in the speaker's shoes and asking 'What would I have meant by that?'" (p. 146).

A potential difficulty with this approach is that simulation in this sense is often used for *predictive* cases: decision prediction (Goldman, 1989; Gordon, 1986a), figuring out solutions to arithmetic questions (Heal, 1995), inference prediction (Stich & Nichols, 1995), and predicting the grammaticality judgments (Harris, 1992). Predictions proceed by moving forward. For instance, in simulational action prediction, one proceeds by moving from imaginatively generated (pretend) mental states towards the possible effects (an action) of those states. An utterance, however, is a generated piece of action that requires *explanation*. Nevertheless, unlike predictions, explanations proceed by moving backward, from an observed action (e.g., an utterance) to the mental states that have caused that action. Can simulation processes run backward? There are two ways we can think of backward simulation: direct and indirect simulation. I will examine each for pragmatic interpretation.

The idea of direct simulation first appeared following the discovery of mirror neurons: a set of visuomotor neurons that discharge both when an individual makes a particular action (e.g., grasping an apple) and when she observes a similar action performed by others (Pellegrino, Fadiga, Fogassi, Gallese, & Rizzolatti, 1992; Rizzolatti, Fadiga, Gallese, & Fogassi, 1996). It was argued that the similarity or overlap in neuronal discharge creates a matching mechanism that provides a direct or unmediated understanding of actions. Mirror mechanisms are simulation mechanisms because they operate in a way that one mechanism/process is used in two modes of action execution and action observation. How would this result in a direct understanding? By mapping the visual representation onto the motor representation of the observed action (Rizzolatti et al., 1996; Rizzolatti, Fogassi, & Gallese, 2001), or linking first- and third-person experiences, i.e., linking "I do and I feel" with "he does and he feels" (Gallese, Keysers, & Rizzolatti, 2004, p. 396). According to Gallese, "we can certainly 'explain' the behavior of others by using our complex and sophisticated mentalizing abilities... Most of the time, though, we do not need to do this. We have a much more direct access to the inner world of others" (2007, p. 659). It is held that all kinds of interpersonal relations, including recognition and attribution of intentions, relies on a mirror-based, or directly, shared manifold of intersubjectivity space (Gallese, 2001, 2003). Drawing on results from mirror neuron studies on monkeys (Fogassi et al., 2005) and humans (Iacoboni et al. 2005), it has been argued that mirror neurons, previously thought to be involved only in action recognition, are involved in direct recognition of intentions (Iacoboni et al., 2005, p. 533). Direct simulation is also advocated in other domains, including recognition of emotions (Goldman, 2006; Goldman & Sripada, 2005), or even language and linguistic communication. Moreover, it is argued that mirror neurons are the evolutionary precursor of language (Arbib, 2005; Rizzolatti & Arbib, 1998), that the neural structures responsible for action execution also play a role in understanding the semantic content of the same actions when verbally described (Gallese, 2007, p. 664), that the matching mechanism created by mirror neurons represents expectations that guide communication and action comprehension (Arbib & Rizzolatti, 1997), or that mirror activation creates a link between the sender of a message and its receiver in a way they can communicate without any cognitive mediation (Rizzolatti & Craighero, 2004, p. 183).[1]

The notion of direct simulation, however, lays down two related requirements, both of which must be satisfied in an account of pragmatic interpretation. First, because success in simulation relies on a similarity between the simulating process and the target process (Goldman, 2006), exogenous activation of mirror neurons must have a content similar to the content represented by endogenous activation. Besides, since the direct simulation is an unmediated process without the agency of intermediary (non-simulational) mechanisms, the content represented by exogenous activation must include mental states that are represented in the target. The two requirements raise the question, also raised by Jacob and others (Goldman, 2009; Jacob, 2008; Jacob & Jeannerod, 2005), as to whether representations created by mirror neurons contain any mentalistic content.

Regarding, the type of mental states involved in pragmatic interpretation, philosophers often make a distinction between *intentions-in-action* (captured by the linguistic form *I am doing A*) and *prior intentions* (captured by the linguistic form *I will do A*) (Searle, 1983). An agent that spontaneously grasps an apple has a motor intention to grasp that apple, but she has no prior intention to do so. An intention-in-action is not temporally prior to the action. Thus, as Searle remarks, we cannot say that an agent tries to carry out her intentions-in-action. Instead, an intention-in-action is in the action and inseparable from the action (Searle, 1983, p. 84). If so, to the extent that intentions-in-action are inseparable from bodily movements,

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[1] For criticisms of the link between language and mirror neurons see Hickok (2010); Toni, de Lange, Noordzij, & Hagoort (2008)

there is a sense in which we can say that activation of mirror neurons in response to the observation of a motor movement represents the intentional content (intention-in-action) of that movement. However, communication seems to require more than the identification of unthinking movements or unintended but intentional actions. It also requires recognition of prior intentions, intentions that are formed prior to actions, and, during communication, are recognized as the mental cause of those actions. So, the first difficulty with direct simulation is that intentions-in-action include only impulsive actions, present even in newborn babies or non-human animals. However, there are two points to note here. First, we should note that proponents of direct simulation often claim that, in addition to intentions in actions, mirroring can deliver knowledge of prior intentions (Fogassi et al., 2005; Iacoboni et al. 2005), where this involves recognition of actions which are more than unthinking movements or unintended but intentional actions. Second, it is often the case that we figure out what we intend to say as we are saying it. In these cases, the act of uttering is obviously not performed with prior intentions but intentions that are in action and part of the action (utterance). If that is right, then, as far as unintended-but-intentional utterances are concerned, mirroring can, in principle, contribute to pragmatic interpretation. Can mirroring deliver knowledge of prior intentions? Only if it fulfills two further requirements.

First, if simulation is a direct mechanism (i.e., represents the target's mental states directly), it requires a set of distinct matching mechanisms that are associated with the recognition of different actions. For action types, say A*1*...A*n*, there must be a set of mirror mechanisms, M*1*...M*n* that respond selectively in recognition of corresponding actions, in a way that the exogenously-generated representations (visual, auditory, etc.) will directly map onto the prior intention that has caused that action. How likely is this possibility? It depends on how well it fits with experimental evidence. Second, even if we suppose that each action corresponds to a mirror mechanism that is causally implicated in recognition of that action, because there is no unique or one-to-one mapping from an agent's action to her prior intentions, in the sense that the same action is always subject to more than one interpretation, an exogenously-generated representation cannot have the relevant prior intention as part of its content. As Jacob (2008, 2009) has pointed out, unless one endorsed behaviorism, one would not be tempted to support the view that perception of an action is a sufficient basis for forming a reliable belief about the agent's prior intention (Jacob, 2009, pp. 236–237). Does it follow that mirroring could not deliver knowledge of prior intentions or alternatively would lead to a form of behaviorism? I think not. There are at least two ways in which simulation can, at least indirectly, contribute to the recognition of prior intentions. First, by reducing the number of salient interpretations of an action. Under this conception, neither the mapping needs to be one-to-one, nor mirroring is required to deliver a single and unambiguous interpretation. Instead, simulation just needs to deliver the one that is more salient than other alternative interpretations. This would be a hybrid view in which mirroring does not need mapping directly to intentions. However, another approach would be that mirroring together with non-simulational processes mediate representation of mentalistic content. Under this notion, the simulation mechanism would need to be accompanied by theoretical considerations of the sorts to which a theory-theorist might appeal. This approach also would result in a hybrid account in which elements of theory and simulation cooperate. An approach like this is advocated by Goldman in his simulational model of emotion recognition (Goldman, 2006; Goldman & Sripada, 2005). The model, labeled as the Generate and Test strategy, consists of two simulation and non-simulation processes in which, to understand an observable piece of action (e.g., an emotion facial expression), an observing agent (i) formulates hypotheses about the prior mental states that might have been the cause of the observed action (the theory-driven stage). Next, in order to test the hypotheses, (ii) a facsimile of the hypothesized state is generated and fed into the mechanism that is responsible for the generation of that effect in the observing agent (the simulation-driven stage). If the generated action matches the observed action, the hypothesized mental states are attributed to the target as the cause of her action, and the action is explained. For example, an agent observing a particular facial expression hypothesizes fear as the possible cause of that expression (the non-simulational state). Next, a facsimile of fear is fed into the mechanism that is responsible for fear experience, e.g., a region in the brain, such as the amygdala. Next, amygdala activation generates a fear-related facial expression. If the generated facial expression matches the observed facial expression, fear is attributed to the target as the mental cause of that expression. By this final stage of attribution, the observing agent can make sense of the observed facial expression. The suggestion is that similar cooperation can be at work for the recognition of prior intentions.

It might be argued that this strategy, at least when used for utterance interpretation, confronts two problems. First, it faces a dilemma with two unsatisfactory horns: either (i) an action (explanandum) is unnecessarily duplicated because the observing agent needs to enact every action s/he wants to make sense of it, but this is not how we understand others (e.g., we do not re-utter every heard utterance), or the agent fails to reproduce the target action (explanandum), in which case cannot evaluate her interpretation (or hypothesized mental states) of that action, precisely because no action is produced that can be tested against the observed action. Second, the process requires trying out different (hypothesized) mental states until it generates an action that matches the observed action. So, it can be argued that while the generate and test strategy might be the mechanism of recognizing lower-level mental states (e.g., emotions), it would be cognitively too demanding and slow for recognition of higher-level states such as prior intentions because it involves generating and testing an open-ended list of hypotheses every time we make sense of an action. This requires listing all possible interpretations and then, through the agency of a highly theoretical mechanism, selecting an interpretation that seems like the most relevant explanation of the observed action. This lengthy and slow process makes indirect simulation virtually ineffective in communication.

However, I think this argument is not persuasive, firstly because it mischaracterizes the dilemma. Proponents of mirroring have consistently maintained that in simulation, actions are not duplicated. For instance, in simulational action prediction, the decision-making system is taken *off-line*, that is, because it is momentarily disengaged from behavior and motor control system, the output of the system (the decision) does not generate an action. At low-level simulational mindreading, Gallese and Goldman (1998) note that "externally generated mirror neuron activity does not normally produce motor execution of the plan in question. Externally generated plan is largely inhibited, or taken 'off-line', precisely as simulation postulates" (1998, p. 497). Similarly, for utterance interpretation, we can say the enaction of the simulation takes in an off-line, counterfactual mode, that would not lead to re-uttering every heard utterance. Besides, an off-line explanatory simulation could still generate a *plan* or *instruction* for the execution of the action. However, although the plan is not executed, it can be used to test or evaluate the interpretation of the target action. In general, the resources for offline, counterfactual reasoning that simulation theory must make use of are fairly rich and perfectly suitable for this kind of off-line retrodiction. Concerning the second objection, one way mirroring can contribute is to be seen as an element in a *stopping procedure* of the sort posited in the Relevance Theory, in which it is reasonable for the hearer to 1) follow a path of least effort and 2) stop at the interpretation that satisfies her expectations of relevance (Wilson & Sperber, 2002). Alternatively, simulationists might reply that the range of possible actions, constrained by previous experience and practicalities, facilitates the cognitively heavy load of the hypothesis testing stage. Besides, our utterances are mostly drawn from a relatively small and often repeated subset of utterances or utterance parts. Most of the time, when we do speak, we do use utterances that others have often used in our presence, or that we ourselves have used. In that case, there seems no basis for supposing that interpretation often could have been honed by prior experience with utterances. If this is right, simulation would be slow only when we are required to process utterances from outside the familiar subset, which might be only occasionally.

So far, I have distinguished between two senses of simulation and discussed the role of each in pragmatic interpretation. Direct simulation involves mere mirroring, and indirect simulation involves mirroring plus non-simulational processes, such as inferential processes of attribution. Our discussion thus far suggests that whereas mirroring alone underdetermines pragmatic interpretation, mirroring in cooperation with non-simulational processes, such as inferential mental state attribution, can play significant roles in pragmatic interpretation. At this point, however, we should distinguish between high- and low-level simulational mindreading. Although, as Goldman notes, a strict definition of high- versus low-level mindreading is lacking, the two are often differentiated in terms of two different prototypes. Whereas low-level prototype is the automatic and mirroring type of simulation, a high-level prototype is a kind that uses mental pretense, perspective taking, and imagination (Goldman, 2006, p. 147). Given the distinction, advocates of simulation theory might argue that our discussion thus far characterizes simulation in a way that is too narrow and constraining. So, the argument goes, although the low-level and mirroring type of simulation that we discussed might not be sufficient for interpretation, the more general sense of simulation, associated with the high-level prototype, is sufficient for delivering unique pragmatic interpretations. Simulation, in this sense, mainly consists of perspective taking, enactment imagination, and mental pretense. Indeed, it is this perspective-taking sense of simulation, which is often intended in simulational accounts of action and intention prediction. For instance, Gordon (1986) holds that we simulate by imaginative projecting into the other's situation in the same way that chess players, while transported in imagination, visualize the board form the other side. Currie & Ravenscroft maintain that it is only the perspective-taking part that is, properly speaking, essential for simulation (Currie & Ravenscroft, 2002, p. 54). Goldman (2006), by insisting on the role of enactment imagination.

A considerable feature of simulation in this broader sense is that it relies on first-order representations only. Perspective taking, as Baron-Cohen (1988) remarks, can be performed by using the strategy of mental rotation on first-order representations (Baron-Cohen, 1988, p. 394). In general, unlike the theory-theory approach in which metarepresentations of the form *I think he thinks* play a crucial role, a distinguishing feature of simulation is that by perspective taking an agent attributes one of her own generated (first-order) representations to the target (Goldman, 2006, p. 40) This is how simulation constitutes a competitor to theory-driven accounts of mindreading. To illustrate this type of simulation, Goldman notes:

> [Simulation] contends that E-imagination is often employed for mindreading. To determine whether my wife, seated elsewhere in the room, can see the bird in the birdfeeder, I might visualize how things look from her perspective. Such perspective taking could lead me to mindread both her visual state and any consequent beliefs about the bird. Analogously, many nonvisual specimens of E-imagining might be utilized for mindreading purposes. In general, E-imagining isn't confined to the production of imagery, visual or otherwise. (2006, p. 149)

The quote illustrates how level-1 and level-2 perspective taking concern the ability to imaginatively slip into the role of another person and imagine how s/he would think in the targeted situation. According to Flavell and his co-workers (Flavell, 1977; Flavell et al. 1981), there are two levels of visual perspective taking. Level-1 is the ability to understand non-egocentrically what object another person does and does not see, and that other people have a different line of sight than ourselves. Level-2 perspective taking is the ability to understand that different people viewing the same item may see different things or have different representations of the same item if their viewing conditions differ. With this distinction in mind, the rest of this paper examines the significance of this broader sense of simulation in utterance interpretation. If simulation underpins pragmatic interpretation, we should expect an association between pragmatic and perspective taking impairments. One could, of course, fail at pragmatic interpretation by being poor at things independent of perspective taking, e.g., poor linguistic comprehension. However, all other things being equal, if simulation is sufficient for the mindreading required for interpretation, we should expect that (i) subjects with no serious difficulty in perspective taking experience no difficulty in pragmatic interpretation, and (ii) subjects with no considerable difficulty in pragmatic interpretation show no difficulty in perspective taking. Drawing on empirical evidence, I will argue that the relationship between simulation and interpretation is not the way simulationists might expect. Specifically, I will show that subjects which are known as having difficulty in pragmatic interpretation often show little difficulty in perspective taking, and subjects with difficulty in perspective taking do not necessarily experience difficulty in pragmatic interpretation. The evidence, I think, suggests that simulation in this sense probably plays no significant role in pragmatic interpretation.

3. Dissociation Between Simulation and Pragmatic Interpretation

Communication impairments are among the typical symptoms of autism spectrum disorder (ASD). Subjects with autism often experience a severely impaired functioning on most pragmatic aspects, including difficulties in using speech acts (Ziatas, Durkin, & Pratt, 2003), comprehending irony and metaphor (Gold, Faust, & Goldstein, 2010; Martin & McDonald, 2004), detecting violations of Gricean Maxims[2] (Surian, Baron-Cohen, & Van der Lely, 1996) and using features of the context in utterance interpretation (Loukusa et al., 2007) (cited in Cummings, 2013, 2014). Besides, the evidence demonstrates that ASD subjects face considerable difficulty in mental state attribution (Baron-Cohen, Leslie, & Frith, 1985; Golan, Baron-Cohen, & Golan, 2008; Leslie & Frith, 1988; Williams & Happé, 2009; Williams & Happé, 2010b). If simulation plays a significant role in utterance interpretation, it is expected that autistic subjects, who are severely impaired in pragmatic interpretation, show serious difficulty when taking others' perspectives. Several studies, however, speak against this expectation.

In an early study on perspective taking by Hobson (1984), autistic subjects were presented a display in which a miniature figure was said to be wishing to hide from one or two other seekers. The task required the subjects to point out where the figure should stand in order to hide from the seekers. In a second task, the Cube test, Hobson asked the subjects to infer the perspective of a dull that faced a cube. Successful performance needed the subjects to visualize points of view very different from their own. The results revealed that autistic subjects, in comparison to controls, had no difficulty in identifying the other figure's visuospatial perspective, nor any difficulty in coordination of different perspectives in the Cube task. In a subsequent study by Leslie & Frith (1988), a plastic board was placed on a table in a way that a doll could be on either side of the board (visible to the child). Then a counter was placed on the board, and, depending on the position of the counter in relation to the doll, the subject was asked whether the doll could see the counter. In several trials, the experimenter varied the position of the doll while the child was asked to change the position of the counter where the doll could or could not see the counter. The results show that autistic subjects, regardless of whether they could recognize mental states or not, had no difficulty in visualizing others' perspectives.

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[2] Principles which, according to Grice, people follow in effective communication.

Baron-Cohen (1989) examined visual perspective taking in autistic subjects compared to normal subjects and subjects with Down’s Syndrome. Small toys were placed around the subject and, from the orientation of an experimenter’s eyes alone, the subject had to identify which toy the experimenter is attending to. Baron-Cohen found no significant differences within or between the three groups: 92.5% of autistic subjects, 94.4% of normal subjects and 89.3% of subjects with Down Syndrome passed the test. The results by Baron-Cohen are replicated in a study by Leekam et al. (Leekam, Baron-Cohen, Perrett, Milders, & Brown, 1997). Using the same procedure, Leekam and colleagues report no significant group differences in the performance of normal subjects, autistic subjects, and subjects with down syndrome.

The evidence reviewed thus far points to an intact ability of level-1 perspective taking in autism, showing that individuals with autism can imaginatively grasp that others might have a different line of sight and what things others do and do not see at any given moment. Following Flavell (1977), this is called level-1 visual perspective taking. Besides level-1 perspective taking, understanding by simulation requires level-2 perspective taking (1977): recognizing that others may represent the same thing a bit differently and have a different perspective on the same thing than we do. Do subjects with autism are capable of level-2 perspective taking?

To answer the question, Reed & Peterson (1990) examined autistic subjects in understanding the contrasting perspectives of individuals viewing the same object from different vantage points. The subjects sat in front of a turntable, and an object (a plastic tiger or a teddy bear) was placed on the table. Reed & Peterson asked participants to “turn it round so I can see the ----” the last word being “nose,” “tail,” “back,” depending on the object presented (1990, p. 460). The results revealed a uniformly high-level performance by all participants in both level-1 and level-2 perspective-taking tasks, with no significant difference in performance between autistic and control groups. Similarly, Tan & Harris (1991) reported no significant difference between autistic and control subjects in level-1 and level-2 perspective-taking tasks. More recently, David et al. (2010) examined visuospatial perspective taking in a task required to detect an elevated object from a virtual character’s perspective. Interestingly, David et al. instructed participants to answer questions by using imagination, for instance, by telling “imagine yourself standing in the position of the virtual character,” or “it is important to imagine your change in position!” (p. 294). Results by David et al. revealed no significant group differences. In a more demanding task presented by Zwickel and colleagues (Zwickel, White, Coniston, Senju, & Frith, 2011), a dot appeared next to a triangle protagonist and participants were asked to press either the left or right button to indicate on which side of the screen the dot appeared relative to the triangle. In some trials, the dot appeared on the same side from the viewpoint of both the triangle and the observer. In other trials, the dot occurred while the triangle was pointing downwards, so a dot on the participant’s right fell on the left of the triangle or vice versa. The results, according to Zwickel et al., were clear cut, revealed no significant differences in group performance.

However, it should be noted that results from perspective taking studies on autism have not always been consistent. Yirmiya et al. (Yirmiya, Sigman, & Zacks, 1994) presented autistic subjects with items on a rotating table and asked them to turn the table until they can see an item in the exact same way that the experimenter can see the item from where she is standing. The majority of the subjects had a good perspective-taking ability, but as a group, they performed less well than controls. A study by Hamilton et al. (Hamilton, Brindley, & Frith, 2009) suggests that low-functioning children with autism have difficulty on level-2 perspective taking in the mental rotation task (compared to their performance on the spatial rotation task). Hobson (1999) shows that subjects with autism have specific limitations in imitating the *style* of another person’s actions. Two points about the contradictory evidence are in order.

First, poor performance does not always demonstrate difficulty in perspective taking. It might be the result of a heavy memory load or a difficulty in executive function than perspective taking. Reed (2002) shows that, at least in some cases, deficits in executive function can cause poor performance in perspective taking. Second, if perspective taking is impaired in autism, then, as Carruthers (2006) has pointed out, on the assumption that introspective faculty is intact in autism, autistic subjects must experience no severe difficulty in reading their own minds. Several studies, however, have demonstrated that subjects with autism have difficulty in discriminating between their intended and non-intended actions (Phillips, Baron-Cohen, & Rutter, 1998), are less able to recognize their mistaken action as unintended (Williams & Happé, 2010a), hardly can think and talk about their inner experience (Hurlburt, Happé, & Frith, 1994), and have problems in reporting their false beliefs (Perner, Frith, Leslie, & Leekam, 1989; Williams & Happé, 2009).

In general, it may be true that subjects with autism, despite communication deficits, do not suffer from limited imagination or difficulty in perspective taking; however, given the contradictory evidence, this interpretation is not wholly straightforward. More explicit evidence for the absence of a relationship between simulation and pragmatic interpretation comes from other resources, specifically, from studies on subjects with schizophrenia and fragile X syndrome. Evidence shows that individuals with schizophrenia exhibit a high degree of pragmatic impairments, including difficulties in proverb comprehension (Brüne & Bodenstein, 2005), processing contextual information (Bazin, Perruchet, Hardy-Bayle, & Feline, 2000; Sitnikova, Salisbury, Kuperberg, & Holcomb, 2002), and decoding of violation of conversational implicatures (Tényi, Herold, Szili, & Trixler, 2002). Moreover, several studies demonstrate to impaired mental state attribution in schizophrenic patients (Bora, Yucel, & Pantelis, 2009; Brüne & Bodenstein, 2005; Corcoran, Cahill, & Frith, 1997; Frith & Corcoran, 1996; Langdon et al., 1997). For instance, difficulties in understanding jokes that require inferring mental states (Corcoran et al., 1997) or making inferences about others' thoughts and intentions (Frith & Corcoran, 1996). Despite this, subjects with schizophrenia do not seem to have any difficulty in perspective taking. Results by Langdon et al. (Langdon, Coltheart, Ward, & Catts, 2001) shows that schizophrenic subjects perform equally capable as controls in judging the location of a block in an array relative to a change of perspective, or in judging what an array would look like if the array rotated while the patients stayed fixed (perspective change judgment). Similarly, subjects with fragile X syndrome suffer from specific pragmatic deficiencies, including the use of repetitive language: utterance repetition, topic repetition, and conversational device repetition (Ferrier, Bashir, Meryash, Johnston, & Wolff, 1991; Murphy & Abbeduto, 2007), and failure to signal non-comprehension language—signaling non-comprehension requires the listener continuously monitor her understanding and formulate responses that make clear to the speaker what aspect are problematic (Abbeduto et al., 2008). In addition, similar to autism and schizophrenia, subjects with fragile X syndrome are impaired in mental state attribution (Cornish et al., 2005; Garner, Callias, & Turk, 1999; Grant, Apperly, & Oliver, 2007). Despite these problems, however, no difficulty arises when the subjects take others' perspective (Mazzocco, Pennington, & Hagerman, 1994; Mazzocco & Reiss, 1999) or during emotion understanding, which is often considered as simulational (Bouras, Turk, & Cornish, 1998; Shaw & Porter, 2013; Simon & Finucane, 1996).

Are there cases in which we find the opposite pattern? That is, are there individuals whose perspective taking is impaired, but whose pragmatic interpretation abilities are spared? Evidence from psychopathic individuals supports the opposite pattern of dissociation. A recent study by Drayton et al. (Drayton, Santos, & Baskin-Sommers, 2018) has examined psychopathic individuals in a dot-perspective task in which the subjects were presented with pictures of a human avatar who were facing either the right or left wall of a room, where up to three red dots could appear on the walls. The task required the subjects to verify the number of dots either they or the avatar could see. The results revealed an impaired ability to think from another's perspective, an impairment which, according to Drayton et al., maybe the cognitive root of the subjects' deficits in social functioning and moral behavior. Despite the impaired ability of perspective taking, psychopathic subjects do not have any difficulty neither in pragmatic interpretation nor in the classic theory of mind tests (Blair et al., 1996; Dolan & Fullam, 2004; Jones, Happé, Gilbert, Burnett, & Viding, 2010). For instance, the subjects show good performance on first- and second-order false-belief tests which, respectively, involves reasoning about what another person might mistakenly think and what one mistakenly thinks another person thinks (Jones et al., 2010). Does the Drayton et al. study show that perspective taking in psychopaths can be impaired without corresponding deficits in pragmatic interpretation? This may, but the interpretation of the findings must be made with caution. First, precisely what the dot perspective tasks tell us is still a matter of dispute, and there are in particular important differences in task design across different studies, making direct comparisons difficult. Second, whereas psychopaths tended to be seen as having somewhat intact cognitive perspective-taking skills, they are generally seen as having a deficit in affective empathy, particularly in recognition of fearful vocal affect (Blair et al., 2002; Blair et al., 2005). So, any interpretation of the findings about psychopaths' abilities is at best speculative and must remain tentative.

4. Concluding Remarks

Mindreading or the ability to represent others' mental representations is involved in different cognitive domains, including pragmatic interpretation, which requires expression and recognition of intentions. The connection between the two is so close that difficulties in interpretation are often explained by reference to mindreading impairments. However, mindreading itself and the question as to how it is executed has been a subject of long-standing debate in the literature. This has given rise to the development of several positions, but the question of which one is explanatorily adequate and more fundamental in pragmatic interpretation has remained unanswered so far. In this paper, I examined the explanatory value of the simulation hypothesis, as one of the most prominent accounts of our mindreading ability, regarding pragmatic interpretation. In the first part of the paper, I argued that low-level mirror-based simulation is not sufficient for the recognition of prior communicative intentions. However, mirroring plus non-simulational processes, such as theoretical and inferential considerations or processes that reduce the number of salient interpretations, can play a significant role in the process of pragmatic interpretation. Next, we examined a more general sense of simulation, high-level simulation, which is characterized in terms of mental pretense, perspective taking, and enactment imagination. To this end, we evaluated level-1 and level-2 perspective taking in several clinical populations, and found no necessary connection between this sense of simulation and pragmatic interpretations. The evidence we reviewed points to a dissociation between the two: individuals with considerable difficulty in pragmatic interpretation show little or no difficulty in perspective taking, and individuals with deficits in perspective taking do not always show difficulty in pragmatic interpretation. This strongly suggests that simulation in this sense plays no significant role in the process of pragmatic interpretation.

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SOCIAL FACTS & THE SEMANTIC CONCEPTION OF NORMS. CUSTOMARY NORMS AS A TEST OF ONTOLOGY[1]

abstract

The essay addresses the debates about the ontology of norms considering the case of accounting for customary norms. It undertakes and defends a stance in favor of a semantic ontology by developing a framework for the explanation of norms as abstract objects and their linking with social facts to be identified in categories like "customary", "enacted", "legal", "grammatical", and so on. Furthermore, the work addresses the rival conceptions (pragmatic and eclectic) by showing the specific impossibility that these face for giving a satisfactory account on customary norms. The inquiry concludes by exploring some possible insights from the philosophy of mind to explain the conceptual nature of norms as mental representations.

keywords

customary norms, ontology, semantic conception, pragmatic conception, social facts, concepts, mind, mental representation

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I. Introduction

As Alf Ross (1968) once stated "'Norm' is a term widely used in legal theory, sociology, linguistics, moral philosophy and logic, but there is no common agreement about its sense. It is in fact used most frequently without being defined at all" (p. 78). There is a wide agreement in considering that whatever law is, it is mainly constituted by norms; and thus, that legal scholars should know a great deal about norms. However, it seems that the ontology of norms has not been a central matter in contemporary legal philosophy. Jurisprudence has primarily developed as a discipline by using intuitive notions of what "legal norms" are focusing on some properties and functions that the term entails in legal practice: promulgation, prescription of behaviors, the standard for judgment, the basis for adjudication, and so forth. (Tamayo, 2013, p. 175).

Nevertheless, the matter of the ontology of norms is important for any theoretical explanation for disciplines dealing with norms since, as Jordi Ferrer and Jorge Luis Rodríguez (2011) highlight: "The position adopted regarding the characterization of normative systems in general, and legal systems in particular, is closely related to the mode in which norms are characterized" (p. 27). In this line of thought, Carlos Alchourrón & Eugenio Bulygin (1981) have brought to light the problem of the ontology of norms for Jurisprudence, pointing out that in general terms there are two possible ontologies of norms, the *hyletic* conception and the *expressive* conception which, for a more acquainted terminology, we might call them the *semantic* and the *pragmatic* conception respectively. Both ontological conceptions are related to two conflicting traditions in the philosophy of metaphysics about the criteria for admitting which kind of entities compose the world, more specifically, the traditions conflict in their views about the problem of universals: realism and nominalism (Caracciolo, 1997). Broadly, nominalism denies the existence of universals and abstract objects that are out of space and time like numbers, geometrical forms, propositions, or logical connectors, while realism accepts the existence of such objects[1].

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[1] An objection to an early version of this essay criticized the fact that I assume the semantic/pragmatic alternative as plainly true, thus implying there must be other postures to consider. Therefore, it seems opportune to say something about the matter. I do assume the semantic/pragmatic alternative as true, but not without justification. As can be seen, both alternatives are related to a higher dispute in philosophy, to the question: Do abstract objects exist? The answer can only be yes or not. Nevertheless, I do take into consideration and further discuss in the essay the posture of those who consider that the semantic and the pragmatic conceptions are not incompatible. There is also another different approach on the subject, very well developed by Maribel Narváez Mora in her essay "Expressing Norms"

Remarkably, developments and debates about conceptions of norms have extensively focused on the analysis of enacted norms (*i. e.* promulgated)[2] as the components of normative systems for developing a logic of norms and norm propositions. Generally, legal philosophers do not deny the existence of other norms like customary ones, but in the vast majority of cases, these norms are accounted only anecdotally with isolated remarks. Moreover, most of those who have embraced acutely into the logic of norms –and thus into the ontology of norms– also focus their attention almost exclusively over norms that are the result of commands, that is, enacted norms[3]. Consequently, at first glance the expressive conception seems adequate since it engages in a less metaphysical domain by focusing on the acts of command. However, the case is not that simple for the expressive conception when accounting for customary norms. For such reason, the present analysis develops a defense of the semantic conception as an adequate ontological conception focusing on the issues that emerge from explaining customary norms. The analysis argues that norms are *per se*, language-independent but are not unrelated to social facts. In that line, it also addresses some of the complications of assuming a pragmatic conception and an eclectic stance for accounting customary norms.

II. The Case for a Semantic Conception

The *semantic* conception characterizes norms as entities similar to propositions or, as Georg von Wright called them: *proposition-like entities* (1963). That is, the meanings of certain utterances called *normative sentences*. For this conception, norms are language-independent entities, although they are only expressible through language. As so, norms are abstract entities, purely conceptual (Alchourrón & Bulygin, 1981).

Taken as conceptual entities, the semantic conception of norms is not itself demanding for accounting norms in general. If norms are meanings, their existence is independent of facts from the material world. In this stance, facts –the quality of facts– are useful to predicate that a norm belongs to a specific category. If the fact by which we identify a norm is a specific action from a legislature, then we are referring to an enacted legal norm. If the facts by which we identify a norm are a set of social behaviors, then we are referring to a customary norm.

(2015), where she sustains that inquiring into the ontology of norms is plainly nonsense. However, I will not discuss Narváez Mora's posture since it would largely overcome the topic I want to address in this essay. Also, in his essay "Norme: cinq référents" (2017) Conte expresses that the question: "What is a norm?" is a false one, arguing that the question presupposes unity in the designator of the term "norm" and thus proposing five referents for the term. Generally I do not agree with Conte. I consider that one thing is the phenomena by which we apprehend and thus refer to abstract entities (deontic statements, deontic propositions, state of affairs), and another different one the ontology, the intrinsic nature of those entities. Still, discussing at length Conte's ideas would largely surpass my paper; nonetheless, I trust that from arguments here developed any reader would have a clearer view about my disagreement with Conte.

[2] I will refer broadly to *enacted* norms as counterparts of customary norms. Properly understood, customary norms are those that emerge out of spontaneous social interaction. On the other hand, e*nacted* norms are commonly written, but this is not a necessary trait of them. Enacted norms are broadly what Joseph Raz calls "mandatory norms", although I consider the name misleading. What characterizes *enacted* norms as opposed to customary norms is the fact that they are the product of the will of an agent that, for some reason, has authority in the social group. For example, in a tribe, whatever the chieftain states the others *ought* to do are enacted norms. Similarly, if the population considers that the elders have authority, whatever they state the tribe *ought* to do, are enacted norms (*See* Raz, 1975). In the realm of law, an enacted norm is that created by an agent with institutional (legal) power. Thus, norms that are the product of the will of Legislatures, Heads of Government and administrative authorities are enacted norms, but like Kelsen (1945) I also consider as *enacted* norms those that are the contained within judicial sentences as the product of an act of adjudication.

[3] Possibly the most notorious case can be found in G. von Wright's Norm and Action (1963), where the Finnish philosopher accepts the existence various types of norms – customary norms among them – but expressively decides to focus his attention and the development of his work on promulgated norms; i.e. norms as the result of an act of command.

Nevertheless, facts do not determine the existence of a norm by itself. The norm is an abstract entity, a conceptual one, so it is independent of language or any communicative act, although only communicable through those means. To give an account of a customary norm, not in as much as to predicate that it is a norm, but in as much as to predicate that it is *customary*, is the result of a set of events that happened in the material world.

According to the semantic conception, it is only necessary to identify the social facts that we associate to the category of *customary* to subsequently apprehend the norm that underlies those facts.

In a recurrent situation *S* there is a customary norm among members of a group *G* if, given a certain conduct *C*,

1. In each instance of *S* each member of *G* behaves in the manner *C*;
2. The members of *G* seem to consider *C* as a binding standard of conduct in *S* ('what one ought to do' in S);
3. Members of group *G* show rejection to other members of the group *G* who do not behave in the manner *C* in an instance of *S*[4].

The facts sketched would not constitute a customary norm. The ensemble of facts makes up a state of affairs that would be a means to identify customary norms. From a description of the set of social facts, we could plausibly state that "In the social group *G* there is a norm that demands to abide to conduct *C* when *S* occurs." The statement contains the proposition "obligatory *C* when *S*" that describes that there is a norm among members of the group *G*. Thereby, the semantic conception seems consistent with our ordinary uses of language and with our intuitions about customary norms. For instance, if a description of the practices of a social group reveals some facts that indicate a convergence of behavior, and there is a hint that allows identifying that members of the community demand such behavior from their peers; for a semanticist, there would be no conceptual inaccuracy.

A. Norms and Social Facts

The semantic conception entails no little controversy as an ontological stance. Riccardo Guastini (2013) considers the semantic conception unsustainable claiming that identifying norms with meanings, as abstract conceptual entities similar to propositions, is to refer to "exquisitely metaphysical" entities. But the problem with norms does not lie in their metaphysical existence. Rather, Guastini's call stresses the necessity of keeping in line with the basic theoretical postulates of legal positivism.

To remember, a crucial postulate of legal positivism is embedded in what Joseph Raz (1979) called the "social thesis," which states that, whatever law is, it is necessarily a matter of social facts (p. 40). The thesis inevitably extends to the account of any phenomena constitutive of law, as the customary norms. So, if customary norms are a component of the law, then, these must-have some association with social facts. Therefore, the broad question that arises is: in which sense can we say that conceptual entities exist and how are these related to the facts of the world?

We are facing the actual problem of the ontology of certain entities called "norms" whose "existence" is independent of the communicative acts that express them and that even lack temporal and spatial dimensions. Effectively, at first sight, this seems to have a Natural Law *façade*, but it does not have to be this way, and it is not the case. What the "social thesis" demands is that to belong to a category of a social phenomenon, the entity must have a connection with specific facts that we use for identifying that category. In the case of enacted norms, for verifying their quality of "enacted," there are some criteria, promulgation usually

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[4] This is a rough and modified sketch taken from Buno Celano's "minimal theory" of custom. Celano (2010).

is conceived as the fundamental one. That is, the act of a normative authority to prescribe a norm publicly through a norm formulation (von Wright, 1963). In the case of the customary norms, we must identify the existence of the qualified social facts that constitute our notion of a specific customary norm.

Let's see a scheme of possible social facts inspired in a model proposed by David K. Lewis (1969) for conventions and reprised by Cristina Bicchieri (2006 & 2017) for explaining social norms:

> In a recurrent situation *S*, it is possible to predicate the presence of a customary norm between the members of a social group *G* if, and only if:

1. In a significant amount[5] of the instances of *S,* a significant amount of the members of *G* behave in the manner *C*;
2. In a significant amount of the instances of *S,* a significant amount of the members of *G* show an adverse reaction when other members of *G* do not abide by behavior *C*;

From such events, an external observer would necessarily make an interpretation of facts[6] that enables him to determine a normative association, inferring that:

3. A significant amount of the member of *G* seems to *expect* that other members of *G* abide by behavior *C* in the instances of *S*, and that
4. A significant amount of the members of *G* seem to be aware that another significant amount of members of *G* expect them to abide by behavior *C* in the instances of *S*.

The scheme broadly matches the set of facts that most theories consider an external observer would identify in accounting for social norms[7]. The challenging part involves explaining the link between that set of facts with the conceptual entities we call "norms" while also clarifying what entails the existence of norms as such. Norms are indeed metaphysical objects whose existence is independent of the material world but that, somehow, maintain some relation with material-world facts that are necessary to identify them into a category like enacted or customary. The task seems to surpass the traditional boundaries of analytical legal theory by entering into problems concerning other areas of knowledge like the philosophy of mind and, inquiring deeper into the branch of *metaphysics.* Nonetheless, if someone considers that holding a semantic conception of norms is contrary to the postulates of legal positivism since this conception of norms depicts them as metaphysical entities not susceptible to cognitive knowledge and with no association to the facts of the world; then it seems opportune to say some words explaining why that is not the case. Further arguments will be advanced in Part IV.

B. Norms and Propositions

One of the more intriguing remarks of the semantic conception of norms is that they are similar to propositions. Thus, inquiring slightly into the nature of propositions concerning norms can be useful for understanding the nature of the latter. As exposed above, we know that norms, like propositions, do not have "existence" if the term *existence* is related – according to our natural use of language– to entities identifiable in parameters of space and time. We also know that propositions must not be confused with the statements that

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[5] Considering D. Lewis' observation that we could hardly ever find a perfect specimen of a convention, I decide to substitute the universal quantifier "all" for a less committed one, "a significant amount", since even "almost all" is highly controversial, as one might plausibly hold that a convention to be such does not a very high degree of followers (Lewis, 1969).

[6] As explained by Riccardo Guastini (2011), interpretation of facts would be inferring the causal explanation of an event (p. 9).

[7] *See* Hart (1994), Celano (2010).

refer to them. The statement is the fact that we can identify in a certain time and space, the proposition is the unit of meaning. Regarding enacted norms, something similar happens; we must not confuse the normative formulation with the norm itself.

With customary norms, the facts that allow stating the presence of a norm within a specific social group are identifiable in time and space; those facts must not be confused with the norms. Then, where can we find the propositions? What are propositions? Where are the norms? Proposition and norm, although both serve as meanings of something, cannot be the same thing, but they share some similarities. Let us see what these entities consist of and how come they are entities of the knowable universe.

Conventionally, in our language, we use statements to make assertions. When syntax between words is grammatically adequate (von Wright, 1984), what the statement contained in phrases or sentences, that which is asserted, is a proposition (García-Carpintero, 1996), an assertion or the denial of a state of affairs, so the proposition is susceptible of being true or false. Propositions come in pairs, as H. Castañeda (1975) stated: "[...] for every true one there is its negation, which is false and vice versa" (p. 34). Propositions are expressed through a set of words but are not identical to those words (Moore, 1953). The same sequence of words can ambiguously express different propositions[8]. Nevertheless, not every grammatically well-formulated sentence expresses a proposition if they do not display a truth-value. Therefore, propositions are found in *declarative* or *constative* sentences. *That* which declarative sentences express, mean or say, are *propositions*.

Hence, language is useful to utter sentences that contain propositions, and it is the primary means to identify them, but it is not the only means by which we apprehend them. The means of expression is contingent since we can imagine propositions that we might have a desire to deliver even before being able to articulate the words that might express them. So, there are propositions that will never be expressed. Also, when we conceive a proposition, we capture some other things that are not propositions; that is, things uttered by some of the words that compose the sentence that contains a proposition. For example, in the phrase "Alejandra read two books," we also get the word "two." "Two" does not express a complete phrase; it does not affirm anything and thus, has no truth-value. However, "two" certainly is something and means something. As a result, when we comprehend a proposition, we do not directly comprehend all the things referred by the proposition. The apprehension of the things the proposition is about is *indirect*[9] (Moore, 1953). A case of this phenomenon is the *normative proposition*, that is, a proposition that informs about the "existence" of a norm (Navarro, 2000). Norms are also meanings contained in sentences or communicative acts, but they do not assert how the world *is*, but how it *ought* to be. Consequently, unlike propositions, norms display no truth-value. When thinking about enacted norms, the means *par excellence* to apprehend them is indirectly through a normative proposition contained in one or several normative texts (codes, laws, regulations) or by normative formulations, that is, by descriptive sentences that assert the presence of a norm.

We must be careful in distinguishing between the category of abstract entities we conceive since apprehension, especially indirect apprehension, can be deceitful. For instance, enacted norms contained in a legal disposition can refer to customary norms, in which case, we apprehend norms of two different qualities: the enacted norm and the actual practice that

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[8] For example, the phrase "I saw Juan with binoculars" could mean: a) that I saw Juan through the use of some binoculars or, b) that I saw Juan that had some binoculars with him. (García-Carpintero, 1996).

[9] The use of the term "apprehend" may seem quite odd, but it is proposed by G. E. Moore to refer to the mental operation of realizing a proposition, to capture the full idea, the "thing" referred by the proposition.

gives place to the customary norm. This is a case of indirect apprehension of norms through enacted norms, since that which the enacted norm is about is another norm, apparently a customary one. This is easy to find in the legal experience where often statutes establish a customary practice as legally binding for certain situations. Thus, one thing would be the norm apprehended from the statue ("obligatory to abide by the customary practice") and another, the actual customary norm. Nevertheless, the referred norm might not even be properly called a customary norm but a "hypothetical norm". Imagine a legal disposition that expresses "In unforeseen cases by legislation, payments must be done according to the uses and practices of traders." We might not even know the actual practices of traders concerning payments, but now we grasp a sense of "normativity" revolving whatever we can plausibly imagine they are. Whatever those practices are, now we know that there is a reason for which they ought to be observed by traders and considered for adjudication.

The peculiarity is that now we have a set of norms –abstract objects– that we have apprehended. All the possible courses of action that we plausibly conceive traders ought to observe for payments other than the foreseen by the legislation. The issue now is that we have not yet captured anything from any actual practice because we do not know the actual practices of traders and we have not seen that community in action. We only have some hypotheses, hypothetical norms. Although implausible, it is conceptually conceivable that traders do not have uses and practices for solving cases of payment unforeseen by legislation. So, the norm referred by the enacted norm would be a hypothetical customary legal norm conditioned on social practice to materialize into an actual customary legal norm. To be an actual customary legal norm the conceivable norm must meet the condition of matching the practice of traders. That is, the norm in question must be the meaning that we associate with certain practices that are required and expected among traders.

From a judge's perspective, the reasoning works similarly to a counterfactual condition. The enacted norm prescribes that for any hypothetical norms that solve the cases of payments not foreseen by legislation, the one that acquires legal status –and that the judge must use in adjudication– is the one that translates as a descriptive statement that best reflects the actual practice expected among traders. Hence, if the conceivable norm is stated as "payment for digital goods must be done with cryptocurrencies", that would be the actual customary legal norm if something like the following statement is true: "most traders pay for digital goods with cryptocurrencies, and they display an aversion to those who do not".

Another deceitful context for apprehending "customary norms" could be through texts that do not contain normative dispositions, and that only contain a description of the practices of a community, informing about the "presence" of customary norms within that context. In these cases, it could be confusing to understand when we are grasping an actual customary norm and when not. Imagine some possible scenarios.

Scenario 1: The description of a normative practice within an imaginary community. In this case, we would apprehend norms, but since the practices were never real, we can only say they are "imaginary customary norms."

Scenario 2: The description of normative practices within a community that does not exist anymore, or that continues to exist, but over time changed their normative practices. In this case, we are not abstracting anything from the observation of material reality, but we trust the description of either someone who saw the practices or someone with trustful sources. Assuming the description of acts and actions is accurate; we did apprehend customary norms, although not in practice anymore. It is important to emphasize, as conceptual entities, it makes no sense to say that norms are born or ceased to exist. It is the practices, the facts that rise and cease to exist. A norm is a norm, and we only call them "customary", "enacted" or "hypothetical" because of the quality of the events by which we apprehend them. In the case of this description, it seems possible to say that we got to know by apprehension through the truthful information some other person gave us. The latter illustrates the idea that norms, like propositions, are units of meanings and not facts.

In this line of thought, possibly the most stimulating manner to apprehend customary norms –because the complexity of mental processes involved– has nothing to do with propositions embedded in statements that assert the presence of a norm, but through direct observation of the social facts, of human behaviors that we interpret in a determinate sense, a normative sense. Metaphorically, we are talking about the image that comes to our mind (possibly not a clear-cut one) that makes us feel entitled to proffer a normative proposition contained in a sentence like "In Sweden, one *must not* greet people one does not know [even if you meet with them regularly at familiar places, like at the building where you work]".

As indicated before, a proposition can have as part of its meaning a norm, *i.e.* a normative proposition. Norms can be part of the whole meaning of a proposition, but the meaning of the norms is different since it has no truth-value. In this line of thought: What is a "norm"? "Norm" is the expression we use to refer to a kind of concept[10], meaning for a sense of action: obligatory, prohibited, and permitted.

III. The (Im) Possibilities of Alternative Ontologies

A. The Pragmatic Conception

For the pragmatic conception, it is only at the practical level of language that it is possible to distinguish the difference between assertions, questions, or orders. There is no difference at a semantic level[11]. One could only identify a norm from the act of command performed by an agent and not because of the meaning of the uttered statement. Thus, one must be careful and distinguish norms from normative propositions; that is, the propositions that assert the existence of a norm or that declares that particular behavior is mandatory or prohibited.

Like the semantic conception, the pragmatic conception supposes that normative sentences can be analyzed in descriptive content, *i.e.* a propositional content that consists in the description of an action or state of affairs resulting from an action, as well as by the normative or deontic operator that qualifies the action (Kristan, 2014), *e.g., obligatory*, *prohibited* and –hesitantly for the pragmatist– *permitted*. However, between assuming one or another stance, there are important theoretical consequences. For the pragmatist, it is not possible to develop and to talk about a logic of norms since they lack truth-value, and, by focusing on the imperative trait, they –generally– deny the possibility of asserting the existence of permissive norms[12]. As Alchourrón & Bulygin (1981) highlight, the pragmatic stance is incompatible with the semantic, and there is no place for eclecticisms. In their own words: "If norms are expressions in a certain pragmatic mood, then they are not part of the meaning; if they are meanings (propositions), they are independent of any use of language or pragmatic mood" (p. 97).

At first glance, the pragmatic conception appears inadequate to account for customary norms. It reduces the conditions of existence of the norms to a prescriptive use of language, *i.e.* commands, something that without many complications can be explicative for enacted norms

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[10] Disputes in Philosophy of Language and Logic over what is a concept, the types of concepts, their referents, and how we get to know them, are dense and convoluted. For that reason, I will limit myself to give a fundamental and generalized account, assuming certain central thesis, and not getting into deep in details, merely focusing on the relevant aspects for what I look to explain. For a full detailed study on concepts, see Peacocke, 1992.

[11] For this conception, there is no semantic difference between the following sentences: "Forbidden to smoke", "Forbidden to smoke!" and "Forbidden to smoke?" The difference could only be noticed with respect to the use of the language of the one who utters the previous sentences.

[12] Although there are exceptions, being Manfred Moritz the first pragmatist to challenge the thesis in his essay "Permissive Sätze, Erlaubnissätze und deontische Logik." Andrej Kristan has addressed deeply the possibility of developing a whole pragmatist logic of norms analyzing the postulates of Moritz and insights taken from Ockham's philosophy. *Vid*. Kristan, 2014.

as prescriptions authorship authority is relatively simple to identify, be it the sovereign, the legislator, the judge. Nonetheless, this is counterintuitive concerning customary norms, since there is no identifiable authority or person with such pretension to make an act of prescription[13]. Even so, in their essay "The Expressive Conception of Norms" Alchourrón & Bulygin hold that the pragmatic conception would be easily adaptable to account for customary norms since their existence depends on certain dispositions revealed in specific actions. Worth mentioning, Alchourrón & Bulygin never developed such an explanation.

The task of developing such an explanation may be simple, but that the outcome can be mildly satisfactory seems doubtful. The central idea of the pragmatic conception is that, for a norm to exist, the sufficient condition is a prescriptive use of language, the utterance of a command. Thereby, to assert that we are in the presence of customary norms, we must determine which are the conditions in which the *command* may be uttered. Regarding enacted norms, it is the act of promulgation the one that creates the norm. Concerning customary norms, we can outline a possible strategy for accounting the dispositions that reveal the action that make the norm:

> Remaining faithful to the thesis that the norm is inseparable from the prescriptive use of language, then, the dispositional fact we must substitute is not the utterance of a prescriptive sentence, but the quality of the subject that makes the utterance. The subject must not have a personal pretension of authority[14] and must sustain the legitimacy of the prescriptive sentence in his epistemic capability for verifying that within the social group, there is a convergence of behavior and attitudes of mutual expectations. A plausible explanation would require the following set of events:

1. In a significant amount of the instances of *S*, a significant amount of the members of group *G* abide to conduct *C*;
2. In a significant amount of the instances of *S*, a significant amount of the members of *G* displays a criticism or reproach reaction when other members of *G* do not abide to conduct *C*;

Being conscious of the facts contained in premises 1 and 2, and being in an instance of *S*, the member of the group *G*1 predicate to members of group *G*2 the sentence "you must do *C*!".

To make the pragmatic conception hold as adequate, we would need to adopt something like H. P. Grice's *implicature* thesis. The sentence "you must do *C*!" implies that the command is backed not by any authority the issuer has, but by the existence of convergence of attitudes and behaviors of a significant amount of members of group *G* in a significant amount of instances of *S*.

The pragmatic conception departs radically from any intuition we may hold about customary norms, not only because it seems there is no plausible possibility to manifest the existence of customary permissive norms or because of the high degree of interpretative fuzziness about facts. In the case of prescriptive linguistic expressions, "customary" would be just a category

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[13] Customary norms can institute an authority (political, religious, and so on), but the norms crafted by that authority are not customary, those would be enacted norms.

[14] This does not means that in the community, there are no subjects with institutional authority. Even those communities that mainly live by customary norms have authorities. What is intended here is to maintain a distinction. If the source of a norm is the act of will of an authority, it is not a customary norms, since one of the fundamental traits that differentiates customary norms and enacted norms is that the latter are the result of an act of promulgation, the public prescription of a conduct. In the case in hand, the subject that has no personal pretension of authority is an ordinary civilian.

to describe those recurrent acts of which we are also led to suppose (to believe?) that their authors perform without a personal claim of authority, but backed up by the context.

As a general conception of norms, the pragmatic stance fails under its epistemic postulates. As Riccardo Caracciolo highlights (1997), the perennial dilemma of the pragmatic conceptions is that: "if there are only facts, the term 'norm' cannot mention any category of entities. Strictly, a 'fact' is not an entity or object" (p. 172).

B. The Eclectic Stance

Ricardo Guastini has cast doubt over the irreconcilability between the pragmatic and the semantic conceptions. For Guastini (2013), although both conceptions seem to confront with each other, in reality, each one offers an answer to diverse and partially independent questions (pp. 293 – 294):

1. Under which circumstances can we assert that as norm exists?
2. Which kind of entity a norm is?

The first question, concerning the origin of norms, would be answered by the pragmatic conception. The second, concerning the nature of the product of a process of normative production, is explained by the semantic conception.

The pragmatic conception explains the genesis of norms. Meanwhile, the semantic conception focuses on the product of the act that creates the norm. Guastini's idea is that one conception refers to the pragmatical analysis of language, while the other concerns the semantic analysis, being both complementary. In this manner, for Guastini (2013), it is possible to hold an eclectic stance in which one can assert that norms are meaning and that, nonetheless, they only acquire existence through acts of language (p. 301).

Although the eclectic conception seems attractive and plausible at first glance, it does not fulfill the irreconcilable gap between both ontological conceptions. It does not manage to give a satisfactory account of customary norms since it inherits the difficulties of the pragmatic conception as there would be no norm without normative formulation. Also, if norms are the meaning of prescriptive statements: what does that meaning refer to? What is the nature of *that* which the statement prescribes?

Furthermore, if the norm as a meaning refers to something, the existence of that something cannot depend on the creation of the sentence that refers to that something. The eclectic stance indeed highlights that we ought not to confuse the act of the creation of a normative statement with its product, where one thing is the linguistic act and another different one, the statement (the norm) that is singled out for having a normative meaning. However, those distinctions seem to have some inaccuracies that Guastini (2013) himself does not embrace, especially the one of characterizing the norms as "statement with a normative meaning" (p. 296).

In other places, Guastini (2017) has stressed that *norm* and *prescriptive statement* are not the same things, not having an identity connection, since the norm is the product of the *interpretation* of a statement (pp. 23 – 24). If the norm is the result of an act of interpretation of a prescriptive statement, it can only imply that norms are independent meanings since, as Gustini (2011) himself notices, to interpret is to assign a meaning (pp. 6 – 8). Which is the nature of those meanings or norms? That is something that the pragmatic conception and, consequently, neither the eclectic, cannot answer.

IV. Abstracts and some "Mind." As a Conclusion

In his 1927 essay "Eingentliche und uneigentliche Begriffe," Rudolf Carnap proposes a characterization of Frege's *concepts* (*Begriffe*) as functions that objects (or classes of objects) satisfy or not. Furthermore, he proposed to distinguish between *real concepts*, which refer directly to the physical reality, and *formal concepts*, like those of mathematics or logic, that do not appoint to real entities but that are essential to talk about the world (Ben-Menahem, 2006). Inquiries and debates over types of concepts continued and continue to this day. For what matters here, it is relevant to single out that "norm" or "rule" is a formal concept whose functionality is expressing how certain non-causal relations manifest in the world.

More precisely, attending to their origins, "norm" (*normae*), and "rule" (*regulae*) are words proper to mathematics, accurately, to geometry. In Latin, both words refer to tools for measuring (Tamayo, 2004). In this sense, the terms "norm" and "rule" are used descriptively in the natural language to denote that a phenomenon suit to a measure or is repeated frequently in the world, and it refers to the notion of "custom," "habit" or "the usual." For instance, the phrases: "as a norm, Mr. Kant always leaves home at noon" or "as a rule, in Mexico City traffic gets heavy around 9 am".

Regularity, assumed as a pattern, is one of the senses we capture when referring to events from which we address the existence of customary norms. However, the notion with which we work does not consist in the description, but in the prescription of behaviors that are required for specific events. By observing defection from the pattern, we apprehend a properly called "norm" when noticing the adverse reaction and also apprehend the sense of *normative pressure.* The latter is similar to Hart's (1994) critical reflective attitude that members of the group hold and that seems to suppose an expectation that coordinates the group for acting in the social world. Remembering the above-proposed scheme based on Lewis and Bicchieri, postulates 3) and 4) would be the elements that allow us to capture a customary norm in its entirety – with the factor of the *normative pressure*– in a given situation within a social group. As Ota Weinberger (1986) points out: "The social reality of norms is also indicated very clearly by the fact that behavior in conformity with norms or contrary to norms, gives rise to positive or negative social consequences" (p. 41).

The fact that we can capture the meaning of the behavior demanded by the prescription of the norm is only a part of our cognitive abilities about how the world works and the meanings of terms like "obligatory," "permitted" and "prohibited." Hence, as abstract and conceptual entities, norms never begin or cease to exist; a norm is a norm in every possible world (Caracciolo, 2008; Lewis, 1986). Norms in one sense exist like arithmetical, geometrical, and logical concepts do, infinitely. Nonetheless, we know that they meet special relations with the material world to the extent that it is proper to talk about them in certain situations and improper in others. In the case of irrational numbers, one does not say "yesterday a saw a π at the park, was nice." The phrase makes no sense, but that does not mean that "π" does not stand for something; that is, it exists in some manner. The modality in which formal concepts exist is, as conceptual functions of reality, uttered by grammatically well-formed sentences in which it makes sense to refer to those concepts. That is, we do not get to *know* formal concepts; we get to *learn* them as we develop the capacity of discerning when it is adequate to refer to them. Eventually, we get to use them without significant difficulties in our natural and scientific languages; they become comprehensible. That is possible because we use those concepts according to grammatical rules that define their significance and that adequate our shared comprehension of the world, constituted by *real concepts* and *formal concepts*.

How do we individuate, numbers, geometrical forms, or norms? Through a process of discernment of facts. We associate a certain numerical quantity by identifying that it matches with the presence of a particular amount of objects before us and that we want to distinguish from other objects that are around. With norms, we carry out a similar relational process. We have (or assume) some empirical criteria for reducing the universe of possible norms to the ones that match a certain quality (customary, enacted, legal, etiquette, belonging to the Spanish legal system, as part of the code of a private club), and that quality to specific events in the real world (Nino, 1983, Dei Veccchi, 2017). That is, one can get to know that in Sweden there is a social norm that demands not to greet strangers by observing the specific behavior of the swedes regarding that stance. On the other hand, one can get to know that in Italy there is a legal norm that forbids throwing things out from moving vehicles because there is a disposition that establishes so in the *Codice della strada* promulgated by the Italian Parliament. In another possible world the social norm of not greeting strangers could rule within the Italian society, while the norm of not throwing things out of moving vehicles most probably is legally in force in actual Sweden. The important thing to remark is that norms –as meanings– are fact-independent; but we can affirm they are in force or rule because certain facts within a population in a certain context meet requirements we associate with the norm.

So, where are formal concepts located? To a large extent, in our minds. Not as mere subjective psychological states that are not susceptible to being cognoscible. They are the result of an ability we possess, to abstract and apprehend general categories from the elements that compose our world; that is, to conceptualize. It is an ability we share and from which we build our social environment. From the world, we can calculate distances, distinguish quantities, and notice social regularities. The cerebral functions we use in those activities are identifiable, and there are scientific theories that look out to explain how we arrange that information (Dehaene, 2006; Gazzaniaga, 1985). Because of such abilities, we create abstractions that synthesize information from the material world that allows us to act upon future cases without the need to stop and reason how to deal with all the facts we find (Elster, 1978).

With such abilities we operate in our social life. Contemporary philosophy of mind has called the images that come before our minds *mental representations* or *conceptual representations*. Earlier, philosophers like John Locke or David Hume called them barely *ideas*, pointing out they were found in the mind (Pinker, 1989; Strawson 1994). There are deep debates and ongoing research about these objects and the processes our mind performs. For the present essay, what has been developed so far may be useful to explain something more about those objects that we call "norms" that rule social life, and that appertain to normative systems like law; not only when we refer to enacted norms but also customary norms. Thus, we can agree that formal concepts are intriguing because of the complex process by which we apprehend them, and although certainly, they are metaphysical, since we do not find them in the material reality, they are not supernatural; they have an explainable relationship with facts, with how we operate in the world and how we talk about it.

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