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# RESEARCH ARTICLE

# Efforts against stem cell hype stuck in the logic of overpromising?: An essay on hype-conducive ways of doing ethics

#### Anja Pichl\*,1 💿

Abstract • Studies on hype have had a strong focus on the role of science, media and markets in overstating potential benefits or risks of emerging science and technologies. Less attention has been paid to the role of ethics in creating or sustaining hype or alarmism. This research article focuses on how bioethical approaches as well as bioethicists' relationship towards science contribute to stem cell and organoid hype. How (if at all) may ways of doing ethics fuel exaggerated expectations and could ethics be done differently? Understanding hype-conducive ways of how ethicists engage with science and technology is of relevance not only for the broader ethical community but also for technology assessment and science and technology studies where an increasing interest in normative dimensions of their object of study has been observed.

Stecken Bemühungen gegen Stammzell-Hype in der Logik überhöhter Versprechen fest?: Ein Essay über hype-fördernde bioethische Zugangsweisen

**Zusammenfassung** • Studien zum Thema Hype haben sich stark auf die Rolle von Wissenschaft, Medien und Märkten bei der Übertreibung potenzieller Nutzen oder Risiken wissenschaftlicher und technologischer Entwicklungen konzentriert. Weniger Aufmerksamkeit wurde der Rolle der Ethik bei der Entstehung von Hype oder Alarmismus zuteil. Dieser Forschungsartikel befasst sich mit der Frage, wie bioethische

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© 2023 by the authors; licensee oekom. This Open Access article is licensed under a Creative Commons Attribution 4.0 International License (CC BY). https://doi.org/10.14512/tatup.32.3.66 Received: 07.06.2023; revised version accepted: 20.10.2023; published online: 13.12.2023 (peer review) Zugangsweisen sowie das Verhältnis von Bioethiker\*innen zur Wissenschaft zum Hype um Stammzellen und Organoide beitragen. Wie (wenn überhaupt) können bioethische Ansätze überzogene Erwartungen schüren, und könnte Ethik anders praktiziert werden? Ein besseres Verständnis, wie Formen der ethischen Auseinandersetzung mit Wissenschaftsund Technologieentwicklung zu Hype führen können, ist nicht nur für die Bioethik von Bedeutung, sondern auch für Technikfolgenabschätzung und STS, die ein wachsendes Interesse an normativen Dimensionen ihrer Forschungsobjekte zeigen.

# **Keywords** • hype, stem cell research, organoids, bioethics, vision assessment

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## Introduction

Is there a way to analyze and communicate current technoscientific developments, their potential trajectories and normative implications without fueling hype? The ubiquity of promissory language and high expectations both within academic and public debate of recent scientific developments and technological innovations does not exactly raise hope that there is an easy path to find. This observation applies to research on science and technology from different fields such as science and technology studies (STS), technology assessment (TA) or bioethics, even though the ways in which they contribute to hype and the challenges of how to avoid it differ. This research article critically analyzes the role of bioethics (broadly conceived) in raising exaggerated expectations with regard to stem cell (SC) research



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and organoid technology. In contrast to the role of science and media, ethicists' contribution to science and technology hype has been rather neglected so far (apart from notable exceptions such as Hedgecoe 2010; Nordmann 2007). Ethicists have often been regarded as fueling what Kristen Intemann (2022) called hype's counterpart, alarmism. Critics also pointed to the role of self-interest in funding and legitimization of ethicists' own relevance, when they overstate potential harms of emerging technologies (Vinsel 2021), which Timothy Caulfield (2016) dubbed 'ethics hype'. Albeit related conditions and incentive structures profoundly shape bioethics, this research article can't do justice to them. It focuses more narrowly on how ethical approaches themselves might contribute to exaggerated expectations and whether ethics could be done differently. Can features of bioethical approaches as well as bioethicists' relationship to science lead ethicists to succumb to a logic of overpromising - ultimately compromising their own aims?

SC research is a suitable case study because of the prominent role of therapeutic promises and efforts to work against hype both from within the scientific community as well as by ethicists and policy makers. I will sketch some key aspects of SC hype, clarify the concept of hype based on Intemann (2022) and show that, notwithstanding prominent measures against and an increased awareness of the problem of hype, it recurs in the recent organoid ethics debate. This indicates that hype cannot be avoided by means of more cautious communication alone. Instead, the relationship of ethics and science, the performative role of expectations, visions and imaginaries, (often implicit) assumptions about science and society and the sociopolitical role of bioethics itself (Lettow 2011) need to be critically analyzed and partly reconfigured in order for ethicists to avoid contributing to hype as far as possible. Ethicists' reluctance to engage in these efforts and to develop a (self-)critical attitude can be interpreted as a sign of crisis of the profession. While ethics plays a minor role in hype dynamics, its understanding is relevant not only to the broader ethical community but also to TA and STS. Here, an ever-increasing interest in normative dimensions of science and technology development has been observed (Dusseldorp 2014; Kollek 2019; Nierling et al. 2021). The closer engagement with ethical issues rightly called for in these fields could benefit from avoiding pitfalls ethicists encountered and improve bioethics by illuminating its blind spots.

### Stem cell hype and countermeasures

Hype is usually broadly understood as raising unduly high expectations or exaggerating the relevance, usefulness, reliability, safety, prospects etc. of scientific findings or technologies (Caulfield et al. 2016). Therefore, it is often regarded as either a problem of science communication (Intemann 2022), be it with the general public, science funding institutions, investors or other audiences, or as a problem of how societal and institutional conditions shape science. The latter includes factors such as pressures to publish and to develop clinical or commercial applications, media and marketing practices, public expectations and scientific bandwagon (Caulfield and Condit 2012, p. 210). Important sources of hype and misrepresentation of SC research have been attributed to the commercial sector with its direct-to-consumer advertising strategies (Petersen et al. 2017) and its "techniques of promissory marketing that offer a vision of the future that may never be realized" (Rajan 2006, p. 13) as well as to overly optimistic media portrayals of stem cells' therapeutic potential and clinical translation timelines (Kamenova and Caulfield 2015; Mason and Manzotti 2009) where regenerative therapies seemed "just around the corner" (Lysaght and Campbell 2013, p. 256).

The metaphor of scientific breakthroughs is a reliable indicator of hype (Brown and Michael 2003) and has accompanied SC research at least since the first cultivation of human embryonic stem cells (hESCs) in 1998. It still features prominently in recent scientific and media portrayals of organoid research. In his analysis of SC promises and related metaphor use, Lawrence Burns coined the term "stem cell superhero" which expresses the widespread belief that stem cells have a "seemingly 'magical' capacity to heal virtually any disease" (Burns 2009, p. 429). It also emphasizes that "to summon them we must make difficult moral choices" and exerts pressure not to hinder researchers from learning to understand and control stem cells (Burns 2009, p. 427). This exemplifies the performative character of such metaphors and related visions that also feature prominently in ethical discourse. Also visions of immortality and reversing ageing were associated with SC research and "used to invent a mandate for action" in speculative ethics (Nordmann 2007, p. 33). Stem cell promises derive part of their appeal and strength from widely shared ideas about nature and the need to gain control over biological processes in order to use the body's self-healing capacities conveyed in the "powerful image of regeneration under technological control, yet which is still being directed by nature's "own dictates" (Franklin 2004, p. 60). Ethicists often uncritically reproduced such images and metaphors, notwithstanding social science critique, e.g. of the metaphor of 'clinical translation', which suggests a one-directional transition from basic science to clinical application (Martin et al. 2008). 'Clinical translation' has also been identified as "one of the policy buzzwords of our era [...] drawing massive public and private investment into areas like stem cell research" (Lysaght and Campbell 2013, p. 255). Whether this concentration of funding was justified in view of other health needs and research interests or not, it enabled the rapid development of SC research. This provides an example of the positive effects hype can have. Apart from financial support, hype can also raise public awareness and literacy of science (Intemann 2022) and be used to involve broader audiences in ethical debate.

However, SC research doesn't seem to be one of the a-political sciences that permit "honest hype to make science public" (Nerlich 2013, p. 43). Stem cell promises fall on the fertile ground of unmet medical needs by desperate patients and relatives as well

as business actors who are keen to exploit societal expectations and hopes for cures. SC hype fosters a business model of private SC clinics offering unproven therapies for a broad range of conditions across the globe, putting patients' health and science's reputation at risk (Turner 2021). The "race to be the first nation/university/lab/scientist to unlock the (hyped up) promise of X, Y, or Z" (Nerlich 2013, p. 47) partly explains the many prominent instances of fraud as well as premature clinical translation in SC research (Daley 2012). Accordingly, more cautious communication strategies (Caulfield et al. 2016) and better public understanding of SC research (Mason and Manzotti 2009) have been called for and were introduced as a requirement of scientific integrity by the International Society of Stem Cell Research (ISSCR) in the 2016 report and retained in the 2021 update of their Guidelines (ISSCR 2021). Important efforts to improve SC science literacy and communication followed, but certain exaggerated assumptions about the state of research and the therapeutic applicability of stem cells and their derivatives seem to have become entrenched within the public imagination. This is at least indicated by the constantly high demand for unproven SC therapies and the massive increase in the number of clinics offering them in recent years in the USA (Turner 2021).

## The role of ethics in stem cell and organoid hype

But how did ethical discourse contribute to SC hype, if at all? In the early 2000s, therapeutic promises of SC research were often cited as a moral argument for funding, research-friendly regulation and for overcoming ethical quandaries in the ethical literature. In addition, the presumed therapeutic potential of adult stem cells or, after 2007, induced pluripotent stem cells (iPSCs) was often contrasted with that of hESCs in order to present the SC type that was considered ethically less or not problematic by the respective parties as scientifically more promising and ethithese factors and the dependence of hype on value judgements, instances of hype cannot be identified by empirical methods alone but require a normative concept of hype as elaborated by Intemann (Intemann 2022) in relation to science communication. She defines hype as an *"inappropriate* exaggeration [...] that depends on two sorts of value judgements: (1) judgements about the proper goals of science communication in specific contexts, and (2) judgements about what constitutes an 'exaggeration' in that context' (Intemann 2022, p. 280, emphasis in original). Hype is "likely to invoke or encourage false inferences or unreliable predictions" (Intemann 2022, p. 290) and obscures risks, whether intentional or not.

Applying this concept to bioethics (whose definition, aims and methods are admittedly contested), two goals appear most relevant for public bioethics following Adam Hedgecoe (2010, p. 165): (1) 'horizon scanning', i.e. to identify, analyze and address potential ethical issues and (2) non-legal regulation, e.g. by establishing norms of scientific conduct and processes of research oversight. Obviously, horizon scanning requires anticipation and going beyond current evidence, thus it inevitably contains a speculative element. This is problematic only if it hinders the goals of ethics according to the above. Horizon scanning must be distinguished from 'speculative ethics' that Alfred Nordmann (2007, p. 34) characterized as a "strategy which construes possibly emerging issues as if they were presenting themselves already" (Nordmann 2007, p. 34). Such an "if-and-then syndrome" (Nordmann 2007, p. 34) is also common in organoid ethics. A whole strand of debate focuses on ethical issues concerning the potential generation of consciousness in brain organoids (either in the petri dish or after transplantation into animal models). Thereby, like in the case of enhancement discussed by Nordmann, "considerations of the present are overwhelmed by the supposed imminence of a highly speculative future" (Nordmann 2007, p. 39) populated by conscious brain organoids. This constitutes a form of hype because, notwithstanding cautionary remarks regarding the speculative character of the brain organoid

Bioethics contributed directly to stem cell hype by means of ethical argumentation.

cally preferable (Lysaght and Campbell 2013). In this way, bioethics contributed directly to stem cell hype by means of ethical argumentation.

Ethicists, who are usually perceived as disinterested and credible, thus provided resonance and legitimacy to therapeutic promises of SC researchers, science journalists and biotech investors. It is, however, not enough to look for explicit overstating of therapeutic potential and time frames. Hype – as a state of exaggerated expectations rather than the act of exaggerating – can also be caused by agenda setting, emphasis, omissions, lack of contextualization etc. (Intemann 2022). Due to debate, its mere existence and dominance in the organoid discourse convey the impression that the fervently debated future scenarios will (sooner or later) become reality and other ethical issues receive less attention. Resuming Intemann's (2022) normative account of hype, it seems obvious that relevant goals of ethics – horizon-scanning and regulation – are hindered thereby.

In contrast to such forms of indirect hype, explicit hype is sought to be avoided in the recent organoid ethics debate. Ethicists explicitly reflect their responsibility for not fueling hype and call for a cautious use of metaphors and choice of terminology as well as a restrained portrayal of potential applications of organoid technology. Megan Munsie and colleagues for example state that "researchers need to avoid the hyperbole that are too often a hallmark of stem cell research and candidly discuss advances and limitations with the public" (Munsie et al. 2017, p. 944). Accordingly, they address technological limitations and challenges of current organoid research and criticize media reports for speaking of a 'miniature human kidney' "which linguistically obscures differences between organoids and organs" (Munsie et al. 2017, 942). Also, Bredenoord et al. (2017, p. 1) explicitly discuss the responsibility "to avoid inaccurate or incomplete representations and excessive expectations" in public communication and call for an "accurate, balanced, and respon-

havior of public and policy makers towards science, they are also deeply engrained and play a performative role in science itself as the sociology of expectations and other work in STS made clear (McNeil et al. 2017; Konrad et al. 2017). They shape the trajectories of science and technology development via agenda setting, coordination of activities, attraction and legitimization of funding and research interests etc. (Brown and Michael 2003). Though a critical assessment of the role of visions, imaginaries and promises is a desideratum and may reorient bioethics towards the present and actual problems (Nordmann 2007) and counteract hype, it is only rarely part of ethical analysis. A notable exception in the organoid ethics debate is a methodolog-

Significant obstacles for a broader uptake of vision assessment in bioethics seem to arise from characteristics of bioethical approaches and from the relationship of ethics to science.

sive public representation of regenerative medicine and stem cell research" (Bredenoord et al. 2017, p. 6) in line with the ISSCR Guidelines (2021). Nevertheless, in the same paper they state that "cultured organoids hold great potential for replacing damaged tissue or even complete organs, a potential that has already been demonstrated in animal models" (Bredenoord et al. 2017, p. 5). In general, therapeutic promises still play a significant role in the organoid ethics debate, e.g. as an argument to continue contested research on cerebral organoids and embryo models. Are they instances of hype and insufficiently responsive towards a public that to a considerable extent already bought into inflated promises of SC cures? Due to the openness of the research process, it is difficult to draw a clear line between hype and realistic expectations of future developments. Also, different standards of caution may apply to public communication in contrast to scientific papers, because the professional community is supposed to be able to handle promissory language better than lay audiences. However, it seems inconsistent to argue that the commitment to careful communication counts only for publications addressing the broader public, because the ethical debate doesn't take place in a vacuum and affects science and its social perception and conditions (Hauskeller et al. 2019), especially as ethicists are often perceived as neutral, knowledgeable and following high standards. Furthermore, ethicists themselves can also be misled about the likely benefits of a technology or the significance of a new research area which may distort their judgements.

## Vision assessment as a remedy?

Vision assessment (Lösch et al. 2021) has been proposed as a means against speculative ethics (Nordmann 2007). Visions, imaginaries and promises not only influence the attitude and be-

ical report on vision assessment concerning the use of organoids and organ-on-a-chip models in personalized medicine (Vogt et al. 2022). Significant obstacles for a broader uptake of vision assessment in bioethics seem to arise from characteristics of bioethical approaches and from the relationship of ethics to science.

Critics have long pointed out that and how features of ethical approaches contribute to narrowing the scope of bioethical inquiry and to a focus on potential consequences and downstream effects of scientific development (Hedgecoe 2004; Hilgartner et al. 2017) which often results in hope-, hype- and fear-debates. A narrow focus on biological entities, their (presumed or anticipated) properties and ethical issues often identified by scientists (Hedgecoe 2010) comes at the expense of more fundamental questions concerning processes of valorization and commodification of biological material, possible changes in the understanding of and relationship toward the body, social relations to nature and ways of life as Susanne Lettow (2011) pointed out for bioethical discourse in general. While leaving other sources of scientific understanding made available by historical, social and philosophical studies of science often aside, bioethicists tend to reproduce self-representations by scientists as a matter of fact and neutral basis for ethical examination.

Bioethicists thus often uncritically adopt scientists' aims and visions which obviously increases the risk of giving in to hype. In the organoid debate, an important goal and quality criterion of bioethical work seems to be to support organoid research: "[P]rocess and progress should not be hampered" (Munsie et al. 2017, p. 945) and ethicists seek to contribute to its social acceptance (Bredenoord et al. 2017). The goal of supporting scientific 'progress' and procuring public acceptance is certainly bound to ethical standards of acceptability and notions of responsible science, but most discussants do not make them ex-

plicit. Insoo Hyun (2017), for example, only specifies the goal of promoting 'scientific progress' by means of anticipation and avoidance of 'moral controversy', but does not further explain his understanding of scientific progress and underlying visions of a desirable future, the role of organoid research in building it and who might share it. Whose needs and future imaginaries are considered and in what way, whose are left out of consideration etc. is hardly ever examined in the organoid ethics debate. Instead, organoid ethicists tend to uncritically accept scientific visions and scenarios, whether they endorse or problematize them, such as the prospect of developing therapies or generating conscious organoids. Organoid ethicists even portrayed themselves as navigators who guide the development of organoid technology carefully into a seemingly separate sphere: society (Bredenoord et al. 2017). This ignores the complex and dynamic reality and intricacies of scientific development as inseparable part of social transformation processes in which ethicists are also actively involved (Lettow 2011) and the need for understanding its dynamics, conditions, framing and underlying visions, let alone for making efforts to shape them. The close and often uncritical relationship to science doesn't seem to be widely perceived as a problem within bioethics, instead, calls for a closer integration of ethics with science are raised in the organoid debate (Hyun 2017). However, it seems obvious that on this narrow basis, both goals of horizon scanning and regulation cannot be properly achieved.

# Conclusion

Measures against hype such as avoiding promises and exaggerations in the portrayal of science and combining statements of future applications with reservations concerning technical limitations and scientific uncertainty are obviously important. However, they are insufficient for preventing hype as they do not address its roots. In the ethical discourse on organoids, lessons were learned from the SC debate in terms of overt hype, but not in terms of reflecting ethicists' own attitude towards the life sciences and ways of ethical thematization that lead to 'inappropriate exaggerations' (Intemann 2022), missing the goals of bioethics. Better understanding and pulling out root causes of bioethical hype such as narrow views of science that separate it from its societal conditions and political dimensions could contribute to better bioethics. Ethicists have the responsibility to critically assess future imaginaries, visions, promises as well as dynamics and conditions of science and technology development, understand their performative role - and perhaps even use it for promoting ethically desirable developments. Methodologically, this requires critical examination and the opening up of bioethical approaches for closer cooperation with other disciplines, especially STS, TA and other strands of social and political science research and philosophy of science. It would be a practice turn that goes beyond merely integrating ethics with science.

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