Queering Vulnerability: A Layered Bioethical Approach

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Abstract

Vulnerability is a concept often used in bioethics. However, it is seldom interrogated from a queer point of view. By queer inquiry, I refer to an umbrella understanding of gender and sexuality as diverse. In this article I discuss lesbian, gay, bisexual, trans, queer and intersex -related (LGBTQI) approaches to vulnerability. Framing these discussions from queer and LGBTQI bioethical theory, I offer an original approach to vulnerability based on queer bioethics and on a layered understanding of vulnerability. After considering queer bioethics and its (queer) critiques, I conclude that a layered understanding of vulnerability has strong potential for analyzing LGBTQI/queer vulnerabilities in bioethics. For further research, I formulate four layers of queer vulnerabilities to demonstrate some of that potential. I call these the layer of ethical sustainability, the layer of queer agency, the layer of interrogatory intimacy, and the layer of troubled kinship. I insist all layers should be critically evaluated and developed further with intersectional approaches.

Keywords: Vulnerability; LGBTQI; Queer Bioethics; Queer-Feminist Anthropology of Vulnerability; Layers of Queer Vulnerabilities

Introduction

In this this article, I discuss queer/LGBTQI vulnerability in bioethics. Following a discussion on queer and LGBTQI bioethics from a theoretical viewpoint, I focus on the concept of vulnerability and concur with the layered approach formulated by Florencia Luna. In my treatment, queer bioethics refers specifically to the theory of Lance Wahlert and Autumn Fiester. LGBTQI bioethical approaches, however, vary in background theory, meaning that while some overlap with queer bioethical theory and methodology, but they might also contradict their premises, such as the element of normativity present in Wahlert and Fiester's queer bioethical inquiry. The search for ethical

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normativity in queer bioethics may also contradict other queer theoretical approaches. Even though the relation between normativity and queer is complicated, the only way to solve that complexity is not, in my view, to demand that all queer theory applications must be categorically non-normative.

Despite these tensions, I use both the terms LGBTQI bioethics and queer bioethics to refer to critical inquiries focused on increasing LGBTQI rights in medicine. However, they are not interchangeable as queer bioethics always refers to a specific theory in my treatment. On another conceptual note, I use the term ethics to refer to a loose set of values and practices whereas the term moral theory refers to a systemic study of these set of values structured within the discipline of philosophy. I do not intend this article as a contribution to moral theory *per se*, albeit I do see that queer bioethics could be further elaborated as a moral theory. Those further elaborations, however, are excluded from this article. On a final conceptual note, following Wahlert and Fiester, I use the term queer identity to occasionally refer to queer agency in medical encounters, systems and policies, although not all queer theoretical approaches agree with this. Further, I use the term queer identity interchangeably with LGBTQI identity as an umbrella term (unless mentioned otherwise).

Based on Luna's account, I promote a layered understanding of vulnerability: that groups like women or LGBTQI *are* not vulnerable but can be *rendered* vulnerable. Although in bioethics, according to Luna among others, traditional analyses and uses of the concept of vulnerability mainly stem from research ethics, I agree with Luna (2009: 133) that the layered notion of vulnerability is a fitting approach not only for research ethics but for other areas of bioethics, and also for multidisciplinary approaches like mine. Ultimately, I suggest that through queer, layered vulnerability we can seek to improve bioethics and multidisciplinary understanding of queer agency, gender and sexual diversity. I will close by offering some directions for further research.

### Making bioethics more ethical

Vulnerability has been one of the concepts through which the ethicality has been subjected to critical inquiry. Bioethics can be defined as a field of philosophy invested in ethical inquiry of social sciences and bio-sciences, using both theoretical and pragmatic tools. According to Arthur Kleinman (1999: 70–71) bioethics is confronted with an extraordinarily difficult quandary: how to reconcile the clearly immense differences in the social and personal realities of moral life with the need

to apply a universal standard to those fragments of experience that can foster not only comparison and evaluation but also action. For philosophers, says Kleinman, the gulf between the universal and the particular may be regarded as 'an irksome and perennial barrier'; but bioethicists, like clinicians and policy implementers, simply cannot function without finding a way of relating ethical deliberation to local contexts. To Katherine Dow (2016: 14), one particularly important point that Kleinman makes is that the critique of universalism in bioethics is to suggest that if bioethicists were to attend to some of the findings of social scientific research, this could inform, and therefore strengthen, bioethical analysis, policy, and practice –and, by implication, 'make it more ethical'.

Dow (2016: 15) urges a critical glance over the individualism inherent in bioethics and the difficulty it has had with conceiving of ethics in a way that accounts for more communitarian values and experiences, which in her view reflects a stereotypical picture of people in Western countries as being primarily self-interested. To Dow, this debate points to a division between ethics as a constant process of self-fashioning and lived practice on the one hand and ethics as a set of codified principles governing a particular profession or practice on the other. In her view bioethics, by its very nature, is required to prioritize principles over practices, which can mean failing to fully recognize the fact that professional ethics and the wider ethical values and practices of the societies in which doctors and researchers operate are inseparable. Paying homage to vast feminist thought on situated knowledge, Barry Hoffmaster (2009: 1–2) believes in bioethics that is 'situated in lived human experience'. He also draws attention to the importance of emotions in ethical decisions:

Putting bioethics in personal, social, and cultural contexts opens the way for modes of moral deliberation that are not general, rational, and impartial but that embrace the distinctive histories, relationships, and milieus of people and engage their emotions as much as their reason. Such a bioethics also recognizes the multiple backgrounds—institutional, economic, historical, and political—that structure moral problems and give meanings to moral concepts. This is a bioethics situated in lived human experience. The ultimate goal of this endeavor is a bioethics that is more attuned to the particular and more sensitive to the personal—a bioethics that is more humane and more helpful.

Hoffmaster (2009: 1-2)

Dow (2016: 16) persists in that bioethicists along with policymakers and regulators need to understand that context is not a euphemism for mitigating circumstances but instead a way of attuning oneself to the contingent realities of people's lives. Nonetheless, bioethics can be seen to have taken an empirical turn, assisted by figures like Daniel Callahan, cofounder of the Hastings Center (that

published one of the first special reports on queer bioethics in 2014), giving greater attention to what Dow calls 'alternative moral positions within bioethics'. Whilst Dow (2016) urges bioethicists to attend to other moral worlds and try to develop models that take account of the multiple interests that may be at stake in any particular ethical decision, they should not assume that moralities could be read from laws or professional codes of conduct, or that moral philosophy is in effect ethical. Moreover, Dow sees bioethics per se as shaped by its context; the 'bioethical' aspects of particular practices and objects are not self-evident but the product of specific socio-political contexts and professional agendas of their time (Wilson 2011: 213). On this note, Dow urges us to consider what makes certain bioethical practices and issues worthy of our ethical attention –and, by extension, what makes others unworthy of such attention. Traditionally, issues of gender and sexuality have been in the latter category. Despite the empiric turn acknowledged by both Dow and promoted by prolific research centers like Hastings, and as gravely pointed out by Wahlert and Fiester, Jamie Nelson, and J.R. Latham, LGBTQI issues have not been given the bioethical attention they require, due most importantly to the cis- and heteronormative bias in the so-called mainstream bioethical contemplation. Unequivocally, this means a myriad of LGBTQI suffering has been ignored and forms of human flourishing have been violently suppressed. For example, practices such as genderbehavioral therapy for gender non-conforming people (cf. Honkasalo 2016; Honkasalo 2018), unnecessary invasive procedures on intersex babies (cf. e.g. Feder 2009) and various religiously-motivated 'therapies' that allegedly alter one's sexual orientation are more accurately described as torture rather than just unethical treatment.

A notable effort in current bioethical inquiry is dedicated to subverting professional power on and increasing public awareness of LGBTQI bioethical issues. Still, however, bioethical debate lacks the polyphony of voices present in other fields. A crucial area of potential marginalization is gender and sexual diversity. During the last decades, LGBT bioethics has been accompanied by queer bioethics combining queer theoretical understanding to bioethical analyses, aiming to increase visibility of and finding solutions to LGBTQI specific issues. Queer bioethics builds on medical humanities and a critical approach toward politics of medicine. Hence, queer bioethics is attuned to the core of queer advocacy: it promotes active involvement in debate on the ethics and moral conceptions in medicine and biosciences. Queer bioethics aims to highlight the political aspects present in the formulation of any ethical principles by unlocking historic contexts and complex dependencies that usually go undetected in bioethical inquiry. Injecting bioethical debates with awareness of normative power and its effects on people whose experiences and existence do not comply with

heteronormativity, a cornucopia of enhanced human flourishing becomes imaginable. Thus queer bioethics does not only serve LGBTQI communities, even though their needs undoubtedly have been ignored in the past.

One theoretic approach to human sexuality and gender variance is to consider them processual and contingent. Queer thinking that critically addresses the complexities of normativity is needed for making changes, understanding diversity, dismantling injustice, and enhancing bioethical justice. According to Nelson among others, mainstream bioethics has not been able to resolve ethical issues in LGBTQI health care in theory or practice. It has not adequately established queer agency or subverted the cis- and heteronormativity of practices (Nelson 1998; 2012; Murphy 2015.). Indeed, LGBTQI and queer bioethical inquiries were marginalized for decades. One persistent example is the question of transgenderism or transsexuality as a psychiatric disorder that has been critiqued by trans human rights activists for decades, another could be accessibility to affordable HIV/AIDS medicine, a third the risk of being denied basic or even life-saving care from a medical professionals who conscientiously objects to treating LGBTQI people, a right guaranteed by law in some states of the U.S.

In the 21<sup>st</sup> century, queer bioethical debate has been established as a consistent field of inquiry frequently present in prestigious mainstream journals like *Bioethics* (see Wahlert and Fiester 2012; Murphy 2015; Richie 2016; Leibetseder 2018). Even though this can be considered a breakthrough in its own right, it must be acknowledged that current prominence has been made possible by decades of systematic queer and LGBT thought and research with often marginal material resources—the latter still very true today. (Kähkönen and Sudenkaarne 2018: xiv.)

Queer bioethics utilizes interdisciplinary methods from, for example, medical history, philosophy, and narrative research. Interdisciplinarity includes the aim to build dialogue between biosciences and humanities. Wahlert and Fiester (2012) name challenging the politics of normativity and revealing discriminative and unjust practices in healthcare as the central aims of queer bioethics. Wahlert (2016) describes the queer bioethical approach as a way of examining the pressing ethical issues that lie at the intersection of gender identity, sexuality and bioethics. At its core to him are bioethics-related challenges facing LGBTQI persons, and questioning their encounters within the medical system. An integral part of queer bioethics is the appraisal of canonical bioethical concerns bearing in mind queer perspectives. (Kähkönen and Sudenkaarne 2018: xiv.)

# Queer bioethical theory and methodology

Wahlert and Fiester (2014; 2012: 2–3) further define queer bioethics as a recently explicated field of bioethics focusing on questions related to LGBTQI people. Topics of queer bioethical interest can include, for example, ethical transition treatment for trans people, bodily integrity of intersex babies, reproduction justice for same-sex couples, or queer hospice care. However, as Wahlert and Fiester (2014: S6; 2012; cf. Dean et al 2016) crucially point out, whilst interest in LGBTQI healthcare aims to highlight important gaps and bring into relief serious LGBTQI issues, such work can inadvertently reinforce both the marginalization of sexual minorities and the cultural norms related to sexuality, gender identity, and the conventional family. To ensure that positive outcomes for LGBTQI patients are essentially paired with real ethical sustainability and decreased marginalization, Wahlert and Fiester advocate for queer bioethics as a methodology of scholastic, bioethical, and critical scrutiny. They set queer bioethics to address both the needs of LGBTQI persons in a healthcare environment but also to consider the perspectives, histories, and feelings of such parties. Further, they see queer bioethics as a specific field of bioethics targeting questions, both historic and present, of sexuality and gender with a norm-critical approach. It identifies LGBTQI people as specific bioethical agents, which Wahlert and Fiester (2012: iii) also call the injection of queer personhood into bioethics. Queer bioethics has two simultaneously operating prongs. On the one hand, it focuses on LGBTQI specific questions, interrogating how and why gender and sexuality are produced and reproduced, critically deconstructing them with the analytical tools of cis- and heteronormativity (cf. e.g. Sudenkaarne 2018b). On the other, it also interrogates why and explains how questions of gender and sexuality are questions of humanity per se and life as we (think we) know it. As recent scientific advances have broadened our understanding of, for example, the non-binary number of chromosomes affecting gendered physiology, or of how many so-called biological parents one can potentially have (cf. the three-parent baby technique, on which see Reardon 2017), it is becoming unequivocally apparent that past-century sexual and reproductive ethics need a 'queer injection' simply to be able to compute contemporary bioethical debates.

Wahlert and Fiester (2012: iii–iv) define queer bioethical aims as placing sexuality and gender identity at the core of ethical discussions brought about by advances and renegotiations of normality in biology and medicine, placing the so-called less powerful central stage, challenging the status quo and the presumptive legitimacy of the normative, and challenging LGBTQI complacency in the face

of injustice and discrimination in medical encounters, systems, and policies.<sup>ii</sup> Last but not least, they define queer bioethics to serve as a moral theory.

I find queer bioethics to indeed have moral theory potential. I suggest it could join forces with feminist bioethics and underlying feminist philosophy to laudably interrogate the notion of bioethical normality: its construction, reconfigurations, and effects on practices, politics, and bodies. As a moral theory, queer bioethics could re-evaluate the classic bioethical principles by looking at cases of gender and sexual diversity to see if there is a need to revise the respect of autonomy, nonmaleficence, beneficence, and justice (on these principles see Beauchamp and Childress 2009; on their feminist reconfigurations see Donchin 2001). One of the key questions for queer bioethical moral theory could be to evaluate whether LGBTQI bioethical practices and legislation respect the classic principles of bioethics. Further, if there are infringes on these principles, are they more likely when LGBTQI issues are concerned (as Wahlert and Fiester, Nelson, Latham, and I suggest)? Last but definitely not the least, queer bioethics as moral theory begs the question of why those infringes persist. In this framing, queer bioethics can be bestowed with both a theoretical and practical aim. Several bioethical cases need to be analyzed with its methodology while simultaneously inquiring further into its moral theory potential. However, further inquiry into queer bioethics as a moral theory falls outside the scope of this article. Suffice it to say that it needs to be completed with metaphysical and epistemic inquiries into bioethical background philosophies and crucially accompanied by feminist intersectionality (see also Sudenkaarne 2018a).

Wahlert (2016) describes queer bioethical methodology as examination of the pressing ethical issues that lie at the intersection of gender identity, sexuality, and bioethics. At its core are bioethics-related challenges facing LGBTQI persons, questioning their encounters within the medical system. To him, an integral part of queer bioethical methodology is the appraisal of canonical bioethical concerns bearing in mind queer perspectives. In queering bioethics, Wahlert wishes to introduce the traditional queer theoretical concept of queering or queer reading into medical ethics. This means the employment of methodologies from queer activism and theory when defining ethical practices in medicine. (ibid.)

Wahlert (ibid.) sees queer bioethics as improving medical practice for LGBTQI people, or 'the queer in the clinic' as he refers to the LGBTQI bioethical patient zero, in three different realms. In terms of clinical practice, queer bioethics ushers in appreciation of queerness as central or valuable to a clinical situation, demands an acknowledgment of queer populations as worthy, and creates a greater tendency not to generalize or to stigmatize. In clinical outreach, queer bioethics can shed light to the need of population-specific resources beyond the clinic referring to, e.g., social services

for LGBTQI persons that should be integrated into clinical practice. Continuity of care for LGBTQI persons must be guaranteed, thus replacing the attitude of suspicion with clinical comfort. Wahlert persists that queer bioethical analyses can enrich clinical training by offering ways for integration of queer patients and families into the canonical fold, with an ethical mindfulness of the complications of queerness in clinical encounters. (ibid.) For achieving this clinical comfort and to enhance queer understanding in bioethical thinking, Wahlert and Fiester (2014: S62) have formulated a methodological tool they call the queer bioethics inventory (Table 1). The inventory is to be used in clinical encounters but also in theoretical, metalevel analyses of bioethical case studies. Acknowledging that even the most sympathetic and well-intentioned cases that include either LGBTQI or queer-related content can decrease bias about sexuality and gender nonconformity in medicine, the inventory helps to approach such bias methodologically. Its set of questions aim 'to better scrutinize the efficacy, legitimacy, and impartiality of cases we use in bioethics (ibid)'. The inventory is intended for both clinical and theoretical use to better attend the needs of LGBTQI parties in the clinic and in biosciences, by not merely dwelling on the presence of queer people in bioethical cases but by offering a queer analysis. I will later discuss the list in more detail and suggest it as a basis for formulating layers of queer vulnerabilities. First, however, I wish to consider queer thinking opposing queer bioethical thought.

# Critical Responses to queer bioethics

Some see queer bioethics as primarily too attentive to sexuality and gender identity, and the intersections thereof, rather than what Cristina Richie (2016) calls upon: providing an alternate account of bioethics from a queer perspective. She criticizes queer/LGBTQI bioethics for focusing too much on reproduction, for example, equality in accessing ART. According to Richie (2016: 367), the general rebelliousness and iconoclasm of commonly accepted scripts, values, and beliefs that characterize the defiant attitude of queer studies should typify queer bioethics as well. She insists queer bioethics should first and foremost build on rejection of heterofuturity (the idea that all fathomable futurity is integrally bound with hetero-reproduction), referring to the historical connection between compulsory heterosexuality and biological reproduction. (Kähkönen and Sudenkaarne 2018: xv.)

To Richie (2016), in a most drastic departure from the ethos of LGBT studies, queer studies tends to view biological reproduction as one of several 'distasteful', overlapping axes of power, along with capitalism, conformity, and even marriage, which must be rejected in order to maintain a radical

stance that exemplifies queerness itself.<sup>iii</sup> For many queer theorists, rejecting both biological reproduction and its attendant goals of heterofuturity is an essential part of queer identity and practice. Some see queer lifestyles radically negative by design. Richie's view draws from the 'antisocial' strand in queer theory (see e.g. Edelman 2004). Richie (2016: 368) notes that it should not be assumed that biological parenting has value for all people, or any people, inclusive of queers. She admits that while reproduction can be a significant part of one's life, queer should offer a competing discourse to the assumption that reproduction is a focal part of everybody's life plan. Secondly, since heteroreproduction is repudiated by queer studies, bioethical banter need not to unduly waste time promoting reproduction. Richie urges applying queer approaches to other areas of bioethics rather than reproduction (Kähkönen and Sudenkaarne 2018: xv).

Richie sees that queer bioethics with little to no investment in unborn humans can upend the anthropocentric discourse by expanding the sphere of ethical consideration to all creatures sharing our planet. Constructing alternative communities is familiar to queers who are accustomed to forming families beyond heteronormative kinship configurations. Queer environmental bioethics challenges the pursuit of carbon intensive individual life projects and prefers an interconnected model, whereby those who have been marginalized, including ecosystems, are embraced. Furthermore, to Richie queer bioethics need not rest on the assumption that climate justice must only occur when one's own descendants are imperiled. Queer bioethics should rather bolster support for conservation on behalf of those currently alive, and the next generation, which we have no genetic association with, 'demanding a nobler ethic removed from biological fetishism'. (Richie 2016: 368–369; Kähkönen and Sudenkaarne 2018: xv)

Richie's third critique is to galvanize the intersectionality of crip studies into queer approaches to life. LGBT bioethics often dovetails with disability critiques of the medical industry that tends to problematize normal human variations as deviant. Queer bioethics should resist colonization of queer bodies by interrupting generally accepted notions of medical desirability, health, and disability. Moreover, queer bioethics challenges medical etiology, diagnosis, and prescription. Medical solutions to disability and queerness tend towards white, middle-class heteroreproductive, able-bodied paradigms and conform to gender, age, and class scripts. Both 'crips and queers' are subversive in articulating what patients ought to value in medical intervention. (Richie 2016: 369–370; Kähkönen and Sudenkaarne 2018: xv–xvi)

An argument countering the negative reproduction approach is to suggest that reproduction must remain at the core of inquiry precisely to enhance LGBTQI intersectionality within itself. Reproduction is also a canonical bioethical concern, the queer investigation of which Wahlert called for. Doris Leibetseder (2018: 139) agrees with Richie that although compulsory reproduction and heterofuturity are key targets for queer bioethics, futurity and even a utopian vision is crucial for queer and trans people (and also in general for people) of color, for whom the struggle to be able to survive is not a question of fulfilling one's life plan. Instead, in Giorgio Agamben's terms, it is a question of *bare life* facing forms of extreme suppression, including reproductive injustices. To Leibetseder, rejecting heterofuturity and assimilation does not necessarily mean that there should be no queer futurity (of color). She sees queer practice seeking to demolish hierarchies and discrimination, which can be equally true in queer reproduction, challenging the norms of who is allowed to reproduce. For Leibetseder, the question of what kind of babies are allowed to be born is the one in most dire need of queer analysis, as assistive reproduction outcomes can be either non-normative or normative. (Kähkönen and Sudenkaarne 2018: xvi.) I agree that investigating reproduction is indeed categorically queer-bioethically inappropriate.

Queer reproduction should further be discussed in relation to race, class, and citizenship with an intersectional approach. On a critical reproductive note, Leibetseder (2018: 143) cautions that if queer and trans people and people with disabilities are using assistive reproductive technologies, the biocolonialism imbedded in these technologies must be carefully navigated. Necropolitics—the interplay between death and violence—established by Haritaworn et al (2014) is to Leibetseder a form of biocolonialism in queer reproduction. An example of queer necropolitics in queer reproduction is Michael Nebeling Peterson's (2015: 100; see also Leibetseder 2018: 144) analysis of a gay couple's transnational surrogacy arrangements. Nebeling argues that the vitalization of the gay man by enrolling into the heteronormative imperative of reproduction rests upon a devitalization of racialized, classed, and gendered others (the surrogate). Undoubtedly, race, class, and citizenship play a pivotal role in shaping queer realities and can serve as excellent conceptual platforms for queer bioethical inquiries to achieve approaches more sufficiently attuned with crip-theoretical understanding of intersectionality. (Kähkönen and Sudenkaarne 2018: xvi–xvii.)

Another key critique suggested by queer scholars is to question the role of normativity in Wahlert and Fiester's queer bioethics, as queer scholarship to some is by definition non-normative. However, as one of the central aims of queer bioethics is to improve existing medical ethics, it must be

able to compute normative claims in order to achieve ethical relevance. Albeit formulating queer bioethics as a moral theory is outside the scope of this article, I suggest encompassing this normativity is to build on the bioethical approach of principalism, a view that bases ethical analyses on certain principles, such as justice. Keeping in mind Dow's critique of principalism—that principles can mean failure to fully recognize the fact that professional ethics and the wider ethical values are inseparable—I suggest a principalist account of bioethics could coincide with queer bioethics under two conditions. Firstly, the principles cannot include hetero- and cisnormative fundaments, as currently is the case in medical ethics of sexual and gender variance. Secondly, the fulfillment of the principles must be critically informed by lived experience. That is, for example, trans people must be consulted when establishing the non-maleficence, beneficence, respect for autonomy and justice of their care in order for such contemplations to have any true ethical relevance.

To tackle its main critique from the so-called mainstream bioethics, queer bioethics is not a rights only position trying to justify minority claims. In Dow's vocabulary, the queer context is not a euphemism for mitigating circumstances but instead a way of attuning oneself to the contingent realities of LGBTQI people's lives. Formulating a queer bioethical, layered approach to vulnerability does not entail reformulating LGBTQI subjects and agency from a vulnerable population's viewpoint by throwing slightly more attuned accounts of specific LGBTQI issues as labels into the mix. By evoking the concept of layered vulnerability, I wish to strengthen queer bioethics as, in Hoffmaster's words, a bioethics situated in lived human experience, or, in feminist vocabulary, situated knowledge. Like Hoffmaster, I see the ultimate goal of this endeavor to be an ethical account that is more attuned to the particular and more sensitive to the personal—a bioethics that is more humane and more helpful. In the big philosophical picture, such sobering treatments should also lead to interrogating other unjust metaphysical and empiric practices that cloud ethical analysis (cf. Latham 2016; Barad 2007), thus ultimately making them 'truer' to the particularities and weaknesses of the world (Luna 2009: 134–135).

Vulnerability: a layered approach

Vulnerability has been a topic of queer and feminist concern across disciplines and from different schools of thought (e.g. Hollibaugh and Weiss 2015; Dahl 2017; Ahmed 2004). Judith Butler (2016)

considers how vulnerability is framed to individuals as a disempowering character trait. However, vulnerability to Butler is not simply a matter of ontology, but rather characterizes a relation to a field of objects, and passions that impinge on or affect us in some way. In other words, vulnerability is based on social relations, and can be contextually contingent. Butler notes that in minority groups there is sometimes animosity to those who establish themselves as vulnerable, as this may unwittingly buy into paternalistic power structures. In Butler's (ibid) analysis of activists, vulnerability can be a political, ontological, or existential category, and people can debunk it as one while simultaneously accepting it as another.

Despite the virtue of the approaches that could perhaps be dubbed a queer-feminist anthropology of vulnerability, the bioethical understanding of vulnerability stems from a notably different tradition, emerging alongside research ethics in the dawn of bioethics in the 1970's. Luna (2009: 122) discusses how this understanding of vulnerability has not been favorable to people considered vulnerable. To her, vulnerability is a concept of special interest to women. Women are sometimes considered a vulnerable group and at other times, removed from such a group. To Luna, labelling women or any group simply as vulnerable is too simplistic and a potential source of grave moral harm. After acknowledging accurate critiques of the concept of vulnerability, Luna persists that the concept of vulnerability should not be rejected but redefined instead.

Similarly to Butler in ethos albeit not in underlining theory, to Luna (2009: 123) the majority of conceptions of vulnerability fail when they perceive vulnerability as 'being vulnerable'—for example, women being essentially vulnerable rather than 'being rendered' vulnerable in certain conditions with certain resources—so that vulnerability becomes a fixed label on certain subpopulation. This includes assuming that there are necessary and sufficient conditions that populations must fulfill to be considered vulnerable. If so, as a consequence, being vulnerable becomes a fixed label on particular subpopulations. Luna calls this approach the metaphor of labels. When vulnerability is used as a fixed label on particular subpopulation, it suggests a simplistic answer to a complicated problem. (See also Uusitalo in this issue.) To address the subject's vulnerability, more than one answer may be needed. Different types of vulnerabilities can overlap, and they should all be adequately considered. Finally but importantly, labeling fixes contents, and labels do not come off easily. (Luna 2009: 124.)

To Luna (2009: 128), then, it becomes necessary to provide an analysis of vulnerability that does not render it vacuous, rescues its force, and avoids some of the most morally grave flaws of labelled vulnerability. She is adamant that trying to fix the concept by searching for necessary and sufficient conditions for who is considered vulnerable. I agree. I further concur that a better strategy for ethically more sustainable, humanely robust, and pragmatically useful results is to understand the concept of vulnerability dynamically and relationally. For these ends, Luna introduces the concept of layers. The metaphor of a layer gives the idea of something that may be multiple and different and that there might be different, overlapping layers; some of them may be related to health and others to work, keeping to my previous example. To Luna, the idea of layers gives flexibility to the concept of vulnerably which she exemplifies by discussing women. In Luna's example, it can be said that being a woman does not, in itself, imply that a person is vulnerable, but in a country intolerant of women's reproductive rights, a woman acquires that layer of vulnerability. If she is poor and illiterate, she has two more layers of vulnerability. Therefore, we should not think that someone is vulnerable, but instead consider a particular situation that makes or renders someone vulnerable, which does not mean categorical lack of power. (Luna 2009: 129.)

It is crucial to recognize that the notion of necessary and sufficient conditions in LGBTQI bioethics is problematic in more ways than in relation to vulnerability. Even though I agree with Luna that vulnerability should not be considered as necessary and sufficient conditions, I urge it must be more widely acknowledged how the so-called mainstream bioethics relies on cis- and heteronormativity as a necessary condition in ethical analyses. This often results in non-acknowledging infringements on basic rights and bioethical principles (cf. Nelson 1998; 2012). To offer a brief example on how to interrogate ethical reasoning for cis- and heteronormative fundaments, I suggest, following Wahlert and Fiester, that we look at canonical bioethical concerns bearing in mind queer perspectives, such as sterilization<sup>iv</sup>. Finland is one of the countries to demand medical proof of hormonal sterilization in order for a transgender person to be eligible for a different legal gender status (see also Honkasalo 2018; Repo 2018). However, if a cisgender person without any medical necessity would like to receive sterilization because they never wish to have children, the law prohibits this procedure from those under the age of 30 with less than three children. It is precisely juxtaposing practices like these that should be subjected to queer bioethical analyses, in which I suggest the key sense-making element is cis- and heteronormativity as the necessary condition. However, even though there are such fundaments to be found in bioethical analyses and sense-making, it is important to note that they are (or in fact, it could be that only cis- and heteronormativity is) necessary conditions in the

ethical analyses and do not define or label individuals or groups *per se*. Further as introduced by Leibetseder (2018), such inquiries should be further examined in relation to race, class, citizenship, and ability.

Moreover to Luna (2009: 134), a layered understanding of vulnerability challenges idealized views of the neoliberal subject and agency, as the most serious shortcoming of the rigid vulnerability approach is to treat vulnerability as a label affixed to a particular subpopulation. In Luna and Vanderpoel's (2013: 326) account, targeting subpopulations with the labeling strategy is to assume a baseline standard, or a paradigmatic subject: a mature, moderately well-educated, clear-thinking, literate, self-supporting person. Further, the subpopulation approach assumes the possibility of identifying vulnerabilities in subopopulations as variations to the paradigm. A consequence of the categorical model is a simplistic answer to a complicated problem, as a person or a group of persons can suffer differ kinds of vulnerabilities. The label approach understands vulnerability as a theory for targeting a permanent and categorical condition that will persist throughout the person's existence. Thus, subpopulation analysis can lead to an overtly rigid and fixed perspective. In contrast, if vulnerability is viewed as layered and dynamic, then there is no single feature that in and of itself defines vulnerability, no solid and unique vulnerability can exhaust a category and most importantly, no single feature can suffice to explain it entirely. (ibid.)

#### Queer bioethics inventory and layered vulnerability

I suggest the queer bioethics inventory by Wahlert and Fiester offers some feasible departures on establishing a layered queer bioethical vulnerability, always distinct from the subpopulation sense so often still adopted in researching LGBTQI specific bioethical issues. The layers I establish here neither are ubiquitous for all vulnerability analyses nor are they numbered in an ascending order by importance. The layers I have drawn from the queer bioethics inventory are those of troubled kinship, the layer of queer agency, the layer of interrogated intimacy, and the layer of ethical sustainability. They may operate as overlapping, but keeping in mind Luna's anticategorical understanding of vulnerability, I find it would not be feasible to formulate rigid, juxtaposed categories. Further, as Luna points out, identifying the layers should be based on the context, making it ill-advised to consider certain layers as categorically more appropriate than others. For example, the layers of troubled kinship, queer agency, and interrogated intimacy may all play a part in infantilizing the queer subject, despite the fact that there is a specific question in the inventory about infantilization. These

anticategorical layers should not be used for labelling individuals or groups *per se* vulnerable in the sense of trying to find *the* criteria for making a subgroup vulnerable. Luna and Vanderpoel's (2013) application of a relational and layered account of vulnerability in their case study of cord blood banking has inspired my approach. I will not be able to offer an exhaustive case analysis of all the layers in this article, but hope my treatment will inspire further discussion of using queer bioethics inventory for vulnerability analyses.

Under the layer of troubled kinship, analysis can focus on asking if the case in question honors the diversity of families and relationships across and within the LGBTQI population, or alternatively, does it prioritize heterosexual marriage or the heteronormative family of origin. Does the case omit, exclude, or dismiss important characters—such as partners, lovers, or caregivers? By these two questions in the inventory, I suggest Wahlert and Fiester wish to highlight the fact that queer kinship often suffers disrespect in medical encounters, systems, and policies. A very common context for analyzing this are cases of decision-making surrogacy: even when the patient has undisputedly identified their partner as their surrogate, the partner is overridden by the biological family if their opinions clash, even when medical professionals have no legal obligation for doing so (when there is legal recognition for their kinship) (see Wahlert and Fiester 2014: S60-61). Further, however, Wahlert and Fiester promote acknowledging the various forms of closeness that fall outside the nuclear family model, be the partakers LGBTQI or not. For example, a friend who is a daily caregiver can have far more insight into the patient's care than their biological parent, and this valuable insight should not be dismissed.

On a metaethical note, it is evident that medical ethics prioritizes heterosexual marriage and heteronormative reproduction over other forms of kinship (see e.g. Mamo 2007; Sudenkaarne forthcoming). These priorities are at the core of explaining why cis- and heteronormativity have become and persist as, albeit unintentionally at times, the necessary conditions in medical ethics and bioethics analyses. Therefore, the layer of troubled kinship may be closely connected to the layer of ethical sustainability. Even though all the layers are obviously useful in research ethics and for interrogating ethical sustainability, this layer includes the metaethical component for analysis of cis- and heteronormativity through kinship, an area where gender and sexuality come together for cis- and heteronormative purposes seemingly so seamlessly. By calling this layer troubled kinship I want to call attention to the fact that there is no logical but only a cis- and heteronormatively biased way of valuing these kinships; if, for example, the family of origin is favored over a partner in a legally

valid queer marriage for decision-making surrogacy, the medical staff's kinship logics are indeed troubled. Further, however, this layer refers to the long research tradition of conceiving queer as something that troubles—subverts, upsets, and interrogates—cis- and heteronormative discourses and practices.

The second layer I suggest can be drawn from the queer bioethics inventory and used for establishing queer vulnerabilities is the layer of interrogatory intimacy. This includes asking if the case has implicitly or explicitly made value judgements on types of sexual relationships: same-sex, crosssex, monogamous, open, or promiscuous. Further, the scenario of the case may conflate 'safe' or 'safer' sex with monogamy or abstinence. The case can also function as a type of bioethical voyeurism, overtly scrutinizing the sexual lifestyle choices of queer persons beyond clinical or ethical relevance, as heteronormative discourses have a long history of an assumed entitlement, or even a mandate, to scrutinize the intimate life of queer persons. (Wahlert and Fiester 2014: S60). This not only includes prioritizing some forms intimacy over others but also promoting some forms of sexual activity over others as safer against medical fact; for example, unprotected anal sex is often associated risky mostly with gay men. However, unprotected anal sex is just as risky between cisgender, heterosexual married couples if the other is not monogamous; there is nothing in cisgender, heterosexual marriage that protects against HIV per se. Obviously, the unsafe sexual act is unprotected anal sex (due to a higher risk of small tears), and its safer form is not heterosexual anal sex but protected anal sex. According to Wahlert and Fiester (2014: S59), medical professionals continue occupying the role of sexual authorities in deciding sexual morals like these. They observe that clinicians are often guided to ask sexuality-related questions in a way that is as seemingly nonjudgmental as possible and in a manner that distinguishes between the behavior and the person. However, Wahlert and Fiester analyze how through innocent implications, anti-queer moral judgements are foisted into medical ethics. To Wahlert and Fiester, following the non-judgmental advice would reveal the clinician's true views on promiscuous, i.e. same-sex, activity, as she would admit that there will be a limit to how nonjudgmental a physician can actually be in the face of such untoward behavior. Clinicians should hold themselves accountable to being only 'as nonjudgmental as possible', in other words, as is humanly possible given the circumstances. To Wahlert and Fiester (ibid.), this message is reinforced by drawing a distinction between the behavior and the person, which to them echoes the notorious hate- the-sin-love-the-sinner argument used for gay Bible bashing. Further according to them, such a distinction can be made only against the backdrop of a profoundly negative judgment about the behavior itself. Moreover, the dichotomy reinforces a moral

critique of the activity as warranted, even though a negative judgment about the person, while perhaps justifiable, is not clinically appropriate.

Despite queer sexual acts and behavior having been and persisting as the object of medical interest in some cases for diagnostic reasons, too, simply understanding this layer as vulnerability through sexual scrutiny would not suffice in my view. Most importantly, that would not encompass the demands for intimacy queer people are subjected to in medical encounters, systems, and policies as they are expected to reveal highly personal knowledge on their sexual preferences historic and present. Queer people are encouraged to intimacy by the medical staff but the intimacy is volatile, ambivalent, and one-way—ipso facto, interrogatory. Similarly, in relation to the third question under this layer, I think bioethical voyeurism and overtly scrutinizing queer sexual choices displays interrogatory intimacy rather than only sexual scrutiny. Titillatingly, by using the term voyeurism Wahlert and Fiester provide an opportunity to play on psychiatric diagnostics, as did Richie, of sexual behavior that label certain practices as fetishist or, going even further back in the history of sexology, as perverse. Including pejorative vocabulary as a methodological tool seeking queer bioethical empowerment may indicate beating the master with his own stick: turning the magnifying glass from the queer subject under scrutiny to the seemingly objective medical observer and labelling their ethically unwarranted interest as inappropriate and perverse is looking at the history of medical ethics and ethics of sexuality through the queer bioethical lens.

The third layer I wish to suggest and which I call the layer of queer agency invites analyses of whether the case patronizes the LGBTQI individuals involved by pitying (or overly sentimentalizing) the queer subject. Vulnerabilities under this layer further include asking, are the queer roles in the case LGBTQI stereotypes or overgeneralizations? Has the case infantilized the queer parties? It is also important to note, are both queer and non-queer subjects treated as equally important and valid? Moreover, a crucial aspect of agency is also the right to non-disclosure; it is important to reflect, does the case respect the queer person's choice and rationale to remain closeted or protective of queer health information? In terms of embodied agency and disability/crip interests, it is pivotal that non-normative bodies are appreciated as legitimate, appropriate, and neutral.

Queer non-normative subjectivity or agency is often misunderstood or not readable within the available epistemological paradigm that defaults to pathology, resulting in problems of erasure and invisibility in clinical encounters, systems, and policies (cf. Horncastle 2018; Honkasalo 2018).

Interrogating queer agency presents significant ramifications of queer autonomy worthy of their own detailed account that I am not able to provide here. I will focus on the question of infantilization because as mentioned, it reverberates through many of the layers of queer vulnerabilities established here.

Overall, heteronormative discourses have a long history of infantilizing queer persons. According to Wahlert and Fiester (2014: S60-61), when adult queer persons—especially gay men and trans people—are in the clinic, they are notoriously treated as adolescents, in striking contrast to the way heterowomen and heteromen are treated. In their analyses of a textbook supposedly guiding clinicians for ethically sustainable encounters with LGBTQI, Wahlert and Fiester note that in general medical ethics, clinicians are often instructed to provide a setting that is safe for disclosure and ensures privacy when treating LGBTQI people. 'Family members and friends may need to be excluded from the conversation. Each situation is unique and certainly requires sensitivity and skill, so as not to alienate loved ones.' (ibid.) It is unthinkable that this advice would be given, for example, to internists about taking a sexual history from a middle-aged straight man who has been diagnosed with gonorrhea:

No clinician could conceive of the man's mother or father being *included* in the conversation, so there would never be a suggestion that they might need to be *excluded*; and there certainly would not be any concern about how those parents might feel about their certain exclusion. Only in the pediatrician's office would this be a valid concern (...).

Wahlert and Fiester (2014: S61)

To briefly point to an example further problematizing the dynamics of infantilization and queer agency, trans and intersex minors suffer from insufficient recognition of this layer of vulnerability. Their agency is jeopardized twice as both their age and their gender non-conformity renders them vulnerable. Increasing the legitimization, appropriateness, and appreciation of non-normative bodies is crucial for the recognition of such queer embodied agency.

The fourth layer of queer vulnerabilities I wish to suggest is the layer of ethical sustainability. Crucially, analyzing this layer begs the question, is there a heteronormative value hierarchy in the case that is given priority over others. Does the case allow itself to be 'dequeered' and still have ethical or clinical relevance? If not, does the queer nature of the case justify or disqualify it as worthy of legitimate study? Finally but importantly, a pivotal factor in establishing ethical sustainability is to

decide whether or not unsympathetic and immaterial details about queer subjects have been included, resulting in bias against them.

Although all of the four layers are to be used in evaluating ethical sustainability in the sense of just treatment, this layer offers particular insight for research and medical ethics. However, the notion of ethical sustainability exceeds traditional research ethics approaches. They often limit themselves to solely dealing with issues of conducting research, albeit they are also important, as addressed by the third question under this layer. Moreover, by ethical sustainability I encourage casting a critical eye on how uninterruptedly ethical sense-making flows from queer subjects to non-queer subjects what does the method of queering or dequeering reveal about not only the medical-ethical relevance of the case but also about how ethical evaluation of care practices and outcomes are informed by cis- and heteronormativity? For example, looking at sterilization practices and legislation in Finland clearly manifests a heteronormative value hierarchy. Medical proof of sterilization is legally mandatory for trans people in order to obtain a new legal gender status, whereas cisgender people are only eligible for sterilization after reaching the age of 30 or after having three biological offspring. Dequeering and queering bioethical cases is a useful methodology precisely for observing the flow of ethical sustainability to determine if all the principles organizing care are fulfilled outside cis- and heternormativity, and if all the practices that consist good care are met with patient satisfaction in queer cases similarly to cis- and heteronormative ones. A layered understanding to vulnerability combined with queer bioethics can improve acknowledging and resolving ethical issues around gender and sexual diversity in medical practices, systems, and policies.

#### Concluding remarks

Critical discussions on and reconfiguring the concept of vulnerability have multidisciplinary value and should be of particular interest to anthropological inquiry based on two arguments made in this article. Firstly, I argued that reconfiguring vulnerability from a queer bioethical and feminist theoretical viewpoint can make (bio)ethics more ethical in the sense that they offer tools to challenge unjust ethical sense-making —the flow of ethical sustainability— to determine, if all ethical principles are fulfilled outside cis- and heternormativity. I further argued that a layered understanding of vulnerability combined with queer bioethics can help acknowledge and better resolve ethical issues around gender and sexual diversity in medical practices, systems, and policies. Secondly, I offered a

queer bioethical take on a layered theory of vulnerability, stating that vulnerability is not an essentialist category; instead, similarly to women on whom Luna's theory of vulnerability focuses on, queer people can be rendered vulnerable in various ways in different contexts but this never means complete lack of power.

Drawing from the queer bioethics inventory of Wahlert and Fiester, I then established four layers of queer vulnerability: the layer of ethical sustainability, the layer of queer agency, the layer of interrogatory intimacy, and the layer of troubled kinship. I suggested these layers should be utilized in actual case studies and be subjected to critical intersectional analyses, which I hope to be especially appealing to a queer-feminist anthropology of vulnerability. The layered approach to vulnerability proves helpful at a conceptual level: when identifying relevant layers in relation to a research subject, the research situation, and the context by drawing from lived experience. At a practical level it is helpful when designing ways to eliminate or diminish a layer of vulnerability. This makes it an interesting crossdisciplinary tool. (Luna 2009: 133).

Besides queer bioethics' ethical gravitas and yet unfulfilled moral theory potential, the work to formulate its theory is still evolving. It has not yet been properly addressed how queer bioethical methodology, including queer vulnerability, can establish intersectional or queer necropolitical agendas. I suggest the layered account of vulnerability and the four layers of queer vulnerabilities could be useful for dialogues with those agendas. However, these layers are not intended as the final say on queer vulnerability and should be subjected to further scrutiny.

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- Heteronormativity refers to the systematic assumption of heterosexuality, from which the unproblematic legitimacy of organizing bioethical practices accordingly seemingly follows. Cisnormativity, then, refers to the assumption that there is a distinct (if not indeed categorical/essential) gender binary of male and female, from which the unproblematic legitimacy of organizing bioethical practices accordingly seemingly follows. (Cf. Wahlert and Fiester 2014; 2012; Dean et al. 2016.) Moreover, hetero- and cisnormativity are often accompanied by the assumption that gender can be divided into social (gender) and biological (sex), whereas a queer approach to sex promoted in this article is that physiology is also gendered socially, not through so-called objective discovery.
- Emerging queer bioethics as a theory and methodology does not mean that these topics would have not been challenged in so-called mainstream bioethics before its arrival (cf. Nelson 1998; 2012) or that no such work could be done without calling it queer bioethics (cf. Latham 2017).

- To Richie, queer bioethics is a wider, mostly unfulfilled project as she sees Wahlert and Fiester's theory lacking in many ways. Hence Richie uses the term queer bioethics differently that I do elsewhere in the article, referring to Wahlert and Fiester's queer bioethics.
- This is obviously a question of great philosophical gravitas, requiring far more detailed justifications than the ones I can offer here, so I will embark on that elsewhere (in my future PhD dissertation; see also Latham 2016).