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Chapter 22

FEMINIST BIOETHICS AND EMPIRICAL RESEARCH

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FEMINIST BIOETHICS AND EMPIRICAL RESEARCH

Stacy M. Carter and Vikki A. Entwistle

This chapter examines *empirical research* as key to furthering feminist bioethical understanding. It attends particularly to the somewhat neglected question of what it means to do feminist empirical bioethics.

Feminist bioethicists are, as Jackie Leach Scully (2016) has explained, inevitably normative in their orientation: as feminists, they have a prior commitment to reducing injustice; as bioethicists, they aim to reach prescriptive or proscriptive conclusions. Feminist bioethicists also tend to share an empirical attitude, typically believing that doing ethics adequately requires taking the empirical seriously, and reflecting as closely as possible what goes on in the world – for people of all genders, for those more and less structurally advantaged, and in everyday lives, not just rare high stakes situations. Feminist bioethicists ground their normative analyses in empirical description or explanation, either by generating empirical evidence themselves, or by attending to and using empirical evidence in particular ways. Their coupling of the empirical with the normative derives from the ontological and epistemological commitments of feminist theory, and is arguably constitutive of feminist bioethics.

Within bioethics, however, feminist empirical research is marginalized in several ways. Mainstream bioethics tends to include feminist bioethics only tokenistically (Scully, Baldwin-Ragaven and Fitzpatrick 2010); some in the mainstream Anglo-American philosophical tradition view empirical bioethics skeptically, partly because of how they problematize the relationship between the descriptive and the normative (McMillan 2016). Feminist empirical bioethicists need to address this double marginalization by both engaging opposing arguments and producing work of demonstrable value. We aim to support both strategies here. The first section outlines what we mean by feminist empirical bioethics, the second provides illustrative case studies, and the final section briefly considers the future of feminist empirical bioethics, including directions for the further development of practices.

What is feminist empirical bioethics?

Defining any area of scholarly work is challenging, and demarcating academic boundaries is both common and potentially problematic (Hansson 2017; Carter 2018). Rather than draw hard boundaries around feminist empirical bioethics, we draw on the conception of “family resemblances”

that Ludwig Wittgenstein introduced to explain how some words get their meaning (Biletzki and Matar 2020). Members of a biologically-related family unit share traits. While not all family members are identical in respect of those traits, they usually share enough of them to allow the family to be identified. Some words get their meaning in a similar way: not via stipulation of a strict set of necessary and sufficient conditions, but via recognition of family resemblance. Analogically, we can look for work that is confidently recognized as feminist empirical bioethics, consider the characteristics of that work as prototypical, and assess whether other candidate examples possess enough of them to be considered the same type of thing.

In one of very few works focused explicitly on feminist empirical bioethics, Jackie Leach Scully took this kind of approach:

In [discussing] the theoretical basis for, and distinctive features of, feminist empirical ethics, I have tried to avoid suggesting that there are defined methodologies that feminist bioethics adopts, or ought to adopt, to do its empirical work. What is distinctive about *feminist* inquiry into an ethical issue has more to do with the features that it prioritises for empirical examination: the elements of the story to which it pays particularly close attention.

(Scully 2016: 203; emphasis in original)

The elements Scully identified as distinctive were: *paying attention to power structures, paying attention to relationality and care, paying attention to embodiment, and paying attention to marginal voices*. She also argued that feminist empirical bioethicists typically took their own moral responsibilities seriously. We agree, and will return to these points, while organizing our thoughts in a slightly different way. Feminist empirical bioethics, we propose, shares distinctive *perspectives* and *practices*, and is conducted at least to some extent in an identifiable *community of practice*. We consider these in turn.

Perspectives

Our first claim is that feminist empirical bioethics tends to be done from a certain perspective.¹ This reflects and shapes its ontological bases and conceptual tools (e.g. assumptions about the nature of personhood and autonomy) and its (interlinked) epistemological and normative assumptions (e.g. commitments to understanding the generation and use of knowledge as social and as a matter for justice).

A feminist empirical bioethics perspective contrasts in important ways with the perspective of the influential mainstream tradition of bioethics. To oversimplify, the latter tradition reflects the assumptions about people and what matters to them that prevailed in Anglo-American moral philosophy in the mid-late 20th century. It tends to assume and idealize personal independence and individuality, emphasize values of personal freedom and responsibility, and downplay social-structural sources of vulnerability. It often also prizes logical argument to apparently universally relevant normative positions. Bioethicists in the Anglo-American tradition generally use the approaches and standards of analytic philosophy to apply, and to some extent develop, general ethical principles that reflect these assumptions.

Feminist empirical bioethics can make good use of analytic philosophical approaches, including logical reasoning. However, feminists typically understand the nature of people and the social world, and the construction of knowledge, differently. We consider both of these in turn to help explain why feminist perspectival commitments can lead feminist bioethicists to focus on different questions and reach different normative conclusions than their more traditional analytic philosophical colleagues.

We start with feminist understandings of people and the social world, and initially with some claims that apply equally to feminist bioethicists who do and do not work empirically. Feminist scholars adopt a social (or relational) ontology of people and treat ontology as perspectival. They take seriously the implications of human relationships and interdependence. This not only encourages attention to practices and experiences of care, responsibility, solidarity and reciprocity, it requires understanding them in particular ways, for example, recognizing the significance of power differentials and social-structural sources of vulnerability. In more general terms, feminists develop relational understandings of these and other concepts to accommodate and reflect the complexity of the social world (Sherwin and Stockdale 2017). Classic examples of work that feminist bioethicists draw on include Carol Gilligan's (1982) and Joan Tronto's (1994) development of care ethics, Margaret Urban Walker's (2007) and Iris Marion Young's (2011) social theorizing of responsibility, and feminist relational theorizing of autonomy (a concept central to traditional bioethics) (Mackenzie and Stoljar 2000). Feminist bioethical theorizing – as evidenced by many chapters in this Handbook – also normatively emphasizes justice, including via attention to structural and systemic mechanisms that perpetuate unjust inequalities (Young 2011).

When working empirically, these feminist understandings of people and the social world provide a rich theoretical resource (including concepts and language) for framing and guiding ethics research. A feminist empirical bioethicist interested in normative aspects of human health, for example, is unlikely to assume that people's health-related behaviors depend on independent choices or are motivated only by their own interests, and unlikely to assume they bear full responsibility for these behaviors. Instead, she will be mindful of the social shaping of autonomy and responsibility, and of structural conditions and issues of justice. She will seek to understand those conditions empirically and to engage with those affected – especially the marginalized and otherwise disadvantaged. Throughout, she will work between empirical investigation and feminist theory, producing normatively insightful interpretations that inspire justice-oriented change in the social world.

When it comes to knowledge, feminist epistemology shapes feminist bioethics via several inter-linked assumptions and commitments. One of the practical implications of feminist epistemology is that ethical argumentation should be based on good evidence about the everyday world and diverse people's experiences within it. Feminist perspectives on epistemology mean feminist bioethics must be empirical in some meaningful way (Scully 2016). Feminist epistemological roots underpin some important contrasts between feminist approaches to bioethics and the "mainstream" or traditional approaches to bioethics, which often take normative concepts as their starting point, and use thought experiments as intuition pumps, without connecting these with the complexity of the world as people experience it.

A feminist bioethics lens shapes what an empirical researcher attends to and "sees" in their investigations. Feminist concepts and understandings provide, in Bourdieu's terms, "thinking tools" (Wacquant 1989: 50) or in Blumer's, "directions along which to look" (Blumer 1954: 7) in collecting data and doing analysis. This idea of theory guiding attention and shaping analytic direction brings the ontological and epistemic commitments of feminism together: this is how the theoretical resources of concepts and language mentioned earlier feature in feminist empirical bioethics. When feminists bring elements such as relationships, inequalities, care, power differences, social justice and the structural conditions for autonomy to the fore in bioethics, the topics they tackle in bioethics not surprisingly include:

- gender inequities and biases in health and healthcare;
- instantiations of responsibility for caregiving;
- how autonomy is supported or undermined in the pursuit of health;

- the implications of reproductive practices, technologies and norms for women's lives, including marginalized women and women from the Global South;
- the benefits, burdens and distributive fairness of research practices; and
- human relations with non-human animals.

The reflexivity of feminist approaches also informs the way empirical work is done and especially the claims made for the knowledge it generates (see later in this chapter). Feminism has produced some of the most influential critical epistemological theorizing, particularly standpoint epistemology and its attendant concept of strong objectivity (Haraway 1988; Harding 1992). The then-radical theorizing of leading feminists proposed that you could “‘have it both ways’ by accepting the idea of real knowledge that is socially situated” (Harding 1992: 438). The idea that objectivity could be strengthened rather than reduced via explicit positioning and reflexivity on the part of the researcher, as well as deliberately prioritizing the perspectives of the marginalized, had profound effects on research practices in the social sciences, well beyond feminism. Equally significant are feminist contributions to epistemology as not just as a matter of truth but also of justice. Miranda Fricker, for example, theorized epistemic injustice, distinguishing testimonial injustice, when testimony is dismissed because of prejudice against the speaker, and hermeneutical injustice, when people cannot adequately articulate their experience, or have that experience understood, because they have been systematically excluded from communities of meaning-making (Fricker 2007). Accordingly, feminist empirical bioethics typically seeks to access and show respect for the perspectives of people who have been marginalized, silenced or excluded.

So then, to summarize, the perspectives taken in feminist empirical bioethics make available interconnected sets of theoretical resources: theories about the nature of people and the social world, including its moral character (feminist social ontology and moral theory); and theories about the construction of knowledge (feminist social epistemology), which then provide sources of justification for methodological decisions. These perspectives encourage attention to some particular kinds of questions and challenge some more traditional ways of doing bioethics, suggesting both that some traditional bioethics theory should be reworked to better reflect the social and moral world, and that there should be space for systematic empirical work within the mainstream of bioethics.

We now turn to the practices that arise from feminist theoretical orientations and commitments.

Practices

What do feminist empirical bioethicists do? So far we have focused particularly on the feminist and bioethical aspects of this question. Now we turn to the empirical. Most commonly, when feminist bioethicists work empirically they generate empirical data by talking with people, especially those from marginalized groups, and then analyze those data informed by the perspectives outlined above, with concepts and principles from feminist bioethics in mind. However feminist empirical bioethics can also involve generating and working critically with quantitative data, studying powerful groups to understand structures and processes of marginalization, or doing normative analysis with careful attention to the body of existing empirical evidence.

Broadly speaking, feminist empirical bioethicists locate themselves in an area of overlap between several research cultures. To participate in conversations within bioethics they need to be able to engage with the traditional mainstream of philosophical bioethics; more generally they must satisfy the theoretical and methodological expectations of empirical social science as well as feminist scholarship. Contributing to existing efforts to articulate markers of quality in empirical bioethics

(Carter 2018; Cribb 2018; Ives et al. 2018), we propose three broad expectations for such work. Working empirically in feminist bioethics requires:

- 1 A well-considered approach to the “is-ought” problem;
- 2 Humility and commitment to methodological standards across disciplines, albeit with a critical eye on the assumptions built into those standards, and a willingness to challenge them if they are unfair or oppressive; and
- 3 Sustained, grounded and inclusive attention to the empirical.

The “is-ought problem,” usually traced back to David Hume, is arguably both essential and sometimes a distraction. The tradition of moral philosophy that helped shape bioethics includes the idea that facts and values are both separable and epistemically distinct. Accordingly, a simplified version of Hume’s “is-ought problem” holds that an “ought” cannot be derived from an “is,” meaning that empirical facts are irrelevant to the drawing of normative conclusions. There are now decades of work arguing against this view (McMillan 2016), not least because it is problematic as an interpretation of Hume’s original text (Putnam 2002). Nonetheless, a deep distrust of empirical work persists in some corners of bioethics. A feminist empirical bioethics relies on epistemological positions that can counter such distrust, including recognition of knowing as a matter for justice, the situatedness of knowers, and the normative importance of starting from the perspective of marginalized people (Scully 2016). These commitments provide support for a normatively inflected defense of the knowledge generated in empirical ethics research.

The relationship between social science and bioethics has long been disputed (Haimes 2002), including via some sustained critiques from social scientists (Fox, Swazey and Watkins 2008; Bosk 2010). We won’t re-work the debate here, but note that as part of it, Adam Hedgecoe suggested that medical ethics should learn humility, as social processes are almost always more complex than philosophical arguments can bear, and “there is rarely a [single] right answer to the question: ‘what should I do?’” (Hedgecoe 2006: 174). We want to pick up on this foregrounding of humility to suggest it is required in multiple directions for feminist empirical bioethics scholarship. Because we sit between disciplines, practicing feminist empirical bioethics requires openness, not only to often-surprising insights from informants, but also to learning about, applying and connecting up the changing “rules of the game” of those disciplines. This means both respecting and critiquing the rules of knowledge production in several domains, and applying those in their own work. Feminist empirical bioethics also requires understanding how diverse both evidence and theory are likely to be on any given question, working systematically across that diversity rather than giving in to confirmation bias, and being cognizant that any perspective – including their own – will always be partial.

Later in the chapter, we provide some detailed examples of feminist bioethicists doing empirical work themselves. But here, to illustrate the demands just discussed, we provide some examples of feminist bioethicists critiquing and proposing refinements to the methodological and epistemological underpinnings of some recognized empirical approaches. The first example is Catherine Womack and Norah Mulvaney-Day’s (2012) writing about the experimental philosophy movement. They both applaud and critique this movement, particularly as it tackles ethical questions, from a feminist perspective. They agree with experimental philosophers that it is fruitful to gather “experimental data on the content of ordinary folk concepts” rather than simply privileging professional philosophers’ intuitions about philosophical concepts and moral reasoning. However, they argue that the movement could and often should go beyond “quantitative fixed-answer surveys about standard philosopher-designed thought experiments,” to instead gather “qualitative information about real-life embedded experiences that use the philosophical concepts in question”

(Womack and Mulvaney-Day 2012: 114). This, they propose, would be consistent with feminist epistemic perspectives, as it would incorporate informants' value judgments and social contexts, and enact respect and inclusion, to form better philosophical accounts of concepts of interest. Their paper demonstrates the importance of methodological and epistemological theorizing to feminist empirical bioethics, and that adopting an empirical attitude does not always entail doing primary empirical work.

In our second example, Katrin Nikoleyczik (2012) argues that neuroscience and neuroethics research have not yet adequately reflected existing knowledge from gender and science studies. She reveals the conceptual muddiness in cognitive neurosciences regarding sex and gender. Not only are gender/sex taken as "natural," indistinguishable, and a "self-explaining category" (Nikoleyczik 2012: 234), but scholars in *gender studies of neurosciences* have different "epistemology, methodology... research aims, contents, and results" to scholars in "*neuroscience of sex differences*" (236; emphasis in original). Further, the discipline of cognitive neuroscience does not provide space for its members to do critical methodological and epistemic work, treating such work as outside of discipline or mere "opinion" (236). She proposes a need for mixed methods, interdisciplinary research to "[fill] in the blanks" in current research agendas (238), and so integrate gender studies and cognitive neuroscience to extend neuroethics in new, feminist directions.

Our third example of methodological and epistemological work is Laura Cupples' (2020) investigation of "quality-adjusted life years" (QALYs). Despite widespread criticism, QALYs are a standard method for assessing the benefits of healthcare interventions. Cupples added to the critical literature from a feminist bioethics perspective, emphasizing that the processes for estimating QALYs are a source of epistemic harm and injustice. Researchers typically rely on the general public, rather than people living with disability or chronic illness, to generate QALY values; they also use methods such as time trade-off which assume that "rational people will readily part with years of life with a disability in exchange for shorter lives in an able-bodied state" (Cupples 2020: 46). Cupples also illustrates the unique contributions that feminist bioethicists can make to empirical practice with methodological and epistemological arguments.

So far, we have suggested that feminist empirical bioethics requires a sophisticated approach to the is-ought problem, and a critical lens on methodological and epistemological standards. Finally, we propose that systematic empirical work in feminist bioethics requires *sustained, grounded and inclusive attention to the empirical*. This is not merely a redundant claim that empirical practices must be empirical. Rather, we stress that there are different *ways* of attending to the empirical and these vary in their acceptability. It is not acceptable to cherry-pick a single story to color and confirm an entirely predictable rehearsal of pre-existing normative commitments. Working empirically requires engaging conscientiously with the empirical evidence, avoiding wild abstraction, attending to diversity and engaging with richness of insight. It also requires recognizing that arguments can harm, especially when those arguments concern women and other marginalized groups. In academic writing and communication, care must be taken not to perpetuate epistemic injustice by communicating the lives of others in terms those others would not recognize. For example, Inmaculada de Melo-Martín (2016) has drawn on feminist theorizing to critique and address mainstream bioethical arguments about reproduction. Some prominent authors have suggested that prospective parents ought to use reprogenetic technologies to ensure and enhance the wellbeing of their children. Drawing on empirical research, de Melo-Martín points out that these arguments sometimes refer to prospective parents in ways that neglect the gendered pattern of bodily risks and burdens that these kinds of technologies are known or likely to impose. She argues that the ethics of these technologies cannot be adequately analyzed without taking seriously the perspective of the women who carry the resulting pregnancies – to do so is to fail the test of ensuring sustained, grounded and inclusive attention to the empirical detail of reproductive practices.

So, what methods do feminist empirical bioethicists use to accomplish all of this? To date, quantitative and experimental work – or theorizing that draws systematically on such research – has been rare. Exceptions include Wendy Rogers' chapter in this volume, which draws extensively on existing quantitative research to make normative arguments about gender and organ donation. Generally speaking, however, qualitative and interpretive methods characterize the field, and studies based on interviews or focus groups with implicated groups predominate. There are coherent epistemological reasons for this, as these methods create space to discuss with participants what matters to them, on their own terms, and to interrogate concepts and concerns in depth. There are also pragmatic reasons: for example, qualitative health research is particularly strong in the UK, which has been a significant contributor to empirical bioethics. It is, however, possible that the dominance of these methods limits the reach and influence of feminist empirical bioethics, which could benefit from at least some mixed methods research to better achieve its social change agenda (more on which shortly).

Another current area of growth in empirical bioethics is deliberative democratic methods. Deliberative democratic processes invite participants to directly engage in the normative project of considering evidence, considering contested questions together, making recommendations and giving reasons (Degeling et al. 2017). Traditional deliberative theory is strongly normative but in a political rather than a moral sense: the goal of deliberative methods is to contribute to a better democracy. Democratic theory and bioethics theory share another similarity: each has a mainstream that has been criticized for excluding feminist insights; and in each, feminists have emerged to challenge the mainstream (e.g. Squires 2011; Dieleman 2015). Deliberative methods are becoming more prominent in bioethics, and feminist empirical bioethicists could usefully develop deliberation with a feminist inflection.

Empirical feminist bioethicists are often involved in practices that entail others as participants, and so must consider human research ethics. The commonly-accepted principles of research ethics are equally relevant in feminist projects: the need for scientific merit, showing respect for participants, avoiding harm and delivering benefit, and being attentive to justice in both design and implementation of research. But feminist commitments will inflect each of these principles in certain ways. For example, showing respect in a feminist sense may require more than providing extensive information about the benefits and burdens of projects, and ensuring participants are free to refuse participation. It may require positive support for autonomy, which could involve e.g. actively making information accessible to those with lower literacy, or taking more time to explain and support decision-making. Feminist commitments may also expand the range of considerations that are taken to matter, including introducing an ethics of care and attending to the micro-ethics of the moment-to-moment decisions and interactions that occur within research interviews and group discussions (Guillemin and Gillam 2004). The fact that feminist commitments make these kinds of concerns visible does not mean that only feminists should be bound by them; feminist approaches could enhance commonly institutionalized approaches to research ethics, and are an important area for future work. Below we discuss a case study of feminist empirical bioethics with examples of feminist research ethics in action.

A final observation about feminist empirical bioethics practices is that they often interleave with activism: unsurprising given the shared commitment to reduce injustice and marginalization. Activism often entails the strategic use of evidence, and accordingly some key organizations that advocate and campaign for better justice and health for women use research to generate evidence to inform their efforts and help substantiate their policy demands (see, for example, the Sama Resource Group for Women and Health based in New Delhi, India: <http://www.samawomen-health.in/research/>).

As highlighted in a recent special issue of *Bioethics* (Draper 2019; Rogers 2019; Scully 2019), there are many ways of doing bioethics, and this can involve activism of various kinds (Scully

2019), but this activism can produce tensions for academics that have to be resolved (Rogers 2019). Given the long history of activism in feminism, as well as the commitments outlined in this chapter and Handbook, it may be more likely that a bioethicist will be involved in activism of some kind if she is a feminist. Scully has suggested that those engaged in activism of various strengths have five core responsibilities: to have a sound evidence base, to ensure that knowledge is not distorted either by bias or by exclusion of affected groups, to avoid exploitation, to take representation seriously, and to attend to power (Scully 2019). Each of these has an epistemic dimension, and each is directly relevant to doing feminist empirical work.

Communities of practice

The final focus in our characterization of feminist empirical bioethics sees it as located in *scholarly and activist communities*. Many of the scholars doing this work are also members of the International Network on Feminist Approaches to Bioethics (FAB – see Chapter 1). FAB led to the establishment of the *International Journal of Feminist Approaches to Bioethics*, has been running international conferences for 30 years (linked to the biennial World Congress of Bioethics), and has an increasing social media presence (Feminist Approaches to Bioethics 2020). Not all empirical bioethicists informed by feminist ideas use the “feminist” label or participate in FAB activities, and feminist empirical bioethics also tends to overlap – at least in its concerns – with some other areas of bioethics such as disability ethics and queer ethics. Nonetheless, we think it is useful to locate feminist empirical bioethics in a community of practice, because connections between identifiable people are epistemically and developmentally important. It is in relationships within a supportive community of storied, embodied scholars that these perspectives and practices are most readily made, shaped, critiqued and improved. Identifying these communities also makes feminist empirical bioethics more accessible for those who may want to take it up.

Feminist empirical bioethics: examples of practice

In this section, we first describe two projects in some detail. Although they differ in terms of the people, settings and ethical issues that they study, and the scale at which they are conducted, both strongly illustrate most of the family resemblances we associate with feminist empirical bioethics.

Investigating gender bias in surgery

Katrina Hutchison sought to inform efforts to address the under-representation of women in surgery (especially in academic and leadership positions) and the gender pay gap among surgeons. She conducted her work in Australia where, as in many countries, there was clear evidence of both problems, and where some of the explicit sexism and “macro” factors that contributed to them (including sexual discrimination and harassment, limited parental leave entitlements, and a lack of role models and mentors) had been quite widely recognized and discussed in the national media. Hutchison saw a need to bring an additional, less obvious, set of biases into clearer view, so they too could be tackled (2020a; 2020b). She designed a qualitative research study “to identify and characterise surgery-specific forms of gender bias, with a focus on subtle biases such as implicit bias and epistemic injustice” (Hutchison 2020a: 236).

Hutchison recruited a sample of forty-six women working in Australia or New Zealand as surgeons or surgical trainees. She was careful to include surgeons from each of nine recognized specialties, at different career stages, and with different perspectives on sexual harassment and bullying

in surgery. She interviewed them all individually, exploring their “career motivations as well as any barriers and supports to their surgical careers” using conversational prompts that “facilitated discussion of many aspects of surgical training and careers, without pre-empting the types of experiences [they] might discuss” (Hutchison 2020a: 237).

Taken at face value, the interviews might not have looked like part of a feminist bioethics project. Hutchison carefully avoided mentioning gender bias in her prompts “to ensure that participants who did not find gender a relevant frame would explain their experiences in the terms that they felt appropriate, and that those who mentioned gender explicitly were doing so based on their experiences rather than in response to leading questions” (2020a: 237). She also took care not to use terms such as “implicit bias” or “epistemic injustice” unless participants themselves introduced them. An explicit prompt, “Have you experienced any discrimination during your training or career?” was left toward the end of the interview (2020a: Supplementary material). The lack of obvious ethics wording and questions about gender within the interviews did not, however, prevent Hutchison from identifying and analyzing ethically salient experiences of bias. It was also helpful, as Carolyn McLeod noted in a commentary on the paper, to ensure her findings and conclusions were not vulnerable to the charge that feminist researchers will see gender bias everywhere, even where it does not exist (McLeod 2020).

Hutchison identified four categories of gender bias that can affect women’s surgical training and career: workplace conditions; challenges to credibility; role factors; and objectification. She used her interview data to illustrate several subtle and implicit types of bias within each of these, including, for example, low-level harassment in the form of sex jokes, and missed opportunities for conversations with peers or supervisors in gender-segregated changing rooms (workplace); being misrecognized by patients as a junior, or being expected to charge lower fees (challenges to credibility); being expected to take on peacekeeping conversations with patients or a higher burden of paperwork (role factors); and being on the receiving end of sexualizing questions or comments about clothes and appearance (objectification).

Hutchison pointed out that “[m]any of the instances of bias described in the study seem minor, and were not necessarily perceived as harmful by participants (‘it doesn’t worry me’).” However, she connected her findings to theoretical work in ethics that considers how “small factors can aggregate to form large harms that are more than the sum of their parts.” Even if particular acts of bias do not harm the individual in a specific instance, she showed that “multiple instances can give rise to harm of a different type” (Hutchison 2020a: 240). She explained that because aggregative harms are systemic in nature, the forces that give rise to them are relatively difficult to see and they may be supported by practices that are expedient for the people faced with the implicit or subtle smaller harms at an individual level. By making the small forms of bias against women in surgery more visible, and showing how they can aggregate, and interact with the more explicit forms of bias that have previously been recognized, Hutchison identifies important scope for addressing the features of healthcare and professional training systems from which aggregate harms emerge.

Journal article length limits mean reports of empirical work in feminist bioethics can rarely include discussion of all the ethical implications or considerations that study data give rise to. Hutchison also notes that she was unable to exhaust her analysis or its implications within the limits of journal article length, such as examining the complex questions of whether and to what extent women surgeons were wronged as well as harmed, and whether anyone should be subject to blame, punishment or demands for repair (2020a; 2020b). This illustrates a more general challenge for feminist empirical bioethics. The value and contribution of an empirical project may not be fully evident in one paper, and when empirical reports are separated from the more theoretical and normative aspects of analysis for publication, feminist empirical bioethics as such is rendered less visible.

Investigating vulnerability in health research in low-resource settings

The REACH (Resilience, Empowerment and Advocacy in Women's and Children's Health Research) project was designed to investigate the ethical challenges surrounding vulnerability as they occur in research in low resource settings (<https://www.ethox.ox.ac.uk/Our-research/major-programmes/reach>). The international project team, led by Maureen Kelley, set out to generate knowledge about the health and social vulnerabilities of women and children in these settings, and to use the research to address these vulnerabilities and advocate for change.

The project builds from feminist critiques of ways of thinking about vulnerability that were, at least until recently, incorporated in most health-related research ethics guidance. Roughly speaking, the guidance reflected a tendency to label broad groups of people (e.g. pregnant women, prisoners, or refugees) as “vulnerable,” and to take this to mean not only that they were more susceptible than others to harms, but also that they were unable to protect their own interests in research contexts. Feminist critics argued that this was problematic for several reasons, not least that it made overly general assumptions about people and their lack of agency and resilience, led to unjust exclusions from research, and discouraged research that could help understand and address the particular problems faced by the people labeled vulnerable.

In response to these critiques, and to the development of more nuanced, layered theoretical models of vulnerability by feminist scholars (Luna 2009, 2019; Rogers, Mackenzie and Dodds 2012), recent research ethics guidance has started to encourage researchers to think more carefully about the sources and forms of vulnerability that can arise in particular research projects.

The REACH project is formally investigating sources and forms of vulnerability – and paying attention to associated questions about agency and resilience – in the context of research projects addressing the health of women or children in low-resource settings in Kenya, South Africa and Thailand. The project will also consider whether, to what extent, and how the issues identified in these contexts might be reflected more broadly. The REACH team intend their empirical work to help provide a firmer grounding for theory and research policy relating to vulnerability, and also, if necessary, to refine or challenge these.

In each of its study sites, the REACH project links its team members (including social scientists and bioethicists) to ongoing health research projects and uses a range of qualitative research methods and broader forms of community engagement to ensure they can characterize the specific vulnerabilities, resilience and agency of women and children as described from their own perspectives.

A REACH team at the Thai-Myanmar border focused on two clinical studies involving migrant women (Khirikoekkong et al. 2020). Both investigate the effects of pharmaceutical treatments in pregnant women. At this REACH site, in addition to investigating women's perspectives, the team also sought to better understand how researchers, fieldworkers, ethics review committees and community advisory boards identify and respond to the potential vulnerabilities, resilience and agency of women, children and families in research. They conducted thirty-two in-depth interviews and ten focus group discussions with research participants, family members, researchers and other key informants, including health workers, ethics committee members and community leaders.

The lead interviewers were native speakers of local languages, had a deep understanding of the research setting and cultural context, and were independent of the clinical studies. Since there is no direct translation of “vulnerability” in local languages, interviewers were careful to use several different words to explore the “challenges” that migrant women could face relating to research participation.

The study illuminated a range of structural issues that together generate a dynamic complex of vulnerabilities for migrant women in their daily lives. Using a richly evocative set of quotations and drawings to illustrate, the research team identified diverse examples of what they called “political vulnerabilities” (including those associated with uncertainty of legal status, lack of

documentation and ethnic conflict), “economic vulnerabilities” (such as the need to pay bribes or fines associated with illegal cross-border travel for work, seasonal employment and barriers to safe movement arising from seasonal drought and flooding), and “social vulnerabilities” (including family separation or displacement, illiteracy, domestic violence, and discrimination based on ethnicity or religion), which combined and contributed to “health vulnerabilities” (such as a high burden of both endemic infections and chronic diseases, seasonal diseases and risks of accident, a lack of health insurance, limited or no access to healthcare, and a lack of knowledge or resources for self-care). These cumulative sources of vulnerability could be mitigated to some extent by support networks that in some cases included clinic and research staff as well as family members and employers.

Migrant women chose to participate in research for various reasons, including to access quality healthcare, gain knowledge and obtain extra money. However, participation could itself exacerbate vulnerabilities, for example if it required more cross-border travel or time off work, made childcare more difficult, and made undocumented migrants more visible.

Although the clinical research program had a longstanding commitment to prioritizing the provision of humanitarian care, clinical researchers reported ethical uncertainties, including the balancing of burden and benefit for study participants and their communities, and their dual roles as healthcare providers and researchers. They were also concerned that cultural tendencies to be respectful, self-effacing and extremely considerate might make it hard for women to decline invitations to participate in research. The REACH interviews, however, revealed that women found ways to decline participation within their cultural norms – just one example of their exercise of agency and resourcefulness. This case study highlighted specific sources of vulnerability, which could generate previously hidden burdens of research participation for migrants (and particularly those who lacked documentation) living on the Thai-Myanmar border.

Both Katrina Hutchison’s study and the REACH project demonstrate several of the key family resemblances of feminist empirical bioethics. They were each shaped from the outset by feminist concerns and oriented to support the pursuit of justice. They drew on feminist concepts and theorizing to guide their data generation, paid attention to the voices of those who were relatively disadvantaged in the situations of interest, and took care to enable participants to speak in their own terms and from their own perspective. The details of their research methods reflect attention to prevailing methodological standards (for example with careful sampling and approach to questioning) and serious consideration of researchers’ moral responsibility to participants. Finally, both generated insights that can be used to enhance the conceptual adequacy of discussion about the situations of interest.

The future of feminist empirical bioethics

In this final section, we note challenges faced by scholars working in feminist empirical bioethics, and consider scope for consolidation, development and expansion within this broad “family” of endeavors.

Key challenges include some persistent opposition to, or at least lack of support for, feminist empirical bioethics in influential areas of the academic establishment. Combined with the requirement for high-level skills in both empirical research and bioethical reasoning, these challenges can make it hard for new scholars in particular to establish research programs and develop careers in feminist empirical bioethics. There are, however, strongholds in which experienced scholars can nurture capacity, and these can be further strengthened and rendered more effective by the kinds of networking, sharing and collaboration encouraged by the International Network on Feminist Approaches to Bioethics and its associated conference. Further strengthening and broadening of

the community of feminist empirical bioethicists is also possible via the development of interest groups within other associations and conferences focused on bioethics, feminism or normatively inflected social science.

Many FAB members and other academics working in feminist empirical bioethics come from privileged positions in rich nations. They often have a longstanding commitment to promoting inclusion and supporting the development of scholars from more marginalized social groups and less affluent countries. However, there is still significant scope to increase attention to the relatively neglected injustices faced by multiply oppressed groups, and those who experience intersectional disadvantage, in both high-income settings and the Global South. As feminist empirical bioethics continues to grow, we suggest that the field should continue to make concerted efforts to support those who experience disadvantage to become scholars within it. Such a cohort is likely to further expand the range of topics considered, voices heard and injustices tackled. It could, for example, develop empirical bioethics scholarship on the move toward feminisms from the Global South, expanding existing work in this area (Hoel 2015; Raghuram 2016; Tomalin 2017; Chisale 2018; Sen, Reddy and Iyer 2018; Zou, Nie and Fitzgerald 2020). The expansion of practical scope and perspectival range should also further conceptual and theoretical development.

In terms of methods, an expansion of repertoire beyond the mainstay of qualitative approaches (which continue to be well suited to deep exploration of normative issues and social processes, and do work that other methods cannot (Pope and Mays 1995)) will allow researchers to ask a wider range of questions and potentially strengthen feminist influence more broadly in the application, development and critique of mixed methods, quantitative methods and deliberative approaches to bioethics.

Finally, feminist empirical bioethics has as yet under-tapped potential to support the practical justice-oriented ambitions for social change of feminist bioethics and feminism more generally. Feminist bioethicists need to wrestle with the practical implications of their work, and perhaps be more directly involved in e.g. policy development, providing expert advice, or stimulating social change. Although feminism has a strong presence as a social movement, explicit and reflexive moves to bridge academic and activist communities and activities are relatively new in feminist bioethics. There is scope to build from a currently live conversation about activism in feminist bioethics. The empirical in feminist empirical bioethics can bring a particular power to policy work and the practical tackling of oppression, providing a sustained, grounded and inclusive evidence base to nuance and support robust normative arguments and actions for change.

Feminist empirical bioethics is not extensive, has not been formalized, and may not be easy for new readers to find. We hope this chapter has given you a sense of the family resemblances that hold feminist empirical bioethics together, via the perspectives it shares, the practices that constitute it, and the community of practice that undertakes it, and that you have been encouraged to explore these further.

Related topics

Feminist bioethics (Lindemann; Chapter 1); justice (Fourie; Chapter 2); epistemology (Hutchison; Chapter 3); power (Ganguli-Mitra; Chapter 4); relational autonomy (Stoljar and Mackenzie; Chapter 5); vulnerability (Luna; Chapter 7); disability (Scully; Chapter 13); women in research (Ballantyne; Chapter 18); gender, science and technology (Ankeny; Chapter 19); globalizing bioethics (Nie, Zou and Thornber; Chapter 17); genomic technologies (de Melo-Martín; Chapter 20); care ethics (Dodds; Chapter 26); organ donation (Rogers; Chapter 30); assisted reproduction (Scott; Chapter 33).

Notes

- 1 Our use of the term perspective here is shaped by mid-20th century symbolic interactionism. In this theorization of the social world, all people have a perspective. These perspectives are somewhat shared and malleable, are constructed through interaction, and shape the way the social world is perceived. This means the same objects, while they may have similar meanings for some social actors, can also have very different meaning to other social actors.

Further reading

- Ives, J., Dunn, M. and Cribb, A. (eds.) (2016) *Empirical Bioethics: Theoretical and Practical Perspectives*, Cambridge: Cambridge University Press. (This book is the only edited collection focused exclusively on empirical bioethics, and includes a chapter on feminist empirical bioethics by Jackie Leach Scully, listed in the references below.)

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