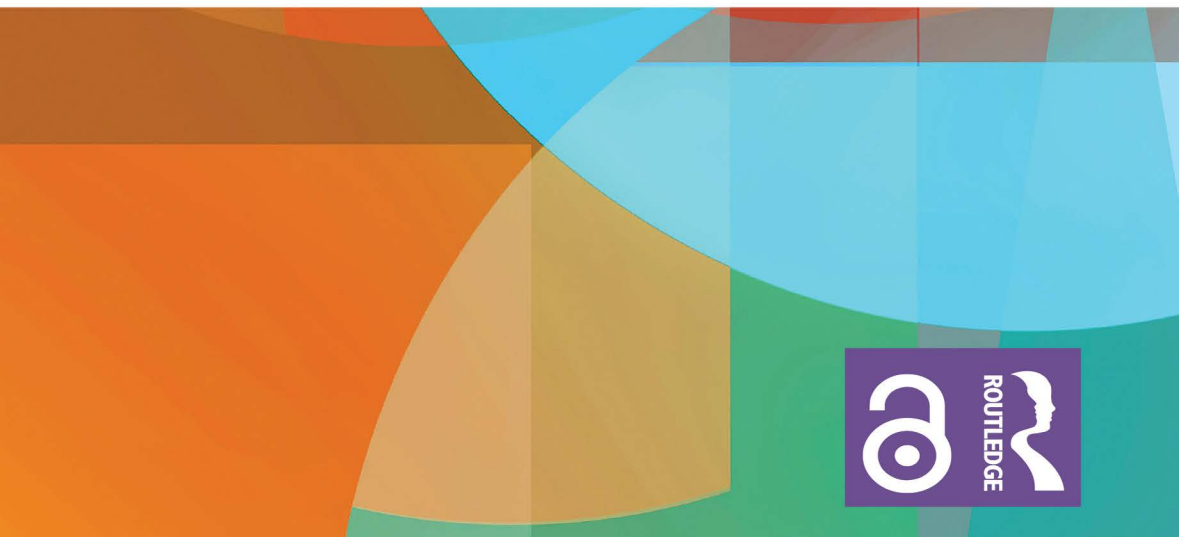
Routledge Research in Gender and Society

HEALTH ACTIVISM AND SEXUAL POLITICS

FEMINIST ENGAGEMENTS WITH HEALTH, ILLNESS AND THE BODY

Edited by
Lisa Lindén, Emily Jay Nicholls and
Josefin Persdotter



Health Activism and Sexual Politics

Health Activism and Sexual Politics: Feminist Engagements with Health, Illness and the Body explores the intersection of health activism and sexual politics through both traditional research chapters and innovative contributions on creative and scholarly practice as activism.

The book showcases the analytical power of feminist research at the intersection of sexuality, health, and activism. As digital technologies create new possibilities and challenges for politics, sex, and health interventions, the contributors demonstrate diverse ways to engage meaningfully with activism. Spanning Latin America, Southern Africa, Northern Europe, the UK, and North America, the collection offers alternative epistemologies to hegemonic biomedical knowledge about illness, pleasure, pain, and marginalization. The interdisciplinary approach incorporates feminist technoscience studies alongside perspectives from the medical humanities, sexuality studies, gender studies, design studies, and drama studies. Each chapter challenges inequities and reimagines possibilities for health and well-being through collective action, creative engagement, and scholarly inquiry. Together, they insist on recognizing the multiplicity of experiences around illness and desire, making knowledge that values lived experiences as communicable, worthy of care, and deserving of recognition.

This book will appeal to scholars, students, activists, and artists interested in health, sexual practice, gender, activism, and public engagement.

Lisa Lindén is an associate professor of gender and technology in the Division for Science, Technology and Society (STS) at Chalmers University of Technology, Gothenburg, Sweden.

Emily Jay Nicholls is a senior research fellow at the Institute for Global Health, University College London, UK.

Josefin Persdotter is an activist-scholar and sociologist, currently a postdoctoral researcher in the Division for Science, Technology and Society (STS) at Chalmers University of Technology, Gothenburg, Sweden.

Routledge Research in Gender and Society

Overcoming Objectification
A Carnal Ethics
Ann J. Cahill

Mapping Queerness in Times of Uncertainty
Stories of Struggle, Invisibility and Space
Arnaud Kurze, Sarah Sturken and Steve The

Intimate Partner Femicide
Contesting the Legal Story
Bethany Wilkinson with Susan Goodwin

Violence, Care, Cure
Self/perceptions within the Medical Encounter
Edited by Marta-Laura Cenedese and Clio Nicastro

Mum Fans
Identity, Feminism and Fan Culture in Contemporary China
Ye Li

Women's Roles in Times of War and Political Violence
Reclaiming Herstory
Inga B. Kuźma and Edyta B. Pietrzak

The Gendering of Hope
Rural and Farming Women's Biographies of Hope, Care and Resistance
Lia Bryant

Health Activism and Sexual Politics
Feminist Engagements with Health, Illness and the Body
Edited by Lisa Lindén, Emily Jay Nicholls and Josefin Persdotter

For more information about this series, please visit: https://www.routledge.com/Routledge-Research-in-Gender-and-Society/book-series/SE0271

Health Activism and Sexual Politics

Feminist Engagements with Health, Illness and the Body

Edited by Lisa Lindén, Emily Jay Nicholls and Josefin Persdotter

Routledge
Taylor & Francis Group
LONDON AND NEW YORK

First published 2026
by Routledge
4 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge
605 Third Avenue, New York, NY 10158

Routledge is an imprint of the Taylor & Francis Group, an informa business

Open Access has been made possible through funding from Linköping University and Chalmers University of Technology.

British Library Cataloguing-in-Publication Data
A catalogue record for this book is available from the British Library

ISBN: 978-1-032-33481-3 (hbk)
ISBN: 978-1-032-33480-6 (pbk)
ISBN: 978-1-003-31981-8 (ebk)

DOI: 10.4324/9781003319818

Typeset in Galliard
by Apex CoVantage, LLC

Contents

Figures

Contributors

Sofia Cifuentes Contador

Sofía Cifuentes Contador is a PhD student in anthropology at the University of Pittsburgh, USA. Since 2021, she has been involved in the menstrual movement, collaborating on different menstrual initiatives as a researcher, menstrual activist, and educator. Her research focuses on the Latin American menstrual movement.

Kelsey Ichikawa

Kelsey Ichikawa is currently a PhD student in history of science at Harvard University, USA, where she focuses on the scientific, securitized, and medical discourses underlying studies of violence. Her background is in science and technology studies, neuroscience, and philosophy. Previously, she worked on collaborative projects about the politics of open science and biomedical algorithms.

Ericka Johnson

Ericka Johnson is a professor of gender and society at Linköping University, Sweden. She has an interdisciplinary background in sociology, gender studies, and science and technology studies. She is the author of several monographs and anthologies, including *A Cultural Biography of the Prostate* (MIT Press, 2021), and editor of *How That Robot Made Me Feel* (MIT Press, 2025). She is a member of the Royal Swedish Academy of Sciences.

Lisa Lindén

Lisa Lindén is an associate professor of gender and technology in the Division for Science, Technology and Society (STS) at Chalmers University of Technology, Gothenburg, Sweden. She takes an interest in how medical technologies and forms of knowledge are enacted, mobilized, and contested in public settings and in everyday healthcare.

Katharine Low

Dr Katharine Low is a practitioner-researcher and senior lecturer in performance and medical humanities at King's College London, UK. She has over

20 years' experience in socially engaged theatre research and sexual health, gender equity, and violence, in the UK and internationally. Her collaborative research practice is embedded in collaborations with arts organizations, medical practitioners, and NGOs to co-facilitate participatory theatre and arts-based projects.

Emily Jay Nicholls

Dr Emily Jay Nicholls is a senior research fellow at the Institute for Global Health University College London, UK. She is a sociologist interested in HIV, sexual health, and health activism. She previously worked at Goldsmiths, University of London, UK, and at the London School of Hygiene and Tropical Medicine, UK.

Venla Oikkonen

Venla Oikkonen is an associate professor at the Tampere Centre for Science, Technology and Innovation Studies, Tampere University, Finland. She has published on the cultural aspects of population genetics and genetic ancestry testing, evolutionary narratives, vaccines and epidemics, self-tracking, pharmaceuticals, and gendered chronic illness and pain.

Josefin Persdotter

Josefin Persdotter is a postdoc at the Division for Science, Technology and Society (STS), Chalmers University of Technology, Gothenburg, Sweden. She holds a PhD in sociology, focusing on everyday technologies of menstruation and the gendered histories of hygiene infrastructures, and works on menstruation and menopause in the workplace.

Marie Louise Juul Søndergaard

Marie Louise Juul Søndergaard, PhD, is a designer and researcher of digital technologies for sexual, menstrual, and reproductive health. Through her feminist design practice, she challenges the status quo of FemTech and shows how technologies could be designed differently to foreground values of embodiment, community, and ecology.

Maria Temmes

Maria Temmes is a postdoctoral researcher in the project *Gendered Chronic Disease, Embodied Differences and Biomedical Knowledge* (GenDis), funded by the Research Council of Finland and the Kone Foundation. Her current research focuses on patient activism and the biomedical management of endometriosis and hormonal migraine.

Louise Ann Wilson

Louise Ann Wilson creates site-specific art and performance that emplaces life events in rural landscapes. Her work has addressed breast cancer and surgery, hysterectomy and menopause, terminal illness and bereavement,

and childlessness-by-circumstance. She holds a PhD in theatre and is the author of *Sites of Transformation*: *Applied and Socially Engaged Scenography in Rural Landscapes* (Bloomsbury, 2022).

Helen Zhao

Helen Zhao holds a PhD in philosophy from Columbia University, USA. Her dissertation critically examined a prevailing conception of feminist science as value-guided science. She has authored articles on counterfactual history, radical science, and sociogenetics, and she is currently a law student with interests in the intersections of labour, gender, the administrative state, and law and organizing.


Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

Part 1
Introduction


Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

1 Introduction: engaging health activism, sexual politics, and feminism

Lisa Lindén, Josefin Persdotter, and Emily Jay Nicholls

Introduction

This edited volume is far timelier than we would have wished. As we write this introduction, we are doing our best to keep up with news from the US where Trump and Musk are rapidly wreaking havoc on sexual and reproductive rights, openly attacking women's health, transgender people, and sexual minorities. To state just some of the many examples, they are issuing a global gag rule on abortion care and banning government agencies from using words such as "gender," "transgender," and "LGBTQ" (Aman, 2025; Harman, 2025; Sekimpi, 2025). Sadly, these policies are part of political currents across the globe, not least evident in the global backlash of abortion rights in the last couple of years (Brysk, 2025), including the overturn of *Roe vs Wade* in the US in 2022. We are at a critical moment for sexual and reproductive rights and transgender and women's health. At the same time, we see how feminists, queer folks, researchers, and others mobilize and join forces, across geographical and thematic boundaries alike. The Green Wave movement ("Marea verde" in Spanish), formed in 2018 around legalizing abortion in Argentina, is an excellent example (Center for Reproductive Rights, 2025). Mobilizing under the slogan "to decide is my right," it not only has grown to encompass activists across all of Latin America but also has managed to establish common ground between trans and feminist/women's movements around reproductive justice (Fernández Romero, 2020) and inspire global and local reproductive rights movements across the world (Braine & Velarde, 2022; Hernandez, 2022; Morales-Garcia & Dahya, 2024).

This edited volume is intended for scholars, students, activists, and artists with an interest in topics of health, sexual practice, gender, activism, and/or public engagement, working across the critical social sciences, public health, and medicine, as well as through creative practice. We hope that its collection of research on, and with, contemporary activism and the politics of health and sexuality can provide a source of community and comfort as well as inspiration, tactics, and tools for moving forward. Scholarship in feminist, queer, and other critical branches of the social sciences has long explored the nexus of gender and sexual politics and activist engagements with health and medicine,

DOI: 10.4324/9781003319818-2

for example, in relation to HIV/AIDS activism, trans health activism, and women's reproductive health. The research has shown how activists and organizations have worked to empower women, LGBTQ+ people, and other marginalized groups, challenged healthcare professionals, and influenced research and policy in medicine and health. Scholarship has highlighted activist efforts to challenge and destabilize the (bio)-medicalization of women's and trans people's bodies, movements to combat neglect of marginalized health issues, as well as countering of stigmatization and discrimination in health and healthcare. This scholarship has also engaged with political questions through its critical and engaged methods and theories, aiming to utilize research as a means to increase public visibility, destabilize the pathologization of women's and transgender bodies, and counter-act the discrimination of stigmatized groups in healthcare.

This interdisciplinary edited volume is indebted to, and expands, this existing feminist and queer scholarship. Under the umbrella of *health activism and sexual politics*, it gathers heterogeneous, yet interconnected, research fields engaging with health and activism, as well as politics of gender and sexuality. The volume brings together contemporary scholars, activists, and artists whose work aims to advance how to think of activism, health, illness, healthcare, and medicine. Some of the contributors are scholars researching activism in the realm of health, gender, and sexuality. Others are artists, designers, and/or researchers who in their chapters reflect upon the activist tenets and/or implications of their work. Several of the contributors are positioned as several or all these things, operating across societal, disciplinary, and methodological boundaries.

How it started

The idea for this edited volume dates back to shared concerns that two of us editors began exploring just before the COVID-19 pandemic hit in 2020. One of us (Lisa) did a postdoc on gynaecological cancer patient activism, and the other (Emily) was part of a research project on how histories of HIV had been mobilized in HIV policy and activism. Both working in the areas of Science and Technology Studies (STS) and medical sociology – with a keen interest in feminist theories and public engagement methods and studies – we started discussing what we experienced as current lack of overlaps and conversation between work on women's (reproductive) health activism on the one hand and the big field of critical engagements with HIV activism on the other hand. While we were aware of research about the 1980s and 1990s breast cancer and HIV/AIDS movements that made linkages between these areas (King, 1992; Diedrich, 2007; Klawiter, 2008), we experienced that they currently – in STS, sociology, and feminist research – existed somewhat in silos. We started talking about other examples connecting health activism to issues of sexuality, such as work related to men, reproduction and health, and we discussed the increase of trans health activism. We saw a value in exploring what would

happen if we gathered all these areas of research under the same umbrella. We decided to propose an open conference panel at one of the major conferences in the STS community: the joint Society for Social Studies of Science (4S) and European Association for the Study of Science and Technology (EASST) 2020 conference.[1]

To our joy, our open panel *Engaging Health Activism, Sexual Politics and Feminist Theory* received so many abstracts that it became no less than three sessions with four presentations in each. There were so many themes and forms of health activism that we had not thought of when drafting the call for abstracts! The conference abstracts included examples of contemporary areas of health activism, covering everything from HIV and pre-exposure prophylaxis (PrEP) activism (Adam Christianson), menstrual activism (Liting Ding), and pro-feminist DIY activism for the development of contraceptives for men (Miriam Klemm). To our surprise, the abstracts, and then conference sessions, also included designers and practitioners who combined social science and feminist thinking with design methods to develop devices and technologies. This included a presentation on open-source DIY menstrual technologies, by sociologist and software developer Marie Kochsiek and researcher and designer Marie Dietze. It also included a presentation on a prototype for a gender-inclusive device utilizing a dental dam-like barrier for cunnilingus and analingus, by researcher and dentist Anisha Gupta and her colleague Carly Billing. Furthermore, the panel attracted examinations of attendees' own scholarly practice as a form of health activism, such as through the example of *The GenderSci Lab*, a collaborative and interdisciplinary research lab focused on generating feminist methods, notions, and theories for scientific research on sex and gender (see Chapter 10, this volume).

There was a lot of excitement and enthusiasm throughout the three panel sessions. While it now, in a post-pandemic 2025, feels like long ago, Lisa and Emily still remember the inspiring feeling of having created something that many seemed to have longed for. A part of the excitement had to do with the panel having taken such unexpected directions – in terms of the topics, approaches, and forms of activism involved – directions so wholly unanticipated. We found ourselves in the midst of what felt like a booming and creative space of not only studies of health activism, gender, and sexuality but also scholarly and artistic engagements that spoke back to us as researchers, by exploring and transforming how feminist and queer theories can be made use of in relation to design and artistic work to achieve societal change. The panel, as a whole, developed into a sense of community, expanding researchers, designers, artists, and activists who all had a joint interest in exploring what contemporary health activism and sexual politics could mean, be, and result in.

Since our panel took place, engagements with health, illness, gender, and sexuality have flourished. Grassroot and activist movements that sit at the intersection of health and/or illness, gender, and sexuality are expanding rapidly. This includes, for example, social media accounts advocating for increased

awareness and better healthcare for specific body- or disease-related matters. In the Swedish context, to take an example close to two of us editors, social media activism connected to endometriosis has gained strong momentum over the last couple of years, with several accounts pushing for the need to make endometriosis pain visible to the public and for crucial improvements in healthcare. The same goes for social media connected to trans health: a range of accounts currently advocate for transgender people's right to good gender-affirmative healthcare and/or aim to provide support and knowledge to transgender communities. More classical forms of health activism have also, in relation to current events of the world, emerged. The growth and expansion of the Green Wave movement, mentioned above, is one example. In the design context, we see a growth of grassroot design interventions for female bodies and trans-bodies, and this serves as another excellent current example. We mentioned open-source DIY menstrual technologies above, and this exemplifies this well. Other examples are collectives of feminist and trans bio-hackers, such as the GynePunk movement (Thorburn, 2017) and TransHackFeminist movement (Mahr, 2021). Simultaneously, a diverse space of startups and organizations draws upon narratives from feminist health movements to market so-called FemTech products for the cis-female body (and sometimes also for non-binary or trans bodies). While feminist research has examined both their "oppressive consequences and liberatory possibilities of innovations" (Burt-D'Agnillo, 2022, p. 13), these grassroots and corporate developments nevertheless suggest that, in the midst of backlash and turmoil, a diverse space addressing marginalized bodies and illnesses is unfolding. This volume is situated in the midst of these transformations.

As goes for many edited volumes, this book has taken its time; some contributing authors have dropped out along the way, and others have joined. In early 2024, Lisa and Emily were joined by Josefin Persdotter as a third editor. As a sociologist and feminist thinker with a decades-long interest and expertise in menstrual health research, activism, and art, Josefin has substantially contributed to this edited volume. Furthermore, we are happy that so many of the authors in the volume have joined in our effort to make this a collective process. We have worked actively with creating a community, for example, through joint online meetings where we have read and discussed each other's works in progress.

In what follows, we start by providing some definitions of key notions we use, and then we provide a brief mapping of key scholarly engagements with health activism and sexual politics, including both studies of health activist organizations and actors and studies exploring creative practice as an activist space.

Health activism? Sexual politics?

The decision to use the wording "health activism" needs to be broken down into its parts: *health* and *activism*. The emphasis on "health" refers back to our

need of a broader term compared to other often used formulations, such as "patient activism" (Petersen et al., 2019) and "healthcare activism" (Geiger, 2021). Following others in their use of "health activism" (Epstein, 2003), we adopt a take on activism that is not delimited to patients or to healthcare but that nevertheless concerns health, medicine, and quite often patients. Our understanding of health activism partly overlaps with the classical definition provided by Brown and Zavestoski (2004, p. 679) of "health social movements." They define health social movements as "collective challenges to medical policy, public health policy and politics, beliefs systems, research and practice which include an array of formal and informal organizations, supporters, networks of cooperation and media." Yet, as Geiger (2021, p. 5) writes, whereas the wording movement

> conjures up images of large and relatively well-organized networks potentially spread over many different organizations, the term activism fully recognizes the political dimension of such collective action yet also acknowledges that this action may not always be carried out by a highly organized or indeed internally cohesive grouping.

The notion of health activism allows us to incorporate different forms of challenges to the dominant orders in health and medicine that can involve organizations and networks or individuals and collectives formed only indirectly via common causes or political goals. Importantly, the wording "activism" is also productive as it allows us to incorporate creative practice and academic work as forms of health activism, such as in the forms of "art activism" (Allen, 2009) and "scholar-activism" (Rasch et al., 2022).

By employing the wording "sexual politics," we actively enrol a long feminist tradition of scholarship. We are inspired by how Carver and Mottier (1998, p. xi) employ the notion to look at "the role of sexuality as a societal phenomenon in relation to politics in a wider context, on the one hand, and the responses of the state to changing ideas about sexuality in society, on the other hand." While we consider this to be a productive definition, we do not wish to delimit the scope to the state, or to relations between the state and its citizens. Instead, with sexual politics, we refer to diverse politics of, and collective actions related to, sexuality. More specifically, in this edited volume, sexual politics refers to collective action and political tactics initiated and deployed by social movement actors, scholars, artists, and others to achieve change within ideas and practices of sexuality. We highlight "sexual" rather than "gender" to afford specificity into health activism connected to sexual practice, sex-organs, and/or reproductive health. In addition, the wording "sexual politics" also allows encompassing how sexuality and gender intersect: with politics of sexuality comes politics of gender.

Thus, we suggest that *health activism and sexual politics* incorporate challenges to the dominant orders in health, medicine, and sexuality that sometimes involve organizations and networks and other times only loosely

connected individuals and/or collectives formed via common causes or political goals. In this definition, we do not, however, include the range of conservative and reactionary health activisms that might be interpreted as fitting our scope of activist actors and/or networks engaging sexual and/or gender politics. This includes, not at least, contemporary pro-life activism (Swank, 2021) and anti-trans/gender-critical activism (Amery & Mondon, 2024). While we acknowledge that all forms of health activism encompass tension, complexities and are non-innocent, we nevertheless want to highlight that these health activisms stand outside – and often in opposition – to the forms of mobilization we envision in this edited volume.

Mapping the field

In this section, we provide a mapping of the field. This mapping is, however, by no means complete. Instead, it is a partial product that we hope can nevertheless provide a common platform. We also view the mapping as an opportunity to make visible some of the connections between empirical and activist areas often not put in dialogue with each other and balance the contributions of this edited volume with other key areas of relevant activism that are not covered in the contributing chapters, such as trans health activism. Indeed, the final version of the edited volume is slightly imbalanced in terms of gender identities and bodies: most chapters address activism focusing on cis-women's health and significantly less address activism related to cis-male-, trans-, and non-binary health. Nevertheless, we hope this mapping contributes to an inclusive and productive version of what the field of health activism and sexual politics could look like, that works with and across boundaries of gender and sexuality. As our mapping shows, existing research demonstrates how health activism connected to gender and sexuality has forcefully politicized medical and healthcare complexes, such as by showing how medical institutions and medical research marginalize and stigmatize already vulnerable groups in society. While health activists at some times have fought against patriarchal medicine and other times against a homophobic society, a recurrent politics – that we still see today – is one that fights against stigma and shame. This has taken different forms: think of the stigma that was so strongly connected to gay men during the 1980s AIDS epidemic, the shame involved in the norm of concealing one's menstruation, or the shame of living with cervical cancer, a cancer connected to female sex-organs and culturally associated with a "promiscuous lifestyle."

Before we go on with the actual mapping, we want to briefly discuss some overarching issues. First, we start our mapping below with accounts of US- and UK-based activism from the 1960s and 1970s. Although this follows the typical narrations of health activism and movements, we do it with some ambivalence, mainly because of the obvious Anglocentrism and also because social movements around, for example, abortion rights have a much longer history. Yet we see key connections and historical trajectories between the health activism

politicizing sexuality and gender, ranging from the 1970s (second-wave feminism), the 1980s (queer activist responses to the AIDS epidemic), and the 1990s (third-wave feminism), with current developments in the area. The field of health activism, gender, and sexuality has had an anglophone epistemic centre, with main research works and movements coming from the US (Epstein, 1996; Morgen, 2002; Klawiter, 2008; Bobel, 2010; Murphy, 2012) constituting the primary reference point to which others relate. These US publications have marked out the route for research into current areas such as gynaecological cancer activism (Lindén, 2021a, 2021b, see also Chapter 3, this volume), PrEP HIV activism (Jones et al., 2020), menstrual activism (Bobel, 2010; Frisk et al., 2023, see also Chapter 4, this volume), and endometriosis activism (Hallström, 2024). We try to nuance this Anglocentrism by including research from other parts of the world. Moreover, we are happy to include a range of geographical places and perspectives represented in the edited volume as such.

Second, we start our mapping in the 1960s to highlight how current forms of health activism and creative work connected to politics of sexuality and gender strongly draw upon feminist second-wave cultural resources of the private as political (Nelson, 2015). The demonstrations after the overturning of *Roe vs. Wade* and the Green Wave are good examples: the slogans "bans of our bodies" and "to decide is my right" connect current protests to those 50 years ago where women declared rights to abortion through the slogan "our bodies, our rights" (Solinger, 1998). Another is transgender people protesting with similar wordings: "trans people's bodies, trans people's choices" and "our bodies, our courts" (National Women's Law Center, 2022). Importantly, such cultural resources from past feminist health movements and second-wave feminism somewhat unite current forms of health activism connected to gender and sexuality (Mahr, 2021). Notably, while the relationship between current trans health movements and women's health movements is complex and marked by both historical tension and intense collaboration (Gupta & Pearce, 2024), we hope that highlighting such commonalities might further support already existing solidarities and collaboration between transgender and feminist health activist communities.

Third, health activism into sexual politics has worked in close proximity with feminist, queer, and/or other social justice organizations and movements, fully or partly outside scopes of health and medicine. Working in tandem with organizations and movements oriented toward feminist, queer, and social justice matters, these forms of activism gather around issues of supporting liveable lives for marginalized groups in society. This also makes these forms of health activism different from how patient activism has more typically been viewed as a matter of patients politicizing and mobilizing patients' own knowledge *per se*. In the settings where actors politicize health areas covered in this edited volume, such knowledge from patients and other concerned actors is always entangled with power dynamics and tactics of gender and sexuality.

Fourth, we want to pinpoint that feminist and queer research, on health, gender and sexuality as well as other themes, has a long tradition of doing

research with political and transformative goals. Countering epistemic injustices, misrecognition, and marginalization, such research has aimed to contribute to social justice, better healthcare and increased visibility of marginalized and/or stigmatized topics, bodies, and diseases. Such research has typically worked from an ethos of "situated knowledges" (Haraway, 1988), where the positioning of the researcher as feminist and/or queer is entangled with the knowledge production of the researcher. Moreover, in research into health activism, gender, and sexuality, the researcher has not seldom been part of the movement and/or patient community it studies (e.g. Morgen, 2002; Pearce, 2018; Severs, 2024) – and has utilized this situated knowledge to do engaged research. This blurring of scholarly and activist work is home-terrain for one of us editors, Josefin, who works in the area of critical menstruation studies. Whereas conservative voices typically highlight this blurring of the boundaries between academia and activism as a threat to academic rigor, what existing research in the field of critical menstruation studies highlights is the vital resources activism affords in terms of producing socially engaged research that is grounded in the issues and stakes that are at the core of concerned communities (Bobel & Fahs, 2020; see also Persdotter, chapter 9, this volume). To give another example, in trans health research, there is a long history of trans people also doing trans research. Pearce (2018), for example, positions herself as an "activist-expert" that is credible through both her training as a scholar and her trans patient experience and involvement in activist communities and circles. Using these two examples, we emphasize that while not all queer, trans, and feminist research (within and outside the context of health activism) describes itself as activist, the tradition of doing transformative research is often a core of feminist and queer research. Many of the chapters in this edited volume build upon this legacy – not least those in Part 4.

The women's health movement and breast cancer activism

Embodying the slogan of the private as political, the feminist classic of *Our Bodies, Ourselves* by the Boston Women's Health Book Collective is one of the most iconic examples of knowledge production within the women's health movement. Its first commercial edition, published in 1973 in the US, utilized "women's embodied experiences as a resource for challenging medical dogmas about women's bodies and, consequently as a strategy for personal and collective empowerment" (Davis, 2007, p. 2). Drawing largely upon women's own embodied experience of reproduction and reproductive issues, it included information about topics such as women's sexuality, menstruation, vaginal health, abortion, birth control, pregnancy, and childbirth.

Our Bodies, Ourselves has been translated, adopted, and updated over the years. Today, versions of the book exist in 34 languages, including Arabic, Japanese, Luganda, Russian, and Portuguese, just to mention a few (OBOS, 2025). The book has been modified and changed to fit local specificities, revealing a complex, ambivalent, and complicated picture of feminism, health activism, and sexual politics (Davis, 2002). In light of critique against

global feminism as a form of cultural imperialism missioning a white and middle-class version of feminism to the rest of the world, Davis (2002) shows that the strategies used by local health collectives and translators have, to a large extent, been sensitive toward "the local political and cultural climate as well as to differences and schisms within their own feminist movements" (Davis, 2002, p. 241). *Our Bodies, Ourselves* has not only for generations shaped how women understand their bodies, sexuality, and health but has also been a catalyst for patient advocacy organizations and forms of health activism, across the world. It serves as a key example of how women have gathered and produced knowledge, aimed at both increased self-knowledge and more inclusive and just healthcare practice. Deliberately building upon the legacy of *Our Bodies, Ourselv*es, other examples of initiatives connected to lay knowledge, sexuality, and gender have emerged. A key example is *Trans Bodies, Trans Selves* (Erickson-Schroth, 2014/2022), which provides information to the trans community, in a similar vein as *Our Bodies, Ourselves* has done to cis-women.

Whereas the example of *Our Bodies, Ourselves* shows in part a complex picture of movement and change in relation to the US and to feminism, other examples further help in telling a geographically complex and nuanced story of the women's health movement. Ram (1998) shows that the urban middle-class women's health movement in India in the 1990s can be understood as a form of contestation over Western (second-wave) feminist notions of choice, autonomy, and right to one's body: meanings of modernity, by involved activists, were situated in local postcolonial specificities and appropriated for this movement's own purposes. Relatedly, Bracke (2023) demonstrates that the constitution of the notion of women's reproductive rights – notably through the establishment of the global articulation of reproductive rights principles at the 1994 United Nations (UN) Conference on Population and Development – was formulated through collaborations and contestations between women's health activists and groups in the Global North and in the Global South. Examples such as these add to, and complexify, the typical narrations of the women's health movement, as stemming from the US and UK (Bobel, 2010; Morgen, 2002; Nelson, 2015; Murphy, 2012). Nevertheless, the women's health movement, as Nelson (2015) writes, "shifted the struggle to revolutionize health care to a focus on ending the sex discrimination and gender stereotypes perpetuated in mainstream medical contexts" (Nelson, 2015, p. 2). Adding to this picture, Morgen (2002) highlights how the movement politicized women's collective, yet heterogeneous, knowledge:

> The power of its collective vision and action grew on many different root stocks, out of the experience of individual women in many different locations – experience that was nevertheless common enough that women recognized their own feelings in others as they talked together about their interactions with the health care system, especially around reproductive issues.
>
> (Morgen, 2002, p. 13)

Finally, Murphy (2012) narrates the US women's health movement through its relations to biomedicine, science, and technology. She shows how women, women's organizations, and feminist health clinics experimented with, and mobilized around, women's reproductive health and biomedicine as a feminist project. In particular, she details how women and women's groups in the 1970s and 1980s "appropriated, revised, and invented reproductive health techniques" (Murphy, 2012, p. 1): they made photographic diaries of cervical variation, crafted health manuals, examined menstruation with microscopes, and formed artificial insemination groups. As this makes clear, the women's health movement did not simply take distance from biomedicine and its technologies but did in multifaceted ways appropriate and reinvent biomedicine to "seize the means of reproduction" (Murphy, 2012).

While the breast cancer movement in part has been influenced by – and overlaps with – the women's health movement, it is primarily known as its own movement. Indeed, the vast impact that the breast cancer movement – if it is possible to talk about it as one singular movement – has had on contemporary health activism and sexual politics cannot be underestimated. The breast cancer movement today is widely known through commercial "pink ribbon" campaigns. This version of the movement has been extensively critiqued for reproducing dominant politics of femininity and for their non-critical positioning toward the cancer-industry complex (King, 2004; Klawiter, 2008; Waples, 2013). In contrast to current pink incarnations of the breast cancer movement, during its earlier days in the 1990s, US (Klawiter, 2008) and UK (Gibbon, 2006) breast cancer activists directed the attention to patriarchal oppression of elected politicians, the healthcare sector, and the cancer establishment and argued that breast cancer was neglected in medical research and in government's research investments. These activists saw the breast cancer issue as an "institutional neglect of women's health in the form of gender bias" (Kolker, 2004, p. 82); they demonstrated topless to make visible their mastectomies and to show the need to politicize breast cancer and its sexual politics. Doing so, they drew upon feminist tactics: they broke the silence around breast cancer by making scars, breasts, bald scalps, and illness stories visible to the public – and by showing that the personal is political.

The tactic of making visible the body with/after breast cancer to the public has also been common in artistic work. Lorde's (1980) *Cancer Journals* is another key example of work that politicizes breast cancer through the lens of the personal. In her writings about her breast cancer diagnosis and her critique of breast cancer culture, she forcefully described the intersecting politics of illness, activism, and sexual politics. Envisioning a strong feminist collective of "one-breasted women," she argued that "the socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other" (Lorde, 1980, p. 16). Cartwright (1998) analyses Lorde's (1980) writings alongside the breast cancer arts activism performed by women with/after breast cancer like Jo Spence, where she and other artists have photographed their one-breasted and scarred bodies and/or hair loss. As Cartwright

(1998) highlights, in doing so, these artists simultaneously politicize breast cancer and trouble dominant normativities of heterosexual, youthful femininity. Similarly, Radley and Bell (2007) argue that artworks produced by women with breast cancer have an important role "in making visible and collective the ideological issues surrounding this disease" (Radley & Bell, 2007, p. 366). In analysing the photography by women with/after breast cancer, they show how women through art demonstrate how their experiences of biopsy and mastectomy are enmeshed with power relations connected to sexuality and gender.

Just as the women's health and breast cancer movements in the 1970s to 1990s have been key for the development of contemporary forms of health activism – not at least when connected to sexuality and/or gender issues – so has HIV/AIDS activism. In feminist and other critical research, it is also typically highlighted that breast cancer activists in the 1990s learnt tactics and mobilization practices from HIV/AIDS activist groups such as ACT UP in the US. Also, queer components of HIV/AIDS activism and breast cancer activism are often highlighted by feminist and queer scholars, such as through attention to the involvement of lesbian/queer women (King, 1992; Kaufert, 1998; Klawiter, 2008). This leads us to the next step in our mapping of health activism and sexual politics: HIV/AIDS activism.

HIV/AIDS activism

Next to breast cancer, HIV/AIDS activism[2] is likely the most well-known example of health activism – within and outside the context of politics of gender and sexuality. Not least because of that, this activism constitutes a crucial component in what health activism related to gender and sexuality has been, is today, and may become in the future. This is also evident in the amount of social science research into this field. The research has largely followed the different phases of HIV treatments, such as the early clinical trials during the 1980s and its activist responses (Gamson, 1989; Epstein, 1996), the development of antiretroviral therapies (ART) for the treatment of HIV and the transformation of HIV into a chronic illness (Chan, 2015), and the arrival of PrEP for HIV prevention in 2012 (Jones et al., 2020; Martinez-Lacabe, 2021). This research area has, to a large extent, explored interconnections between HIV/AIDS activism and gay activism (Gamson, 1989; Epstein, 1996; Jones et al., 2020), but it also includes research into HIV activism for and/or with women (Jungar & Oinas, 2010; Watkins-Hayes, 2019) and transgender people (Kirey-Sitnikova, 2024).

Epstein (1996) famously examines how US-based ACT UP AIDS activists managed to gain expertise to assess and assert scientific credibility and to achieve "a seat at the table" to impact on the conduct of AIDS medical research. Through this lens, Epstein did not only contribute to STS and sociological research into how activists and patients manage to achieve the status of "lay experts" but also to how this form of health activism incorporates politics of sexuality, gender, and identity. Further, adding feminist and sociological

perspectives on emotions and affect to current understandings of health activism, Gould (2009) analyses AIDS activism, embodied in and through ACT UP's public demonstrations, protests, and meetings, as a form of "moving politics" that inhabits emotions like anger and pleasure, as well as bodily intensities. She shows how ACT UP in the US functioned as a space of sex radicalism, queer sexual practices, and diverse gender expressions.

To take a more recent example, in the context of PrEP activism in the UK, Jones et al. (2020) highlight how activists portray "an imagined gay community whose past, present, and hopeful future is entangled within the complexities and contractions of a state-funded health system," and where PrEP functions as an orientation of an "imagined gay communities towards a hopeful future by demanding and accessing essential medicines and ensuring the absence of needless HIV transmissions" (Jones et al., 2020, p. 172). Notably, Jones et al. (2020) show how PrEP activism culturally positions PrEP as a hopeful counter-point toward stigma and shame. We highlighted above how current health activism connected to sexuality and gender connects to cultural resources from second-wave feminism and its slogan of "our bodies, ourselves." Differently, the example of PrEP activism shows how current incarnations of HIV activism rather draw upon community tropes and tactics from the 1980s AIDS epidemic to highlight issues of stigma, marginalization, and hope. To take a final recent example, Severs (2024) traces the radical HIV/AIDS movement in late twentieth-century England. In examining the UK version of ACT UP, he portrays a HIV/AIDS activism that ranges from "radical acts" of demonstrations and marches to "everyday activism" played out in workplaces, universities, and church halls across England. In addition to addressing how ACT UP gathered around gay politics, he also addresses how groups formed in England focused on women living with HIV, such as Positively Women.

As with the women's health movement and the breast cancer movement, there is something of an Anglocentrism in research into HIV/AIDS activism. This is in particular the case for research investigating the relation between HIV/AIDS activism and gay activism where the research has been "primarily informed by the American experience," as Chua and Hildebrandt put it (2014, p. 1583). In contrast, in studies on women and HIV activism, a common focus has been on southern Africa (Manchester, 2004). However, a range of examples that complicates this picture of studies about gay HIV/AIDS activism in the Global North and HIV/AIDS activism for and with women in the Global South exists. Jungar and Oinas (2010, p. 188) analyse HIV activism – encompassing not only women but also men and transgender people – in South Africa as a feminist struggle "connected to private and public politics – questions of dignity, rights and inequalities." Watkins-Hayes (2019, p. 14) examines how women living with HIV in the US have engaged in "transformative projects" and used "their power, however limited, to create dramatic and positive personal and social change while simultaneously engaging with the social, political, and economic conditions they seek to escape or

alter." There is also research that focuses on HIV in relation to global health governance studying HIV across national boundaries. Drawing on research conducted across eighteen countries, Chan (2015) highlights how AIDS activists across the world are united in how they act as "knowledge makers and breakers" in relation to scientific and governance actors. More specifically, through case studies into different geographical contexts, she zooms in on how HIV/AIDS activist groups deal with, for example, matters of stigmatization and human rights in the Middle East and with access to treatment and the criminalization of HIV transmission in Africa.

Research about HIV/AIDS activism, as research on breast cancer activism, has included explorations of creative practice and the arts as activism. Indeed, the HIV/AIDS epidemic in the 1980s (Hallas, 2009; Cifor, 2022), its aftermath (Björklund & Larsson, 2018) and current lives with HIV (Campbell & Gindt, 2018; Coombes, 2019) have generated a vast body of artistry and archival projects to collect political experiences and knowledge about HIV/AIDS. This includes scholarship documenting the use of the arts to destigmatize and increase knowledge about lives with HIV in southern Africa (Allen, 2009; Coombes, 2019; see also chapter 6, this volume). Following how "art activism" (Allen, 2009) has come to play an important role in the fight against HIV in southern Africa such scholarship has investigated how the arts functions as a tool to address and challenge stigma (Coombes, 2019). At the same time, in the context of the Global North, as part of AIDS activism organizations such as ACT UP, the arts and creative media have been utilized in powerful and playful ways to gain public and political attention and achieve societal change (Epstein, 1996; Severs, 2024). For example, Hallas (2009) examines documentary, experimental and narrative queer AIDS media by gay men as an important strand of AIDS activism. Such AIDS video activism, he shows, functions as transformative means to bear witness to the historical trauma of the 1980s AIDS epidemic. As another related example, Cifor (2022) attends to how current activists, artists, and curators shape AIDS archives and collect knowledge about HIV/AIDS and its queer sexual politics, knowledge that otherwise would be marginalized, suppressed, or forgotten.

Emerging forms of health activism and sexual politics

We started this introduction by discussing our sense of excitement in bringing together current research, activism, and artistry in areas connecting health activism to politics of sexuality and gender, both in terms of activist groups and organizations and in terms of scholarly, design and artistic explorations that define, or reflect upon, their work as a form of activism. As presented above, there currently seems to be an intense increase in both the amount of activism the scholarly interests in this area. We see three key themes in the research on contemporary forms of health activism and sexual politics:

First, there is an increased amount and attention to trans health activism research and practice in recent years. In particular, as a *gender dysphoria*

diagnosis is typically used as a prerequisite for trans-affirming legal and healthcare services, trans health activism, and transgender people engaged in such activism, have formed a complex relation to processes of pathologization of transgender identities, and the depathologization movement has pushed for the removal of gender transition from diagnostic classification systems and manuals (Burke, 2011; Davy et al., 2018). Hanssmann (2023), based on ethnographic fieldwork in New York City and Buenos Aires, shows how trans health activists have taken on the project of depathologization. Using an STS perspective, he traces how trans-activists in both settings enrol medical statistics and personal biographies to reveal state violence directed against trans-people. Through this work, he also demonstrates the importance of understanding transphobia in relation to gendered racism, ableism, and anti-poverty – something which also exemplified an intersectional approach to issues of health activism and sexual politics. While this is just one example of recent work on trans health activism, it speaks to broader themes and needs of conceptualizing work within health activism and sexual politics through a multilayered lens. Hanssmann's work on trans health activism encourages analytical and political attention to feminist politics that not only moves beyond the binary of men and women but also encompasses an intersectional social justice lens to health activism in general. Another example is a recent study by Blus-Kadosh and Hartal (2024, p. 1) in which the authors examine how the Israeli trans community has responded to trans-exclusionary features and institutionalized discrimination by accumulating communal experiential knowledge and transferred it to physicians and policymakers in a localized and informal manner.

Second, the research highlights how the impact of social media on women's reproductive health activism and trans health activism has been, and continues to be, huge in the last decades. Recent research into trans health activism highlights social media as a key space for collective support, public visibility, and political mobilization (Ciszek et al., 2023). Lindén (2021a, 2021b) shows that much gynaecological cancer activism today happens in online settings, via social media platforms. In scholarship on menstrual activism, social media has been positioned as a key catalyst of the recent growth of the movement, as well as having shaped how activism is carried out (Haymond, 2020; Zhou et al., 2022; Tomlinson, 2025). Research on abortion activism (Belfrage et al., 2021; Hunt et al., 2022), side effects from contraceptives activism (Gunnarsson & Wemrell, 2023; Turrini, 2023) and endometriosis activism (Zhao et al., 2024; Seo et al., 2025; and Chapter 2, this volume) present similar accounts. Through social media, emerging health activism has gained unprecedented visibility, enabling individuals and communities to share personal experiences, mobilize support, challenge medical stigmas, and exert political pressure in ways that transcend traditional institutional and geographic boundaries.

Third, the research highlights how current activists utilize and are inspired by their historical predecessors, often directly building upon previous decades of health activism, such as the example of current activism connected to PrEP provision that builds on existing HIV/AIDS activism (Severs, 2024). We also

see how contemporary menstrual activism iconize and get inspiration from feminist artists such as Judy Chicago in the 1970s (Mørk Røstvik, 2019). As another telling example, Lindén's research into gynaecological cancer patient activism (2021a, 2021b; see also Chapter 3, this volume) also showcases how activists enroll tropes of gynaecological cancer as a stigmatized women's illness that is neglected and under-funded. In doing so, Lindén highlights, activists effectively borrow tactics from the breast cancer movement of past decades.

This volume and its contribution

The edited volume includes traditional research chapters on studies *about* health activism but expands from this to also include chapters on creative and scholarly practice *as* health activism. By elaborating on different modes of health activism and sexual politics – in creative practice and through scholarly work – the volume situates different modes of feminist, queer, and critical engagements with health activism and sexual politics today. It is our hope that this book will contribute to discussions of the location of feminism, critical thinking, and activism in scholarship and public engagement. While several of the contributing chapters use theoretical perspectives from feminist technoscience studies, many of them also deploy approaches from other feminist perspectives, as well as from fields such as the medical humanities, sexuality studies, gender studies, and design and drama studies. As such, it is our hope and belief that this book's interdisciplinary scope will allow it to travel between and across disciplinary boundaries, communities, and conversations. Finally, we hope that this collection of works can assist in current critical efforts to safeguard and strengthen human rights to good and just healthcare.

The contributions in this volume are organized into four parts, each reflecting a distinct yet interconnected perspective. This introductory chapter (Part 1, Chapter 1) introduces the overarching themes of the edited volume, provides a mapping of the research field, and sets the stage for what follows. Part 2 focuses on health activism and public mobilization, exploring contemporary examples of how activism has brought attention to critical health issues and worked to reshape healthcare practices, policy, and education. In Chapter 2, Maria Temmes and Venla Oikkonen examine endometriosis patient activism in Finland, and in Chapter 3, Lisa Lindén attends to the sexual politics of gynaecological cancer patient activism in Sweden. In both these texts, the authors showcase how patient activism may complement, problematize and further biomedical approaches to healthcare. Temmes and Oikkonen do this by showing how endometriosis, through patient activism in social media and other digital platforms, is allowed to proliferate into multitudes of disease experiences, and multitudes of female and non-binary bodies, engendering productive alternatives to bio-medicalized versions of what personalized and individualized care practices can be. Relatedly, Lindén brings forth how contemporary gynaecological cancer patient activists challenge hegemonic notions of sex as "risky" and "clinical" by carving out a space for sexual practice as

also being about pleasure and desire. Lindén showcases therein, similarly to Temmes and Oikkonen, how activist practices offer alternatives to healthcare: new ways forward for both patients and healthcare professionals. In the following chapter, Chapter 4, Sofia Cifuentes Contador explores health activism outside the role of the patient. Her analysis offers a unique overview of menstrual activism in Latin America, showcasing an array of examples, based on the region's history and postcolonial positionality, contributing with needed perspectives on menstrual health. Cifuentes Contador highlights how menstrual activism has challenged local health policies, as well as normativities of the global menstrual health movement, engendering novel approaches to both language and rationale. Taken together, the three contributions illustrate the multifaceted ways in which activists mobilize to transform medical knowledge, lived experiences, and cultures of gendered and sexualized health.

Part 3 delves into the role of creative practice and the arts as tools in health knowledge and health activism. The three texts present designerly and artistic methods as highly viable ways to share, challenge, and proliferate knowledges of embodied experiences of pleasure and pain alike. In Chapter 5, Louise Ann Wilson invites the reader into her excruciating experience of hysterectomy and surgical menopause in the UK. Connecting to the legacy of artist-patients such as Jo Spence who have shown the power of the arts to challenge medicine and marginalization, she describes the process of creating an immersive art-installation to make her experiences understandable. Her work integrates medicine, menopause, and mountains to enact and transform under-communicated and under-valued knowledge of hysterectomies known to healthcare practitioners as well as future patients. In Chapter 6, Katharine Low highlights feminist performance-making as a method for addressing and challenging the vulnerabilization and victimization of women with HIV and in otherwise marginalized positions. Therein, Low – together with her collaborators – offers the arts as a medium for resistance and transformation. Through collective and creative ways of sharing and knowing otherwise silenced or marginalized stories the performance methods enable reclaiming control of the definitional narratives of health vulnerability that are imposed on marginalized bodies. In Chapter 7, Marie Louise Juul Søndergaard explores feminist strategies for designing sex technologies that challenge patriarchal and capitalist frameworks. Based on her research-through-design practice in the Nordic countries, she positions sexual desire and pleasure as powerful catalysts for change by clashing them against dominant systems of modern-day digital capitalism. She shows how feminist design practices can critically engage with and reimagine sex toys and pleasure technologies and thereby allow for a broader diversity of experiences, as well as for new ways to think about human–technological interactions in sex and sexuality. All three of these contributions invite activists, practitioners, and scholars to think and work with designerly and artistic methods. Compared to more classical academic methods, they show how art and design can birth other ways of knowing, sharing, and learning – and function as forms of health activism that push for social change and/or better healthcare. This includes work that enables

bridging disciplinary and experiential boundaries that otherwise might seem insurmountable, and it makes new things count as relevant for both medicine and politics.

Part 4 situates feminist scholarship itself as a vital form of health activism, showcasing how academic inquiry and activism can intersect to challenge health inadequacy and inequity. In a time where feminist, activist, queer, and critical scholarship is increasingly questioned, this is both timely and crucial. In Chapter 8 Ericka Johnson, based on her and her colleagues' work with prostate care, argues for feminist health activism and scholarship as providing ways to bridge the divide between women's and men's health. In her chapter, issues of toilets and the infrastructures of the city, prostate exams, and men's concern about their prostate are all read through the lens of (lessons from) women's health activism and feminist health scholarship. In Chapter 9, Josefin Persdotter offers a reflection of her experience of being both a sociologist of menstruation and a menstrual activist. She contemplates how the two overlap and interact in rewarding ways and asks how scholars can make use of their specific positionality and power by actively engaging to improve the lives of those they (we) research. In Chapter 10, finally, Helen Zhao and Kelsey Ichikawa offer insights from the GenderSci Lab at Harvard University, demonstrating how feminist empiricism can serve as a form of activism, using scholarly methods to address biases in health research and practice. In addition to intervening in contested science, Zhao and Ichikawa contend that scholars can play the role of movement builders and consciousness-building against hegemonic ways of knowing.

Through these contributions, this edited volume highlights the power of collective action, creative engagement, and scholarly inquiry to challenge inequities and reimagine possibilities for health and well-being. The chapters cover Latin America, Southern Africa, Northern Europe, the UK, and North America. By engaging with these varied cultural and political contexts, the chapters highlight how local dynamics intersect with broader feminist and health-related movements. All contributions, in their respective local cases and contexts, offer alternatives to hegemonic knowledges: alternative epistemologies of illness, pleasure, pain, and marginalization, to ways of thinking about vaginas, prostates, hysterectomies, viruses, and sex-toys. They all insist on the value of that overwhelming chorus of voices: that there is not one uniform experience of illness nor desire, making knowledge that challenges hegemonic biomedical notions of health, bodies, and sexuality. All persist in the pursuit of making lived life understandable: as communicable, as worthy of care and compassion, as worthy of language, and of recognition. Finally, the contributions offer routes of practicing scholarship as well as health activism and sexual politics that make life more just, healthy, and liveable for all.

Notes

1 The conference was supposed to be held in Prague, but because of the COVID-19 pandemic it was held online.

2 Here, we use "HIV/AIDS activism" to refer to historical activism, where actors conceptualized themselves as "AIDS activists" or activism prior to the identification of HIV, and "HIV activism" to describe more contemporary activist responses.

Reference list

Allen, R. (2009). Art activism in South Africa and the ethics of representation in a time of AIDS. *Critical Arts: A Journal of South-North Cultural Studies*, 23(3), 396–415.

Aman, J. (2025). Trump's banned words and disastrous health policies. *Health and Human Rights Journal*. https://www.hhrjournal.org/2025/02/04/trumps-banned-words-and-disastrous-health-policies/

Amery, F., & Mondon, A. (2024). Othering, peaking, populism and moral panics: The reactionary strategies of organised transphobia. *The Sociological Review*, 00380261241242283.

Belfrage, M., Didier, E., & Vázquez-Quesada, L. (2021). Voicing abortion experiences to reduce stigma: Lessons from an online storytelling platform in Mexico. *Women's Reproductive Health*, 9(3), 203–217.

Björklund, E., & Larsson, M. (Eds.). (2018). *A visual history of HIV/AIDS: Exploring the face of AIDS film archive*. London: Taylor & Francis.

Blus-Kadosh, I., & Hartal, G. (2024). "We have knowledge that is unique": Patient activism and the promotion of trans-inclusive primary care. *Social Science & Medicine*, *344*, 116654.

Bobel, C. (2010). *New blood: Third-wave feminism and the politics of menstruation*. New Brunswick: Rutgers University Press.

Bobel, C., & Fahs, B. (2020). The messy politics of menstrual activism. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T. A. Roberts (Eds.), *The Palgrave Handbook of Critical Menstruation Studies*, 1001–1018. London: Palgrave.

Bracke, M. A. (2023). Contesting 'global sisterhood': The global women's health movement, the United Nations and the different meanings of reproductive rights (1970s–80s). *Gender & History*, 35(3), 811–829.

Braine, N., & Velarde, M. (2022). Self-managed abortion: Strategies for support by a global feminist movement. *Women's Reproductive Health*, 9(3), 183–202.

Brown, P., & Zavestoski, S. (2004). Social movements in health: An introduction. *Sociology of Health & Illness*, 26(6).

Brysk, A. (2025). *Abortion rights backlash: The struggle for democracy in Europe and the Americas*. Oxford: Oxford University Press.

Burke, M. C. (2011). Resisting pathology: GID and the contested terrain of diagnosis in the transgender rights movement. In P. J. McGann, D. Hutson, & B. K. Rothman (Eds.), *Sociology of Diagnosis*. Bradford: Emerald Group Publishing Limited.

Burt-D'Agnillo, M. (2022). FemTech: A feminist technoscience analysis. *The iJournal: Student Journal of the Faculty of Information*, 8(1), 13–23.

Campbell, A., & Gindt, D. (2018). *Viral dramaturgies: HIV and AIDS in performance in the twenty-first century*. Cham: Springer International Publishing.

Cartwright, L. (1998). Community and the public body in breast cancer media activism. *Cultural Studies*, 12(2), 117–138.

Carver, T., & Mottier, V. (1998). *Politics of sexuality*. London: Routledge.

Center for Reproductive Rights. (2025, March 14). *Latin America's green wave*. https://reproductiverights.org/latin-america-green-wave/

Chan, J. (2015). *Politics in the corridor of dying: AIDS activism and global health governance*. Baltimore: Johns Hopkins University Press.

Chua, L. J., & Hildebrandt, T. (2014). From health crisis to rights advocacy? HIV/AIDS and gay activism in China and Singapore. *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 25, 1583–1605.

Cifor, M. (2022). *Viral cultures: Activist archiving in the age of AIDS*. Minneapolis: University of Minnesota Press.
Ciszek, E., Haven, P., & Logan, N. (2023). Amplification and the limits of visibility: Complicating strategies of trans voice and representations on social media. *New Media & Society*, 25(7), 1605–1625.
Coombes, A. E. (2019). Positive living: Visual activism and art in HIV/AIDS rights campaigns. *Journal of Southern African Studies*, 45(1), 143–174.
Davis, K. (2002). Feminist body/politics as world traveller: Translating our bodies, ourselves. *European Journal of Women's Studies*, 9(3), 223–247.
Davis, K. (2007). *The making of our bodies, ourselves: How feminism travels across borders*. Durham: Duke University Press.
Davy, Z., Sørlie, A., & Schwend, A. S. (2018). Democratising diagnoses? The role of the depathologisation perspective in constructing corporeal trans citizenship. *Critical Social Policy*, 38(1), 13–34.
Diedrich, L. (2007). Doing queer love: Feminism, AIDS, and history. *Theoria*, 54(112), 25–50.
Erickson-Schroth, L. (Ed.). (2014). *Trans bodies, trans selves: A resource for the transgender community*. Oxford: Oxford University Press.
Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. Berkeley: University of California Press.
Epstein, S. (2003). Sexualizing governance and medicalizing identities: The emergence of 'state-centered' LGBT health politics in the United States. *Sexualities*, 6(2), 131–171.
Fernández Romero, F. (2020). "We can conceive another history": Trans activism around abortion rights in Argentina. *International Journal of Transgender Health*, 22(1–2), 126–140.
Frisk, M., Andreasen, L. U., Søndergaard, M. K., Røstvik, C. M., Ghanoui, S. L., & Persdotter, J. (2023). Exploring critical menstrual studies in the Nordic region: The importance of local specificities. *Nursing Clio*. https://nursingclio.org/2023/10/04/exploring-critical-menstrual-studies-in-the-nordic-region-the-importance-of-local-specificities/
Gamson, J. (1989). Silence, death, and the invisible enemy: AIDS activism and social movement "newness". *Social Problems*, 36(4), 351–367.
Geiger, S. (Ed.). (2021). *Healthcare activism: Markets, morals, and the collective good*. Oxford: Oxford University Press.
Gibbon, S. (2006). *Breast cancer genes and the gendering of knowledge*. London: Palgrave Macmillan UK.
Gould, D. B. (2009). *Moving politics: Emotion and ACT UP's fight against AIDS*. Chicago: University of Chicago Press.
Gunnarsson, L., & Wemrell, M. (2023). On the verge between the scientific and the alternative: Swedish women's claims about systemic side effects of the copper intrauterine device. *Public Understanding of Science*, 32(2), 175–189.
Gupta, K., & Pearce, R. (2024). From conflict to collaboration: Solidarity and compromise in trans and women's movements. In S. L. Connaughton & S. Pukallus (Eds.), *The Routledge Handbook of Conflict and Peace Communication*. London: Routledge.
Hallas, R. (2009). *Reframing bodies: AIDS, bearing witness, and the queer moving image*. Durham: Duke University Press.
Hallström, I. (2024). Endo episteme: Epistemic injustice and the misrecognition of endometriosis. *Feminist Philosophy Quarterly*, 10(4).
Hanssmann, C. (2023). *Care without pathology: How trans health activists are changing medicine*. Minneapolis: University of Minnesota Press.
Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3), 575–599.

Harman, S. (2025). We must fight even harder to protect women's health in the era of Trump and the global right. *BMJ*, 388.
Haymond, R. (2020). #PeriodsAreNotAnInsult: Hashtag activism meets menstruation. *Women's Reproductive Health*, 7(2), 73–86.
Hernandez, J. (2022, June 27). How green became the color of the abortion rights movement. *NPR*. https://www.npr.org/2022/06/27/1107717283/abortion-rights-green-symbol
Hunt, L. K., Goldstein, C. M., Garnsey, C. L., Bogen, K. W., & Orchowski, L. M. (2022). Examining public sentiment surrounding abortion: A qualitative analysis of #YouKnowMe. *Women's Reproductive Health*, 9(4), 237–258.
Jones, C., Young, I., & Boydell, N. (2020). The people vs the NHS: Biosexual citizenship and hope in stories of PrEP activism. *Somatechnics*, 10(2), 172–194.
Jungar, K., & Oinas, E. (2010). A feminist struggle? South African HIV activism as feminist politics. *Journal of International Women's Studies*, 11(4), 177–191.
Kaufert, P. A. (1998). Women, resistance and the breast cancer movement. In M. Lock & P. A. Kaufert (Eds.), *Pragmatic Women and Body Politics*. Cambridge: Cambridge University Press.
King, K. (1992). Local and global: AIDS activism and feminist theory. *Camera Obscura: Feminism, Culture, and Media Studies*, 10(1), 78–99.
King, S. (2004). Pink Ribbons Inc: Breast cancer activism and the politics of philanthropy. *International Journal of Qualitative Studies in Education*, 17(4), 473–492.
Kirey-Sitnikova, Y. (2024). Transgender HIV activism in Eastern Europe and Central Asia. *Sexualities*, 13634607241260205.
Klawiter, M. (2008). *The biopolitics of breast cancer: Changing cultures of disease and activism*. University of Minnesota Press.
Kolker, E. S. (2004). Framing as a cultural resource in health social movements: Funding activism and the breast cancer movement in the US 1990–1993. *Sociology of Health & Illness*, 26(6), 820–844.
Lindén, L. (2021a). Moving evidence: Patients' groups, biomedical research, and affects. *Science, Technology, & Human Values*, 46(4), 815–838.
Lindén, L. (2021b). Running out of time: The case of patient advocacy for ovarian cancer patients' access to PARP inhibitors. *Sociology of Health & Illness*, 43(9), 2141–2155.
Lorde, A. (1980). *The cancer journals*. Argyle, New York: Spinsters.
Mahr, D. (2021). Radical feminist movements and the re-imagination of performative epistemology. In D. Mahr (Ed.), *The Knowledge of Experience: Exploring Epistemic Diversity in Digital Health, Participatory Medicine, and Environmental Research*. Cham: Springer.
Manchester, J. (2004). Hope, involvement and vision: Reflections on positive women's activism around HIV. *Transformation: Critical Perspectives on Southern Africa*, 54(1), 85–103.
Martinez-Lacabe, A. (2021). The PrEP response in England: Enabling collective action through public health and PrEP commodity activism. *Critical Public Health*, 31(2), 226–234.
Morales-Garcia, M., & Dahya, A. (Hosts). (2024–present). *Green tide rising*. [Podcast] https://greentiderising.com/
Morgen, S. (2002). *Into our own hands: The women's health movement in the United States, 1969–1990*. Rutgers University Press.
Murphy, M. (2012). *Seizing the means of reproduction: Entanglements of feminism, health, and technoscience*. Duke University Press.
National Women's Law Center. (2022). *Our bodies, our futures: Connecting abortion rights and trans and intersex rights*. https://nwlc.org/resource/our-bodies-our-futures-connecting-abortion-rights-and-trans-and-intersex-rights/

Nelson, J. (2015). *More than medicine: A history of the feminist women's health movement*. New York: New York University Press.
OBOS, Our Bodies Ourselves. (2025, April 3). *Global translations and adaptations of "Our bodies, ourselves"*. https://ourbodiesourselves.org/global-projects
Pearce, R. (2018). *Understanding trans health: discourse, power, and possibility*. Bristol: Policy Press.
Petersen, A., Schermuly, A. C., & Anderson, A. (2019). The shifting politics of patient activism: From bio-sociality to bio-digital citizenship. *Health*, 23(4), 478–494.
Radley, A., & Bell, S. E. (2007). Artworks, collective experience and claims for social justice: The case of women living with breast cancer. *Sociology of Health & Illness*, 29(3), 366–390.
Ram, K. (1998). Ná Shariram Nádhi, My body is mine: The urban women's health movement in India and its negotiation of modernity. *Women's Studies International Forum*, 21(6), 617–631.
Rasch, E. D., van der Hout, F., & Köhne, M. (2022). Engaged anthropology and scholar activism: Double contentions. *Contention*, 10(1), 1–12.
Røstvik, C. M. (2019). Blood works: Judy Chicago and menstrual art since 1970. *Oxford Art Journal*, 42(3), 335–353.
Sekimpi, C. (2025). Trump's global gag rule on abortion care will damage women's health, rights, and futures. *BMJ*, 388.
Seo, H., Burkett, K. M., Okocha, M., Ha, H., Chaif, R., Izhar, N., Coelho, M. B., Jona, B., & Iqbal, A. (2025). Social media activism and women's health: Endometriosis awareness and support. *Digital Health*, 11, 20552076251314905.
Severs, G. (2024). *Radical acts: HIV/AIDS activism in late twentieth-century England*. Bloomsbury Publishing.
Solinger, R. (1998). *Abortion wars: A half century of struggle, 1950–2000*. Berkeley: University of California Press.
Swank, E. (2021). The gender conservatism of pro-life activists. *Journal of Women, Politics & Policy*, 42(2), 124–137.
Thorburn, E. D. (2017). Cyborg witches: Class composition and social reproduction in the GynePunk collective. *Feminist Media Studies*, 17(2), 153–167.
Tomlinson, M. K. (2025). The impact of the media and the mediated menstrual movement on young people's attitudes towards activism, menstruation, and menstrual stigma. In M. K. Tomlinson (Ed.), *The Menstrual Movement in the Media. Palgrave Studies in Communication for Social Change*. Cham: Palgrave Macmillan.
Turrini, M. (2023). "There are many of us": Online testimonies from 'pill victims' as a new form of health activism. *Qualitative Health Research*, 33(7), 567–577.
Waples, E. (2013). Emplotted bodies: Breast cancer, feminism, and the future. *Tulsa Studies in Women's Literature*, 33(1), 47–70.
Watkins-Hayes, C. (2019). *Remaking a life: How women living with HIV/AIDS confront inequality*. Berkeley: University of California Press.
Zhao, X., Feigenbaum, A., & Tønnesen, Ö. D. (2024). Between comments and collective action: The potential of TikTok in Endometriosis advocacy. *International Journal of Communication*, *18*, 23.
Zhou, Q., Qiu, H., & Yang, X. (2022). Social-mediated frame alignment: A study of menstrual activism in China during the COVID-19 pandemic. *Asian Journal of Women's Studies*, 28(3), 358–381.


Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

Part 2

Health activism and public mobilization


Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

2 The changing landscape of endometriosis activism in Finland: at the crossroads of personalization and digitalization of health

Maria Temmes and Venla Oikkonen

Introduction

Several ongoing societal changes are reshaping the environment in which patient activism takes place. One significant development is the emergence of national personalized medicine initiatives and strategies. Such initiatives and strategies maintain that unique bodies need to be treated with tailored strategies that reflect the specific characteristics of the patient, such as their sensitivity to drug compounds (Hood & Flores, 2012; Prainsack, 2017). As Lindén (2021c) has shown with ovarian cancer patient activism in Sweden, patient organizations have a central role in mediating knowledge of targeted treatment options as well as lobbying for the national approval for new medications. Another central development affecting patient activism is the digitalization of society. The digitalization of health care manifests in the increasing use of telecare and eHealth technologies in the treatment of a growing number of conditions (Roberts et al., 2012; Schwennesen, 2019; Warr et al., 2021). It is also visible in the popularity of online platforms, especially social media channels, for the promotion of health information, the formation of peer support, and campaigns for public recognition of health conditions (Petersen et al., 2019).

This chapter asks how these two ongoing developments impact patient activism on a common chronic gynaecological illness: endometriosis. Individual differences in symptoms and treatment outcomes constitute an important challenge in the treatment of endometriosis. Endometriosis is characterized by the growth of endometriosis tissue (tissue similar to the uterine lining) outside the uterus. The ways endometriosis tissue responds to changes in the body's hormonal levels differ between people, resulting in considerable variation in patterns of inflammation and pain, which may range from periodic and moderate to constant and debilitating. Endometriosis is still largely treated with hormonal products, yet it is estimated that a third of endometriosis patients experiencing pain do not respond to hormonal medication (Taylor et al., 2021). The need for targeted drug therapies is widely recognized, but no new targeted drugs are currently accessible in clinical care (Dolmans & Donnez, 2022). At the same time, the clinical treatment of endometriosis increasingly

DOI: 10.4324/9781003319818-4

acknowledges the need for personalized treatment in that different patients are understood to benefit from different types of care, such as physiotherapy and sexual counselling (Chapron et al., 2019). We are interested in the role of patient activism in envisioning personalized care, especially in how patient activism draws attention to what types of individual differences fall outside the current logic of biomedical care and targeted treatment. We suggest that patient activism makes visible differences that are highly relevant for the improvement of care but that are not captured by biomedical approaches to personalized medicine. In doing so, we raise questions about what personalization is understood to be about in contemporary health care and biomedicine and show the relevance of patient activism in bringing up concerns about how individualized care is realized. At the same time, we argue that digitalization provides significant new platforms through which patient activism draws attention to tensions around ideas of good care arising from the plurality of endometriosis as an illness and the differences among endometriosis patients.

Focusing on endometriosis activism enables us to explore specific challenges that patient activism on gendered illnesses need to tackle when addressing questions of personalization and digitalization of health. Previous social research on endometriosis has traced the ways in which patient activism and peer support around endometriosis foreground gendered embodied experiences of illness and its treatment (Seear, 2016; Whelan, 2003, 2007). The history of doctors misdiagnosing or underestimating pain related to gynaecological conditions calls for a continuing emphasis in endometriosis activism on the gender-specific nature of diagnosis and treatment. At the same time, ongoing discussions concerning non-binary gender and transgender have made it clear that the category of "women" does not adequately capture the embodied, lived realities of many endometriosis patients. Endometriosis activism is thus faced with the challenge of highlighting the gendered nature of the illness without resorting to essentialist and binary categorization of gender.

We argue that the move toward digitalization and personalization of treatment emphasizes both the urgency and difficulty of this balancing act. Crucially, the need to balance between a collective, gendered experience – endometriosis as a women's disease – and individual, differently gendered experiences also shows that digitalization and personalization of health care have complicated implications seldom articulated in healthcare initiatives and strategies. Focusing on a gynaecological patient organization and social media endometriosis activism in Finland, we trace how patient activists navigate the tensions between the multitude of embodied differences that underpins personalization and digitalization initiatives and the conceptualization of menstruation related pain and disorders as binarily gendered in health care.

Changing forms of patient activism in Finland

We approach patient activism as a broad field that covers both established and structured forms of advocacy such as patient organizations and more informal

types of activism such as social media blogging. These types of activism are not separate: patient organizations in Finland are increasingly providing social media training to activists who are interested in blogging about their experiences with illness to reach wider audience, especially young people. At the same time, there are many bloggers who are not trained by a patient organization but who share content created by the organization while discussing their personal experiences with illness or providing information about endometriosis. We do not approach these sites as separate from one another but rather as overlapping and relational, with the same people sometimes participating in multiple forms of activism.

Patient organizations represent the formally organized end of the activism continuum. Patient organizations play an important role in many countries, advocating, for example, for the public recognition of underrecognized diseases, further biomedical research on diseases they represent or better availability of important drugs (Lindén, 2021b, 2021c; Moreira, 2011; Panofsky, 2011; Rabeharisoa et al., 2014). In Finland, patient organizations are a common site of patient activism. For a country of less than 6 million people, Finland has a remarkable number of registered patient organizations: a 2010 study (Toiviainen et al., 2010) identified 130 patient organizations, with the oldest one established at the end of the nineteenth century and with significant increase in numbers especially since the 1970s. Unlike more informal or exploratory forms of patient activism, Finnish patient organizations have formalized structures, often consisting of a national steering committee and local associations or subgroups, as well as clearly defined objectives and established sets of practices (Toiviainen et al., 2010).

In Finnish society, patient organizations are widely seen as mediators between patients, clinics, policymakers, and the pharmaceutical industry. As Toiviainen and colleagues note, they "have traditionally been considered to represent objectivity, independence, the common or specific 'good' and the patient's best interest in social realm, with clear activities and boundaries" (Toiviainen et al., 2010, p. 231). Accordingly, many of the patient organizations – especially the older and larger ones for widely recognized diseases – focus on peer support and coordination of services, and many operate in close collaboration with hospitals and pharmaceutical companies (Toiviainen et al., 2010). However, also smaller and younger organizations, such as the gynaecological patient organization discussed in this chapter, have often established connections with key clinicians and specialized public clinics. Reflecting this perceived mediator role, patient organizations are eligible for public funding. The conditions of such funding, at the time of our data collection, required that patient organizations continued to strengthen their core operations, but organizations could also apply for additional project funding to, for example, develop strategies to increase patients' participation (Suominen, 2021). While the funding guidelines left space for new forms of activism within patient organizations, the organizations needed to carefully consider potential forms of activism in terms of their perceived role as mediators.

These formal structures of patient organizations shape what kind of activism around endometriosis is possible. As patient organizations are expected to represent their entire membership situated across the political spectrum, it could be challenging for the representatives of an organization to frame the organization's activities as being explicitly feminist. Tensions in how patient activism operates in relation to feminist politics have also been identified in the case of other gendered illnesses, for example, breast cancer activism (e.g. Klawiter, 1999, 2008). Yet the activities and goals of patient organizations on so-called women's diseases are informed by observations shared by feminist health activists globally: that conditions affecting primarily women are understudied, that women's experiences of pain are underdiagnosed and undertreated, and that many women struggle to have their experiences acknowledged during healthcare appointments (e.g. Cleghorn, 2021; Davis, 2007; Lindén, 2021b). This chapter shows that the tensions between activism and mediation, and the aim to address gendered biases in medicine, underlie how the gynaecological patient organization is able to respond to the changing landscape of health care in Finland.

The role of patient organizations within the healthcare sector is expanding in the Nordic countries as public health policies seek to involve patients in health research. Importantly, such policies see patient organizations as a medium through which patients can be recruited in clinical research (Sand et al., 2020, p. 120). Furthermore, while patient organizations have traditionally provided peer support within their own peer groups, emerging healthcare policies seek to involve people with illness experience in the clinical context. These *expert patients* are trained by regional health service authorities, and increasingly also by patient organizations (Jones & Pietilä, 2020; see also Boulet, 2016). In the context of personalized medicine initiatives, how to increase participation by the patients and patient organizations is viewed as one of the key challenges for the successful implementation of broader changes in health care (Stefanicka-Wojtas & Kurpas, 2023). Nevertheless, Finnish patient organizations' role in the implementation of such policies remains undefined (Jones & Pietilä, 2018).

At the same time, the role of experience-based expertise is expanding with digitalization and new forms of patient activism on social media. While digital media has shaped the patient organizations' work since the 1990s and organizations' own Facebook accounts and moderated discussion forums have been established forms of social media presence for more than a decade, platforms such as Instagram, TikTok, and various blog sites are providing new channels through which individual stories of illness can be told to hundreds of followers (Kerr et al., 2021; Petersen et al., 2019). For illnesses such as endometriosis, often characterized by uncertainty and versatility of symptoms between patients, social media offers space for documenting diverse experiences in receiving care and could help clinicians to gain a new perspective (Holowka, 2022). However, increasing digitalization does not necessarily lead to new forms of activism but can, rather, adjust to existing expectations for good

citizenship, working with the established environment instead of openly challenging it (Schermuly et al., 2021).

Our study shows that patient organizations are increasingly providing social media training for patient activists. Individuals have also started to frame their personal social media accounts in relation to their experiences with endometriosis. In the Finnish language context, social media accounts focusing on endometriosis have begun to emerge in the past few years, especially on Instagram. These accounts are mostly personal accounts, depicting everyday life, but they also include accounts organized by groups aiming to share information about endometriosis. Some of the personal accounts have later become associated with the gynaecological patient organization, tagging the organization in selected posts. Some other bloggers have no link to the organization on social media but might participate in the organization's other activities. The patient organization has also aimed to increase its social media presence with an additional Instagram account directed at young people. The account's social media content is produced by voluntary members who have the freedom to design the posts as they wish and often produce content about their own experiences.

Materials and methods

The materials analysed in this chapter were collected as part of a larger research project on the treatment of gendered chronic illness in Finland, *Gendered Chronic Disease, Embodied Differences and Biomedical Knowledge*, launched in 2021 and funded by the Research Council of Finland and Kone Foundation. As part of the project, we have conducted interviews with people living with endometriosis, clinicians specializing in endometriosis, healthcare professionals working at endometriosis clinics, and representatives of a gynaecological patient organization, as well as patient activists who have been active on social media. In this chapter, we draw primarily on interviews with the patient organization and patient activists. The data includes four in-depth interviews with current and past representatives of patient organizations and eight in-depth interviews with patient activists. Additionally, we drew on 16 in-depth interviews with people living with endometriosis to better understand the role of the patient organization and patient activism in the lives of people with endometriosis. In addition to the interviews, we have analysed the publicly available materials produced or circulated by the patient organization, such as materials produced for schools, as well as their public websites and public social media channels. We have also followed endometriosis health activists on social media platforms, such as Instagram and Facebook, to gain a sense of themes brought up on these platforms.

The patient organization was established as an endometriosis organization but has since evolved into a broader gynaecological patient organization, covering also three other gynaecological conditions. The organization currently has under 2000 members. Its activities include both established forms of advocacy, such as a quarterly magazine for members and annual theme weeks on

each of the diseases, and newer forms of advocacy, such as a blogsite addressing younger audiences and the development of a self-tracking app for symptoms and medication. The organization employs four people in its office in a large urban centre, while local activities across the country are mostly carried out by volunteers. As stated on the organization's public website, it intends to be a reliable and responsible societal actor committed to long-term advocacy, providing correct and up-to-date information, and emphasizing participatory activities. This role of the organization as a provider of accurate information and peer support became clear in our interviews with people living with endometriosis: 12 out of the 16 participants mentioned the patient organization or the Facebook peer support group run by the organization when asked where they found information and help.

The interviews with patient organization representatives and patient activists were semi-structured. With patient organization representatives, the interviews focused on the organization's strategies and practices and especially changes over time as well as future challenges. With patient activists, the interviews focused on their personal involvement in activism and their experiences of the current cultural contexts in which activism takes place. In analysing the interviews, we paid special attention to mentions of challenges and opportunities for patient activism on gendered chronic illness as well as similarities and differences among our interlocutors' experiences of patient activism. In the sections that follow, we first explore the ways Finnish endometriosis activism is situated in relation to health care structures and outline the strategies and preconditions of activism, and then we move to the challenges and opportunities posed by the larger societal processes described above.

Possibilities and need for collaboration with clinicians in endometriosis activism

When asked about the state of endometriosis care in Finland, patient organization representatives as well as other patient activists highlighted that doctors often missed endometriosis-related symptoms, dismissing them, for example, as "normal" menstrual pain. They also saw regional differences in gaining a diagnosis and treatment for endometriosis. The need to raise awareness among clinicians was a theme that recurred in our interviews. However, while the representatives of the patient organization raised awareness of problems in the Finnish healthcare system, their criticism was mostly targeted on the difficulties in accessing specialized care in the first place, not the specialized care itself. From the point of view of the patient organization, the collaboration with specialists appeared as a personal and confidential connection with a shared interest in offering the best possible care for gynaecological illnesses.

The collaboration with clinicians took multiple forms in the patient organization. Representatives described their collaboration with key clinicians as "ordinary" as they had regular contact with them and saw that this was a normal practice for patient organizations in general. The main form of collaboration was clinicians sharing their expert information by checking the accuracy

of the medical information used in the organization's materials or by giving public lectures. Other forms of collaboration had also emerged from the patient organization's projects. One such example was the development of a mobile self-tracking app to enable a more extensive tracking of symptoms and medication than what was possible with commercial menstrual tracking apps. Developed in consultation with clinicians, the app was established to increase awareness about endometriosis among young people to cut down the delay in endometriosis diagnosis. This provided the patient organization with further ideas for how the self-tracking app could be utilized, for example, by integrating it into clinical treatment. The development of the app is a good example of how digitalization may provide new opportunities for patient activism. It also illustrates the tight link that the patient organization has formed with clinicians. Similar models of collaboration with clinician-researchers have been deployed by patient organizations in other national contexts (Lindén, 2021a; Panofsky, 2011; Rabeharisoa et al., 2014). The integration of the app into existing digital healthcare systems eventually faced challenges such as the hospitals' standardized data security measures. Still, without the link to clinicians, even the plan to integrate the app would have been inconceivable.

From a strategical viewpoint, close collaboration with clinicians was seen by the patient organization as beneficial as funders appreciated that the organization had created close relations with specialized doctors. As the representatives of the gynaecological patient organization noted, the received funding dictates to what extent the patient organization can maintain its core activities and further develop its advocacy. The main funding channel for the gynaecological patient organization is the Funding Centre for Social Welfare and Health Organizations (STEA), where they apply annually for funding for their core activities and extensions to the core activities, as well as new independent projects, such as the self-tracking app mentioned above. While the gynaecological patient organization has received funding from STEA for both its core activities and independent projects, the representatives of the organization highlighted that further funding would be essential for them to increase their activities, as the funding received for core activities goes almost fully to the maintenance of the existing forms of peer support and voluntary work.

The established relations with clinicians were formed with a clear sense of division of duties between clinicians and the patient organization. The patient organization offered clinics the possibility to have people with endometriosis come to share information at the hospital, while information about the organization was spread by the specialized doctors. While it was evident in the interviews with the representatives of the patient organization that they did not wish to go against expert views on treatment, they maintained that the chronic nature of endometriosis allowed for a specific role for the organization in supporting the wellbeing of people. One patient organization representative states:

> The role of a patient organization isn't, and shouldn't be, to replace something that public, or any official, sector can offer. But no official

> healthcare provider can offer extensive support. . . One has to be in really bad chronic pain, the situation has to be difficult before multi-expert knowhow is included and a psychiatrist, physiotherapist, pain specialist, all possible experts, even nutritionists, are brought together. At that point, you are in a specialized clinic.

In this interview quote as well as elsewhere in our interview data, the multi-expert specialized clinics are seen as sites where patients could receive extensive care that could attend to their various individual needs. The notion of individualized care in these instances is equated with the access to specialized clinics with multi-expert teams. However, as the quote indicates, this care would be available only to those with severe chronic pain, suggesting that the patient organization has an important role in the broader structures of endometriosis care. Similar sentiments were raised in the interviews with people living with endometriosis. The available specialized care was often highly regarded and the problem with care was linked to problems in accessing treatment or limitations in how long a person could receive treatment in the specialized clinic. The patient organization was seen as an important source of support and information to fill those gaps.

The above quotation also shows how the notion of chronicity framed the patient organization's relation with available care: if the possibilities of receiving extensive, personalized care were limited, patient organizations could offer tools to support the overall wellbeing of people with chronic illness. The same representative continues in the interview: "when we speak of a chronic illness, it does not end at the point of receiving surgery or good medication." This approach to chronicity informed the organization's activities. They focused, for instance, on raising awareness of the pricing of hormonal products, many of which are not reimbursable even if they are used as the main treatment for endometriosis. Importantly, the organization's limited funding meant that they were not able to allocate enough resources for advocacy. Thus, their main avenue for activism was the nationwide umbrella organization, the Finnish Federation for Social Affairs and Health (SOSTE), under which patient organizations form their specific network. When SOSTE, for example, advocates for better access to treatment or highlights the price of the treatment, the gynaecological patient organization can bring forth specific challenges faced by their members. Their activism, thus, is not framed in terms of "urgency" invoked by patient organizations advocating for the availability of new medication for life threatening illnesses (Lindén, 2021c). Instead, their activism aims to facilitate living with a chronic condition such as alleviating the financial burden on people who need hormonal products for treatment.

Arising tensions – attending to individual differences in health care

While the patient organization representatives stressed the distinction between their work and that of clinicians and noted the high quality of specialized

health care in Finland, they also drew attention to cases that fall outside the existing structures of health care. Such cases include, for example, people who do not respond to available pain treatment options or who find that their gender or sexuality influences the treatment they receive. These examples show the current limits to endometriosis treatment in Finland and, consequently, question the extent to which the current care guidelines can account for individual differences between patients.

When asked about policies concerning pain medication, patient organization representatives acknowledged that some of their members have faced challenges in receiving help. One representative notes in the interview that healthcare policies failed to address the differences in the intensity of pain experienced by people with endometriosis with the result that extreme pain would go untreated:

> I understand the worry and discussions around [pain medications], but, at the same time, you can't abandon a person. This is what happens a lot to our members with serious chronic pain. They are left alone. They are not treated. Because [the healthcare professionals] do not want to prescribe something that's wrong so they prescribe nothing. Then they are left alone with the pain. There's no valid reason for not treating someone. . . . Not treating is not treating. It is so sad to read stories from our patients, how they go to the emergency room, and no one helps them. "Go home, we cannot do anything about your pain." What do you mean you can't? I can't. They are healthcare professionals, they should be able to do something. I don't want to pretend to be a doctor. I don't know what's the best way to treat people in those situations with pain, but it can't lead to not treating them at all.

This answer acknowledges the ongoing politics around strong, especially opioid-based, medication in Finland, where young chronic pain patients, in particular, are not prescribed opioids in fear that they would develop addiction. This answer also maintains the distinction between the role of healthcare sector and the patient organization by acknowledging the reasoning behind the worry of strong pain medication and stressing that the patient organization does not know a better way of organizing treatment for people to whom existing treatment options are insufficient. Simultaneously, however, the answer also points toward the problem of not offering any kind of treatment, which is the case, for example, for people with endometriosis who have undergone all standard treatment options in specialized care but whose pain continues. That is, even within the specialized care context, the available treatment might not meet the needs of the patient.

In these kinds of situations, the patient organization's emphasis was to try to raise awareness among healthcare providers, trying especially to offer further information on how diseases such as endometriosis might influence chronic pain to prevent patients from being labelled as addicts when they ask for stronger pain medication. While the possibilities for the patient organization

to influence treatment options were seen as limited as there were little funds for advocacy, the organization had thought about the possibilities of visiting pain clinics to discuss how patients' gynaecological illness impacts their pain. By drawing attention to the relationship between gynaecological illnesses and chronic pain, the organization hoped to address situations where the available treatment options are not sufficient to cover the individual needs of the patients.

Social media has introduced new platforms for patient activism, giving room for versatile experiences of living with a chronic illness, including experiences from clinics. As most social media accounts discussing endometriosis focus on personal experiences, stories shared through these accounts include critical comments toward received care. This was also the case with bloggers associated with the patient organization. One social media content producer, for example, says in the interview that she was comfortable in sharing content about her own experiences in receiving treatment, which included her frustration toward limited treatment options as she did not want to use hormonal products. Furthermore, social media platforms can help activists to form new collaborations with other activists. One such example is a group behind a social media account dedicated to sharing up-to-date information about endometriosis. One of the aims of this group is to provide information about rare cases or symptoms of endometriosis. A representative of the group comments in the interview: "some [doctors] can still live with the 80s information about endometriosis and diagnose, or not diagnose, patients, even if we have taken huge steps forward in the 2010s in recognizing this disease and theories have changed."

Bloggers linked to the patient organization emphasize in the interviews that they do not feel constrained when talking about their personal experiences in the clinic. Nevertheless, some note that they were hesitant when making critical comments regarding available treatment. One blogger mentions that she prefers to share critical notes about medication on her personal account, even though no one has explicitly forbidden her from sharing these views on the organization's official site. She explains:

> On my personal account, I have actively taken a stance on discussions around medication, on different hormonal drugs and their side-effects and how those are seen in health care. Then in the [patient organization] I feel that it might not be okay to talk, for example, about specific drugs. Of course, this might be all in my head but that's how I've experienced it, that it's easier for me to take a stance on these kinds of things on my own social media account.

This quotation shows the careful balancing act between sharing personal stories and conducting patient activism on social media when representing an organization. Another blogger, who was posting on her own account but affiliated with the organization, saw no issues in critically commenting on

treatment practices. However, she explains that the organization had advised her not to discuss any prescribed strong pain medication she was currently taking in her personal posts. She explains that she would not have done that in any case as "people who have problems with those can really try to find out where you live." She prefers not to talk about strong prescription drugs in her posts publicly due to the fear that someone might try to steal them from her. However, as she saw this guideline mostly as a safety concern, she had still chosen to share information about her hormonal medication as well as stronger pain medication received in the hospital. These two accounts show that the guidelines from the patient organization, as well as the awareness of representing the organization, could shape the individuals' ways of posting.

While the content of the social media posts affiliated with the patient organization was not regulated by the patient organization, some themes were suggested. One such theme was the experiences of people who do not fit into the assumed framings of binary gender and heterosexual relationships. One of the representatives of the organization notes in the interview that the need to raise awareness of trans and non-binary people's experiences in health care has become more prevalent in recent years as more members have shared their personal experiences. She tells us:

> After gender-affirming surgery you can still have endometriosis and then you are being treated in the clinic for women's diseases. How people behave towards you there and whether the experts have enough information about how different hormonal changes and other things might affect your endometriosis. . . . Then there is the general attitude, for example, if you say that you are non-binary, then they might not take into consideration your wish to have a child in the near future. There's no focus on that. If you go to treat your endometriosis as a 20-year-old woman, they might say to you that the situation is so bad that if you want children, you should consider having them within the next two years. But, if you tell them that you are non-binary and, for example, also in a relationship with a woman, then they may disregard the possibility that you want to have children. It can be a difficult situation in any case, and then you yourself have to bring that up and if it's not acknowledged even after that, it's a very difficult situation for a person and a horrible experience of course.

As shown in this quote, the experiences of trans and non-binary people demonstrate that suggested treatment may depend on gendered social expectations. Previous research on trans and non-binary healthcare highlights that trans and non-binary people often have to become experts in their own health care, which is challenging as knowledge on treatment risks is not always available, as is the case with endometriosis treatment (Irni, 2017, Jeffrey et al., 2024). Furthermore, as Steven Epstein (2003) has argued, the integration of LGBT approaches to public health initiatives faces the risk of medicalizing gender

identities and sexualities without attuning to issues faced by the communities. As the above quotation shows, gendered social expectations can impact the treatment in multiple ways. By publishing these kinds of experiences on their social media accounts, the patient organization can help to make visible how clinicians' assumptions about gender or lack of awareness hinder patients' access to treatment.

These cases show the need to rethink the notion of personalization of treatment and what it means from the viewpoint of patient activism. While the distinction between the roles of clinicians and activists was emphasized in the interviews, the multiplicity of experiences that the organization as well as individual activists represent raises critical questions about the types of individual differences that need to be accounted for in the current healthcare context. When we asked the patient organization representatives about the value of personalized medicine, they discussed the highly varied symptoms among the members of the organization. This variability demonstrates the limits of existing treatment: available treatment options cannot cover the needs of everyone. While the representatives of the organization and activists did not disagree with the challenges involved in prescribing potentially addictive pain medication, they did not accept the outcome if it meant that a person would be left without treatment.

To further sum up, social media platforms offer a space for activists to raise awareness about how difficult it can be to receive treatment for a chronic pain condition. Social media platforms also provide a space to directly advocate for a different clinical approach, for example, by tagging politicians in posts commenting on existing pain medication policies. However, drawing a line between sharing personal experiences and critically evaluating the existing healthcare system can be challenging when representing a patient organization. Some of the activists saw that not being affiliated with an official organization gave them more freedom to quickly counter-argue with other social media users' posts, for example, if they saw that statements about endometriosis were not based on existing research. Furthermore, activists' accounts, including those associated with the patient organization, can help to show how the treatment of chronic gynaecological diseases happens in a highly gendered context where patients are assumed to be cis-women. The trans or non-binary patient activists' clinical encounters illustrate how the parameters of "personalized" treatment are shaped not only by biomedical conceptualizations of the body but also by gendered expectations concerning, for instance, hormones and future plans for pregnancy.

Gendered experiences and gynaecological patient activism

The need to challenge gendered assumptions about patients in the gynaecological clinic is evident in the patient organization's encouragement to bring forth experiences by trans and non-binary people. However, abandoning the framework of "women's diseases" altogether was considered challenging.

When asked in an interview about problems that the patient organization has faced when trying to acknowledge trans or non-binary people in their work, a representative of the organization replied:

> We applied [for funding] again, stating that it would be important to acknowledge these groups of people, but the answer [from the funders] has been that there is no need as we didn't receive any money. . . . We are speaking after all about gynaecological illnesses, which are treated under women's diseases. Then this whole thematic, how are we playing this out: how do we acknowledge all the groups and simultaneously work towards gaining recognition for these illnesses in society. It's a complex combo. We would like to recognize all the groups in the best possible way, that's why we applied for the additional funding, so that we could balance with this big picture.

This quote demonstrates that the possibilities to approach gynaecological illnesses without framing them as women's diseases were seen as challenging as the representation of illnesses such as endometriosis as neglected women's diseases has been central in raising societal awareness. As portrayed in this answer, the goal to go beyond this gendered conceptualization of gynaecological illnesses was not seen as effective in terms of funding applications. This highlights the tensions between framing endometriosis in gendered terms (e.g. stating that one in ten women have endometriosis) and addressing experiences that trans or non-binary people have with an illness that is gendered. Seen in this context, digitalization of activism has provided new tools to raise awareness even if no additional funding is received. While the patient organization's social media presence was not established to raise awareness of experiences of trans and non-binary people particularly, but inform young people more broadly about endometriosis, social media has offered a convenient platform to develop their activities. Through publicly shared personal experiences, digital social media platforms have allowed for versatile voices to be represented.

Framing illnesses such as endometriosis as a "women's disease" can be seen to bring strategic benefits as well as help patients share their experiences. Funding applications can continue to highlight that diseases such as endometriosis have not received sufficient research funding because they are not seen to impact men, that the treatment of endometriosis is shaped by a long history of considering pain as a normal part of female bodies due to menstruation and childbirth, and that cultural gendered expectations about sexual activity might push women with endometriosis to have vaginal sex even if it is painful for them. As previous studies show, foregrounding women's experiences in the clinical context has helped to highlight existing neglect toward endometriosis and gendered biases in the medical research and care (see, e.g., Cole et al., 2021; Denny, 2009; Young et al., 2018). From the patient organization's viewpoint, emphasizing gendered aspects of living with gynaecological illness

can function as a basis for peer support as members can find comfort in sharing similar experiences. One of the representatives notes:

> We are talking about patient groups that have long been dispersed because people have felt shame about their own symptoms and so on. Because we are a patient organization and we speak clearly and loudly from one person with an illness to another, shame is not present in those conversations. Because we can speak with a language that we each understand, and we can identify with others' experiences. I feel that it's one of our big strengths at the moment.

Despite differences in experiences of endometriosis among the members of the organization, highlighting some similarities in terms of gendered experiences could thus form a source of communality. Whelan has noted in an earlier study of endometriosis activism that patient groups based on shared experiences face a challenge as "individual group members must be able to 'recognize' their experiential narratives in the group account in order to accept its representativeness" (Whelan, 2007, p. 960). In other words, if members do not share similar experiences, the foregrounding of experiences may no longer provide an effective way to frame the need for the organization.

The notion of gendered shame is present in other gynaecological illnesses as well, and, as a concept, it can help a patient organization to highlight how gynaecological illnesses have not received enough attention (Lindén, 2021b). However, this does not mean that a gendered understanding of shame and societal expectations requires identifying all the members of the organization as women. To the contrary, looking at gynaecological illnesses from the viewpoint of non-normative gender and sexuality can make visible how clinical practices are gendered (Jones, 2021). Examples presented in this chapter have emphasized the value of voicing individual experiences of people with chronic gynaecological illnesses within the patient organization. Comparing different experiences within a similar context can help in identifying the gendered frames of treatment, for example, why pregnancy advice would be given to a young cis-woman but not to a non-binary person. When examining how biomedicine addresses differences between individuals, these kinds of gendered frames of treatment can often be overlooked, but in the work of patient organizations, when representing the multiplicity of experiences, their multidimensional impact on the treatment is shown.

While the organization could raise awareness of versatile experiences, including those of trans and non-binary people, the aim to raise societal awareness about endometriosis still relies largely on speaking of "women's diseases." Patient organization representatives we interviewed noted that it was challenging to balance between emphasizing the gendered history of endometriosis as an women's illness and acknowledging how the very same binary logic dismissed gender and sexual minorities. As advocating for "women's diseases" was still seen as the most effective strategy to receive societal attention and funding,

the organization did not have the monetary means to further develop, for example, societal campaigns or clinical training that would support developing more inclusive practices. This shows the extent to which patient organizations' advocacy is shaped by the funding structures in Finland. Still, emerging digitalization has given organizations more tools to draw public attention to the diversity of experiences of living with gendered chronic illness.

Conclusion

Initiatives to personalize health services and increase digitalization in society are shaping the ways in which patient organizations operate. This chapter has analysed the effects of these ongoing changes on patient activism on gendered chronic illness through the case of endometriosis activism in Finland. Our analysis suggests that these ongoing societal processes pose both challenges and opportunities for activism. Our interview data shows that the official role of patient organizations as mediators structures how a patient organization can respond to such changes. Crucially, funding structures and the need to establish and maintain good collaborative connections with key clinicians shape what new forms of activism and advocacy are considered as feasible and strategically wise. For example, even though the organization we studied is actively attempting to be inclusive and represent the range of gynaecological patients, including non-binary and trans people, they are also acutely aware that it is important to continue to highlight that chronic gynaecological conditions have been understudied and underfunded because they are labelled women's diseases. Sometimes the funding structures concretely limit the possibilities of the organization to promote a new angle. In our case study, the organization had sought funding for inclusivity work to address non-binary gender, transgender, and non-heterosexual patient groups but had not received funds despite their attempts.

Digitalization and personalization often appear as distinct projects in health policy discourse, but they are mutually entangled and inseparable in health activism (Geiger, 2021). Digitalization through social media platforms has enabled wider representation of patient organization's members by making visible diverse experiences of illness and treatment. Digitalization is further enmeshed with questions of increased personalization of care: if experiences of, for example, pain differ and the effects of medication can be unique to each individual, as social media stories suggest, then personalization of health care should take these differences as a starting point for improving care. Yet the kinds of differences made visible through experience-based online activism are not necessarily the kinds of differences that the public health initiatives to personalize medicine seek to address. This poses a challenge for patient organizations, which, in the Finnish context, typically do not wish to directly challenge biomedical models of treatment.

Finally, our study makes visible an issue arising from the entanglement of digitalization and personalization that is specific to patient activism dealing

with so-called women's diseases. Activism through digitalization highlights the multiplicity of gendered embodied experiences, making it clear that "women" is not a uniform category. The experiences of medication working radically differently in different bodies show that the boundaries of "women" as a biomedically meaningful entity are far from fixed. The experiences emerging through digital technologies such as social media platforms demonstrate that the bodies affected by chronic gynaecological conditions are gendered differently, sometimes in non-binary terms. Current societal discussion on gender diversity – especially non-binary gender and transgender – have been noted by the patient activists, who are increasingly trying to avoid pinning chronic gynaecological conditions to essentialized bodily processes – for example, ovulation or menstruation – and instead highlight the biological and medical complexity of these conditions. However, as the discussion about funding structures suggests, activism on gendered health conditions cannot easily abandon the long-standing use of the category of women as a basis of advocacy and support. This echoes the observations made by other feminist scholars on the persistence of the category of women as an organizing principle and a tool of knowledge production in feminist health activism (see, e.g., Murphy, 2012). Even amidst societal discussions about the diversity of gender, the argument that health conditions affecting women have been underfunded and understudied continues to provide a persuasive means through which a gynaecological patient organization can receive funding for their core activities. Yet, our analysis demonstrates, perceived gendered similarities and differences among patients can be mobilized *simultaneously* – even if such mobilizations are structured by unresolved tensions. As we have shown in this chapter, the strength of the patient organization is its ability to represent multiplicity of experiences and, consequently, engender alternative visions of individualized care.

Reference list

Boulet, L. P. (2016). The expert patient and chronic respiratory diseases. *Canadian Respiratory Journal*, 9454506. https://doi.org/10.1155/2016/9454506.

Chapron, C., Marcellin, L., Borghese, B., & Santulli, P. (2019). Rethinking mechanisms, diagnosis and management of endometriosis. *Nature Reviews Endocrinology*, *15*(11), 666–682. https://doi.org/10.1038/s41574-019-0245-z.

Cleghorn, E. (2021). *Unwell Women: A Journey Through Medicine and Myth in a Man-Made World*. London: Weidenfeld and Nicolson.

Cole, J., Grogan, S., & Turley, E. (2021). 'The most lonely condition I can imagine': Psychosocial impacts of endometriosis on women's identity. *Feminism & Psychology*, *31*(2), 171–191.

Davis, K. (2007). *The Making of Our Bodies, Ourselves: How Feminism Travels across Borders*. Durham, NC: Duke University Press.

Denny, E. (2009). 'I never know from one day to another how I will feel': Pain and uncertainty in women with endometriosis. *Qualitative Health Research*, *19*(7), 985–995.

Dolmans, M.-M., & Donnez, J. (2022). Emerging drug targets for endometriosis. *Biomolecules, 12*(11), 1654. https://doi.org/10.3390/biom12111654.

Epstein, S. (2003). Sexualizing governance and medicalizing identities: The emergence of 'state-centered' LGBT health politics in the United States. *Sexualities*, *6*(2), 131–171. https://doi.org/10.1177/1363460703006002001.

Geiger, S. (Ed.). (2021). *Healthcare Activism, Marketization, and the Collective Good*. Oxford: Oxford University Press.

Holowka, E. (2022, November 10). Mediating pain: Navigating endometriosis on social media. *Frontiers in Pain Research*, *3*. https://www.frontiersin.org/articles/10.3389/fpain.2022.889990.

Hood, L., & Flores, M. (2012). A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory. *New Biotechnology*, *29*(6), 613–624.

Irni, S. (2017). On the materialization of hormone treatment risks: A trans/feminist approach. *Body & Society*, *23*(2), 106–131.

Jeffrey, S., Ashton, L., Ferfolja, T., & Armour, M. (2024). Transgender and gender diverse people with endometriosis: A perspective on affirming gynaecological care. *Women's Health*, *20*, 17455057241251974.

Jones, C. (2021). Queering gendered disabilities. *Journal of Lesbian Studies*, *25*(3), 195–211.

Jones, M., & Pietilä, I. (2018). 'The citizen is stepping into a new role' – Policy interpretations of patient and public involvement in Finland. *Health & Social Care in the Community*, *26*(2), e304–311.

Jones, M., & Pietilä, I. (2020). Alignments and differentiations: People with illness experiences seeking legitimate positions as health service developers and producers. *Health*, *24*(3), 223–240.

Kerr, A., Chekar, C. K., Swallow, J., Ross, E., & Cunningham-Burley, S. (2021). Accessing targeted therapies for cancer: Self and collective advocacy alongside and beyond mainstream cancer charities. *New Genetics and Society*, *40*(1), 112–131.

Klawiter, M. (1999). Racing for the cure, walking women, and toxic touring: Mapping cultures of action within the Bay Area terrain of breast cancer. *Social Problems*, *46*(1), 104–126.

Klawiter, M. (2008). *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*. University of Minnesota Press.

Lindén, L. (2021a). Initiators, controllers and influencers: Enacting patient advocacy roles in cervical cancer screening policy practices. In Geiger, S. (Ed.), *Healthcare Activism: Markets, Morals, and the Battle for the Common Good* (pp. 140–164). Oxford: Oxford University Press.

Lindén, L. (2021b). Moving evidence: Patients' groups, biomedical research, and affects. *Science, Technology, & Human Values*, *46*(4), 815–838.

Lindén, L. (2021c). Running out of time: The case of patient advocacy for ovarian cancer patients' access to PARP inhibitors. *Sociology of Health & Illness*, *43*(9), 2141–2155.

Moreira, T. (2011). Health care standards and the politics of singularities: Shifting in and out of context. *Science, Technology, & Human Values*, *37*(4), 307–331.

Murphy, M. (2012). *Seizing the Means of Reproduction: Entanglements of Feminism, Health, and Technoscience*. Durham: Duke University Press.

Panofsky, A. (2011). Generating sociability to drive science: Patient advocacy organizations and genetics research. *Social Studies of Science*, *41*(1), 31–57.

Petersen, A., Schermuly, A. C., & Anderson, A. (2019) The shifting politics of patient activism: From bio-sociality to bio-digital citizenship. *Health*, *23*(4), 478–494. https://doi.org/10.1177/1363459318815944

Prainsack, B. (2017). *Personalized Medicine: Empowered Patients in the 21st Century?* New York: New York University Press.

Rabeharisoa, V., Tiago, M., & Madeleine, A. (2014). Evidence-based activism: Patients', users' and activists' groups in knowledge society. *BioSocieties*, *9*(2), 111–28.

Roberts, C., Mort, M., & Milligan, C. (2012). Calling for care: 'Disembodied' work, teleoperators and older people living at home. *Sociology*, *46*(3), 490–506. https://doi.org/10.1177/0038038511422551.

Sand, A.-S., Grimsgaard, S., & Pettersen, I. (2020). Patient and public involvement in health research: A Nordic perspective. *Scandinavian Journal of Public Health*, *48*(1), 119–121. https://doi.org/10.1177/1403494819863522.

Schermuly, A., Petersen, A., & Anderson, A. (2021). 'I'm not an activist!': Digital self-advocacy in online patient communities. *Critical Public Health*, *31*(2), 204–213. https://doi.org/10.1080/09581596.2020.1841116.

Schwennesen, N. (2019). Algorithmic assemblages of care: Imaginaries, epistemologies and repair work. *Sociology of Health and Illness*, *41*, 176–192. https://doi.org/10.1111/1467-9566.12900.

Seear, K. (2016). *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*. Routledge.

Stefanicka-Wojtas, D., & Kurpas, D. (2023). Barriers and facilitators to the implementation of personalised medicine across Europe. *Journal of Personalized Medicine*, *13*(2), 203.

Suominen, S. (2021, October 6). Terveyden ja sosiaalisen hyvinvoinnin edistämisen valtionavustukset (STEA). *Soste*. https://www.soste.fi/terveyden-ja-sosiaalisen-hyvinvoinnin-edistamisen-valtionavustukset/

Taylor, H., Alexander, M., & Valerie, A. (2021). Endometriosis is a chronic systemic disease: Clinical challenges and novel innovations. *The Lancet*, *397*(10276), 839–852.

Toiviainen, H. K., Vuorenkoski, L. H., & Hemminki, E. K. (2010). Patient organizations in Finland: Increasing numbers and great variation. *Health Expectations*, *13*, 221–233.

Warr, D., Luscombe, G., & Couch, D. (2021). Hype, evidence gaps and digital divides: Telehealth blind spots in rural Australia. *Health*. https://doi.org/10.1177/13634593211060763.

Whelan, E. (2003). Putting pain to paper: Endometriosis and the documentation of suffering. *Health*, *7*(4), 463–482.

Whelan, E. (2007). 'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community. *Sociology of Health & Illness*, *29*(7), 957–982.

Young, K., Fisher, J., & Kirkman, M. (2018). 'Do mad people get endo or does endo make you mad?': Clinicians' discursive constructions of medicine and women with endometriosis. *Feminism & Psychology*, *29*(3), 337–356.

3 Risks, pleasures, and desires: attending to the sexual politics of gynaecological cancer patient activism

Lisa Lindén

Introduction

In 2019, I attended a series of seminars about gynaecological – cervical, ovarian, uterine, vaginal, and vulva – cancer organized by the patient organization I call The Gynae Cancer Group (GCG). One of the invited speakers, a sexologist, talked about "sex after cancer treatment," that is, ways of supporting concerned cancer patients and their partners to have a good sex life after cancer treatment. Gynaecological cancer treatments such as radiotherapy and surgery may significantly impact on patients' sex lives, resulting in, for example, dry mucous membranes and vaginal pains. One important aim of the sexologist's talk was to encourage further integration and use of sexual rehabilitation services within cancer care in Sweden. In addition to cancer patients and their relatives and friends attending the seminars were policymakers, cancer care practitioners, and medical scientists. At the seminars, the sexologist stressed the predominant heteronormative focus on vaginal sex as a problem. She emphasized that we need to broaden our understanding of sexual practice and mentioned massage and touch as forms of sexual intimacy. At all the seminars, she said that her goal is to allow patients and their partners to feel as good as possible and that this might mean many different things for different people. She explained that she talks with the patients and their partners about what they want, what their sexual desires and pleasures are and might be. "We need to have a dialogue with our own body," she stressed. "What do I want, what is pleasurable to me?" The audience nodded and smiled enthusiastically, some whistled, and many applauded extensively and loudly afterward, and I sensed that the topic of "sex after cancer treatment" was both highly appreciated and long missed by the other attendees. While also appreciated, a presentation promoting human papillomavirus (HPV) testing as the primary method in the cervical cancer screening program did not generate the same level of applauds, or enthusiastic nods and smiles, by far.

Building on my ethnographic fieldwork with the GCG, this chapter explores the sexual politics of gynaecological cancer patient activism. I deliberately use the notion of "sexual politics" to refer to both *power dynamics* and *political actions* – such as those initiated and carried out by patient organizations

DOI: 10.4324/9781003319818-5

and other social movement actors – related to gender, sex and sexuality. As indicated by my fieldnotes from the seminar above, gynaecological cancer patient organizations and patient advocates have increasingly intervened in policy debates and healthcare practices concerning, for example, sex and sexuality.[1] As gynaecological cancers are located at or in the female sex-organs, they are permeated with societal tropes and material practices that entangle health and disease with often politicized notions of sex and sexuality (Lindén, 2021b). In biomedicine and public health, extensive resources, and high hopes are invested in technologies used for HPV-related cancer prevention, notably HPV screening testing (Lindén, 2021a; Mamo et al., 2022; Mamo, 2023) and HPV vaccines (Lindén, 2017; Lindén & Odenbring, 2022). Given the strong association between cervical, vulva, and vaginal cancers and sexually transmitted HPV infections, the hope is that lives will be saved through these technologies.[2] At the same time, the technologies may reproduce a biomedical discourse of sex as a so-called "risk factor" for cervical cancer (Lindén, 2016) – for example, in how (cis)-women carrying an HPV infection experience notions of "bad lifestyle" and "promiscuity" being associated with them in healthcare (Kosenko et al., 2012). More generally, because of the connotations to female sex-organs and sex, patients living with a gynaecological cancer may experience these cancers as taboo and sensitive to talk about (Wray et al., 2007; Solbrække & Lorem, 2016; Ashmore et al., 2022).[3]

Concerns have been raised that the extensive efforts invested in preventive technologies and new biomedical pharmaceuticals for gynaecological cancers may neglect or devalue other forms of gynaecological cancer care, such as those focused on *living well with cancer* (Lindén & Singleton, 2021; Kragh-Furbo et al., 2023). In relation to sex and sexuality, Stewart et al. (2024) emphasize the need to attend to "missing conversations about sex and sexuality" (Stewart et al., 2024, p. 98) in posttreatment gynaecological cancer care. They highlight a need to take seriously patients' feelings and thoughts about sex and sexuality as vital for how gynaecological cancer care might be improved.

In one of the few previous studies of gynaecological cancer patient activism, Gottlieb (2013) shows how a US cervical cancer advocacy organization worked to de-couple the HPV vaccine *Gardasil* from sex and sexuality. This is not surprising considering how sexual practice has been "side-lined" in HPV-related practices; attention has predominantly been on cancer prevention and cancer risk (Mamo et al., 2010; Lindén, 2016). Moreover, in my previous publications on gynaecological cancer patient activism, I have primarily focused on discussing sex and sexuality in terms of HPV technologies and risk management politics (e.g. Lindén, 2021a). Doing so, I have contributed to maintaining "sex as risk" as how sex and sexuality are predominantly approached in gynaecological cancer care. To stay with this reflexivity toward how to approach and conceptualize sexual matters, I, indeed, prefer the formulation "sex and sexuality" compared to the predominantly (and, often, unreflectively so) used notion of "sexual health." As Epstein and Mamo (2017) argue, the very pairing of "sexual" and "health" ultimately risks sanitizing and

legitimizing (conservative and unjust) societal and political courses of action related to sex and sexuality.[4]

In this chapter, I take my cue from the sexologist's talk at the gynaecological cancer seminar above to approach "sex and sexuality" in gynaecological cancer care differently. The chapter aims to show how the GCG, in and through its patient activism, enacts, strengthens and marginalizes versions of "sex and sexuality" in gynaecological cancer care. The notion of "versions" I borrow from Science and Technology Studies (STS) scholar Annemarie Mol (1999, 2002). Mol is interested in how different versions of an object – such as a disease – are enacted in specific sites or situations. She focuses on multiple enactments of objects to ask questions about what she defines as "ontological politics": if objects are made and come in versions, what versions do we want? I make use of the notion of "versions" to show how "sex and sexuality" is enacted differently in different practices. Accordingly, and differently from Gottlieb (2013) and my own previous work, I draw upon my fieldwork with the GCG to examine very different practices of sex and sexuality; this, I believe, allows me to intervene in the political stakes of what "sex and sexuality" is made to be in current gynaecological cancer care, and patient activism. More concretely, in the chapter, I will discuss the sexual politics of, what I will define as, three versions of "sex and sexuality": *sex as risk*, *sex as pleasure* and *sex as desire*. I do so by drawing upon GCG's patient activism around HPV testing and "sex after cancer treatment," respectively. Whereas HPV testing predominantly enacts "sex and sexuality" as a matter of risk and risk management, I will show how non-risk focused versions of sex may, by patient advocates, be incorporated within this broader focus on risk. Moreover, I will show how patient activism focused on "sex after cancer treatment" may place "sex and sexuality" as integral to patients' everyday life.

In focusing on versions of "sex and sexuality," I take an interest in not only sexual politics but also *practices of world-making*. I explore how patient organizations and patient advocates intervene in care arrangements and how such practices, in turn, enact, strengthen and/or marginalize possible gynaecological cancer worlds. Therefore, I attend to how different versions of "sex and sexuality" in gynaecological cancer patient activism are enacted – made real – in patient organizational practice. Importantly, in different practices, the relation between "gynaecological cancer care" and "sex and sexuality" is enacted differently, and these differences matter for how gynaecological cancer worlds are envisioned, positioned, and enacted. Moreover, we, as feminists, ethnographers, and researchers, participate in world-making, too. In thinking about politics and world-making, I situate my work within Feminist Technoscience Studies (FTS).

Feminist Technoscience Studies, politics, and world-making

My thinking on world-making and politics is indebted to research that has taught me that worlds are made and can be remade – and that I, as a

researcher, have a responsibility in the worlds I strengthen, bend, or marginalize through the analytical decisions I make (Mol, 2002; Haraway, 1997; Jerak-Zuiderent, 2015). The assumption that human and non-human actors participate in enacting worlds is key for branches of material-semiotics concerned with performativity, materiality and ontological politics. Indeed, Mol (1999) developed the notion of "ontological politics" to denote that worlds (or "realities" as she calls it) are multiple, are enacted into being, and can be enacted differently. For her, the different versions of an object relate to ontologically different realities. When some versions of an object – and their realities – get predominance, other versions risk getting eroded, less real. Similarly, for Haraway (1989, 1997), there is no single or given world. Instead, there are different worlds being brought into being in more or less power-saturated practices. Learning from Mol and Haraway, the question for me becomes: how to intervene in gynaecological cancer worlds to generate more liveable and less dominant alternatives? "How to trope, to bend versions of the real, to strengthen desirable realities that would otherwise be weak?" (Law, 2008, p. 637). What worlds to make stronger, more real – and what worlds to weaken? Given the dominance of biomedicine, when and how might it be important to strengthen other alternatives in care, or to enact biomedicine differently? This is how it is possible to understand Haraway (1989, p. 204) when she asserts that "[t]he language of biomedicine is never alone in the field of empowering meanings, and its power does not flow from a consensus about symbols and actions in the face of suffering." If we can trope biomedicine differently, we can challenge and restage predominant versions and articulate alternatives.

Drawing upon scholars like Haraway and Mol, others – including myself – have engaged in analytics of articulating "glimpses of" other worlds within otherwise dominant articulations (Jerak-Zuiderent, 2015; Lindén, 2016). Another example can be found in Moser (2011), who has articulated non-biomedical ways of caring for dementia patients to strengthen practices that may support better care for concerned patients. Similarly, elsewhere Singleton and I have engaged in an FTS "speculative commitment" to the easily neglected and overlooked as a form of ontological politics. In contrasting the predominant focus on new biomedical treatments with palliative care in gynaecological cancer care, we aimed to "restage what gets to count as care and . . . support care practices that are more liveable for those concerned" (Lindén & Singleton, 2021, p. 426).

Building upon insights such as these, in this chapter, I want to contribute to current understandings of *the political implications of* how different actors in gynaecological cancer care and biomedicine – patient organizations, patient activists, researchers, health practitioners, feminists – intervene in the making of worlds. Through my attention to sexual politics, I seek to highlight how enactments of "sex and sexuality" in relation to "gynaecological cancer care" matter for how gynaecological cancer patient worlds may be envisioned, acted upon and remade into the better. My focus on "sex after cancer treatment" – and my wish to approach sex and sexuality differently – can

be understood as a speculative commitment to the "missing conversations about sex and sexuality" (Stewart et al., 2024, p. 98) in gynaecological cancer worlds. Here, my politics both differs and aligns with the GCG. While we both have – me in my earlier publications, the GCG in its patient activism – put extensive efforts into what I in this chapter call a version of "sex as risk," we have done so with partly differing goals. The GCG often pushes for new technologies and biomedical research, such as around HPV, to contribute to the improvement of healthcare practices. As an STS scholar, I have rather concentrated on biomedicine – including biomedical practices articulating "sex as risk" – to critically scrutinize dominant technoscientific visions and configurations. Our politics, however, converge to a higher extent in relation to the importance of the issue of "sex after cancer treatment."

Case and methods

This chapter builds upon ethnographic fieldwork with the GCG, primarily carried out between 2018 and 2019. The project has been granted ethics approval from the responsible regional ethics board. I have anonymized names and the organization, as well as excluded information about positions on the board (e.g. chair and secretary), thus throughout the chapter I write "GCG representatives." In total, 15 interviews with board members, ex-board members, and volunteers have been conducted. I also observed the organization's gynaecological cancer seminars in 2018 and 2019 (five seminars in total), a research priorities seminar with politicians in 2018, and two patient council meetings in 2018. Moreover, I observed 11 board meetings and 14 working group meetings (both in place and digitally) during 2018 and 2019. The material also consists of an extensive amount of media material from the GCG's Facebook and website, opinion pieces, campaign material, and media coverage. In line with an ethnographic approach, the whole set of material has informed this chapter. Nevertheless, in particular, I draw, here, upon field notes from the three 2019 gynaecological cancer seminars. I also make use of observations of board meetings, interviews and the media material (such as a debate article about HPV testing).

The data was analysed by using abductive analysis, which meant that I moved back and forth between empirical data and theory. This allowed me to use existing research and theories to guide the coding and to identify surprising and new findings in light of existing theories (Timmermans & Tavory, 2012). The data was analysed in two rounds. An empirically close coding round was refined through a second one that was more theoretically informed. The coding was influenced by medical sociology and anthropology studies of cancer patienthood (Jain, 2013; Bell, 2014; Solbrække & Lorem, 2016) and STS and social movement theories concerning patient activism (Klawiter, 2008; Rabeharisoa et al., 2014).

The GCG has approximately 1800 members. In Sweden, patient organizations are most often funded by the state, but such funding is conditioned on a structure of national alliance with local chapters. As the GCG functions as

a group without local chapters, it stands outside such funding. During my fieldwork, the organization had no employees; people engaged in the organization in their spare time. The GCG representatives' professional backgrounds varied, but the majority had a university degree, working in areas such as management, research, and healthcare. The organization's volunteers and board members consisted of people in their 20 to senior citizens. They had personal experience of cancer or cancer risk and/or are relatives of cancer patients.

The organization puts extensive efforts into influencing healthcare and research, as well as improving public and professional knowledge of gynaecological cancers. During my fieldwork, one of the GGC's key foci was aimed at "speeding up" the implementation of the HPV test as the primary method in the national cervical cancer screening program. Other areas were, for example, increasing the funding for ovarian cancer research as well as the public and professional awareness of ovarian cancer. The GCG representatives frequently "team up" with scientists and practitioners to push for change in health policy and care practice, such as by writing joint opinion pieces. The organization also hosts Facebook support groups and organizes other patient services, such as seminars about cancer care and rehabilitation and digital patient meetings. The GCG is increasingly participating in top-down forms of patient participation, such as government-initiated patient councils. Nevertheless, a large part of its activities is initiated by the organization's representatives themselves, outside of governmental or regional organizational structures and support systems.

Three versions of "sex and sexuality" in gynaecological cancer patient activism

In the analysis, I will attend to the three versions of "sex and sexuality" in the GCG's practices mentioned in the introduction: *sex as risk*, *sex as pleasure*, and *sex as desire*. I start by "sex as risk," through the example of HPV testing and attention to "saving lives." I will then move on to discuss how the GCG incorporated an alternative *within* this attention to risk; "sex as pleasure." Subsequently, I will discuss "sex as desire," through the case of "sex after cancer treatment," which puts emphasis on "living well." Finally, in the discussion, I will relate these three versions to questions of world-making and marginal worlds, to discuss the politics of gynaecological cancer activism and care.

Sex as risk: HPV testing and saving lives

The management of sexual risk is a predominant version of "sex and sexuality" in gynaecological cancer care, as well as in accompanied gynaecological cancer patient activism (Gottlieb, 2013; Mamo, 2023). As I have already mentioned, this encourages attention to HPV technologies aimed at cancer prevention: HPV vaccines and HPV tests (Lindén, 2021b). Consequently, as mentioned in the introduction, the organization included the implementation of HPV

testing as the primary method in the screening program, as a key topic during their 2019 seminars. That the organization included this presentation was not a surprise to me; it was one of their "standard" topics during the time. The HPV test is currently promoted by scientists, practitioners, and patient advocates alike as a more accurate cervical cancer prevention diagnostic test than the contested – but nevertheless long-standing policy standard – Pap smear test (Hogarth et al., 2015; Lindén, 2021a; Mamo, 2023).[5] For example, in the current Swedish national guidelines for the screening program it is stated "All participants in the screening should be offered HPV analysis. Then the risk of cervical cancer is discovered earlier than with analysis for cytology" (RCC, 2022). While the decision to initiate a so-called "primary HPV screening" program was made in 2017, during my fieldwork in 2018 and 2019, several regions had still to implement the program fully within their cervical cancer screening practices. During my fieldwork, the GCG was highly critical toward the delay of the implementation of primary HPV screening in several Swedish regions.[6]

During the presentation on HPV testing, one of the GCG representatives said that it is "awful" that the new screening program has not been fully implemented; she stated that the GCG is ashamed of all the regions that have not done so. Directed to concerned policy-actors in the room, the GCG representative said that "you don't care about your women"; many women's lives would be saved if the program was quickly, and fully, implemented. In other parts of its patient activism around the HPV test, the GCG mobilized in the media to articulate the problem that some regions had not implemented the new HPV screening program. At the seminar and in the media, the GCG linked the delay of the process with cervical cancer prevention being a women's health issue – and therefore being less prioritized than other healthcare areas.

With its focus on "saving women's lives," the GCG entangled biomedicine with sexual risk. Indeed, in a setting of HPV, "risk" is predominantly equalized with sexual activity as a "biomedical risk factor" for cervical cancer. As suggested by the presentation at the seminar, the HPV test opens a space for patient activism focused on an urgency to improve the management of sexual risks now, to prevent cervical cancer cases in the future. Moreover, in presenting cervical cancer prevention as a women's health issue, the GCG articulated the delay of the implementation as a question of gender.

In this practice, "sex and sexuality" is a matter of sexual risk and technoscientific solutions. As Epstein and Mamo (2017, pp. 176–177) write, in a setting of sexually transmitted infections such as HPV, "sexuality is understood essentially as a risky practice, health is construed as risk reduction and the opposite of sexual health is the spread of disease." In general, patient activism focused on HPV testing is not primary concerned with a sexual practice assuming and/or cherishing sex and sexuality as being part of people's everyday life. A practice invested in the urgency of HPV testing is not usually interested in sex and sexuality in terms of how it matters for people themselves, in their personal lives.[7] This is, in itself, not a problem. Primary HPV testing will

most likely contribute to lives being saved, when a life being saved is counted as a matter of not dying from cervical cancer. Nevertheless, the predominance of the notion of "sex as risk" might contribute to the marginalization or devaluing of sexual practices not centring "saving lives" – like those attending to pleasure and desire (Jones, 2019). However, other versions of sex and sexuality than sexual risk may be incorporated as part of HPV testing-focused patient activism. I will now return to the public seminars discussed above to show one such example.

Sex as pleasure: HPV testing and older women's changed sex lives

To the public seminars in 2019, the GCG had invited a medical scientist and gynaecologist that had conducted a study indicating that cervical cancer is detected at later stages in older women compared to younger women, and that there is an increasing rate of cervical cancer in older women. During my fieldwork, the GCG mobilized around an increase of the upper age-limit for the HPV test in the screening program (the upper age-limit at the time was age 64).[8] By the GCG representatives, inviting the scientist was seen to support this goal of increasing the upper age-limit. As many current patient organizations do, they, as they often called it, "joined forces" with the scientist to achieve change (cf. Panofsky, 2011; Rabeharisoa et al., 2014). During one of the seminars, I wrote the following fieldnote:

> "Cervical cancer is diagnosed in later stages in women over 65 years old and the prognosis is bad", the scientist says. She stresses that there's several reasons to expect this trend to increase and mentions changed sexual behaviours in older age as one of them. Older women today, she explains by drawing upon sexual prevalence statistics, have more sex and they change sexual partners later in life. Therefore, she argues, there are good reasons to increase the age-limit in the screening programme. She stresses that it needs to be the HPV test [used in the screening]; "the Pap smear doesn't work for older women". Her research group, she continues, has recently conducted a study that shows that the Pap smear didn't detect precancerous lesions in 80 percent of the tested women between 60 and 89 years old. She explains that older women's genitals are different, which makes it more difficult to use the Pap smear.
>
> (Fieldnote, 2019)

When the GCG representatives reported the scientist's presentation on their Facebook site they wrote: "also older women enjoy sex!" To understand this, some contextualization is needed. The year before the seminar, in 2018, the GCG had initiated a policy discussion about older women and HPV testing by writing a debate article. In the article, the GCG enrolled the study by the scientist above and emphasized that many women today become single in older age. The GCG highlighted that if these women enter a new sexual

relationship, they are at risk of an HPV infection that is not followed up. The organization wrote that it has been assumed that older women do not have an active sex life and asserted that this is a case of age discrimination. Hence, the GCG enrolled the evidence from the scientist's study and translated it into a case of age discrimination. Doing so, the organization politicized the relation between sex and older women. This is also how the statement "also older women like sex!" needs to be read. The sexual prevalence statistics from the study by the scientist at the seminar were mobilized by the GCG in support of its claim that the current policy discriminates against older women.

In an interview, one of the GCG representatives repeatedly said that the decision not to screen older women is "so cynical":

> It's like "okay, now you've turned 70 so we don't need to check you for anything at all any longer". And, at the same time, it's said that 70 is the new 50. You change partner and you . . . you get married again and get divorced and the husband dies and . . . you know. So . . . it's so cynical! . . . It's age discrimination big time!
>
> (Former GCG representative, September 2019)

In stressing that women take on new sex partners later in life, the representative drew upon what she had learned from the above scientist and entangled this knowledge with the GCG's claim that the current age-limit is discriminatory. When I asked why she thought such discrimination exists, she used the argument about gynaecological cancer and gender discussed in the previous section: because it has to do with women's health. She said that "it's business as usual I was about to say . . . it's women's issues." "People still barely know what [gynaecological cancer] is," she continued. In another interview, she formulated it like this: "I mean it's so intimate, both our sex, our sexuality and issues of sexual intimacy, so, you don't talk about it." The answer that older women are discriminated against because gynaecological cancer is a women's issue is slightly different from the claim that the age-limit has to do with an assumption that older women do not have an active sex life. Nevertheless, both these claims articulate gynaecological cancer as a neglected area – and as gendered – because of its connection to female sex-organs.

Through the seminars and the debate article, the GCG engaged a sexual politics focused on *being able to have an active sex life*. We can think of this as a version of "sex and sexuality" that includes sexual pleasure as a key component in how sex matters for people in their (everyday) lives. I define this version as "sex as pleasure" to highlight how the GCG focused on older women "enjoying" sex. Instead of only concentrating on sexual risk, the GCG's practice focused on a need to adjust the screening policy in relation to older women's *actual* "enjoyable" sexual practices. If older women enjoy sex and have more sex with new partners, the screening policy needs to be adapted to this. Here, the HPV test is envisioned as important for maintaining *the possibilities of* sexual pleasure in older age, this by reducing accompanied sexual risks.

Therefore, within the organization's dominant focus on sexual risk in its HPV testing advocacy, it incorporated an alternative version within the dominant one: sexual pleasure matters.

Sex as desire: sex after cancer treatment

In contrast to HPV testing, matters of sex and sexuality after cancer treatment do not centre risks and "saving lives." Instead, the emphasis is on "living well." Different from the GCG's incorporation of sexual pleasure *within* a practice of sexual risk, "sex after cancer treatment" can be understood as a completely different practice. As already mentioned, the area of "sex after cancer treatment" holds a marginal position in gynaecological cancer care (White et al., 2013; Stewart et al., 2024). This was also something the GCG representatives were aware of and wanted to challenge during the period of my fieldwork; they recurrently discussed how to include "sex after cancer treatment" as one of their focus areas. Nevertheless, in comparison to HPV testing, it remained a minor area for the GCG. In fact, the inclusion of the sexologist's talk at its 2019 gynaecological cancer seminars was the major way the GCG did so during my fieldwork period (they had previously, e.g., organized a webinar on this theme). I believe this first and foremost reflects the marginal position sexual rehabilitation holds within gynaecological cancer care; it should not be read as the GCG not caring about this topic. Moreover, the marginal position of "sex after cancer treatment" in gynaecological cancer care is, I argue, in interesting tension with the highly appreciative response from the audience after the sexologist's presentation at the GCG's 2019 seminars. In fact, the presentation was by far the one that received the most applauds and appreciative cheers during the three seminars. Finally, as I have already mentioned, centralizing sex after cancer treatment in this chapter I see as a "speculative commitment" to the "missing conversations about sex and sexuality" (Stewart et al., 2024, p. 98) in post-gynaecological cancer care.

What is, then, "sex and sexuality" enacted as in this practice of "sex after cancer treatment"? Let us, again, return to the 2019 GCG seminars. Key rationales with the presentation were both to give patients an opportunity to rethink what sex is and how it can be practiced with a post-cancer body and to encourage them to request the inclusion of sexual rehabilitation in their care, in their regions. Consequently, at the seminars, the sexologist encouraged the audience to put efforts into sexual rehabilitation. She emphasized that cancer care services do talk very little about issues of sexuality; in line with Stewart et al. (2024, p. 98) the sexologist pleaded for engagement with the "missing conversations about sex and sexuality" in posttreatment gynaecological cancer care. Reminiscent of findings from social science research (Wray et al., 2007; Solbrække & Lorem, 2016), she related the little attention this issue receives to female sex-organs as taboo. She said that knowledge about sexuality and sexual rehabilitation is lacking, both within healthcare and among concerned patients and their partners. She articulated the sexual

politics involved: while men have long been able to talk about the penis, women have not been able to talk about the vagina. At this, the audience applauded and cheered.

Through the presentation, the sexologist focused on "sexual desire" (or, rather, she used the wording "lust," which is predominantly used to mean desire in general, in Sweden). I borrow her use of "desire" to highlight what version of sex and sexuality this practice enacts: sex as desire. She explained that she works with exercises – like mapping out one's sexual habits and thoughts – with her patients, so that she can learn about their sexual desires and help them to approach, and practice, sex differently. She also mentioned mindfulness and acupuncture as helpful for patients to achieve better knowledge of their own body and to learn about their sexual desires. Moreover, she said that she asks the patients about what values they and their partner have about sex and sexuality. This can be interpreted as aimed at helping the sexologist to get a better understanding of her patients' views on sexuality, helping her to help them to approach sex differently. She also told us that she talks with the patients about sexual desire as something that requires extensive effort; it is work and requires practice. She mentioned that she encourages her patients to set aside two minutes every morning and evening to exclusively focus on working on one's sexual desires. "It's like brushing your teeth! Take care of yourself, massage a little," she said.

At one of the seminars, the sexologist started with an exercise where she asked us in the audience to notice the first thing on our mind when we think about sex. Afterward, she told us that it was likely as many different thoughts in the room as people; sex and sexuality are many different things, for different people. As I discussed in the introduction, in her presentation, she promoted broadening our understanding of what sex and sexuality is. She did so by, for example, challenging the predominant focus on vaginal sex and by mentioning touch and massage as forms of sexual intimacy.

The sexologist said that "we need to talk about what has been"; we cannot just move on and be grateful about having survived cancer. Her reference to "moving on and being grateful" needs to be understood in relation to a dominant cancer survivorship discourse of cancer affording people a new profound thankfulness for life (e.g. Jain, 2013; Bell, 2014). Indeed, "[p]revalent constructions of survivorship can feel alienating" for patients, "especially when these are accompanied by expectations to move on and put negative feelings behind them despite the 'ongoing presence of cancer' in their lives" (Stewart et al., 2024, p. 91). In sharp contrast, the sexologist emphasized the need to talk about the side effects of gynaecological cancer treatment, such as damages to the vagina. This, indeed, articulates that "it is very important to stress that treatment of gynaecological cancer very frequently leaves women with severe side effects" (Solbrække & Lorem, 2016, p. 1264). In focusing on damages on the vagina and their relation to patients' sex lives, she articulated a need to consider side effects to reorient oneself sexually, and to learn about one's sexual desires anew, with an altered body.

One particular technology used in sexual rehabilitation is the dilator. "Dilator" is a medical term for a vaginal wand that is used after, for example, radiotherapy. A specific form of radiotherapy – brachytherapy – means that a radioactive implant is inserted into the patient's vagina, and after such treatment, the vaginal walls might grow together (Solbrække & Lorem, 2016). Dilators aim at preventing narrowing of the vagina and increasing vaginal elasticity. It has a similar form as a large tampon, and patients are usually encouraged to use the dilator for two to three years (Miles, 2017). Dilators have been critiqued for being painful and uncomfortable and for ignoring sexual desire (White et al., 2013; Stewart et al., 2024). However, in this chapter, I attend to a dilator-focused practice that I consider may be treated as potentially being in line with "sex as desire."

The sexologist at the GCG seminars did encourage patients to practice with dilators. However, importantly, she urged the audience to also demand better dilators from the cancer care services. During the seminars she compared – and had brought with her – old dilators in plastics with new ones in silicon. "Women have the right to good rehabilitation!" she said at one of the seminars and referred to that they have the right to silicon dilators. She said that the ones in plastics, that she had used before, "were awful." At one of the seminars, she encouraged the patients in the room to "demand silicon" (again, generating applause and appreciative nods and smiles from the audience). The sexologist's promotion of silicon dilators taps into the critique from patients and practitioners, stressing that plastic dilators are uncomfortable and painful. The dilators given to patients by most hospitals are made of plastics; patient advocates, patients, and practitioners have therefore increasingly started to push for the inclusion of silicon dilators within the cancer care services (e.g. Cohen & MacGregor, 2021; Gustavsson, 2022).

The sexologist's promotion of silicon dilators was aligned with the GCG's patient activism. During the months prior to the seminars, the GCG representatives had discussions at meetings about how to support increased integration of silicon dilators in cancer care. While a doctor had encouraged them to write a debate article, they had concluded that politicians would consider the topic to be too minor. Instead, they had decided to allow a company designing silicon dilators to have a stand at their seminars – and to include the presentation by the sexologist. The company's silicon dilators were also the dilators the sexologist had brought with her as the example of "good" dilators.[9]

Stewart et al. (2024, p. 97) raise the concern that dilators risk colonizing the topic of "sex and sexuality" in cancer care. They write that the "dilator as a technoscientific artefact" might shape "knowledge about sexual anatomy as sites for future medical exams, and not of sexual pleasure or intimacy which remains largely invisible."[10] They warn that "the attention to dilators may be suppressing other vital conversations that must be had if we are to support post-treatment matters of sexuality and wellbeing" (Stewart et al., 2024, p. 98). Similarly, Ashmore et al. (2022, p. 41) write that a "purely clinical perspective on the use of dilators does not acknowledge that using dilators is

also about your relationship with your own body and your sexual self, in both physical and emotional ways." With a "purely clinical" approach they refer to a cancer care service that assumes that the main purpose of dilators is to prevent adhesions and facilitate gynaecological exams – an approach that ignores sexual desire and sex as part of people's everyday life (White et al., 2013; Ashmore et al., 2022).[11] While I very much see the problems with this, the GCG and the sexologist focused on the need to improve dilators, and silicon dilators as *one component* hopefully facilitating a good sex life. They enrolled critiques of plastic dilators as "unnatural, painful and intrusive" (Stewart et al., 2024, p. 97) to push for improvements in care, well beyond a "purely clinical" focus on dilators as facilitating gynaecological exams, and where sexual desire and silicon dilators were part of the same practice.[12]

Through the inclusion of the sexologist's presentation, the GCG articulated an alternative to a risk-focused version of what "sex and sexuality" is in gynaecological cancer care. The sexologist's presentation enacts a sexual politics devoted to learning what sexual desires might be in an embodied, relational, and non-heteronormative manner. It promotes a cancer care practice that considers that cancer patients are sexual, sensing beings. This version of "sex and sexuality" promotes a cancer care that extends beyond technoscientific solutions, while promoting the use of technoscientific artefacts – as one of several components – that may facilitate a good sex life posttreatment.

Discussion

In this chapter, I have analysed the sexual politics of gynaecological cancer patient activism. I have contrasted what I have defined as three versions of "sex and sexuality" in gynaecological cancer care: *sex as risk*, *sex as pleasure*, and *sex as desire*. I have argued that incorporating the versions of *sex as risk*, *sex as pleasure*, and *sex as desire* in the same chapter allows me to attend to the politics of gynaecological cancer care and gynaecological cancer patient activism. In concentrating on, first, HPV testing and, second, "sex after cancer treatment," I have described very different enactments of "sex and sexuality" in the context of gynaecological cancer care and patient activism. I have shown that, in its practices around the implementation of HPV testing, the GCG enacts sex as a matter of the management of risk and an urgency to manage sexual risks now to "save women's lives." This version aligns with a predominant attention to "sex as risk" in gynaecological cancer contexts, articulated in national guidelines, policy, research, and so forth (Epstein & Mamo, 2017; Lindén, 2021a). I have contrasted this with the case of "HPV testing for older women," where I have argued that the GCG incorporates "sex as pleasure" *within* its broader attention to managing sexual risk. Finally, I have contrasted both these HPV-related practices with the attention to sexual desire in the GCG's practices around "sex after cancer treatment." Given these findings, I argue that the GCG, in attending to sexual pleasure and desire, contributes to a challenging of "sex as risk" as what "sex and sexuality" is made to be in

gynaecological cancer contexts, by providing alternatives that assume sexual desire and pleasure to be vital for people's everyday lives.

Why do I find it important to analyse and contrast these three versions of "sex and sexuality"? In articulating different versions of "sex and sexuality," my aim has been one of world-making and politics: my aim has been to contribute to a broadening of what "sex and sexuality" get to be in the context of gynaecological cancer worlds. Indeed, as the GCG, I want to challenge the dominance of the "sex as risk" version of sexual politics in gynaecological cancer care and activism. The 2019 GCG seminar audience's appreciative response toward the sexologist's presentation is illuminative in this regard. Learning from Ashmore et al. (2022) and Stewart et al. (2024), listening to patients is important to engage in the "missing conversations about sex and sexuality" (Stewart et al., 2024, p. 98). And when listening to the patients during, and after, the sexologist's presentations, I heard something akin to a standing ovation. How can we, then, understand the audience's response? I believe that the sexologist's challenging of the marginal position of "sex after cancer treatment" aligned with the audience's own experiences. Moreover, the sexologist challenged the very assumption that "sex and sexuality" in the context of gynaecological cancer is about risks and clinical function (such as the dilator only to be used to facilitate gynaecological exams). This assumption, I argue, legitimizes the marginal position of sexual desire and pleasure in gynaecological cancer contexts. As others have argued, all too often "sex and sexuality" in the context of gynaecological cancer is envisioned as a "purely clinical" matter of managing sexual risks (Mamo, 2023) and facilitating medical exams (White et al., 2013; Ashmore et al., 2022). When listening to patients challenging these assumptions through words and applauds, there, indeed, seems to be a need for further change.

The GCG values the topic of "sex after cancer treatment" and included it as a key theme at the 2019 seminars. However, during my fieldwork, it was not one of the organization's key working areas. Perhaps that had to do with the GCG representatives fearing it to be considered too small to gain traction among politicians and policymakers. Furthermore, current gynaecological cancer patient organizations and patient advocates often emphasize new biomedical treatments and more research funding, and not "sex and sexuality" in terms of people's everyday lives, pleasures, and desires (cf. Gottlieb, 2013; Lindén, 2021a, 2021b, 2021c). Worth mentioning is that the European Network of Gynecological Cancer Advocacy Groups (ENGAGe) initiated a large-scale international survey in 2022 regarding sexual health after gynaecological cancer diagnosis and treatment. The network writes: "Its results will serve as the starting point for a significant ENGAGe campaign on sexual health, which will provide informational material and online help to all gynaecological cancer survivors who need it" (ENGAGe, 2022).[13] Yet again, while informational material and online help may be important, this is different from patient activism that intervenes in policy and practice to improve healthcare, such as by directly targeting and "joining forces" with policy actors, scientists,

and health practitioners. Moreover, within and outside of Sweden, it is still rare that sexologists/sex therapists are included as part of cancer rehabilitation teams (RCC, 2024; NCCC, 2025). The predominant sexual rehabilitation technology being used at hospitals is also still plastic dilators despite recurring critique from both patients and practitioners (Miles, 2017). Learning from the sexologist's presentation and the audience's response at the 2019 GCG seminar, I assert that patient activism in this area may most likely contribute with important change and, indeed, more liveable gynaecological cancer worlds.

Notes

1 Patient activism focused on cervical cancer prevention has since the invention of the Pap smear screening test in the 1940s been prominent in countries such as the UK and the US (Gardner, 2006; Löwy, 2011; Moscucci, 2016). However, this has not up until recently been the case for the other gynaecological cancers, and other forms of cervical cancer patient activism. Nevertheless, during recent years, a growing gynaecological cancer patient movement has emerged. Gynaecological cancer patient advocacy groups concentrate on educating about early detection and HPV technologies, raising awareness and advocating for more research funding and patients' access to new treatments and screening technologies (Lindén, 2021a, 2021b, 2021c).
2 There is a strong connection between HPV and anal, neck, and penile cancers. See Lindén and Odenbring (2022) for an analysis of the introduction of HPV vaccination "for everyone."
3 Gynecological cancer patient advocacy is becoming more trans-inclusive (see, e.g., The Eve Appeal, 2024). During parts of my fieldwork, the GCG discussed transgender health issues, for example, in relation to cervical cancer screening. However, predominantly, the GCG and its scientist and practitioner interlockers referred to "women" and "female sex-organs," and therefore, I use these terms. Despite this, I want to emphasize that gynaecological cancer concerns trans and nonbinary people with a uterus. For a discussion on transgender and nonbinary genders in relation to gynecological patient activism, see Temmes and Oikkonen in this volume.
4 However, I use "sexual health" as an empirical notion, when it appears in the field.
5 Previously I have discussed how the GCG leaves out existing knowledge – and practitioners and advocates enrolling that knowledge – supportive of a continued use of the Pap smear (Lindén, 2021a). A key factor in debates about the HPV test concerns how primary and sole HPV testing programs might generate overtreatment, that is, that more and more people are being placed under continued surveillance because of HPV infections that most likely will never develop into cervical cancer (as HPV infections are significantly more common than cytological abnormalities, more people are held in surveillance in primary or sole HPV screening programs). As research suggests, people "living with HPV" are anxious about cervical cancer; primary or sole HPV testing schemes will most likely increase this anxiety (Kosenko et al., 2012).
6 The empirical examples used in this section have previously been discussed in Lindén (2021a). In that chapter, I used these examples to discuss policy practices and the relational dynamics of patient activism. Differently, here I use them to analyze sexual politics and versions of sex and sexuality.
7 The biomedical framing of "sex and sexuality" as matters of risk and risk management is, of course, very prominent in the case of HIV/AIDS prevention (Nicholls & Rosengarten, 2020). Other examples where sexuality is framed in

terms of risk are, for instance, contraceptives (Takeshita, 2011); sex work (Moore, 1997); and hook-up devices (Race, 2015).

8 The upper age-limit has since then changed to 70 years old. However, a patient's age can vary between 64 and 70 years, as screening invitations are based on the most recent examination. The Swedish national guidelines recommend that people between 23 and 49 years old are invited for cervical cancer screening every fifth year and that people aged 50–70 years are invited every seventh year (RCC, 2022).

9 There are some discussions about possible alternatives to dilators. For example, there is a discussion about whether regular vibrators might be a better alternative (Miles, 2017).

10 Similarly, White et al. (2013, p. 194) show that the gynaecological cancer patients in their study "were taught dilator use in a limited technical manner, avoiding the use of sexual language."

11 This "purely clinical" approach to dilators is a good example of what Epstein and Mamo (2017, p. 181) describe as a niche of sexual health "addressing failures of sexual functioning." They write that "sexuality is understood largely in mechanic or neurological terms as a matter of physiology, while health is viewed as matter of potency, performance, or enhancement." They continue: "The opposite of sexual health, therefore, is the inability to perform (or the presence of pain or discomfort during sexual activity)" (Epstein & Mamo, 2017, p. 181).

12 While the sexologist questioned heteronormativity and promoted a broadening of sexual practice from vaginal sex, this was not addressed when she talked about dilators. As researchers have discussed, dilators easily reproduce a heteronormative view of sex as a matter of penile–vaginal intercourse and heterosexuality. For example, in relation to gynaecological cancer, White et al. (2013, p. 193) highlight that, in relation to dilators, both clinicians and patients tend to construct sexuality "as solely expressed within a heterosexual relationship." As another example, outside the cancer context, Guntram (2013) has attended to how intersex patients after vaginal reconstruction reconstruct hetero-relational normality in relation to dilator use. Learning from this, I believe that the topic of heteronormativity is important to raise in patient activism aiming to promote sexual practice as vital for improving gynaecological cancer patients' lives posttreatment.

13 By the time of finalizing this chapter in January 2025, it still said on the ENGAGe webpage that the network "will be sharing the results soon to better understand the experiences of survivors" (ENGAGe, 2024).

Reference list

Ashmore, L., Singleton, V., & Kragh-Furbo, M. (2022). *We Need to Talk About Radiotherapy for Gynaecological Cancer*. Lancaster: Lancaster University.

Bell, K. (2014). The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease. *Social Science & Medicine*, *110*, 56–63.

Cohen, M., & MacGregor, S. (2021, December 17). Sex toys for sexual health. In *Sex[M]ed: A sexual health education platform for healthcare practitioners*. https://thesexmed.com/sex-toys-for-sexual-health/

ENGAGe. (2022). *ENYGO-ENGAGe survey on sexual health after gynaecological cancer*.https://engage.esgo.org/enygo-engage-survey-sexual-health-gynaecological-cancer/

ENGAGe. (2024). *Sexual health*. https://engage.esgo.org/sexual-health/

Epstein, S., & Mamo, L. (2017). The proliferation of sexual health: Diverse social problems and the legitimation of sexuality. *Social Science & Medicine*, *188*, 176–190.

Gardner, K. E. (2006). *Early Detection: Women, Cancer and Awareness Campaigns in the Twentieth-Century United States*. Chapel Hill: University of North Carolina Press.

Gottlieb, S. D. (2013). The patient–consumer–advocate nexus: The marketing and dissemination of Gardasil, the human papillomavirus vaccine, in the United States. *Medical Anthropology Quarterly*, *27*(3), 330–347.
Guntram, L. (2013). Creating, maintaining and questioning (hetero) relational normality in narratives about vaginal reconstruction. *Feminist Theory*, *14*(1), 105–121.
Gustavsson, M. (2022, March 25). *Ingen kvinna förtjänar en kall plastpinne*. https://www.dagensmedicin.se/opinion/kronika/ingen-kvinna-fortjanar-en-kall-plastpinne/
Haraway, D. (1989). The biopolitics of postmodern bodies: Determinations of self in immune system discourse. *Differences*, *1*(1), 3–43.
Haraway, D. (1997). *Modest_Witness@ Second_Millennium. FemaleMan©_Meets_OncoMouseTM*. London: Routledge.
Hogarth, S., Hopkins, M., & Rotolo, D. (2015). Technological accretion in diagnostics: HPV testing and cytology in cervical cancer screening. In Consoli, D., Mina, A., Nelson, R. R., & Ramlogan, R. (Reds.), *Medical Innovation: Science, Technology and Practice* (pp. 88–116). London: Routledge.
Jain, S. L. (2013). *Malignant: How Cancer Becomes Us*. Berkeley: University of California Press.
Jerak-Zuiderent, S. (2015). Keeping open by re-imagining laughter and fear. *The Sociological Review*, *63*(4), 897–921.
Jones, A. (2019). Sex is not a problem: The erasure of pleasure in sexual science research. *Sexualities*, *22*(4), 643–668.
Klawiter, M. (2008). *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*. Minneapolis: University of Minnesota Press.
Kosenko, K. A., Hurley, R. J., & Harvey, J. A. (2012). Sources of the uncertainty experienced by women with HPV. *Qualitative Health Research*, *22*(4), 534–545.
Kragh-Furbo, M., Hutton, D., Stewart, H., Singleton, V., & Ashmore, L. (2023). The ambivalence of radiotherapy: Re-framing effects and their temporalities in treatment for gynaecological cancer. *Social Science & Medicine*, *336*, 116183.
Law, J. (2008). On sociology and STS. *The Sociological Review*, *56*(4), 623–649.
Lindén, L. (2016). *Communicating Care: The Contradictions of HPV Vaccination Campaigns*. Lund: Arkiv Academic Press.
Lindén, L. (2017). You will protect your daughter, right? In Johnson, E. (Ed.), *Gendering Drugs: Feminist Studies of Pharmaceuticals*. London: Springer.
Lindén, L. (2021a). Initiators, controllers and influencers: Enacting patient advocacy roles in cervical cancer screening policy practices. In Geiger, S. (Ed.), *Healthcare Activism: Markets, Morals, and the Battle for the Common Good* (pp. 140–164). Oxford: Oxford University Press.
Lindén, L. (2021b). Moving evidence: Patients' groups, biomedical research, and affects. *Science, Technology, & Human Values*, *46*(4), 815–838.
Lindén, L. (2021c). Running out of time: The case of patient advocacy for ovarian cancer patients' access to PARP inhibitors. *Sociology of Health & Illness*, *43*(9), 2141–2155.
Lindén, L., & Odenbring, Y. (2022). The needle pricking and two modes of 'doing good' in the Swedish school-based human papillomavirus vaccination programme. *Sociology of Health & Illness*, *44*(8), 1344–1360.
Lindén, L., & Singleton, V. (2021). Unsettling descriptions: Attending to the potential of things that threaten to undermine care. *Qualitative Research*, *21*(3), 426–441.
Löwy, I. (2011). *A Woman's Disease: The History of Cervical Cancer*. Oxford: Oxford University Press.
Mamo, L. (2023). *Sexualizing Cancer: HPV and The Politics of Cancer Prevention*. Chicago: University of Chicago Press.
Mamo, L., Nelson, A., & Clark, A. (2010). Producing and protecting risky girlhoods. In Wailoo, K., Livingston, J., Epstein, S., & Aronowitz, R. (Eds.), *Three Shots at Prevention: The HPV Vaccine and The Politics of Medicine's Simple Solutions* (pp. 121–145). Baltimore: John Hopkins University Press.

Mamo, L., Pérez, A. E., & Rios, L. (2022). Human papillomavirus self-sampling: A tool in cancer prevention and sexual health promotion. *Sociology of Health & Illness*, *44*(1), 218–235.
Miles, T. (2017, April 4). Vaginal dilator therapy: Vibrate, dilate, or wait? *Evidently Cochrane*. https://www.evidentlycochrane.net/vaginal-dilator-therapy-vibrate-dilate-or-wait/
Mol, A. (1999). Ontological politics. A word and some questions. *The Sociological Review*, *47*(1_suppl), 74–89.
Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham: Duke University Press.
Moore, L. J. (1997). 'It's like you use pots and pans to cook. It's the tool': The technologies of safer sex. *Science, Technology & Human Values*, *22*(4), 434–471.
Moscucci, O. (2016). *Gender and Cancer in England, 1860–1948*. Basingstoke: Palgrave Macmillan.
Moser, I. (2011). Dementia and the limits to life: Anthropological sensibilities, STS interferences, and possibilities for action in care. *Science, Technology, & Human Values*, *36*(5), 704–722.
National Cervical Cancer Coalition. (2025). *Sex and intimacy after cancer*. https://www.nccc-online.org/hpvcervical-cancer/sexuality-cancer/
Nicholls, E. J., & Rosengarten, M. (2020). PrEP (HIV pre-exposure prophylaxis) and its possibilities for clinical practice. *Sexualities*, *23*(8), 1327–1342.
Rabeharisoa, V., Moreira, T., & Akrich, M. (2014). Evidence-based activism: Patients', users' and activists' groups in knowledge society. *BioSocieties*, *9*(2), 111–128.
Race, K. (2015). 'Party and play': Online hook-up devices and the emergence of PNP practices among gay men. *Sexualities*, *18*(3), 253–275.
Regional Cancer Centres in Sweden, RCC. (2022, November 15). *Nationellt vårdprogram för livmoderhalscancerprevention*. https://cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/vardprogram/
Regional Cancer Centres in Sweden, RCC. (2024). *Sexuell rehabilitering*. https://cancercentrum.se/samverkan/vara-uppdrag/cancerrehabilitering/funktionella-besvar-efter-cancer-i-backenet/sexuell-rehabilitering/
Panofsky, A. (2011). Generating sociability to drive science: Patient advocacy organizations and genetics research. *Social Studies of Science*, *41*(1), 31–57.
Solbrække, K. N., & Lorem, G. (2016). Breast-cancer-isation explored: Social experiences of gynaecological cancer in a Norwegian context. *Sociology of Health & Illness*, *38*(8), 1258–1271.
Stewart, H., Ashmore, L., Kragh-Furbo, M., Singleton, V., & Hutton, D. (2024). Ghosts in the machinery: Living with and beyond radiotherapy treatment for gynaecological cancer. *Health*, *28*(1), 90–107.
Takeshita, C. (2011). *The Global Biopolitics of the IUD: How Science Constructs Contraceptive Users and Women's Bodies*. London: MIT Press.
The Eve Appeal. (2024). *Information for trans, non-binary and intersex people*. https://eveappeal.org.uk/information-and-advice/gynaecological-cancers/information-for-trans-men-and-non-binary-people/
White, I. D., Faithfull, S., & Allan, H. (2013). The re-construction of women's sexual lives after pelvic radiotherapy: A critique of social constructionist and biomedical perspectives on the study of female sexuality after cancer treatment. *Social Science & Medicine*, *76*, 188–196.
Wray, N., Markovic, M., & Manderson, L. (2007). Discourses of normality and difference: Responses to diagnosis and treatment of gynaecological cancer of Australian women. *Social Science & Medicine*, *64*(11), 2260–2271.

4 Abya Yala bleeds, exists, and resists: introducing the Latin American social movement for menstrual dignity

Sofia Cifuentes Contador

Introduction

Even though activists from Western countries have been challenging the negative narratives associated with menstruation since at least the 1970s (Bobel, 2010), in recent decades a global menstrual movement has grown stronger, seeking to make menstruation part of a global body politics with diverse expressions and practices (Gaybor & Harcourt, 2022; Bobel et al., 2020). This movement has questioned menstrual taboos and stigma (Johnston-Robledo & Chrisler, 2013), promoting alternative meanings of menstruation. The menstrual movement is concerned with health activism, while including social demands, such as feminism, ecology, consumer rights, human rights, and decolonization (Bobel, 2010). Gaybor and Harcourt (2022) identify two strands in the movement: menstrual activism and Menstrual Hygiene Management (hereinafter MHM) projects. Menstrual activism has been described as "a mobilizing effort that challenges menstrual taboos and insists that menstruators[1] have the support they need to live healthy happy lives" (Bobel & Fahs, 2020b). MHM projects are linked to the water, sanitation, and hygiene (WASH) sector, which is related to development policy and practice as well as international cooperation, and it is concerned with "period poverty," which refers to lack of access to sanitary products, education on menstrual health, and infrastructure for waste management (Plan International, 2021).

The global menstrual movement has become more visible and relevant during the past 20 years, especially since 2015 due to the rise of period-positive publications (Weiss-Wolf, 2017). International organizations have also played a role: in 2019, the United Nations called to address the negative impact that menstrual stigma has on gender equality and on the exercise of the human rights of menstruators.[2] In 2022, the World Health Organization issued a statement to consider menstruation as a health and human rights issue and not just hygiene. Interdisciplinary academic research has accompanied the surge of the global menstrual movement. In 2020, the field of *Critical Menstruation Studies* was solidified with the publication of *The Palgrave Handbook of Critical Menstruation Studies* (Bobel et al., 2020). Even though the Palgrave handbook does an excellent job of showing the diversity of the menstrual

DOI: 10.4324/9781003319818-6

movement, with 134 contributors from all over the world, only 2 came from Latin America.[3] Furthermore, in Global South studies about menstruation, Latin America is clearly underrepresented: most studies refer to MHM initiatives in South Asia and Africa, in countries such as India, Nepal, Kenya, and Uganda (Bobel, 2019). Similar invisibility is to be found in global dissemination spaces of menstruation. For example, in 2023, at the 24th Society for Menstrual Cycle Research conference, Latin American researchers were only 4 of about 150 people from all over the world, and in previous conferences the numbers have been even lower, a problem that the Society has acknowledged (Bobel, 2019).

So, it is inevitable to ask: why is Latin America so invisible to the global menstrual community? It is not because nothing is happening. Latin America is a socioculturally rich and diverse region where discussions around the menstrual cycle have significantly increased during the past 15 years. Within the general Latin American menstrual movement, I have been following a particular strand that I call the Latin American social movement for menstrual dignity, a movement rooted in the regional history of critical thinking and resistance, feminism, and decolonization. This movement brings new ideas, concepts, and debates of high relevance to the global menstrual community because of their insistence on tackling the roots of menstrual taboo and stigma. To the best of my knowledge, this is the first study that seeks to report on the Latin American menstrual movement from a transnational perspective, exploring the main characteristics of an emerging, vital, and developing social movement. Thus, the aim of this exploratory study is to introduce the Latin American social movement for menstrual dignity, discussing the role it can play in vitalizing the global discussion around menstruation.

Background

Menstrual activism and MHM share the concern with improving the menstrual experience but also have critical differences. Building on the women's health movement and the consumer rights movement, menstrual activism gained strength during the 2000s in North America. Bobel (2010) has identified two currents of menstrual activism: "spiritual feminism" and "radical feminism." "Spiritual feminists" consider menstruation as sacred and indispensable, as menstruation would unite all women through their shared biology. This notion has been criticized for essentializing gender and sex and upholding gender binarism. On the contrary, "radical feminists" decouple menstruation and gender, influenced by queer feminism. "Spiritual feminists" promoted a change in individual attitudes toward menstruation and personal development, undermining how systems of power and privilege generate social inequalities that shape the menstrual experience, which are issues addressed by "radical feminists" and influenced by anti-capitalism (Bobel, 2010). In Europe, Persdotter (2013) characterized the "menstrual countermovement" of the 2000s as a fragmented movement concerned with the abject status of

menstruation. Most activists challenged the boundaries between public and private by, for example, sharing intimate experiences regarding menstruation through social media. Consumerism of reusable products was enhanced, with political consumerism being a means for women's exercise of political power and social change (Persdotter, 2013). In India, menstrual activism gained visibility in the 2010s, through public, student-led campaigns that sought to "break the silence" regarding menstruation. These campaigns were part of a broader continuum of feminist articulations and mobilizations focused on gender violence. More recently, menstrual activism has addressed the interplay of caste, sanitary work, and environmental concerns, advocating "sustainable menstruation" through reusable menstrual products (Mitra & Karunakaran, 2024).

MHM has gained traction during the past 15 years, mainly through interventions in schools and communities in the Global South. Even though MHM frames menstruation as a human rights issue, related to development and gender equality, it has received a lot of criticism. Bobel (2019) argues that the simplistic view that underlies most of MHM projects accommodates, rather than challenges, menstrual stigma. Most MHM initiatives encourage a simplistic neoliberal approach: "Give a girl a pad and change the world." This approach puts too much responsibility on the individual and fails to address structural systems of oppression (Bobel, 2019). MHM's framing of "menstrual dignity" as a human rights issue has been criticized for accommodating a Western view of embodied care, where "dignity" depends on girls' ability to conceal their menstrual status through discipline, modernity, and efficiency (Bobel, 2019). McCarthy and Lahiri-Dutt (2020) criticize how MHM focuses on private space and individual-level "empowerment." Organizations in the Global South, such as ZanaAfrica (Kenya) and Sachhi Saheli (India), acknowledge the need to go beyond the provision of menstrual products, urging for sexual and menstrual education to address menstrual taboo (Cousins, 2020). The Global South Coalition for Dignified Menstruation stands against the hygienist perspective of MHM and provides a framework for promoting "dignified menstruation," a counter concept that criticizes "period poverty" (Paudel, 2020), a debate in which I will delve when analysing the Latin American social movement for menstrual dignity. Influenced by concerns on "period poverty" in Global South countries, the US and other Global North countries started to address issues of access and affordability of menstrual products within their borders. These initiatives were sometimes framed under the term of "menstrual equity," which led to the surge on bills for menstrual rights, especially regarding access to products for marginalized populations in the Global North (Weiss-Wolf, 2017). Scotland was the first country to make menstrual products free for all in 2022, bringing worldwide attention (Diamond, 2022), despite Kenya pioneering with banning value-added tax (VAT) on menstrual products in 2004. As presented, there are differences and tensions between menstrual activism and MHM. On the one hand, Bobel and Fahs (2020a) and Bobel (2019) criticize that menstrual activism has been

co-opted by MHM discourse, making activism less radical. On the other hand, Gaybor and Harcourt (2022) believe that both strands ensure that menstruation remains visible on the global health agenda. Within this debate, the lack of inclusion of what is happening in Latin America is evident. As I will bring forth here, the region's menstrual movement holds potential for informing the global menstrual movement with educative and activist strategies that put the experiences and knowledge of women and menstruators at the centre, while addressing the structural factors that negatively affect menstruation.

Latin America is a diverse continent with 21 countries and has a complex history shaped by European colonization. This event produced a demographic collapse that decimated Indigenous populations and opened the arrival of enslaved people from Africa. This mix of Indigenous, African, and European colonists formed the foundation for racial, social, and gender-based inequalities that still endure (Andrews, 2018). Today, Latin America is the most socio-economically unequal continent (CEPAL, 2023). The region is marked by the hybridization of beliefs, traditions, and practices of Europeans, African-descent, and Indigenous populations, especially regarding notions of health and healing (Cueto & Palmer, 2014). European colonization affected ideas about gender and menstruation in the region. According to Ochoa Muñoz (2014), the colonization of America was a misogynist process and Indigenous people were feminized, emphasizing women's inferiority and reinforcing heterosexuality and gender binarism. In many pre-Columbian cultures, there was greater gender diversity, beyond binarism (Lugones, 2008). Colonization is inseparable from the racialization that marked Indigenous people, especially women, as savage, soulless, and evil (Salazar, 2006), whose menstrual blood was considered inferior, more pathological, and dangerous than the menstruation of European's (Eraso, 2015). In contrast, unlike the Judeo-Christian tradition that considers menstruation as impure (Gottlieb, 2020), for various Indigenous communities menstruation had a positive significance as it was understood as a fertility sign of both Indigenous women and the group, ensuring the vital force required for social reproduction (Vásquez Santibáñez & Carrasco Gutiérrez, 2017). With colonization, the Western view of menstruation was disseminated as well as its view on disciplining women's bodies in a contradictory way: while menstruating was a women's issue, being "womanly" meant concealing menstruation (Tarzibachi, 2017). In the 1960s, menstrual concealment was reinforced with the introduction of US disposable menstrual products that were marketed to make Latin American women "modern," encouraging them to leave behind their "backward" reusable menstrual products, in a way that Tarzibachi (2020) deems neocolonial. Latina's bodies have been shaped by sexualized, gendered, and racialized categories, indicating the multiplicity of relationships that constitute bodies, and the ambivalence tied to identity (Rivera, 2011).

Sexual and reproductive rights in the region are frail, even though as early as the 1930s Latin American feminists were demanding legal abortion and access to contraception (Marino, 2020). The history of birth control reveals

mistreatment to Latin American women. The testing of "the pill" was related to eugenics concerns regarding "overpopulation" in Puerto Rico. In 1956, Searle company tested the first oral contraceptives in Puerto Rico, where over half of the participants dropped because of negative side effects, putting their health at risk while paving the way for the development of contraceptives that benefited mostly Global North women (O'Connor, 2014). The main obstacles for the exercise of sexual and reproductive rights are the weak political will of governments to address sexual education, political-administrative changes, insufficient budget, and oppositional conservative groups (Cimmino et al., 2024). The unwillingness of governments to address comprehensive sexual education and reproductive rights affects the 166 million menstruators that live in Latin America and the Caribbean (Weinberger et al., 2024). No Latin American school provides menstrual education, not even in Argentina, which has a comprehensive sex education law since 2006 (Barone Zallocco, 2021). Before the current menstrual movement, menstruation was not explicitly addressed neither by feminism (Molina Torres, 2017) nor by public programs (Prado, 2024). Very few MHM programs have been implemented in the region, most of them with the support of international organizations and in partnership with menstrual hygiene corporations (Plan International, 2024). There are few studies about menstrual education and intervention, pointing out to the invisibility of menstruation as a public health issue, despite the many challenges Latin American countries share with other lower- and middle-income countries, such as lack of adequate infrastructure, lack of basic sanitation, and difficulty of access to menstrual products (de Oliveira et al., 2023).

Despite the challenging context in Latin America, the menstrual movement in the region is flourishing, following grassroots mobilization and popular education as strategies that have characterized Indigenous peoples and colonial subjects when challenging colonial frameworks in Latin America (Maldonado-Torres, 2011). The challenge of hegemonic views of menstruation started in the early 2000s, when women's circles started to be held all over the region. These were spaces where a sacred narrative of the female body was enhanced, fostering a more positive view about menstruation (Ramírez-Morales, 2022). Women's circles facilitated the use of the menstrual cup, because participants sold them and provided menstrual health counselling (Felitti, 2016). As in Europe (Persdotter, 2013), reusable menstrual products and their sellers played a crucial role, as using the cup supported changes in attitudes toward menstruation and promoted ecofeminist ideas (Ramírez-Morales, 2022). Between 2016 and 2020 grassroot collectives and menstrual education projects grew, with Argentinian Economía Femini(s)ta collective pioneering with its 2017 #MenstruAcción. This campaign sought to account for the economic inequality faced by menstruators because of the 21% VAT paid on menstrual products in a country in constant economic crisis (Suárez Tomé & D'Alessandro, 2019). Since the late 2010s, various countries of Latin America have started to pay more attention to menstruation.

Advances in women's rights attained by feminism (Ramírez-Morales, 2020) were gateways to talk about sexual education and forward discussion around menstruation. Chilean student movement demands for non-sexist education in 2011–2016 (Lillo-Muñoz, 2019; Cifuentes Contador, 2023) and Argentina's "green wave" mobilization for free, safe, and legal abortion, conquered in 2020, are some examples. Massification of social media gave rise to "experiential menstrual cyber activism" (Ramírez-Morales, 2020), initiating conversations around "Conscious Menstruation": the embracing of different psycho-emotional fluctuations related to the menstrual cycle and linked to feminine archetypes, favouring the embodiment of cyclicity (Almanza Towgood, 2018). In 2018, Colombia pioneered VAT elimination for menstrual products, as bills for menstrual rights have been increasingly proposed (Calderón-Villarreal, 2024). The coronavirus pandemic opened discussions around "period poverty," pushing bills on menstrual rights in more countries in the region (Bean, 2021). In 2022, Mexico approved a mandate to reform the General Education Law to favour menstrual dignity in public schools (Díaz, 2022). In 2021, Brazil implemented the "Program for the Protection and Promotion of Menstrual Health and Dignity," distributing menstrual products to those in need (Prado, 2024). Furthermore, research has surged (Costa et al., 2024), especially master's theses (see Aravena Pulido & García Acevedo, 2023; Jiménez Serrano, 2024) and doctoral theses (see Morais, 2021; Accerenzi, 2023). These examples highlight the rich context of the Latin American menstrual movement and lay out the evident value in filling the knowledge gap about menstruation in Latin America.

Methodology

Since 2020, I have participated, collaborated, and studied the menstrual movement in Latin America, positioning myself as a researcher, educator, and menstrual activist. As a feminist researcher, I bring my own embodied experience to my work, and I am involved in the communities I study (Castañeda Salgado, 2019), not at least because I identify as a menstruating woman. This chapter draws from fieldwork carried out between 2021 and 2024, including diverse empirical materials (online posts, books, talks, conferences) and six online semi-structured interviews with key actors of the movement in 2024 (see Table 4.1). The interviewees were recruited via email, all identifying as female/cisgender women. Each interview was preceded by observations of the participant's online material and/or academic work, and, in two cases, we had met in person before. All participants read and signed an informed consent, giving permission to use their names. The interviews were held in Spanish, lasted between 60 and 120 minutes, and were recorded and transcribed. Interviewees received transcripts and manuscript drafts, commenting on them for improvement.

The analysis focuses on what I have called the Latin American social movement for menstrual dignity, a specific strand within the regional menstrual movement. The chosen focus has consequences: I deliberately omitted

Table 4.1 Participants' information

Name	*Country*	*Age*	*Criteria for inclusion*
Andrea Isabel Aguilar-Ferro	Guatemala	34	Co-founder of the "Menstrual Guatemala" [*Guatemala Menstruante*] collective, researcher
Núria Calafell Sala	Argentinian nationalized, born in Spain	42	Menstrual activist and researcher
Rosario Ramírez-Morales	Mexico	40	Menstrual activist and researcher
Emilia Almanza Towgood	Mexico	38	Founder of "The Rise" [*La Crecida*] menstrual health education project
Laura P. Contreras-Aristizábal	Colombia	40	Founder of "Women's medicine" [*Medicina de Mujer*]
Carolina Ramírez-Vásquez	Colombia	42	Founder of the menstrual education project "Menstruating princesses" [*Princesas menstruantes*]

people and projects that I deemed not part of the critical approach, mostly MHM-inclined projects, which inevitably means a risk of omitting relevant data – while on the other hand enabling a more in-depth analysis. The movement for menstrual dignity is suspicious toward MHM, as it questions the effects of (neo)colonization, racialization, and capitalism associated with it. Furthermore, this research is an exploratory study of an emergent contemporary social movement, which means that what I am presenting is likely to change. Finally, a very important limitation is that, although I seek to report on the overall panorama of the Latin American social movement for menstrual dignity, the experiences from Mexico, Colombia, Guatemala, and Argentina are emphasized and the Caribbean is omitted. The included countries were chosen because i) they have pioneered the movement, ii) I had established contact with their key actors, and iii) there was a high degree of written information available from them, which made them more accessible for analysis. In future research, I aim to expand to other countries.

The Latin American social movement for menstrual dignity

In what follows, I will present my analysis of what I call the Latin American social movement for menstrual dignity. I will first present an overview of the movement, then dive deeper into five key characteristics of the movement, and finally highlight some of the tensions within the movement.

The movement at large

What is specific of the Latin American social movement for menstrual dignity, and that differentiates it from the broader Latin American menstrual movement, is its critical perspective that urges its participants to go beyond the

concerns about economic aspects of menstruation (as VAT elimination) and simplified versions of menstrual education (e.g. centred on the "correct use" of menstrual products). The Latin American social movement for menstrual dignity instead aims to tackle the roots of menstrual taboo and stigma, addressing patriarchy, colonialism, racism, and capitalism (Macías-Rea, 2023), informing the ways they pursue menstrual education, do advocacy, and create materials. The movement draws criticisms from decolonizing and liberation perspectives that follow the critical thinking tradition that has shaped the region since the 1960s, especially popular education and community-based organizing as developed by Brazilian Paulo Freire and feminism, particularly decolonial, popular, and communitarian feminism. Decolonial scholarship studies the implications of the power structures in knowledge production and explores other epistemologies that position knowledge from oppressed or marginalized groups for freeing subjugated knowledge, challenging dominant Western epistemes. Latino decolonial scholars have worked for constructing epistemes that centres Latinas/os knowledge and contributes to the "flourishing of life" [*buen vivir*] (Isasi-Díaz & Mendieta, 2011). Because bodies are the bearers of the memory of knowledge power, they are privileged sites for uncovering "subjugated knowledge" and decolonial Latinx theory requires that Latina women create alternative theorizations of embodiment (Rivera, 2011). Within this framework the Latin American social movement for menstrual dignity has been developing, aiming to create new menstrual knowledge, strategies and, ultimately, a different world that makes women and menstruators lives better (Macías-Rea, 2023). Through activism, promotion of menstrual health and menstrual education that seeks to dismantle menstrual taboo and stigma, the movement describes itself as working toward menstrual dignity for all menstruators (Ramírez-Vásquez, 2022a; Prado, 2024). Therein, they challenge neoliberalism and the ways in which it makes menstruation subjected to hygiene and control (Pelúcio, 2022).

The main venue of encounter and debate of the Latin American social movement for menstrual dignity is the Latin American Meeting of Menstrual Education, Health and Activism, coordinated by *Emancipadas*,[4] a school for menstrual education. The meeting has been held annually since 2020 in different countries in the region, being an autonomous, self-organized, and non-profit space that lasts three days. The Menstrual Visibilization Days [*Jornada de Visibilización Menstrual*], hosted online yearly since 2021 and coordinated by the Mexican Network of menstrual education [Red de educación menstrual], also provides a meeting space for the movement.

The Latin American social movement for menstrual dignity points out to the relationship between menstrual taboo and violence as it pervades other areas of life, linking it with experiences of sexual violence and oppression in general, similar to what has been described in India (Mitra & Karunakaran, 2024). Thus, activists highlight the need for menstrual dignity in feminist marches, especially on International Women's Day on March 8, where thousands of protestors all over Latin America go to the streets denouncing violence

against women and demanding human rights. Since 2022, the "Red Block" [*Bloque Rojo*] initiative invites protesters to dress in red and hold banners that say: "Let's normalize menstruation, not rape!," "The menstrual taboo is patriarchal violence," and "Dignified Menstruation and life, from Abya Yala [Indigenous term referring to the Latin American region] to Palestine!" (Hor-Moonal, 2024). These phrases are examples of the interlocking of patriarchal violence and oppression through the lens of menstruation. Currently, one of the concerns discussed within the movement is the extended use of long-acting contraceptives (like *Implanon*) in impoverished adolescents, as a means for preventing teenage pregnancy. The movement for menstrual dignity is concerned with how long-acting contraceptives are promoted without providing menstrual education, and they push for public actors to address their relation to gender violence and to consider the negative health effects associated with their use (Prior & Goshtasebi, 2019). As it was discussed in the 4th Latin American Meeting on Menstrual Education, Health, and Activism in 2023, activists view this practice as a form of violence that resembles the birth control trials in Puerto Rico. Emancipadas denounces that pregnancy can signal child rape, that could go unnoticed with long-acting contraceptives inserted indiscriminately: "But let us remember that a pregnant girl is an abused girl, so the primary concern of States should be that rape does not happen" (Escuela de Educación Menstrual Emancipadas, 2024). Therefore, long-acting contraceptives as a policy for preventing teenage pregnancy is a superfluous policy that does not address sexual violence nor provides sexual education, undermining sexual, and reproductive rights.

The movement is worried about the commodification of menstruation, which could easily happen when implementing public policies focused on the free provision of disposable menstrual products to people in need. In the 4th Latin American Meeting on Menstrual Education, Health and Activism, it was discussed how paradoxical it would be that transnational hygiene corporations increase their revenues with these policies, as menstrual products brands have based their marketing on menstrual taboo. As Prado (2024) argues, these policies could maintain menstruating bodies in a colonialist logic: bodies exploited for profit and the accumulation of foreign capital. Thus, menstrual activists make a call to accompany the provision of menstrual products with menstrual education provided by local menstrual educators, not by the menstrual hygiene brands whose messages around menstruation are centred on biomedical and heterosexual mandates (Tarzibachi, 2017).

Key characteristics of the movement

Five key characteristics of the Latin American movement for menstrual dignity emerged through the analysis: spiritual-political feminism, hybridization of knowledge, critical assessment of MHM, restating of menstrual dignity, and epistemic activism, described in what follows.

Spiritual-political feminism

As mentioned earlier, women's circles have been key for addressing menstruation. These were influenced by Indigenous spirituality and by the ideas of renowned Global North menstrual activists, such as Miranda Grey (UK), Deanna Lam (Israel/US), and Erika Irusta (Spain). Although some of the women's circles in Latin America reproduced gender binarism and essentialism (Calafell Sala, 2020), some were open to all the genders that menstruate (Felitti, 2021). Like Bobel's findings in the US (2010), women circles focused on a spiritual view of menstruation with a caveat: many Latin American women started to incorporate a more political perspective of menstruation, questioning the call of Global North activists to "love" menstruation. Women's circles participants questioned the lack of mention of the structural factors that shape the menstrual experience, as inequality. As Laura Contreras-Aristizábal mentions:

> Menstrual activism [in Colombia] gained strength from a spiritual conception of menstruation, in spaces that talked about menstruation from a spiritual point of view. But women who had a history of political activism went to these spaces and we began to transform the conception of menstrual blood, from a view of wellbeing and health to a view of power and sovereignty.
>
> (Personal communication, May 3, 2024)

In contrast to the "spiritual feminists" described in North America, the self-knowledge promoted in the Latin American women's circles during the early 2010s was channelled to political demands for structural changes for better menstrual health, like the demands of the Boston Health Collective (Bobel, 2010). Many participants of women's circles were also active feminists, giving an important role to body autonomy, joy, and pleasure for social transformation, seeing the personal and the spiritual as political (Felitti, 2021), not limiting the discussion to an individual level. Therefore, discussions in women's circles easily moved from individual to collective concerns, questioning why menstruation was such a negatively framed experience and what should happen to change this view.

Hybridization

Around 2016, grassroot organizations began to address menstruation, publishing fanzines and manuals on natural gynaecology (Calafell Sala, 2020) that were built on both ancestral knowledge and the North American women's health movement, generating a mix between tradition and modernity, resisting the ways in which menstruation would be colonized (Calafell Sala, 2019). The combination of ancestral and popular knowledge with scientific

evidence by activists facilitated a hybridization of knowledge, as Emilia Almanza put it:

> I infuse my activism and educational approach with insights from leading menstrual health experts in the United States, while also drawing deeply from the work of Latin American movements, community feminisms, and spiritual traditions. It's a process of hybridization – a blending of traditions – where we discard what has stripped us of autonomy and create something new and empowering.
>
> (Personal communication, April 11, 2024).

The concept "body-territory" delineates a perspective that permeates the Latin American movement for menstrual dignity. The concept is drawn by communitarian, ecofeminism, and decolonial feminism, disseminated by Lorena Cabnal, Maya-Xinca from Guatemala. From this perspective, the violence that the female body confronts is the same that the local territories face: extractivism, which is the extracting of a resource through wiping the location and leaving the place in a precarious situation (Carbajal, 2020). The parallels between the menstruating body and land can be exemplified in the importance given to using a decolonizing language (Calafell Sala, 2020). For example, Latin American menstrual activists and educators encourage people to say "uterine tubes" [trompas uterinas] instead of "fallopian tubes" [trompas de Falopio] because the latter term, named after the sixteenth-century Italian priest and anatomist Gabriele Falloppio, reinforces the idea of women's body as a territory for male conquest. In this way, a parallel is placed between the female body and the territories: defending female body autonomy is like defending territory sovereignty, just as caring for the menstruating body aligns with caring for the environment in a context of climate change (Carbajal, 2020). Within this feminist framework, Aguilar-Ferro (2022) coined the term "menstruating feminisms" [feminismos menstruantes] to refer to how different Latin American feminist contributions articulate the relevance of the materiality of menstrual blood, as it signals the cyclicity of the menstrual body, being an agentic materiality that detonates emancipatory searches for social transformation toward a more just society that fosters menstrual dignity. This feminism considers healing the personal and collective menstrual experience as a political action (Aguilar-Ferro, 2022). Therefore, we see how the movement doesn't separate the menstrual body from the materiality of the context where it is and the violence that runs through it.

Critical assessment of MHM

Participants of the Latin American movement for menstrual dignity have continuously criticized MHM enterprises, sharing many of the criticisms described before in the Global South (Bobel, 2019). They argue that "hygiene" is a

colonial re-traumatization that sees Indigenous women's bodies and blood as impure (Eraso, 2015) and Latin American women as "backward" (Tarzibachi, 2020). Emancipadas (2023) criticizes "humanitarian" MHM assistance programs and "period poverty" for its prioritization of menstrual products over access to information, the reaffirmation of class difference ("poverty"), the ignorance of the capacity for the self-management of menstruation, and for ignoring that the lack of products is a consequence of the feminization of poverty and its functionality for a consumer society. Thus, Emancipadas holds that "period poverty" is based on the purchasing capacity of menstruators, reducing the problem to a "hygienic crisis," ignoring the structural elements that make the menstrual experience precarious (Escuela de Educación Menstrual Emancipadas, 2023).

Latin American menstrual activists critique the organization of May 28 as "Menstrual Hygiene Day," an international event organized since 2014 by German NGO Wash United. Activists point out that in 1987 the Global Network of Women for Reproductive Rights established May 28 as the "International Day of Action for Women's Health," a milestone proposed at the Fifth International Meeting on Women's Health in Costa Rica (Felitti, 2016). Latin American menstrual activists critique the erasure from Global North actors of the work pursued by Global South feminists, calling to remember May 28 history before it was "MHM day" (Ramírez-Vásquez, 2022b). Nowadays, on May 28, some Latin American menstrual activists share online posts about the history of this day and make a call for menstrual dignity and menstrual health – and not for "menstrual hygiene." For example, in 2024 a Peruvian collective published on Instagram "We need kinder ways to talk about menstruation, let's talk on our terms! Let's talk about caring practices, let's talk about menstrual dignity for everyone!" (Veraciclos et al., 2024).

As mentioned before, very few MHM interventions have been pursued in Latin American countries, despite facing similar challenges regarding education, infrastructure, and sanitation with other low- and middle-income countries (de Oliveira et al., 2023). According to menstrual activist Laura Contreras-Aristizábal, one possible explanation for the fewer MHM interventions (as compared to other Global South countries) is the suspicion of Latin Americans toward foreign intervention:

> The funding is focused on Asia and Africa, because it is very easy to intervene there since there is not as much resistance or questioning as in Latin America, where we are more decolonial. Even in Nepal, where Radha Paudel [founder of the Global South coalition for dignified menstruation] is, you see that she does not have as much funding as other projects because Radha is a critical thinker, and the funding is given to projects that believe that a girl is empowered by simply giving her a cloth pad. . . . In Latin America we [Latin American people] question, we propose, and we do not let the intervention be as simple as that, because we seek emancipation and that is where the decolonial in Latin America is.
>
> (Personal communication, May 3, 2024)

The suspicion toward international funding is related to the breakdowns that Latin American feminists had with international NGOs during the 1990s, as it was accused that feminism was being institutionalized and responding to NGO needs over their community's needs, creating tensions and suspicion within social movements (Barrig, 1998). Given this mistrust, it is expectable that if an international organization will do an MHM program, then it must comply with the requests for specific conditions by local menstrual actors: "*If they* [international MHM agencies] *are going to put the money, we* [local actors] *will decide where it is put*" (Contreras-Aristizábal, personal communication, May 3, 2024).

The pedagogies that menstrual educators of the Latin American movement for menstrual dignity use are also related to the critical assessment of MHM, as they recur to ludic models for generating candid conversations around menstruation. One of the most famous menstrual education organizations is "Menstruating Princesses" *[Princesas menstruantes*], a project founded in 2014 that has developed its own pedagogical tools, methodologies, and strategies. They call their education "emancipatory menstrual education," a "critical educational model that enables the autonomy of people through the questioning and subversive action of the patriarchal order of society, giving central importance to the transformation of negative and oppressive narratives built on menstruation" (Ramírez-Vásquez, 2022a). Even though the gendered name of the organization can be easily critiqued, they state that through their project they are "giving a voice" to classical princesses. The organization points out that princesses' stories have been told from an outsider perspective (a man), never from the princess's standpoint, contributing to the patriarchal narrative of an "ideal woman." By giving voice to princesses, this educational project offers transformative menstrual narratives for girls (Princesas Menstruantes, n.d.). Carolina Ramírez-Vásquez, co-founder of the organization, asserts that there are important differences between how menstrual education is pursued in Latin America compared to other contexts:

> Europe builds menstrual education to intervene, we [Latin Americans], to resist . . . that is why the menstrual education of the Global North is so insipid, so product-centred. They [Global North MHM interventions] remain in the discourse of "menstrual poverty", of poverty in general. . . . it is definitely welfarist [as opposed to the emancipatory aim].
>
> (Personal communication, April 25, 2024)

This vignette shows how an activist contrasts menstrual education in the Global North and from a critical Latin American standpoint. The main contrast she posed was between welfarism in the Global North, understood as a framing of a solution of "period poverty" mainly through menstrual products provision and education regarding hygiene, and the "emancipatory" aim of Latin American menstrual education. As described before, participants of the Latin American social movement for menstrual dignity follow the region's tradition of critical thinking, which is wary of colonialism, including the

negative hegemonic view of menstruation attributed to the Western tradition. Therefore, resistance in menstrual education is about questioning hegemonic narratives of menstruation in a playful and open way, allowing concerned participants to create more inclusive, transformative and positive narratives around menstruation. Mere "intervention," as Ramírez-Vásquez called it above, is a reductive, welfarist lens, in the sense that it only provides products as an aid for managing blood, barely questioning hegemonic narratives around menstruation. Therefore, this kind of education doesn't allow women and menstruators to develop the critical tools for dismantling menstrual taboo and stigma, advancing emancipation.

Restating menstrual dignity

"Menstrual dignity" is a relevant concept of the global menstrual movement, and it is often mentioned as one of its aims. However, the ways menstrual dignity is conceptualized and achieved are critical and vary across different groups of menstrual activists and educators. Bobel (2019) found that in many countries of the Global South, even though presented from a human rights perspective, menstrual dignity was claimed to be achieved through the concealment of menstruation, which is an accommodation of menstrual stigma, rather than its dismantling. Contrary to this approach, participants of the Latin American movement for menstrual dignity state that menstrual dignity is constructed over the dismantling of menstrual taboo and stigma, having an emancipatory horizon of transformation. It does not imply that menstruation itself is undignified but rather that the conditions necessary for menstruating with dignity are not in place, as Laura Contreras-Aristizábal argues:

> Some people do not want to talk about "menstrual dignity" because they say that menstruation is not "undignified" so the concept of "menstrual dignity" does not make sense to them. But what we say is not that menstruation is undignified, but that today there are no conditions to live menstruation in dignified conditions. Therefore, it is necessary to talk about the crisis that exists around menstruation, the gender inequalities that are constructed by menstruating and demand menstrual dignity.
>
> (Personal communication, May 3, 2024)

Menstrual dignity can also be understood from an anti-colonial perspective, as Prado and Mendes (2024) conceptualize it for the Brazilian context. They highlight the work of activists that promote anti-colonial menstruation, which the authors characterize as non-productivism, care (for oneself, other people, and nature), rest and self-knowledge, and respecting diversity (Prado & Mendes, 2024). Menstrual activists pay attention to structural factors and contextual elements that have a relevant role to play when doing menstrual education and activism. Structural factors include socio-economic status and consideration of marginalization, while contextual elements include access to

water and rural versus urban settings. Menstrual activists and educators tailor their work to the needs of the communities in which they engage and discuss with them how these factors and contextual elements shape the menstrual experience of the communities (Macías-Rea, 2023). One example of integrating structural and contextual factors into menstrual education is the online seminar "How to transform your menstrual education practice into a social laboratory," co-taught online by Aurora Macías-Rea and Carolina Ramírez-Vásquez. The purpose of this seminar is to "offer strategies and tools for the promotion of social laboratories to analyse the social representations that sustain the menstrual taboo, a proposal for ongoing research to make educational practices a living and transformative process" (Escuela de Educación Menstrual Emancipadas et al., 2024). Seminars like this help participants to analyse how their own menstrual experiences are shaped by structural factors and contextual elements and the ways in which they can work toward the dismantling of oppression.

Epistemic activism

Epistemic activism refers to the set of activist practices that exert epistemic frictions against dominant sensibilities that hinder the epistemic agency of hermeneutically marginalized groups (in this case, menstruators). It resists epistemic injustices, entwined with other social injustices, thus clashing against dominant visions and favouring the generation of emancipatory social changes (Medina, 2021 in Suárez Tomé et al., 2023). The Latin American social movement for menstrual dignity does epistemic activism. For example, they generate data regarding the cost of menstruation and the way this affects the gender gap (Suárez Tomé et al., 2023). They also create new concepts to better understand the experience of menstruators in a world where menstrual taboo and stigma rule. As Emilia Almanza states:

> We are in a fertile ground for creation, and it's worth creating new concepts – even though it feels challenging, as we often question ourselves, "Who am I to create something? I'm not an author, a spokesperson, or a leader. But I learned from my colleagues at Lunáticas [school of menstrual education] that we can play, we can create. And isn't that decolonial too? We don't need permission to innovate, as long as we do so responsibly, without appropriating from other cultures or people's ideas."
>
> (Personal communication, 11 April 2024)

Latin American menstrual activists are continually creating new concepts to understand menstruation in a new, generative way (see Table 4.2). For example, they create concepts that point out the invalidation of embodied menstrual experience (as *menstrual epistemicide*) and seek to put menstruation as a category of analysis (*menstrucentrism*). As the participants of this study have

Table 4.2 Concepts of the Latin American movement for menstrual dignity

Concept	*Description*
Menstrual Epistemicide	"Systematic invalidation and destruction of knowledge, wisdom and ways of understanding the world that emerge from the experience of the menstrual body" (Macías-Rea, 2023, p. 253).
Menstruartivismo (menstrual-art-activism)	Feminist tool that allows to re-signify the notions associated with menstrual blood and menstruating bodies (Valadez Angeles, 2019).
Menstrucentrism	The consideration of menstruation as a central axis and category of multidimensional analysis. Consequently, it deconstructs and transforms the narratives that negatively impact menstruating and non-menstruating people and society in general (Escuela de Educación Menstrual Emancipadas & Ramírez-Vásquez, 2023).
Decolonial menstrual health	Accounts for the menstrual cycle and how it affects the physical, emotional, mental, and spiritual dimensions of girls, women, and menstruators. It is considered a process because it changes according to the social, economic, cultural, and political context in which the person develops (Contreras-Aristizábal, 2023).

mentioned, wording new concepts is an active way to fight against generalized ignorance around menstruation and foster social transformation, aligning with decolonial epistemologies and nurturing. Thus, the concepts created by participants of the movement contribute to a new understanding of gendered oppressed bodies that can also be helpful in other contexts as it invites us to question colonialist, patriarchal, and capitalist narratives that sustain menstrual taboo and stigma. Some of the concepts that the movement has created are presented in Table 4.2.

The most significant texts that inform the Latin American movement for menstrual dignity are manifestos, hence political statements that in this context of menstrual activism can be considered a form of knowledge production. Signing a manifesto is a way of highlighting relevant ideas to which its signers are committed, in this case, discussions around menstruation in Latin America. The manifestos define the contours and values of the movement, key for shaping its ethical and political values. Two examples are the *Menstrual Education in Latin America Manifesto* (2020)[5] and the *Manifesto of the Menstrual Educators on Mexican soil* (2023).[6] Both share a critique of menstrual taboo and limited narratives around menstruation. The latter was written during the first national gathering of menstrual educators in Mexico, coordinated by the Mexican Network of menstrual education (REM), which starts with the following paragraph:

> We, historical, social and political subjects, give name and meaning to menstrual education. We are collectives and individuals working from

> our bodies-territories for menstrual dignity, from the south to the north, from the coast to the highlands of Mexico. We challenge menstrual taboo and stigma through innovative practices that impact the reality of diverse populations.
>
> (REM, 2023)

This manifesto affirms that their kind of menstrual education is anti-patriarchal, anti-capitalist, decolonial, anti-racist, intersectional, anti-hygienist, and community-based. Manifesto adherents make a call for mutual recognition, dialogue, collaboration, and construction of knowledge within the communities (REM, 2023). They oppose the instrumentalization of the menstrual cycle to "interests alien to our needs and autonomy." The Mexican network aims to make menstrual education accessible to all people, so they reinforce the work of local menstrual educators (REM, 2023). These manifestos are based on the lived experiences of Latin American women and menstruators, putting at the forefront of the movement their own definitions, ethics, and contours of how menstrual issues should be addressed in the context of Latin America. Because manifestos are a result of the collective work of activists and educators who meet, discuss, and arrive at consensus that guide action and are then written down, they create a common ground that enables epistemic activism. By affirming that there is an "historical debt to those who have suffered the consequences of menstrual taboo and stigma" (REM, 2023), they encourage women, menstruators, and menstrual grassroots organizations to actively affirm their right to demand justice and create a world that acknowledges and respects the different menstrual experiences. Because they demand change to create a world that respects the menstrual cycle and advances menstrual health including the perspective with whom menstrual educators are already working, the manifestos encourage epistemic activism and the inclusion of knowledge created through menstrual education practice.

Tensions within the Latin American movement for menstrual dignity

As all social phenomena, the Latin American movement for menstrual dignity has its contradictions and tensions. The main ones are currently what I call appropriation and extractivism: two malpractices that imply using another's person, place, or institution for personal or one-party benefit, generating suspicion among colleagues and eroding the movement. As explained above, extractivism refers to the extraction of a resource (i.e. menstrual knowledge) while leaving the location in a precarious situation. Indigenous and Global South thinkers denounce epistemic extractivism when Indigenous and local knowledge are decontextualized and depoliticized usually for the benefit of Western academia (Grosfoguel, 2019). With appropriation, in this context, I refer to when a person or institution takes something from another (e.g. a menstrual education tool) without permission of the original author or without giving proper credit, claiming that the material (e.g. menstrual education tool) was a novelty of the person or institution that does the appropriation.

Several interviewees referred to plagiarism among menstrual educators, a form of appropriation. This has also happened at the collective level, whereas in Mexico a relevant tension exists between the "Digna Mexico" collective (which had a crucial role in achieving menstrual public policies), and the Mexican Network of menstrual education, which accuse it of invisibilizing their work (REM, 2023). Participants of the Latin American movement for menstrual dignity have highlighted that menstrual activists should recognize what is their work and what is drawn from other activists:

> It is necessary to name ourselves, to recognise ourselves in a fair way, not to call ourselves "the first ones". It is fairer and more honest to say, "I am the one who is doing this, and this is my proposal", knowing that we never build in a vacuum, there are other people who did it before me.
>
> (Ramírez-Morales, personal communication, 12 April 2024)

This vignette stresses the need of menstrual activists and educators to acknowledge previous efforts in the menstrual space and show from where they build up their work. Unfortunately, this simple exercise can be counter-current in a neoliberal context characterized by economic precarity, limited social welfare, and uncertainty, while holding individuals accountable for their survival and success (Calafell Sala, 2024a). This challenging context could partly explain why some menstrual educators/activists recur to malpractices (as appropriation) in an attempt to make their work more visible and profitable. This appropriation and extractivism can be pursued not only at the individual level but also at the institutional level, as MenstruAcción activists have reported.

MenstruAcción has criticized the institutionalization (by the state) and commodification (by menstrual products corporations) of Argentinian menstrual activism, which resulted in, as they defined it as, "epistemic ghosting." This they used to refer to the appropriation of the knowledge and symbolic discourse produced by activism and their subsequent effacement by the state and corporations, as the state and corporations used the activists' work to their advantage but then "ghosted" the menstrual activists (unilaterally severed the relationship) (Suárez Tomé et al., 2023).

Finally, interviewed activists accused foreign agencies of extractivism as they offered consultancies to activists under precarious conditions, such as not offering a payment for the work and stating that the "visibility" of the activists would be enough "retribution" for the work (Ramírez-Vásquez, 2024). In other cases, organizations paid for the work but did not give proper credit to the authors (Almanza Towgood, 2024). These are unfortunate examples of how international organizations aim to *extract* the knowledge created by menstrual activists and educators based on the work they do with the communities in which they work.

In sum, appropriation and extractivism are threatening the Latin American social movement for menstrual dignity from within (as plagiarism) and without (conducted by foreigner organizations). These malpractices generate

mistrust, frustration, and erode key collaborations that, ultimately, constrict advancements on menstrual health and dignity. By openly discussing these challenges and thinking about ways to resolve the problems they bring, the movement can bring strategies for other contexts of the menstrual movement that would likely experience similar tensions as the ones presented here.

Conclusion

In this chapter, I aimed to introduce the Latin American social movement for menstrual dignity, an emerging, transnational movement characterized by spiritual-political feminism, hybridization of knowledge, critical assessment of MHM, restating of menstrual dignity, and epistemic activism. This movement follows the regional history of critical thinking and resistance, feminism, and decolonization, differentiating itself from the broader Latin American menstrual movement that assimilates Global North initiatives regarding menstruation. By maintaining a critical standpoint, the Latin American social movement for menstrual dignity avoids operating under the logic of (neo)colonization that risks accommodating to menstrual stigma instead of addressing the structural issues that reinforce it, as it has been found in other countries of the Global South (Bobel, 2019).

Through this exploratory study, I argue that it is important to explore the Latin American social movement for menstrual dignity because it is working in novel and creative ways for comprehending the menstrual cycle as a process that goes beyond physiology. The movement argues how menstruation in Latin America is shaped by colonial, gendered, racist, and capitalist perspectives, undermining the process of emancipation for girls, women, and people of other genders who menstruate. The Latin American social movement for menstrual dignity was initiated by grassroots collectives led by Latin American women who are working and theorizing menstruation from the embodied experiences of Latina American women and menstruators, contributing to decolonial scholarship as they challenge the understanding of menstruating bodies shaped negatively by European and US (neo) colonization.

It is important to note here that this doesn't mean that emancipatory menstrual education is not also pursued by Global North initiatives, nor that all menstrual education projects in Latin America are emancipatory. On the contrary, many menstrual education projects, advocates, and activists in the region are unaware of the critical tradition or choose not to follow it. Moreover, menstrual activists and educators all over the world pursue critical interventions, aligning with the decolonial pursuit of questioning Western epistemology and creating other forms of knowledge.

Despite the movement sharing some similarities at its beginning with menstrual activism in North America and Europe – as women circles, dissemination of reusable menstrual products, and surge in menstrual bills – it differentiates from them in their marked and historically grounded suspicions toward simple solutions and quick wins regarding menstruation. The movement insists on

the need of addressing structural changes as a more sustainable way for achieving menstrual dignity, even though it is a long-term endeavour.

The Latin American social movement for menstrual dignity is based on activism and menstrual education that follows the model of popular education and community organization promoted since the 1960s by Brazilian educator Paulo Freire, which has been pivotal in community organizing and social movements in the region. By scrutinizing MHM's framework, participants of the Latin American social movement for menstrual dignity avoid being "co-opted" by MHM. Even though resistance toward foreign intervention is not restricted to Latin America –as we find it in many other countries of Asia and Africa – in the case of MHM, Latin America has been very sharp with its criticism. Still, it is important to reflect on potential risks of what can be seen as intransigency, particularly regarding potential alliances. By defining ethical principles, participants of the Latin American social movement for menstrual dignity create a common ground that can be challenging to follow, especially when it comes to deciding who can finance menstrual education projects. For example, the difficulties in sustaining anti-capitalist endeavours in a neoliberal world in the most socio-economically unequal region of the world can inhibit the implementation of menstrual education projects. This tension can be easily spotted in the debate on whether menstrual education projects should or should not be funded by transnational menstrual hygiene corporations. Corporations have financed MHM projects in the region; could they finance projects of the Latin American social movement for menstrual dignity? This is an open question where the ultimate beneficiaries – girls, women, other menstruators – must be considered. Here, the idea of negotiating the conditions in which menstrual education projects are conducted is very crucial, as it could potentially create a middle ground for conducting menstrual education projects. Eventually, good practices of menstrual education projects in Latin America where the specific needs of the communities are put at the forefront and where menstrual management is not the only issue addressed by the project could be illustrative for other contexts.

Similar lessons from collective organizing and creativity for the Latin American social movement for menstrual dignity can be explored in other contexts, such as the collaborative networks of menstrual educators, the organizing of the "Red block" and transnational meetings such as the Latin American Meeting of Menstrual Education, Health and Activism. The previously mentioned spaces foster mutual learning and generate innovative discussions and debates that are necessary to have in other contexts, such as the debates of profits behind the supply of menstrual products or policies such as the use of long-acting contraceptives as a policy for addressing teenage pregnancy. By insisting on the need to address gender-based violence, as we also see in India's menstrual activism, Latin American activists and educators include menstrual education as an important demand of feminism. By organizing "Red blocks" in feminist marches, they make visible to the general public the need to advance the understanding of how menstruation is a lens for seeing social

issues as embodied, showing the need to challenge limited gender roles and the exploitation of menstrual bodies that have been fostered through colonial and gendered understandings of the menstrual body. By creating words for a new understanding of social reality that considers the menstrual cycle (such as *menstrucentrism*) menstrual activists and educators do epistemic activism that can inform menstrual activism worldwide. Seeking to challenge the deleterious effects of *menstrual epistemicide*, menstrual activists and educators seek to promote embodied menstrual knowledge that helps to advance collectively to a society that dismantles menstrual taboo and stigma and aims for emancipation.

Despite the malpractices of the movement, such as appropriation and extractivism, it is impossible to separate the activist's work from the ongoing achievements of the Latin American movement, as the advancement of bills on menstrual rights surge and public debates on menstruation expand, endeavours that have not been possible without activism.

In conclusion, by aiming to challenge structural factors for dismantling menstrual taboo and stigma, the Latin American social movement of menstrual dignity intertwines different aspects of menstrual embodiment and public life, weaving toward a decolonial and comprehensive understanding of the menstrual cycle, environmental issues, health, politics, and gender-based violence. As menstrual dignity functions as a horizon for social transformation, menstrual educators and activists grapple with different initiatives that seek to better the experience of menstruation, being nonconformist with simplistic perspectives and betting that through the development of critical consciousness regarding menstruation, the longed-for menstrual dignity can be achieved. The Latin American social movement for menstrual dignity is walking toward the decolonization of menstruation and of the female and menstrual body in particular ways from which the global menstrual movement could learn.

Notes

1 "Menstruator" is a term coined by North American menstrual activists that acknowledges that not all the people who menstruate identify as women and that not all women menstruate (Bobel, 2010). It is one of the main contributions of menstrual activism and is nowadays a widespread term.
2 Including the human right to equality, health, housing, water, sanitation, education, freedom of religion or belief, safe and healthy working conditions, and the right to participate in cultural and public life without discrimination.
3 Argentinian Eugenia Tarzibachi and Brazilian Ursula Maschette.
4 Emancipadas hosts seven menstrual education projects: Medicina de Mujer and Homoonal (Colombia), Sintonía Lunar (El Salvador), Rubra Fluidez and Herself (Brazil), and Sembradoras Menstruoteca (Mexico).
5 People from nine countries participated: Puerto Rico, Mexico, Colombia, Costa Rica, Brazil, Ecuador, Chile, Guatemala, and Peru. Available at: https://www.youtube.com/watch?v=HUYgeOmffHM.
6 Written at the "First Encounter of Menstrual Educators in Mexican Soil" in 2023 with the participation of over 69 collectives and independent menstrual educators (https://redmenstrual.com/about/).

Reference list

Accerenzi, M. (2023). *Políticas corporales, menstruación y cooperación al desarrollo. Un estudio de caso en Santa Rosa de Copán, Honduras.* [Programa de doctorado: Estudios sobre Desarrollo, Universidad del País Vasco/Euskal Herriko Unibertsitatea]. http://addi.ehu.eus/handle/10810/61154

Aguilar-Ferro, A. I. (Ed.). (2022). *[Contra] narrativas menstruales desde Abya Yala*. Catafixia Editorial.

Aguilar-Ferro, A. I. (2024, May 1). [Personal communication].

Almanza Towgood, E. (2018, July 3). ¿Qué es la 'menstruación consciente'? *EcoRed Feminista en México.* https://ecoredfeministamx.wordpress.com/2018/07/03/que-es-la-menstruacion-consciente/

Almanza Towgood, E. (2024, April 11). [Personal communication].

Andrews, G. R. (2018). Inequality: Race, Class, Gender. In A. de la Fuente & G. R. Andrews (Eds.), *Afro-Latin American Studies: An Introduction* (pp. 52–91). Cambridge University Press. https://doi.org/10.1017/9781316822883.003

Aravena Pulido, G. I., & García Acevedo, M. (2023). *Vivencias y autonomía en salud menstrual en adolescentes en una comuna semi-rural de la Región Metropolitana, año 2022* [Tesis para obtener el grado de magíster en salud pública, Universidad de Santiago de Chile]. https://descubridor.usach.cl/discovery/delivery/56USACH_INST:56USACH_INST/1275436360006116

Barone Zallocco, O. (2021). Teñir la ESI de rojo menstrual. *Praxis Educativa*, *25*(1), 1–16.

Barrig, M. (1998). *Los malestares del feminismo latinoamericano: Una nueva lectura*.

Bean, R. (2021, April 29). *"Menstruactivismo": The menstrual movement in Latin America and the Caribbean*. EDUC 503: Global Citizenship, University of Pennsylvania.

Bobel, C. (2010). *New blood: Third-wave feminism and the politics of menstruation*. Rutgers University Press.

Bobel, C. (2019). *The managed body: Developing girls and menstrual health in the global south*. Palgrave Macmillan. https://link.springer.com/book/10.1007/978-3-319-89414-0

Bobel, C., & Fahs, B. (2020a). From bloodless respectability to radical menstrual embodiment: Shifting menstrual politics from private to public. *Signs: Journal of Women in Culture and Society*, *45*(4), 955–983. https://doi.org/10.1086/707802

Bobel, C., & Fahs, B. (2020b). The Messy Politics of Menstrual Activism. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave Handbook of Critical Menstruation Studies* (pp. 1001–1018). Springer. https://doi.org/10.1007/978-981-15-0614-7_71

Bobel, C., Winkler, I. T., Fahs, B., Hasson, K. A., Kissling, E. A., & Roberts, T.-A. (Eds.). (2020). *The Palgrave handbook of critical menstruation studies*. Springer. https://doi.org/10.1007/978-981-15-0614-7

Calafell Sala, N. (2019). Menstruación decolonial. *Revista Estudos Feministas*, *28*. https://doi.org/10.1590/1806-9584-2020v28n157907

Calafell Sala, N. (2020). La ginecología natural en América Latina: Un movimiento sociocultural del presente. *Sexualidad, Salud y Sociedad*, *33*, 59–78. https://doi.org/10.1590/1984-6487.sess.2019.33.04.a

Calafell Sala, N. (2024a). "La salud menstrual es un estado completo de bienestar físico, mental y social": Búsquedas terapéuticas, mercado y procesos de subjetivación en los activismos menstruales argentinos. *RECERCA. Revista de Pensament i Anàlisi*, *29*(1). https://doi.org/10.6035/recerca.7661

Calafell Sala, N. (2024b, April 22). [Personal communication].

Calderón-Villarreal, A. (2024). Taxing women's bodies: The state of menstrual product taxes in the Americas. *The Lancet Regional Health – Americas*, *29*, 100637. https://doi.org/10.1016/j.lana.2023.100637

Carbajal, F. (2020). *Laboratorio de soberanía cíclica 1.*
Castañeda Salgado, M. (2019). Perspectivas y aportes de la investigación feminista a la emancipación. In M. Luxán, T. Portugal, M. Legarreta-Iza, & D. Zarranz (Eds.), *Otras formas de (des)aprender. Investigación feminista en tiempos de violencia, resistencias y decolonialidad* (pp. 19–40). Universidad del País Vasco/Euskal Herriko Unibertsitatea, Hegoa, Seminario Interdisciplinar de Metodología de Investigación Feminista.
Cifuentes Contador, S. (2023). *Desafiando el tabú y estigma menstrual en Chile: Una lectura feminista de los discursos que, desde la sociedad civil, buscan resignificar la menstruación* [Tesis para optar el grado de magíster en ciencias sociales, Universidad de Santiago de Chile]. https://descubridor.usach.cl/discovery/delivery/56USACH_INST:56USACH_INST/1277754190006116
Cimmino, K., Gogna, M., & Rossi, D. (2024). *A 10 años del consenso de Montevideo: La Educación Integral de la Sexualidad en América Latina y el Caribe 2013–2023.* https://lac.unfpa.org/sites/default/files/pub-pdf/a_10_anos_del_consenso_de_montevideo.pdf
Comisión Económica para América Latina y el Caribe. (2023, September 27). *CEPAL presenta Portal de desigualdades en América Latina.* https://www.cepal.org/es/noticias/cepal-presenta-portal-desigualdades-america-latina
Contreras-Aristizábal, L. P. (2023, July). *What we talk about when we talk about decolonial menstrual health: Perspectives to emancipate the menstrual health, Latin American experiences* [Conference]. 'The period is political' Society for Menstrual Cycle Research, Washington, DC, US.
Contreras-Aristizábal, L. P. (2024, May 3). [Personal communication].
Costa, C. R. N. da, Costa, N. C. V., & Manica, D. T. (2024). Menstruation as a research topic in the humanities in Brazil: A state of the art. *Tapuya: Latin American Science, Technology and Society*, *7*(1), 2424097. https://doi.org/10.1080/25729861.2024.2424097
Cousins, S. (2020). Rethinking period poverty. *The Lancet*, *395*(10227), 857–858. https://doi.org/10.1016/S0140-6736(20)30605-X
Cueto, M., & Palmer, S. (2014). *Medicine and public health in Latin America: A history.* Cambridge University Press. https://doi.org/10.1017/CBO9781139152174
de Oliveira, V. C., Pena, É. D., de Andrade, G. N., & Felisbino-Mendes, M. S. (2023). Menstrual hygiene access and practices in Latin America: Scoping review. *Revista Latino-Americana de Enfermagem*, *31.* https://doi.org/10.1590/1518-8345.6736.4029
Diamond, C. (2022, August 15). *Period poverty: Scotland first in world to make period products free.* https://www.bbc.com/news/uk-scotland-scotland-politics-51629880
Díaz, P. (2022, January 14). *Las mujeres en México luchan para que la menstruación deje de ser tabú|.* https://news.un.org/es/story/2022/01/1502512
Eraso, M. (2015). Mujeres peligrosas. Menstruación y limpieza de sangre. *Intervenciones En Estudios Culturales*, *2*, 107–141.
Escuela de Educación Menstrual Emancipadas [@emancipadas.educacionmenstrual]. (2023, May 28). *En el marco del Día Internacional de Acción por la Salud de las Mujeres reivindicamos las experiencias menstruales y nos* [Photograph]. Instagram. https://www.instagram.com/p/CszcOaKvMSW/
Escuela de Educación Menstrual Emancipadas [@emancipadas.educacionmenstrual]. (2024, October 11). *#diainternacionaldelaniña Intervenir y medicalizar los cuerpos de las niñas no es prevención ES VIOLENCIA. Vivimos en una sociedad donde se* [Photograph]. Instagram. https://www.instagram.com/p/DA_YkJuOIP0/
Escuela de Educación Menstrual Emancipadas [@emancipadas.educacionmenstrual], Princesas Menstruantes [@princesasmenstruantes], & Sembradoras menstruoteca [@sembradoras_menstruoteca]. (2024, March 4). *ATENCIÓN. Con mucha alegría*

queremos compartir nuestro nuevo seminario: Como convertir tu practica de educación menstrual en un laboratorio social. [Photograph]. Instagram. https://www.instagram.com/p/C4GMcx8L3zH/

Escuela de Educación Menstrual Emancipadas [@emancipadas.educacionmenstrual], & Ramírez-Vásquez [@caro_educadoramenstrual], C. (2023, May 19). *Hacemos ciencia, producimos conocimiento, creamos conceptos, cuestionamos y construímos. Somos una Escuela Menstruocéntrica, desde el interior de emancipadas hemos desarrollado* [Photograph]. Instagram. https://www.instagram.com/p/CsbWhlhOLE-/

Felitti, K. (2016). El ciclo menstrual en el siglo XXI. Entre el mercado, la ecología y el poder femenino. *Sexualidad, Salud y Sociedad*, 175–208. https://doi.org/10.1590/1984-6487.sess.2016.22.08.a

Felitti, K. (2021). "Unidas en un gran conjuro": Espiritualidad y feminismos en la Argentina contemporánea. In K. B. Bárcenas Barajas & C. Delgado Molina (Eds.), *Religión, género y sexualidad: Entre movimientos e instituciones* (Primera edición, pp. 141–171). Universidad Nacional Autónoma de México, Instituto de Investigaciones Sociales.

Gaybor, J., & Harcourt, W. (2022). Seeing the colour red: Menstruation in global body politics. *Global Public Health*, *17*(10), 2388–2400. https://doi.org/10.1080/17441692.2021.2016886

Gottlieb, A. (2020). Menstrual Taboos: Moving Beyond the Curse. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave Handbook of Critical Menstruation Studies* (pp. 143–162). Springer. https://doi.org/10.1007/978-981-15-0614-7_14

Grosfoguel, R. (2019). Epistemic Extractivism: A Dialogue with Alberto Acosta, Leanne Betasamosake Simpson, and Silvia Rivera Cusicanqui. In *Knowledges Born in the Struggle*. Routledge.

HorMoonal. (2024, March 6). *¡ESTAMOS MUY CERCA DEL 8M!* Instagram. https://www.instagram.com/hormoonal.co/p/C4MFkJLxWpV/

Isasi-Díaz, A. M., & Mendieta, E. (Eds.). (2011). Introduction: Freeing Subjugated Knowledge. In *Decolonizing Epistemologies: Latina/o Theology and Philosophy* (pp. 1–16). Fordham University Press.

Jiménez Serrano, I. del R. (2024). *Menstruación, migración y derechos humanos: Salud y gestión menstrual de mujeres venezolanas en tránsito por la Ciudad de México (2022–2023)* [Tesis para optar al grado de maestra en antropología social, Centro de Investigaciones y Estudios Superiores en Antropología Social]. http://ciesas.repositorioinstitucional.mx/jspui/handle/1015/1795

Johnston-Robledo, I., & Chrisler, J. C. (2013). The menstrual mark: Menstruation as social stigma. *Sex Roles*, *68*(1), 9–18. https://doi.org/10.1007/s11199-011-0052-z

Lillo-Muñoz, D. (2019). Política, cuerpo y escuela: Expresiones feministas en el marco del Movimiento Estudiantil Secundario 2011–2016 en Chile. *Debate Feminista*, *59*, 72–93. https://doi.org/10.22201/cieg.2594066xe.2020.59.04

Lugones, M. (2008). Colonialidad y Género. *Tabula Rasa*, *9*, 73–102.

Macías-Rea, A. I. (2023). *Hacia una pedagogía de la dignidad experiencias latinoamericanas de educación menstrual emancipadora* [Tesis para obtener el grado de Maestra en Ciencias Sociales con Orientación en Estudios Latinoamericanos, Universidad de Guadalajara]. https://www.academia.edu/113295778/HACIA_UNA_PEDAGOGIA_DE_LA_DIGNIDAD_EXPERIENCIAS_LTM_DE_EDUCACI%C3%93N_MENSTRUAL_EMANCIPADORA

Maldonado-Torres, N. (2011). Epistemology, Ethics, and the Time/Space of Decolonization: Perspectives from the Caribbean and the Latina/o Americas. In A. M. Isasi-Daz & E. Mendieta (Eds.), *Decolonizing Epistemologies: Latina/o Theology and Philosophy* (pp. 193–206). Fordham University Press.

Marino, K. M. (2020). *Feminism for the Americas: The making of an international human rights movement*. The University of North Carolina Press.

McCarthy, A., & Lahiri-Dutt, K. (2020). Bleeding in Public? Rethinking Narratives of Menstrual Management from Delhi's Slums. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave Handbook of Critical Menstruation Studies* (pp. 15–30). Springer. https://doi.org/10.1007/978-981-15-0614-7_3

Medina, J. (2021). Injusticia epistémica y activismo epistémico en las protestas sociales feministas. *Revista Latinoamericana de Filosofía Política*, *10*(8), 227–250.

Mitra, S., & Karunakaran, K. (2024). Challenging stigma, shame and the social control of the menstruating body: Women's resistance in contemporary India. *Indian Journal of Gender Studies*, *31*(3), 351–371.

Molina Torres, M. (2017). La emergencia de la regla: Reflexiones sobre la mesa "Salud y Derechos Reproductivos". In M. F. Valenzuela Tapia (Ed.), *Nuevas voces del feminismo chileno*. Fundación Friedrich Ebert en Chile y Observatorio Contra El Acoso Callejero de Chile.

Morais, J. de A. (2021). *Portal Vermelho: Uma etnografia sobre gênero, corpo, sangue, emoções e experiência* [Tese apresentada ao Programa de PósGraduação em Ciências Sociais da Universidade Federal de Juiz de Fora como requisito parcial à obtenção do grau de Doutora em Ciências Sociais, Universidade Federal de Juiz de Fora]. https://repositorio.ufjf.br/jspui/handle/ufjf/13739

Ochoa Muñoz, K. (2014). El debate sobre las y los amerindios: Entre el discurso de la bestialización, la feminización y la racialización. In Y. Espinosa Miñoso, D. M. Gómez Correal, & K. Ochoa Muñoz (Eds.), *Tejiendo de otro modo: Feminismo, epistemología y apuestas descoloniales en Abya Yala* (pp. 105–118). Editorial Universidad del Cauca.

O'Connor, E. (2014). *Mothers making Latin America: Gender, households, and politics since 1825*. Wiley Blackwell.

Paudel, R. (2020). *Dignified menstruation: The dignity of menstruators throughout their life cycle*. Kathmandu Publication.

Pelúcio, L. M. (2022). O Sangue na rede: Mercado menstrual, menstruapps e tecnopolíticas de resistências. *Política & Sociedade*, *21*(51), 95–118. https://doi.org/10.5007/2175-7984.2022.e91483

Persdotter, J. (2013). *Countering the menstrual mainstream a study of the European menstrual countermovement*. University of Gothenburg. https://gupea.ub.gu.se/handle/2077/34369

Plan International. (2021, May 27). *Pobreza menstrual, una problemática de la que se habla muy poco en América Latina*. https://plan-international.org/es/latin-america/pobreza-menstrual

Plan International. (2024, May 28). Rompiendo Tabúes de Salud Menstrual entre generaciones. *Plan International América Latina*. https://plan-international.org/america-latina/noticias/2024/05/28/rompiendo-tabues-de-salud-menstrual/

Prado, I. C. de A. (2024). Políticas Públicas sobre a Saúde Menstrual no Brasil: Olhares pelas Lentes dos Movimentos Sociais da Menstruação. *Mediações – Revista de Ciências Sociais*, 1–17. https://doi.org/10.5433/2176-6665.2024v29n1e49150

Prado, I. C. de A., & Mendes, C. H. F. (2024). *Menstruação anticolonial e dignidade menstrual*. Seminário Internacional Fazendo Gênero 13, Florianópolis. https://www.fg2024.eventos.dype.com.br/anais/trabalhos/lista

Princesas Menstruantes. (n.d.). Quienes somos. *Educación Menstrual Emancipadora con Princesas Menstruantes*. https://www.princesasmenstruantes.com/educacion-menstrual-2/

Prior, J. C., & Goshtasebi, A. (2019, November 27). *Why is "the pill" harmful for bones in adolescent women?* The Centre for Menstrual Cycle and Ovulation Research. https://www.cemcor.ca/resources/why-%E2%80%9C-pill%E2%80%9D-harmful-bones-adolescent-women

Ramírez-Morales, M. del R. (2020). Ciberactivismo menstrual: Feminismo en las redes sociales. *PAAKAT: Revista de Tecnología y Sociedad*, *17*. https://doi.org/10.32870/Pk.a9n17.438

Ramírez-Morales, M. del R. (2022). *Mujeres en Círculo: Espiritualidad y corporalidad femenina*. https://doi.org/10.28928/omp/ebook/2022/ramirezmoralesm

Ramírez-Morales, M. del R. (2024, April 12). [Personal communication].

Ramírez-Vásquez, C. (2022a). *Educación Menstrual Emancipadora: Una vía para interpelar la misoginia expresada en el tabú menstrual*. Fallidos Editores.

Ramírez-Vásquez, C. (2022b, May 8). *Dato importante*. Instagram. https://www.instagram.com/p/CdTY3VJrBFT/

Ramírez-Vásquez, C. (2024, April 25). [Personal communication].

Red de Educación Menstrual [@red.educacion.menstrual]. (2023, December 5). *El fin de semana del 02 y 03 de diciembre de 2023, educadoras menstruales activas en el territorio mexicano nos* [Photograph]. https://www.instagram.com/p/C0e4EJdSlwK/

Rivera, M. R. (2011). Thinking Bodies: The Spirit of a Latina Incarnational Imagination. In A. M. Isasi-Diaz & E. Mendieta (Eds.), *Decolonizing Epistemologies: Latina/o Theology and Philosophy* (pp. 206–225). Fordham University Press.

Salazar, C. (2006). Pueblo de humanos: Metáforas corporales y diferenciación social indígena en Bolivia. *Anthropologica*, *24*(24), 5–27. https://doi.org/10.18800/anthropologica.200601.001

Suárez Tomé, D., Belli, L. F., & Mileo, A. (2023). Ghosteo epistémico: El borramiento del activismo feminista a través de su institucionalización y mercantilización en el activismo menstrual argentino. *Debate Feminista*, *67*, 127–158. https://doi.org/10.22201/cieg.2594066xe.2024.67.2383

Suárez Tomé, D., & D'Alessandro, M. (2019). Economía Femini (s)ta: Activismo científico con perspectiva de género. In M. Larrono & C. Ponce (Eds.), *Activismos feministas jóvenes: Emergencias, actrices y luchas en América Latina* (pp. 171–186). CLACSO.

Tarzibachi, E. (2017). *Cosa de mujeres: Menstruación, género y poder*. Penguin Random House Grupo Editorial Argentina.

Tarzibachi, E. (2020). The Modern Way to Menstruate in Latin America: Consolidation and Fractures in the Twenty-First Century. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave Handbook of Critical Menstruation Studies* (pp. 813–831). Springer. https://doi.org/10.1007/978-981-15-0614-7_59

Valadez Angeles, E. (2019). *Menstruartivismo: Una herramienta para la agencia de las mujeres menstruantes* [Tesis de Maestría, Universidad de Ciencias y Artes de Chiapas]. https://doi.org/10.29043/CESMECA.rep.975

Vásquez Santibáñez, M. B., & Carrasco Gutiérrez, A. M. (2017). Significados y prácticas culturales de la menstruación en mujeres Aymara del norte de Chile: Un aporte desde el género a los estudios antropológicos de la sangre menstrual. *Chungará (Arica)*, *49*(1), 99–108. https://doi.org/10.4067/S0717-73562016005000036

Veraciclos [@veraciclos], Somos Menstruantes [@somosmenstruantes], Bruja Lunar [@bruja.lunar.pe], & Córdova [@madreluna.peru], L. (2024, May 28). *#28DeMayo Hoy es un buen día para hablar de dignidad menstrual y justicia menstrual. Dejemos de hablar de higiene y* [Photograph]. Instagram. https://www.instagram.com/reel/C7h3vVsPjaI/

Weinberger, M., Eva, G., Bellows, N., Reidy, M., Sanders, R., & Ahsan, S. (2024). *LEAP: Landscape and projection of reproductive health supply needs. reproductive health supplies coalition*. https://leap.rhsupplies.org/menstrual-health/overview

Weiss-Wolf, J. (2017). *Periods gone public: Taking a stand for menstrual equity*. Simon and Schuster.

Part 3

Creative practice and the arts as health activism


Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

5 *Hysterectomy: BedRock* – emplacing and making visible experiences of surgery for hysterectomy and surgical menopause through creative practice

Louise Ann Wilson

This chapter is written from a practitioner's perspective. I am a UK-based artist and researcher who creates site-specific walking-performances and immersive, multimedia art installations.[1] My practice is situated in the field of socially engaged scenography and promotes the development of scenography as a distinctive type of applied art and performance practice that seeks tangible, therapeutic, and transformative outcomes, or what is termed "scenography with purpose" (Baugh, 2012, p. 36).

The focus of this chapter is an autobiographical body of artwork, provisionally entitled *Hysterectomy: BedRock*, made in response to my personal experience of a hysterectomy, necessary due to the growth of a fibroid in and around my womb, and its challenging physical and psychological consequences, including a surgical menopause. *Hysterectomy: BedRock* is designed to imaginatively reveal and express the hysterectomy process from diagnosis and surgery to recovery, surgical menopause, and beyond. This body of work falls into two interconnected phases. The first phase is complete and took place in real-time leading up to, during, and immediately post the surgery. Artworks created include a series of photographic, drawn and printed images made to document, process, and express the experience. These sit alongside collected materials, including MRI scans, texts drawn from my hospital letters, and surgery notes. Together, these artworks and medical materials make visible the external effects of the fibroid and surgery (swollen, cut, stitched, and bruised abdomen), the interior of my body with fibroid and uterus, and these organs following their surgical removal. They also documented my time in hospital and my at-home convalescence, which was long and painful.

As well as functioning as stand-alone artworks that sit within a tradition of artist-photographers (Elena Brotherus, Elinor Carucci, and Jo Spence who have documented deeply personal medical experiences including IVF treatment, hysterectomy surgery, and breast cancer), this work provides materials, inspiration, and themes for the second phase of this body of work, which is still in the process of being made. This means that the exact nature and form the *Hysterectomy: BedRock* will take and how and where the completed works created within it will finally be presented remain unresolved. So, this chapter

DOI: 10.4324/9781003319818-8

offers a snapshot of where I am now. What I do know is that I am working toward making a series of still and moving (film) images. These images might form part of an exhibition and an immersive, multimedia installation that incorporates a bed and other objects, including bed linen, rock, and surgical and/or quarrying equipment, as well as sound and voice recordings that may be heard emanating from within and around the bed.

To make the second phase of this body of work, I have brought in a further layer of material that is being drawn from the landscape of two abandoned slate quarries in the Little Langdale area of the Lakeland Fells, Cumbria. This type of landscape was specifically chosen because of how it enables me to draw a metaphorical link between the excision of parts of the body in the process of surgery and the removal of parts of the landscape in the process of quarrying. And, because of how I can use it to take viewers/audiences inside the physical, emotional, haptic, and psychological realms of hysterectomy surgery and surgical menopause.

My intentions behind making this body of work are as follows. First, to express and make visible patient centred insights of the realities of hysterectomies and surgical menopause experiences. Second, to create artworks in which other women+ preparing for, or recovering from surgery, can recognize their own experiences.[2] Third, to bring about greater awareness, and more nuanced and empathetic levels of understanding to medical and healthcare professionals, policymakers, and the wider public toward hysterectomy patients.

My aim in writing this account is to show how my scenographic practice can offer a powerful means – a tool – to reveal and give a voice to the patient's lived experience with tangible and transformative "real-world" outcomes that can be understood and deployed as a form of health advocacy and activism. To this end, the chapter reveals my creative process including how I start with in-depth research, which has three strands: the site I have identified, the life-event I am concerned with, and the people affected by it.

It shows how this research produces rich layers of material that can then be creatively distilled and processed into a final artwork or works. The chapter also draws on seven scenographic principles that I have evolved over many years of working and that underpin my practice. See Appendix 1 for an overview of these principles (for full details, see Wilson, 2019, 2022). Of particular significance to this chapter are the principles that encapsulate my use of autobiography, metaphor, and the importance I place on being located (or in other words, site- and subject-specific) when creating my work.

Background – practice in context

Scenography is a visual, multisensory, and interdisciplinary art form with origins in stage and performance design that uses space, sight, light, sound, bodies, text, and objects to evoke complex sensory environments that take on powerful meanings. I specifically use scenography to emplace – by which I mean put or site – challenging, marginal, and "missing" life-events into a

carefully chosen, often rural landscape, thus creating a *site of transformation* in which an audience, participant or viewer can reflect upon and reimagine their relationship to the life-event being explored.[3] Working this way reflects how my scenography is located both to a specific site and to a life-event.[4] I also use scenography to face, rather than look away from, and give a voice to lived experiences that are ordinarily overlooked or outside of social and cultural discourses and in so doing see them afresh, and reimage and transform them.[5] With the ability to function at a symbolic – nonverbal – level, scenography is well suited to this transformative work. The connection between life-event, landscape, and performance/art is important in my practice because together they combine to evoke metaphors for, and expression of, situations and circumstances that are difficult, if not impossible, to express in words alone. In so doing my practice acts as an instrument for individual, social, and cultural change and has informed, and reflects, the ways in which contemporary scenography engages with major issues and concerns "of our contemporary world" (Baugh, 2012, p. 11) and creates environments that "inspire us to act" (Lotker & Gough, 2013, p. 4).

I have created artworks that have addressed terminal illness, death and bereavement, infertility and involuntary childlessness, immobility and memory, and breast cancer and surgery. These have been made and performed (emplaced) "on-site" in landscapes that range from mountain summits in Snowdonia and subterranean caves and limestone pavement in the Yorkshire Dales, to crumbling coastlines in Cornwall and remote tarns in The Lake District. I also create works that are shown "off-site" in galleries or other found spaces where I use materials (film, sound, and objects) gathered or recorded in the landscape to create installations.

Each performance or installation is developed through a three-strand research method that involves: 1) in-depth site research, often with people who have knowledge of the landscape. These have included: beekeepers, geologists, and fishermen; 2) collaboration with medical or social scientists who are expert in the field of the life-event that is in focus. These have included: neuro-oncologists, surgeons, embryologists, sociologists, and palliative care nurses; and 3) creative exchanges with people affected by the life-event. These have included: childlessness-by-circumstance women, care home residents, the bereaved, and people recovering from surgery. As well as the hysterectomy and surgical menopause work explored in this chapter, I am currently making a series of art, performance, and installation/film works entitled *Becoming Rock* for which I am emplacing my personal experience of surgery for breast cancer into rocky, often limestone, landscapes. For another current project entitled *Walking the Menopause*, I am creating a series of bespoke menopause-specific walks inspired by my menopause experiences, and those of other women+.

My decision to work with personal life-event experiences and explore and express them through landscape follows a pattern in my practice which began with *Fissure* (2011), a three-day long walking-performance in the style of a pilgrimage that traversed the Yorkshire Dales and was created in response to

the death of my sister aged 29 from a brain tumour. In this work, the landscape became a multidimensional and metaphorical environment in which the performance was composed of the land (cave, rock, water, and weather) together with creative interventions that used sung poetry, pre-recorded sound, and dance combined with interventions made by a geologist and my sister's oncologist, and a neuro-imager. The combination of art, performance, science, walking, and landscape produced complex layers of material in which each participant found meaning that was specific to them and their personal experiences of illness, death and grief.

Later, two works, *The Gathering* (2014), a walking-performance created and performed on a sheep farm on Snowdon, a mountain in Wales, and *Warnscale: A Land-Mark Walk Reflecting on In/Fertility and Childlessness* (2015) made in the Lakeland Fells in Cumbria were informed by my own, and other women's, experiences of childlessness-by-circumstance and the "missing" life-event of biological motherhood. As well as live "in-time" performance *The Gathering*, like other of my works, incorporated film and sound that formed a central part of three multimedia installations within the performance. These three installations were created inside farm buildings; they incorporated filmed footage and sound recordings of one-off annual and seasonal events (birthing, adoption, scanning, gathering, weaning) that happen on the farm but that it was not possible to see in September when the performance was staged. The footage was then projected onto objects including fleeces, wool sacs, and farm equipment, and spaces such as barns and derelict farm cottages were filled with moving image, sound, and recorded voices – creating multimedia and immersive environments. This aspect of the work provides an insight into how the second phase artworks within the *Hysterectomy: BedRock* project might develop.

Another example of my use of film and landscape within an installation is *Dorothy's Room* (2018). This work, which centred around a bed, was inspired by Dorothy Wordsworth's *Rydal Journals* (1831–1835) and was created in Dorothy's bedroom at Rydal Mount, near Grasmere. Objects mentioned in her journals were placed together with extracts of journal entries, hand-stitched into the bed linen. These revealed how she used memory to transport herself into the landscapes she had once walked in and now longed for. A film that morphed imagery and sounds recorded in her remembered landscapes was projected over the bed, creating a dream-like environment that evoked memory and belonging.

Hysterectomy: BedRock – catalyst and reality

Having outlined the aims of this chapter, my practice, my vision for *Hysterectomy: BedRock*, and the position from which I write, I will now describe the personal experience of surgery for hysterectomy, and the subsequent surgical menopause that led to this body of work.

As indicated, the catalyst for *Hysterectomy: BedRock* was my personal experience of a radical, or complete, hysterectomy to remove my uterus, ovaries, cervix, and fibroid – and the surgical, or as I term it, "cliff-edge," menopause that ensued. Performed in February 2021, this procedure was necessary due to the growth of a fibroid in and around my womb, the size of which meant I appeared to be six months pregnant.

A hysterectomy is defined as "a surgical operation to remove all or part of the uterus [that] may also involve the removal of the cervix, ovaries, Fallopian tubes, and other surrounding structures" (NHS, 2022a). "It is one of the most frequently performed major gynaecological surgeries in women worldwide" (Mukhopadhaya & Manyonda, 2013), and each year approximately "55,000 hysterectomy operations are carried out in the UK. This means about one in five women will have a hysterectomy at some point" (Woodward, 2024). However, perhaps due to its frequency, the seriousness, scale, and effects of this type of surgery do not seem to be widely discussed or acknowledged. There appears to be, in my experience and that of other women I have spoken to, an "information gap" between what, as patients, we are told we might experience, in terms of both the surgery itself and our recovery from it, and the reality of those experiences.

That was certainly the case for me. In the hours, days, and weeks immediately following surgery, I experienced agonizing pain in my abdomen that left me barely able to stand or walk, and meant I spent weeks convalescing in bed. Indeed, it took many months to recover, and over a year and a half to gain full strength and fitness. This is much longer than the time frame outlined in NHS patient information sheets and online which, while recognizing everyone is different, state that it takes "about 6 to 8 weeks to fully recover after having an abdominal hysterectomy" (NHS, 2022b). This estimation does not, it seems, communicate the severity of the operation, nor does it recognize the time needed to "fully recover" from it. To compound the physical challenges soon after my operation, I began to experience the extreme effects of a "surgical menopause" that impacted my physical body, cognitive processing, and psychological well-being, in ways I was utterly unprepared for. I experienced hot flushes that felt like electric shocks charging through my body and an un-locatable fluttering in my chest and under my skin. I had night sweats, brain fog, and memory loss that meant I struggled to complete sentences and had to draw visual motifs on my shopping list because I could not remember words. At times, I felt uncharacteristic levels of irritation and frustration, my body, bones, and muscles ached, and I gained weight. Coping with these symptoms meant my work, including the completion of a book (Wilson, 2022) and the creation of a new performance (Wilson, 2021), was a huge challenge. But I was digging deep, and the mentally and physically demanding nature of these projects compounded my symptoms and led to anxiety and exhaustion, which manifested in the need for large amounts of sleep, low mood, and lack of confidence.

Prior to my operation, I asked the gynaecology consultant whose care I was under what exactly she meant, in the context of a hysterectomy, when she said that the procedure might cause some menopausal symptoms. Her response was to say that I could experience "a dry vagina and hot flushes," before writing down a link to the Royal College of Obstetricians & Gynaecologists (RCOG) website that I could visit for more information. This site told me that because I was having my ovaries and my uterus removed, in addition to the potential symptoms outlined by the consultant, I might experience "dry skin," "feeling low and anxious," and being "less interested in sex" (RCOG, 2023). In reality, the symptoms of what only later did I learn is termed a "surgical menopause" went way beyond what I was expecting and had been prepared for.

After a few months, my GP prescribed hormone replacement therapy (HRT), an intervention that surprisingly had not been suggested at an earlier date, and my symptoms began to ease. To work out what had happened to me and how I might further improve my health and wellbeing, I undertook research into the perimenopause and postmenopause transition, soon finding that sudden and extreme menopause symptoms are common in patients who, like me, have had a radical hysterectomy. These occur because oestrogen is required by receptors located throughout the body in all tissues, organs, and systems, from the nervous and cardiovascular systems to the digestive, muscular, and urinary systems. Without this endocrine hormone (and progesterone and testosterone too), these systems cannot function effectively, causing menopausal symptoms such as memory loss, hot flushes, palpitations, sleeplessness, aches and pains, and anxiety to take hold rapidly.[6] Furthermore, the reduction in hormones, writes menopause specialist and campaigner, Louise Newson, means there is also an increased risk of medical conditions such as "osteoporosis, cardiovascular disease, dementia, and depression" and diabetes, many of which, "are usually improved with HRT" because it replaces hormones "lost during and after menopause" (Newson, 2024).

Gradually, through the HRT, exercise, and healthy eating, my health and sense of self were managed and restored. However, I was left asking: why, like with the information gap around the physical implications of hysterectomy surgery, was the likelihood that post-op, due to the immediate loss of hormones produced by the now absent organs, I would experience surgical menopausal symptoms not made clear? Why are the drastic cognitive and physiological effects not recognized and/or mistaken for anxiety, depression, or other illnesses? Why was HRT not put in place in advance of the surgery rather than months later by which time my symptoms were raging?

In recent years, and especially since my operation, the subject of peri menopause and menopause has entered mainstream conversation with growing media recognition of a life transition that affects over 50% of the population, and a proliferation of literature (Codrington, 2022; McCall, 2022; Frostrup & Smellie, 2021; Newson, 2021, 2023). For most, menopause occurs between 45 and 55 years of age, although for some it can start earlier and happens gradually. For many – let alone those going through surgical menopause – this

major life-event can negatively impact physical and mental health, careers and work, relationships, and families. I now comprehend these impacts in a way I never did presurgery and understand why many women+ feel a sense of despair, leave relationships, experience breakdowns, or quit jobs and careers they have spent their working lives building. A 2022 poll undertaken by the Fawcett Society looking at *Menopause and the Workplace* revealed that "One in ten women who have been employed during the menopause have left work due to menopause symptoms. Mapped on to the UK population that would represent an estimated 333,000 women leaving their jobs due to the menopause. 14% of women had reduced their hours at work, 14% had gone part-time, and 8% had not applied for promotion" (Bazeley et al., 2022, p. 6). In extreme cases, these impacts mean some, "suffering with low mood and poor mental health, which can rapidly deteriorate during the perimenopause," even take their own lives (Newson, 2022). "There is a high rate of suicide in women aged 45–54 years that may be related to the biological changes associated with the menopause" (Kulkarni, 2018).

Arising from the personal experiences I have described, I knew I wanted, as an artist, to address hysterectomy surgery and surgical menopause in ways that are consistent with my practice, hence the *Hysterectomy: BedRock* (and *Walking the Menopause*) body of work. Not wanting others to be underprepared and ill-informed when navigating this type of surgery and menopause gave me a desire to reach out – if I am struggling with a situation, then other people are likely to be struggling too. By facing what was happening to me, and turning my experience into tangible, material forms through artistic practice, my intention was to reach others in the hope of making their own experiences and feelings expressible, better understood, and less isolating. It is not equitable or fair that lives, livelihoods, relationships, health, and wellbeing should be negatively impacted in the ways they are at present. Rather, we need to be fully informed and supported – socially, medically, and financially – leading up to, during, and post-surgery, and through the surgical menopause, should it ensue. We must therefore find different paths and better ways to do hysterectomy surgery and surgical menopause. So, creating *Hysterectomy: BedRock* is an act of health activism that advocates for raised awareness for patients, medical teams, and policymakers. My creative intentions and the socially engaged purpose behind making this body of work resonate with that of the author Helen Kemp who, in her book entitled *Surgical Menopause: Not Your Typical Menopause* (2021), seeks to ensure there is "a better way" through surgery and/or surgical menopause. Kemp specifically recognizes the implication and impact of surgical menopause and draws on the experiences of twelve women through a series of case studies. In her introduction, she writes:

> I believe surgical menopause is different when compared to a gradual menopause. It can feel brutal. Even more so when it occurs at a young age. Yet women seldom receive accurate information prior to, or even after surgery. How is it we can have a significant chunk of our endocrine

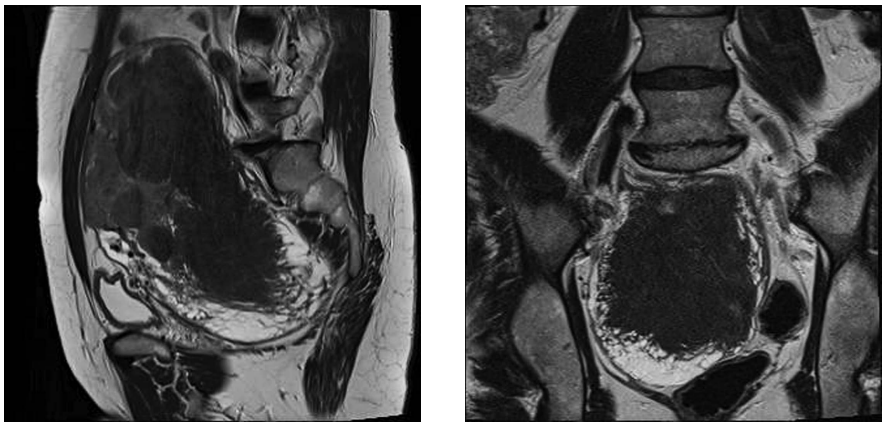


Figure 5.1 MRI scans of my abdomen showing the fibroid and uterus. Lancaster Royal Infirmary, Morecambe Bay Medical Trust.

> system removed, only to be sent on our way with advice not to lift anything heavier than a kettle full of water for six weeks, and to abstain from sex for the same duration? From my own lived experience and from hearing women's experiences up and down the country, I know how often surgical menopause completely floors women. Their mental wellbeing suffers, their relationship suffers and invariably their careers suffer too. I was totally unprepared for the aftermath of my surgical menopause, and I'd like to ensure other women don't follow the same path. There has to be a better way.
>
> (Kemp, 2021, p. 1)

Hysterectomy: BedRock – body of work in two phases

Phase 1: documentary photography

As discussed earlier, the first step in my work is to undertake three-strands of interdisciplinary – site-, life event-, and people-specific – research. For *Hysterectomy: BedRock*, each of these strands is rooted in autobiography, and all strands inform each other. With this work, Strand 1 came later than Strands 2 and 3 into the life-event (including the medical science) and those affected by it (me in this instance). These two strands have gone hand-in-hand and have taken the form of research and investigation into my own hysterectomy surgery and surgical menopause. This process and the images it has produced offer an unswerving study of a deeply personal experience that stand as artworks in their own right. They also provide content for the second phase of this body of work.

Presurgery, I photographed my fibroid-heavy body and requested copies from the hospital of the magnetic resonance imaging (MRI) scans that revealed the otherwise hidden fibroid inside my abdomen (see Figure 5.1).

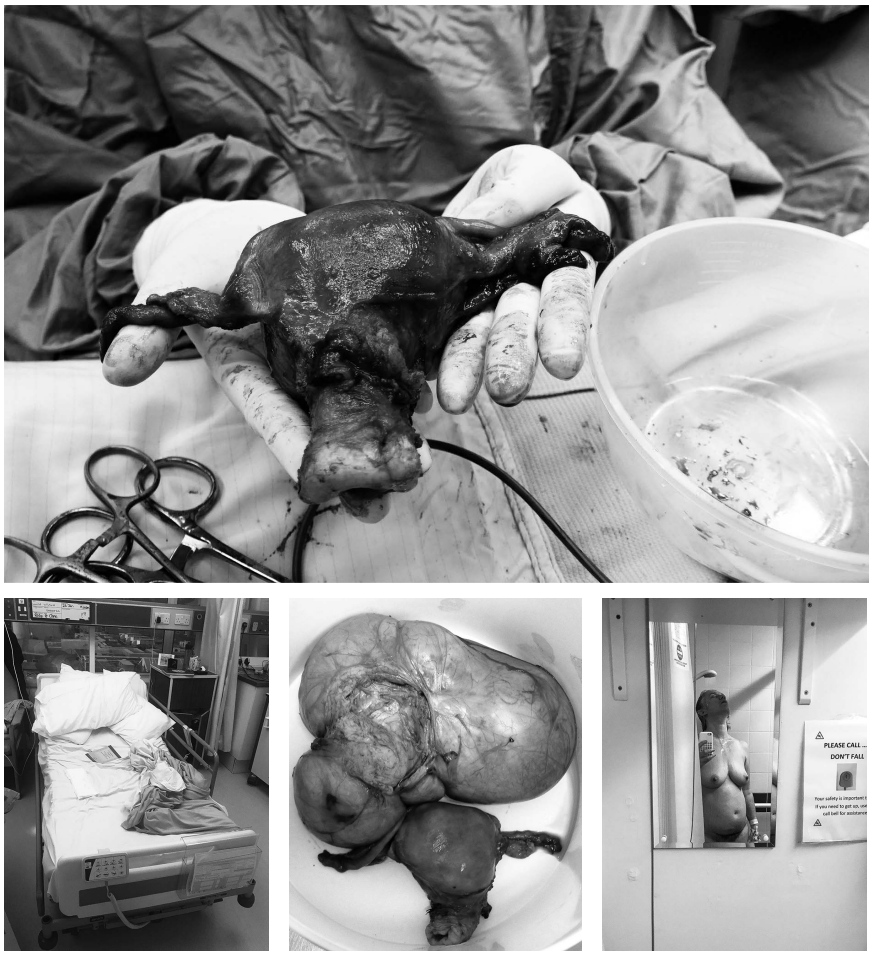


Figure 5.2 (a) My uterus, fallopian tubes, and cervix. (b) My hospital bed. (c) My fibroid, uterus, and fallopian tubes. (d) Me in the shower in hospital post-surgery. Photographs: (a) and (c), Mr Mohanraj and surgical team; (b) and (d), Louise Ann Wilson.

In hospital, I asked my surgeon, Mr Mohanraj, to use my camera and take photographs of my organs and fibroid post their removal (see Figure 5.2). In one photograph, a pair of hands wearing bloodied creamy-white surgical gloves offers up my bright red uterus to the camera lens. Another shows my extracted body parts (the spoils) in the bottom of a white bucket ready to be sent for biopsy, then incinerated. Later, looking at these photographs, which I could barely do to begin with because I found them shocking, was both disconcerting *and* fascinating. To face my sense of abjection, I looked even harder at these photos and the MRI scans and, as discussed later, made a series of drawing and prints inspired by them – a process that both deepened my

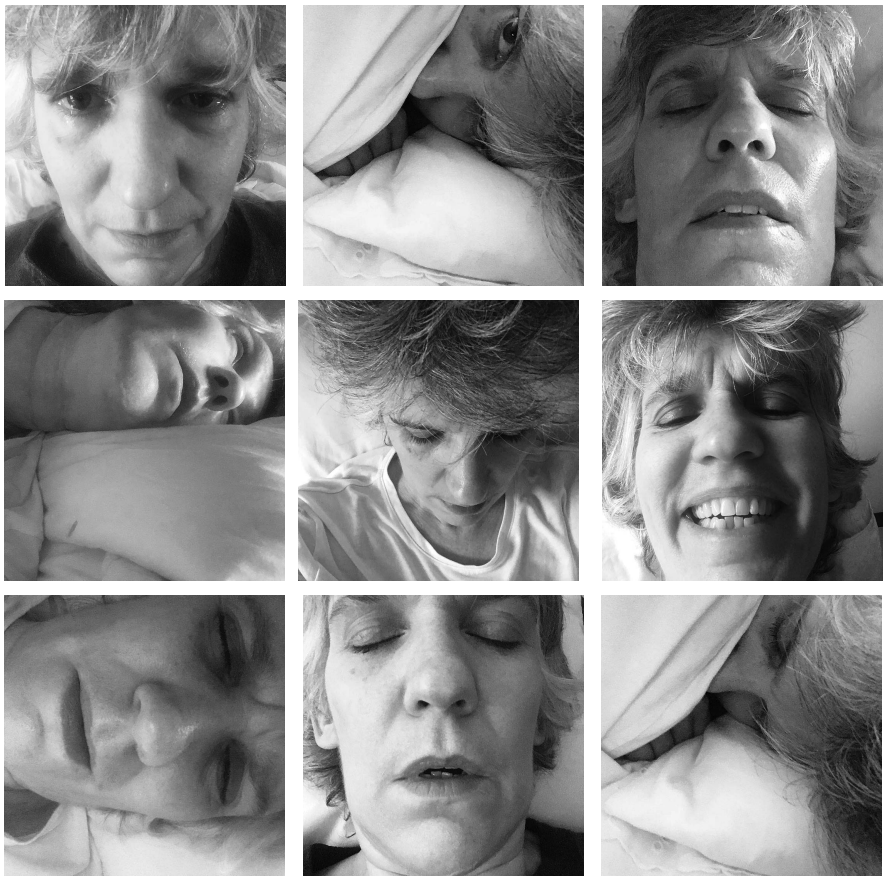


Figure 5.3 Hysterectomy face. Photographs by Louise Ann Wilson.

fascination and brought me closer to my body, and the medical condition that had affected it.

Post-surgery, using my mobile phone, I documented my time on the hospital ward, photographing my bed, my meals, and my first shower. Soon, my attention turned to what was closest to hand – my wounded sutured body and the fabric and stitches of the bed linen and blankets – and I began to see links between these things. Later, recovering at home and bedbound, I documented my face etched in pain or exhausted (see Figure 5.3), my suture scar; the folds, contours, and textures of my bed sheets and blankets; the shapes, forms, and colours of get-well flowers and bowls of fruit.

Using photography, drawing, and printmaking to look in this observational way brought an aliveness to the materials of my surroundings and produced a sense of awe and wonder at the inherent beauty, and horror, of the surgical body.[7] It also revealed and made visible everyday (ordinary/extraordinary) materials and processes – physiological and medical – that are usually invisible

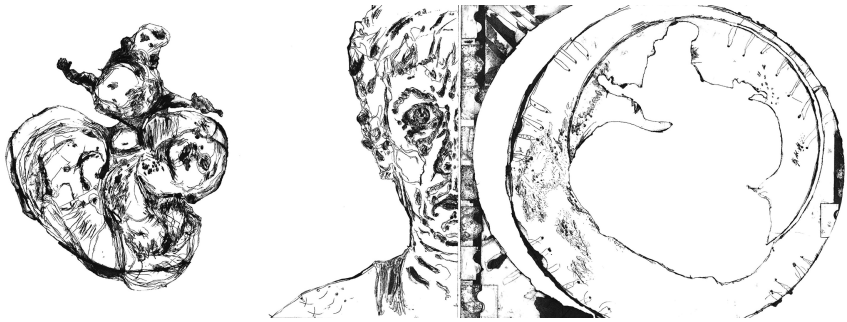


Figure 5.4 Hysterectomy Void-Space: Spoil, drypoint print on paper by Louise Ann Wilson.

to the naked eye, hidden or rarely seen in close-up. Through it, I began to understand better the anatomical structures of my body, how wounded flesh heals, and the way pain looks. This understanding was deepened through ongoing conversations with Mr Mohanraj, who spoke to me in more detail about the surgery and the techniques he used, for example, for cutting and suturing. He found my fascination about his work compelling and, recognizing how my practice could bring insights for him and his team to learn from, was keen to understand the patient's experience through our exchanges, and any artworks I would go on to create.

Echoes of my practice – how I document, make visible, and confront physically and emotionally challenging life-events – including the *Hysterectomy: BedRock* body of work, can be found in artist Sofie Layton's works *Making the Invisible Visible* (2016) and *Under the Microscope* (2015), which reveal and transform body, disease, and medical processes that ordinarily remain hidden, or little discussed in wider contexts. Similarly, in a work simply titled *My Uterus* (2015), the photographer Elinor Carucci was granted permission to photograph her surgically removed uterus (Carucci, 2019, pp. 96–98). For Carucci, having her "uterus taken out was a catalyst for a sudden, overwhelming sense of loss" not only for this physical part of her body but also, she writes, "of something more: the definitive end of my fertility. It felt like the final loss of youth. . . . like part of me was thrown away too, forever" (2019, p. 128). *My Uterus* is part of a body of photographic works, entitled *Midlife*, taken over four-years that for Carucci represent this period of her life in images, making it "fully visible" (2019, p. 129).

Phase 2: from printed image to landscape

My study of the surgical and recovery process was taken yet further when I began to create a series of drawings and prints based on the imagery I had collected – a process that was one of assimilation and reclamation for me personally. One print, entitled *Hysterectomy Void-Space: Spoil* (Figure 5.4), consists of two sections. In the centre and right hand section of the print my

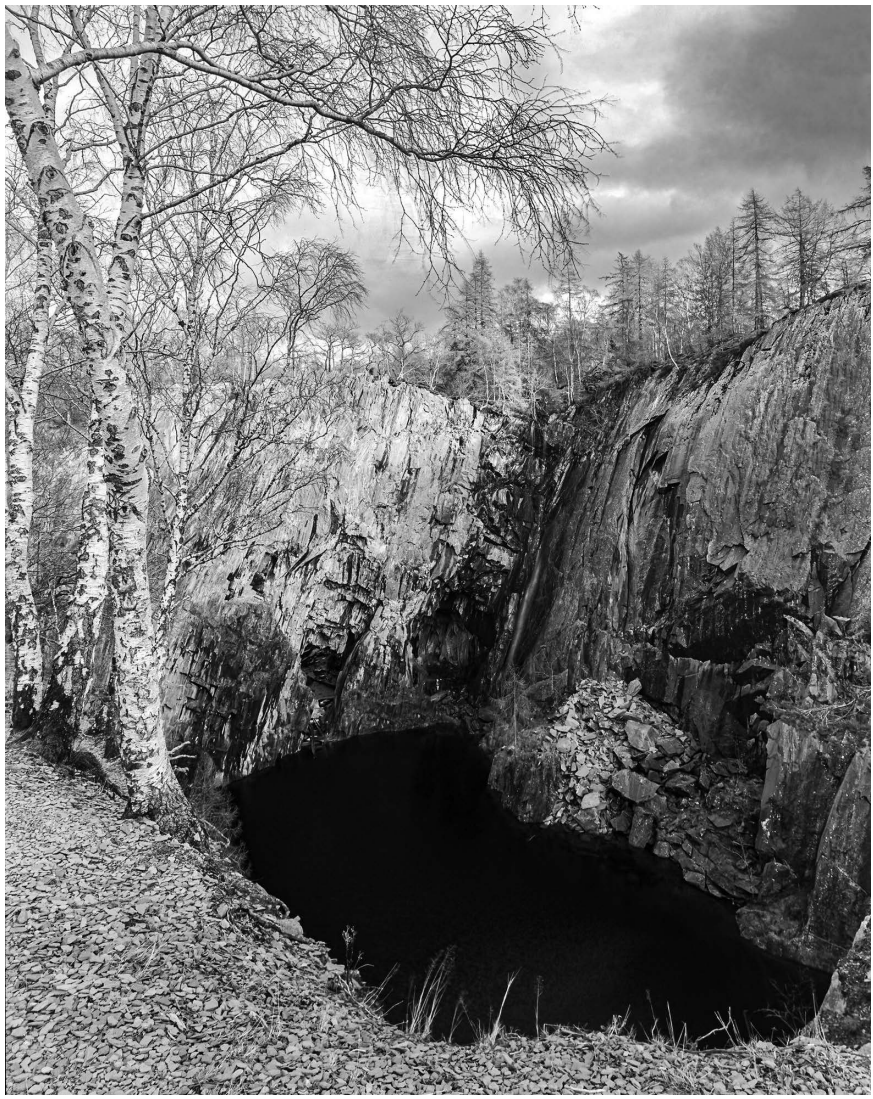


Figure 5.5 Looking down into Hodge Close Quarry from above. Photograph: Lee Metcalfe.

face is intersected by a crescent moon-like form holding within it a circular full moon-like form in the centre of which is a negative or void space. This void is the shape of my excised organs (uterus, fallopian tubes, and cervix) and the fibroid (drawn from the photograph of my organs in the bucket taken post-surgery). The left-hand section of the print shows these removed organs – the spoil.

The print was made using a drypoint technique where metal tools are used to scratch and mark a foil plate with an image that is then inked up, fed through a roller, and printed onto paper. Making the print involved me drawing directly onto the foil, and then, using a surgical knife, I literally cut parts of the image – the fibroid and organs – away, separating them from the remainder of the image and leaving an empty space in the print. This cutting apart and removal process drew my attention to the idea of a void or excised space and was in part what then led me to choosing to work with a quarried landscape as physical and metaphorical site into which I could emplace my hysterectomy experiences.

To pursue this line of land-enquiry, I looked for a site, or sites, that evoked not only my surgically altered body with its cuts, stitches, void spaces, and missing parts but also the visceral, embodied symptoms – pain, vertigo, heat – of the surgery and surgical menopause (I unpack my emplacement of menopausal symptoms into the landscape more fully later). Soon, I identified two disused slate quarries in the Little Langdale area of the Lake District that offered exactly what I was looking for. In fact, a year before my hysterectomy I had visited one of these two quarries, Cathedral Cave Quarry, a cavernous slate quarry with pillared rooms and passageway named for its cathedral-like scale and grandeur, and suddenly – through the making of the print discussed above and remembering Cathedral Cave – the visual and symbolic link between the quarried body and a quarried landscape struck me. This site and another equally awe-inspiring ravine-like quarry nearby called Hodge Close Quarry, see Figure 5.5, provided the relationship between the removal of organs from the body and slate from the land, and the empty spaces and waste products that are left behind following surgery and quarrying, that I was looking for.

Site exploration: emplacement and film installation

Further looking at maps and plans of both quarries, the physical and metaphorical parallels between the void spaces in the land, my print, and my body came together, and I began a series of site visits during which I gathered inspiration and raw materials.

Initially, I investigated the quarries with a view to making a live performance work in the landscape. However, early site visits soon indicated the scale and inherently dangerous and physically challenging nature of the landscape – vertical drops, rocky terrain, water-filled passageways. This meant that bringing the site inside, as a film and/or into an immersive installation, was the best option for this project. Furthermore, the remote and inaccessible nature of the quarries threw up access issues, which meant an on-site work would not reach the intended range of audience. The fact that the quarries are a site full of physical jeopardy that makes them too dangerous for me to take an audience to, draws a parallel to the surgery and the surgical menopause, all of which put the body at risk. Having therefore decided not to take audiences to the quarries but rather "bring" the site indoors, into controlled environments

such as galleries or hospital spaces, I chose to use digital film and still cameras and sound recording equipment to capture the site – all the time working through the lens of hysterectomy surgery and surgical menopause.

This involved archival research in a local museum[8] into the history of slate quarrying, particular to the Little Langdale area, and repeated trips to photograph, film, and make sound recordings at the quarries. Of interest were any parallels and metaphorical equivalents between the surgical (hysterectomy) body and the quarries, and any technical links – vocabulary, equipment used, processes – between the act of quarrying and surgery. For example, mountain-like mounds of set-aside waste or spoil compared to the removal of organs and tissue set aside for biopsy and disposal (see Figures 5.2 and 5.5). Only later, once I have completed my landscape-related research, do I begin to work out how to use these materials (along with the medical and personal materials) to represent the hysterectomy journey and surgical menopause.

So far, I have filmed within the darkness of narrow passageways and cavernous spaces held up by pillars of slate, and from the vertiginous edges of hollowed-out ravines flooded with ink-black pools of freezing water. I have also filmed people and activities associated with the site, including climbers scaling the quarry walls and have studied climbing maps that show me the names and phrases used to describe the site, climbing routes and techniques used. I have filmed modern-day quarrymen at work, made sound recordings of stone being quarried and machinery moving and sorting slate, feet clattering on slate, voices echoing in caverns, and tunnels dripping with water. Swimmers and divers training in the waters at Hodge Close have told me of routes into the lower part of the quarry that on my next trip I will seek out and add to my own map of the site, and routes through it that I can track with a camera. My work in the archive allowed me to study photographs that show the quarries when they were fully in use, and maps and plans that reveal their architecture, tunnel systems, and access passageway that are now submerged by water. Books documenting quarrying terms and techniques, the names of the tools used for excavating, splitting, and dressing slate have given me words and language to work with, and inform the making of the film and installation. I intend that the site-recorded sounds I have gathered are later edited to form part of a soundtrack that, along with recordings of texts distilled from surgical and quarrying terminology and my own reflections, underscores the moving (film) imagery.

Latterly, I have begun to emplace my body into the landscape. Using a drone and wearing a head camera I have been filmed, and filmed myself, while costumed in a hospital gown, walking, climbing, crawling, and feeling my way through the quarries (see Figure 5.6).[9] Wearing a hospital gown in this context brings an incongruity – a collision – designed to defamiliarize and make strange the everyday. The artistic aim of this particular design intervention is to bring fresh and unexpected perspectives – or "moments of being" – that can lead to "new" or alternative ways of seeing and understanding.[10]

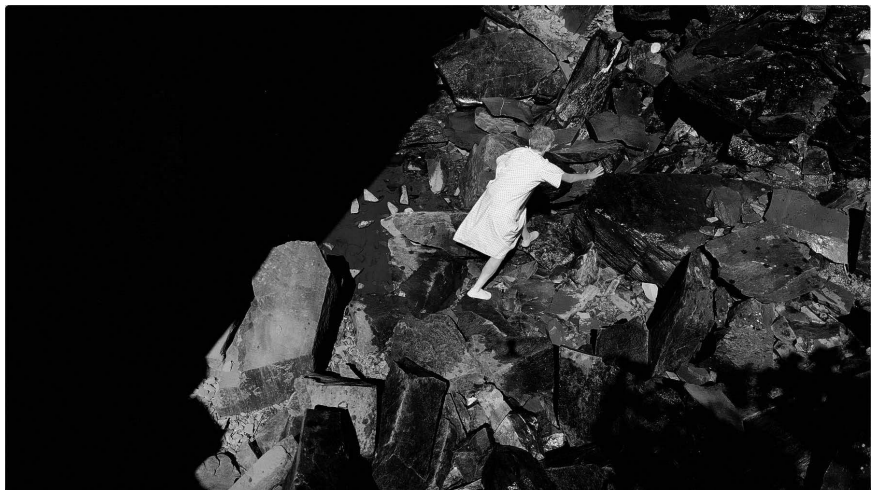


Figure 5.6 *Hysterectomy: BedRock*, still from film footage of Louise Ann Wilson moving through Hodge Close Quarry wearing a hospital gown. Directed by Louise Ann Wilson. Filmed by Lawrence Cox.

Landscape and menopause symptoms

The physical effects of the menopausal symptoms I experienced were hot flushes that felt like electric shocks streaming upward from my feet and through my body into my chest – like a flock of birds flapping their wings – that gave me a fluttering sensation in my heart and wave-like pulses through my armpits. This description is the closest I can get to putting these sensations into words. However, when stepping onto a viewing platform that protrudes over a steep-sided valley in the Lake District, I realized, as my reflections below suggest, that the terror-inducing vertigo I felt rising through my body was exactly like a hot flush.

> As I approach the viewing platform, I have a sense of dread. With trepidation, I step forward taking small faltering steps onto the wooden platform. As soon as it comes into reach, I grab for the handrail and inch myself along, not looking over the edge at the ravine beneath or down through the gaps between the wooden boards under my feet. Halfway, I stop frozen to the spot and unable to advance further. My heart races, my temperature rises, my chest tightens.[11]

With sudden clarity, this vertiginous – hot flush like sensation – seeded an idea in my mind of finding landscape sites that emulate or map onto menopausal symptoms and experiences, an emplacement process that makes them tangible and material in such a way that others can understand by feeling them too. With that in mind, while on a visit to scope Hodge Close, I ventured to the

top edge of the quarry where, standing well back – wedged next to a boulder and clinging to a Silver Birch tree – I peered into the vast gouged-out chamber deep below. At its base, a small lake of impenetrable water absorbed the light and acted as a mirror to the sky above and the slate-cut walls that plummeted vertically beneath its surface. Immediately, despite being in no real danger on this wind-free day, vertigo-induced hot flushes and electricity ran through my body. Here was a site-invoked physical sensation that I wanted to find of a way of expressing on film, through my use of the camera, the body and the landscape – this is one aspect of the work I am currently engaged in.

The final film, when complete, will consist of multilayered images – still and moving – that bring together and juxtapose the imagery created in Phase 1 (photographs, drawings, prints, medical scans, and texts) with landscape materials gathered in Phase 2 (maps, photographs, films, sounds). It will morph between the external and the internal, the body and the land, the surgical and the environmental, the physical and the psychological, and from the tangible to the remembered or imagined.

Structurally, the film will follow a route through the quarried landscape that passes by mountainous heaps of slate spoil, excavated caverns, void spaces and shafts, dark pools of floodwater, and lightless passageways that open out into green woodland lit by hazy sunlight. Underpinning this physical structure is a dramaturgical shape that echoes the hysterectomy journey from surgery to recovery. For example, leaving the open air to enter pitch-dark quarried tunnels will reflect the process of being anesthetized, and its soundtrack will combine sounds recorded in the tunnels with sounds of surgery and quarrying activity. Walking back out into the daylight and a woodland of vivid green trees and bird song will reflect coming back to consciousness. Imagery of my removed organs, my stitched and wounded body, and my pain-etched face will be layered with film of wrenched-open slate, spoil heaps, and climbers clinging to sheer rock, the effort of which can be seen on their faces. The latter part of the film will move into the surgical menopause phase, and I will now unpack how I am relating this to the quarries and why.

How my research continues to develop, and the end results, adapt, and change as my creative explorations and thinking progress. Only as this process progresses and the film is edited will it become clear to me how, in what form, it should be presented (either as a stand-alone film and/or within an installation where it might be projected onto objects such as bed linen or piles of slate waste). This cannot yet be determined – the key thing at this stage is to follow the subject and the site and see where they take me. To ensure that the final outcome reaches as many people as possible, my intention is to present the *Hysterectomy: BedRock* body of work in hospitals and arts venues that curate bio/medical and socially engaged art-practice.

Conclusion

This chapter has focused on the process of making a body of work that explores, communicates, and expresses an intense personal experience of hysterectomy

surgery and surgical menopause. I have shown how my approach is to rigorously investigate and confront the realities of a medical condition, surgery, and its effects, as well as the ways my interdisciplinary, scenographic-led methods combine art with medical and earth sciences to make visible and give a voice to a specific – yet not isolated – experience.

Although rooted in autobiography my use of a visual language, landscape, and metaphor means others will be able to find resonance and meaning in the completed work, widening out its impact beyond an autobiographical account toward a body of work in which others can identify something of their own experience.

The main aim is that this body of work serves to deepen levels of understanding and engagement with the subject in ways that resonate with other women+ who have had similar experiences. It strives to do this in two distinct yet interconnected ways. First, bringing the subject into the open air takes away silence and shame and enables others to recognize they are not alone. Second, it might create a space and provide a means through which women+ can share their own experiences of hysterectomy surgery – why they needed it, how they were prepared, how they recovered, and any side effects including surgical menopause symptoms. For those who find that talking openly is hard or that words alone do not adequately express their experience, my use of metaphor and multilayered imagery that juxtaposes the body, surgery, and landscape offers an alternative form of expression that goes beyond words.

There is clearly a considerable discrepancy between the understandable focus on skills and techniques among the doctors and surgeons and the physical and psychological effects on patients. I am interested in how this body of work might narrow this gap by representing the patient experience and, in so doing, make clinicians more aware of the effects. To that end, my practice seeks to find new or alternative ways of looking at and interpreting the landscape as a means to bring about new or alternative ways of understanding and doing hysterectomy surgery and surgical menopause.

My hope is that this chapter shows how the works discussed offer different, creative paths and "better ways" of doing hysterectomy care and attending to experiences of this and of life after the surgery. It can advocate for women's health by expressing and exposing medical information gaps and health inequalities. It will be of value to those directly involved in the hysterectomy process and its aftermath, but also inform medical professionals and contribute to health activism, in raising awareness at all levels including policymaking, and so bring about change.

Appendix 1

Seven Scenographic Principles – based on the Feminine "Material" Sublime – for Creating Walking-Performance in Rural Landscapes

Principle 1 – Being Located

"Views from Somewhere": Combining specificity of site, biological and social science, and people affected by a life-event.
"Situated knowledges" and interdisciplinary exchange.
"Views from Somewhere" and "Situated knowledges"
are concepts developed by Donna Haraway (Haraway, 2016, p. 1).

Principle 2 – Auto-Biography

First-Person Points of View: Facing and giving-a-voice to life-event experiences that sit – "Outside Belonging" – on the edges of mainstream dialogues and discourses.
A place to re appear.
"Outside Belonging" is a theoretical term developed by Elspleth Probyn.

Principle 3 – Landscape and Environmental Forces as Metaphors for Self

Harnessing Features and Processes: Geological, topographical, human and non-human, botanical, meteorological, seasonal, and planetary.

Principle 4 – Composing the Scene

Hybridization of the "Real" with the "Imagined": Drawing a walking-performance *out of* and *into* a landscape. Combining objects, film, sound, performance, actions, science, text and landscape features.

Principle 5 – Walking Beyond Knowledge

Beating New Tracks: Therapeutic, solitary, side-by-side, companionable, and surrogate walking.

Principle 6 – Alternative Perspectives

New Ways of Looking and Thinking: Moving-through and dwelling-in a landscape of constantly changing images, scenes and topographies.

Principle 7 – Wonderment and Defamiliarization

"Moments of Being": Aliveness-to and observational looking-at the material of the everyday. Making it visible.

"Moments of Being" is a concept developed by Virginia Woolf. (Woolf, [1972] 1978, pp. 83–84).

Notes

1 An "immersive installation" is a multisensory environment that is all encompassing and allows participants to enter the created environment, stand, sit, or lie within it and become sensorially immersed in imagery and sound.
2 Recognizing that the menopause is experienced by cisgendered women and people with wombs who identify as trans, I use the term "women+."
3 By "missing life-event," I mean the absence of a hoped- or planned-for event and the "missing" social status or identity that would otherwise have occurred, such as parenthood (Wilson, 2022, p. 179).
4 This approach informs scenographic principle 1 – being located, "Views from Somewhere": Site-, life-event (science)- and people-specificity. The principle is a literal application of philosopher Donna J. Haraway's term "being located," used to describe how situated and embodied knowledge bring about "a view from somewhere" that is nuanced and made up of distinct points of view (1988, p. 590). Haraway argues that "the only way to find a larger vision is to be somewhere in particular," to be located and materially specific (p. 590).
5 This approach is embedded in Principle 2 – autobiography/ethnography, First-Person Points of View: Facing and giving-a-voice to life-event experiences, which applies Haraway's concept of "staying with the trouble" (Haraway, 2016, p. 1).
6 These symptoms do not only occur in a surgical menopause situation but can affect people with certain medical conditions that affect oestrogen or who are having treatment such as chemotherapy.
7 This approach is embedded in scenographic Principle 7 – wonderment and defamiliarization, "Moments of Being": Aliveness-to and observational looking-at the material of the everyday. This principle applies the writer Virginia Woolf's concept of "moments of being" (Woolf, [1972] 1978, p. 81).
8 Armitt Museum in Ambleside, UK.
9 To ensure the gown holds its shape – giving a clear silhouette that prevents it merging into the surrounding landscape – I have modified it with a thick cotton lining.
10 This approach is another aspect of Principle 7 – wonderment and defamiliarization.
11 Louise Ann Wilson, transcript of voice-recorded description made on-site, April 26, 2023.

Reference list

Baugh, C. L. (2012). Scenography with purpose: Activism and intervention. In A. Aronson (ed.), *The Disappearing Stage: Reflections on the 2011 Prague Quadrennial*. Prague: Institut umeˇní – Divadelní ústav, pp. 36–49.

Bazeley A., Marren, C., & Shepherd, A. (2022). *Menopause and the Workplace*. Fawcett Society. Retrieved July 29, 2024, from https://www.fawcettsociety.org.uk/Handlers/Download.ashx?IDMF=9672cf45-5f13-4b69-8882-1e5e643ac8a6.
Carucci, E. (2019). *Midlife*. New York: The Monacelli press.
Codrington, K. (2022). *Second Spring: The Self-Care Guide to Menopause*. London: HQ an imprint of Harper Collins Publishing Ltd.
Frostrup, M., & Smellie, A. (2021). *Cracking the Menopause: While Keeping Yourself Together*. London: Bluebird an imprint of Pan Macmillan.
Haraway, D. J. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, *14*, 575–599.
Haraway, D. J. (2016). *Staying with the Trouble: Making Kin in the Chthulucene*. Durham, NC: Duke University Press.
Kemp, H. (2021). *Surgical Menopause: Not Your Typical Menopause*. Helen Kemp, Lulu.com.
Kulkarni, J. (2018). Perimenopausal depression – an under-recognised entity. *Australian Prescriber*, *41*(6), 183.
Layton, S. (2015). *Under the Microscope*. Retrieved April 23, 2023, from http://www.sofielayton.co.uk/installations.41.html.
Layton, S. (2016). *Making the Invisible Visible*. Retrieved April 23, 2023, from http://www.sofielayton.co.uk/installations.43.html.
Lotker, S., & Gough, R. (eds.) (2013). On scenography: Editorial. *Performance Research*, *18*(3), 3–6.
McCall, D. (2022). *Menopausing*. London: HQ an imprint of Harper Collins Publishing Ltd.
Mukhopadhaya, N., & Manyonda, I. T. (2013). The hysterectomy story in the United Kingdom. *Journal of Mid-Life Health*, *4*(1), 40–41.
Newson, L. (2021). *Preparing for the Perimenopause and Menopause*. London: Penguin Random House.
Newson, L. (2022). *My Story: Losing my Wife – An Avoidable Tragedy?* Retrieved May 2, 2023, from https://www.balance-menopause.com/menopause-library/my-story-losing-my-wife-an-avoidable-tragedy/.
Newson, L. (2023). *The Definitive Guide to the Perimenopause & Menopause*. London: Yellow Kite an imprint of Hodder & Stoughton.
Newson, L. (2024). Diabetes and menopause factsheet. *Balance*. Retrieved July 29, 2024, from https://www.balance-menopause.com/menopause-library/diabetes-and-menopause-factsheet/.
NHS. (2022a). *Hysterectomy: Overview: How it's Performed*. Retrieved December 12, 2023, from https://www.nhs.uk/conditions/hysterectomy/what-happens/.
NHS. (2022b). *Hysterectomy: Recovery*. Retrieved December 12, 2023, from https://www.nhs.uk/conditions/hysterectomy/recovery/.
Royal College of Obstetricians & Gynaecologists. (2023). *Hysterectomy: Information for Women, their Partners and Families about Hysterectomies*. Retrieved February 6, 2023, from https://www.rcog.org.uk/for-the-public/menopause-and-later-life/hysterectomy/.
Wilson, L. A. (2019). Dorothy Wordsworth and her female contemporaries' legacy: A feminine 'material' sublime approach to the creation of walking-performance in mountainous landscapes. *Performance Research*, *24*(2), 109–119.
Wilson, L. A. (2021). *Tell it to the Bees*, site-specific performance, Exeter, Devon: Outside the Box: Open Air Performance as Pandemic Response.
Wilson, L. A. (2022). *Sites of Transformation: Applied and Socially Engaged Performance in Rural Landscapes*. London: Bloomsbury Publishing.

Woodward, Z. (2024). Hysterectomy: Your questions answered. *Circle Health Group*. Retrieved May 22, 2024. https://www.circlehealthgroup.co.uk/health-matters/ask-the-expert/hysterectomy-your-questions-answered

Woolf, V. ([1972] 1978). Sketch of the Past. In J. Schulkind (ed.), *Moments of Being: Autobiographical Writings*. London: Triad/Panther, pp. 78–160.

Wordsworth, D. (1824–35). *Rydal Journals*. Grasmere: The Jerwood Centre, Wordsworth Trust (Wordsworth Grasmere).

6 Feminist performance-making: radically kind theatre-making redressing the act of being vulnerabilized

Katharine Low

My performance practice-as-research is based in challenging and shifting narratives of cultural representations of living with HIV or women's health challenges, including gender-based violence, maternal grief, and femicide. This chapter considers how health activism that employs a feminist performance-making methodology can trouble the lens of vulnerability that is imposed on women[1] who are marginalized, in this case women living well[2] with HIV and women who experience the threat of gender-based violence. This vulnerabilization has many facets, but the focus here is on how women's lived narratives are often marginalized, leading to a lack of recognition and validation of the diversity and multiplicity of their experiences. Thus, this consideration explores how health activism that employs a feminist performance-making methodology enables these women to be viewed through a multifaceted non-reductive lens. The value and need for counternarratives to redress such a vulnerabilization of women is where feminist performance-making has a role to play. The repetition of tropes and stereotypes placed on these women as vulnerable beings vulnerabilizes them further and suggests that they are without agency. Shifting these entrenched societal perceptions allows for a more truthful and complicated picture to emerge and enables an important exploration and addressing of what it means to live with particular health conditions and experiences of gender-based violence. This health activism through performance involves exploring multiple stories, which capture the complexity through the creation of material, artefacts, and performances as a means of interacting and articulating these counternarratives. My approach and methodology are a form of trans-national applied theatre work on health issues that I have developed and been working on since 2003, and the practice evolves with the input from the co-researchers on each project. These co-researchers are drawn from the communities I collaborate with.

Using performance-based methodologies in researching and unpacking the seemingly less obvious aspects of certain health conditions is key to the practice. The performance-making focuses on small, seemingly insignificant actions or artefacts, such as improvised scenes, choreographed dances, collaboratively crafted poems, and embroidered crafts, to resist and refuse particular perceptions of health and invites a closer engagement and consideration of the affect

DOI: 10.4324/9781003319818-9

and value of those activities or artefacts. In doing so, we as a collective take up space to investigate everyday experiences and affects of particular health conditions and events. In the making of performance or creative artefacts, we problematize, strategize, and push back on particular notions of women's perceived vulnerability. This approach to practice is very much informed by the feminist, scholar, and activist Pumla Dineo Gqola, who argues "It is never enough to simply illustrate how patriarchy works in order to understand it. The feminist imperative is to think against it, strategize against it, and consistently work to destroy it" (2021a, p. 14). I read this as a call to action exemplifying the work that needs to be done on many levels and informs my way of practicing and engaging with groups, particularly when the subjects include women's health and the perception of women's positions in society.

In this chapter, the authorship moves between "I" to articulate my (Katharine Low's) analysis and uses "our" to acknowledge the partners whose projects the chapter examines. These partners are the HEXlappies Collective in South Africa and Positively UK, who support women living well with HIV, in London, England. While these two groups may seem disparate in terms of their geographical locations or their health concerns, gender-based violence and femicide have roots in the same misogynistic, racist, and colonial attitudes, which all have a consequential impact on women's health and wellbeing. Both groups endure under what bell hooks calls, "imperialist white-supremacist capitalist patriarchy" (Hooks, 2000, p. 46). In this context, our performance-making is a form of health activism which includes undertaking arts-based activities and making of artefacts, such as improvised scenes, choreographed dances, collaboratively crafted poems, and embroidered crafts, to resist and refuse particular perceptions of health.

I begin this chapter by situating my co-researchers, the HEXlappies and Positively UK, and explain my approach to performance-making and collaborative research. From here, I address the key themes of our work, which includes *vulnerabilization* as an experience by drawing on ideas from United Kingdom (UK) and South African artists and writers, *radical kindness* as a research and practice methodology, and *embodied knowledge* conveyed through creative endeavours. Using this frame, I explore what it is performance-making does in these situations and draw on moments of practice with the organizations I co-research with to extend my analysis.

Co-researchers: the HEXlappies Collective and Positively UK

I have had the great joy of collaborating with two extraordinary organizations: the HEXlappies, a grassroots art-making collective, based in De Doorns, South Africa, and Positively UK, a national charity based in London, UK, without whom this writing and the academic research would not have been possible. It is imperative to name, wherever possible and with permission, the co-researchers Silvia, Neo, Maryam, Sarah, Erica, Nicky, Hendritta, Sophia, Elizabeth, Wilma, Mariette, Simone, Katrina, Sally, and Linda. These

individuals, alongside others who are not named here but are held in our hearts and thoughts, are the backbone of our practice. My ethics of practice lies in a co-collaborative approach (Low, 2024) whereby the participants are central to any engagement and decision-making as without them there is no project. Participants are co-researchers and together we consider what they would like to explore or discuss before the practice is delivered. Our shared work is always striving toward emancipatory research (cf. *Emancipatory Research and Vulnerability* website)[3] and practice whereby the tools and findings of the research practices are developed by the community as co-researchers who decide how the knowledge and outcomes are disseminated. In this way, there is a real sense of ownership of the methods and the outcomes of the practice research by the participants, which enables them to be in the role of co-researchers, which is the basis of emancipatory practice research (cf. Ledwith, 2020).

The partnership with the HEXlappies Collective began in 2020. What was conceived as an in-person project became a carefully distanced gathering for the group in De Doorns and a virtual engagement from me, based in the UK. Established in early 2020, the motivation for our practice was to create spaces in which these women's knowledges, griefs, and joys could be heard and recorded. The impetus for the project was the acknowledgment that within many individuals' family structures, mothers lack emotional and physical space for the maternal experience (Smith-Greenaway & Trinitapoli, 2020), the situation only heightened by the constrictions in place due to COVID-19. However, the creative practice in our collaboration was open to all: daughters, mothers, and grandmothers who attended. The project was offered as a place to take account of women's individual stories, to record and document their hopes, dreams, and experiences, and creating material artefacts, such as a memory quilt or an embroidered narrative, for them to keep and share as they wished.

Our partnership with Positively UK began in 2016, when Dr Shema Tariq and I were awarded a small grant to extend conversations about what it means to live with HIV and experience menopause. Positively Women was the first organization to support women living with HIV and AIDS in the early 1980s and 1990s, working in a context where medical professionals did not believe it was possible for women to contract HIV (Low, 2023). Now named Positively UK,[4] their overall motivation is to challenge and shift the cultural representations of what it means to live well with HIV as a woman. Our partnership is based on collaborative practice, which has culminated in a series of creative outputs. We have facilitated open creative workshops aimed at improving the general public's awareness around living well with HIV, thereby challenging, instead of reinforcing, existing stigma around HIV. We have created artworks and held semipublic, and most recently public, performance events. Our most recent project works with Positively UK's archive held at the London Metropolitan Archives. We are developing creative responses to the archive with women living with HIV including currently recording a series of podcasts, which are capturing the history of the organization which began in 1987 as Positively Women.[5]

My practice

Since 2003, I have worked at the cross section between performance, community artmaking and health, specifically the broad field of sexual and reproductive health in the UK and South Africa. Through the practice, which often involves performance and creative arts-based workshops, specific issues and topics are explored with individuals and communities. My practice values the veracity of people's lived experiences as a source of legitimate knowledge. Attending to the lack of attention to many women's lived experiences is a tenet of my practice. The ethics of the practice between the women and NGOs I co-research with are constantly negotiated and discussed, and I hold an awareness of both how the practice is discussed and considered. Written analyses, like this chapter, are just one such methodology of analysis. The ethics underpinning this practice aims to counter what Miranda Fricker has usefully identified as epistemic injustice, whereby "someone is wronged in their capacity as a giver of knowledge" (2007, p. 7). Many of the women we work with experience epistemic injustice in that their lived experiences and their knowledges are routinely overlooked and dismissed resulting in them being silenced. Performance-making is another way of exploring and harnessing lived experiences so that the women can share and be "givers" of their knowledge. In this way, embodied knowledge, that is to say the validation of the body as a key site of knowledge formation,[6] forms a cornerstone of my practice. The ethos of feminist performance-making informs the atmosphere and context in which I co-collaborate in my research-practice. In this, I am principally informed by the work of Clean Break Theatre company, Lois Weaver and Peggy Shaw's company Split Britches, and Jill Dolan, among others.[7] From this positionality, my practice has evolved, broadened, and slowed down, recognizing the impact and importance of a radically kind invitational offer to explore health and societal concerns that impact women on the margins. This notion of "radically kind theatre practice" is explored later in the chapter.

When I use the phrase "women on the margins" I refer to women who are dismissed, marginalised and challenged due to their racial, immigration, socio-economic, and health status. This phrase also includes the general patriarchal perception, which often views women as lacking in worth; an attitude that pervades much of traditional religions and cultural norms across the globe. I now consider the three key theoretical frames that underpin my approach to practice: vulnerabilization, radically kind performance-making, and embodied knowledge.

Theoretical framing

For many women, their bodies and their experiences of health are routinely neglected, and it is my contention that this neglect leads to two things: first, women and their bodies are made vulnerable and through this, they are vulnerabilized. Second, if women reject the perception of them or their bodies as being vulnerable, it is very difficult for them to be heard or listened to, so

in essence their health experiences are erased. To gain attention, women must speak about the health condition that has been used to suggest that they are vulnerable. However, that does not offer the whole picture of women's lived experience. Our practice is a means of redress; we place utmost importance in creating spaces in which to recognize and acknowledge embodied knowledge. In this way, we work with Marié-Heleen Coetzee's view that "[o]ur bodies, continually in a process of becoming, organize our knowing, feeling and being" (2018, p. 1).

The terms "vulnerability" and "being vulnerabilized" are closely connected, but importantly the term vulnerabilized is the "ongoing process through which vulnerability is created and sustained" (Garrett & Altman, 2024, p. 177). Both vulnerability and vulnerabilized are often employed in medical settings. Their use often places "undue deficit-oriented emphasis at an individual level" (Garrett & Altman, 2024, p. 177), which traps those individuals who have been categorized as vulnerable. When an individual experiences a health crisis, especially highly stigmatized conditions like HIV, the medical encounter often views their bodies as "vulnerable." There is a parallel experience with gender-based violence where women are deemed to be both emotionally and physically vulnerable. This limited view can often result in individuals being vulnerabilized as they are reduced to their assumed vulnerable category.

This act of vulnerabilization is reinforced by a societal viewpoint that is readily reductionist, with individuals being vulnerabilized through a stigmatized perception of who they are and what their lived experiences are or have been. Women who experience particular health conditions are intrinsically linked to their medical status and any alternative view of them is mediated through this prism.[8] With both the medical encounter and societal perception, those individuals have little space for consideration of their lived experiences or the opportunity to engage in any forms of heuristic capacity building (see Figure 6.1). Such capacity building involves sharing knowledge and by doing so exploring new knowledge which complicates the wider understanding of these women's lived health experiences thus producing a more complicated herstory.[9] This avoids reductivist, single-storied narratives of what a particular health condition means to a person's identity and role. While as individuals when we experience illness, we do experience a level of vulnerability, what is different here is the impact of the vulnerabilization of individuals experiencing long-term, chronic health conditions or the on-going emotional and physical impacts of gender-based violence, whereby those herstories are often reduced to single-sided blanket narratives of victimhood.

Judith Butler's theorization of vulnerability (2016) is a useful frame for my thinking here. Specifically, Butler considers what it is that vulnerability means, and how it is experienced as a shared human condition. We have "bodily" vulnerability – our bodies are vulnerable and can be attacked and we rely on each other's bodies to help us. Butler's conceptualization of the epistemic frame of vulnerability (Butler, 2009) is of most use to this chapter in terms of their idea

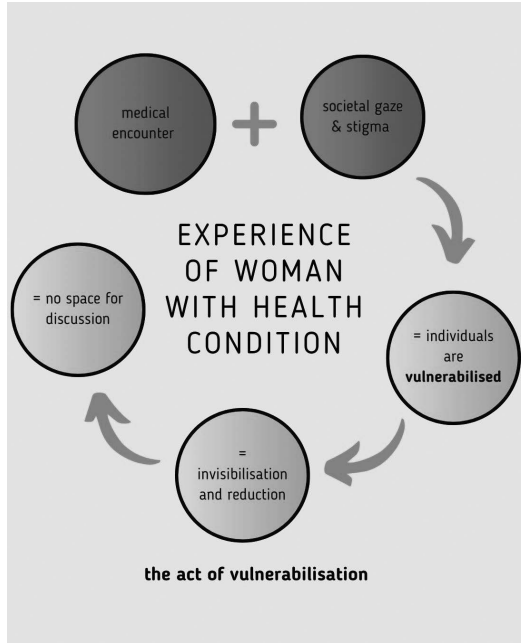


Figure 6.1 A diagram outlining how vulnerabilization can occur.

that we can "know" through vulnerability; it is a potential space of knowledge creation. Through my way of working there, it is an opportunity to refute and reject acts of vulnerabilization.

Sara Ahmed's notion of "feelings of structure" (building here on Raymond Williams' "structures of feeling") is helpful here. Through the notion, she considers how "feelings might be how structures get under our skin" (2018, p. 62). Here Ahmed names that these feelings are knowledges from lived and felt experiences. While Ahmed is speaking to fragility and how "feminism hurts/feminist is a space of learning," in essence, there is an acknowledgment of how these experiences are marking our bodies and these feelings are felt and "impressed upon" our bodies. These feelings are a form of knowledge. Ahmed goes on to argue: "It matters how we think about feeling. Feelings are how structures become affective; how we are 'impressed upon' in our encounters with others; how we are impressed differently, affected differently, by what we come up against" (2018, p. 65).

In my research, I build on the idea of kindness as a pedagogical tool informed by Shoshana Magnet and colleagues, transferring this approach into the socially engaged theatre making space (Low, 2021). They argue for "a form of kindness . . . that can bear the vulnerability of others and that bothers to do the labour of being compassionate" (Magnet et al., 2014, p. 3). Specifically, I argue for a particular approach to practice that can be

seen as a radically kind methodology. Advocating for this approach to practice involves four things: it resists perceptions of vulnerable and stigmatized bodies; it advocates for a consideration and valuing of everyday occurrences; it acknowledges the reciprocal nature of the practice between facilitator and participants, inviting a co-researcher shared status; and finally, it recognizes that while outcomes of the practice may appear to be subtle they are worthy of valuing (Low, 2021 and see Low's work on *Apertures of Possibility* from 2020 for more information). Considering our practice as a methodology of radical kindness acknowledges that inclusivity goes beyond identifying individuals' specific health status, social status, or need and adopts a position of kindness with its offer for reciprocity. These ideas inform the practice we deliver; every workshop in which we gather to make work and co-research together is a gentle holding and involves kindness. This kindness is not an offer of care; there is an element of obligation that accompanies care, often mediated by societal expectations. In this way, the act of kindness holds and supports the creative space and begins to resist a labelling or a reductive perception of vulnerable, often stigmatized women (Low, 2021). The practice invites a communal act of "holding" of one another – communally holding the space so that it functions collaboratively. Furthermore, this communal holding and a radically kind space also makes room for recognizing embodied knowledge as legitimate, which is a key tenet of the practice.

Accordingly, my radical kindness practice offers an insight into the heuristic potential found in embodied performance-making as a means of exploration and discussion, a working against epistemic injustice. Through this knowing, the practice offers an opportunity to refute and reject the act of vulnerabilization. Performance-making as a means of exploration and discussion here can offer insights that arise from the heuristic potential found in such an embodied practice. Part of my thinking is that it is through the act of performance-making and the coming together through radical kindness that we are able to come together to co-create spaces in which the act of being vulnerabilized (and thereby reduced) is redressed and recreated. Rather the act of making is the space in which both vulnerabilization is refuted and new knowledges are made. In order to explain this argument further, I first discuss the affect of vulnerabilization before moving to describe how the mode of practicing and making collaborative embodied performance, which I describe as a form of radical kindness, is both a response to the act of being vulnerabilized and the means through which vulnerabilization is countered through embodied performance.

To begin, speaking to the vulnerability of individuals experiencing chronic somatic illnesses, Shelley Tremain highlights the act of vulnerabilization that they may experience (Tremain, 2021, cited in Carel & Kidd, 2021, p. 485). Havi Carel and Ian James Kidd draw on Tremain's work to articulate how individuals' health testimonies may be affected by institutional opacity. They draw attention to how individuals who are experiencing ill health (or the effects of specific treatments) may experience an impact on their "epistemic

and interpersonal capacities." In other words, these individuals "may lack the confidence and energy needed for physically and cognitively demanding interpersonal epistemic practices" (p. 285), that is, articulating their needs with others. We see this experience illustrated in the work of the poets Polly Atkin and Hannah Hodgson, which I discuss below.

I was introduced to the idea that "Every body is vulnerable, not every body has been vulnerabilised" (2022) by Polly Atkin, a British poet who lives with a chronic health condition. Through her writing, Atkin exposes the flaws of this vulnerabilization and the impact this can have on individuals and takes back control of her health narrative and of her vulnerability. Atkin shares her experience about negotiating the vulnerabilities forced onto her body and her identity as a result of the identification of "clinically extremely vulnerable" individuals and the UK government's COVID-19 regulations that removed individual choice in decision-making about one's own body and its health care. Speaking to a fellow poet, Hannah Hodgson's response to the UK government's "do not attempt resuscitation" (DNAR) protocol issued in April 2020 (Iacobucci, 2020; Dyer, 2020),[10] Atkin draws attention to how the act of being vulnerabilized is experienced. In her poem, Hodgson details how the vulnerabilized individual is reduced by others. Hodgson's poem is explosive: the extract below illustrates how it succinctly highlights the lack of choice and agency accorded to her and her refusal of this lack of care:

> The GP rang this afternoon
> trying to talk about a DNR order. I refused.
>
> (Hodgson, 2021)

The poem highlights how in the removal of choice her body is rendered vulnerabilized. However, she pushes back, and she states her right to the living that is left to her and refuses to be constricted to a particular reading as a vulnerable, ill body. Rather, she powerfully reclaims her alterity; she demands to be seen as more than her health status and perceived vulnerability. I employ Emmanuel Levinas's term alterity (2006) here to acknowledge how the other, in this case Hodgson, is a being of unknowable multiple possibilities and cannot be reduced to a status of vulnerabilized. It is this lens of imposed vulnerabilization that informs my thinking around health status and women who are labelled as "vulnerable" by health systems. This critical frame is the basis of a riposte to the limitations such an external viewpoint places on women and their health. Within this approach drawing on key examples, our practice calls out and challenges the patriarchal impulse to control, manage, and define women's health by offering counternarratives because at present these uncomfortable women's stories are seldom being heard. This marginalization also concerns women living with HIV in the UK who feel invisible and marginalized. This is not just a feeling, it is a reality: these women are invisibilized and marginalized. A joint study by the Sophia Forum and the Terrence Higgins Trust (2018, pp. 7, 37) concluded that women living with HIV report

often feeling "invisible"[11] or "overlooked" by healthcare professionals. One respondent in the study explained this experience further, noting:

> [I] find that as a woman and person you are overlooked, and you become a statistic. [I] realised women are marginalised because we are not in the majority. We are not gay men. Why are our issues not being addressed?
>
> (Sophia Forum and Terrance Higgins Trust, 2018, p. 37)

It is in response to this discounting, this erasure, that my co-researchers (Positively UK and the HEXlappies) and I collaborate. Much of our performance practice-as-research is based on challenging and shifting narratives of cultural representations of living with HIV or women's health challenges, including gender-based violence, maternal grief, and femicide. Our work is thus centred on ensuring that women and women's health experiences of these matters are present and expressed and documented; that this counternarrative is heard.

Counteracting the act of vulnerabilization is key to this kind of feminist performance-making as it is a means of making the viscerality of health tangible through the creation of material artefacts and performances. It is a way of enacting and materializing these counternarratives (see Figure 6.2).

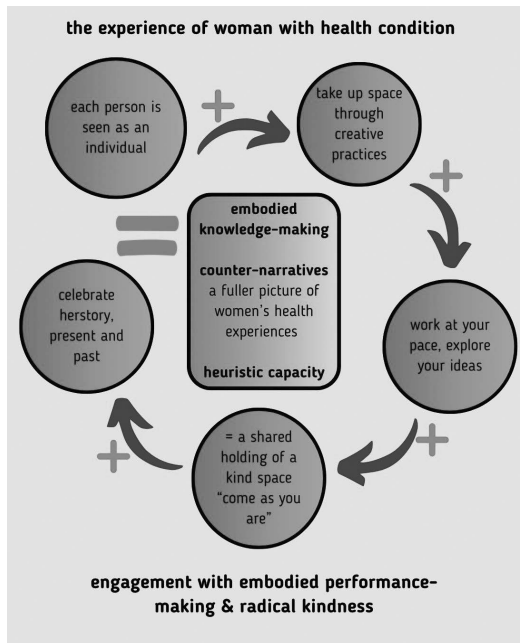


Figure 6.2 A diagram outlining what happens through engagement with embodied performance-making and radical kindness.

Accordingly, my approach to practice is about facilitating stories for individual women to recount their herstories, locate allyship, and engage in creative practice. I begin by acknowledging each individual's place in the project, that each person is an individual with different needs and wants and experiences. The offer of creative practice is an invitation to take up space as a woman, to explore different ideas and experiences. Within this thinking, individuals are invited to work at their pace and in the areas, they wish to explore to shape the direction of the work. The engagement is often quiet, kind, reciprocal, and "care-full." Here, the use of the term "care-full" makes reference to Sue Mayo's (2021) argument about the "care-full" (or "full of care") way of working a group of participants can personify. This way of working as a group engenders a shared holding of space, to contribute to making a kind space, with the invitation to come as you are, which is radical kindness. We make space to celebrate history, past and present through creative practices. This results in an embodied knowledge-making that builds counternarratives to this prism of vulnerabilization. This engagement allows the participants to refuse and refute the label of vulnerabilization, whereby a fuller picture arises of the lived experience of these women (counternarratives).

Here, I am drawing on Donna Haraway's (2016) thinking. Haraway builds on Marilyn Strathern's theories and argues: "It matters what matters we use to think other matters with; it matters what stories we tell to tell other stories with; . . . It matters what stories make worlds, what worlds make stories" (2016, p. 12). Through this storytelling practice, new worlds are imagined and built. The types of stories we tell, and the manner through which we tell them, allow complicated narratives of what it means to be a woman with a particular health condition to be recognized; counternarratives are powerful. If your body is labelled as being "unhealthy" or "ill," there is something exciting about the regenerative action of that body, of showing how the supposedly "sick" or unhealthy body is capable of extraordinary, powerful poetry, physical performance, and so on. In doing so, we are countering cultural representations by offering up other narratives, which acknowledge the multiplicity of these women's lives. The doing of performance sets up a material space for these conversations, for different and counter-stories and experiences to be experienced and shared in a collective space; an idea which moves me to the notion of radically kind performance-making.

Women's lives are multiple and therefore have multiple stories and experiences. We work from the principle of recognizing the multiplicities, the multiple embodied knowledges that each person brings to the room, inherent in "any body" but especially those bodies which have been marked as ill, vulnerable, or "unhealthy/dangerous." We see performance-making as a means of exploring, analysing and researching which has the possibility to lead to a regenerative action in which new knowledges emerge and are accounted for.[12] We work from this principle in a co-collaborative manner. This chapter now turns to examining how our collaborative practice redresses the act of being vulnerabilized. First, I look at the HEXlappies and consider how creative acts can reenvision vulnerability.

The HEXlappies and creative acts that reenvision vulnerabilities

The HEXlappies, whose name comes from the local river, the Hex, which runs through the Hex Valley, and "lappies" is an informal Afrikaans word for a cleaning cloth. De Doorns is a small rural town in the Hex River Valley, a major grape-producing area in the Western Cape. Many of the women involved in HEXlappies live in the informal housing area called Stofland, next to De Doorns. The Hex River Valley's main employment is agriculture, specifically exporting grapes. It remains the only major employment prospect for most people in the valley, but the intense farming has serious ramifications for the environment. During the grape picking harvest, there is work for four months. Some of the women are employed as seasonal workers but struggle to find work in the other eight months of the year. The HEXlappies collective runs in that fallow period, between May and November each year. Under leadership from Katrina Mokwena, a community leader in De Doorns, and curated by Erica Lüttich, a visual artist and crafter, a group of women from Stofland meet once or twice a week and, occasionally, for intense projects lasting a few weeks every year since 2020. With the first lockdown in 2020, the group began to meet in person, appropriately physically spaced to undertake the visual and craft work together. However, for me, the performance work happened virtually where I delivered online short performance-based activities for the group to do in person. I would offer creative prompts through recordings and live zooms and as a group, the women would play, devise, and create.[13]

Their first project was an invitation to learn different embroidery techniques and use these techniques, which captured a symbolic nonverbal commentary of their lives during COVID-19. From the photographs below, we can see representations of COVID-19, the women's homes, their families, and the countryside. These cloth stories are in turn made into skirts, aprons or wall hangings, extending the narrative into their everyday life. Being a part of these creative acts, the women offer and share insight into what it means to be a woman of colour living in rural South Africa during COVID-19, countering a single perception and narrative of their quotidian existence.

It is important to acknowledge that in general, the contemporary lived experiences of South African women are complex, especially so for women of colour. There exist extremely high rates of femicide and prior to COVID-19, eight women were murdered every day in South Africa. That is nearly 3,000 women each year (Brodie, 2020, p. 190), and these numbers continue to rise. For example, in 2023, the South African Police Service Crime statistics recorded 3,880 femicides, an average of 10.6 women a day (Outlier Reporter, 2024), which was an increase of 2.6 women a day, that is, 949 additional deaths in a year. Alongside this, for decades, there has been little consideration of women of colour, from the racist policies of apartheid to the HIV pandemic and the lack of government-provided Nepravine[14] for HIV+ mothers to prevent the transmission of HIV during birth (Chigwedere et al., 2008). More recently, COVID-19 lockdowns led to an increase in domestic workloads

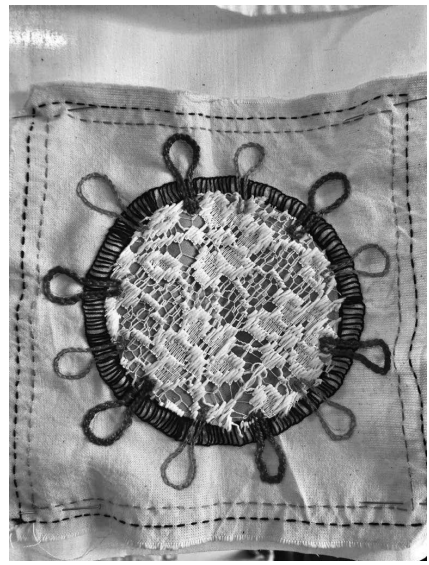


Figure 6.3 An embroidery of the COVID-19 virus. Photography by Erica Lüttich.

and a loss of income (of usually lower-paid jobs), and women of colour were predominantly overrepresented in frontline healthcare staffing, all of which has been increasing poverty for women and their dependents, especially in female-headed households (Chitiga et al., 2022).

The recounting of the HEXlappies' experiences requires careful work. I am conscious that violence and reading of said violence that occurs in the Global South requires recognition of the ongoing legacy of colonialism. The Brazilian feminist researcher Natália Maria Félix De Souza describes it as the residual systems of violence enacted during colonialism: "the persisting effects of colonialism not only in the open system of violences that affect the (gendered, racialized) bodies of the colonised, but also their/our minds" (De Souza, 2019). I write this in the awareness of my white settler background and hold this carefully so as to avoid the othering and paternalistic slide into the emotive and sensational recounting of individuals' lived experiences for a particular academic argument. In doing so, I am informed by two South African feminists. The first is Nechama Brodie and her pertinent argument for the need to make space for South African women's overall life experience, particularly in light of femicide (Brodie, 2020). The other is Gqola, Research Professor at the Centre for Women and Gender Studies and NRF SARChI Chair in African Feminist Imagination at Nelson Mandela University, who has written widely on the topic of Black women in South Africa, most recently *Female Fear Factory* (2021a), an expanded account of *Rape: A South African Nightmare* (2015). Specifically, Gqola argues that a lack of feminist engagement allows for patriarchal violence and patriarchal disregard to continue, that is,

Figure 6.4 A depiction of the different cloth statements the HEXlappies embroidered and their translations. Photography by Erica Lüttich.

the erasure of women. Gqola draws attention to the importance of using literary responses to challenge this patriarchal violence. Fundamentally, Gqola's argument is an offer. It is a feminist principle of not leaving the viciousness of patriarchal action uncommented on for those able to do so and an invitation to consider how action can be taken towards the unmaking legacies of colonialism and the apartheid regime.

The act of not leaving events or occurrences uncommented upon and the ways of doing this is the work that we do together. For example, in December 2021, the HEXlappies collective took part in the national South African "16 Days of Activism for No Violence Against Women and Children" campaign. They discussed and embroidered a series of cloth statements about what they want and what they do not want in their communities (see Figure 6.4 with translations from the Afrikaans on the right of the image).

These embroideries were transferred onto postcards and then distributed and placed throughout their neighbourhoods in and around Stoflands and De Doorns. These postcards began to disrupt viewpoints; they challenged the observer to look, and through this encounter, maybe engage. It is a gentle form of resistance: a way of being heard without fear of repercussions and the cumulative impact of the words can linger beyond the initial reading of the text. Collectively, this lingering has the potential to disrupt prevalent narratives. As women, many of the HEXlappies are vulnerable, but their vulnerability has

knowledge and expertise; they know how to start a conversation without a threat of immediate violence on their person or for others; those postcards are a subtle way into that conversation. It is also a means of preventing erasure. As will be demonstrated shortly, these creative acts are preventing a collective forgetting of women's health narratives and of the individuality of their experiences. Here, with the postcards of the embroideries, the HEXlappies are naming and keeping the matter of gender-based violence present in the conversation in their communities. As performance makers, by not challenging the idea of this vulnerabilization or prescribed vulnerability, we are missing an opportunity to reach broader understandings of health and empathy toward others. We challenge vulnerability where we can, often with small acts that have deep resonances. For example, as we saw in Hodgson's poem with the one line about "and all the living I have left to do," it is the one statement from the HEXlappies which resonates and carries on beginning to unmake, refusing a collective forgetting.

Art-making and performance-making can help counter this vulnerabilization, but it requires a particular approach. I now turn to discussing how the coming together of performance-making allows for both a dismantling of the "vulnerabilized" and a space to consider what that proscribed "vulnerability" actually contains: expert and individual knowledge. This chapter now turns to how radically kind performance methodologies can offer a refusal of erasure through counternarratives.

Refusing a collective erasure: examining the work with Positively UK

Positively UK is an organization that began initially to support women living with HIV and now works with all individuals living with HIV. Our work together focuses on the collaborative practice with the women's group of Positively UK and explores the feminist history of the organization as a means of refusing a collective erasure. We begin by considering the practice created with Positively UK.

Dear Mariella,

Have you ever had a secret, but not like a normal secret, the type of secret that isn't really a secret until you think about how the other person might react to the secret and if you do tell people and they don't understand the secret will you wish you'd never told them the secret?

Do you get it?

Yeah I'm not too sure I do either . . . .

A Letter to Mariella, anonymous, 2016.

This is an extract from a monologue, performed in front of an invited audience but written as a response to the first project we ran with Positively UK,

which was a series of creative workshops exploring womanhood and HIV in the run-up to International Women's Day in 2016. The monologue explores Mariella's understanding of her HIV diagnosis and how she navigates the world after knowing about her health status. Listening to the monologue, written as a letter to her younger self, the audience witnesses the difficulty of articulating a health status that has been kept a secret until now. The viscerality of this lived health experience can be difficult to communicate and is not captured in medical reports or statistics. Performance allows a sharing of different forms of embodied knowledge production; it is a means through which to embody and respond to both the questions that emerge and those that have been left unspoken or unheard. This act of performance-making allows for the knowledge held within vulnerabilities to emerge, as we discover in the rest of the letter to Mariella.

The focus of much of my work with Positively UK is in holding creative spaces in which current representations of what it means to live with HIV are problematized. Our practice importantly offers the space to consider what can happen when the multiple everyday elements of a woman's lived experience are considered within a dedicated workshop space itself. By contemplating these seemingly small actions as a whole, their potential to hold significance beyond the "making and creating" (Pottinger, 2016, p. 215) is worth considering. Laura Pottinger's analysis of the turn towards "quiet activism" in the field of geography echoes my thinking in this area of applied feminist performance-making. Pottinger describes quiet activism as "small, everyday, embodied acts, often of making and creating, that can be either implicitly or explicitly political in nature" (ibid, p. 221). Specifically, she considers "the implications of activism performed at low volumes" (ibid, p. 216). Knowledge emerging from our practice also reveals what Pottinger calls, "the affective, emotional and embodied dimensions of 'making' as it intersects with social, environmental and political action and critique" (ibid, p. 217). Pottinger calls for such learnings to be recognized and "the need for scholars to attend to the embodiments called for by various modes of activism, and their particular impacts, emotions and affects" (Brown & Pickerill, 2009 cited in ibid, p. 221). I also like the analysis that Paul Chatterton and Jenny Pickerill discuss when they highlight how everyday practices, like those that occur in the workshops we run, are a means of "build[ing] hoped-for futures in the present, but that this process is experimental, messy and contingent, and necessarily so" (Chatterton and Pickerill, 2010, p. 475).

This messiness is very apparent in our collaborative art making, and I have come to see the flow between actions, ideas, and conversations, allowing for hoped-for-futures to be explored at this "low volume." This quiet activism sits counter to traditional understandings of activism, which often requires the weight of visible and outspoken protest.[15] In essence, the approach and the manner in which collaborative art-making is held and facilitated is rooted in what I term a radical kindness methodology in performance-making. Making tangible the experience of the ephemeral viscerality of health requires a

particular kind of "care-full" work. This idea speaks to the creation of a particular kind of facilitation and holding of the space for the work to occur. I have written about this approach as being a form of radical kindness (see Low, 2021). A radical kindness positionality enacts and sets up a space where all who participate are able to do so on their own terms, no matter their frame of mind; contribute whatever they feel able to offer, and all is offered in the knowledge that they will be held with kindness.

Radical kindness is central to the feminist health activism that the work with Positively UK embodies. It is about creating and holding spaces within which individuals are able to consider and reflect on their health challenges and share their knowledge and lived experiences with others. An example is the manner in which the group *holds* "Sally,"[16] a woman who attends many of our events and workshops but who does not "participate" in a conventional manner. Rather, she sits on the side, loudly commenting on the work that others are doing, sometimes directing them in their work. Sally comes for the food and the companionship. Sally takes up a lot of the space, in the way that she can sometimes be disruptive, loudly commenting and critiquing from the sidelines. Yet she is held with kindness by everyone in the room. Her vulnerability, her right, and her need to be in this space are all recognized, and rather than challenging her, she is held with kindness.

In this holding of Sally, the radical potential of a small act of kindness is evident; we are communicating that she is welcome in the space as it is her space as well. Her being, her prickliness and disruptive presence, is both acknowledged and held, and invitations to join at whatever level she wishes to do so are offered and never retracted. Sally's being in the space and her presence dismantles the idea of the vulnerabilized woman who is unable to make decisions for herself because what she is so clearly doing is articulating what her needs are, which in this instance to be with others and not participate. At Positively UK's recent public event in November 2023, Sally came as an audience member. She spent the evening celebrating everyone in the space, the women who had performed and took a moment to find me and thank me for the work we were doing with Positively UK. Thus, we see, eight years later, the impact of being held with kindness; we learn more about ourselves and others, about patience and joy and the unexpected outcomes that can emerge from this practice of radical kindness. Sally's decision to attend could have easily been overlooked. However, if attention is paid to these smaller moments, something else begins to emerge.[17] By looking at this tiny moment, we can dismantle the vulnerability that Sally demonstrates and consider what it might signify. That is, in this instance, Sally being held with such kindness has created a space whereby her vulnerability has also been held. Articulated nearly eight years later, her act of thanks is perhaps a recognition of the value that the space offered her all those years ago as well as a recognition that the group benefited from engaging with the practice.

In the act of making together, of holding a radically kind space (Low, 2021), if we are open to the embodied modes of knowledge production offered by theatre and performance, we can have a better understanding of health and

empathy between ourselves and toward others. Performance and art allow a different way into having that conversation. Within our creative practice together, it means that the performance space is one that is responsive, open, and full of invitation. The feminist performance space we have carefully developed over the years has become a space which resists perceptions of a "vulnerable" and "reduced," stigmatized body; rather it is a space which holds the potential that lies in a consideration of the quotidian and quiet activism.

This is apparent in our most recent project, *Positively Women: Past & Present* (2022–2023), where through engagement with the archives of Positively Women held at the London Metropolitan Archives. Through participatory workshops with women living with HIV, creative engagements and responses to the archival material, a podcast series and a public performance event, we, the facilitators from Positively UK, myself and Maryam Shaharuddin and the women who were participating explored the past to learn how it can inform our present. We sat and explored the ephemera of past engagements and events, exclaiming over old photographs of protest marches, the ground-breaking reports about Nepravine, healthy and safe pregnancies, the leaflets about "HIV and your rights" and advice on funerals, grief – the memory of those people lost, those who died – insurance: the magazines which featured women living with HIV on the front cover. This shows the importance of taking up time and space to sit with the past, to learn the history, to widen and extend our collective knowledge of women's experiences of being diagnosed, living, and dying at different times. It was not just ephemera, rather how we considered and held the everyday lived experience of that organization, the act of coming together to look, reminisce, and think forward is a radical act because it is such a rare opportunity for women to explore and discuss these topics. In the doing of these actions, we are saying this organization, these lives, these decisions, these actions and findings and reports are valued and important. We held a space for the past to be revisited and recognized again, to prevent erasure, to deepen collective knowledge, and we took the space to do so.

We see this deepening of collective knowledge and the rare opportunity to come together in an interview from 2022 with Neo Moepi, a member of Positively UK's staff who co-led the Past & Present workshops:

> Most of the women who are accessing the project are actually very isolated. To bring them together, to look at the history of the organisation that is supporting them to get back on their feet, for the first time to come and talk about HIV and confront the stigma that we are living with, is absolutely amazing. I think it's a great project and I'm glad that I am part of it. It brings joy to my heart, and it also helps me to have a closure and to come to terms with people we have lost on the journey. The women who started Positively Women, the women who were our first peer support members, getting to remember them and see them in the archives and just reminiscing about the past and getting joy from the present is absolutely amazing.

Together we held the space for people's histories and lived experiences to be seen, held, and recognized. In doing so, we acknowledge the multiplicities of these women's lives and paths taken, which in turn makes space for the next woman. The vulnerability of the other is a space of learning – what we have learnt about their lives is knowledge that works towards bolstering collective understanding and being a part of collective histories. We can then apply this knowledge to ourselves and to others. We see this happen in the last workshop of the year in mid-December 2022, where on a freezing cold day, a new woman is welcomed into the workshop space. Others are encouraging her to play and share her ideas and thoughts; she is welcomed with hugs, giggles, and cups of tea. All seemingly small acts, but those tiny offers are kind, and when considered as a whole show us the kindness and celebration of the other in that space; the reciprocal care and celebration of each individual. The radical act of taking up space to discuss, learn and sit side-by-side allows for intimate knowledges to be shared and learning to occur, with careful kindness, exuberance, gracious charm and energy. It is, as the final words of the monologue note, the culmination of having space to think and work together:

> The opportunity to collaborate with the past, present and future. Running workshops with inspirational, creative, powerful women with stories that demand an honest, truthful stage. And here they are.
>
> (Anonymous, 2016)

The HEXlappies and refusing a collective erasure

We see echoes of this demand for a stage, a space to speak from and be listened to, in the HEXlappies' practice, which helps explain how performance-making can work against erasure; how it takes up space and allows for other possibilities, how it unmakes and dismantles.

Let us return to the first cloths the women stitched in May 2020 (Figures 6.3–6.5). Through a weekly series of activities, some led in person by Erica, others remotely by me, the women employed movement, dance, and words to begin sharing and exploring their identities, the relationships and stories they wanted to share. At this moment, I recall Gqola's reading of Miriam Thali's work and argument that "without our history, we are nothing" (Thali speaking in 2009, cited by Gqola, 2021b, p. 3). In her analysis, Gqola makes the argument about the importance of history to the present day, the opportunity to make connections between moments and movements that do not always appear to be obviously linked. These ideas and experiences were stitched onto cloths that became an exhibition and celebration held on August 10, 2020.[18] What you can see on these cloths are embroidered depictions of their homes, their children, their streets, the flowers that grow in the veldt (the surrounding fields), as shown in Figures 6.5.

The women invited people to come and attend their narrative cloths exhibition – again carefully socially distanced. These cloths were a means of

Figure 6.5 Photos of different cloth panels embroidered by the HEXlappies. Photography by Erica Lüttich.

dismantling perceptions of who the HEXlappies are both because they take the form of an accepted female domain – cloths – and because their messages are personal, "I am brave" and also there is a call to which is collective, "Raise your Voice," "I am free." Here, we see a more complex account of their lives and their lived experiences because their stories push past the idea that there is only a single narrative of what it means to be a woman who lives in Stofland. Their work makes connections between individuals' histories against a backdrop of collective national histories.

After two years of working remotely, in May 2022, I met the HEXlappies in person for the first time. It was joyous, an opportunity to hug, to see each other in full, in person. To exclaim about height differences and to see and touch their work. It also became an opportunity to make and play with performance. One of the first things we made was a soundscape, using recorded sounds and occurrences from the women's lives. In the soundscape, we hear the disrespect Sophia's neighbours show her, a 65-year-old woman, by playing pounding dance music all through the night from Thursday to Sunday each week. You hear Hendritta being shouted at by her neighbour, threatening her and her children. You also hear the sound of the rubbish; the plastic and the bottles being broken at people's houses and the dumping of litter and rubbish, which blows across the veldt into people's living areas. The HEXlappies wanted to talk about some of the challenges they face in their everyday lives, the events that confronted their sense of self and who they are and how they

are perceived by their community. This became a way into thinking about the voices of women of colour in South Africa. Questions emerged: what do women need in order to feel able to speak? What does a woman's voice sound like? What does authority sound like?

The soundscape came about through conversations and sharings. It exemplifies, in a heightened manner, the cacophony of their quotidian and the anger and the inevitability that they feel. Katrina spoke of how she had recently stood up to one of the local taxi drivers by whom she often felt discriminated and disrespected due to her religion – Katrina is a Rastafari. Marietta spoke of not feeling safe following a violent attack in her home the previous year. What is not captured in the soundscape is the outrage that the women felt on behalf of each other, in telling their stories. The woman comforted and bolstered each other, crying at the unfairness of what some were experiencing but also with solidarity of understanding, offering to stand alongside and support individual women in the group. The verbal comforting happening among the women was indicative of how this group had become a collective. Despite the fact that the majority of them are neighbours, living on the same road in Stofland, it was in the coming together in a separate space that is important here. In the midst of the pressures of everyday living, there is no time to have these conversations. This practice affords time in collaborative creative making, offering a sharing space that becomes deeply significant. It is, as Gqola (2021b) draws attention to, the opportunity to record and share and make one's own history to work against confinement. The HEXlappies work hard to not bring any of their young children into their creative space as it is very much a space for them to be women just responsible for themselves, to meet, to talk and to make. We see this in the posters created that do not depict roles like "mother" (see Figure 6.6).

This discussion turned to a debate about women's voices in Stoflands and the Western Cape/South Africa and understandings of collective voices, of multiplicity, and of holding each other. This conversation moved into dance and performance, playing with some of the moves and sounds they would like to do and say or are doing and saying. We fell into Beyoncé's *Run the World (Girls)* – and we played, ultimately deciding to create a short TikTok-style video.[19] To the backdrop of Beyoncé, this video shows women strutting, holding their space, being bad-ass. And it is cherished. It also epitomizes the importance of play alongside the seriousness of the discussions undertaken. This playfulness helps support other discussions and ways of thinking through big challenges. Playfulness is vital: the opportunity to play, to resist, and challenge oppressions in contexts that are not playful and the release stemming from laughter and being "silly." All in all, this enacts a loosening up, a relaxing into the space. It is not about dismissing and ignoring the difficult circumstances, rather the playing and being playful is a route into difficult, sensitive, and sad conversations as connections have been made through play, and support is in place. The works created become a means through which to extend these

Figure 6.6 Posters created in May 2022 in De Doorns.

Figure 6.7 Creation of a dance to go with the Soundscape (HEXlappies Film: https://www.youtube.com/watch?v=7j9e72jDDCg).

conversations. For example, the women first created the soundscape and then worked with Adrian "Smurf" Tony, a young South African/British choreographer, to develop a dance that codified their experiences and what they wanted to say about it (see Figure 6.7 and the YouTube link to watch the film).

Fundamentally, in the coming together, the HEXlappies are discussing women of colour's roles in South Africa, the patriarchy, ways of supporting each other and through the making, they are dismantling and unmaking some of these challenges: the way in which women are viewed and considered in South Africa – they are exploring and playing with possibilities. The

performance-making, the dancing, the art-making is a space from which the women can choose to perform against the confinement of their social roles into a space where they are not being erased. These acts are echoed in the work of the women in the Positively UK projects, who also perform against confinement and reduction of their selves to one single story, to that of being HIV positive. Rather, through the making together they are making their own histories, those which act as counternarratives to the vulnerabilization.

Conclusion

For women living with HIV, there are a couple of externally cultural representations or tropes imposed on their health status, either that of "victim," refugee or migrant woman fleeing, or women marked with shame as a result of drug use or sex work. Similarly, for women living in often impoverished rural communities in South Africa, in communities with high rates of gender-based violence, there is a perception of a vulnerable, victim-like woman who has no agency or cultural capital. These limiting narratives of "victimhood" that view these women's lives solely through one lens of their "health" conditions or the impact on them of gender-based violence returns us to Gqola's point; the stories we tell matter and through offering other narratives we can illustrate women's quotidian lives and in doing so dismantle patriarchal and often colonial and racist lenses.

Elif Shafak argues in her treatise, *How to Stay Sane in an Age of Division*:

> Stories bring us together, untold stories keep us apart.
>
> Not being able to tell your story, to be silenced and shut out, therefore, is to be dehumanised. It strikes at your very existence; it makes you question your sanity, the validity of your version of events. It creates a profound and existential anxiety in us. In losing our voice something in us dies.
>
> (2020, p. 9)

Here, Shafak's words call to Gqola's argument about the need for alternative stories, and this need is certainly true for many of the women with whom I co-research. Although Shafak is talking more generally about humanity, her insight on the cost of "losing our voices" is particularly apposite to women living with HIV whose stories are often carefully curated if they are seeking asylum, or seeking protection with the ever-present sense of stigma that pervades living with an HIV diagnosis carries. To a woman in Stofland and the daily injury to self of surviving in these conditions similar pressures are experienced.

Indeed, we acknowledge the importance of creating spaces to share stories, especially those which could be seen as inconvenient, unpopular stories because the women are perceived as difficult, disobedient women. In holding those spaces, which is a radically kind action, women are invited to share their

stories in whatever format that suits them. This is a form of radical kindness and quiet feminist (health) activism, as this practice allows for women to work against the confinement or erasure of vulnerabilization. Facilitating this work within a methodology of radical kindness feminist performance methodologies offers a counternarrative to the vulnerabilization that is being enacted on these women and their bodies. It is, as I stated at the start of this chapter, exactly what the HEXlappies and the women at Positively UK do: they reclaim control of the definitional narratives of health vulnerability that are imposed on them. This new knowledge acts as counternarratives to vulnerabilization; it offers up a collective, shared knowledge. It is an invitation to the other to learn more, becoming a form of quiet feminist activism and advocacy to dismantle and challenge. The women disrupt this external narrative by taking back space to articulate a different narrative, one that is not focused on their health. They dismantle such readings of vulnerabilized bodies and tell their stories.

Notes

1 The focus of our practice is on the health of women, and by women, we mean all those who identify as such. We recognise that trans and nonbinary people and other minoritized genders experience many of the challenges outlined here.
2 The term "living well" is drawn from Mel Rattue, an HIV activist and poet, and it acknowledges that living with HIV is a chronic illness but manageable with good healthcare. It deliberately counters the idea that people with HIV are incapacitated or "sick."
3 Please visit www.erav.co.uk.
4 Please see Positively UK's website for more information: https://positivelyuk.org/.
5 For an account of this project, please see Low et al. (2025).
6 For an interesting account of this, see *The Body Keeps the Score* by Bessel van de Kolk (2015).
7 Clean Break's work can be explored here: https://www.cleanbreak.org.uk/, Weaver & Shaw's Split Britches here: https://www.split-britches.com/ and I recommend Dolan's *Utopia in Performance* (2005).
8 This can be seen all too frequently in the perception of women who live with HIV who are often deemed to be either victims or at fault for their HIV status, and placed into categories of "poor, vulnerable" women, a gaze/perception which both reduces and makes invisible their multiplicities, their multiple roles, and ways of being (see Low, 2024, for more discussion on this idea).
9 "Herstory" is a deliberate use of "her" to counter the patriarchy of his + story = history.
10 DNARs are often called "DNRs," which stand for "do not resuscitate."
11 "Women living with and affected by HIV have so far been mainly invisible in the narrative and response to HIV in the UK, despite making up a third of all people living with HIV and a quarter of new HIV diagnoses in 2016" (Sophia Forum and Terrence Higgins Trust, 2018, p. 7).
12 Even though the women have come because they all identify as HIV positive, they resist medical assumptions that treat their bodies as the same – immunocompromised (vulnerabilized) in the same way.
13 A film about the first year of the project can be viewed here: https://www.youtube.com/watch?v=BmTg8GOxQKI&t=38s [accessed 19 September 2023]. Over the past three years the HEXlappies have continued to collaborate with various other organizations (APECV and COP26 in Glasgow) to address climate justice

and gender justice issues, making blankets and embroidered contributions which address land use and mapmaking in the unequal and historical landscape of South Africa.

14 *Nepravine* is an antenatal drug that helps to prevent mother-to-baby transmission of HIV.

15 Compare this to the often "in yer face" activism of ACT UP and other HIV protest organizations and events which often do not have much space for women who are not "out" with their status. Please see Low (2024) for a discussion of this.

16 All the names of the women who attend Positively UK events and meetings have been changed.

17 This is an idea that I have developed, using the metaphor of an aperture of possibility – the invitation to take a closer look at what might be happening, to pause and reflect on the smaller moments (cf. Low, *Applied Theatre and Sexual Health Communication: Apertures of Possibility*, 2020).

18 In South Africa, Women's Day falls on August 9 to celebrate the 1956 walk to the Union Buildings to protest against the pass laws and the "dompas," which the then apartheid government wanted people of colour to carry at all times.

19 To view the video, please see here: https://www.youtube.com/watch?v=7j9e72jDDCg.

References

Ahmed, S. (2018). Feminist Hurt/Feminism Hurts. In Koivunen, A., Kyrölä, K., & Ryberg, I. (Eds.). *The Power of Vulnerability: Mobilising Affect in Feminist, Queer and Anti-Racist Media Cultures*. Manchester: Manchester University Press, pp. 59–68.

Anonymous. (2016). *Spoken word performance*. International Women's Day 2016, March 8 2016. Hosted by Positively UK at the Royal Central School of Speech & Drama, UK.

Atkin, P. (2022). *A social model of vulnerability. Talk by the author – notes and podcast available on request*. https://le.ac.uk/vulnerability-studies/vulnerability-studies-network/events

Brodie, N. (2020). *Femicide in South Africa*. Cape Town: Kwela Books.

Butler, J. (2009). *Frames of War: When Is Life Grievable?* London: Verso.

Butler, J. (2016). Rethinking Vulnerability and Resistance. In Butler, J., Gambetti, Z., & Sabsay, L. (Eds.). *Vulnerability in Resistance*. Durham: Duke University Press, pp. 12–27.

Carel, H., & Kidd, I. J. (2021). Institutional opacity, epistemic vulnerability, and institutional testimonial justice. *International Journal of Philosophical Studies*, 29(4), 473–496. https://doi.org/10.1080/09672559.2021.1997393

Chatterton, P., & Pickerill, J. (2010). Everyday activism and transitions towards post-capitalist worlds. *Transactions of the institute of British Geographers*, 35(4), 475–490. https://rgs-ibg.onlinelibrary.wiley.com/doi/full/10.1111/j.1475-5661.2010.00396.x

Chigwedere, P., Seage III, G. R., Gruskin, S., Lee, T. H., & Essex, M. (2008). Estimating the lost benefits of antiretroviral drug use in South Africa. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 49(4), 410–415. https://doi.org/10.1097/qai.0b013e31818a6cd5

Chitiga, M., Henseler, M., Mabugu, R. E. *et al.* (2022). How COVID-19 pandemic worsens the economic situation of women in South Africa. *The European Journal of Development Research,* 34, 1627–1644. https://doi.org/10.1057/s41287-021-00441-w

Coetzee, M. H. (2018). Embodied knowledge(s), embodied pedagogies and performance. *South African Theatre Journal*, 31(1), 1–4. https://doi.org/10.1080/10137548.2018.1425527

Dolan, J. (2005). *Utopia in Performance: Finding Hope at the Theater*. Ann Arbor: The University of Michigan Press.
Dyer, C. (2020). Covid-19: Campaigner calls for national guidance to stop DNR orders being made without discussion with patients and families. *BMJ*, 369, m1856. https://doi.org/10.1136/bmj.m1856
Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
Garrett, C. M., & Altman, R. (2024). Vulnerabilized: Revisiting the language of the vulnerable populations framework. *American Journal of Public Health*, *114*(2), 177–179. https://doi.org/10.2105/AJPH.2023.307532
Gqola, P. D. (2015). *RAPE: A South African Nightmare*. Johannesburg: Jacana Media.
Gqola, P. D. (2021a). *Female Fear Factory*. Cape Town: Melinda Ferguson Books.
Gqola, P. D. (2021b). *Miriam Thali: Writing Freedom*. Cape Town: HSRC Press.
Haraway, D. J. (2016). *Staying with the Trouble: Making Kin in the Chthulucene*. Durham and London: Duke University Press.
Hodgson, H. (2021). 'April 10th 2020'. *Where I'd Watch Plastic Trees Not Grow*. Verve Poetry Press.
Hooks, B. (2000). *Feminism is for Everybody: Passionate Politics*. Cambridge, MA: South End Press.
Iacobucci, G. (2020). Covid-19: Government to issue new guidance on DNAR orders after legal challenge. *BMJ,* 370, m2848. https://doi.org/10.1136/bmj.m2848
Ledwith, M. (2020). *Community Development: A Critical and Radical Approach*, 3rd edition. Bristol: Policy Press.
Levinas, E. (2006). *Entre-Nous: Thinking-of-the-Other*. Trans. Michael B. Smith & Barbara Harshav. London: Continuum.
Low, K. (2020). *Applied Theatre and Sexual Health Communication; Apertures of Possibility*. London: Palgrave Macmillan.
Low, K. (2021). The potential of radical kindness as a methodology in applied theatre in arts and health. *Performance Paradigm*, 16, 164–182.
Low, K. (Host). (2023). Histories: Caroline Guinness and Kate Thompson (S2, E1), *Positively Past, Positively Present*. Positively UK. https://open.spotify.com/episode/6IK7qFshtpXlngRzzVzSWK?si=78b20827f6154550
Low, K. (2024). Quiet activism – a space to dare. In Bouchard, G. & Mermikides, A. (Eds.). *The Routledge Companion to Performance and Medicine*. Abingdon: Routledge.
Low, K., Lowry, C., Shaharuddin, M., & Petretti, S. (2025). DEFEND, DEFEND, DEFEND: women's HIV health activism, embodied feminist performance-making and radical kindness. *BMJ Medical Humanities*, 51, 276–285.
Magnet, S., Mason, C. L., & Trevenen, K. (2014). Feminism, pedagogy, and the politics of kindness. *Feminist Teacher*, 25(1), 1–22.
Mayo, S. (2021). "We know . . .": Collective care in participatory arts. *Performance Paradigm*, 16, 184–198.
Moepi, N. (2022). *Interview*. Personal Records.
Outlier Reporter. (2024, February 26). *Women murders in SA: Filling in the details*. Retrieved March 22, 2024, https://www.theoutlier.co.za/crime/2024-02-26/86877/crime-statistics-2024
Pottinger, L. (2016). Planting the seeds of a quiet activism. *Area*, 49(2), 215–222. https://doi.org/10.1111/area.12318
Shafak, E. (2020). *How to Stay Sane in an Age of Division*. London: Profile Books & Wellcome Collection.

Smith-Greenaway, E., & Trinitapoli, J. (2020). *Measuring maternal grief in Africa*. Retrieved July 25, 2023, https://theconversation.com/measuring-maternal-grief-in-africa-134530

Sophia Forum and Terrance Higgins Trust. (2018). *Women and HIV: Invisible No Longer*. https://www.tht.org.uk/sites/default/files/2018-08/women-and-HIV_report_final_amended.pdf

Souza, N. M. F. D. (2019). Introduction: Gender in the global south: Power hierarchies, violence and resistance in the postcolony. *Contexto Internacional*, 41(01), 09–14. https://doi.org/10.1590/S0102-8529.2019410100001

van de Kolk, B. (2015). *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma*. New York: Penguin.

7 Feminist activist strategies for designing sex technologies

Marie Louise Juul Søndergaard

Introduction

There is a booming market for FemTech (female technologies), which is the industry's term for digital technologies that support women's health, specifically menstrual, sexual, and reproductive health (Frost & Sullivan, 2018). While research in women's health is still underfunded and the technology industry slowly catches up on its historical male-dominant culture, FemTech is a promising new arena with the potential to create wider access to health care and empower people with knowledge and body literacy that in turn can equip them to advocate for their health (Wiederhold, 2021). However, with an ambition to normalize typically stigmatized women's health issues, many of these technologies run the risk of instead medicalizing female bodies (Ciolfi Felice, Juul Søndergaard, & Balaam, 2021). As a domain within FemTech, sexual health is a case, where the distinction between what Foucault (1990) terms *scientia sexualis* and *ars erotica* conceptualizes the fine line between a medicalized sexuality and human eroticism, including desires and sexual pleasures. SexTech is the industry's term for technologies designed to innovate and support human sexuality and sexual experiences; and it includes technologies designed to support diagnostics of sexual diseases, as well as to enhance sexual pleasure and educate about sexual health. Digital technologies entering the domain of sexual health is not new, and an increasing amount of research is exploring relations between sexuality and technology in the field of human–computer interaction (Kannabiran, Bardzell, & Bardzell, 2011). The design of sex toys, specifically, is an example of how technologies reconfigure humans' intimate relations and their experiences of sexual pleasure (Bardzell & Bardzell, 2011). With new technologies, such as self-tracking and Internet-of-Things,[1] the design of sex toys goes beyond size, colour, and texture. With sensors and internet-connected apps, sex toys can, for example, track the intensity and length of orgasms or let a partner control a vibrator using a remote control from a distance. The decisions designers and engineers make, when they are developing new kinds of sex technologies, impact how humans quite literally experience pleasure and broader sociotechnical understandings of what pleasure, intimacy, and desire mean. New kinds of sex technologies can open our

DOI: 10.4324/9781003319818-10

imaginations and extend our bodily capacities, but they can also close them down, reproduce existing norms, and narrow what we think is possible.

In this chapter, I present three cases from my own design research practice, where I have explored feminist approaches to the design of sex technologies. The aim of the chapter is to show how a feminist designerly practice can challenge and reimagine understandings and experiences of sexual pleasure. I contribute three feminist activist strategies for designing sex technologies: 1) resist and trouble dominant oppressive discourses in SexTech by critically interrogating norms, 2) destigmatize and open up expressions of desire by holding space for collectives to share experiences through making, and 3) reimagine what pleasure could feel like by speculating and prototyping radically different ways that pleasure could be experienced. By analysing the three cases, I question if and how these strategies can aid in designing sex technologies that critique dominant norms in SexTech, such as patriarchal heteronormative desires and capitalist logics. While critique is integral to this form of feminist activism and while design can exist as a form of critique, the creative practice of design shows that feminist activism through design does not end with critique but that alternatives to dominant sex technologies are possible and that design can show the way. I argue that design practice offers a space of possibilities for reimagining experiences and understandings of sexual pleasure. Technology is a non-innocent actor in this process, yet it is in this meeting – between technology, design, pleasure, and bodies – that we negotiate and open new possibilities for anti-patriarchal and anti-capitalist experiences and expressions of pleasure, intimacy, and desire, which can have liberatory power beyond erotic acts themselves.

Background: sex and technologies

Technological developments have coevolved with human sexual activity, pleasure and desire from its early days. One of the first text-generating algorithms, written in 1952 by Christopher Strachey, was a "Love Letter Generator": an algorithm with the ability to write endless love letters (Gorionova, 2014). A few years later, between 1956 and 1958, an IBM programmer wrote the code for one of the very first graphic images shown on a computer screen: a naked pin-up woman that would appear on the screen to signal that data had been transferred between two computers (Edwards, 2013). Whereas the first example points to technologies as an expression of love, the second highlights how technology development has also been entangled with human desires and sexuality (Cramer & Home, 2007). But perhaps not any kinds of desire. A desire of computer programmers – mainly white men working at academic or military institutions – expressing a patriarchal, heteronormative, and sexist desire objectifying women's bodies. While technologies have been used for sexual content, sexual desires have also been driving forces for the development of new technologies and innovations. We see this up through the second half of the twentieth century, where it has been argued that VHS became

the standard video medium because of its early acceptance of pornographic content and that internet speed has continued to grow because of increasing demands to distribute and watch porn (Barss, 2011). Early 90s virtual reality experiments were imbued with sexual content, sex robots are exhibiting increasingly life-like looks (Levy, 2008), and some of the most recent algorithmic advancements in machine learning, deepfakes,[2] has taken off in the area of revenge porn, creating illegal fake pornographic content. The history of the vibrator also reveals the entanglement of technological developments and gendered human desires (Maines, 2001), although it has now been disproven that a male doctor invented the electric vibrator to treat women's "hysteria." Women's use of vibrators grew in the 70s with the "magic wand" and 80s with "the rabbit," and in the beginning of the twenty-first century, we have seen an expansion in the Western market with sex-positive commercial vibrators, including vibrators connected to the internet (Hua et al., 2022).

As this nowhere exhaustive history of sex and technology shows, normative understandings of sexual activity and pleasure are constantly changing and updating as technology develops (Levy, 2008). In addition, as argued by cultural scholar Luciana Parisi, "transformation of human sex in relation to technology has reopened the question of gender and power in cybernetic capitalism" (Parisi, 2004, p. 2). Feminists have argued that digital technologies have emancipatory potential for women and female bodies, because they separate sexual activity from reproduction. Yet it has also been argued that the mediation of sexual activity through the internet (in cybersex, porn, virtual reality porn) creates an unrealistic portrayal of sex and erases corporeal presence and, in consequence, reinforces a dominance of male pleasure and patriarchal dreams of a disembodied independence from matter (Parisi, 2004). Tracing these politics of sex, gender, desire, and technology is important to better understand sexual politics today and to imagine what feminist futures of sex and pleasure might look and feel like.

In the essay "Uses of the Erotic: The Erotic as Power," Audre Lorde writes about how patriarchal oppression has taught women to suppress their erotic power and even used it against them (Lorde, 1984). As a Black lesbian feminist, Lorde emphasizes how the oppression of the erotic is intersectional, particularly suppressing the erotic power of women of colour and people whose sexuality challenges heteronormative norms. In Lorde's characterization of the erotic as being in touch with what we are feeling, arises a spiritual-political relation that brings capacity for the sharing of joy and of radical change:

> Recognizing the power of the erotic within our lives can give us the energy to pursue genuine change within our world, rather than merely settling for a shift of characters in the same weary drama. For not only do we touch our most profoundly creative source, but we do that which is female and self-affirming in the face of a racist, patriarchal, and anti-erotic society.
>
> (Lorde, 1984, p. 59)

Feminist programmers, designers, and artists have been engaging with desires in technology contexts for well over half a decade. Early cyberfeminism, such as the cyberfeminist media artist collective VNS Matrix, thrived on the liberatory potential of sex and technologies, as expressed in their 1991 manifesto including the line "the clitoris is a direct line to the matrix" (Barratt et al., 1991, p. 1). Referencing computer language, such as zeros and ones, male and female connectors and cyberfeminists have resisted the oppressive forces of male-dominated technologies (Perez, 2019) and advocated for the emancipatory power brought forward with technoscience (Haraway, 1991). A similar emancipatory agenda was seen in the women's health movement, in the US as well as in Scandinavia, where women made their own information material, events and tools for educating themselves about their sexual health (Murphy, 2012). The women's health movement was characterized by strong self-help practices, such as through the handbook "Our Bodies, Ourselves" (Davis, 2020). It also included practices of looking at one's own and each other's intimate anatomy, and it focused closely on women's lived experiences as a way of creating situated, critical knowledge about bodies and health (Davis, 2020; Murphy, 2012).

Contemporary feminist designers and artists, such as GynePunk and Maja Malou Lyse, build on these traditions in their work on 3D-printing speculums and arranging gatherings of women, femmes, queer, and trans folks around topics of sexual health and body politics (Thorburn, 2017). Through sex and body-positive practices, these artists show how technology-mediated practices can be critiqued and reimagined through anti-capitalist and anti-patriarchal radical care. While the recent development of FemTech seeks to bring change to the long tradition of technologies made by men for men, SexTech still operates within patriarchal and capitalist discourses, where sexual liberation is something that is bought through pastel-coloured vibrators, and orgasms are something that can be tracked and "optimized" through data-driven algorithms. This brings a number of sociocultural and ethical implications to the arena of SexTech, including how sex toys in this context tend to reproduce stereotypical gender norms and biases (Hua et al., 2022) and how intimate life becomes managed and controlled within a surveillance capitalism (Gregg, 2011) and comes with risks of data privacy (Hern, 2017). Answering to calls for design to explore how sex technologies can "improve sexual autonomy, sexual self-determination, and sexual independence of women" (Hua et al., 2022, p. 400), I present three cases from my own design practice and propose three feminist activist strategies for designing sex technologies that challenge patriarchal and capitalist discourses of pleasure and desire.

Feminist design as research inquiry

The cases in this chapter use practice-based and arts-based methods to examine implications of sex technologies and reimagine how they could be designed differently. The projects follow a research-through-design methodology, where

design practice contributes to knowledge production (Redström, 2017). Design here exists as a norm-critical and norm-creative approach (Nilsson & Jahnke, 2018), where design is a means to ask questions, explore new opportunities, and evoke new beginnings, rather than a problem-solving approach. Designing can be a way of questioning the status quo and gathering people in creating counter-objects that affirm that other worlds are possible beyond capitalist models of design (Dunne & Raby, 2013). The feminist activist strategies that I present are intersectional, by seeking to nurture joy and desire and bring radical change to bodies whose powers of the erotic have historically been suppressed, including women, non-binary and transgender folks, people of colour, and people with disabilities (Hua, Bardzell, & Bardzell, 2023). Feminist and justice-oriented design practices grapple with such power hierarchies and systems of oppression in serving people who are marginalized, including reflecting on and disentangling the ways that design itself contributes to such marginalization through the systems, buildings, and objects that designers design (Costanza-Chock, 2020). The feminist strategies seek to "stay with the trouble" (Haraway, 2016) of power hierarchies and critically challenge how oppressive systems constitute some bodies' desires as less than others. These strategies are anti-capitalist by seeking to resist the dominant commercial and capitalist goals that design too often serves, in and beyond the domain of sexual health. The strategies invite designers, activists, researchers, and others to use the power of the erotic and the sharing of joy outside of monetary practices, where the production, buying, using, and disposing of objects keep desiring subjects in a capitalist loop, or in Lauren Berlant's term in a state of "cruel optimism" (Berlant, 2011). Instead of designing objects for people to consume, the feminist activist strategies consider designing as a creative world-making practice that invites the power of erotic to cultivate in people themselves in "intra-actions" (Barad, 2007) with technologies, rather than in the objects per se.

Feminist activist strategies of designing SexTech

In the following three sections, I present the three strategies and examples that demonstrate their use, as well as questions that practitioners can consider in their appropriation of the strategies. The *feminist activist strategies* for designing anti-patriarchal and anti-capitalist sex technologies include: 1) trouble dominant SexTech, 2) express a plurality of desires, and 3) reimagine pleasure.

Trouble dominant SexTech

The first strategy advocates for resisting and troubling dominant oppressive discourses of desire by critically interrogating the biases and harm in technologies. This strategy emphasizes that technologies are not neutral tools but that they shape our experiences of sexuality, desire, and the erotic in ways that are potentially reproducing oppressive patriarchal and capitalist logics of desire.

This strategy suggests that we critically and curiously engage with dominant technologies to show how they are wired and how they wire our desire. We could, for instance, critically analyse how SexTech, such as internet-connected vibrators, apps that track sexual activity, or virtual learning platforms, invite certain kinds of bodies into certain kinds of pleasurable acts and, in this way, enact a certain sociotechnical imagination of desire. *We-Vibe Sync* is an internet-connected vibrator that allows a partner to wirelessly control the vibrator with an app on their phone. Advertisement material often portrays heteronormative relations where the man is in control and domination of the woman's stimulation, thus reproducing harmful discourse of women's sexual passivity and innocence in their own pleasure. With the goal of empowering women to take their sexual pleasure into their own hands, *Lioness* is an application that shows videos, illustrations, and education material for how women might explore their sexuality. It uses the screen not to portray hypersexualized, unrealistic acts of sex but to build up pleasure literacy. A newer example is the soft robotic clothing, *Lovewear*, which is a new innovation in soft wearable technology designed for movement-impaired people (Corti, Parati, & Dils, 2023). In contrast to many sex toys that are built on ableist assumptions of being able to hold a sex toy or move easily around, Lovewear is an item of clothing that becomes a co-producer in stimulating sensitive parts of the body, thus adding a second-skin supporting an erotic touch. Finally, *Spreadsheets* was an app launched in 2017 that tracked when and how one is having sex and gave data-driven recommendations and predictions based on one's input on how to "optimize" one's sex life. While some of these examples show technologies' heteronormative and ableist assumptions and logic of optimization and efficiency, they also demonstrate that SexTech could be designed to educate and improve sexual pleasure, tapping into new user-groups and knowledge previously under-supported.

Critical analysis as a form of resisting and troubling dominant oppressive discourses in SexTech can be done by interpreting forms and functions, uses and aesthetics of objects and services. However, this analytical method keeps the object at a distance and contrasts more situated and embodied feminist methods. As an alternative, we can also resist and trouble SexTech by critically interrogating the objects themselves through situated interactions or embodied interventions of use. One such example is the design intervention "Hey Google. What is sexual health?" (Figure 7.1). The 15-minute short film is a compilation of questions and responses from a 1.5-hour tea session with Google Home, where I asked the Google Assistant various questions related to sexual health, such as: what is sex, what is a vagina, how to get an abortion, and how do I masturbate? This video was a critical interrogation and response to the female gendering of voice assistants, which has harmful consequences not only for the cultural values that are reproduced in technology innovations like speech interaction but also, more widely, for the gender divide and inclusivity of girls and women in technology education and profession. The latter can be exemplified through the UNESCO (2019) publication "I'd Blush if

Figure 7.1 Screenshot of video documentation of conversation with Google Home about sexual health information. From "Hey Google. What is sexual health?" (2018). Retrieved from https://vimeo.com/366238012. Video recorded by Marie Louise Juul Søndergaard.

I Could," named after the inappropriate answer from Apple's Siri when receiving sexual insults from users. It has been shown that voice assistants, like Siri and Google Assistant have inadequate and inappropriate advice and responses to basic questions related to sexual health (Wilson et al., 2017). For instance, a study from 2017 found that when asked about trans health, Siri suggested an ambulance service called Health-Trans, and many questions are answered by Siri and Google Assistant with reference to magazines and blogs with varying quality. In the tea session of "Hey Google. What is sexual health?" I challenged myself to openly and provocatively ask Google Assistant questions about sexual health, with the curiosity and criticality toward what kinds of answers and responses it would give me. The conversation itself was fun, but it was also problematic because of sexist answers. For instance, when I asked "what is a vagina?" (02:39), Google Assistant answered:

> The vagina receives the penis during sexual intercourse, and also serves as a conduit for menstrual flow from the uterus. During childbirth the baby passes through the vagina. The hymen is a thin membrane of tissue that surrounds and narrows the vaginal opening.

In just 15 seconds, Google Assistant disclosed its own patriarchal biases by making heterosexual assumptions, reproducing the hymen myth, and connecting vaginas to reproduction rather than pleasure. However, when I later (04:50) asked what sexual pleasure is, the assistant referenced a blog post from

Planned Parenthood stating that "the clitoris is the only human organ whose sole function is sexual pleasure," thus showing that technology can be a way to relevant knowledge of female sexuality. Google Search is the dominant platform to access sexual content and information, and as Google's voice assistant becomes increasingly used, it is relevant to problematize, or trouble, how it frames sexual health and pleasure. Through this curious and troubling conversation, in collaboration with Google Home, I uncovered some of the various and often contradicting sexual politics and biases implicitly coded into Google Assistant, where female sexuality for instance is configured either as reproduction or as pleasure depending on how the question is framed. While a Google Search allows users to choose what sources to access, a voice assistant chooses the source themselves, and can give either useful or inappropriate information, influencing how users understand and practice their sexuality.

This strategy of using design intervention to resist and trouble dominant oppressive discourses in technology can be considered a form of creative non-human ethnography. It is situated, performative, and embodied.

In the video, it was critical to record not only the voice interaction but also the context in which the conversation took place. This context was stylistically staged, as a performative element, that foregrounded the supposedly cozy and intimate setting of a conversation about sexual health. In addition, elements such as candles and incense manifest the time passing, which is in contrast with the fast temporality of technologies, especially voice interactions, where there is no time for pauses and hesitations. Instead, interactions are designed to be faster and more efficient. In opposition to this fast tech paradigm, the combination of tea, candles and incense invites a slowness, sensitivity, and sensibility, where senses are opened and eroticism cultivated. This is a way of resisting the harm present in the conversation with voice assistants about sexual health, and a way of troubling it by building tensions between intimacy and search algorithms and questioning the status quo of contemporary sex education, including the education that Google Search gives us late at night.

To enact the strategy of *resisting and troubling dominant oppressive SexTech discourses*, researchers, designers, activists, and health practitioners might ask themselves:

- *What systems of oppression (e.g. patriarchy, colonialism, heteronormativity, ableism) are reproduced in dominant SexTech?*
- *How can we critically uncover, intervene in, resist, and trouble SexTech's biases and harms?*

Express a plurality of desires

The second strategy actively seeks to destigmatize diverse expressions of desire by holding space for collectives to share experiences and make their own sex technologies. The strategy emphasizes that desire and pleasure are not only personal health concerns but also collective concerns and that the public

collective realm can be a space to challenge normative representations of desire by opening up, sharing, and showing a diversity of expressions of desire. This strategy suggests using critical-making (Ratto, 2011) as an act of materializing diverse expressions of desire, and argues that the creative and designerly process of making a thing or an object is an appropriate activity to engage in and cultivate intimate, sometimes taboo, conversations. We could, for instance, host participatory events or design workshops that invite people into material ways of expressing their desire, which could contribute to destigmatizing sex and pleasure by bringing taboo topics into a collective space and representing the diverse ways sex is expressed and enacted.

Building on the previous strategy, dominant SexTech discourses are often upholding normative sexual ideals, and there is a need to critically interrogate these and destigmatize other ways of expressing desire. Sex-positive festivals often create an open, respectful space where non-normative sexual expressions are celebrated. An abundance of creativity characterizes the sex-positive community, and indeed some people engage in their own ways of making: of objects, furniture, and practices, to stimulate and manifest their desires. As an example of making, the Touchy-Feely Tech project by Alice Stewart is a design kit and workshop subscription that makes it easy for people to shape to their own vibrator and learn the basics of electronics and software. This project has invited people into creative expression of their own desires, making it possible for them to make things that they could not otherwise buy. Artists also manifest diverse desires in various mediums, such as the medium of film. The Romanian 2022 Venice Biennale pavilion "You Are Another Me – A Cathedral of the Body" by Adina Pintili was a multichannel film installation portraying desires and erotic practices of individuals, including portraying a person living with physical disabilities. While much SexTech is not committed to disability, this film showed how creativity is often implicit in critical disability activism where "crip technoscience" is a crucial practice of critique and alternation of material-discursive worlds not committed to disability (Hamraie & Fritsch, 2019), such as the worlds of SexTech.

To form "groups, networks and collectives, to tear down barriers of secrecy and shame around women's bodies and illnesses" (Cleghorn, 2021, p. 370) is a central element in feminist health movements. Activists today can be inspired by the ways feminist health practitioners have joined together to look at and touch themselves, creating a direct embodied knowledge that gave them confidence to resist and demand better care from institutional health systems. Inspired by such collective practices that destigmatize health concerns and advocate for bodily autonomy and bodily difference, this feminist activist strategy focuses on the power of the collective to destigmatize and diversify expressions of desire. An example of this strategy is the design workshop "Make-your-own-vibrator" that I facilitated at a digital culture and arts festival in Berlin, Germany, 2017 (Figure 7.2). In the workshop, I invited participants to make their own sex technologies, following a simple instruction sheet of how to create a sex toy by using materials including mouldable skin-safe plastic

Figure 7.2 Documentation of "Make-your-own-vibrator" workshop, in Berlin, Germany, 2017. A) People gathering out the materials used for making a vibrator: mouldable skin-safe plastic, colour pigment, electronic circuit of a small vibration motor and an on/off switch, and batteries. B) A workshop participant's final vibrator mimicking the shape of a vulva. Photographs by Marie Louise Juul Søndergaard.

pebbles, colour pigment, and simple electronic circuits. Then, 15–20 people joined the workshop (including designers, artists, technologists, and scholars) and gathered around a big table.

The participants at the design workshop were instructed on how to use mouldable plastic to shape a sex toy of their taste. The participants could mix different colours into the plastic and decide where to place the vibration motor and the button to turn the vibrator on or off. Participants used 30 minutes to create their own vibrators. While some participants enjoyed focusing quietly on making their sex toy, other participants were eager to enter into casual conversations about what kinds of sex toy other participants were making, asking questions such as *what colour do you prefer? How intense do you want the vibrator? How do you make the power button accessible from this angle? Are you making it for yourself or a partner?* The participants reacted curiously to the task as hand, and expressed joy of being able to make their own sex toy and encouragement in having a conversation about sexual pleasure in a public museum context. Talking about the design of the sex toy itself, rather than one's own personal, or private, sexual behaviour, allowed for open and generous conversations and cultivated a caring and creative space. The materials made it impossible to make beautiful, crafted sex toys, and they looked nothing like industrially produced sex toys. Instead, the dominant "one-size-fits-all" was exchanged with custom-made objects; each of them representing different preferences, needs, and desires. In addition, the workshop emphasized making one's own sex toy as an anti-capitalist strategy, where participants by making their own sex toys, rather than buying it, understood the electronic components and materials

that the sex toy was made of, and in this way would be able to repair their sex toy or even remake it at a later stage if their desires for another shape would develop, since the plastic could be reheated and remoulded at a later stage.

Lessons from this workshop teach us that there is potential in carving a space for people to express their own sexual needs and desires through physical making, and that a semipublic or collective space in design workshops can hold together heterogeneous desires. The workshop showed that conversations about sexual pleasure might be hard because of societal stigma surrounding the sexuality of disabled people and the LGBTIQA+ community, leading to a silencing and lack of focus on the sexual pleasure of these groups, as well as for heterosexual women. Instead, the workshop proved that the creative process of tangible making can support the expression of sexual pleasure as a plurality of desires. This second strategy proposes using design workshops to destigmatize and diversify expressions of desire by bringing an active participation of diverse bodies and communities. In workshops where people can make their sexual desires tangible, people are invited to curiously get in touch with their own desires and manifest them into physical shape through making. Key questions to ask ourselves in enacting the strategy expressing a diversity of desires are:

- *What diverse expressions of desires need more representation?*
- *How can making and design workshops be used to destigmatize and hold together a space for collective conversations and diverse manifestations of desires?*

Reimagine pleasure

The third strategy prompts researchers, designers, artists, activists, and health care practitioners to imagine feminist futures of pleasure by speculating and prototyping how sex technologies could be designed otherwise. The process of speculating and reimagining moves away from trajectories of "predicting" *the* future or seeing the future of sex and pleasure as a universal or determined point where we will eventually arrive. Instead, speculation is a process of opening up many possible future*s*, in plural, emphasizing that different futures are indeed possible. This strategy emphasizes feminist technoscience commitments of not only performing critique but also bringing attention to articulating alternatives and making other worlds possible (Haraway, 2016). Specifically, this strategy directs action toward actively imagining and designing prototypes of radically different ways that pleasure could be experienced and understood.

Speculative design is an anti-capitalist design approach that challenges the inherent capitalist logics of design and explores how designing can respond to social, cultural, political, and environmental issues by imagining other possible futures (Dunne & Raby, 2013). Drawing on speculative design, this strategy proposes that the imagining and making of anti-capitalist and anti-patriarchal

futures of pleasure can bring awareness, dialogue, and alternative avenues for sex technologies. Examples of speculative design often push boundaries and make us reflect on the ethics and politics of human activities. For instance, the speculative design "Happy Cow" by Ece Tan is a project critically exploring whether cows' artificial insemination and milking process can be made more pleasurable. The designer created tools with the aesthetics of human sex toys to raise awareness of animal rights and critique humans' exploitation of animals in dairy production, as well as questioning pleasure as a uniquely human experience. Another example is artist Arvida Byström's internet and gallery performance "A Doll's House" with a sex doll looking like a copy of herself. In this performance piece, women co-exist with female-presenting sex dolls, but rather than affirming this practice, the performance works as a critique of sex doll developments and their gendering by critiquing the sexualization of women's bodies more generally.

Objects, prototypes, and performances can work as a manifestation of a future of desire and, in this way, help us reflect upon, debate, and navigate toward what kinds of futures we want, and if these futures reproduce current sexist desires, or if they represent anti-patriarchal and anti-capitalist desires. Design can bring physical shape to an imagined future, so we can experience it and have a starting point for dialogue and further action in the present. An example of the strategy of reimagining pleasure is the case "Marcelle." To advocate for sexual rights and bodily autonomy and explore what such feminist concepts might mean within new hyperconnected realities, I imagined and designed a wearable sex toy "Marcelle" (Figure 7.3) (Søndergaard Juul & Hedegård Schiølin, 2017). "Marcelle" is a pair of white underwear with integrated silicone vibrators that react to the surrounding Wi-Fi

Figure 7.3 Image of "Marcelle," a wearable sex toy, made of vibrators sewn into underwear, placed on a white bedsheet (2016). Photograph by Marie Louise Juul Søndergaard.

landscape: the more open Wi-Fi hotspots in the immediate surroundings, the more the vibrators will vibrate. In the underwear is a microcontroller (a small computer) and an embroidered circuit and battery. I programmed the microcontroller to continuously scan for open Wi-Fi hotspots and map the number of hotspots to the intensity of the vibrators. This means that, for instance, in a space with many hotspots, such as a central public space, the vibrators would vibrate a lot, whereas in a rural environment with no Wi-Fi connection, the vibrators would not vibrate. By searching for open Wi-Fi hotspots, the vibrator taps into a technical infrastructure that is invisible in the public space yet critical for human connections and maps it directly onto intimate parts of the body. The vibrators can be placed on four different spots in the underwear to allow the user to decide where they want the stimulation. I chose to use open Wi-Fi hotspots to control the vibrators, because of their importance in public space.

Female sexuality is something often reserved for the private sphere, yet women's bodies are sexualized in the public space through advertisement and sexual harassment. The wearable sex toy "Marcelle" was aimed at supporting women with bodily autonomous feelings of sexual pleasure in the public space. It aimed to, by foregrounding playfulness and unpredictability, show how women could take advantage of existing technology to achieve sexual pleasure. Since the underwear and interactions themselves would be hidden for others, the idea was that this design would sustain feelings of bodily autonomy. This prototype challenges patriarchal oppression of women's sexuality and heteronormative values in stereotypical internet-connected vibrators that delegate control of a woman's vibrator to a male partner, rather than the woman herself. So, instead of letting a partner control the vibrators, or the woman control the vibrators herself in a closed technological ecosystem, the control of the vibrators is distributed to Wi-Fi routers, a non-human agency, to, as stated above, play with uncertainties and the public space. The prototype was tested and exhibited, including at a public library, to initiate conversations about how sex technologies could be designed differently to promote feminist values of consent and bodily autonomy. It does not exist as a consumer product, but as an experimental prototype, useful mainly for bringing the body into speculation and debate of possible futures of pleasure.

The strategy suggests that we use our bodies as sites of speculation and reimaginings of futures of pleasure; that we bring our bodies and our intimate relating to the world first into an imaginary space of "this could be possible," and then back again to present action of "this is how it would look and feel like." By including our bodies in the work of imagination, we ensure that our lived and diverse experiences are acknowledged as valid factors in imagining otherwise. Disembodied future visions have been argued to represent masculinist ideals and not represent the complexities of the everyday and inequalities experienced by marginalized people (Haraway, 1991). By bringing bodies to speculation, we resist the dangers of disembodied future visions in favour

of futures that can be felt and that can touch us today and bring action and change in present realities (Bellacasa, 2017). Design practice works to manifest and make our imaginings more concrete – for instance, through a visual sketch, drawing, model, or prototype – so that our imaginings can be critiqued or affirmed as a future that is desired or not desired. This strategy proposes using design prototypes for embodied speculation and reimagining of futures of pleasure, and it invites us to expand not only what we consider desirable but also what we consider possible. To enact this strategy, we might ask ourselves:

- *What is the dominant future of pleasure, and how can we expand our imagination of other possible futures?*
- *How can reimagining and prototyping possible future SexTech initiate debate and advocate for sexual rights and pleasure today?*

Conclusion

In this chapter, I have shown how feminist norm-critical and norm-creative design can be a world-making practice centring sexual pleasure and desire as powerful catalysers of change. I have proposed three feminist activist strategies for designing sex technologies: troubling dominant SexTech, expressing a plurality of desires, and reimagining pleasure. The three strategies seek to open reflections and possibilities for designing feminist sex technologies; technologies that challenge patriarchal norms and capitalist logics of dominant sex technologies, and instead promote a diversity of desires and reimagining of what sexual pleasure could mean in sociotechnical relations of humans and technology. The strategies promote feminist activist engagements through advocating for embodiment and plurality and through challenging norms and power hierarchies of whose bodies deserve pleasure and have the right to express it. The strategies suggest practical ways forward for engaging with pleasure through designerly practice. The strategies are related to each other and can be enacted in combination. "Marcelle," for instance, works across the first and third strategy, by troubling dominant SexTech discourses of internet-connected vibrators and showing how these could be designed differently. Similarly, "Hey Google. What is sexual health?" uses the first and second strategies to carve a space for expressing diverse desires through conversations within the dominant system of Google Home. Yet the strategies can also be used independently according to the purpose and aim of a given project. The examples and strategies have centred around sex and technologies and argue that new developments of technologies radically reconfigure how humans experience pleasure, and thus sexual pleasure must be understood through its enactments in sociotechnical relations of humans and technology. In conclusion, I invite sexual rights activists, healthcare practitioners, and researchers to see the potential in feminist designerly practices with technology when engaging with the topic of sexual pleasure in feminist health activism and sexual politics.

Notes

1 "Internet-of-Things" are things connected through the internet, allowing users to control and access different objects, such as surveillance cameras, ovens, light bulbs, speakers, and vibrators, from a physical distance through an app on their smartphone.
2 Deepfakes are fake images, videos, or audio that are generated by artificial intelligence, often convincingly replacing one human's face or voice with another's.

Reference list

Barad, K. (2007). *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Second Printing edition. Durham: Duke University Press Books.
Bardzell, J. & Bardzell, S. (2011). Pleasure is your birthright: Digitally enabled designer sex toys as a case of third-wave HCI. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 257–66. CHI '11. New York, NY, USA: ACM. https://doi.org/10.1145/1978942.1978979.
Barratt, V., Pierce, J., da Rimini, F. & Starrs, J. (1991). *VNS Matrix*. https://vnsmatrix.net/about/.
Barss, P. (2011). *The Erotic Engine: How Pornography has Powered Mass Communication, from Gutenberg to Google*. Anchor Canada.
Bellacasa, M. (2017). *Matters of Care: Speculative Ethics in More than Human Worlds*. Minneapolis: University of Minnesota Press.
Berlant, L. (2011). *Cruel Optimism*. Durham: Duke University Press.
Ciolfi Felice, M., Juul Søndergaard, M. L. & Balaam, M. (2021). Resisting the medicalisation of menopause: Reclaiming the body through design. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–16. CHI '21. New York, NY, USA: Association for Computing Machinery. https://doi.org/10.1145/3411764.3445153.
Cleghorn, E. (2021). *Unwell Women: Misdiagnosis and Myth in a Man-Made World*. New York: Dutton.
Corti, E., Parati, I. & Dils, C. (2023). Lovewear: Haptic clothing that allows intimate exploration for movement-impaired people. *Leonardo*, *56*(2), 139–46. https://doi.org/10.1162/leon_a_02340.
Costanza-Chock, S. (2020). *Design Justice: Community-Led Practices to Build the Worlds We Need*. Cambridge, MA: The MIT Press.
Cramer, F. & Home, S. (2007). Pornographic coding. In Jacobs, K., Janssen, M. & Pasquinelli, M. (Eds.). *C'Lick Me: A Netporn Studies Reader*. Amsterdam: Institute of Network Cultures, pp. 159–70.
Davis, K. (2020). *The Making of Our Bodies, Ourselves: How Feminism Travels Across Borders*. Durham: Duke University Press.
Dunne, A. & Raby, F. (2013). *Speculative Everything: Design, Fiction, and Social Dreaming*. Cambridge, Massachusetts, London: MIT Press.
Edwards, B. (January 24, 2013). The never-before-told story of the world's first computer art (It's a sexy dame). *The Atlantic*. Retrieved March 12, 2025, from https://www.theatlantic.com/technology/archive/2013/01/the-never-before-told-story-of-the-worlds-first-computer-art-its-a-sexy-dame/267439/.
Foucault, M. (1990). *The History of Sexuality, Vol. 1: An Introduction*. New York: Vintage.
Frost, A. & Sullivan, R. (2018). *Femtech – Time for a Digital Revolution in the Women's Health Market*. https://ww2.frost.com/frost-perspectives/femtechtime-digital-revolution-womens-health-market/.

Gorionova, O. (2014). *Fun and Software: Exploring Pleasure, Paradox and Pain in Computing*. New York: Bloomsbury Academic.
Gregg, M. (2011). *Work's Intimacy*. Cambridge, UK; Malden, MA: Polity.
Hamraie, A. & Fritsch, K. (2019). Crip technoscience manifesto. *Catalyst: Feminism, Theory, Technoscience*, *5*(1), 1–33. https://doi.org/10.28968/cftt.v5i1.29607.
Haraway, D. (1991). A cyborg manifesto: Science, technology, and socialist-feminism in the late twentieth century. In Haraway, D. (Ed.). *Simians, Cyborgs, and Women*. New York: Routledge, pp. 291–324.
Haraway, D. (2016). *Staying with the Trouble: Making Kin in the Chthulucene*. Durham: Duke University Press Books.
Hern, A. (2017, March 14). Vibrator maker ordered to pay out C$4m for tracking users' sexual activity. *The Guardian*. https://www.theguardian.com/technology/2017/mar/14/we-vibe-vibrator-tracking-users-sexual-habits.
Hua, D. M., Bardzell, J. & Bardzell, S. (2023). Embodied embroidery: Somaesthetic interaction design for women's masturbation. In *Proceedings of the Seventeenth International Conference on Tangible, Embedded, and Embodied Interaction*, 1–15. TEI '23. New York, NY, USA: Association for Computing Machinery. https://doi.org/10.1145/3569009.3572803.
Hua, D. M., Jones, R., Bardzell, J. & Bardzell, S. (2022). The hidden language of vibrators: A politico-ontological reading. In *Designing Interactive Systems Conference*, 400–14. DIS '22. New York, NY, USA: Association for Computing Machinery. https://doi.org/10.1145/3532106.3533448.
Kannabiran, G., Bardzell, J. & Bardzell, S. (2011). How HCI talks about sexuality: Discursive strategies, blind spots, and opportunities for future research. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 695–704. CHI '11. New York, NY, USA: ACM. https://doi.org/10.1145/1978942.1979043.
Levy, D. (2008). *Love and Sex with Robots: The Evolution of Human-Robot Relationships*. New York: Harper Perennial.
Lorde, A. (1984). Uses of the erotic: The erotic as power. In *Sister Outsider: Essays and Speeches by Audre Lorde*. Berkeley: Crossing Press.
Maines, R. P. (2001). *The Technology of Orgasm: Hysteria, the Vibrator, and Women's Sexual Satisfaction*. Baltimore London: Johns Hopkins University Press.
Murphy, M. (2012). *Seizing the Means of Reproduction: Entanglements of Feminism, Health, and Technoscience*. Durham, NC: Duke University Press Books.
Nilsson, Å. & Jahnke, M. (2018). Tactics for norm-creative innovation. *She Ji: The Journal of Design, Economics, and Innovation*, *4*(4), 375–91. https://doi.org/10.1016/j.sheji.2018.11.002.
Parisi, L. (2004). *Abstract Sex: Philosophy, Biotechnology and the Mutations of Desire*. New York: Bloomsbury Academic.
Perez, C. (2019). *Invisible Women: Exposing Data Bias in a World Designed for Men*. London: Chatto & Windus.
Ratto, M. (2011). Critical making: Conceptual and material studies in technology and social life. *The Information Society*, *27*(4), 252–60. https://doi.org/10.1080/01972243.2011.583819.
Redström, J. (2017). *Making Design Theory*. Cambridge, Massachusetts: The MIT Press.
Søndergaard Juul, M. L. & Hedegård Schiølin, K. (2017). Bataille's bicycle: Execution and/as eroticism. In Pritchard, H., Snodgrass, E. & Tyżlik-Carver, M. (Eds.). *Executing Practices*. http://www.data-browser.net/06/.
Thorburn, E. D. (2017). Cyborg witches: Class composition and social reproduction in the GynePunk collective. *Feminist Media Studies*, *17*(2), 153–67. https://doi.org/10.1080/14680777.2016.1218353.

UNESCO. (2019). *I'd Blush If I could: Closing Gender Divides in Digital Skills Through Education*. UNESCO Digital Library. https://unesdoc.unesco.org/ark:/48223/pf0000367416.page=1.

Wiederhold, B. K. (2021). Femtech: Digital help for women's health care across the life span. *Cyberpsychology, Behavior, and Social Networking*, *24*(11), 697–98. https://doi.org/10.1089/cyber.2021.29230.editorial.

Wilson, N., MacDonald, O., Mansoor, D. & Morgan, J. (2017). In bed with Siri and Google Assistant: A comparison of sexual health advice. *BMJ,* 359. https://doi.org/10.1136/bmj.j5635.

Part 4

Feminist scholarship as health activism


Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

8 Feminist prostate care?

Ericka Johnson

Introduction

The prostate is a small, walnut-shaped gland just below the bladder that helps to produce some of the fluids in ejaculate.* It surrounds the urethra, much like a ping-pong ball with a cocktail straw stuck through it, so urine needs to pass through the prostate on its way out. In some older patients, the prostate starts to grow and expand (called benign prostate hyperplasia [BPH]), which can cause problems with urination. It can also be the site of cancer, which looms large in our *zeitgeist*. Treatments for prostate conditions can sometimes lead to incontinence and impotence. The healthy prostate can also be an erogenous zone. However, what could it possibly have to do with feminist activism? And what could feminism possibly have to say about the prostate?

A lot.

The account I present here comes from a nine-person medical humanities project that traced the ways masculinity, sexuality, and aging are engaged by the prostate in different discourses. The seven-year project drew on research from a variety of fields (anthropology, sociology, science and technology studies, history, sexology, gender studies). In our various projects within the prostate study (see Björkman & Persson, 2020; Brüggemann, 2021; Danemalm Jägervall et al., 2019; Gleisner & Johnson, 2023; Johnson, 2021), we looked at heterogeneous aspects, conflicting understandings, and the culturally contextual contours of the prostate, to explore the ways its diverse and multifeatured identity reflects changing cultural and historical aspects of the bodies it is in. However, one thing all nine of us in the project had in common was that we were all inspired at some level by feminist theory and applied it to our work with the prostate. For us, this seemed very natural, but we noticed that for many other people, there was always a moment of confusion when we mentioned this approach. So, in this chapter, I will discuss why the prostate needs feminism and feminist health activism.

DOI: 10.4324/9781003319818-12

What is a feminist approach?

Our understandings of the body – how we imagine various parts of them, what we think those parts do, what problems they are blamed for – are intimately related to the metaphors, tropes, and narratives we tell about them or use to describe or contextualize them. Susan Sontag (1978) taught the medical humanities this early on, of course, but it is also a staple of feminist technoscience studies. Much work on the role of tropes in the production of scientific knowledge has been inspired by early studies that started where Sontag left off, like the empirical analysis of tropes in biology and primatology by Haraway (1997), Martin's (1991) critique of metaphors in fertilization research, and Oudshoorn's (1994) work on the body in reproductive science. More recently, feminist technoscience studies have engaged with new materialities (Thompson, 2005; Barad, 2007; Suchman, 2007) to integrate material aspects of the body and the technologies of knowing it with an analysis of the metaphors and discourses used to describe it.

All of these studies give theoretical tools – and terms – to help show how laypeople and medical professionals describe the body and to show how the words a body is embedded in both reveal and impact on what we think it is, what we think it does, and what we think medicine should do to or about it. Examining discourses is useful as a starting point to think about how understandings of the body are influenced by (and what they reveal about) tropes of gender, sexuality, aging, and health, both in historical material and in current medical texts and practices.

Thus, in our projects, we looked closely at the material-discursivity of scientific practice that makes prostate knowledge possible, and the networks of human and non-human actors which accompany it (cf. Latour, 2000). Through observations from ethnographic research, interviews, analysis of historical material and current medical texts, and in reflections on popular cultural material that engaged the prostate, we saw how one can understand the prostate and its ontological states through intersecting histories and actualities of medicine, the body, and gender. This unshrouded the prostate gland, explaining what it is and what we know about it, but also – more importantly – discussed how the prostate has discursively been connected to aging, masculinity, sexuality, and health, which has consequences for the bodies seeking or offered medical treatment for the prostate. We also looked at how values associated with (healthy, young) masculinity have shaped the physical world that bodies with aging prostates inhabit. This particular work was inspired by feminist norm critical design (Börjesson et al., 2016; Wikberg & Jahnke, 2018), critical aging studies (Marshall & Katz, 2002; Potts et al., 2006), and disability studies (Moser, 2000, 2006). These fields and our approaches were also heavily influenced by the feminist epistemological critique found in research on women's health and its historically porous border to activism (Davis, 2007; Ehrenreich & English, 1973; Epstein, 2007; Murphy, 2012; Tuana, 2006). And, as Almeling points out, the field of men's

health in general and the missing study of men's reproductive health in particular, are in dire need of inspiration from feminist critiques of medicine (Almeling, 2020).

Theoretical terms and discursive methods engaged by feminist work has also helped us articulate aspects of our material that employed cultural assumptions about hegemonic masculinities, heterosexuality, and "typical" male behaviour in explaining the prostate (i.e. Martin, 1991; Marshall, 2006; Tiefer, 2006). By using feminist approaches, we were able to tease out and articulate how culturally specific, cis-normative, and heteronormative concepts of male, man, sexuality, and masculine are engaged and employed in connection with the prostate. This is, of course, not to say that all bodies with a prostate identify with those understandings of male and masculine, even those bodies that are lived as cis-male. However, it did help us call out places (many places) in discussions about the prostate that rely on hegemonic understandings of masculinity to legitimate diagnostic practices and treatment strategies. And I use the phrase "call out" in that sentence intentionally, because "calling out" social power structures and their subtle forms of application is one of the challenges feminist academic work rises to, and is an approach which we all brought with us to our medical humanities work. Attention to power is what a critical stance to the production of knowledge about bodies – even bodies with prostates – needs.

Thus, from the medical humanities, we drew on its critical take on the institution of medicine (Illich, 1975; Sontag, 1978), its various incarnations in different times and places (Johnson et al., 2016; Timmermans & Berg, 2003), and its willingness to engage different fields of science and different ways of doing research through an interdisciplinary approach (Viney et al., 2015; Whitehead & Woods, 2016). From feminism, we gleaned a sensitivity to power, were reminded to look for imploded knots (Haraway, 1997, explained further below), and supported in tracing trajectories and genealogies of knowledge making about the body. Feminist theory helped us engage an understanding of the body as an entangled object of study – entangled with the power dynamics that infuse our worlds, with the values and norms involved in the body's material-discursive production.

What, specifically, can feminism give to a study of the prostate?

Here, I will discuss four domains of knowledge and practice (generatively considered as phenomena, see Barad, 2007) wherein feminist theories can expose the prostate as entangled in hegemonic notions of gender and sexuality. Then, in the discussion, I will think through some specific "lessons learned" about the prostate that would be easily translated into activism, taking a page from feminist health activism over the last decades. I hazard to posit that these insights may have been missed if the research my colleagues and I did had not been using a theoretical lens partly shaped and polished with feminist grit. Specifically, I will discuss what this helped us see in the production of

knowledge about the prostate; in the production of embodied prostate patient subject positions; in the way our material world is not designed to address the needs of prostate patients; and in the way our understanding of a prostate patient would benefit from an intersectional approach.

Knowing a prostate

One way that feminist theory has shaped our research is by showing us the usefulness of closely and meticulously pulling apart what Haraway (1997) calls imploded knots of entangled, culturally contingent values, norms, and expectations that are part of scientific knowledge production. Loosening and tugging at these knots of entangled social elements that become integral parts of scientific facts can articulate how tropes, norms, discourses, paradigms, and structures shape and form the very questions science (and medicine) asks and produce the answers it can recognize. In critical studies of women's health, this has been generative when working with knowledge about the body (Martin, 1991; Murphy, 2012; Oudshoorn, 1994), and particularly poignant when dealing with anatomical structures related to gender, reproduction and sexuality (Almeling, 2020; Jordanova, 1999; Sengoopta, 2006; Thompson, 2005). And, of course, this is applicable when studying the production of knowledge about the prostate.

The prostate exists – it is a thing – but it is also a scientific object of study, an object that medicine explores, produces diagnoses about, and treats. Scientific objects, as Daston points out, have a history. They become entangled in "webs of cultural significance, material practices, and theoretical derivations" (Daston, 2000, p. 13). Thus, the physical object "prostate" and our ways of knowing it, our ways of talking or writing, imaging or imagining it, are messy, tangled nodes of relations. Tracing these relations means following the ways of knowing that make the prostate more salient (Daston, 2000, p. 9) or produce it through material-discursive cuts (Barad, 2007).

Take, for example, the way the (healthy or pathologized) prostate is produced in the use of diagnostic guidelines for BPH (AUA, 2010; Foster et al., 2019). BPH is a condition when the prostate begins to grow again in older men. According to international diagnostic guidelines, determining whether a man has BPH involves a series of tests that measure urination (how much, how frequently, how strongly) and try to measure the prostate, as a gland. One of the first steps in the diagnostic process is a questionnaire that asks about the man's urination (how frequently he must go to the bathroom during the day, how often he must wake up to go during the night, if he can pause mid-stream, for example) and specifically about how bothersome his current urination patterns are. As one current online version asks, "If you were to spend the rest of your life with your urinary condition the way it is now, how would you feel about that?"[1] After this questionnaire, the man is usually then asked to conduct a series of tests which measure urine volume, stream strength, retention, and so forth.

In these diagnostic processes, measurements of urination become indicators of an enlarged prostate, and thereby turn a practice (urinating) into a thing (the gland). Yet embedded in these practices are moments when social elements of life are bracketed into medical knowledge about the prostate – expectations of sleeping through the night, habits like playing 18 holes of golf, driving in slow moving traffic jams or on long road-trips, dreams of white-water rafting; all images or practices referred to in measurements or representations of bothersomeness which are coloured by culture, location, class, race, and so forth (Johnson, 2021; Sarma et al., 2005). By bracketed, following Mol (2002), I mean that the production of an object (e.g. a prostate, BPH, blocked urine) makes invisible the social and technological contingencies that produce that thing in very specific ways. The scientific and the social become blurred, and the diagnostic practices hide that blurring.

However, it is not just the expectations of what a person should be able to do with their body that are bracketed in knowledge about the prostate. Clinical practices of examining the prostate, which include diagnostic tests that analyse urination, also bracket the people, infrastructures, and technologies used to produce them, turning the practices of knowing urination and the prostate into facts, numbers, and estimates about the size of the prostate and the patient's lower urinary tract symptoms.

How can these reflections be a part of untangling the knot of a diseased prostate? Well, they help us to consider the production of knowledge about the prostate in its wider social contexts (and contexts in the plural). Historical examples of prostate treatments from the turn of the last century reveal a time when the prostate and its health could be a stand-in for talking about appropriate sexuality, masculinity, and vigour (Björkman & Persson, 2020; O'Shea, 2012). At the end of the 1800s, a man's identity could also be used to discuss and diagnose his prostate, just as his prostate could say something about the man. There may be a tendency to think that medical diagnostic practices are not similarly imbued with overtones of cultural identity today, but questions from the diagnostic guidelines for BPH would suggest otherwise. Background questions about the patient's health are meant to give an idea about who that man is and what he has been through before. The "bothersome" questionnaire draws heavily on preconceived ideas about what a man's body should be able to do in various social situations. Likewise, a treatment's success is gauged by, among other things, a patient's ability to resume "normal," daily life.

This is not necessarily a bad thing. Asking medicine to consider and respect the individual and their social contexts in diagnostic practices is something patient activism has long agitated for – to encourage the allegedly emotionless, neutral, objective eye of medicine to see and recognize the patient as a person rather than an assemblage of flesh and bones (e.g. Balint, 1957; Berg & Mol, 1998; Epstein, 1996; Hoffman et al., 2011). This way of seeing the body, it could be asserted, would produce knowledge about the prostate-in-the-person (cf. Martin, 1987) rather than the prostate by itself. How this is done – the details of practice, including the negotiated and taken-for-granted power

assumptions and cultural norms bracketed by them – is important for what worlds are enacted and how individuals (and their bodies, organs, and diseases) are allowed to live, are treated, are defined as healthy or sick, given hope or termed chronically ill. As these practices are multiplied, reproduced, spread (e.g. through internationally accepted questionnaires, "best practices" policy documents, and clinical guidelines), these ways of bringing into existence people and patients, age, urination practices, and prostates create spaces and definitions within which both "healthy" and "sick" people may be categorized. There is a great deal of structural and cultural biopower at play here, and a great deal at stake for those people who are about to be categorized as healthy or diseased. Feminist work helps us to see that power and discuss those stakes, especially when related to the body.

**That* exam*

A second place in our study which feminist theory and previous feminist research gave us tools to guide our analysis was in thinking through how the digital rectal exam (DRE), that infamous prostate exam that has the doctor's finger inserted in the anal cavity to examine the prostate, and which features in numerous Hollywood comedies and off-colour jokes, is conducted in a way which clearly produces an embodied patient subjectivity engaging a particular notion of masculinity for the patient.

The DRE is used to determine the size, consistency, shape, and presence or absence of nodules suggesting cancer (AUA, 2010). Before the PSA test (a blood test that measures prostate-specific antigen in the blood) was well-established as an indicator of prostate cancer, the DRE was the primary method of finding prostate cancer, and it is still useful for discovering tumours that are large enough to be palpable. It allows the doctor to feel if the prostate is abnormally shaped or bumpy, indicating possible cancerous growth (SBU, 2011), and it is used by both general practitioners and urologists. It is a quick exam, often over in less than a minute, but many men dread and avoid it, possibly because of cultural associations of anal penetration with homosexuality (Winterich et al., 2009) (which is probably also why it is the topic of all those jokes and Hollywood comedies). It can also, on occasion, hurt. Many men find it unpleasant.

Jenny Gleisner, a medical anthropologist, has studied the way intimate examinations are taught to medical students in Sweden (Gleisner & Siwe, 2020), which resonates with similar studies in the USA (see also Underman, 2020). While her focus has been on gynaecological examinations in the context of our research project, she observed how the rectal examination was taught to medical students, and compared this with how the bimanual pelvic examination (an equally invasive and potentially uncomfortable gynaecological process) was taught (Gleisner & Siwe, 2020). The differences were striking. While the gynaecological examination was embedded in lectures and course literature about care for the patient's discretion, respect for, and wonder at

their reproductive anatomy, and concern over any potential emotional history of abuse or fear the patient might be carrying with them into this intimate and invasive examination, the prostate examination was taught and conducted as a straightforward, disease-focused process which the patient (and, to a large extent, the medical student) was expected to perform in a perfunctory way, with little regard for how patient or doctor was experiencing the examination and even less respect for, or wonder and amazement at, the anatomy and what it can do (Gleisner, 2018). And in fact, just writing that sentence sounds odd – wonder and amazement at the prostate and the anal canal are hardly what one expects to find in general but specifically not in a medical examination. Nor does one think of patients undergoing a DRE as a group that would demand gentle, more respectful care. Or necessarily be carrying with them emotional baggage from past sexual traumas. But why do we not imagine them that way? This group often consists of older men, and is generally perceived as the standard, normal, patients for whom medical care is designed. We expect them to be stoic, to take their examinations, diagnoses and treatments in a matter-of-fact way, like a man (Dowsett, 2018). We do not expect them to agitate for better, kinder care the way women's health collectives and activist groups have organized (see Kedrowski et al., 2007; Murphy, 2012). We imagine urology patients and gynaecology patients very differently, and those imaginaries contribute to the types of care practices they encounter in the clinic: care practices which bracket our presumptions about what a male patient is and what that masculinity needs, wants, or can put up with. This impacts patient care and the doctor/patient relationship significantly. Where there has been patient organizing around prostate cancer care such as The Movember movement[2] and Active Surveillance Patients International,[3] there seems to be less activism focused on how the prostate patient would like to be met and cared for, emotionally. We probably have stereotypes about hegemonic masculinity to "thank" for this.

Our imaginaries may not be serving us well, though. When I was talking with an American urologist about how he learned his rectal examination techniques in medical school, he said that it was not until much later, after years of examining patients, that he had gradually changed his examination techniques and demeanour. He started to taking time to first listen to and engage with the barrage of jokes he had heard a hundred times before, then encourage the patient to relax, finding ways to reduce the tension in the room and respect the vulnerability the patient might be feeling. These shifts in practice made the examination easier, and probably better.

The jokes this urologist hears from his patients, the ones I heard during interviews with men, and the prevalence of the gloved and lubricated finger as a staple of slap-stick comedies and stand-up routines about getting older, can all be read to indicate the physical, but also the social, discomfort associated with the rectal examination. If we read humour as a coping mechanism, obviously the rectal examination is having an impact on patients and looms large as an unwelcome part of men's healthcare – for young and old alike. The jokes

may be a way of making light of a situation many patients find unpleasant and scary, in contexts where humour is exposing a tension that medical care practices could address. And perhaps this tension is related to a vulnerability not always associated with a hegemonic imaginary of masculinity. What if we were to open up the medical encounter to vulnerability? What if we began to envision a urological care environment that does not expect stoic masculinity but allows for patients with baggage, with fear, with vulnerability? What type of medical education would we need to produce doctors comfortable with dealing with that vulnerability from the very beginnings of their careers? Questions like these have been at the forefront of feminist activism and academic critiques of medical training and women's healthcare for decades (see Murphy, 2012; Tuana, 2006). They are, I would argue, equally applicable to care that addresses bodies with prostates. And a feminist lens has helped us see the need to think about the way prostate patients are imagined/understood/produced in the clinical encounter in our research.

A world designed for men?

When I started this project, I was heavily pregnant and then, a bit in, gave birth – with all the embodied awareness of bladders and bathroom-needs the state of carrying and delivering a child produces. Then, for several years, I had a child with me, one who needed diapers changed or, after a couple of years, needed to find a clean toilet herself – often with minimal time margins. During those years, my need for public toilet access was pretty demanding, and I often found myself cursing the urban designers who had not provided me with an infrastructure that met my needs (and echoing the agenda that activism around public toilets from within disability and feminist movements has been pushing for decades, see Greed, 1995; Penner, 2014). In my frustration, I assumed that the public toilet infrastructure had been designed for men, and that was why it did not fit my needs in these cases. What did not occur to me was to ask *which* men – or better yet, which *bodies* – it had been designed for. That would have been a more generative question (see Rommes, 2014).

However, during the course of my interviews with prostate treatment survivors, I found that many of the men I spoke with talked about how their prostate problems had changed their way of being in the public sphere – because of the public toilet infrastructure. Prostate issues affect behaviour like going to movies, taking long car trips, and outdoor sports (Sarma et al., 2005). That the body makes itself known through our ways of being in the world is a standard assertion in medical humanities studies, especially the way the body makes itself loudly, painfully, and incessantly known when it is diseased, while the healthy body is a silent body (Leder, 1990; Zeiler & Käll, 2020). Incontinence is a prime example. It makes the body known. Surgical procedures have been developed to treat it, and an industry producing incontinence pads exists to provide for it. Many men, after a prostate treatment, first find they need large pads – and pejoratively take to calling them diapers – but with time, most men

can begin to use smaller incontinence pads. Commercial market forces have responded to this need, producing pads in dark, masculine packaging to differentiate them from feminine products. There *are* individual-based solutions and work-around to urinary incontinence, but it still impacts on a man's life, often seriously.

However, one surprising thing that emerged from my interviews was the awareness of how a post-prostatectomy man's body was *suddenly* not a good fit for the public toilet infrastructure of the built environment *anymore* and how this change was something they talked about. They spoke of a changed awareness of an infrastructure that had previously been well suited to their needs. That the public toilets no longer were caught many of the men I met off-guard. I found myself being told about how they *suddenly* realized they knew where the most convenient public toilets were, or which bus rides would be OK and which would be too long, given their leakage or their voiding urgency issues. It was as if their bodies were no longer the imagined standard body for which the public toilet infrastructure was made. And, actually, their bodies *were* no longer the imagined standard body for which the public toilet infrastructure was made. That sudden awareness made what had previously been a transparent infrastructure painfully visible (cf. Johnson, 2020).

Prostate patients are affected by their interactions with the physical world we live in. For example, most of us live in a built environment that discourages frequent urination in a public space. However, it does not have to be that way. One can ask what a public space that allowed for frequent urination would look like. What different facilities would need to be provided? How many more? Where? Our public bathroom infrastructure has changed as a response to social activism in the past, reflecting the entrance of women into the workplace in larger numbers, the civil rights movement, demands for wheelchair-accessible facilities, and trans and non-binary people's needs (Cavanagh, 2010; Cooper & Oldenziel, 1999; Gershenson & Penner, 2009; Greed, 1995). What would a public toilet infrastructure that fits the needs of older men with prostate issues look like? I imagine that all public toilets would have receptacles for the disposal of incontinence pads, for one thing. And that they would be more available to those on the move. One can also ask what sort of home environment could be designed to address frequent nocturnal urination? What personal artefacts or interior design changes would facilitate this (cf. Galis, 2019; Moser, 2009; Schillmeier, 2010)? There are often underlying medical conditions affecting changed urination, and these, of course, should be addressed with medical treatments. But those treatments do not have to work in a vacuum. A better designed world could help address them, too, which is one of the lessons learned from feminist and other activist movements about the provision of public services. An awareness of how power dynamics in our physical world can be challenged is found in the academic work and activism espoused by norm critical, norm creative and universal design (fields of design studies which actively articulate and manipulate the social norms, assumptions, prescriptions and imperatives which are built into our material

world, see Hamraie (2017) on universal design and Costanza-Chock (2020) on design justice). The activism materialized by these design movements for public spaces is potentially very useful to men with prostate issues, as well.

An intersectional approach to men's prostate health

Noting that the public toilet infrastructure was not serving the needs of prostate treatment survivors also pointed out that the category "men" is too large to be analytically useful. It needs to be nuanced with an intersectional approach (Crenshaw, 1989; Cho et al., 2013, and nuanced in Monk, 2022), just as feminism and feminist research has embraced the concept of intersectionality to address the complexity of power dynamics and diversity of identities within the category "women." This, then, is the final lesson from feminist theory that we were able to draw in our prostate research.

In our various studies, we encountered many different cultural understandings of masculinity in modern prostate discourses, understandings that associated healthy male bodies with physically demanding sports, outdoor activities like golf, and road trips, all of which appeared frequently in pharmaceutical advertisements for prostate medications (Johnson et al., 2016, Johnson, 2021). These examples show modern discussions of the prostate that associate the (healthy) prostate with productive masculinity in the workplace (being able to sit for long periods versus having a stand-up desk, being able to attend long meetings, using the bathroom quickly enough), and associated with subjectivity which participates in masculine leisure activities like motorcycle-riding without long underwear or fly-fishing in cold water (at least in the Nordic context – and context is key, another lesson from feminist theory). But, while these imagined types of masculinity did show some variety, they were, nonetheless, fairly homogenous. They were largely based on middle-class, white, North American, and Northern European norms of masculinity. And many of the norms of masculinity also appeared in discussions related to sexuality.

Arguably, when we started this work, we were already keenly aware of the presumed heterosexuality in many of the conversations about prostate cancer, in discourse around it, and research about it (cf. Bergman & Litwin, 2018). Presumed heterosexuality can make prostate cancer rehabilitation even more painful for some men, who may not identify as heterosexual and therewith feel marginalized by the way they are met in the clinical setting and by the heteronormative assumptions in the majority of information available to cancer patients (Doran et al., 2018; Ussher et al., 2018). When one is confronted with even just the possibility of cancer, one is already in a vulnerable position, and may not have the strength or desire to also educate one's doctor or clinic that the presumptions of heterosexuality and a female partner are wrong. One may not feel like disclosing – and one is probably not even going to be asked about – one's sexuality or partners (Ussher et al., 2018).

Additionally, and to make the conversation more complex, all men's sexual practices are varied, and do not directly overlap with identity categories like

hetero, gay, and bi. Depending on what sexual practices he engages in, the side effects of various prostate treatments will be experienced differently for different men. For example, erectile dysfunction is the stereotypical "problem" associated with prostate treatments, and losing the ability to produce an erection can be very difficult for many men to deal with. But there are other side effects, too. Urine may leak out during sex. Some men will experience pain during sex – at orgasm, for example – or maybe the experience of prostate or anal stimulation will be affected – either lessened or perhaps even painful, at least initially. After some treatments, desire will decrease, especially in cases where hormone therapies are involved. And sometimes sexual satisfaction will decrease. Some men will no longer ejaculate at orgasm, and for some men, ejaculation has been an important part of their sexual practice. Some studies indicate that the loss of ejaculate (dry ejaculations) bothers heterosexual men less than gay and bisexual men (Danemalm-Jägervall et al., 2019; Rosser et al., 2018), but we suggest that those identity-based categories are not necessarily mapping onto the way practices are engaged for many men, an additional reason to think through how categories are used in treatment guidelines and practices. There is a plethora of side effects to consider, yet in many cultural imaginaries of prostate treatment side effects, it is erectile dysfunction that looms large, reinforcing the hegemonic imperative of penetrative sex. Attached to this fear, seemingly almost inevitably, are often found both heteronormative presumptions about and emotional associations with failed masculinity (see also Steinberg, 2015).

All of which should be addressed. And all of which make completely invisible women with prostates and prostate cancers. The cis-normativity of the discussions tends to mask the fact that trans women and some non-binary people also have prostates and will potentially need prostate care that can address their needs, outside of the cis- and heteronormative framework currently shaping our care discussions.

The sexologist who worked with our team, Carina Danemalm-Jägervall, has done a little bit of work in this direction, as well as written about the complexity of providing rehabilitation for people who have undergone prostate cancer treatments (Danemalm Jägervall et al., 2019). But there is more to do. Danemalm-Jägervall is employed at a urology clinic in southern Sweden, and her work is largely made up of consultations with men prior to and after prostate treatments, helping them to find sexual practices that work for their bodies as they now are. This is not a straightforward task, and what solutions work vary from patient to patient. Much of the complexity stems, of course, from the fact that different types of treatment will produce different side effects, so depending on if a person has had radiation treatment, hormone therapy, or a surgical procedure, the body will react and recover differently. But a lot of the complexity also stems from the fact that sexuality and how it is performed is very different from person to person. Even if one is asking only about a particular aspect of sexual practice – for instance, the ability to achieve a sufficiently hard erection – there are variations to consider: How is that erection

going to be used? Does it need to be hard enough for anal penetration? Or just for a hand job? Or a blow job? Or to penetrate a vagina? And erections are only a part of many people's sexual repertoire. Opening up for other aspects of arousal, intimacy, orgasm, and so forth, or for the prostate to be an erotic zone in and of itself (Danemalm Jägervall et al., 2019; Dowsett, 2018), in the clinical conversation can be generative, but it takes more time, and any problem will not necessarily be "solved" by the pharmaceuticals (delivered by pills, sticks, and injections) usually prescribed for impotence.

A more open and flexible approach to posttreatment therapy requires a clinical encounter that conceives of sexual function as a way of relating to and being with other bodies: of *doing* sex with other people. And, even within a cis-normative framework, of thinking of masculinities in the plural, as aspects of identity produced through intersectional relations with other people and a plethora of contingent norms and power structures. This intersectional approach would see not only the diversity of the category "prostate patient" but also the category "man," pointing to the diversity of the way "man" is done in sex as a relational practice.

So yes, a feminist approach to prostate health

Feminist work in the social sciences and humanities on women's and reproductive health has shown how the uterus, pregnancy, and menopause have been medicalized and simultaneously therewith used to pathologize female bodies, turning them (and in particular sex, reproduction, and aging) into sites for medical control and profit. Much of the analytical work done in our project on the prostate was informed by that body of feminist theory; in particular, studies of women's health issues and the relationship between medical research and health activism.

Lessons can be drawn from this literature on how knowledge has been transformed into campaigns that demand better medical care aimed at women's health and well-being and *vice versa* (see Murphy, 2012). These campaigns, and the changes to healthcare provision they have instigated during the last 50 years, are benefiting women around the world. To a degree, these moves are currently being engaged by campaigns to improve medical care for transgender people (see Nicholls et al., 2023). And, I would argue, activists for prostate care are also learning from them, even if there is much work still to be done. The Movember movement, for example, and other prostate cancer survivor groups have already copied some of the strategies for organizing, funding and public information campaigns from breast cancer survivor mobilization.

However, I think there are other, concrete, lessons that can be shared across the divide between women's and men's health to support and improve prostate care. This has become apparent to me as, after the publication of *A Cultural Biography of the Prostate* (2021), I began speaking about the book and our group's research at various prostate health gatherings. At times, I was even

asked to speak specifically about the lessons prostate care activism could gather from feminist health care activism.[4] At these engagements, I often tried to translate the theoretical insights feminism gave us (as discussed above) into what this could mean for prostate patients or others concerned about changing and improving care.

For example, one of the lessons may be drawn from what is academically called the "epistemological critique": the demand that medicine take into consideration the way a person knows their own body (a patient's lived experience) and engage patient/person-generated knowledge about health, and about what it means to be healthy to that individual. In this research, one can find acknowledgment that medical knowledge about our bodies and pathologies is coloured by understandings and expectations of socially appropriate behaviour, especially when sex and reproduction are involved, and that these are highly gendered understandings of appropriate behaviour – historically and today. Pointing out the parallels between discussions of women's bodies and discussions about the prostate reminds us that knowledge can be contested from both within and outside of medicine. It recognizes that what the prostate "is" can be very complicated because in different discourses it "is" a messy entanglement of not only glands, muscles, hormones, disease, and health but also sexuality, sexual practices, understandings of masculinity, sporting activities, cultural events, and social expectations. To translate that into an activist campaign, the epistemological critique means recognizing that the patients who are being treated for prostate issues are people with very personal ways of being in and living through their bodies. It reminds us that those people should be asked about how they have used their bodies before treatment, and their desires to use their bodies in similar ways after treatment should be acknowledged and supported. It would mean demanding that medical care consider, inform about, and evaluate the side effects of treatment, not just the attempt to "cure" or "eliminate" a pathology.

This also means acknowledging that medical practices and treatments of our body can affect our physical and emotional well-being (positively and negatively), including our relationships with others and our ways of being in the world. And it means demanding that patients are involved in making truly informed decisions about their health.

Another point that our academic discussions can help articulate in activist terms is the way our built environment impacts us in different ways. Here, I draw on the discussions about norms and design to help prostate patients ask questions about where and how often toilets are available, for example, or how information about them is distributed, or which facilities have receptacles for the disposal of used incontinence pads. These design conversations can be moved outside the academy and into interactions with the city planners who build our public spaces, imagine building codes, or design our transportation infrastructures.

A similar conversation could be held with those who educate, institutionalize, and administrate the healthcare systems we live within. This system is, in

most countries, currently based on a binary understanding of gender, with specialist care provided by urologists or gynaecologists. That binary divide has consequences for bodies with prostates, shuffling them into urology care and a medical specialty that has a particular history of dealing with men, masculinity, sex, and the prostate in very particular ways. But it could be otherwise.

Finally, the last lesson I think can be valuably translated from academic theories to prostate activism is that bodies with prostates are not all the same. "Man" is not a natural, stable, homogeneous category, even for cis-men. Prostate health could benefit from decentring gender and taking an intersectional approach (cf. Hankivsky, 2012). To complicate things even more, people with prostate issues are relational beings, becoming who they are in their interactions with others, be those colleagues, family, friends, and lovers. Their identities are intimately entangled with those relations. Inevitably, the prostate also becomes enrolled in this entanglement of relations. Its health is intimately associated with the health of the person, social connections, and the worlds inhabited. Had I written that about an aspect of a woman's reproductive system, it would hardly seem controversial, given the last 50 years of women's health research and activism into which the statement would be embedded. Our research suggests it is time to turn the wisdom of these conversations to bodies with prostates, as well. Feminist theory is a good tool to help us do so.

Notes

* Parts of this chapter have been extracted from *A Cultural Biography of the Prostate* (MIT Press, 2021).

1 https://www.urolift.com/patients/bph-symptom-score Accessed 26 September 2022.

2 https://se.movember.com Accessed 26 September 2022.

3 https://aspatients.org Accessed 26 September 2022.

4 See, for example, a talk I gave to Active Surveillance Patients International, https://aspatients.org/meeting/the-secret-life-of-the-prostate-the-good-the-bad-and-the-ugly/Accessed 26 September, 2022.

Reference list

Almeling, R. (2020). *Guynecology: The Missing Science of Men's Reproductive Health.* Berkely: University of California Press.

American Urological Association. (2010). *American Urological Association Guideline: Management of benign prostatic hyperplasia (BPH)* (Revised). Linthicum, MD: American Urological Association.

Balint, M. (1957). *The Doctor, his Patient and the Illness.* London: Pitman.

Barad, K. (2007). *Meeting the Universe Halfway.* Durham: Duke University Press.

Berg, M., & Mol, A. (Eds.). (1998). *Differences in Medicine: Unraveling Practices, Techniques, and Bodies.* Durham: Duke University Press.

Bergman, J., & Litwin, M. (2018). Foreword. In Ussher, J. M., Perz, J. M., & Rosser, B. R. S. (Eds.), *Gay and Bisexual Men Living with Prostate Cancer from Diagnosis to Recovery* (pp. ix–x). New York: Harrington Park Press.

Björkman, M., & Persson, A. (2020). What's in a gland? Sexuality, reproduction and the prostate in early twentieth-century medicine. *Gender & History*, *32*(3), 621–636.

Börjesson, E., Isaksson, A., Ilstedt, S., & Ehrnberger, K. (2016). Visualizing gender–norm-critical design and innovation. In Hytti, U., Alsos, G., & Ljunggren, E. (Eds.),

Research Handbook on Gender and Innovation (pp. 252–273). Cheltenham, UK: Edward Elgar Publishing.
Brüggemann, J. (2021). Redefining masculinity– Men's repair work in the aftermath of prostate cancer treatment. *Health Sociology Review*, *30*(2), 143–156.
Cavanagh, S. (2010). *Queering Bathrooms: Gender, Sexuality and the Hygienic Imagination*. Toronto: University of Toronto Press.
Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and Society*, *38*(4), 785–810.
Cooper, P. A., & Oldenziel, R. (1999). Cherished classifications: Bathrooms and the construction of gender/race on the Pennsylvania railroad during World War II. *Feminist Studies*, *25*(1), 7–41.
Costanza-Chock, S. (2020). *Design Justice*. Boston: MIT Press.
Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, *1989*(1), 139–167.
Danemalm Jägervall, C., Brüggemann, J., & Johnson, E. (2019). Gay men's experiences of sexual changes after prostate cancer treatment – a qualitative study in Sweden. *Scandinavian Journal of Urology*, *53*(1), 40–44.
Daston, L. (2000). *Biographies of Scientific Objects*. Chicago: University of Chicago Press.
Davis, K. (2007). *The Making of Our Bodies, Ourselves: How Feminism Travels Across Borders*. Durham: Duke University Press.
Doran, D., Williamson, S., Margaret Wright, K., & Beaver, K. (2018). "It's not just about prostate cancer, it's about being a gay man": A qualitative study of gay men's experiences of healthcare provision in the UK. *European Journal of Cancer Care*, *27*(6), e12923.
Dowsett, G. (2018). 'Losing my chestnut': One gay man's wrangle with prostate cancer – ten years on. In Ussher, J. M., Perz, J. M., & Rosser, B. R. S. (Eds.), *Gay and Bisexual Men Living with Prostate Cancer from Diagnosis to Recovery* (pp. 258–270). New York: Harrington Park Press.
Ehrenreich, B., & English, D. (1973). *Witches, Midwives and Nurses: A History of Women Healers*. New York: Feminist Press at the City University of New York.
Epstein, S. (1996). *Impure Science*. Berkeley: University of California Press.
Epstein, S. (2007). *Inclusion: The Politics of Difference in Medical Research*. Chicago: University of Chicago Press.
Foster, H., Barry, M., Dahm, P., Gandhi, M., Kaplan, S., Kohler, T., Lerner, L., Lightner, D., Kellogg Parsons, J., Roehrborn, C., Welliver, C., Wilt, T., & McVary, K. (2019). Surgical management of lower urinary tract symptoms attributed to benign prostatic hyperplasia. AUA guideline amendment 2019. *Journal of Urology*, *202*(3), 592–598.
Galis, V. (2019). We have never been able-bodied: Thoughts on dis/ability and subjectivity from Science and Technology Studies. In Watson, N., Roulstone, A., & Thomas, C. (Eds.), *Routledge Handbook of Disability Studies* (pp. 404–418). London: Routledge.
Gershenson, O., & Penner, B. (2009). *Ladies and Gents: Public Toilets and Gender*. Philadelphia: Temple University Press.
Gleisner, J. (2018). Prostataundersökningen och den (o)känslige mannen. In Björkman, M. (Ed.), *Prostatan – det ständiga gisslet?* Lund: Nordic Academic Press.
Gleisner, J., & Johnson, E. (2023). Caring for affective subjects produced in intimate healthcare examinations. *Health*, *27*(3), 303–322.
Gleisner, J., & Siwe, K. (2020). Differences in teaching female and male intimate exams. A qualitative study. *Medical Education*, *54*(4), 348–355.
Greed, C. (1995). Public toilet provision for women in Britain. An investigation of discrimination against urination. *Women's Studies International Forum*, *18*(5/6), 573–584.

Hamraie, A. (2017). *Building Access: Universal Design and the Politics of Disability*. Minneapolis: University of Minnesota Press.
Hankivsky, O. (2012). Women's health, men's health, and gender and health: Implications of intersectionality. *Social Science and Medicine*, *74*(11), 1712–1720.
Haraway, D. J. (1997). *Modest_Witness@Second_Millennium. FemaleMan©_Meets_OncoMouse™: Feminism and Technoscience*. New York: Routledge.
Hoffman, B., Tomes, N., Grob, R., & Schlesinger, M. (Eds.). (2011). *Patients as Policy Actors: A Century of Changing Markets and Missions*. Rutgers University Press.
Illich, I. (1975). *Limits to Medicine: Medical Nemesis – The Expropriation of Health*. Marion Boyars.
Johnson, E. (2020). *Refracting through Technologies*. London: Routledge.
Johnson, E. (2021). *A Cultural Biography of the Prostate*. Boston: MIT Press.
Johnson, E., Sjögren, E., & Åsberg, C. (2016). *Glocal Pharma: International Brands and the Imagination of Local Masculinity*. Taylor & Francis.
Jordanova, L. (1999). *Nature Displayed: Gender, Science and Medicine 1760–1820*. London: Longman.
Kedrowski, K. M., Sarow, M. S., & Sarow, M. S. (2007). *Cancer Activism: Gender, Media, and Public Policy*. University of Illinois Press.
Latour, B. (2000). On the partial existence of existing and non-existing objects. In L. Daston (Ed.), *Biographies of Scientific Objects* (pp. 247–269). University of Chicago Press.
Leder, D. (1990). *The Absent Body*. Chicago: University of Chicago Press.
Martin, E. (1987). *The Woman in the Body*. Boston: Beacon Press.
Martin, E. (1991). The egg and the sperm: How science has constructed a romance based on stereotypical male-female roles. *Signs*, *16*(3), 485–501.
Marshall, B. (2006). The new virility: Viagra, male aging and sexual function. *Sexualities*, *9*(3), 345–362.
Marshall, B., & Katz, S. (2002). "Forever functional": Sexual fitness and the aging male body. *Body & Society*, *8*(4), 3–70.
Mol, A. M. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham: Duke University Press.
Monk, E. P. (2022). Inequality without groups: Contemporary theories of categories, intersectional typicality, and the disaggregation of difference. *Sociological Theory*, *40*(1), 3–27.
Moser, I. (2000). Against normalisation: Subverting norms of ability and disability. *Science as Culture*, *9*(2), 201–240.
Moser, I. (2006). Disability and the promises of technology: Technology, subjectivity and embodiment within an order of the normal. *Information, Communication & Society*, *9*(3), 373–395.
Moser, I. (2009). A body that matters? The role of embodiment in the recomposition of life after a road traffic accident. *Scandinavian Journal of Disability Research*, *11*(2), 83–99.
Murphy, M. (2012). *Seizing the Means of Reproduction: Entanglements of Feminism, Health and Technoscience*. Durham, NC: Duke University Press.
Nicholls, E. J., McGowan, C. R., Miles, S., Baxter, L., Dix, L., Rowlands, S., McCartney, D., & Marston, C. (2023). Provision of cervical screening for transmasculine patients: A review of clinical and programmatic guidelines. *BMJ Sexual & Reproductive Health*, *49*(2), 118–128.
O'Shea, C. D. (2012). "A plea for the prostate": Doctors, prostate dysfunction, and male sexuality in late 19th- and early 20th-century Canada. *Canadian Bulletin of Medical History*, *29*(1), 7–27.
Oudshoorn, N. (1994). *Beyond the Natural Body*. London: Routledge.
Penner, B. (2014). *Bathroom*. London: Reaktion Books, Objekt Series.

Potts, A., Grace, V., Vares, T., & Gavey, N. (2006). "Sex for life"? Men's counter-stories on "erectile dysfunction," male sexuality, and ageing. *Sociology of Health & Illness*, *28*(3), 306–329.

Rommes, E. (2014). Feminist interventions in the design process. In Ernst, W. & Horwath, I. (Eds.), *Gender in Science and Technology* (pp. 41–56). Berlin: transcript Verlag.

Rosser, B. R. S., Hunt, S., Capistrant, B., Kohli, N., Konety, B., Mitteldorf, D., Ross, M., Talley, K., & West, W. (2018). Understanding prostate cancer in gay, bisexual, and other men who have sex with men and transgender women. In Ussher, J. M., Perz, J., & Simon Rosser, B. R. (Eds.), *Gay and Bisexual Men Living with Prostate Cancer from Diagnosis to Recovery* (pp. 12–37). New York: Harrington Park Press.

Sarma, A., Jacobson, D., McGree, M., Roberts, R., Lieber, M., & Jacobsen, S. (2005). A population-based study of incidence and treatment of benign prostatic hyperplasia among residents of Olmsted county, Minnesota: 1987–1997. *Journal of Urology*, *173*(6), 2048–2053.

Schillmeier, M. (2010). *Rethinking Disability: Bodies, Senses and Things*. London: Routledge.

Sengoopta, C. (2006). *The Most Secret Quintessence of Life: Sex, Glands, and Hormones, 1850–1950*. Chicago: University of Chicago Press.

Sontag, S. (1978). *Illness as Metaphor*. New York: Farrar, Straus & Giroux.

Statens Beredning för Medicinsk och Social Utvärdering (SBU). (2011). *Godartad prostataförstoring med avflödeshinder. En systematisk litteraturöversikt*. Swedish Council on Health Technology Assessment.

Steinberg, P. (2015). *A Salamander's Tale*. New York: Skyhorse.

Suchman, L. (2007). *Human-Machine Reconfigurations: Plans and Situated Actions* (2nd ed.). Cambridge: Cambridge University Press.

Thompson, C. (2005). *Making Parents. The Ontological Choreography of Reproductive Technologies*. Cambridge, MA: MIT Press.

Tiefer, L. (2006). The Viagra phenomenon. *Sexualities*, *9*(3), 273–294.

Timmermans, S., & Berg, M. (2003). *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Healthcare*. Philadelphia: Temple University Press.

Tuana, N. (2006). The speculum of ignorance: The women's health movement and epistemologies of ignorance. *Hypatia*, *21*(3), 1–19.

Underman, K. (2020). *Feeling Medicine: How the Pelvic Exam Shapes Medical Training*. New York: New York University Press.

Ussher, J. M., Perz, J., & Rosser, B. R. S. (Eds.). (2018). *Gay and Bisexual Men Living with Prostate Cancer from Diagnosis to Recovery*. New York: Harrington Park Press.

Viney, W., Callard, F., & Woods, A. (2015). Critical medical humanities: Embracing entanglement, taking risks. *Medical Humanities*, *41*(1), 2–7.

Whitehead, A., & Woods, A. (Ed.). (2016). *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press.

Wikberg Nilsson, Å., & Jahnke, M. (2018). Tactics for norm-creative innovation. *Shi Ji The Journal of Design, Economics, and Innovation*, *4*(4), 375–391.

Winterich, J., Quandt, S., Grzywacz, J., Clark, P., Miller, D., Acuna, J., & Arcury, T. (2009). Masculinity and the body: How African American and white men experience cancer screening exams involving the rectum. *American Journal of Men's Health*, *3*(4) 300–309.

Zeiler, K., & Käll, L. (2020). Still alice? Ethical aspects of conceptualising selfhood in dementia. In Bleakley, A. (Ed.), *The Routledge Handbook of the Medical Humanities* (pp. 290–299). London: Routledge.

9 Always already menstrual activist: elaborations on being activist-scholar

Josefin Persdotter

Introduction

So, I found myself utterly confused. I sat, lips painted red, at a seminar in a fancy house just outside of Gothenburg and was among a selection of specially invited guests from a range of disciplines asked to explore whether academic researchers can or should "also be activists." In what is now my long-time engagement in both menstrual activism and menstrual scholarly work in sociology – in Sweden and beyond – I have often been asked to discuss – or rather defend – that position, and I have thought, read, written, and talked quite a lot about it. However, that time I could not find the words. The well-known political scientist, who had been asked to get the discussion going, started the seminar by arguing for a hard separation: that scholars should absolutely not be active in society in the field they study, or as he put it; that a political scientist cannot "barge into party summits" and have their say. He suggested that engagement in society in general was important for academics but that we ought to stay away from the subjects we research. He might not have meant it that harshly; perhaps he was mostly trying to get the discussion going, but I lost my footing at the premise. My mind went numb, overwhelmed with questions and thoughts. Around the table colleagues from the humanities, natural and social sciences, representing a range of subjects and perspectives, discussed. Some agreed with him, others argued against him, but it seemed like no one else represented a way of thinking close to my own. It seemed they all thought that activist ambitions were, in fact, problematic for scholars. I remember mumbling something about the questions being incorrectly phrased, feebly insisting that no research is apolitical, and haltingly delivering my personal example with how research in fact can be preceded by and built from activism. But no one seemed to understand what I was saying. They seemed to use the word activist in a caricature sense, as if being activist was equal to being extreme, polarizing, and blazingly biased. They seemed to argue that direct involvement with the field was somehow detrimental to scholarly work. It was like I witnessed their discussion through a thick glass, where I could not quite hear what they were saying, and they could not hear me. I drove home from the seminar with a sinking sensation in my gut. What

DOI: 10.4324/9781003319818-13

had they all really been talking about? What did they even mean by activist? Why could I not find a way into the conversation? Then, about a week or so after, I got angry. That is probably exactly how that political scientist had wanted me to react at the seminar. Better late than never. It angered me that they all had seemed to think that researchers should be so detached. I fumed to colleagues in the lunchroom: Why on earth should we not, as researchers, be actively engaged in the fields that we have been assigned and (state) financed to generate knowledge about? How far up the ivory-tower are these people? If we would indeed stay away from our fields, then how should we be of any use to anyone? What right to exist does academia have if we never get involved? It angered me that they questioned my (and others) proficiency. I fumed: Do they really think that me being activist makes me less of a sociologist? Moreover, it angered me that they seemed to consider personal engagement and personal experiences harmful to "good" science. Have they wilfully ignored scholarly insights for the last 30 years that have led us way past positivist notions of objectivity?

As the years have passed since that seminar, I have gotten less angry, all the while observing a growing need to strengthen my response on the values of activism in academia. In the ongoing so-called academic culture war,[1] we now see not only right-wing extremists but even members of parliament, arguing gender, race, postcolonial, and climate studies to be "excessively activist" and problematically political (Goldschmidt Pedersen, 2021; Meret, 2021; Rahbari et al., 2024). Academia has retorted that such notions distort academic freedom and risk the very foundations of democracy (Nielsen, 2021; SULF, 2024), but the accusation lingers and upholds a false – long ago firmly rejected and unwanted – discourse of some kind of academic absolute objective neutrality. In this moment in time, it is therefore particularly important to elaborate on ways of thinking about activism in academia. In this text, I, from my own experiences of working within the area of menstrual health as scholar and activist, provide a reflection on what I think the many advantages of combining activism and scholarship can be, hoping it can strengthen the counterargument – that scholars indeed both can and should be activists.

Definition

In the early years of my academic work, I spent considerable time and energy trying to understand how to separate "myself as activist" from "myself as scholar." My activism in menstrual health has continuously been questioned by (some) colleagues and journalists. Although there have been several (feminist) islands of respite, I have had a constant feeling of being a topic of debate, some odd curiosity, feeling that I must defend my position or find a way out of it. Numerous scholar-activists report similar experiences (see, e.g., Collins, 2013; Trauger & Fluri, 2012; Hale, 2001; Rahbari et al., 2024). As I have gotten deeper into my scholarly training, including feminist epistemologies and methodologies, I have grown to allow for a cognitive integration.

Dictionary definitions of the term activist hold that is the use of direct and noticeable action to achieve a result, usually a political or social one (Cambridge Dictionary, n.d.). With that definition, surely there can be very little social science research that is not understandable as activist to some extent. Feminist, indigenous, and anti-racist scholars have long been at the forefront in efforts to make marginalized knowledges impact social change (Brown & Strega, 2015), and large institutions argue the need for all scholars to be agents for social change. UNESCO's (2018) recommendations on research position the scholar as one who should work for inclusion, equality, and human rights. Therein, as well as in Swedish law (SFS, 1993) and EU strategies (EC, 2020), it is a key part of scholars' role and responsibility to contribute to and cooperate with the society outside campus walls. Many call that activism, others not. The term is used differently by different actors and disciplines, as well as differently in different languages and national contexts.

In Swedish the word *aktivist* – although semantically defined as the English equivalent – has long been used pejoratively, alluding to strongly extremist or radical methods of trying to change society. When I began working with menstrual health, I avoided using the term to describe what I today call activism, as it then seemed somewhat too violent and radical (see Persdotter, 2013). People doing the very same thing in the US seemed to use the term activist much more lightly (Bobel, 2010). In a Swedish national context, notions of activism in academia are clearly contentious. As a telling example, the Swedish Association of University Teachers and Researchers (SULF) recently hosted a public debate with the heading "Academy and activism – taboo or goddamn duty?"[2] (SULF, 2024), pinning activist scholarship somewhere between an absolute forbidden and a moral imperative. There are many contexts across the globe where the situation seems similar: activism in academia is questioned or cautioned against – and is vigorously defended (Rahbari et al., 2024, Wilson, 2018). In contrast, there are disciplines and research milieus where the term "activist" seems way less controversial. Colleagues of menstrual and other feminist research fields from other parts of the world seem to view activism as a standard and given aspect of their research. They position themselves as having given roles to play in activist communities, participating in protests and demonstrations, doing activist social media, and by without hesitation being directly involved in social movements adjacent to their field of study (see, e.g., Persdotter, 2013; Bobel & Fahs, 2020; Cifuentes Contador, this volume). Colleagues here in Sweden, however, seem to much more carefully avoid using the term to describe their efforts to have their research improve society. Although this might be changing, as some have noted that the concept might be going through a process of de-dramatization in Swedish (SULF, 2024), the term "activist" remains contentious in my local research context, and many others. Although a growing number of scholars generally argue the need for social sciences to more overtly engage outside of academia and acknowledge our political viewpoints (see, e.g., Burawoy, 2014; Romano & Daum, 2018; Santos, 2012; Speed, 2006; Sprague, 2016; Collins, 2013; Wilson, 2018;

Rahbari et al., 2024), many choose less contested titles (as "Public Sociologist" or "Engaged Scholar"). I join those who argue that there is a specific value in the term "activism." The term demands action, standing firm as a conceptual antidote to the comforts of desktop research. "Get up!" the term requests. "Let's do something about it!"

A recent article by a group of international and interdisciplinary scholars (Rahbari et al., 2024) presents a broad but excellent definition delineating activist scholarship, or academic activism, as "concerned with integrating academic scholarship with social and political activism," aiming to use their expertise and platform to engage in social issues actively, arising from criticism against research and academia for "operating in isolated 'Ivory Towers'." Academic activism challenges the notion of academics adopting a "detached" and supposedly "neutral" or "objective" stance toward their field and rejects the idea that academics should merely study the world, without actively trying to change it. Academic activism, they argue, bears an advantage and a responsibility to "employ their knowledge and expertise in non-academic projects that aim to improve life and society" (Rahbari et al., 2024, p. 74). Activist-scholars, thus, do not stop at knowledge production but share a commitment to have that knowledge put into use. Although public communication is imperative therein, activist-scholars understand their role outside academia as more than communicative. They understand it as an *engaged* imperative (see Fraser & Honneth, 2003), being an active player in how their results move the world. Moreover, activist-scholars make a *public commitment to a cause* (Santos, 2012). They state openly what and whom they work to help. And there are huge benefits of such transparency. With the public profession of activism, the inevitable biases of the researcher are more systematically scrutinized. Finally, the activist-scholar challenges powers that be. They work within an area of study where injustice and malpractice persist, and they act to change that by actively engaging in struggles for recognition and redistribution (Fraser & Honneth, 2003).

Bobel and Fahs have defined *menstrual activism* as "a mobilizing effort that challenges menstrual taboos and insists that menstruators have the support they need to live healthy happy lives" (2020, p. 70). As a menstrual activist-scholar, I thus engage to unearth and meet the misrecognized needs of menstruants and help them – women and others who menstruate – to live healthy, happy, and comfortable lives (see Persdotter, 2020, 2022). I work to unpack and convey marginalized knowledges of what it is to menstruate, and continuously cooperate with actors outside of academia to impact policy, practice, and technologies.

Diffraction

I join the wealth of scholars within, for example, feminist methodologies and philosophy of science who press that there is no such thing as value-neutral knowledge, no such thing as a "modest witness" that can observe the world

objectively from above (Haraway, 1988, 1996, 1997). In feminist critiques of science this is a foundational principle (see, e.g., Asdal et al., 2007). Beginning in the 1980s, feminists who exposed the male dominance in science critiqued the idea of the male researcher as objective, problematizing the impact of their specifically gendered experiences on everything from problem formulation to how they wrote up their results (see, e.g., Harding, 1992; Haraway, 1988; Martin, 2001[1987]; Fox Keller, 1982). The fact that those men thought themselves neutral was highlighted as an epistemological problem and many argued that including women would make for better science (as described by Harding, 1992). Haraway questioned this and underscored the importance of investigating *all* positions; that all involved in the production of knowledge occupy a specific situation, that *always* needs to be scrutinized.

Haraway famously argued that when scholars position themselves as if observing the world with a positivist notion of objectivity, they perform a so-called "God-trick" (1988), taking a god-like position ("a view from nowhere") presumably without bias and body. Haraway posited that a feminist rendition of objectivity is "situated knowledges" (1988, p. 581); an epistemology that understands knowledge as something produced from certain positions, as "positioned rationality" (p. 590); that all researchers generate knowledge through a view "from somewhere" (p. 591). Thus, it matters who makes the science. It matters what bodies they have, what lives they have lived, what power they hold in the world, and so on. As she put it elsewhere: "It matters what matters we use to think other matters with" (Haraway, 2016, p. 12). Haraway posed that the way forward for academic work is to seriously acknowledge the situatedness of the research(er) and take ethical and political responsibility over how we as researchers actively and partially view and make the world. This implies acknowledging that politics is an integral part of knowledge production, that all researchers are partial, as they view the world through a specific set of eyes. There is no such thing as neat, neutral, objective knowledge; we are all *immodest witnesses* (Murphy, 2012) rather than modest ones. Through this epistemological lens, no scholar can ever be neutral or apolitical. All scholars' ideals and experiences impact their research.

Haraway argues that knowledge should be made from a *diffractive* (rather than reflexive) multitude of different positions, where the knowing self with all its partiality can join and see together with others in a kind of "critical consciousness" (1997, p. 273), finely attuned to how differences are being created in the world. The diffractive viewpoint acknowledges that everything and everyone involved in research greatly impacts its results. Seeing and thinking diffractively thus implies a self-accountable, critical, and responsible engagement with the world (Geerts & van de Tuin, 2021).

As a counterargument to those waving flags of "excessive activism" in academia, the Harawayian way of understanding knowledge production positions academic freedom as being that which allows multitudes into the eternally collective process of academic work. Therein, all researchers (activist or otherwise) must try to understand how we are entangled with our research, hold

ourselves answerable to how we see and what we do (Haraway, 1988, 1997). We all need to try to craft a process that helps us generate reliable and relevant knowledge, despite as well as because of ourselves. The important question, then, is not whether one can combine scholarship and activism; the question to ask is *how to do it*. The question and the task at hand, then, becomes one about *how* we can take ethical and political responsibility over who we are, what questions we ask, and how we and our results impact the world (see Haraway, 1988). Through positioning myself within activist scholarship in menstrual health, I am made acutely aware and exposed in my situatedness, which demands – much more explicitly than for scholars generally – that I grapple hands on with the scholarly responsibilities of world-making.

Integration

My engagement with menstruation began at a Christmas arts-fair in 2006. I was in my second year of Sociology studies and sold feminist art and crafts to boost income. I'd been drawing feminist illustrations for years, making statements about everything from body-hair and dildos to depression and history books. Sure, I did try to provoke, but the pictures were funny rather than radical, playful rather than punk. However, when I first sold my – now rather infamous – tampon earrings (see Figure 9.1), it was a whole different story. About a hundred miniature clay tampons, dipped in glossy reds and pinks, hung on a pink board with the text "Hang them in your ears instead!" I was excited, but I never anticipated the storm of reactions from people visiting the fair. Suddenly, people crammed around my little stall. Some were just curious,

Figure 9.1 Tampon earring by author (2006). Photographer: Anja Sjögren (2007), used with permission from photographer.

others truly outraged. One old lady came at me fist flying, yelling "Do you call this is art!?" Another looked me deep in the eye and told me in a calm and slow voice to "never stop doing what you do." Then, after only a few hours I had to take the earrings down, because the other vendors were – probably rightly – worried that the commotion decreased their sales (Persdotter, 2013). As I stood there in astonishment, the earrings under the counter as if they were contraband, I tried to grasp why people had reacted so strongly. The earrings had obviously struck a nerve. Being a sociology student, ethnomethodological methods of making visible invisible norms came to my mind (Garfinkel, 1984). What, I began to wonder, could this tell of the state of women's rights and position in contemporary Sweden? In comparison with other countries, Sweden often stood out as one of the world's most gender equal (see, e.g., United Nations, 2022; Martinsson & Griffin, 2016). Yet there were obviously some major persistent inequalities alive and well also in good old Sweden. I realized then what I still firmly adhere to: that it is an outrage that such a large part of so many people's life – the very issue of menstruation – has so firmly been locked out of public discourse. Making menstrual matters visible has been a key concern of mine ever since.

At the beginning, I felt quite alone in my endeavour. I found very little written on the topic and experienced quite great pushback when I tried to bring it up to fellow feminist activists. Fellow feminist activists would dismiss the theme of menstruation as not being "empowering" enough, as risking reinforcing negative stereotypes of women, and perhaps also because menstruation is related so explicitly to sex rather than gender (see Persdotter, 2013). Menstruation did not have a place even in feminism at that moment in time in Sweden (see Persdotter, 2013). In 2009, I started a blog, anonymously, where I explored the boundaries for my own menstrual shame and ignorance of the theme. People around me started to reach out and tell me their stories of cramps, PMS, and menstrual technologies. When I wore my earrings while out clubbing, or at the university, those who saw what they were would react, and menstruation would burst out of its confinement and take up space in the world. I hoped that with every earring I sold, that would be the case. When I, back then, read Chris Bobel's (2010) *New Blood – Third Wave Feminism and the Politics of Menstruation*, I realized there were others like me who worked to change oppressive ideas of shame and secrecy of menstruation, all over the world. No less, our struggle had deep roots in the history of the women's movement, integral to the work of long-ago pioneers of women's health (see, e.g., Murphy, 2012; Bobel, 2008, 2010; Bobel & Fahs, 2020; Johannisson, 2013). Bobel's work led me to *The Society for Menstrual Cycle Research*, and I attended my first conference in 2011 (heart pounding), and I found a home and a growing ground. As I basked in the riches of menstrual knowledges, I realized that menses could be a vocation, and even a scholarly one at that. Moreover, I identified a need to develop menstrual activism and knowledges closer to my own home country. The trip to the conference was long and expensive, and most of the participants and the research presented were US-based or Anglo-centric.

A year later, I quit what I had until then pretty much considered my dream job and decided to devote all my energy to menstruation. I began drafting the bylaws for the organization *Mensen – forum for menstruation*, today Sweden's leading menstrual advocacy and education actor, I wrote a master's thesis on menstrual activism in Europe and began collaborating with like-minded people both in Sweden and abroad. In 2013, Sweden suddenly opened to menstruation. American news media declared 2015 "the year the period went public" (Jones, 2016; Gharib, 2015), but in Sweden, periods can be said to have already "gone public" in 2013 (Persdotter, 2014, 2022) when the local popular feminist graphic novelist Liv Strömquist devoted two hours of prime-time national public radio to menstruation. Strömquist presented historical and present-day absurdities of menstrual shame, silence, and secrecy and showed how they were (are) used as ways to discriminate women and menstruants.[3] It was an absolute tide-turner. Before that show, I would introduce myself at parties and have people, *literally*, turn their back at me when I described what I was doing. They just left mid-conversation. After that radio-show though, the reactions I got came to be completely different.

Scholarly work was one of many paths I viewed as imperative to mend the epistemological injustices surrounding menstruation. I was accepted to a PhD program in sociology in early 2014. At that time, there was so much going on in the local menstrual activist scene that I had to take part-time leave from the university just to keep up. I and Arvida Byström curated the art show *Period Pieces*, with menstrual art from a range of international artists, with extensive media coverage, long lines at the door, and (barring a couple of online trolls) overall acclaim (Jacobson, 2014). As we stood there, in the midst of the crowd, we could see and hear and feel the shifts in ideas about menstruation and its role in life and society. "I never thought it could be beautiful," someone said. Others discussed bloody genitals as signs of sexual trauma. People were disgusted, intrigued, surprised, in awe, curious, and everything in between. Henrik Tikkonen has said that "only art has the ability to describe what you cannot understand" (Holmgren, 2022), and we operated somewhere in that space – an exploration of ideas that were going somewhere, but we did not know where. Then, the organization Mensen had its first board meeting, and we began to post online, recruit members, draft mission statements, and action plans. National news and social media seemingly exploded with menstruation posts and articles, suddenly covering everything from PMS to the care of endometriosis. I must have been interviewed by more journalists that half year, than during all my other years at the university to date. In Swedish, we call that a "ketchup effect"; first nothing, then everything at once.

Since then, menstruation has really taken its overdue place in the Swedish public sphere. Although there has been some backlash – mainly from far-right conservatives who have used menstrual art as a political weapon – menstruation has a continued high presence in the media, and the menstrual activist community has consolidated and keeps progressing its agenda. Just to give a few examples: menstruation and menopause are by now discussed as an important workplace issue (Cubilla, 2022; Rydström et al., 2019; Akademikerförbundet,

n.d.; IF metall, n.d.), endometriosis national care guidelines have been developed, there are a multitude of long-lived projects developing menstrual education for children, youth,[4] and adults and global standards for menstrual products[5] as well as menstrual and menopausal health in the workplace guidelines being developed.[6]

When I started working at the university, I made research rather than activism my top priority. However, I continued working as an activist as much as I was able. In Mensen, I have been chair, co-chair, board member, and election committee member over the years, as well as headed study circles, consulted on educational materials, written op-eds, created social media content, and arranged public workshops and lectures. At the moment of writing, I am part-time employed by the organization to develop guidelines for menstrual and menopause-friendly workplaces. As I have progressed in my scholarly proficiency, I have played an increasingly scholarly role as a menstrual activist. I "[put] my sociological imagination into serving a cause" (Sprague, 2016, p. 210) and try to utilize my specific situatedness as a fertile ground for doing valuable research (Earl, 2017), to create more potentials for more liveable lives (Haraway, 1988). I have designed surveys, developed reading lists, compiled literature reviews, and developed handbooks, checklists, and education materials utilizing a wealth of perspectives from both methodological and theoretical sides. I remain somewhat active in the menstrual art community, although I have not created any pieces of my own during the last decade. I have especially valued how my piece "A glass of red" (see Figure 9.2) – a pair of mannequin legs from which you are invited to pour (and drink!) red wine from its crotch – has toyed with the boundaries of pollution and danger, provoking at the same time disgust, unease, laughter, and deliverance. The piece has been "covered" by a theatre group and live on through them.[7]

Amalgamation

Looking back, my activism and the art that it has included have greatly spurred my sociological imagination and have sharpened and enriched my analytical gaze. Research questions have quaked from entanglements of art, people's reactions, stories in study circles, and ideas from critical scholarly works (see Persdotter, 2022). Therein, scholarship and activism came into being, and have continued to grow, as two sides of a whole. I am proud to say that my work has managed to shed light on aspects of menstruality that have been belittled or avoided even in activist and critical research contexts prior. It seems I have been able to make visible everyday menstruality in a more explicit and thorough way than others have before me (see review by Mørk Røstvik, 2022). That was made possible by my specific combination of experiences, as much through art and bylaws as from survey questions, theories, and interview transcripts.

Within the questioning of whether scholars should be activists, there is a problematic dichotomization of scholarship and activism that engenders a stereotyping that caricatures both: the scholar becomes a beige passive bore

Figure 9.2 Installation "Ett glas rött" by author (2013). Photographer: Karolin Knutsson (2014), used with permission from photographer.

and the activist a crazed angry rebel. I have very seldomly encountered any of those creatures in real life. The menstrual activists that I meet are often just as interested as scholars – if not more – in reliable and up-to-date data and complexities in problems. They (we) study or work at the university, read research, conduct surveys, interview scholars, and cooperate with them (us). This is a well-reported aspect of a lot of activism in today's knowledge society in general and in relation to health issues in particular (see, e.g., Epstein, 1995; Landzelius, 2006; Rabeharisoa et al., 2014; Lindén, 2021a, 2021b; Persdotter, 2013; Bobel & Fahs, 2020). Therefore, I argue, that there is no clear distinction, no real either/or but rather activism and scholarship overlap. Relatedly, my activist ambitions do not disqualify me as researcher, nor does it somehow relieve me of my scholarly skills and aims. Although activist, I still have years of education and training in sociological methods, I can still perform systematic and rigorous analysis of data, and I remain careful and reflexive in my interpretations. I do not zigzag between the two or opt out of the one to do the other. I am *both* a scholar *and* an activist.

In critical menstruation studies and menstrual research generally, activism is a given (if not inevitable) part of research. Choosing to do the research has for many been an activist choice, the subject often being belittled and stigmatized in our respective research milieus (Owen, 2022; Frisk et al., 2023). The research field has long enjoyed a close connection with activist communities, as has of course feminist/gender/women-studies generally (Bobel, 2010,

2020). Activists have often been acclaimed for their role in identifying epistemological injustices and advancing boundaries of knowledge as they spur new lines of scientific inquiry by bringing attention to problems that have been unrecognized, under-researched, and undervalued (see, e.g., Brown & Strega, 2015; Fricker, 2007; Hauswald, 2018; Sprague, 2016). It is a case in point that in the case of menstrual research, it is difficult to distinguish whether it was activists or scholars that got the ball rolling. To state some concrete examples, activists and scholars have *in tandem* progressed research of queer and trans experiences of menstruation (see, e.g., Bliss, n.d.; Bobel, 2010; Chrisler et al., 2016; Berg, 2017; Frank, 2020; Rydström, 2020), of crip-studies of menstruation (Steward et al., 2020), as well as research on the contents of menstrual products (see, e.g., Reame, 2020; Vostral, 2011, 2018). Activists and scholars in the area of menstruation share epistemic interests (Hauswald, 2018) of expanding knowledges about menstruation as well as the overall goal to make life better for menstruants (see Bobel & Fahs, 2020). My own research has, indeed, been greatly inspired by what activists in Mensen, Menssäkrad,[8] the architect-scholar-activist Clara Greed (2010, 2016, 2019), and activist-journalist Anna Dahlqvist (2016) have done to highlight the need to take menstruation into consideration in bathroom design in schools and workplaces in Sweden. I have been inspired by artists – who are also activists and scholars in varying degrees – such as Jen Lewis,[9] Judy Chicago,[10] Miriam Wistreich,[11] Ingrid Berthon-Moine,[12] and Arvida Byström,[13] who have challenged me to think about menstrual substances, personal hygiene, bathrooms, dirt, and disgust in new ways. And vice versa; my research has inspired some of them, and I hope it will continue to do so. There are no clear lines between us. We follow each other on social media, attend the same conferences, co-organize events, attend each other's lectures, read each other's texts, some of us even co-author op-eds, and apply for funding together.

Valuation

Being both a scholar and an activist has its advantages and its drawbacks. Though difficult to distinguish between the two – as discussed above – I will share three examples below that illustrate central aspects of how my activism has impacted my scholarship in sometimes tricky, but always rewarding ways. I have chosen these examples as they span key aspects of research: problem formulation, access to data, and, last, the intricacies of analysis of that data.

First of all, it is safe to say that had it not been for my years of activism prior to the research, I would never even have thought menstruation worthy of scholarly pursuit. Notably, I realized the sociological relevance of the subject early on in my own work as an artist, through reading activist-scholarly work about other activists (Bobel, 2010), and by meeting and working with other (more or less scholarly) activists and (more or less activist) scholars. Later, as I formulated my first research proposal, I drew from years of activist experiences in terms of research questions, methods, and literature. My years as

activist gave me a very concrete head start and provided cognitive and practical tools to produce valuable and innovative research. As so many people had told me of their menstrual lives, I did not only carry with me my own menstrual experience but a chorus of others, already from the get-go. There could, of course, theoretically have been value in starting out with a "clean slate," but as I have personal experiences of menstruating, I think that also having other people's voices with me meant that I entered the field with a broader view – to some degree with more sets of eyes to view the world through. Thereby, I think that my years of activism gave me a position to do research that went deeper than it would have otherwise. On the downside, my activist activities (both before and during my research career) have likely also limited possible research questions. For example, due to my vocal critique of certain menstrual product companies, I have to live with a likelihood that I might not be able to gain the same access to these companies as (less publicly critical) scholars might. Although I do think that a laboratory study of pad designing and engineering would be very valuable, I think I must leave that to others to pursue (see Vostral, 2018, 2020; Mørk Røstvik, 2022 for such examples).

Second, I have often as a researcher built from activist infrastructures. I have used words created at menstrual activist events. I have utilized activist social media venues, some of which I personally once set up, to recruit research interlocutors. That gave me the opportunity of reaching thousands of people that were probably more likely to share in-depth details on menses than most. Had it not been for (mine and others) activism they would not have existed. Naturally, using those channels was a choice that had consequences. It meant that my data represented a special segment of the population, and that I had to analyse them accordingly. For example, I explored what aspects of menstruation were difficult even for the uncommonly open to talk about. Although they could comfortably describe everything from menarche to menstrual sex, some of them haltered when the questions regarded the "gory," "slimy," and "smelly" aspects of menstruation. Eventually, I ended up studying just that. As all researchers do, I made certain choices with the knowledge and tools available, generated certain data, and interpreted the data in relation to its whole – what was (un)said, how it was collected, by whom, when, and so forth. Furthermore, I have been able to use those same venues for sharing my results to an interested public.

Third, being a scholar-activist has elevated my reflexivity and transparency. When I initially started to interview interlocuters, I thought I ought to keep quiet about my activist position as I worried it might interfere with their narratives. This was naïve for several reasons. Due to my mass-media presence and my choice of recruitment strategy, many of the participants knew who I was before they replied to the call. I found it quite awkward at first as my ideas of how a scholar ought to be clashed with reality, but it also served as an excellent reminder of my (the researcher's) inevitable presence in and impact on the field. It enforced the importance of including myself as part of the analysis, considering my own impact – as both researcher and activist – on how interlocuters

talked, what they talked about, and so forth. One cannot extract oneself from the equation. It has truly been uncomfortable and difficult – but it has also been immensely rewarding. In order to understand my own role, I have in part utilized auto-ethnographic tools – such as auto-interviewing (Boufoy-Bastick, 2004) – but foremost I have utilized the collegial systems integral to academic work. Through sharing data and tentative analysis with colleagues since the very first stages of the research, I have been able to see my empirical material – and myself – through the eyes of others, creating perhaps something like that multiple diffractive view that Haraway (1997) describes. Moreover, the inherent transparency of values that comes with being an activist-scholar has meant that I have likely received a higher degree of scrutiny than many others. In most cases that scrutiny has been part and parcel of a collective process of academic work, and it has improved my research greatly. Other times, like when the mere relevance of my subject has been questioned from other scholars (see Persdotter, 2022) or by far-right debaters, it has been less constructive. However, it is always an immensely valuable thing – and a fundament of scholarly work – to be questioned, critiqued, and challenged. It progresses thought, deepens analysis, and pushes us to do research that matters.

Conclusion

As social sciences, and critical social sciences in particular, are increasingly under attack for being "excessively activist," it is easy to opt for avoiding any association with, and try to distance research from, activism. However, the ambition to engage actively as scholars and to stand up for the marginalized and deprived is more important now than ever. More of us scholars should find ways of being activists. We have an immensely important role to play also outside the confines of peer-reviewed journals. For some of us scholars of women's health, at this moment in time – thinking not least of the current situation around defunding of research on women's health, about the violations to rights to abortion and of trans rights (see, e.g., Thoreson, 2025; Oldroy et al., 2025) – being activists is perhaps even a requirement. We must take seriously the value in our roles as intellectuals, consider how we can impact the societal debate within our fields of study, and recognize and elaborate how we can contribute with our perspectives, skills, and resources. We all, both as individuals and as institutions, need to improve the ways in which we can both be scholarly while also being active parts in our fields. This menstrual scholar and (health) activist sees the benefits of such daily. Being an activist makes me a better a scholar, and being a scholar makes me a better activist.

That does not mean that I think that scholars should, as it were, "barge into party-summits." Such would indeed be a violation of democratic principles and an abuse of power. It might however mean that we do attend those party-summits. It might mean that we write op-eds in relation to it, and that we come prepared and well read on relevant research and up-to-date data. We

should not be there, or anywhere else where our research matters, as passive bystanders nor crazed maniacs but still as active contributors. To, by principle, retract from these contexts is nothing but a grave misuse of power.

Notes

1 "The academic culture wars" refer to ideological conflicts within academia over issues such as free speech, diversity, equity, inclusion, and the role of social and political values in shaping research, teaching, and institutional policies (see, e.g., Holmberg & Selberg, 2022; Marris, 2024).
2 Original title in Swedish was "SULF 40 år: Akademi och aktivism – tabu eller förbannad skyldighet?," Available on https://sulf.se/en/sulf-play/seminarium/sulf-40-ar-akademi-och-aktivism-tabu-eller-forbannad-skyldighet/.
3 The term *menstruant* is used to underline that not all women menstruate and not all who menstruates are women (see Persdotter, 2022; Bobel, 2010; Chrisler et al., 2016; Berg, 2017; Frank, 2020; Rydström, 2020; Vostral, 2018).
4 See Liv Livmoder (https://livlivmoder.se) and Mensen (https://mensen.se), respectively.
5 ISO/TC 338 Menstrual products https://www.iso.org/committee/8933440.html.
6 ISO/CD 45010 Menstruation, menstrual health and menopause in the workplace – Guidance https://www.iso.org/standard/64365.html.
7 https://www.gp.se/teater-tamauer-mens.3a804594–741a-41b1–8319-cf9ad84811a1.
8 The company Menssäkrad (previously an activist project) works to make menstrual products accessible in public bathrooms https://www.menssakrad.se.
9 The artist Jen Lewis' work is discussed in Lewis 2020 and can be found at http://www.beautyinblood.com.
10 See "Menstruation Bathroom" (1972) here: https://www.tate.org.uk/art/artworks/chicago-menstruation-bathroom-from-womanhouse-p15228, and "Red Flag" (1971) here: https://judychicago.com/gallery/early-feminist/ef-artwork/.
11 Some of Miriam Wistreich's work can be found at https://www.miriamwistreich.net.
12 Some of Ingrid Berthon-Moine's work can be found at https://www.ingridberthonmoine.com/work/older-work.
13 One explicitly menstrual series of photographs by Arvida Byström can be found at https://www.vice.com/sv/article/kwn34w/there-will-be-blood.

Reference list

Akademikerförbundet SSR. (n.d.). *Mens – en facklig fråga*. https://akademssr.se/rad-stod/likabehandling/mens-och-arbetsmiljo. Accessed September 9, 2022.
Asdal, K., Brenna, B., & Moser, I. (Eds.). (2007). *Technoscience: The politics of interventions*. Unipub.
Berg, B. (2017). *Transgendering menstruation: En kvalitativ studie av uppfattningar kring menstruation i relation till transidentitet i Sverige* [Bachelor's thesis, University of Gothenburg]. https://gupea.ub.gu.se/handle/2077/53970
Bliss, C. [@theperiodprince]. (n.d.). [Instagram profile]. Accessed September 9, 2017.
Bobel, C. (2008). From convenience to hazard: A short history of the emergence of the menstrual activism movement, 1971–1992. *Health Care for Women International*, *29*(7), 738–754.
Bobel, C. (2010). *New blood: Third-wave feminism and the politics of menstruation*. Rutgers University Press.
Bobel, C. (2017, June 22). [President's introduction speech]. *22nd Biennial conference of the society for menstrual cycle research: Menstrual health: Research, representation, and re-education*. Kennesaw, Atlanta, USA.

Bobel, C. (2020). Introduction: Menstruation as lens – Menstruation as opportunity. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 1–6). Palgrave Macmillan.

Bobel, C., & Fahs, B. (2020). The messy politics of menstrual activism. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 1001–1018). Palgrave Macmillan.

Boufoy-Bastick, B. (2004). Auto-interviewing, auto-ethnography and critical incident methodology for eliciting a self-conceptualised worldview. *Forum: Qualitative Social Research*, *5*(1).

Brown, L. A., & Strega, S. (Eds.) (2015). *Research as resistance: Revisiting critical, indigenous, and anti-oppressive approaches* (2nd ed.). Canadian Scholars' Press.

Burawoy, M. (2014). Sociology as a vocation: Moral commitment and scientific imagination. *Current Sociology*, *62*(2), 279–284.

Cambridge Dictionary. (n.d). Definition of activist. In *Cambridge advanced learner's dictionary & thesaurus*. Cambridge University Press. https://dictionary.cambridge.org/dictionary/english/activist

Chrisler, J. C., Gorman, J. A., Manion, J., Murgo, M., Barney, A., Adams-Clark, A., Newton, J. R., & McGrath, M. (2016). Queer periods: Attitudes toward and experiences with menstruation in the masculine of centre and transgender community. *Culture, Health & Sexuality*, *18*, 1–13.

Collins, P. H. (2013). Truth-telling and intellectual activism. *Contexts*, *12*(1), 36–41.

Cubilla, K. (2022). Mensledigt leder inte till jämställdhet. *Arbetet*. https://arbetet.se/2022/05/17/mensledigt-leder-inte-till-jamstalldhet/

Dahlqvist, A. (2016). *Bara lite blod: Ett reportage om mens och makt*. MTM.

Earl, C. (2017). The researcher as cognitive activist and the mutually useful conversation. *Power and Education*, *9*(2), 129–144.

Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology, & Human Values*, *20*(4), 408–437. https://doi.org/10.1177/016224399502000402

European Commission. (2020). *Strategic plan 2020–2024*. DG Research and Innovation. https://ec.europa.eu/info/sites/default/files/rtd_sp_2020_2024_en.pdf

Frank, S. E. (2020). Queering menstruation: Trans and non-binary identity and body politics. *Sociological Inquiry*, *90*(2), 371–404.

Fraser, N., & Honneth, A. (2003). *Redistribution or recognition?: A political-philosophical exchange*. Verso.

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

Frisk, M., Andreasen, L. U., Søndergaard, M. K., Røstvik, C. M., Ghanoui, S. L., & Persdotter, J. (2023). Exploring critical menstrual studies in the Nordic region: The importance of local specificities. *Nursing Clio*. https://nursingclio.org/2023/10/04/exploring-critical-menstrual-studies-in-the-nordic-region-the-importance-of-local-specificities/

Garfinkel, H. (1984). *Studies in ethnomethodology*. Polity Press.

Geerts, E., & Van der Tuin, I. (2021). Almanac: Diffraction & reading diffractively. *Matter: Journal of New Materialist Research*, *3*, 173–177.

Gharib, M. (2015 December 31). *Why 2015 was the year of the period, and we don't mean punctuation*. NPR, Your Health. https://www.npr.org/sections/health-shots/2015/12/31/460726461/why-2015-was-the-year-of-the-period-and-we-dont-mean-punctuation

Goldschmidt Pedersen, L. (2021). The academic culture war comes to Denmark. *Jacobin*. https://jacobin.com/2021/06/denmark-parliament-motion-research-fields-academic-freedom-feminism-postcolonial-migration-race-studies

Greed, C. (2010). Creating a nonsexist restroom. In H. L. Molotch & L. Norén (Eds.), *Toilet: Public restrooms and the politics of sharing* (pp. 117–141). New York University Press.
Greed, C. (2016). Taking women's bodily functions into account in urban planning and policy: Public toilets and menstruation. *Town Planning Review*, *87*(5).
Greed, C. (2019). Join the queue: Including women's toilet needs in public space. *The Sociological Review*, *67*(4), 908–926.
Hale, C. R. (2001). What is activist research. *Items & Issues*, *1*(2), 13–15. https://items.ssrc.org/from-our-archives/what-is-activist-research/
Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, *14*(3), 575–599.
Haraway, D. (1996). Modest witness: Feminist diffractions in science studies. In P. Galison & D. J. Stump (Eds.), *The disunity of science: Boundaries, contexts, and power* (pp. 428–442). Stanford University Press.
Haraway, D. J. (1997). *Modest–Witness@Second–Millennium.Femaleman–Meets–Oncomouse: Feminism and technoscience*. New York: Routledge.
Haraway, D. J. (2016). *Staying with the trouble: Making kin in the Chthulucene*. Duke University Press.
Harding, S. (1992). Subjectivity, experience and knowledge: An epistemology from/for rainbow coalition politics. *Development and Change*, *23*(3), 175–193.
Hauswald, R. (2018). The epistemic effects of close entanglements between research fields and activist movements. *Synthese*, *198*(1), 597–614.
Holmberg, R., & Selberg, R. (2022). Mellan kulturkrig och byråkrati–om akademisk frihet och universitetslärares professionalitet. *Högre utbildning*, *12*(3).
Holmgren, L. (2022, September 10). Värna den fria konsten. *Kristianstadsbladet*. https://www.kristianstadsbladet.se/artikel/varna-den-fria-konsten/
IF Metall. (n.d.). *Ett MENSkligare arbetsliv*. https://www.ifmetall.se/medlem/arkiv/mens---en-arbetsmiljofraga/
Jacobson, K. (2014). *Köer till menskonst i Göteborg*. Fempers.se. https://feministisktperspektiv.se/2014/03/12/koer-till-menskonst-i-goteborg/
Johannisson, K. (2013). *Den mörka kontinenten: kvinnan, medicinen och fin-de-siècle*. Norstedts.
Jones, A. (2016, April 20). The fight to end period shaming is going mainstream. *Newsweek*. https://www.newsweek.com/2016/04/29/womens-periods-menstruation-tampons-pads–449833.html
Keller, E. F. (1982). Feminism and science. *Signs*, *7*(3), 589–602.
Landzelius, K. (2006). Introduction: Patient organization movements and new metamorphoses in patienthood. *Social Science & Medicine*, *62*(3), 529–537.
Lewis, J. (2020). To widen the cycle: Artists engage the menstrual cycle and reproductive justice. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 803–811). Palgrave Macmillan.
Lindén, L. (2021a). Initiators, controllers, and influencers. In S. Geiger (Ed.), *Healthcare activism: Markets, morals, and the collective good* (pp. 140–164). Oxford University Press.
Lindén, L. (2021b). Moving evidence: Patients' groups, biomedical research, and affects. *Science, Technology, & Human Values*, *46*(4), 815–838.
Marris, E. (2024). Culture wars are raging on US campuses. Will they affect research? *Nature*, *626*(7999), 474–476.
Martin, E. (2001 [1987]). *The woman in the body: A cultural analysis of reproduction*. Beacon Press.
Martinsson, L., & Griffin, G. (2016). *Challenging the myth of gender equality in Sweden*. Policy Press. https://doi.org/10.3402/edui.v5.24618

Meret, S. (2021). *Attacks on academic freedom escalate in France and Denmark*. openDemocracy. https://www.opendemocracy.net/en/countering-radical-right/attacks-academic-freedom-escalate-france-and-denmark/

Mørk Røstvik, C. (2022). Challenging "anaemia" in critical menstrual studies: Menstruslime, pollution, and cleaning in contemporary Sweden. *Women's Reproductive Health*, *10*(2), 321–322.

Murphy, C. M. (2012). *Seizing the means of reproduction: Entanglements of feminism, health, and technoscience*. Duke University Press.

Nielsen, A. N. (2021). *Formand for Rektorkollegiet: Folketingets nye erklæring er et angreb på forskningsfriheden*. Videnskab DK. https://videnskab.dk/kultur-samfund/formand-for-rektorkollegiet-folketingets-nye-erklaering-er-et-angreb-paa-forskningsfriheden/

Oldroyd, J., Shresta, N., & Hughes, A. (2025). Trump 2.0 – a backwards step for women's sexual and reproductive rights. *BMJ*, *388*.

Owen, L. (2022). Researching the researchers: The impact of menstrual stigma on the study of menstruation. *Open Library of Humanities*, *8*(1). https://doi.org/10.16995/olh.6338

Persdotter, J. (2013). *Countering the menstrual mainstream – A study of the European menstrual countermovement* [Master's thesis, Gothenburg University]. https://gupea.ub.gu.se/handle/2077/34369

Persdotter, J. (2014). Sweden's year of menstruation – Is it the menstrual decade? Maybe the menstrual millennium? [Blog post]. https://www.menstruationresearch.org/2014/10/24/swedens-year-of-menstruation-is-it-the-menstrual-decade-maybe-the-menstrual-millennium/

Persdotter, J. (2020). Introducing menstrunormativity: Toward a complex understanding of 'menstrual monsterings.' In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 357–373). Palgrave Macmillan.

Persdotter, J. (2022). *Menstrual dirt: An exploration of contemporary menstrual hygiene practices in Sweden*. Arkiv Förlag. https://doi.org/10.13068/9789179243685

Rabeharisoa, V., Moreira, T., & Akrich, M. (2014). Evidence-based activism: Patients', users' and activists' groups in knowledge society. *BioSocieties*, *9*(2), 111–128.

Rahbari, L., Kramer, D., Deserno, M., Tse, T., & Matos, T. R. (2024). Activism and academia: an interdisciplinary dialogue on academic freedom and social engagement. *Journal of Higher Education Policy and Management*, *47*(1), 73–89.

Reame, N. K. (2020). Toxic shock syndrome and tampons: The birth of a movement and a research 'vagenda.' In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 687–703). Palgrave Macmillan.

Romano, S. T., & Daum, C. W. (2018). Conclusion: Teacher-scholar-activists in the era of trump: Where do we go from here? *New Political Science*, *40*(3), 599–604.

Rydström, K. (2020). Degendering menstruation: Making trans menstruators matter. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 945–959). Palgrave Macmillan.

Rydström, K., Hallencreutz, R., & Simon, A. (2019, April 11). *Inkludera menstruation i arbetsmiljöarbetet*.Arbetet.https://arbetet.se/2019/04/11/inkludera-menstruation-i-arbetsmiljoarbetet/

Santos, A. C. (2012). Disclosed and willing: Towards a queer public sociology. *Social Movement Studies*, *11*(2), 241–254.

SFS nr: 1993:100. *Högskoleförordningen*. Utbildningsdepartementet. https://www.riksdagen.se/sv/dokument-och-lagar/dokument/svensk-forfattningssamling/hogskoleforordning-1993100_sfs-1993–100/

Speed, S. (2006). At the crossroads of human rights and anthropology: Toward a critically engaged activist research. *American Anthropologist*, *108*(1), 66–76.
Sprague, J. (2016). *Feminist methodologies for critical researchers: Bridging differences*. Rowman & Littlefield.
Steward, R., Crane, L., Roy, E. M., Remington, A., & Pellicano, E. (2020). "Life is much more difficult to manage during periods": Autistic experiences of menstruation. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 751–761). Palgrave Macmillan.
SULF. (2024, March 21). *SULF 40 år 2024: Akademi och aktivism – tabu eller förbannad skyldighet?* [Video]. https://www.youtube.com/watch?v=UovnzaTVCqQ
Toreson, R. (2025, January 23). *Trump administration moves to reject transgender identity, rights – Sweeping executive order seeks to dramatically curtail protections*. https://www.hrw.org/news/2025/01/23/trump-administration-moves-reject-transgender-identity-rights
Trauger, A., & Fluri, J. (2012). Getting beyond the "god trick": Toward service research. *The Professional Geographer*, *66*(1), 32–40. https://doi.org/10.1080/00330124.2012.705738
United Nations. (2022). *Gender equality index: Sweden*. http://hdr.undp.org/en/countries/profiles/SWE
UNESCO. (2018). Recommendation on Science and Scientific Researchers https://unesdoc.unesco.org/ark:/48223/pf0000263618
Vostral, S. L. (2011). Rely and toxic shock syndrome: A technological health crisis. *The Yale Journal of Biology and Medicine*, *84*(4), 447–459.
Vostral, S. L. (2018). *Toxic shock: A social history*. New York University Press.
Vostral, S. L. (2020). Of mice and (wo)men: Tampons, menstruation, and testing. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 673–686). Palgrave Macmillan.
Wilson, J. (2018). *Defining faculty roles: In defense of the activist-scholar*. The James G. Martin Center for Academic Renewal. https://www.jamesgmartin.center/2018/04/defining-faculty-roles-in-defense-of-the-activist-scholar/

10 Feminist empiricism as feminist activism: lessons from the GenderSci Lab

Helen Zhao and Kelsey Ichikawa

Introduction

In this chapter, drawing on our experiences as members of the GenderSci Lab, we illustrate one model of feminist scholar-activism: "speaking truth to power" (Collins, 2013). We show how the GenderSci Lab speaks truth to power by intervening in institutionalized practices of studying sex and gender in the biomedical and health sciences. While other members of our lab have discussed how the GenderSci Lab integrates intersectional feminist frameworks into biomedical research (Shattuck-Heidorn et al., 2023) and models a feminist approach to analysing COVID-19 sex disparities (Boulicault et al., 2022), here, we offer our intimate, proud, and deeply honest reflections on the lab's achievements and flaws as a feminist health activist space. The GenderSci Lab is a collaborative, interdisciplinary research community, based at Harvard University in Cambridge, Massachusetts, and comprising scholars in the United States and Europe, that aims to excavate and criticize "binary biological sex-essentialist" assumptions underlying studies of health, with implications for clinical treatments, legal reasoning, and public beliefs about identity and difference. This chapter reflects on our lab's knowledge-making practices and argues that they exemplify feminist health activism by troubling empirically shallow frameworks and offering intersectional, biosocial approaches to the biomedical sciences.

The GenderSci Lab's research is consistent with epistemic principles central to "feminist empiricism" (Anderson, 1995; Longino, 1990; Nelson, 1990): not only is it committed to rigorously evaluating theories on the basis of empirical evidence, but it seeks to do so while taking into account the social context, values, and histories that inform situated inquiries. Moreover, like other creative mobilizations of feminist politics and health activism in this collection, the lab aspires to produce "knowledge that matters" (Tatman, 2001) and explore alternative modes of existing and labouring in the academy, as other feminist scholars have reflected upon (Mountz et al., 2015; Caretta & Faria, 2020). It devotes considerable resources to cultivating intellectually agile, interdisciplinary, and resolutely feminist scholars, committed to "punching up" and making change. Both its research and efforts to build a nourishing community

DOI: 10.4324/9781003319818-14

within the lab are central to how the GenderSci Lab speaks truth to power. Meanwhile, practical, institutional, economic, and affective constraints complicate the lab's everyday routines in the "corporate academy" (Mohanty, 2003). In addition to celebrating the GenderSci Lab's research processes, achievements, and community norms, this chapter also grapples with uneasy frictions that arise between the lab's ideals and inequitable practices of academic knowledge production.

Interrupting sex-essentialist biomedical discourses and their afterlives

The GenderSci Lab grew out of a ten-year gender, feminism, and science reading group based at Harvard University. In 2018, Sarah S. Richardson, Heather Shattuck-Heidorn, and Meredith Reiches founded the lab to question and interrupt sex-essentialist assumptions, which posit that biological sex is binary at all levels, and biological sex differences are large in magnitude and extend to every human biological system (Richardson, 2022). Poorly established scientific claims presupposing sex essentialism have been used to justify discriminatory legal policies, such as blocking gender minorities' access to healthcare, bathrooms, and employment protections (Sudai et al., 2022). Meanwhile, when binary biological sex essentialism operates as the default background, scientists and funders often focus on sex-linked pathways at the expense of well-established social and gender-related causal variables (Homan, 2019; Joel et al., 2015; Richardson, 2022; Shattuck-Heidorn & Richardson, 2019; Springer et al., 2012).

Since its founding, the GenderSci Lab has strived to challenge sex-essentialist assumptions, enabling harmful practices in law, science, medicine, and public life. In addition, it has aimed to advance rigorous, socially responsible research by generating robust successor concepts and methods for studying sex and gender. The lab's research has begun to change how scientists and policymakers think about gender/sex in biomedical and health contexts. We believe that the lab's success can be partly explained by the focus, background strategies, and organization of our collaborative research process.

Lab-wide projects and research streams

Every year, the GenderSci Lab undertakes a lab-wide research project in which most or all members of the lab participate. We choose the research questions that guide these projects carefully with an eye to producing original, timely, and consequential interventions on contested areas of science. As we show below, we try to stay focused on excavating and criticizing sex-essentialist assumptions, deployed or implicated by cutting-edge and often over-hyped biomedical research programs. By doing so, we set ourselves up to pursue ambitious critiques that stay current with ongoing developments in high-profile and high-impact research fields. For example, in 2020 and 2021, the lab waded

into COVID-19 research. We interrogated sex-essentialist explanations of sex disparities in COVID-19 mortality rates. We were interested in whether men really were dying at higher rates than women, and if so, whether this was best explained by mechanisms linked to biological sex differences (e.g. mosaicism, oestrogen versus testosterone).

Out of this project emerged several peer-reviewed publications. A team of ten GenderSci Lab members led by Ann Caroline Danielsen published one of the first longitudinal studies to quantify variation in COVID-19 gender/sex disparities across the US. Analysing 55 weeks of sex-disaggregated data from the Data Tracker, they illustrated that sex disparities in COVID-19 mortality were not large, stable, or consistent across time and place (Danielsen et al., 2022). Meanwhile, based on data from the lab's COVID-19 Data Tracker, Tamara Rushovich and colleagues produced the first analysis in America of COVID-19 mortality rates by sex and race (Rushovich et al., 2021). They also generated the first and most comprehensive compilation of gender/sex-disaggregated data on COVID-19 cases and fatalities across the US states and territories. This project used the term "gender/sex" to acknowledge how gender- and sex-related variables are often entangled, and differences in public health data tagged as "female" and "male" could be driven by sex, gender, or both. Their research was widely reported by *Bloomberg*, *The 19th*, *Slate*, *CBS News*, *Huff Post*, and *MIT News* and became part of high-level conversations about the pandemic and the future of healthcare and research.

Through reflecting on the methodologies of our COVID-19 projects, members have made conceptual contributions to feminist bioethics (Boulicault et al., 2022) and theories of intersectionality (Shattuck-Heidorn et al., 2023). Aside from informing the lab's research on patterns of COVID-19 mortality, our COVID Tracker, which reported gender-/sex-disaggregated data on US COVID-19 cases and fatalities between April 2020 and November 2021, has been used for public health studies by other actors, including state public health researchers.[1] The lab's COVID-19 projects sought to model a rigorous and fruitful approach to investigating sex disparities in health. This approach rejected default assumptions of intrinsic thorough-going sex differences and gave due attention to social context, heterogeneity, and gendered variables. Lab members' other interventions in men's reproductive biology (Boulicault et al., 2021) and the study of sex as a biological variable in preclinical science (Richardson, 2022) have similarly aimed to provide scientists and science and technology studies (STS) scholars with live conceptual alternatives to sex-essentialist science.

In general, the GenderSci Lab aims to produce "big papers" that speak to and interrupt sex-essentialist discourses. This approach has helped the lab to crack open ossified paradigms and teach lab members to navigate journal systems. However, there are also limits to this approach. For instance, sometimes members withhold from communicating the full brunt of their criticism in order to render their insights legible and credible to established scientific audiences. They learn to write in the language of the dominant knowledge

community, unacquainted with feminist, philosophical, and STS theories. Publication of research is occasionally slowed by a painful and deeply frustrating peer review process (Shattuck-Heidorn et al., 2023). Nonetheless, because of the unique political and cultural authority that biomedical knowledge possesses, we continue to intervene in these discourses in hopes that critiques in these contexts will be especially effective at weakening sex essentialism's influence and appeal at large.

Sex essentialism underlies not just one or two areas of biomedical research but huge swaths of deeply entrenched and well-resourced health sciences theory, policy, and practice. It undergirds fields as varied as women's health, sex and gender medicine, pharmaceutical science, and basic research. Thus, lab members are encouraged to pursue research projects across a wide sweep of areas in tandem with lab-wide projects. Within these parallel "research streams," members have made critical interventions on a diverse array of subjects, including healthcare and finance, sociogenomics, precision medicine, and law and public policy (Bruch et al., 2020; DiMarco et al., 2022; Richardson et al., 2019; Sudai et al., 2022).

Research streams have contributed to the impressive range and volume of the lab's research outputs. They have helped members to find their niche within the lab and furthered uptake and public conversation about our work. Members have published articles in peer-reviewed medical, scientific, policy, philosophy, and science studies journals. This versatility would not have been possible without our interdisciplinary community. Lab members possess a broad range of skills and interests, and they vary in career stage and institutional affiliation. Their expertise runs the gamut: philosophy, sociology, human evolutionary biology, neuroscience, computer science, epidemiology, women and gender studies, history, and science and technology studies. By bringing into the fold intellectually diverse scholars, the lab is better equipped to engage in "transformative criticism" (Longino, 1990). Interdisciplinarity gives us the theoretical and methodological tools to mount multipronged offensives against sex-essentialist science.

Critical voices in public discourses and the classroom

Challenging sex essentialism requires not only changing practices within scientific communities but also transforming the dominant beliefs, frameworks, and claims at play in wider publics. For this reason, the lab devotes considerable time and resources to producing public-facing writing and translating our knowledge for non-academic audiences. Members have written editorials for popular press outlets such as *The New York Times, The Guardian, Boston Globe, STAT, Health Affairs,* and *Ms. Magazine*. Many of us have written posts for the lab's public-facing blog, which has allowed our research to travel in more digestible forms. By taking care to frame and accessibly communicate our findings, we hope to produce "knowledge that matters" (Tatman, 2001). One member's blog post (Gompers, 2021) was widely shared on Twitter/X by

immunologists and cited by the lab member's own professor during a graduate school training. Another blog post series explained and contextualized the Gender Equality Paradox (Shattuck-Heidorn, 2020), the claim that countries with more gender equity exhibit a larger gender gap in STEM. It continues to be cited by tech workers in discussions about gender representation in STEM and has been cumulatively viewed over 10,000 times.

Besides op-eds and blog posts, lab members have worked directly with journalists to shape public narratives. The lab has been interviewed by varied publications and by journalists from around the world, including the UK, Russia, Israel, Sweden, Germany, and France. We contributed to a *ProPublica* article on the disproportionate number of deaths of Black men during the pandemic (Johnson & Martin, 2020). In addition, in 2020 and 2021, we collaborated with a research team at *The Atlantic* to track and properly contextualize race and gender disparities in COVID-19 outcomes.

During the period from April 2020 to November 2021, the lab published seven "US state report cards" based on our COVID-19 Data Tracker. These report cards evaluated state-level data reporting practices, considering such things as whether data was disaggregated by both race and sex and whether trans/gender-expansive people were counted at all. Our goal was to encourage public health departments to report important variables for understanding intersectional health disparities. In addition, we aimed to explore structural reasons for frequent lack of reporting of those variables and document shifts in reporting practices over the course of the pandemic. We hired undergraduate RAs to work on the Tracker and the US state report cards. This became the basis for a *Health Affairs* commentary on the need for more inclusive data collection. This commentary, Perret et al. (2021), was cited in Congressional Reports and the Presidential Health Equity Task Force Report (Nunez-Smith et al., 2021), illustrating how public-facing scholarly interventions can have a swift impact on civic agendas.

More recently, in September 2022, lab members collectively drafted a public comment on former President Biden's call for "inclusive and responsible" federal data collection practices on "disparities that LGBTQI+ individuals, families, and households face, while safeguarding privacy, security, and civil rights" (Executive Office of the President, 2022). In this comment, we emphasized that more data is not always better. For example, LGBTQI+ data linked to biological materials or samples without oversight could encourage biological explanations of social behaviour that risk stigmatizing or pathologizing non-normative sexual behaviours. We encouraged the subcommittee tasked with developing a Federal Evidence Agenda of LGBTQI+ Equity to place high priority on trust, privacy, and consent. We underscored the importance of critically analysing gender and sexuality as variables and not linking social categories to biomedical materials without special review and oversight. Moreover, we emphasized the need to fund research that contextualizes and critically examines the construction of identity categories (Zhao & Richardson, 2022).

Alongside research publications and public writing, the lab has created publicly available teaching modules for use in undergraduate and graduate classrooms. In 2020, the lab published a toolkit for teaching COVID-19 sex disparities, with an emphasis on social and gender-related explanations (Danielsen, 2020). In 2022, we assembled a teaching toolkit on "sex contextualism," a conceptual framework first articulated by Sarah S. Richardson (2022) that implicitly guides much of the lab's research.

Sex contextualism foregrounds the plurality and context-specificity of operationalizations of "sex" in experimental laboratory research. It calls on experimental scientists to define "sex" as applied in practice precisely, and to attend to the ethical implications of different operationalizations of "sex" in research. It argues that both science and society would be better off if "sex" were defined in ways that meet context-specific explanatory needs, in modest lockstep with the best available evidence. To communicate the framework's central insights, we published an open-access teaching toolkit for classroom use, supplemental Q&A blog post with Sarah, and a digestible research guide for experimental scientists (Ichikawa, 2022).[2] Materials included ready-to-go slides, lecture notes, and suggestions for classroom activities. Lab members have given presentations using these materials in a range of class settings to AmeriCorps trainees, high school students, and undergraduates. The GenderSci Lab spends time and labour to produce pedagogical materials because it treats their production as constitutive of the lab's commitment to producing knowledge that matters.

Cultivating a space outside-inside the university

Taking our cue from feminist science studies' call to scientists to study the inquirer, the *subject* of inquiry, with the same rigor and criticality as they study the *objects* of inquiry (Harding, 1992), in the GenderSci Lab we try to theorize and transform not only what kinds of knowledge are produced but also how *we* produce knowledge: our values, habits, and investigative practices. The content of science is deeply shaped by an inquirer's standpoint and by the networks of power and institutional logics that marginalize some perspectives while elevating others (Haraway, 1988; Harding, 1986; Keller & Longino, 1996). Ongoing articulation and reflection upon our community norms and context of inquiry are thus a central part of the lab's rituals.

The lab tries its best to do science in ways that sustain our community without mirroring the perverse incentives and insularity of many academic fields today. We believe that in order to reshape biomedical discourse, feminist scholars of science have to relearn how to be in the academy. Through encouraging joyful, honest, accountable, and caring practices of inquiring together, our hope is to generate friction in relation to embodied habits of individual entrepreneurship. These habits have tended to encourage solitary inquiry and suspicion of others; they are habits routinely reinforced by the neoliberal and corporate university (Mohanty, 2003; Mountz et al., 2015; Smyth et al., 2020).

The GenderSci Lab Manual, which outlines the lab's goals, structures, and community agreements, emphasizes that one of our priorities is "people and community" within the GenderSci Lab. As a case study for other feminist experiments, below are three principles that serve to guide and structure our knowledge-making practices and community formations. First, the GenderSci Lab attends to power. Second, we embrace mess in the writing process. Third, we are committed to building trustworthy relationships that are a precondition for accountability. These principles are aspirational; we recognize that we do not always successfully live up to our ideals. Moreover, different positionalities within the lab may have different perspectives on the space, community, and norms that regulate it. While the lab collectively negotiates and regularly discusses its values, other lab members may experience the lab's community differently than the authors do. The following notes are therefore the authors' own reflections on the lab's ideals: their content and their realization.

Attending to power and unsettling hierarchies

The lab is devoted to questioning and unsettling unjust power structures in the neoliberal university. Partly, it does this through a membership structure that is both cross-rank and cross-institution. Some of our most cited publications include undergraduates alongside tenured faculty. In recent years, for instance, the lab has expanded from Harvard to include members from University of Southern Maine, University of Michigan, Columbia, MIT, Tulane, and University of Chicago.

Peer mentorship is an important element of lab life. Our leadership team devotes two roles to cultivating mentorship and community. These leaders ensure that incoming members are paired with long-time members who share a research field, institution, or career stage. The lab's leadership organizes vertical and horizontal mentoring opportunities about career paths, skills sharing, and grad school expectations. We also encourage a culture of sharing resources: some of our most active Slack channels are those for spreading news of job postings, events and opportunities, grant calls for applications, and new articles of interest.

Through its assignment of authorship and credit, the lab endeavours to challenge hierarchies of value implicit in academic knowledge production. We try to grant authorship to everyone who contributes substantially to a paper, and oftentimes, this means author lists of up to 10–15 people. Given authorship restrictions imposed by many academic journals, especially in the humanities and social sciences, it can be difficult to ensure that everyone has a chance to be an author. One strategy our lab has adopted to overcome authorship restrictions is to diversify our research outputs so that different kinds of contributions have a chance to be recognized. For example, in a recent lab-wide project, we aimed to publish three big papers in different journals in order to ensure fuller coverage of our research findings. We also hoped that this would enable lab members who vary in expertise, specializations, and levels of experience to each be an author on at least one big paper.

The GenderSci Lab is not embarrassed by power and uses it to further its mission where possible. We are aware that a Harvard affiliation is useful for being taken seriously, especially when we openly and ambitiously criticize high-octane biomedical research. Thus, we deploy this advantage when it helps, and we encourage ongoing critical reflection about the kinds of credibility and resources that being based at Harvard uniquely affords us. For example, before the lab was recently awarded a generous external grant, we relied heavily on internal funding, which at Harvard is much more bountiful than at other institutions. Later in this article, we discuss how the uncommon resources our community has access to not only empower us but also limit the scope and horizons of our scholar-activism by introducing new forms of inequity and exclusion.

Embracing mess

As previously discussed, interdisciplinarity is an integral element of our community. We would not produce our range of outputs or powerfully critique sex-essentialist discourses without it. Nonetheless, collaborating across disciplinary divides is not easy, and often interdisciplinary research gets messy. As scholars and scientists hailing from different intellectual traditions, we approach problems with different methods, reference points, and assumptions. We write according to different stylistic and research conventions. We critique science in different registers. However, rather than reject or attempt to discipline this feature of our work, we have found it essential to embrace the mess of our practice.

To give an example, at the write-up stage for lab-wide projects, we usually begin the collaborative drafting process with an event we call "Paper-in-a-Day." Paper-in-a-Day is just what it sounds like: members brainstorm, draft, and revise a manuscript together in real time over the course of a day. Those who aim to take responsibility for the project gather together in an office for nearly eight hours and, working from an outline, attempt to complete a "zero draft" of a paper. They expect what they produce to be a monstrous mess. By "monstrous," we mean that the text becomes "both strangely other and part of [ourselves]," exhibiting "its own sets of agencies that the writer must live with" (Henriksen et al., 2021, p. 562). At the beginning, it is hard to imagine how a coherent argument will ever emerge from this "monster," containing a Frankensteinian motley of seemingly ill-fitting pieces informed by diverse disciplines. Understandably, many lab members find this part of our research process deeply uncomfortable and often do not know how to start or finish it. However, through collectively revising and rewriting sometimes upward of fourteen drafts, so far, the lab has always managed to pull a cohesive paper together.

Paper-in-a-Day requires faith that mess will give way to a coherent synthesis. It involves making hard choices about what parts of an argument to keep, discard, postpone, or foreground. People have to rely on each other's varied domains of expertise to complement their own partial points of view. They

have to trust the lead author or Lab Director to take their contributions and, with wisdom and generosity, consolidate, cut, and structure. At odds with an individualized model of knowledge production, authors have to relinquish their need to control the final product. They have to accept the ability of their "monstrous text-body" to "question and dodge the will of its creator[s]" (Henriksen et al., 2021, p. 566).

To be clear, "embracing mess" here is not envisioned as a rejection of method, or as "trying to make and know realities that are vague and indefinite" (Law, 2004, p. 14). It is enacted as a cacophony of voices on the page, only partially intelligible to each other, speaking at once in demonic chorus. This chaos of sound/text can lead to jarring productions, many-headed texts that seem impossible to tame or to make sense of. But, by embracing mess in the writing process, we learn to reject the implicit expectation, present in many university spaces, that we must approach our research already polished, prepared, and finished.

Mess encourages lab members to remain open to possibilities, to be comfortable with uncertainty, and to sit in chaos and dwell in doubt. Our willingness to embrace mess/cacophony makes us more alive to the unfamiliar and alien in knowledge. In addition, it is a way of enacting a feminist ethic of dissensus that emphasizes creative tension as opposed to closure (Grebowicz, 2005; Ziarek, 2001). Thus, despite its challenges, it remains a cornerstone of the lab's research, writing, and editing process.

Building and rebuilding trust

Feminist and STS scholars have highlighted how trust in science depends on a complex web of interactions and social practices among researchers (Rolin, 2002; Scheman, 2011; Tubig & McCusker, 2021). These scholars have often focused on the construction of trustworthiness in experts and their knowledge claims. Here, we join other feminist labs in analysing the conditions of (mis) trust in interdisciplinary endeavours (Leighton & Roberts, 2020). We turn to the conditions of interpersonal trust among GenderSci Lab members, necessary for working together across disciplinary boundaries. Trust plays a central role in three dimensions of our lab's research process: when we hold each other accountable to the practices and outcomes of our research; when we engage in candid and open communication, including on uncomfortable topics; and when we perform small, yet important, daily acts of care and nurture.

In the GenderSci Lab, we hold each other to high standards of research quality, check each other's work, ask for clarification, and raise questions with an eye to rigor and constructive improvement. We have found that this accountability is especially crucial in collaborative, interdisciplinary endeavours, where each team member cannot know every component of the project with equal comprehensiveness and depth. It is especially important when accountability "emphasizes the self *in relation* to a collective" and entails attending to not only one's individual contribution but also the collective research process: its

emergent shape, robustness, and means of inquiry (Kenney, 2015, p. 750). As a result, trust in both our capacity and willingness to hold each other accountable is central to the integrity of our scholar-activism.

Because we are responsive and accountable to the situatedness of knowledge production, we encourage each other to acknowledge our ignorance. As Sarah S. Richardson once put it, we hope that others will tell us when we are smiling with spinach in our teeth. In order for this to work, we have to trust that our words and actions will be interpreted generously and that we will tell each other hard truths. When on the receiving end of criticism, we have to trust that our fellow lab members are acting in good faith, and when giving criticism, that our feedback will be taken with an open mind and gratitude. This has been crucial to sustaining the integrity of both our scholarly output and interpersonal bonds and encouraging trust, especially when resolving disagreements and engaging in repair after conflict. When actualized, these elements of trust support an atmosphere of open and honest communication, whether it be expressing a contrary opinion on a recent publication, hesitations we have about lab policies, or disagreements with long-term strategy.

For instance, as one of our research teams approached manuscript submission, a lead author on the paper noted that they were not comfortable with cutting an empirical detail. This led to a dialogue between the two lead authors, resulting in a reincorporation of the detail with new framing language that reflected the critical dialogue. In another instance, a junior member of the lab approached lab leaders about concerns with the rigor of their colleague's research protocols. Because of this person's forthright communication, lab leaders were able to clarify the colleague's actions and correct the deviation from the research protocol.

Trust functioned to ensure that conflicts and problems were raised for discussion and remedy in formal channels, rather than being repressed or festering in back conversations. Importantly, in the lab, we do not assume that trust is something achieved once and for all but, rather, must be made and remade in every new interaction. Relationships *worthy* of trust have to first be cultivated. Such relational elements resonate with theory that understands "matters of care" as essential for the world-making practices of STS and technoscientific endeavours (Puig de la Bellacasa, 2011). Nurturing the relational conditions of trust is a long-term and challenging endeavour, involving affective work that often labours unseen beneath the skin.

These are the "mostly dismissed labours of everyday maintenance of life" (Puig de la Bellacasa, 2011, p. 100) that are necessary for trust and candour to flourish and which a politics of care foregrounds. Our attempts to foster those conditions take the form of small acts to produce a collegial, welcoming culture in the lab. We centre joy and playfulness in our interactions at work, using first names to address each other, celebrating birthdays and graduations, encouraging each other to rest and take breaks, inviting people to share personal and professional updates each week, and providing support for each other's projects outside of the lab. Members are encouraged to get

to know each other in one-on-one and group meetings with our direct mentors and with Sarah, the Director. We try to build connections and cultivate more-than-working relationships through labouring side by side on yearlong projects, attending annual visioning retreats, and learning together in weekly meetings.

Uneasy labour: reflections on the limitations of our activist-scholarship

Labouring to cultivate a lab culture and community that attends to and unsettles hierarchies, revels in mess, and builds trustworthy relationships is an important aspect of our scholar-activism. However, we are often reminded that these efforts to intervene on how we know do not stand outside of extractive logics, racism, patriarchy, and settler-colonial histories that continue to animate the neoliberal university's halls. Our research is produced under conditions that often scrape against our cherished feminist values and ideals. It is important to name and sit with these difficult and unsettling features of our work. Doing so represents not only an act of care toward ourselves but also a way of honouring our feminist commitments to strong reflexivity and accountability.

In this section, we elaborate on the tensions, limitations, and challenges we have observed in the GenderSci Lab's research pursuits and practices over the past five years. Some lessons are intended to serve as practical considerations for those scholar-activists attempting to build their own feminist labs, collectives, and communities. Other lessons we hope will contribute to studies of health activism and academic political cultures. Here, we illuminate the particular trade-offs and quandaries confronted by our efforts to interrupt sex-essentialism from within the constraints of the corporate academy.

The GenderSci Lab faces a reality of doing progressive, feminist research in a sociopolitical environment with strong factions that oppose our political values. Unsurprisingly then, corresponding authors on our papers have sometimes received unprofessionally angry or hateful emails accusing our work of being politically motivated and insulting gender studies departments. When we first launched our Twitter/X account, we had to restrict commenting privileges on our tweets because we were initially flooded with internet trolls. Multiple lab members have published individual articles or tweeted threads that have garnered vicious attention on social media. Consequently, prior to publishing our research on sperm counts (Boulicault et al., 2021), which touched on issues of interest to alt-right and men's rights activist communities, we developed safety resources and plans to protect lab members from doxxing, the practice of publishing on social media someone's private information as a means of malicious exposure.

While our lab work can be a feminist labour of love and joy, it is also difficult labour that, in the compromises it demands, can leave us feeling uneasy. We recognize that the GenderSci Lab is an academic group at an elite private university, intervening in primarily academic discourses and high-level

policy and media conversations. In the context of the lab, members are not involved in the business of movement-building. We are not "on the ground" in locally rooted communities. These are crucial modes of political agitation that much existing scholarship on activism has rightly underscored. We have begun to explore ways of joining forces with activists and community actors, such as designing publicly available data tools in partnership with journalists (e.g. COVID Data Tracker), drafting a public comment on an administrative agenda (Zhao & Richardson, 2022), and exploring the incorporation of community advisory boards in shaping our research agenda. However, these efforts are preliminary, and our work remains no substitute for the enduring, often erased, and under-appreciated work of community organizing and political protest.

In addition, the intrinsic exclusiveness of the lab's membership constricts the horizons of our scholar-activism. Only a tiny few have a chance to be a part of our space, and lab members hold varying amounts of privilege and resources. While nearly all GenderSci Lab members are cis or trans women and/or LGBTQIA+, all come from formal academic institutions, and most either have or are receiving graduate-level training in their fields. As we reflect on in other pieces, the majority of the lab is white (Shattuck-Heidorn et al., 2023). Because our membership is not representative of the broader public, our internal attempts to redistribute power through the GenderSci Lab's mentorship and training have only limited impact.

Furthermore, since its founding, our group has grown in size to over 20 members at the time of writing. We have come to acknowledge that principles of inclusion and justice applied to deciding membership can stand at odds with the practical reality of maintaining a healthy community life. The more people who participate in the lab, the more challenging it is to provide holistic mentorship for each person. Rising attendance at lab meetings makes it difficult to hear everyone's voices and ensure full participation.

Meanwhile, the lab's explicit commitment to cross-institutional research entails special forms of administrative labour and bureaucratic know-how. Gathering our community together is not a frictionless endeavour. At times, it is impeded by institutional gatekeeping of digital platforms and financial resources designed to increase the efficiency of collaboration within a university or school but not across a broader academic network. Adding people from more institutions means more hybrid interactions, which in turn demands more effort and labour to cultivate rich, affective relationships that, as previously described, are foundational to building trust. In general, sustaining a level of order and working infrastructure underneath the generative messes of our research is hard and often hidden work, much of it shouldered by the Lab Director and Lab Manager. It includes but is not limited to project-managing ongoing research streams; writing grants and administering them; maintaining the lab's public communication platforms, including its academic blog, website, email, and Twitter/X accounts; and providing administrative support.

Running the lab is considerably time-intensive, in addition to being resource-intensive. Finding ways to compensate lab members who are not Harvard grad students is a continual challenge that requires creative solutions within the university's constraints on honoraria, part-time positions, and visiting scholars. Acquiring temporary university appointments is necessary to give non-Harvard lab members full access to research resources and communication platforms, such as Slack, which otherwise provide only second-tier access, if any access at all. Collaborating in teams of five to ten authors requires identifying, scheduling, and setting aside regular meeting times across many conflicting schedules and time zones. It involves the oft-hidden labour of drafting agendas and catching up members who missed important meetings.

The lab strives to provide annual salary and benefits for full-time staff like the Lab Manager and postdoctoral fellows, as well as fair wages for research assistants and summer salaries for professors. However, our funding pursuits are constrained by our research, which, by nature of being timely, organic, and responsive to emergent sex difference claims, does not always lend itself to grant funding. Funding bodies often expect a multiyear project with a research question and method clearly defined in advance. This misalignment between our research goals and the resource landscape speaks to the specific challenge of compensating researchers who directly and quickly intervene on harmful studies or policies, given such research is not typically prioritized within federal and private funding agendas.

Time in the lab develops members' academic skill sets. We are taught to do public-facing work, which often is not a structured part of undergraduate or graduate school curricula. We are taught to communicate clearly to others in different disciplines and to sharpen our nose for questions that matter and that we ourselves can uniquely answer. That said, the lab can also present career tensions for graduate students and postdoctoral fellows. While many members' experiences on the job market have shown that lab work is well-regarded, we often worry that our research is not as prized as conventional forms of academic scholarship. Because of the value ascribed to specialization, our interdisciplinary research is often at odds with traditional markers of scholarly promise. Despite resulting in high-impact scholarship, its outputs may be less applauded by home disciplines. We may write and publish work in journals or venues that do not carry cachet within our academic fields. Moreover, much of our research is necessarily collaborative. But, because both the American university and the wider system for judging expertise in some academic disciplines continue to assume the myth of the isolated scholar, shared authorship is usually less valued than single authorship, especially in the humanities (Nyhan & Duke-Williams, 2014).

Meanwhile, research is stressful, time-consuming, and hard. We are morally attached to the work, and we want to do it well. Sometimes, caring for our work seems to stand at odds with caring for ourselves and our personal relationships. Thus, Nicholls, Henry, and Dennis, reflecting on "the darker side" of care, caution against uncritically framing care as a "positive feeling" or

as a political good (Nicholls et al., 2021). Puig de la Bellacasa (2011, p. 100) writes that "a way of caring over here could kill over there." That is, forms of attachment are not innocent feelings. They can become conscripted into technologies of self that discipline the subject and reify precarity.

Still, in the lab we cannot but care about care. Caring is what drives us to grapple with and take responsibility for the tensions, challenges, and contradictions in our work, holding them in view even when they are not resolvable. The question begged is not whether to care but " 'how to care' in each situation" (Puig de la Bellacasa, 2011), as well as how to "develop and maintain relations of care as a site of critique and refuge from processes that seek to individualize, depoliticize and contain care as a personal (extracurricular) concern" (Nicholls et al., 2021, p. 73). Cultivating affects of collegiality and humour, offering gestures of material and emotional support to one another, uplifting neglected or taboo topics such as navigating academic careers as a parent or as a committed partner, and negotiating the mattering of ourselves and our work – these are all formations of care that can open up possibilities for balancing competing needs, correcting our mistakes, and forging ahead.

Conclusion

The GenderSci Lab's work is hard work. It involves writing, research, teaching each other, and learning to translate and probe the gaps between sometimes incommensurate disciplinary languages. Collaborative inquiry can be deeply rewarding, but it can also leave us disappointed, stressed, and frustrated.

Still, every day and every week, we throw ourselves into it anew. The GenderSci Lab offers the promise of a dream, a refuge from the routine violence and emotional damage of the traditional academic department "inscribed on our nervous system" (Mazzarella, 2009, p. 292). One might compare it to a "feminist coven in the university," alluringly painted by Araby Smyth, Jess Linz, and Lauren Hudson as a "temporary home" and "comforting space for nursing wounds, soothing aches, building each other up, [and] gaining strength" (Smyth et al., 2020, p. 870).

But is the GenderSci Lab a home, or a workplace? Is it a refuge from violence, or a training ground? When the lab discussed Smyth, Linz, and Hudson's piece, we were unsure whether "home" was the best way to characterize what we had painstakingly built. Specifically, we were unsure whether it was an innocent analogy. After all, far from an escape from hostility, home is often a site of domination, violence, and patriarchal grooming. Here, Smyth, Linz, and Hudson's definition of the feminist coven as "something admittedly imperfect itself, which carves spaces out of larger structures for alternative conventions to incubate" (Smyth et al., 2020, p. 855) offers a better guide for visioning the GenderSci Lab's efforts.

Through our uneasy labour to make knowledge that matters and foster a community of accountability and care, we hope to chip away at hidden walls splintering the academy and keeping us from joining forces. We aim to carve

out, with all of the sweaty labour implied, a space for doing science against the grain, in ways more consistent and faithful to our feminist ideals and values than the traditional academy. The feminist coven is not perfect and cannot be perfect, so long as it remains yoked to the corporate university, the private sector, and the military industrial complex. Nonetheless, a feminist coven offers a chance for "alternative conventions to incubate." In moments of doubt, this promise is enough for us to continue building our community with joy, pride, and reflexive understanding of our limits.

Usually, when one thinks of "activism," one thinks of activities undertaken outside of the university: on the streets, in the courts, and on the shop floor. However, in this chapter, we have aimed to convince our readers that research projects and practices, too, may constitute a form of "activism," indirect protest against the norms of the academy. To be sure, "speaking truth to power" represents only one mode of scholar-activism. Other modes include "speaking truth to the people" and doing research in direct collaboration with community participants (Collins, 2013; Hale, 2001). Nonetheless, intervening in contested areas of science is not just scholarship. We contend that it can also constitute movement-building and consciousness-building against hegemonic ways of knowing.

In the GenderSci Lab, pursuing high-impact research and developing critical feminist scholars are the means by which we attempt to disrupt sex essentialism, underwriting large swaths of the biomedical and health sciences. We hope that attending to the successes, strengths, and limitations of our work can help to illuminate strategies and modes of resistance, perhaps available to other feminist health activists as well. At its best, criticizing scientific discourses and building our community's capacity to do so complements the necessary labour of organizing, policy advocacy, and solidarity campaigns in health activism movements. It can undermine the grip of empirically weak and socially harmful claims, offering transformative knowledge on the road to gender and sexual liberation.

Notes

1 The tracker is still available online at https://www.genderscilab.org/gender-and-sex-in-covid19.
2 All of these materials are available online at genderscilab.org/blog. The teaching toolkit can be found at https://www.genderscilab.org/blog/sex-contextualism-teaching-tool; the Q&A can be found at https://www.genderscilab.org/blog/q-and-a-sarah-richardson-on-sex-contextualism; and the research guide can be found at https://www.genderscilab.org/blog/faq-for-scientists-applying-sex-contextualism.

Reference list

Anderson, E. (1995). Knowledge, human interests, and objectivity in feminist epistemology. *Philosophical Topics*, *23*(2), 27–58. https://doi.org/10.5840/philtopics199523213.

Boulicault, M., Gompers, A., Lee, K. M., & Shattuck-Heidorn, H. (2022). A feminist approach to analyzing sex disparities in COVID-19 outcomes. *IJFAB: International Journal of Feminist Approaches to Bioethics*, *15*(1), 167–174.

Boulicault, M., Perret, M., Galka, J., Borsa, A., Gompers, A., Reiches, M., & Richardson, S. S. (2021). The future of sperm: A biovariability framework for understanding global sperm count trends. *Human Fertility*, *25*(5), 888–902. https://doi.org/10.1080/14647273.2021.1917778.

Bruch, J. D., Borsa, A., Song, Z., & Richardson, S. S. (2020). Expansion of private equity involvement in women's health care. *JAMA Internal Medicine*, *180*(11), 1542–1546. https://doi.org/10.1001/jamainternmed.2020.3567.

Caretta, M. A., & Faria, C. V. (2020). Time and care in the "lab" and the "field": Slow mentoring and feminist research in geography. *Geographical Review*, *110*(1–2), 172–182. https://doi.org/10.1111/gere.12369.

Collins, P. H. (2013). Truth-telling and intellectual activism. *Contexts*, *12*(1), 36–39, 41. https://doi.org/10.1177/1536504213476244.

Danielsen, A. C. (2020). *New teaching tool from the GenderSci Lab on gender/sex disparities in COVID-19 outcomes.* [Blog Post]. Retrieved from https://www.genderscilab.org/blog/gender-sex-disparities-in-covid19-outcomes-teaching-module

Danielsen, A. C., Lee, K. M., Boulicault, M., Rushovich, T., Gompers, A., Tarrant, A., Reiches, M., Shattuck-Heidorn, H., Miratrix, L. W., & Richardson, S. S. (2022). Sex disparities in COVID-19 outcomes in the United States: Quantifying and contextualizing variation. *Social Science & Medicine, 294*, 114716. https://doi.org/10.1016/j.socscimed.2022.114716.

DiMarco, M., Zhao, H., Boulicault, M., & Richardson, S. S. (2022). Why 'sex as a biological variable' conflicts with precision medicine initiatives. *Cell Reports Medicine*, *3*(4), 1–3.

Executive Office of the President. (2022, June 15). Advancing equality for lesbian, gay, bisexual, transgender, queer, and intersex individuals. *Federal Register*. https://www.federalregister.gov/documents/2022/06/21/2022-13391/advancing-equality-for-lesbian-gay-bisexual-transgender-queer-and-intersex-individuals

Gompers, A. (2021). *No evidence for a sex difference in immune response to COVID-19: An explainer of the GenderSci lab's nature matters arising article.* [Blog Post]. Retrieved from https://www.genderscilab.org/blog/nature-matters-arising-explainer

Grebowicz, M. (2005). Consensus, dissensus, and democracy: What is at stake in feminist science studies? *Philosophy of Science*, *72*(5), 989–1000. https://doi.org/10.1086/508955.

Hale, C. R. (2001). What is activist research? *Items & Issues*, *2*(1–2), 13–15.

Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, *14*(3), 575–599.

Harding, S. (1986). *The Science Question in Feminism*. New York: Cornell University Press.

Harding, S. (1992). Rethinking standpoint epistemology: What is 'strong objectivity'? *The Centennial Review*, *36*(3), 437–470.

Henriksen, L, Kjær, K. M., Blønd, M., Cohn, M., Cakici, B., Douglas-Jones, R., Ferreira, P., Feshak, V., Gahoonia, S. K., & Sandbukt, S. (2021). Writing bodies and bodies of text: Thinking vulnerability through monsters. *Gender, Work & Organization, 29*(2), 561–574. https://doi.org/10.1111/gwao.12782.

Homan, P. (2019). Structural sexism and health in the United States: A new perspective on health inequality and the gender system. *American Sociological Review*, *84*(3), 486–516. https://doi.org/10.1177/0003122419848723.

Ichikawa, K. (2022). *New teaching tool from GSL about sex contextualism.* [Blog Post]. Retrieved from https://www.genderscilab.org/blog/sex-contextualism-teaching-tool

Joel, D., Kaiser, A., Richardson, S. S., Ritz, S. A., Roy, D., & Subramaniam, B. (2015). A Discussion on experiments and experimentation: NIH to balance sex in cell and

animal studies. *Catalyst: Feminism, Theory, Technoscience*, *1*(1), 1–13. https://doi.org/10.28968/cftt.v1i1.28821.

Johnson, A., & Martin, N. (2020, December 22). *How COVID-19 hollowed out a generation of young black men*. https://www.propublica.org/article/how-covid-19-hollowed-out-a-generation-of-young-black-men?token=Et9-BFFxtA4W9ek9a6nnyQciZohsnG1D

Keller, E., & Longino, H. (Eds.). (1996). *Feminism and Science*. New York: Oxford University Press.

Kenney, M. (2015). Counting, accounting, and accountability: Helen Verran's relational empiricism. *Social Studies of Science*, *45*(5), 749–771. https://doi.org/10.1177/0306312715607413

Law, J. (2004). *After Method: Mess in Social Science Research*. London and New York: Routledge.

Leighton, M., & Roberts, E. F. (2020). Trust/distrust in multi-disciplinary collaboration: Some feminist reflections. *Catalyst: Feminism, Theory, Technoscience*, *6*(2), Article 2. https://doi.org/10.28968/cftt.v6i2.32956.

Longino, H. E. (1990). *Science as Social Knowledge: Values and Objectivity in Scientific Inquiry*. Princeton: Princeton University Press.

Mazzarella, W. (2009). Affect: What is it good for? In Dube, S. (Ed.), *Enchantments of Modernity: Empire, Nation, Globalization* (1st ed., pp. 291–309). London: Routledge India.

Mohanty, C. T. (2003). *Feminism Without Borders*. Durham, London: Duke University Press.

Mountz, A., Bonds, A., Mansfield, B., Loyd, J., Hyndman, J., Walton-Roberts, M., Basu, R., Whitson, R., Hawkins, R., Hamilton, T., & Curran, W. (2015). For slow scholarship: A feminist politics of resistance through collective action in the neoliberal university. *ACME: An International Journal for Critical Geographies*, *14*(4), 1235–1259.

Nelson, L. H. (1990). *Who Knows: From Quine to a Feminist Empiricism*. Philadelphia: Temple University Press.

Nicholls, E. J., Henry, J. V., & Dennis, F. (2021). 'Not in our name': Vexing care in the neoliberal university. *Nordic Journal of Science and Technology Studies*, *9*(1), 65–76. https://doi.org/10.5324/njsts.v9i1.3549.

Nunez-Smith, M., Alvarez, M. E., Hildreth, Sr., J. E. K., Imparato, A., Joseph, V., Khaldun, J., Martinez, Jr., O. N., Putnam, T., Toranzo, V. C., Turner, M., Venters, H., Watts, B., & Yoon, H. (2021, October). *Presidential COVID-19 health equity task force: Final report and recommendations*. https://hogg.utexas.edu/news-resources/covid-19-health-equity-task-force-final-report.

Nyhan, J., & Duke-Williams, O. (2014). Joint and multi-authored publication patterns in the digital humanities. *Literary and Linguistic Computing*, *29*(3), 387–399. https://doi.org/10.1093/llc/fqu018.

Perret, M., Jillson, K., Danielsen, A. C., Trinh, M., Zubizarreta, D., & DuBois, L. Z. (2021). *COVID-19 data on trans and gender-expansive people, stat!*. [Blog Post]. Retrieved from https://www.healthaffairs.org/do/10.1377/hblog20210510.756668/full/ (accessed 26 May 2021)

Puig de la Bellacasa, M. (2011). Matters of care in technoscience: Assembling neglected things. *Social Studies of Science*, *41*(1), 85–106. https://doi.org/10.1177/0306312710380301.

Richardson, S. S. (2022). Sex contextualism. *Philosophy, Theory, and Practice in Biology*, *14*(2). Michigan Publishing. https://doi.org/10.3998/ptpbio.2096.

Richardson, S. S., Borsa, A., Boulicault, M. et al. (2019). Genome studies must account for history. *Science*, *366*(6472), 1461–1461. https://doi.org/10.1126/science.aaz6594.

Rolin, K. (2002). Gender and trust in science. *Hypatia*, *17*(4), 95–118.

Rushovich, T., Boulicault, M., Chen, J. T., Danielsen, A. C., Tarrant, A., Richardson, S. S., & Shattuck-Heidorn, H. (2021). Sex disparities in COVID-19 mortality vary across US racial groups. *Journal of General Internal Medicine*, *36*(6), 1696–1701. https://doi.org/10.1007/s11606-021-06699-4.

Scheman, N. (2011). Epistemology resuscitated: Objectivity as trustworthiness. In Scheman, N. (Ed.), *Shifting Ground: Knowledge and Reality, Transgression and Trustworthiness* (pp. 207–231). Oxford University Press. https://doi.org/10.1093/acprof:osobl/9780195395112.003.0012.

Shattuck-Heidorn, H. (2020). *The GenderSci Lab takes on the gender equality paradox hypothesis: introduction and primer*. [Blog Post]. Retrieved from https://www.genderscilab.org/blog/the-gendersci-lab-takes-on-the-gender-equality-paradox-hypothesis-introduction-and-primer

Shattuck-Heidorn, H., Boulicault, M., Rushovich, T., & Richardson, S. S. (2023). Intersectionality as live theory and practice in the biomedical sciences. In Nash, J. C. & Pinto, S. (Eds.), *The Routledge Companion to Intersectionalities* (1st ed., pp. 420–434). Routledge.

Shattuck-Heidorn, H., & Richardson, S. S. (2019, May 30). Focusing on differences between the sexes is leading medical researchers astray. *Washington Post*. https://www.washingtonpost.com/outlook/2019/05/30/focusing-differences-between-sexes-is-leading-medical-researchers-astray/

Smyth, A., Linz, J., & Hudson, L. (2020). A feminist coven in the university. *Gender, Place & Culture*, *27*(6), 854–880. https://doi.org/10.1080/0966369X.2019.1681367.

Springer, K. W., Mager Stellman, J., & Jordan-Young, R. M. (2012). Beyond a catalogue of differences: A theoretical frame and good practice guidelines for researching sex/gender in human health. *Social Science & Medicine*, *74*(11), 1817–1824. https://doi.org/10.1016/j.socscimed.2011.05.033.

Sudai, M., Borsa, A., Ichikawa, K., Shattuck-Heidorn, H., Zhao, H., & Richardson, S. S. (2022). Law, policy, biology, and sex: Critical issues for researchers. *Science*, *376*(6595), 802–804. https://doi.org/10.1126/science.abo1102.

Tatman, L. (2001). *Knowledge That Matters*. United Kingdom: Bloomsbury Academic.

Tubig, P., & McCusker, D. (2021). Fostering the trustworthiness of researchers: SPECS and the role of ethical reflexivity in novel neurotechnology research. *Research Ethics*, *17*(2), 143–161. SAGE Publications Ltd. https://doi.org/10.1177/1747016120952500.

Zhao, H., & Richardson, S. S. (2022, October 17). *GSL Pens public comment on federal evidence agenda for LGBTQI+ equity*. [Blog post]. Retrieved from https://www.genderscilab.org/blog/public-comment-on-federal-evidence-agenda-lgbti-equity

Ziarek, E. P. (2001). *An Ethics of Dissensus: Postmodernity, Feminism, and the Politics of Radical Democracy*. Stanford, CA: Stanford University Press.

Index

Note: Page numbers in *italics* indicate a figure and page numbers in **bold** indicate a table on the corresponding page. Page numbers followed by "n" with numbers refer to notes.