

# Undoing Threads of Knowledge

## Exploring Power, Activism, and Undone Science in Medical Teaching

AWA NAGHIPOUR & LUCIA MAIR

**Abstract** In medical training, students are often presented with an image of scientific knowledge as an inherently neutral, benevolent catalyst for societal progress and understanding. Yet, growing evidence shows the uneven distribution of research interest, prioritization, and funding, resulting in gaps of ‘undone science’ (FRICKEL *et al.* 2010). As a result, knowledge about bodies who are not male, cis, white, and abled is lacking, and medical care suffers. In this text, we reflect on our experience working with ‘undone science’ as an analytical framework with which to fill conceptual gaps in contemporary medical education, based on a joint teaching project at the Medical University of Vienna. Centering on three examples of ‘undone science’ – endometriosis, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and ‘male’ contraception – we conducted interviews with eight health activists in four countries. In this article, we discuss how bringing these voices into the classroom gave medical students an understanding of long historical continuities of health-related struggles and emphasized the socio-political responsibility of healthcare. We ultimately argue for the pedagogical potential of ‘undone science’ in medical teaching to encourage a critical analysis of knowledge construction surrounding health and illness, and a conscious shift in future healthcare workers from passive to vocal actors.

**Keywords** health activism – medical education – endometriosis – ME/CFS – reproductive health

*We need seminars, we need training, we need discussions,  
we need more people who do it, in the end, it  
takes a whole network of open libraries and  
exchange of knowledge ...*

Beat, a 59-year-old therapist from Zurich, furrows his brows. It is mid-October 2023, and he is speaking from a large screen in a seminar room, in front of twenty-four medical students. The room is quiet as we listen to Beat telling of his early twenties, when he became involved in leftist activist groups in Switzerland. After a while, frustrated with male members’ lack of “anti-patriarchal engagement” in light of the uneven burden of contraception, a small and committed group formed who later invented an experimental method for temporary at-home ‘male’ sterilization: the “Zurich testicle bathers” (Zürcher Hodenbader-Gruppe), he explains, to our students’ fascination.

We are holding a course titled “Undone Science – Power(lessness) in Scientific Research” (Die (Ohn)macht in der Wissenschaft) as part of the fourth-year public health block at the Medical

University of Vienna. ‘Undone science’, the core concept our seminar is named after, is rooted in Science and Technology Studies (STS) and Social Movement Studies, and describes research areas “identified by social movements and other civil society organizations as having potentially broad social benefit that are left unfunded, incomplete, or generally ignored” (FRICKEL *et al.* 2010: 445). Via discussion of three cases of ‘undone science’ – endometriosis, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and ‘male’ contraception – and their related activist movements in Austria, Germany, France and Switzerland we wanted to introduce students to ways of thinking about the politics of medicine, science, and technoscientific innovation they had not yet encountered in their medical training. Even more so, we hoped to create a moment of criti-

cal self-reflection, humility, and a sense of how ‘undone science’ can be brought to bear on their own role and social responsibility as future physicians.

The class, however, unfolded in multiple layers, stirring up personal questions and discussions among us as healthcare professionals, and with our students as future ones:

*Is the healthcare system beyond salvaging?*

*Can any system be changed from within, and if so: how?*

*How do we realize that the knowledge so often presented as undebatable is deeply rooted in selection and bias?*

*When and how do we acknowledge that we are not only bystanders in medicine, but that we are active and agile, able to shape and mold?*

*Are all the ‘good ones’ leaving clinical care?*

*Can medicine change to make them stay?*

In this text, we reflect on ‘undone science’ as an analytical framework with which to fill conceptual gaps in our students’ medical education; and as a way to tend to fissures in a fraught medical system. We ultimately argue for the pedagogical potential of ‘undone science’ in medical teaching to encourage a critical analysis of knowledge construction surrounding health and illness, and a conscious shift in future healthcare workers from passive to vocal actors.

### **The socio-political responsibility of healthcare**

We came into this teaching project as two former medical students, now physician-researchers. Planning our seminar, our underlying aim was to create a teaching format which we felt lacking during our own medical training: accessible, critical, stimulating, political. Medicine is not solely a life science, nor only effective in the realm of medical disciplines. It is at the center of society, and shapes worlds and realities of people in their most vulnerable moments in life. Working in healthcare, and shaping it from within, therefore holds a socio-political responsibility that is well-known in the social studies of health and healing,

but far too often neglected and left unmentioned in medical curricula.

We wanted to attend to this aspect concretely, but also de-center our own voices and make room for others. This was to break with usual epistemological hierarchies in medicine, as a social context where authority over knowledge tends to lie with doctors over patients. At the heart of our course were interviews with eight health activists from Germany, Austria, France, and Switzerland: Michelle and Ines from the Endometriosis Association Germany and Austria, respectively; Johannes and Laura from the Austrian Society for ME/CFS; and Belette, Félix, Pierre and Beat, all part of ‘male’,<sup>1</sup> thermal contraception initiatives in France and Switzerland. Following SUSI GEIGER (2021: 2), we understand health activism as “political and pragmatic action aimed at criticizing and/or achieving change in the status quo of research, practice, and market structures in the healthcare domain”, and chose interview partners who fell under this definition. Her definition aligns with what DAVID HESS (2022; 2015: 12f.) describes as the “social movement pole” on the continuum of health advocacy, as opposed to the work of mere “interest groups” who do not fundamentally try to challenge common assumptions about causes and treatment of diseases, and do not touch the status quo of ‘undone science’.

We wanted to know: when, how and why did our interlocutor’s role shift from patient to activist, and did they view themselves and their work as activist at all? What does this work consist of? What hindered or helped it, and which part did medical professionals play? All interviews were conducted over the summer of 2023, lasted around an hour, and were recorded, transcribed and edited for length.

All eight interlocutors were engaged with questions and afflictions which neither of us had heard much about in medical school ourselves, if at all, and we assumed the same for our students. This turned out to be the case. Endometriosis, a chronic gynecological condition, is estimated to affect 10 % of women,<sup>2</sup> or 178 million women globally (HUDSON 2022: 21), yet its aetiology remains unclear and treatment options sparse, in part due to limited political interest and lacking funding for endometriosis research worldwide. Similarly, ME/CFS is marked by severe debilitating fatigue not

helped by rest, which is medically only partially explained to date. It affects women approximately 1,5-2 times more often than men<sup>3</sup> (LIM *et al.* 2020: 4) and is considered a contested and blurry diagnosis, an “illness you have to fight to get”, to quote JOSEPH DUMIT (2006: 578). Lastly, ‘male’ contraception configures an intriguing paradox. It epitomizes the dissonance in the gendered burden of responsibility within the context of reproductive health, whilst simultaneously broaching the issue of lacking options for ‘male’ contraceptive autonomy. Non-hormonal ‘male’ contraception, too, is an underfunded and scarcely researched field, despite its considerable potential in terms of cost-effectiveness and mitigation of side effects compared to hormonal contraception for people with uteri (AMORY *et al.* 2016: 1306f.).

These three examples illustrate the enduring influence of sex/gender bias, and the persistent androcentric skew in medical scientific knowledge, which manifests in a lack of research interest, prioritization, and funding for some questions over others. Over time, this has created a resilient, normative knowledge base, purportedly framed and taught in medical school as neutral. Yet this knowledge base inherently standardizes a specific body type – male, cis, white, and abled – as its point of reference, and ultimately restricts understanding of bodies beyond this assumed norm. Bodies outside of this norm exist in the gaps of ‘undone science’. This has profound implications in research, in medical practice and in patient experience, underscoring the importance of critically analyzing these underlying mechanisms and addressing them in medical curricula.

### “Are we in 1980 or are we in 2023?”

To illustrate these connections, we first presented each of the three cases in a structure and language familiar to the students – epidemiology, clinical presentation, treatment options – before showing interview excerpts.

In the interviews, personal, often intimate stories and experiences were shared alongside hopes and frustrations in healthcare systems of all four countries. The students listened attentively, and with curiosity. From the first moments, we noticed the atmosphere was different. Students can tell when lecturers stand in front of them and talk

passionately about topics they identify as pressing and relevant. We could tell. More importantly, this time it was not only us, but eight other voices present in the room who addressed the group with urgency:

To be honest, I don’t know, sometimes I think *nothing* has happened. If I had fallen asleep yesterday, woken up after forty years and someone had said to me, ‘male’ contraception [orig.: *Zeugungsverhütung*], where do we stand, I would have said: are we in 1980 or are we in 2023? Nothing has happened! And the fears are the same, the social situation is the same. (Beat, ‘male’ contraception activist, Switzerland)

Beat ended his comment on the dire lack of progress in the field of ‘male’ contraceptives with an incredulous chuckle over this absurdity. Others, too, pointed out the tedious, slow trajectories to action, giving students a sense of long historical continuities of health-related struggles:

I think especially Belette and I [are lucky], that we came at a time when there’s interest and there’s feedback, uh, positive feedback. There’s of course a lot of backlashes, but there’s also a lot of people who support [our work]. I don’t know how Pierre [who has been an activist since the 1970s] did this through the desert for decades. I have no idea how that’s possible. (Félix, ‘male’ contraception activist, France)

Even if, as I mentioned, we’ve accomplished *some* successes, it is still quite a struggle. Especially getting from [the point of] exchanging information, and explaining requirements and needs, to the point where something actually happens, where something is put into action. (Michelle, endometriosis activist, Germany)

Interdisciplinary cooperation was described as prerequisite for this work:

Working together with different institutions within hospitals, with medical staff, is really important to us, because I believe that only cooperation between everyone – those affected, the support groups, specialists, scientists, doctors – can keep pushing this topic forward in the long run. (Ines, endometriosis activist, Austria)

Importantly, all interlocutors hinted at specific ideas for a potential professional role of our students in the future:

I cannot say that the industry or the government has a place in [male contraception] because they're not helping yet, but it still relies on the activists [orig.: *militants*], and the doctors that are involved. It takes for doctors [...] to really go into a more political perspective of their job as a doctor, to really go into this type of topic. (Félix, 'male' contraception activist, France)

There are doctors who have been supporting the self-help groups really quite immensely from the beginning, and without this support, I think we would not exist in this form right now. (Ines, endometriosis activist, Austria)

I think something has to happen with the students ... that this thing, this knowledge, is demanded [...]. You have to collect it, but you also have to demand it, in the sense of: yes, we want this, we need this. (Beat, 'male' contraception activist, Switzerland)

After each interview finished, we asked the students to share their thoughts in small rounds, before opening up to a bigger group discussion. Students were moved and genuinely curious about all three topics and narratives. Having seen faces and heard stories to connect with made decades-long histories of vocal, persistent health activism tangible.

After the last interview, the questions started. How is activism different when energy is a scarce resource, as it is for ME/CSF activists? In which ways do humor and playfulness help in keeping 'male' contraception activists going? How is it possible that there is still so little knowledge on where endometriosis comes from? Overarching themes were identified between the three cases, and more funding for research, more political involvement, more acknowledgement, and public awareness were distinguished as key demands. The importance of listening carefully and valuing knowledge from all spheres of society gradually crystallized.

Eventually, reflections shifted from the narratives of others to a look inwards. Some asked where to even start taking action, especially when it feels, as someone shared, like power lies not with them but elsewhere, somewhere 'up there' with 'those at the top'. Slowly the group arrived at the question: what can we do about that?

## Becoming activist(s)

The shift from healthcare worker to advocate and for some, to health activist is a gradual process. It is perpetually encountering social injustice, and then finding and holding onto an idea of the best leverage for change. Letting the realization sink in: *I can be a change agent*. As part of a group, as part of political movements, as part of policy-making, as part of the next discussion in class, and as an active member of one's field. Especially with the privileges of being in a position to study medicine. For many, advocacy and health activism can serve as a potent way to grapple with the backbreaking and overwhelming sense of powerlessness when confronted with injustice, in a system that is supposed to help and heal but at times harms instead. Medicine is a system very successful in providing barriers, pain and discriminatory practice on all levels, beginning from how knowledge is produced and taught, up until quality of care in actual clinical practice.

How do activists become activist(s)? When posing these questions to our interviewees, their own transition was often rooted in having to navigate and confront a frustrating reality that caught them off guard.

The reason is simply sheer necessity. [...] There is [...] this paradox that these are people who already barely have any energy, and yet they still are the ones who strive to somehow be seen and heard. [...] In order for us to reach a point where we can demand improvement, we must first clear away so many prejudices. Whether it's in small interactions within the family, during a single visit to a doctor, or on a larger, socio-political scale. (Laura, ME/CFS activist, Austria)

Integrating critical thinking and awareness about structural injustice into the medical curriculum and reflecting with our students holds opportunities for them to deliberately face the many inconsistencies, unjust continuities and habits which shape medical knowledge and clinical care. This has the effect that they do not have to be taken by surprise when being confronted with it in real life. Ideally, they would have the chance to reflect and react when needed, and the tools for taking action.

## Questioning the story medicine tells about itself

Not least since the COVID-19 pandemic, nurses and doctors across Europe are leaving their clinical jobs in record numbers, and healthcare systems face increasingly high rates of burnout among healthcare workers (WHO 2022). The reasons are undoubtedly complex. But among friends and colleagues, we observe an increasing sense and awareness of structural injustice in medicine among healthcare staff playing an important role – especially among younger medical professionals – without space to reflect and channel one's affective response to it and navigate one's own role in it. The growing number of critical health activist groups and initiatives formed in Germany and Austria in the last 5 to 10 years supports our observation. Medical students are taught all throughout medical school and clinical training that they, by default, are a part of not only an intellectually superior, but a morally virtuous profession, and that they and their colleagues care for others. In the first clinical years, disillusionment and demoralization often set in.

Being overtaken by injustice, be it everyday discriminatory language or medical knowledge deeply rooted in androcentrism, can be numbing. Understanding dimensions of oppression within a system that is supposed to first and foremost care equally for all, can be suffocating. Finding the words to describe these phenomena, finding engaged colleagues to talk to, who have mobilized their energy to resist and foster change, is where power begins to shift.

Critical appraisal and discussion of the role of power in knowledge creation should be an inherent part of all life sciences. It would foster an understanding that knowledge does not develop in a vacuum but within a humanly predefined, patchy system in no way immune to, but rather heavily influenced by power imbalances, political interests, and patriarchal logic. The centrality of social movements and civil society to identify areas as “worthy of more research” (FRICKEL *et al.* 2010) is a core tenet of ‘undone science’. Their growing involvement in the form of a “public shaping” of knowledge (HESS 2015: 2) implies a major change in where students can imagine analytic authority, over

which forms of knowledge, based on whose experiences. The potential of the concept of ‘undone science’ in medical education ultimately lies within the self-authorization to understand knowledge selection and production – science in general – not as an amorphous, finished entity beyond reach, but rather as something to grapple with, to analyze, criticize and reshape by setting new – just – standards and priorities.

## Notes

- 1 ‘Male’ in inverted commas, to reflect on using a widely established, yet insufficient binary category when talking about contraceptive methods for persons with testicles.
- 2 Our use of the term *women* is based on a body of literature mostly distinguishing between (cis-)women and (cis-)men, yet we are well aware of the insufficiency and non-inclusivity of the term, as endometriosis can affect all people with uteri.
- 3 Here, too, epidemiological data is generally disaggregated – if at all – by binary sex/gender.

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**Awa Naghipour** is a physician and research associate. She earned her medical degree from Charité University in Berlin and worked clinically in internal and emergency medicine before joining the Department of Sex/Gender-Sensitive Medicine at the University of Bielefeld. Her research, teaching, and advocacy focus on sex/gender- and discrimination-sensitive medicine, intersectionality, and the translation of scientific knowledge into medical practice, education, and policy. Her current research explores the integration of sex/gender considerations in clinical practice guidelines, as well as questions around moving toward context-sensitive, critically conscious clinical practice. Her doctoral research centers on medical conditions in patients with intellectual disabilities and hearing loss. She holds various roles in committees and advisory boards, e.g. the National Council of German Women's Organizations, the German Medical Women's Association, and the Medical Women's International Association.

University of Bielefeld  
Department of Sex and Gender Sensitive Medicine – Medical Faculty  
Universitätsstraße 25, R.1 A1-11  
33615 Bielefeld  
Germany  
e-mail: awa.naghipour@uni-bielefeld.de



**Lucia Mair** is a medical anthropologist and physician. Currently, she is a PhD candidate and University Assistant in the group Health Matters at the Department for Social and Cultural Anthropology at University of Vienna. She holds an MSc in Medical Anthropology and Sociology from University of Amsterdam (2021), an MD from Technical University Munich (2017), and a BA in European Ethnology from Ludwig Maximilian University Munich (2017). In her doctoral research, she explores emergent practices of care and understandings of health, illness and healing in neighborhood-based, primary health centers in urban Germany. Her broader interest lies at the intersection of political mobilization, healthcare experience and welfare state infrastructure. Having gained experience in healthcare facilities in Germany, Israel, Kenya and the UK, she teaches at different universities on questions of health, social inequality, gender medicine, medical ethics and healthcare politics.

University of Vienna  
Department of Social and Cultural Anthropology  
Team Health Matters – Medical Anthropology and Global Health  
Neues Institutsgebäude (NIG), B0416  
Universitätsstraße 7  
1010 Wien  
Austria  
e-mail: lucia.mair@univie.ac.at