RADICAL HEALTH

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Editorial

Health and healthcare provision are an utterly complicated affair. Current times are shaped by proliferating socioeconomic inequalities, anthropogenic climate change, and environmental degradation. People across the globe face violent political conflict and war, while they struggle for justice and equity. Critical medical anthropologists have shown how even the most intimate aspects of illness and health are to be understood in the light of such larger political-economic forces that shape human existence and experience. In the cache volume *Radical Health*, authors attend to the multiple ways in which health is envisioned, theorized, and actually 'done' despite and in response to what anthropologist Sherry Ortner has described as the "harsh and brutal dimensions of human experience, and the structural and historical conditions that produce them."[1]

The contributions in our volume emphasize the relations between health, power, and inequality, but also look at diverse aspirations for collective care, solidarity, friendship, and thus better and more just futures. Examples include attempts to provide community care as a right in Europe, build peace through indigenous healthcare initiatives in Colombia, or establish primary healthcare in Kerala, India. With Joel Robbins we propose to not "dismiss people's investments in realizing the good in time as a mere utopianism," but "challenge our own versions of the real."[2] This goal is specifically reflected in contributions where activists, anthropologists, and practitioners enter into conversation, to gauge the cross-fertilization between emancipatory social science and action in the field of health broadly understood. Our volume thereby contributes to understanding power structures in the medical realm, for example in the domain of reproductive or migrant health, and to conceptualizing alternatives; it also shows practitioners' diverse attempts to provide healthcare in radically novel or different ways in locations across the globe.

Marxist sociologist Erik Olin Wright's "real utopias" is an appropriate term for us to frame these heterogeneous processes. Wright argued that real utopias "may seem like a contradiction in terms," but reality and utopia need to be thought together pragmatically. He wrote: "Utopias are fantasies, morally inspired designs for a humane world of peace and harmony unconstrained by realistic considerations of human psychology and social feasibility. Realists eschew such fantasies. What we need are hard-nosed proposals for pragmatically improving our institutions. Instead of indulging in utopian dreams we must accommodate to practical realities."[3] What is crucial about the concept of 'real utopias' is that it "embraces this tension between dreams and practice. It is grounded in the belief that what is pragmatically possible is not fixed independently of our imaginations, but is itself shaped by our visions."[4] By focusing our attention on health-related real utopias, and by listening to scholars, practitioners, and activists who struggle to realize them in their everyday work in clinics, community health centers, or feminist workshops, we contribute to the recently growing scholarly work that explores "the contingent, experimental forms in which ideas of future better worlds are investigated"[5] and put into practice.

When we speak of 'Radical Health' in this context, radicality refers to unconventional forms of designing or doing healthcare and therapeutic processes that share a transformative ethos. Radicality, however, is not restricted to novelty but also implies stubborn forms of insistence on and experimentation with healthcare otherwise, particularly in primary healthcare settings. This includes accounting for social determinants of health that have long emphasized the political, economic, and environmental roots of health and well-being. It also means addressing intersectional inequalities and the pharmaceutical industry's ceaseless search for financial profit, which creates and profoundly shapes experiences of disease and ill-health. Countering such developments requires not only medical or technological interventions, but also political, economic, and ecological change. Radicality further refers to defying customary social and professional hierarchies in the clinical encounter, aiming for novel forms of collaboration and solidarity between patients; patients and practitioners; or practitioners, scholars, and activists. In short, radicality suggests openness and curiosity toward alternative, relational forms of methodological inquiry and healthcare practice in the attempt to understand what really matters when it comes to nurturing and sustaining the existence and flourishing of human beings in their social and natural environments.

This collection derives from an online conference entitled "Radical Health. Doing Medicine, Health Care, and Anthropology of the Good" that was organized by the Work Group Medical Anthropology (German Anthropological Association), the Association for Anthropology and Medicine (AGEM), and the Institute of Social and Cultural Anthropology at Freie Universität Berlin and took place amid the COVID-19 pandemic, in June 2021. The event gathered a wide range of scholars, artists, and activists from the social and public health sciences, who discussed how 'healthy futures' could be envisioned, theorized, and actually 'done' in times of multiple crises. The hybrid cache format seemed to us, the conference convenors, a good way to continue our online discussions, and we came together as an editorial collective in 2022. Cache, we hoped, would allow us to integrate the varied conference contributions and multimodal approaches. The prospect of experimentation and multiplicity seemed fitting to represent our interdisciplinary exchanges at the intersection of social theory, academic debate, healthcare practice and activism, and artistic intervention. During the editorial process – an entirely remote collaboration between Berlin, Leipzig, Bremen, Münster, Goa, and Vienna – we thus maintained the open-ended and heterogeneous spirit of the conference. Choosing their own expressive styles, the authors of our collection worked with photographs, drawings, or film stills as they saw fit. They also experimented with novel formats like conversations, drawing-based ethnography, or auto-ethnographic writing. Their contributions thus significantly test the boundaries of classical academic articles in the social and health sciences, which are increasingly standardized concerning length and language.

Editing this collective volume has been a challenging experiment for us as an editorial collective. We adapted the possibilities of the cache format to the topic of radical health by playing with text sizes, picture emplacement, and visual accentuation in the content management system to best represent our authors' highly diverse materials. We managed to assemble ethnographic material, and first-person experiential and workshop accounts. The result is an experimental volume that conveys well the heterogeneous positionalities and writing styles of our author-scholars, author-activists, author-practitioners, and author-artists. All in all, we hope, the multiplicity of materials and formats brought together in our volume grants an in-depth and convincing multisensorial idea of what radical health can be in different locations of the world. Due to its interdisciplinary, activist, and ethnographic set-up, *Radical Health* also goes beyond prior cache volumes that have been more historical and source-based in nature. It thus constitutes a polyphony of voices, writing styles, and multimodal formats, integrating ethnographic, activist, dialogical, as well as highly intimate contributions.

Drawing on research and engagement in a diverse range of medical settings and ethnographic locations, the contributions are assembled in four thematic parts:

'Communities' features contributions that critically reflect on the pillars of health and wellbeing beyond biological conditions and gauge ways of reorganizing healthcare so as to make it more easily accessible, collaborative, and socially inclusive, i.e. to create community care in the true sense of the term. Collective care initiatives in European cities figure here as much as peace-building in Colombia and primary healthcare in Kerala, India.

In 'Infrastructures' the contributors consider three different dimensions of the radical nature of health infrastructures: First, they focus on the crucial intangible infrastructures of human relations that enable or impede social processes such as wellbeing and social relations among healthcare workers. Second, they take into account the built and natural environment and the importance of infrastructures as sociomaterial relationships, particularly in hospitals. Third, they look at prevention and take mental health seriously as part of the work context, in higher education as well as in healthcare institutions.

The contributions in 'Practices' deal with clashing perceptions and conceptions of health in the fields of migration, psychiatry, and alternative healing methods, which not only pose a challenge to actors practically involved in the respective healing settings but also raise the question of how to adequately research and represent such perceptions and conceptions. The section offers reflections on research methods that are able to integrate scientific, aesthetic, and artistic aspects. Furthermore, it picks up the questions addressed in previous chapters in terms of how subjectivities are put into practice within certain communities and embedded in particular infrastructures. In doing so, the contributions in this section explore concrete strategies and practices to improve health and wellbeing within and beyond biomedicine.

Finally, in 'Subjectivities' the contributors turn our attention to experiences of health and wellbeing as a radically relational project far beyond an individualist ethos. Attaining and sustaining states of wellbeing in the UK, the US, and Germany often involves much more than adhering to therapeutic regimes. Rather, health and wellbeing are the products of continuous relational labor in the sense of reconciling expectations and exigencies from both the world of the ill and the world of the healthy. Establishing relationships of mutual care and recognition with like-minded others also provides irreplaceable support in not only enduring but also struggling against exclusionary health policies and social structures.

Last but not least, we would not have succeeded in putting together this collection without the countless hours of hard and patient work by the student assistants Julia Koroknai and Friederike Rosenbaum. They entered the contributions into the content management system and played creatively with text, citation, and image formats, all the while communicating relentlessly with the authors for over two years. The editorial collective would like to extend their deepest gratitude to both of them for their tireless and most efficient work, without which *Radical Health* undoubtedly would have remained a non-real utopia.

Notes

1 Sherry B. Ortner: "Dark Anthropology and Its Others: Theory since the Eighties", HAU: Journal of Ethnographic Theory 6/1 (16 July 2016), p. 49, https://doi.org/10.18103/hau6.1.004.
2 Joel Robbins: "Beyond the Suffering Subject: Toward an Anthropology of the Good", in: *Journal of the Royal Anthropological Institute* 19/3 (1 September 2013), p. 458, https://doi.org/10.1111/1467-9655.12044.
3 Erik Olin Wright: *Envisioning Real Utopias,* Verso Books (2010), p. 4.
4 Wright, 4.
5 Ruth Prince, Tom Neumark: "Curious Utopias: Dreaming Big Again in the Twenty-First Century?", in: *Social Anthropology/Anthropologie Sociale* 30/2 (1 June 2022), p. 4, https://doi.org/10.3167/saas.2022.300202.

COMMUNITIES

Daniela Krüger, Angela Schuster, Beatriz Aragón Martín, Marta Pérez,
Lucia Mair, Janina Kehr

COLLECTIVE CARE Glitch

What is made visible in moments of transition and crisis, and how can collective existence be upheld? In their 2016 essay *The Commons: Infrastructures for Troubling Times*, the late Lauren Berlant, literary and queer theorist, ruminates on the recognition of a "glitch" in times of crises. More precisely, Berlant considers what the glitch reveals about the infrastructural scaffolding, or "patterning" of our lives: where it is unstable, fraying, even perpetuating harm. Berlant's understanding of infrastructure is broad, encompassing roads, hospitals and schools as well as families and norms, as "the living mediation of what organizes life: the lifeworld of structure".[1] Published several years before the onset of the COVID-19 pandemic, Berlant's essay is taken up in this contribution as an invitation and entry point to re-think collective ways both of looking at and looking after infrastructures. To Berlant, crucially, the "glitch" opens up a window of opportunity for repair, in ways which encourage new forms "from within brokenness beyond the exigencies of the current crisis, and alternatively to it too".[2]

"All times are transitional. But at some crisis times like this one, politics is defined by a collectively held sense that a glitch has appeared in the reproduction of life […] an interruption within a transition, a troubled transmission. A glitch is also the revelation of an infrastructural failure."

Lauren Berlant: "The Commons: Infrastructures for Troubling Times", in: *Environment and Planning D: Society and Space* 34/3 (2016), pp. 393–419, p. 393.

In the following conversation, anthropologists, physician-anthropologists, a sociologist and a physician-epidemiologist jointly reflect on how they each experienced broken healthcare infrastructures before, during and after the COVID-19 pandemic, how they imagine alternative futures of health and care and how these futures might be collectively realized. Together, we reflected on the layered, acute and chronic infrastructural failures of the last two-and-a-half pandemic years, while speaking from different regional and disciplinary perspectives as well as particular positions within healthcare systems. Marta Pérez, an anthropologist, and Beatriz Aragón Martín, a physician-anthropologist, both work in public health centers and activist health movements in Madrid. Angela Schuster is a physician, epidemiologist and part of the neighborhood community health center the Berlin Health Collective, while Daniela Krüger is an urban sociologist researching emergency medicine in a German metropolitan city. In this interview, Angela expresses her experiences and thoughts as a researcher and member of the Berlin Health Collective; however, her positions do not necessarily reflect those of the Collective. Both Lucia Mair, a physician-anthropologist, and Janina Kehr, a medical anthropologist, share a common research interest in novel forms of social medicine and the iterations of public healthcare today, respectively in Germany and Spain. Our conversation aimed for an exchange to share regional experiences and foster connections to think about the problems and possibilities of healthcare during the long pandemic moment.

How can one work within, alongside or against the system to reach transformation, repair and community in a troubled world?

But while the infrastructural failures and affordances we talked about were laid bare by the COVID-19 pandemic, in many cases, they also preceded it in the face of increasingly profit-oriented logics of and pressures on public health systems in the last thirty years. In this troubling context, though, not only failures, but also new collectivities, collaborations, networks of sharing and care emerged. Renewed appreciation for community-engaged healthcare as one potential arrangement to move past the ″glitch″ happened in Germany and Spain alike, as Marta, Bea, Angela and Daniela recount. The following conversation is thus testimony to how public healthcare is defended on the street in both countries, how the pandemic changed the relationship between providers and patients, and what radicality means in theory and practice. It is an invitation to reflect on how to work within, alongside or against the system to reach transformation, repair and community in a troubled world.

Photograph by Lucia Mair (2022).

Image of half torn off posters with political slogans, plastered on a wall in Berlin. The slogans are: ″Health is a human right. It is denied to me″, supporting access to healthcare for asylum seekers; ″Who do I save first?″, and ″We save you. Who saves us?″, both from the trade union ver.di in support of improvement of nurses' working conditions.

Lucia Mair: The projects you, Marta and Bea, are engaged in are part of a powerful movement in Spain, the *Marea Blanca*, which has protested against the privatization of hospitals and austerity policies in the healthcare sector since 2012. I would be interested to hear from you, Angela and Daniela: do you see anything comparable happening in Germany, in the past or future? Do you see particular topics of concern that could motivate both health professionals, but also the broader society, to become more aware of the problems regarding cuts and privatizations in healthcare that many of us here are worried about?

Angela Schuster: I think from a structural point of view, the German health system is very fragmented. This leads to a situation where change is enacted rather slowly and is probably also transferable to other aspects of the German welfare system. In the last years, I have had the impression that there is an increased collaboration and interest in community care in the context of primary healthcare centers. What the Health Collective[3] is doing (by opening a community health center), for example, also happens in other cities. Most of these initiatives were born from activism for undocumented migrants, who are excluded from formal healthcare in Germany. It thus seems to me that there are two different possibilities against fragmentation, to provide integrated care: one comes with a political impetus to create community-integrated care while considering social and economic determinants of health; the other one can be subsumed under a managed care approach, which might nevertheless amount to a similar form of care provision. From a historical point of view, then, there is a long history of polyclinics in the former German Democratic Republic, which we, in Western Germany, have tended to forget and haven't re-implemented. Besides forms of healthcare provision, I also think that a driver for change could be the increasing awareness of health workers' stressful working conditions, and their increasing loudness in expressing their dissatisfaction about their working conditions. I am thinking for example of the *Berliner Krankenhausbewegung,* or Berlin Hospital Movement, which might be a pull factor for change. Because health workers – and I see that from my students as well – are not willing to work under these conditions anymore.

The *Berliner Krankenhausbewegung* (Berlin Hospital Movement) was founded in 2021 by healthcare workers from Berlin's two largest state-owned hospital groups, Charité and Vivantes, and Vivantes' subsidiaries, with the goal of improving working conditions. Almost 2'000 workers, including nurses, midwives, medical-technical assistants, kitchen staff and cleaners, went on strike for several weeks in the summer of 2021. One of the longest strikes in the history of the German healthcare system, it culminated in a collective bargaining agreement. In October 2022, more than 1'000 of Charité's physicians followed suit, going on strike for the first time in over ten years.

"Berliner Krankenhausbewegung", https://berliner-krankenhausbewegung.de.

Daniela Krüger: Berlin is very rich in NGOs and political activism, which is also something particular about the city – a very rich scene, like a movement. What I see from my case, emergency care, in Germany and other contexts, is that there's large motivation to improve the responsiveness of healthcare. Emergency care providers have been observing two changes: on the one hand, an increase in the overall number of patients; and on the other hand, an increasing number of patients who circulate between different service providers without receiving the social or medical care they would benefit from. These professions, and the decision makers and planners within the organizations, are increasingly moving towards approaches resembling community healthcare or holistic care, understanding their jurisdictions as too narrow, too specific. Some advocate for a paradigm shift of cooperating with other professions, even including them in their work or within their organizations. And I see this as a very interesting example of the motivation to change something within the system, from within regular care.

COLLECTIVE CARE System

Janina Kehr: System is a good keyword here, because Spain and Germany have quite different healthcare systems: Spain has a National Health Service (NHS), universal in access and free at the point of use, and Germany has a Social Security-based system with built-in healthcare exclusions for those who are not insured. In Spain, universal access exists only in theory, however, and has been continuously reduced through legal measures in the last decades. But at least there is an idea of universality of access, which partly translates into practice, and which is defended when it is attacked. So what we have seen in Spain in the last ten years are different forms of healthcare activism, which struggle against problems with access to care, particularly for undocumented immigrants and other marginalized or vulnerable groups. How did this come into being? What is your take on this, Marta and Bea?

Photograph by Janina Kehr (2013).

This picture stems from a large *Marea Blanca* demonstration in October 2013. Protesters chanted *"Sanidad Publica, no se vende, se defiende"* ("Public healthcare should not be for sale, but should be defended"). On the protesters' numerous signs, one could read *"Recortes en sanidad matan"* ("Cuts in public healthcare kill") and *"Se vende tu salud"* ("Your health is up for sale").

The *Marea Blanca*, in English *White Tide*, is an activist movement by citizens and healthcare sector employees. It emerged progressively in October 2012 in the Autonomous Community of Madrid to protest against the privatization of healthcare institutions in the region as well as budget cuts due to national and regional austerity measures. The movement assembled thousands of protesters in its first years of existence, sociologically cutting across society and activist organizations. Until today, *Marea Blanca* demonstrations are regularly organized by the *Mesa en Defensa de la Sanidad Publica de Madrid*.

"Mesa en Defensa de la Sanidad Pública de Madrid, MEDSAP - Marea Blanca", https://mesaendefensasanidadpublica.wordpress.com/about.

Marta Pérez: At that moment, in 2012, many things were coming together. The *White Tide* or *Marea Blanca*, for example, was partly a consequence of the mobilization of the *Indignados* movement. This context of popular uprisings made it possible for people to imagine actually organizing large demonstrations, occupying hospital halls, taking over the streets and the public institutions. It was a moment of possibility. At the same time, a very direct attack on public healthcare in Madrid – the so-called privatization plan – was being implemented by the regional government. This was so massive that it was too much for people to take. Thirdly, people were excluded from healthcare in Madrid, particularly undocumented or illegalized immigrants, although I think healthcare exclusion was not the main driving force behind the *Marea Blanca*.

The *15-M* or *Indignados* movement – in English movement of the enraged – was a vast, heterogeneous popular movement that emerged on May 15, 2011 in Spain. After large-scale demonstrations for more democracy across the country, several groups of people decided to camp out in the main squares of different cities, among them Puerta del Sol in Madrid, thereby consolidating the movement. Participants wanted more political participation, and also intended to collectively call attention to how people lived through the crisis after years of recession and precarization in Spain. The *Indignados* movement has profoundly transformed Spanish activism. It has also contributed to the politicization of parts of Spanish society, including portions of its healthcare workforce.

Bryan Cameron: "Spain in Crisis: 15-M and the Culture of Indignation", in: *Journal of Spanish Cultural Studies* 15/1–2 (2014), pp. 1–11.

Beatriz Aragón: Healthcare exclusion was further proof of the attacks the healthcare system was suffering from. People were not worried about healthcare exclusion as such, you know. It was more what it represented. The fear was: they are reducing healthcare for migrants, maybe they will also, after that, reduce it for us. Healthcare exclusions were proof that an attack was taking place. People were not demonstrating because of healthcare exclusion. They were demonstrating because, at that moment, they thought their healthcare system was going to become worse, also because of the privatizations that were going on at the same time.

Marta Pérez: I agree. There was a sense that they were taking something from us, they were taking away our healthcare. This sentiment was shared among people who were socially very different: a cardiologist working in a hospital, and a woman in her sixties from a very working-class neighborhood. That was unique. And it's not very common. The organization of the *Marea Blanca* was driven by the primary care sector, but hospital staff were strongly represented as well. It was a shared feeling that went beyond party politics. Just a sense of owning the public system, whatever the government was. And that was really special. This is not happening anymore, even though in this very moment we are actually worse off, also in comparison with what Angela and Daniela recount about Germany and Berlin. Particularly in the domain of primary care, people are so tired, and the pandemic was so hard on them, not only for their bodies and minds. Many feel that work has become unbearable – in the sense that work does not make sense anymore. It's a lot to take. Imagine: all of the hard work you do seems futile. It's a very difficult moment now for politicization. Because there is this feeling of: 'what I do has no value'. I dont know whether at any moment in the history of Spanish healthcare, or Madrid healthcare, that feeling has been so widespread.

Beatriz Aragón: Absolutely. I think that's one of the interesting things, the difference between Germany and Spain. In Spain, our public healthcare system is based on the idea of Alma-Ata, with primary healthcare as the basis of the healthcare system. In the end, it has never been truly like that, because most of the social factors that feed into health or disease are not well recognized. Plus, the budget for primary healthcare in Madrid has steadily decreased since 2012.

The Alma-Ata Declaration was the outcome of a 1978 summit on Primary Health Care hosted by the World Health Organization. Signifying a shift from traditionally curative approaches, the declaration's core recommendation was community-determined primary healthcare as the basis for attaining health for all. Disease prevention and health education were key components. The language introduced in the declaration was soon taken up by health planners and activists around the world.

World Health Organization: "International Conference on Primary Health Care: Declaration of Alma-Ata", https://www.who.int/teams/social-determinants-of-health/declaration-of-alma-ata (1978).

Beatriz Aragón: I started my activism inside the institution, while I was doing my residency, because I had all this training about social determinants of health and how important they were. But what can you actually do from within the institution, from an institutional point of view? Since my initial training, I have seen all this deterioration, and this loss of a sense of our practice, even to the point that work has become completely unbearable in a way. Not everybody asked themselves: "What is your purpose as a general practitioner, in this idea about health inequalities?" In some of the health centers I worked in, some of us were actually trying to act on health inequalities from within the institution. But now you can't even find a way to do that. With the healthcare exclusions that we see now, work has become so frustrating.

People no longer understand what is going on. There is a lot of frustration, and a lot of clashes between the population and healthcare workers. This gap is very difficult to handle.

From 2012 onwards there was a bit of a rebellion against health exclusion, but it was mostly people coming from migrant health or primary care, not the rest. No cardiologists there. I mean, it's a joke, but it is also important: why does a cardiologist not care when healthcare exclusion has so much to do with all this? In 2012, we were defending public healthcare for us, but also for everybody else. And now it's clear that we have to defend it for us, in the sense of: try to save yourself first. This is causing a lot of rupture, because the workload is increasing. There are a lot of issues with the population because the quality of care has deteriorated. Also, if you feel that what you're doing doesn't make any sense, you don't do it, right?

COLLECTIVE CARE Radicalities

Janina Kehr: What you are saying is very moving, and it struck me that there seems to be so little hope for change. Both Marta and you have alluded to the loss of meaning, a futility in everyday work, which seems to have become structural, almost permanent. What place does radicality hold here? What kind of radicality can one even imagine in a system which is not only non-functional, but also nonsensical? What does radicality mean to all of you in your work?

Daniela Krüger: Bringing our cases together, we thought of radicality as an idea of challenging dominant positions or structures and processes. In my case, this becomes obvious when jurisdictions and professional boundaries are challenged. It sounds so simple and not very exciting, but it is a huge issue, as these professional boundaries and jurisdictions appear natural to us, yet determine so much: funding, practices, protocols, knowledge, self-identification of professionals. Changing protocols in emergency care, and including other professions or ways of responding to emergencies, is a paradigm shift that changes these permanent or historically grown structures. The same applies for Angela and the challenges that the Health Collective in Berlin and other cities in Germany have to confront: there are all these jurisdictions and funding schemes which prevent working easily, smoothly together (with other professions or organizations).

I'm still wondering how to consider this notion of radicality, because in what way is better-coordinated care, more responsive care really radical?

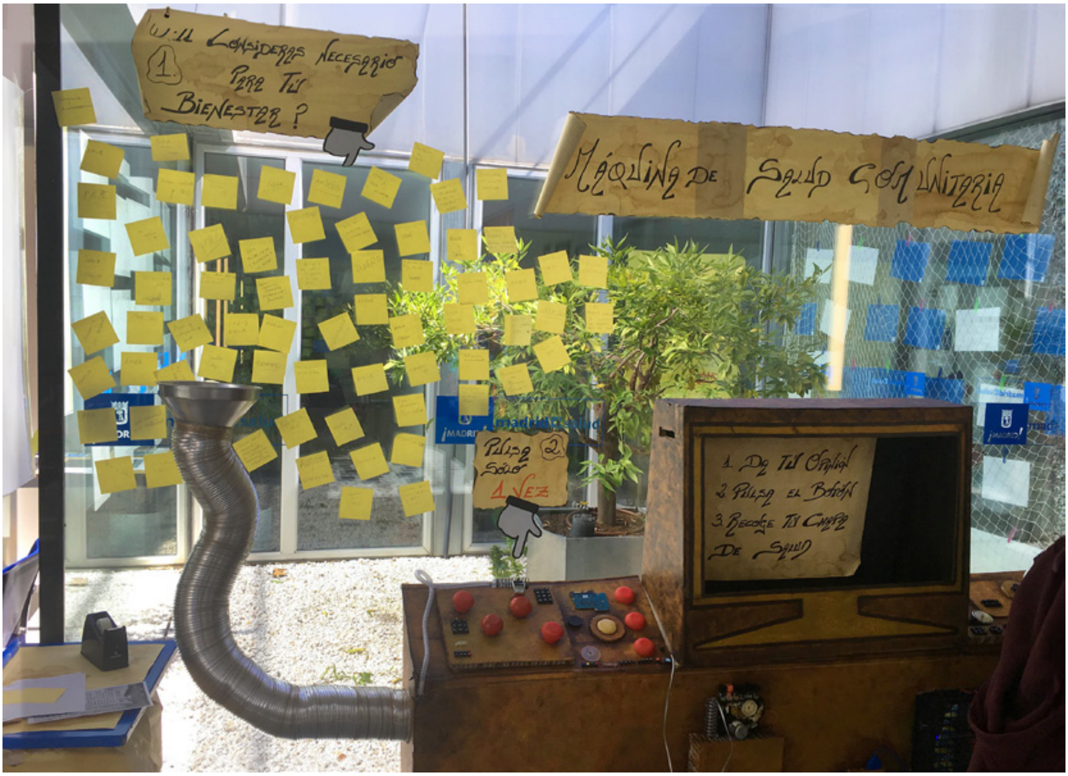
Is acknowledging that there are social determinants of health (by changing the set-up of teams and protocols), that they affect healthcare, and then letting this information travel into the policy and planning arena already a political act – albeit a small one, because this acknowledgment is not yet part of these structures? Becoming an advocate for people in this sense is also a part of radicality that challenges epistemologies and dominant structures.

Angela Schuster: One point I would like to add is the need to start from a critical self-perception on how our professional identity has formed. We need to acknowledge that we, as medical doctors, have been formed to lead. To question this is something which I see as a continuous struggle when working in an interdisciplinary way. This includes, for example, how we as doctors are used to talking and discussing within a group. Overcoming these patterns requires a lot of critical reflection and discussion among interdisciplinary teams, which is not easy. It's also important to strengthen the therapeutic knowledge and self-identification of all professional groups in medical care, not only of doctors.

Maybe acknowledging social determinants of health is enough or at least a first step.

But it would also be a big step to include public health services in this, the *Gesundheitsämter*, which are the third column of our health system in Germany. There is a lot of unused potential there, because it is their duty to serve the most underprivileged populations and to facilitate access to healthcare services. The COVID-19 pandemic has underlined this point, that the third column of the healthcare system must be strengthened. The people working there are increasingly aware of what their potential role could be.

Beatriz Aragón: I completely agree with the point of questioning professional identity: from what position does each of us carry out their practice? We are still in a very hierarchical set-up, with patients, but also with colleagues and administrative staff. This was one of the goals when primary healthcare began here in Spain: to make it teamwork. This ideal – of taking care of the population as a team, as a part of and together with the population – only became true in rare situations. It's true that medical training is completely not about this but, instead, quite the opposite: it molds you into people who are specialists on just a tiny piece of someone's body. The other aspect are these fragmented, neoliberal logics of healthcare. It is both difficult to make sense of care in such a landscape, and to reconcile these configurations with care. It's one of the issues we are suffering from now in Spain. I mean, the general practitioner gives you pills for high blood pressure, the nurse controls your weight, and the social worker asks for house aid. And between the three of them, nobody talks about the person: why have all these things happened? This is due to these institutional, fragmented logics. Radicality, for me, is going against this.



Photograph by Janina Kehr (2018).

The *Maquina de Salud Comunitaria,* or community health machine, was in use during an open house in a community health center in the south of Madrid in March 2018. It was a playful means to ask local residents what they needed for their well-being. Residents could write a Post-it note with their perspectives on well-being, then push a button on the machine and in return they would receive a badge with a community health slogan.

COLLECTIVE CARE Tension

The militant research collective, *Entrar Afuera* tries to re-think and imagine urban practices of care, reflecting and acting upon the bond among public institutions, territories and people. Some of them are located in Madrid (Spain) and others in Trieste (Italy) and get their practical inspiration from the rich genealogy of institutional critique and invention in Europe, especially in health and healthcare.

"Entrar Afuera - de lo público y lo común", https://entrarafuera.net.

Marta Pérez: In one of the militant research projects we are involved in (as part of the collective *Entrar Afuera*), we are working with people in Trieste, Italy. One of the questions we have learned from the Trieste system is to ask: who is responsible for this person? And that is a very difficult question because you can have a pack of services, with a list of tasks, but is there a professional responsible for what happens to a person, overall? If you want a system which holds responsibility for every person that comes in, this responsibility has to be clearly assigned. To me, that is one of the definitions of radicality: it's radical to organize a system around that, and difficult. The healthcare system now in Madrid is going in the other direction. Administrative staff screen your passport to know if you have access to healthcare services or not. In the minds of the doctors, this is a completely separate administrative problem, unrelated to the clinical, and the psychosocial part of healthcare. Even if you want to take responsibility for the overall process, you can't, because the work is organized in such a way that you can only do your part. That creates frustration.

Since the COVID-19 pandemic, there is a growing distance in healthcare relationships in Madrid which is not only physical.

We mostly provide primary care by phone now, and some patients say: "I won't ask for an in-person appointment because I know healthcare workers are overworked. I'm going to restrain myself, and not allow myself to see my doctor, to care for her or him". This distance between healthcare providers and patients sometimes comes from a place of care, but at the same time, it gets to a point where you don't feel that you are doing something together.

Beatriz Aragón: I think it's not only the loss of value or sense for healthcare workers, but also for the population: the realization that the general practitioner may not be able to help me. This was something that you were not thinking before COVID-19.

Still from Antonio Girón and Raquel Congosto, Los Cuidados (Taking care), Spain (2019) (licensed under CC-BY-3.0).
VIDEO ▶ cache.ch/1725

The film follows community healthcare workers in a working-class barrio in Madrid.

Marta Pérez: And if you don't feel that you are doing something together with your primary care physician, you're going to do it yourself, if you can, right? It's only logical. There is a lot of tension in healthcare centers because of the waiting list, because people are sick and they are worried. That tension escalates if it is not recognized and incorporated into (health) care.

Lucia Mair: You, Marta and Bea, described vividly how the situation of the COVID-19 pandemic changed your daily work in Spain, but also the interpersonal relationships that ground your work and drive it, in a way. Daniela and Angela, what of this resonates with you? And what do you do with this sense going forward?

Angela Schuster: I can respond to that from my perspective as a general practitioner: Taking care of these patients and vaccinating them was the absolute priority in the beginning of the COVID-19 pandemic, and everything else beyond it was not. This culmination of being overworked has also reached German practitioners. There was a lot of unhappiness and frustration among primary healthcare providers when political decisions were made which were not transparent, and not congruent. We (providers) didn't really know what to do about them, but we were the ones who needed to take care of our patients. In France, a lot of people who were against COVID-19 measures were distributed along political lines, including the left wing. In Germany, however, most of these movements came from the right-wing political parties. There was not such a fragmentation of political positioning towards the COVID-19 measures in Germany as in other European countries. My impression is that many in the politically active population have maybe not agreed with all measures, but were not completely against them, sometimes to avoid being put on the right-wing spectrum. The situation after COVID-19 will be a new start, to see how we are going to deal with the fact that many aspects of the social determinants of health have been not addressed for at least two years.

What is interesting is that for the first time during the COVID-19 pandemic, we asked doctors and patients alike to look at health not only from the individual perspective, but also the public health perspective.

Health workers are usually not trained for this task, and patients are not used to seeing this perspective. That was what we asked them when we prompted them to get vaccinated, although they might not perceive the individual risk. I think this shift in perspective is something we saw which challenges our health systems and our perspective on health.

Daniela Krüger: I might add some insight on pre-COVID times from my fieldwork on this tense relation between practitioners and patients. People working in emergency rooms and the rescue service were naming this as a very significant shift they encountered, and which they could not really grasp. They used this term, that people were more 'demanding' of services which they perceived as a right, in a sense. I think there is this notion that people are more engaged in their healthcare. In the field of emergency care during COVID, we saw a great recognition of the work that people do (in hospitals, practices or the rescue service). In addition, whether it was thankfulness, reservation or the fear of contracting COVID-19, the numbers of people using emergency rooms and the rescue service initially declined dramatically. Providers understood this at least partially as a recognition of medical care as a public good, not merely as a service. I talked to a doctor working in an emergency room, and she said they experienced this as people re-evaluating their situation more again and not using their services so easily. There are problems behind these notions as well. But some initially experienced declining numbers at least in part as an acknowledgment.

COLLECTIVE CARE Dis/Connection

Lucia Mair: Most of you are in the double role of social scientists and medical professionals. Where do you see the role of the social sciences, specifically, in responding to this shift in the ways patients and medical professionals are thinking about health and healthcare, when and how to use health services, and how to navigate them?

Marta Pérez: There is something inherent to the social sciences that really engages with discussion. You don't have to be a militant researcher to do that. There is a huge need for everybody to discuss the moment we are in. For healthcare professionals, this need may be even greater.

There is a lot of disconnection between the theory of community healthcare, family medicine and primary care, and the practice of it.

This disconnection has been going on for a long time now, but it became more visible with the pandemic and the crisis of primary care. It's difficult to make peace with this. There is a sense of possibility, however, among the younger medical residents, and social science is very keen to explore that: How do we make sense of this disconnection and what do we imagine going forward? Maybe we have to abandon some theories and create new ones to have that discussion. The problem is that its very difficult because people are afraid, they are tired and busy, and it hurts to talk about this. I think it's a very good moment to have these discussions, and at the same time, emotionally and practically, very difficult.

Angela Schuster: Meeting Daniela and her team was very fruitful for me. I'm a health scientist and general practitioner, and Daniela is a social scientist. In the last year we have been working on different projects and it has been very interesting, because I am from a pragmatic science where we directly go into action.

Scientific medicine has a positivist approach, you always focus on doing. It was very interesting and healing for me to spend so much time discussing and thinking.

Lucia Mair: If you could ask each other any questions, as a final round, what would they be?

Beatriz Aragón: I have a question for Angela, coming from an ambivalent position about institutional healthcare myself. I wonder if it's possible to build a different practice from within the public healthcare system, or whether it is necessary, as you have done, to create something from the outside?

Angela Schuster: When I see your project, I see it has a future, but I don't see it as scalable. You need well-intentioned and engaged people who are also politicized, and there are not that many, as I realized during our process. If scalability is there, then maybe it's okay to have health systems or primary health care centers which may be efficient, but not so political.

I see the risk of this political approach getting lost on the way somewhere, at least partly.

I would also have a question for you. I was very intrigued by the fact that you endorse primary healthcare, because I always have the impression that the principles of the 1978 Alma-Ata Declaration are something we talk about, but we don't really live them. What are the determinants for endorsing Alma-Ata in your health system?

Beatriz Aragón: This is done arbitrarily. Most of the medical training units try to incorporate it, but it is not very popular. If 2'000 general practitioners finish their residency every year, only one-third of them end up working in primary healthcare. Despite the training around the idea of primary healthcare as the base of the healthcare system, at the end of the day, this does not apply in practice. And the COVID-19 pandemic changed everything so quickly, while beforehand, privatization in the healthcare sector happened gradually.

Marta Pérez: Maybe it’s a crystallizing moment.

It’s not like all of this happened because of the pandemic, but it was the perfect context for everything to collapse in a certain way.

Beatriz Aragón: There is so much frustration among healthcare workers. Before, people who were quitting were the people who didn’t care about primary healthcare, who were there because it was just a job. But now, those quitting are those that believed in primary healthcare, who wanted to build another kind of primary healthcare, little by little. Because we feel that it is not possible to do it from inside the institution. The question is: where do you find the value in your practice, in the daily things that you do? Because if you do not find it, then you end completely in cynicism in a way, you know?

Notes

1 Lauren Berlant: ”The Commons: Infrastructures for Troubling Times”, in: *Environment and Planning D: Society and Space* 34/3 (2016), pp. 393–419, p. 393.

2 Lauren Berlant: ”The Commons: Infrastructures for Troubling Times”, in: *Environment and Planning D: Society and Space* 34/3 (2016), pp. 393–419, p. 393.

3 ”Geko - Stadtteil-Gesundheits-Zentrum in Neukölln”, https://geko-berlin.de.

Marta Pérez, Beatriz Aragón Martín, Ana Zamora, Adrián Carrasco,
Estrella Sánchez-Gamborino

RUPTURE & REPARATION Talk We Must

We write this paper from a shared state of disorientation. Our starting point is a question: what has happened to us since the winter of 2020? Can we share the experiences we did not have the time or energy to share during the worst part of the pandemic? What use can we make of these experiences stored in our memories? We are part of a larger and heterogenous group in Madrid that tries to work in community healthcare: we come together participating in research projects, attending discussions on social determinants of health, working as professionals in primary health care (PHC) centres, engaging in mutual support groups to fight poverty and healthcare exclusion in different neighbourhoods, or writing pieces like this that help us get together, interrupt the accelerated time we live in, and reflect on what these experiences mean to us.[1]

> ”Think we must. Let us think in offices, in omnibuses, while we are standing in the crowd [...] let us never cease from thinking - what is this ’civilization’ in which we find ourselves?”
>
> Virginia Woolf: *Three Guineas,* New York: Harcourt, Brace and Company (1938), pp. 94–95; quoted by: Isabelle Stengers, Vinciane Despret: *Women Who Make a Fuss: The Unfaithful Daughters of Virginia Woolf*, Minneapolis: University of Minnesota Press (2015).

Since the summer of 2020, our discussions have revolved around the loss of common sense: in the post-pandemic context, both healthcare workers and citizens express serious concerns about the meaning and value of the work being done in PHC centres. The term we have come to use in these discussions is rupture: rupture between ourselves and PHC work, between PHC centres and their territories, and between people and PHC. How can we reflect on these ruptures? How can we repair them? These are the two main questions we address in this text, which is a collage of voices, thoughts, and experiences from people both from inside and outside primary healthcare. Thinking together, we attempt to initiate a process of reparation, to bring together the broken pieces of the ruptures we suffered individually, to rescue those pieces that are still valuable, and to build something anew. By doing this, we locate ourselves at a sort of threshold between inside and outside and find the urgent need to connect the two sides as a collective endeavour.

Asociación Valiente Bangla*, Red solidaria de acogida and Red interlavapiés*, 2020.

”How can I take care of myself if those who take care of me do not understand me?” (Authors´ translation). This flyer was issued by the campaign to claim language interpreters at the PHC centres promoted by several neighborhood associations. Although the flyer specifically refers to communities that do not speak fluent Spanish and need an interpreter during healthcare visits, it can also be understood in a broader sense: what happened in PHC centres during the pandemic such that they no longer understand what people are going through? Were we so happy together before? If in her book, *Three Guineas*, Virginia Woolf urged us to think, we feel that to think we must talk to each other.

RUPTURE & REPARATION Tensions

The *Marea Blanca* movement brought together healthcare workers and citizens who accused the government of politically motivated neglect of the public healthcare system.[2] A flashy sign hanging in the gynaecologist´s waiting room advertised the sale of the obstetrics and gynaecology service as if it were a real estate property. Such signs are normally used to advertise a house for sale in Spain. This kind of protest highlighted the fact that the regional government was selling a public good for private interest.

Photograph by Beatriz Aragón (2013).

Healthcare worker showing her support for universal healthcare in her workplace.

Photograph by Beatriz Aragón (2013).

"Gynaecology and obstetrics for sale" (Authors´ Translation). The pictures were taken inside a public healthcare centre in Madrid in 2013 in the aftermath of the financial crisis. It led some European countries such as Spain to implement austerity measures that took a great toll on public services. Budget cuts were accompanied by a national structural shift that altered the universality principle of the National Healthcare Service (*Sistema Nacional de Salud*, SNS): in September 2012, a Royal Decree-law came into force, excluding undocumented migrants and other groups from healthcare and thus undermining universal coverage. While the initial response brought together professionals rejecting the law, media reports on the gravity of the effects of this exclusion, and collectives organizing mutual support to fight for universal access on the ground, healthcare exclusion compounded processes already in place in PHC. These processes included the prevalence of individual versus collaborative interdisciplinary work within the PHC centres, coupled with the increasing precarity of workers and bureaucratization, which very often contributes to racist practices. Furthermore, some regions, such as Madrid, profited from the austerity measures and the budget cuts, which made it easier for private companies to run public healthcare facilities. Out of the popular discontent generated by the cuts to public services, such as the *Indignados* movement, also called *15-M*, a widespread movement called *la Marea Blanca* (*The White Tide*) arose to defend the SNS from the attempts to privatise it.

Before the COVID-19 pandemic, PHC in Madrid was not at its best: underfunded and marginalised in a hospital-centric system, it had progressively lost most of its communitarian foundations.

To better convey the tensions underlying PHC, we need to provide some context about healthcare in Spain. The Spanish healthcare system, *Sistema Nacional de Salud* (SNS), was conceived in the eighties during the transitional years to democracy after the Franco dictatorship. The SNS is a decentralised system (every regional government oversees the provision of healthcare) financed through general taxation that originally aimed to provide universal health coverage. PHC was conceived as the basis of the SNS, theoretically grounded on George Engel's biopsychosocial model and the Alma Ata principles in which essential healthcare is ″made universally accessible to individuals and families in the community through their full participation″.[3] However, this kind of community-based care was not developed in all PHC centres, neither in Madrid nor at a national level. We need to add to these tensions the fact that PHC has never been one of the most appealing medical specialties: it has little social and medical recognition in the Spanish hospital-centric context.

″The availability of good medical care tends to vary inversely with the need for it in the population served. This inverse care law operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced. The market distribution of medical care is a primitive and historically outdated social form, and any return to it would further exaggerate the maldistribution of medical resources.″

Julian Tudor Hart: ″The Inverse Care Law″, in: *The Lancet* 297/7696 (1971), pp. 405–412, p. 405.

″I have witnessed and experienced the processes that have eroded the communitarian foundations of primary healthcare little by little. Although the Marea Blanca movement succeeded in stopping the privatisation of 6 hospitals and several PHC centres, the achievement did not translate directly to our workplace, where we had to manage everyday work with fewer resources due to the continuous budget cuts. The increasing workload diminished the capacity of healthcare workers and their enthusiasm for the defence of the SNS. The picture of the paediatricians' door at the PHC centre shows how overwhelmed many healthcare workers felt. On the paediatricians' closed door, different messages warned patients about what was considered an adequate use of the healthcare system with the purpose of avoiding the collapse of the system. The use of these closed doors to communicate with people is a metaphorical representation of the rupture between healthcare workers and the rest of us: a shift in this relationship whereby healthcare workers become gatekeepers of the healthcare system and people seeking care find themselves in a disempowered position. Instead of working with people, as healthcare workers we were closing our doors (and therefore our eyes) to what was happening to the people we attended to, trying to control what were perceived as inadequate demands.″

Interview with a general practitioner (2013).

″The waiting room is packed, as it is always. It is difficult not to recognise familiar faces, people from the neighbourhood. Sometimes, when you feel nervous about your appointment, meeting someone you know is a blessing because you can chat a little bit until the doctor opens the consulting room door and reads your name from the list. She greets us with her head because she knows some of us from a long time ago. I am lucky because my doctor does not get nervous when I ask her several things and we need to take more time than she expected. Other neighbours say that they can only spend five minutes with their doctor. […] The PHC centre is one of those places where you feel safe in the neighbourhood. Some time ago we were closer to the healthcare workers, we were more connected: we researched together about the neighbourhood's housing conditions, about people's working conditions, about unemployment… Still, some days ago one neighbour told me that her doctor mentioned they were thinking about conducting new research together with the neighbourhood. There is a new group of young women (doctors) who want us to join them and think about the research. I hope they have time to do it before they are displaced again to another PHC centre.″

″Centro de salud″, in: Carabancheleando (eds.): *Diccionario de las periferias: métodos y saberes autónomos desde los barrios*, Madrid: Traficantes de Sueños (2017), pp. 71–73. Authors' translation.

Despite the enthusiasm of the first generations of general practitioners and nurses who contributed to building a PHC network rooted in the territories where they worked and organised as multi-disciplinary teams, the family and community speciality remains one of the least attractive for junior doctors. Even a big percentage of those who finish their training as family doctors choose not to work in PHC. The data is alarming: in 2018, just 13% of the general practitioners working in Spain were less than forty years old, so we do not know where the 19'000 family doctors trained in the last ten years are. What we do know is that they are not working in PHC. Despite this far-from-ideal scenario, in 2013 people still trusted the public PHC system. Some people had better experiences with their PHC professionals, others had worse, but the PHC was still somehow considered the trustworthy base of the public healthcare system.

RUPTURE & REPARATION Rupture

"One of my hardest memories from that time was an evening in the Emergency Room, where there was not enough space for all the sick patients who came in. There were so many patients that there weren't any spare beds, stretchers, or even chairs, so the patients were sitting on the floor - waiting next to their oxygen bottles."

Interview with a general practitioner who worked as a junior doctor at the emergency room during the first months of the pandemic (2022). Authors' translation.

The first months of the pandemic were a period of self-organisation for both PHC centres and communities. Due to the lockdown measures imposed by the public health emergency, PHC restricted face-to-face care to specific cases, while most of the care was provided remotely, mainly by phone. Similarly, to avoid interpersonal contact, health centres were ordered not to participate in community interventions. Still, PHC professionals had some autonomy and managed to organise themselves to adapt to the changing reality, remaining united, supporting each other and seeking adaptations as a team to be able to continue attending to the population in the new scenario. During those same first weeks of the Lockdown, dozens of neighbourhoods created mutual aid groups independent of the healthcare centres.

As time passed, the distance between the PHC centres (the inside) and the population (the outside) widened.

While the mutual aid groups were struggling to cope with the growing needs of an increasingly vulnerable population, they could only see the closed door of the PHC centre and the difficulty of reaching their healthcare professionals by phone. What they could not see from the outside was that, inside those centres that seemed empty, their healthcare professionals were working harder than ever trying to respond to most of the phone calls. The gap between the PHC and the populations they worked with widened during that time of isolation.

The rupture, sharing feelings around a cup of tea.

Conversation between Adrián Carrasco and Estrella Sánchez, conducted on 13 September 2022. VIDEO ▶cache.ch/1705

Photograph by Adrián Carrasco (2020).

"One of the moments I remember the most was seeing the empty waiting room on my way out of the (healthcare) centre. It was impressive because although we never stopped working, we could not see the people we were working for, and giving advice to [...] Sometime later, the message that we were not working was spread, and it was because all our work was being done over the phone. Many patients were calling and nobody answered because we could not cope. Others wanted to come and see us but they were not allowed to enter the building."

Interview with a general practitioner who worked at PHC during the first months of the pandemic (2022). Authors´ translation.

During the first months and the following ones, we were working hard while trying to protect ourselves from getting sick (despite the widespread lack of protection equipment). We had never worked harder, with so much stress, and doing so many extra hours, all while ultimately not being able to reach everyone who attempted to contact us. We had to cover for colleagues who got sick and who, in most instances, were not replaced. We even had to deal with the death of some colleagues. We also saw the increasing paperwork piling up on our desks: sick leaves, drug prescriptions, referral reports to A&E, etcetera. But while all this was happening, the waiting rooms remained empty.

We provided care through phone calls, but we lost in-person contact with our patients. It felt as if we were alone in a little fortress.

When patients tried to come to the PHC centre, they were stopped at the entrance and after being triaged were rarely allowed in. When patients tried to call, there were not enough people to answer all the calls, so many of these calls were unattended or received a delayed answer. Despite these access difficulties, PHC centres kept on being the most frequented facilities of the overall healthcare system, which shows that, to some extent, people kept on trusting the PHC system. Moreover, people showed their support in different ways, from daily public applause to more personal gestures of care.

Photograph by Adrián Carrasco (2020).

The COVID-19 pandemic increased paperwork to an unprecedented level.

As we explained previously, the historical lack of resources in PHC worsened during the pandemic, so when people felt sick and worried, they found it harder to be treated by their PHC professionals. Some people got the impression that the PHC centres were closed and even that PHC professionals were not working at all, even though we were working harder than ever. After the first wave, when our PHC centres started reopening to provide face-to-face care, the damage came to light: the pandemic had depleted the scarce resources of our PHC centres while increasing the healthcare needs of a population that had been left either unattended or not properly cared for. New administrative tasks (like processing paperwork for quarantine) took a significant amount of our limited time. More and more people shared the impression that the PHC centres were closed and that healthcare professionals were neglecting their patients. Somehow, we felt that while at the beginning there was some recognition and trust from the population, after the first wave distrust spread.

"The pandemic has also brought out the distance between the PHC centres and the population. People have their problems, and we are not able to solve them. This has happened before, but now it is even worse."

Estrella S.-Gamborino, a general practitioner (2022). Author´s translation.

Overall, the pandemic has deeply affected the PHC teams. It has caused some colleagues to resign because they were exhausted and frustrated due to the increasing feeling of incompetence they had while working in such a dysfunctional system. They had to run away to protect themselves from greater threats to mental and physical health. Some of them did so publicly as a means of protest. As a result of the chronic underfunding and lack of physicians, to which resignations, sick leaves, and early retirements were added, those remaining professionals in PHC felt even more overwhelmed by the amount of work.

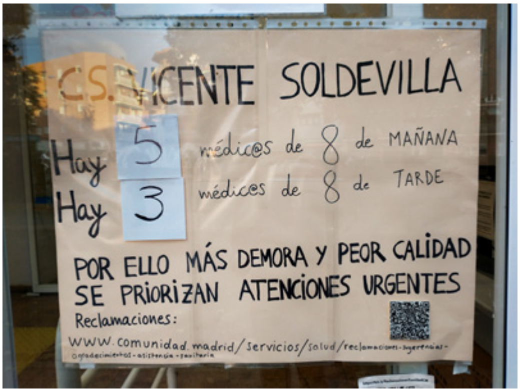
"Yo Renuncio, a PHC professionals collective invites you to join our COLLECTIVE JOB POSITION RESIGNATION as a means of protest due to its outstanding deterioration."

X (formerly Twitter)-Tweet from @ApRenuncio (1 October 2020), since deleted. Authors´ translation.

"Today is my last day in a practice as a family physician in PHC. I quit."

X (formerly Twitter)-Tweet from @iguqui (29 December 2021). Authors´ translation.

The public administration failed to replace those who resigned and to support the collapsing medical teams. In 2020, posters alerting people about the lack of doctors in PHC became a common practice. The posters, made by healthcare workers, informed people about the possible delays and the loss of quality of care while encouraging complaints to the regional government via the displayed link. Years later, this situation has not been solved, and many PHC centres still lack professionals. However, the lack of medical professionals is not evenly distributed. PHC centres located in socially deprived neighbourhoods lack more physicians than those in affluent neighbourhoods, which is a clear example of how the inverse care law works. Furthermore, in Madrid in 2021, only 21 of the 128 jobs offered in PHC were accepted, as these jobs are still not attractive for most of the brand new specialists in family and communitarian medicine. We are concerned about the impact that the personnel shortage may have on the wellbeing of those professionals that keep on working under those dire conditions, but above all we are concerned about how this increases the barriers for citizens to access good PHC.



Photograph by Berta Herranz (2021).

The flyer at the entrance door of the PHC centre *Vicente Soldevilla*, in Vallecas, Madrid, 2020 says: "Health centre Vicente Soldevilla. There are 5 doctors out of 8 in the morning shift. There are 3 doctors out of 8 in the afternoon shift. Therefore there is a delay and worsened quality. Emergencies are a priority". Authors´ translation.

"When a physician or a nurse gets sick, there is no replacement, so their work has to be distributed among the rest. This is normally hard, but during the pandemic medical practitioners could get sick or burn out with all that extra workload. Some people couldn't take it anymore and had to say 'enough'. That's why there are so many centres with no doctors in the afternoon. And unfortunately this happens more in the underprivileged neighbourhoods. The Government was not able to find replacements to replace sick professionals, so their colleagues had to do more work, hence arriving at the same situation. It is like a snake biting its own tail."

Adrián Carrasco and Estrella S.-Gamborino, both general practitioners (2020).

RUPTURE & REPARATION Community Care

While PHC centres and professionals lost contact with patients, the community started to organise itself to share mutual care between neighbours and families. Some of us participated in these activities and witnessed how, as the production system was switched off, the care system was switched on: a peer-to-peer support system based on proximity and selfless help was working full time.

As many people were unable to go to work, they stayed home and provided mutual care in their communities. These caring communities mobilised to provide people with the daily living support they needed.

For example, they helped other neighbours to get some food, they organised child or pet care, they were on alert in case someone didn't communicate frequently enough, they acted as translators 24 hours a day, they drove their sick or dependent neighbours to a health centre or a hospital, etcetera. While problems with the health exclusion of migrants with and without residence permits persisted, these neighbours also managed to maintain certain access to the health system, connecting people's needs to the health workers inside the PHC centres. This caused a well-meaning envy in some healthcare workers who tried to re-connect or keep connected to the neighbourhood's networks. So, although healthcare workers were not allowed to participate in community-based activities, PHC professionals who were previously involved in these networks kept using them to adequately reach their patients' needs in such a complex situation. However, these networks were not a place to envy. People who supported and cared for each other did so at great cost.

"We were working from home, taking care of family members, and delivering food and other products to neighbours. On top of the fear of the virus, there were these mixed feelings of not having enough time to do it all, not having the opportunity to come together and think things through, and anger at public workers who referred people to the networks without contributing any kind of resources to them."

Interview with a participant in a support group during the pandemic (2020). Authors´ translation.

"Where were the healthcare professionals, where were the public officers, where were the social workers, where was everyone that used to be physically present and holding responsibility for the common care? Even if they were working, they were not there, they were behind their closed doors."

Interview with a participant in a support group in Lavapiés during the pandemic (2020). Authors´ translation.

Many people were also facing economic struggles and were themselves beneficiaries of already existing or newly improvised foodbanks. For example, in the Lavapiés neighbourhood, located in the city centre, a team of volunteer translators from Bangla and Senegalese communities, together with other members of *Red Interlavapiés*, visited households to explain general protection measures and to translate public officers' and healthcare professionals' epidemiological and clinical indications. These same people spent hundreds of euros on phone calls and text messages to promote vaccination among their communities, to reduce accessibility barriers, and to help mitigate doubts and fears.

"I spent the first weeks of the pandemic making calls to PHC centres. We wanted to figure out what they were doing with people without a healthcare card. Some people were being referred to mutual support groups by healthcare professionals, some were being denied care or threatened with being charged for it. The fear and the feeling of abandonment was huge. I myself, having been involved in the struggle for universal healthcare since 2012, could not believe some of the things I heard. The exhaustion being felt inside PHC centres in many cases turned into rejecting those who were in more vulnerable situations. It was the first time in nearly a decade that we had to go to court so a young woman could be treated for her illness, given the hospital's denial of her care. But we were also able to unlock situations of exclusion by explaining what the 'outside' situation was to professionals: 'yes, it is raining inside the healthcare centre, but there is a flood here outside'."

Marta Pérez, a participant in the social movement for universal healthcare (2020).

"Are we all more alone in our difficulties? Which is the real support that we can receive from our public institutions, and particularly from PHC centres? Are we entitled to also care and support those struggling inside PHC centres, who are also not being cared for enough by their own institutions? To what extent? How can we cope with it all? Where do we regain dialogue and common sense? How can we make sense of these developments?"

Interview with a participant in a support group during the pandemic (2020). Authors´ translation.

These questions about how to take on the contradiction of doing public professionals' work were also shared in a mutual support network in Vallecas, a neighbourhood in the south of Madrid, called *Somos Tribu* (*We are Tribe*). The experience of the people working against healthcare exclusion can also testify to the impact of the pandemic closure of the healthcare system. The pandemic experience of having to assume the care of oneself and others without public support still persists in people's lives, especially for those in the most vulnerable positions. It raises the question of deservingness, which has been discussed previously in healthcare, especially regarding undocumented people. Today, the possibility of shutting down care for all has deepened.

RUPTURE & REPARATION Repair

In these final paragraphs, we offer some ways to begin a reparation. All of them come from formal and informal meetings with our wider network of friends and colleagues involved in community healthcare in which we have discussed how to talk about our concerns. Our experience tells us that we are on our own, with our own endless list of patients to attend to and our own despair while trying to reach our PHC physicians. How can we escape from it? How to talk about all this with others and, in doing so, identify commonalities, differences, and links between inside and outside concerns? How can we think from the threshold, together? In sum, how to politicise the pain and the rage but also the impotence and fear we feel towards the past, present, and future? If we - both professionals and the public - share a common loss of the sense and value of PHC, could it be that this sense and this value have been expropriated from us? Could it be that the conditions to create, construct, and nurture this sense and this value are not there anymore? How can we re-appropriate these conditions, and how can we create new ones, to produce a new sense and a new value? Time - or more precisely, the experience of both lacking time and feeling time accelerating - is one of our most pressing issues. Interrupting this relationship with time could be a way to open up possibilities for new presents and futures. What could happen if professionals and patients of a PHC centre came together, liberating two hours of consultation time to dedicate them to gather in an assembly? Would that be enough of a break for us to think together and share our experiences of the rupture from both sides?

"I write this text two weeks before I go back to clinical practice, it is a very timely reflection. Two years ago, I felt my professional world was breaking apart, and I was not able to make sense of my clinical practice. I stopped. I cherish my profession and I did not want to burn out completely. I took my time: I mourned the lost hopes and projects, I stood together with other friends and colleagues who were feeling the same way, and together we tried to reconstruct a valuable PHC. I am going back to clinical practice, and the rupture feels more like an Interruption: the initial burst that made me stop and take time out now feels like a burst between an interrupted past and an uncertain present. I hope the time I took helps me to maintain an interruptive attitude – to interrupt the individualistic logics that split us apart, the administrative nonsense that widens the gap between public and professionals, the overwhelming feeling of impotence."

Interview with a general practitioner who resigned in October 2020. Authors' translation.

Some of us working inside healthcare centres think common assemblies might help to shake up the exhaustion and lack of imagination that daily work in our current PHC brings. In our discussions, this little change immediately opened up our minds to possibilities for connecting grassroots movements to institutional work around health and wellbeing: to have free time and space not filled with programmed tasks, to let things happen, and to let ourselves value that indeterminacy as a health practice. Those on the outside think these spaces might provide meaning by enabling us to see that health workers show up, that they stand with the community, that they are there for us, and that our needs are heard and taken into account - within their limits, we know. Such spaces show us that we do not need to face things alone and that there might be things to think about and to do as a team. Physicians and patients share the core values of protecting our health and nurturing our right to care for each other. However, the institutional support for this is minimal: if they take place at all, these discussions are corseted into programmed groups about health education. Health workers themselves do not share the same need to create these spaces. In many PHC centres there is not even a team anymore, just a group of individuals trying to survive their daily work, with little sharing and common practice. Many are still hurting, angry, burned out. Still, as we finalize this text, PHC physicians in Madrid are on strike claiming for better working conditions to be able take better care of their patients.

It is a great task to repair these ruptured teams while agendas are full, patients suffer long waiting lists, and their health needs have been partially neglected or superficially addressed over the last few years.

How can we open new paths where even the mere thought of adding more work is unbearable? How can we gain a common sense from the inside? How to create and nurture time and space with the public outside while giving the best care possible to all our patients? How can we care for ourselves and recover the joy of creating new possibilities for better care and stronger relationships with our patients in our day-to-day? We do not have answers to many of these questions, and we know that interventions at different levels are necessary. But we intend to start where common people do things on an everyday basis, where the life of neighbourhoods and their PHC centres meet.

Notes

1 The authors would like to thank Irene Rodriguez Newey, Paloma Quintana and Peter McAndrew for their valuable contributions to the English editing of the text.

2 Janina Kehr: "Against Sick States: Ebola Protests in Austerity Spain", in: *Somatosphere: Science, Medicine, and Anthropology*, www.somatosphere.net (2014).

3 World Health Organization, Regional Office for Europe: "Declaration of Alma-Ata" (1978), https://www.who.int/publications/i/item/WHO-EURO-1978-3938-43697-61471.

COORDINATING CARE Radically?

In *The Birth of the Clinic*, Michel Foucault proposed the term ″clinical gaze″ as a description for the dominant epistemological framework of clinical medicine.[1] He traced this framework's origin to the large teaching hospitals of the 19th century. It was here that the doctors' focus shifted from asking patients 'What is the matter with you?' to 'Where does it hurt?'.

″The clinical gaze effects a nominalist reduction on the essence of the disease.″

Michel Foucault: *The Birth of the Clinic: An Archaeology of Medical Perception,* New York: Vintage Books (1994), p. 118.

Foucault noted that this narrower focus on measurable signs of pathology came at the expense of other explanations for illness, chiefly those rooted in the patient's lifeworld. Other scholars have criticized that healthcare practitioners following a purely biomedical model often ignore the patients' social context. The dominance of this model is also reflected in the traditional split between healthcare and social services. This is despite the large body of epidemiological scholarship demonstrating a strong link between a patient's social position and a variety of health outcomes. The significance of these social determinants of health has led many scholars to advocate for more integrated forms of care.[2]

Tudor Hard already voiced the need for the integration of fragmented services in the 1970s. He found that there was an inverse relationship between the need for services and their actual provision. In practice, this ″inverse care law″ means the most disadvantaged, with the highest need for medical and social services have the lowest level of service provision. Conversely, it is known that e.g., privileged patient groups, disproportionally access preventive health care interventions, such as cancer screening, thereby further increasing underlying health inequalities. The fragmented nature of social and healthcare services furtherly exacerbate inequalities in health and healthcare.
Fragmented services require users to become ″active″. They need to find, appraise, and choose their way in the vast landscape of public service provision. The ability to navigate this public service landscape is equally dependent on education, time autonomy, and other social factors. Difficulties in navigating services regularly result in delays to requests for help or taking ″the wrong path″, i.e. approaching a service unable to meet a client's specific need. It can also lead to discontinued care or people not accessing services altogether.

Julian Tudor Hart: ″The Inverse Care Law″, in: *The Lancet* 297/7696 (1971), pp. 405–412.

The German public service provision is often described as particularly fragmented and provider-centered.[3] Services follow professional boundaries, mandates, and jurisdictions to the detriment of the coordination and cooperation between services. More recently, locally practiced forms of coordinated and integrated care move away from such provider-centeredness, toward more patient-centered services (an internationally formulated healthcare policy aim). However, this change is not straightforwardly implemented and 'up-scaled'. It encounters various challenges and resistance. Of crucial interest to researchers studying this emerging shift in healthcare provision thus is: What makes the current arrangement so inert?

Can breaking up jurisdictions and boundaries be radical?

In answering this question, we find inspiration in Pierre Bourdieu's challenge of orthodox institutional arrangements in fields such as public services.[4] Orthodoxy describes a dominant belief. Heterodox positions contradict and challenge these by questioning the legitimacy of the dominant. Healthcare and social service arrangements and jurisdictions are historically grown structures that manifest culturally ingrained classifications and social inequalities; they store and reproduce powerful positions of – and relations between institutional actors as well as professionals and clients. We postulate that challenging or changing these arrangements and classifications through heterodox positions – as illustrated by our case studies – can thus be deemed radical.

Patient-responsive forms of care go beyond the biomedical model and provide methods of coordinating services.

The two case studies presented illustrate the inertia of the institutional arrangements of the German healthcare and social service system. By referring to them, we want to highlight heterodox attempts to institutionalize coordinated and more patient-responsive forms of care. Research suggests that coordinated care may reduce the impact of social inequalities in health care access and improve health outcomes.[5]

COORDINATING CARE Two Case Studies

The first case study portrays a shift in the provision of emergency rescue services towards the coordinated provision of social and health services. This change was triggered by the emergency telephone service 112 regularly being utilized to request help for low-acute medical problems or lacking social provision. The increase in low-acute calls prompted the need for institutional change. Krüger used interviews and participant observation to conduct research on the rescue service of a German city. For this article, she draws on current debates about the organization of the rescue service as well as on an interview excerpt with Mr. Reimann (pseudonym), an employee of her case study's rescue service planning department. The second case study, describes the work of the *Gesundheitskollektiv Berlin (GeKo)*, a German community health center, which brings together activists, medical providers, and psychosocial service providers, thereby providing coordinated, holistic and patient-centered care under one roof. Schuster's description of a German community healthcare center in Berlin (*GeKo*) relies on her participation in *GeKo's* working group on research and evaluation since 2018. As a medical doctor and member of *GeKo*, Schuster takes a reflective position inspired by the approach of observant participation. She reflects on the work of *GeKo* both as an activist and healthcare practitioner, as well as a health service researcher. Schuster's positions do not necessarily reflect the positions of the Berlin Health Collective.

Both case studies demonstrate heterodox positions in relation to the existing public service provision.

Their quest to provide care differently follows different trajectories. The first relies on a more conventional approach, and the second is more 'political'. We postulate that they represent two poles of the continuum of radically responsive, patient-centered care. At first glance, both cases appear incompatible. The rescue service and community healthcare center represent two distinct medical organizations, employing providers with different professions, trainings, and foci. The rescue service provides first aid and, in part, first medical interventions in case of medical emergencies. The *GeKo* is a community health centre aiming at implementing integrated primary health care at the neighbourhood level (Berlin, Germany). Yet, both cases experience similar problems and struggles to address these. Rescue services document increases in their use as well as frequent encounters with patients who not only suffer ill health or injury but also (psycho)social needs that are involved or stipulate a 112 call and ambulance operation internationally.[6] Primary care providers similarly observe (psycho)social needs.[7] Providers in each sub-field agree that not-addressing (psycho)social needs deemed as a mismatch to the (bio)medical model of illness influences patients' health and well-being, as well as their work, resulting e.g., in unmet needs and frustration. This chapter shows how planners in rescue services and primary health providers start to complement the limited toolboxes to address varied needs by re-scaling their focus from specific organizational mandates to responsive, patient-centeredness, i.e., from fragmentation to integrated and coordinated care.

COORDINATING CARE The Rescue Service

The field of emergency (para)medicine has seen increases in client numbers in emergency rooms (ERs) and the rescue service (inter)nationally. These increases are not related to a rising number of medical emergencies alone, i.e., life-threatening conditions and those that risk harming the health of clients. Many of these operations concern low acute cases in which clients are vitally stable – mandatory transports to ERs appear not necessary and in which clients might benefit from ambulatory, nursing, or social care. Yet, ER transports are usually issued. They follow the institutionalized logic of the 'chain of rescue'. The chain of rescue is conceptualized and practiced as a form of care that involves support by laypeople or professionals on the ground and includes first aid, the issuing of a 112 call, and eventually medical intervention by an ambulance crew and transport to the emergency room of a hospital. First aid and transport have long been considered the working focus of the rescue service in Germany.[8] In this context, alternative care provision is not envisaged or conceptually and organizationally facilitated. Yet, rescue services face a historic challenge: an increase in operations (in Germany, annual increases of 5%) of which many clients mismatch the original mandate of life rescue.[9] Frontline workers and researchers identify particular client groups who might benefit from other forms of care (e.g. nursing care, social work, housing, psychosocial crises support, ambulatory healthcare, self-help groups, and community services).[10] Frontline workers are regularly confronted with needs outside their mandate, with partly impoverished, chronically ill, and helpless clients, and evaluate their time-sensitive but short-term interventions as "insufficient". Rescuing a client from suffering that is "distal" to urgent biomedical causes has not been part of the paramedical toolbox, nor of its agenda. The rescue service works according to a specific rhythm: it responds promptly, processes quickly, and addresses acute healthcare needs. This logic developed to - and succeeded in - rescuing many lives and preventing damage to health.

While designed to respond to the extremes of the body and psyche, it has difficulties addressing other temporalities or conditions like homelessness, long waiting times for ambulatory appointments, depression, loneliness, or elderly, homebound care issues.

Frontline workers see such conditions as partly responsible for an increase in operations. The low threshold access to the rescue service and its outreach work brings some clients with difficulties in accessing other services regularly in contact with emergency care. A 112 call can trigger an operation, and an operation usually triggers a hospital transport while providers cannot necessarily be responsive to the client's non-medical problems. The chain of rescue can turn some clients with mismatching needs into a cue ball in the system (Mr. Reimann; rescue service planning unit). However, health service researchers and providers themselves started to regularly express their heterodox demands of a paradigm shift in publications, reports, and conferences. In an interview, Mr. Reimann explained instead of giving a uniform response (along the chain of rescue) to a diverse range of operational situations, rescue services "need to start to give different answers" to rethink healthcare provision.

"As in other countries, emergency rescue and emergency rooms are showing rising utilization rates. A sensible approach to managing this situation is to break away from the (linear) logic of '112 – ambulance – transport to the emergency room'. Internationally, experts agree that emergency rescue must be expanded into an integrated assistance system. This includes alternative services such as acute services with social workers, special services for crises as well as acute treatment for psychosocial and psychiatric emergencies, case management of frequent users, and better care for institutionalized facilities such as special forms of housing. Only by investing in this area can unnecessary transports and admissions be avoided – but this is not very easy to implement with separate sectors and responsibilities."

Rajan Somasundaram, Denis Gümbel, Stefan Poloczek, Harald Hasselmann, Joachim Seybold, Axel Ekkernkamp: "Notfallversorgung in Berlin - heute und morgen: It takes a system to save a life.", in: *Beitrag zum Denkanstoß 8: Gesundheitsregion Berlin-Brandenburg,* https://edoc.bbaw.de/frontdoor/index/index/docId/3644 (2022).

Recent years brought about an increasing understanding among providers, researchers, and planners in emergency care to adapt the rescue service and establish an integrative and coordinated aid service. In that, planners and practitioners aim at both: networking outside their mandate and profession and cooperating with various professions that respond to needs within and beyond emergency medicine. Such a heterodox position attempts to break with the linearity of the chain of rescue. In that, actors suggest a move from an organizationcenteredness to a patient-centeredness understanding of the rescue service, coordinating and facilitating access to other local services. Such a form of navigation may mitigate the effects of social inequality in service access and might increase a sense of responsiveness for clients.

Photographs by Daniela Krüger (2023).

One of the authors saw the metaphor of flowers, separated and grouped in one image and mixed and intermingled in a second, in a presentation by an emergency care planner who used similar images to explain the difficulties and benefits of working across professions and sectors to mitigate current challenges in emergency care.

As some providers and authors suggest, the shift may include an integration of different providers and sectors, bridging and integrating institutional turfs and professional boundaries. The first attempts in this direction are already in the making. The German city of Oldenburg introduced a pilot project called *Der Gemeindenotfallsanitäter*.[11] Their task is to evaluate whether a client can be sorted into other institutional paths such as nursing care, general practitioner care, or psychosocial services on-site. In a similar vein, the city of Copenhagen introduced *Sociolance* in 2015 as a pilot study, catering to unhoused people who often lack access to regular healthcare and institutionalized psychosocial support. The Berlin fire brigade established a preventive rescue unit within its service, and case management for those clients who frequently call 112, often for psychosocial needs, and facilitates access to other (social) services.[12] These approaches represent niches of more coordinated and holistic care. However, scaling up these niches from pilot studies to regular care faces challenges. Integrating and fully coordinating care by a prehospital aid service encounters sectoral and professional boundaries imposed by different jurisdictions, and funding schemes as well as trainings and professional self-understandings between e.g., ambulatory and hospital care, rescue service, nursing or psychosocial care.[13]

COORDINATING CARE The Community Health Centre

The main goal of *GeKo* is to provide coordinated curative and preventive care, and health promotion while taking into consideration social determinants of health such as rent increases, low income, precarious employment, racism, or poverty. The *GeKo* was developed as an association between healthcare providers and political activists. One of the aims is to address a shortcoming of the healthcare system: its fragmentation and the professional dominance by physicians. In 2022, *GeKo* opened its doors to provide integrated and coordinated community care, but decentralised activities in the community have taken place since 2016. *GeKo* provides care in an interdisciplinary and interprofessional, patient-centred, easily accessible, and participatory manner. These core values of the center's care provision have been developed in a cocreation process among its members in close cooperation with local stakeholders in the community it serves. The complex interaction between physical, mental, and social conditions of health are addressed by four main pillars: primary medical and psychotherapeutic care, community organizing and projects in the neighbourhood, self-help, and counselling and research and evaluation. The community health centre works with a multi-professional team of psychotherapists, community health nurses, social workers, health and social scientists, doctors, and physiotherapists. Dominant hierarchies within and between occupational groups are challenged by promoting shared, equal decision-making, regular exchange in collective case discussions, and knowledge transfer. Hierarchies between providers and patients are also addressed. Participation plays a role in medical care as well as in the ongoing organization and development of the health centre. The development of the centre and the services it offers are directly aligned with the needs of the people in the neighbourhood and thrive on close, direct contact with them. To understand the local populations' comprehensive social space and needs, we performed a needs-based analysis between 2017 and 2020. Mapping of existing structures and actors in the neighbourhood and focus group discussions with local stakeholders provided information on health care needs, care gaps, resources, and wishes. The analysis further included an exhaustive survey of the neighborhood's residents. It showed a strong association between ill health and a low educational degree. Also, housing-related struggles due to fear of eviction, difficulties to cover the rent, and overcrowding were common. Impairment in mental health was highly prevalent.

Among the *GeKo* team an understanding prevailed that health care would require more than consulting and treating patients along the biomedical model of health and illness.

The team actively created networks and cooperation with local providers. Neighbourhood groups focussing on problems in the community such as housing our nursery search strengthen the existing local structures and allow for coordinated referrals to community services, ranging from youth centers and pupils support to social care counseling in older age. Mobile health counseling has been implemented. It aims to improve access to information, counseling, and care, and to encourage the exchange and support of self-help among residents. Activity programs on a local public square are used as a way for community organizing which allows people to get in contact with neighbours, hear their problems, needs, resources, and ideas, and potentially exchange social support. While *GeKo* increased its providers satisfaction with the care it can provide together, it had to overcome various hurdles to institutionalize it. Difficulties included overcoming classical hierarchies, integrating different professional cultures, and living with the constant need to do more while being underfunded.

COORDINATING CARE Actually Radical?

However sharp the senses of providers for the social hardship of their patients, other than biomedical needs usually remain 'distal' to their practice.[14] They are neither part of the medical curriculum nor of its tool box. Waitzkin describes this as the "irony" of medical practice.[15] Insufficient nutrition, precarious working, and living arrangements, lack of access to regular healthcare, domestic and neighborhood violence, and lack of social support and nursing care are among such aspects that may be observed and even documented in screenings but are rarely addressed.[16] Although healthcare workers increasingly assess patients' socio-medical history, a knowledge base for identifying selection criteria for such interventions is scarce. Moreover, available institutionalized solutions to address social risks to health are lacking.[17]

The (para)medical gaze regularly hampers a responsive approach to the distal factors that influence patients' health outcomes.

It is cast in a historically grown and orthodox set-up of the field of healthcare. Recent attempts by planners, practitioners, and political activists to create more responsive institutionalized care for patients with mismatching needs lead to radical shifts, changes, and challenges. Rescue services and community care centers like *GeKo* appear to represent two poles of a continuum aiming for radically responsive care. Yet, radicality is a question of perspective. Other healthcare systems show different institutional arrangements and degrees of professional cooperation. So that actors of heterodox positions formulate other demands than overcoming sectoral and professional boundaries. And radicality is ever-changing. The approaches presented here challenge the persistent institutional healthcare arrangement while, simultaneously, producing residues. In this sense, radicality may be understood as processual and dialectical. Institutional changes in certain arenas and on specific levels may be accompanied by unintended consequences that undermine well-intended aims. To address previously described challenges rescue service personnel suggests assuming the role of a navigator concerning social and healthcare services. In doing so, they challenge a deeply rooted, historically grown role, position, and mandate – and, at the same time, the understanding of their profession. It is a change stipulated by planners and decision-makers. Professionals at the frontlines may experience a sense of deprofessionalization, feeling out of place due to the widened focus of their organization. *GeKo* bases its work on lowered professional hierarchies and participative formulated goals. Their approach is based on collective decision-making. The center attempts to break with professional turfs and hierarchies, including those between medical experts and laypeople.

Persistent knowledge hierarchies in biomedicine and social welfare procedures require continuous individual and collective reflection to address persistent (hierarchical) patterns.

Another residue concerns the question if coordinated and integrated care can prevent or increase fragmentation? Who has oversight and will be responsible for the (whole) person? *GeKo* brings together different professions and shared case discussions under one roof. This is certainly more difficult to achieve for large providers like rescue services. Case management, as tried by the Berlin fire brigade, could be a viable solution, but responsibility and mandate must lie with one provider. Also, a distant service navigator like a rescue service may not detect client needs based on participation. Can their suggested care arrangements be more responsive if they rely on healthcare planning from the top? *GeKo* uses participative methods to adjust its services and to pursue patient-centered care. Thereby, the determination and reflexivity about what kind of needs clients see as relevant have greater weight. Yet, the scalability of their methods needs to be evaluated. Finally, integrated and coordinated care may increase the degree of responsiveness to clients' needs, overcome professional boundaries, and address non-medical needs – but does this merely mean that illness and psychosocial needs are managed better or can their distal sources really be addressed?

Notes

1 Michel Foucault: *The Birth of the Clinic: An Archaeology of Medical Perception*, New York: Vintage Books (1994).

2 Doris Schaeffer, Kerstin Hämel: ”Kooperative Versorgungsmodelle”, in: Peter Kriwy, Monika Jungbauer-Gans (eds.): *Handbuch Gesundheitssoziologie*, Wiesbaden: Springer Fachmedien Wiesbaden (2020), pp. 463–480.

3 Bruna Koch, Michal Wendt, Christian Lackner, Friedrich Ahnefeld: Herausforderungen an die Notfallversorgung der Zukunft: 'Regional Health Care' (RHC). Ein Strategiekonzept”, in: *Notfall & Rettungsmedizin* 11/7 (2008), pp. 491–499.

4 Pierre Bourdieu: *Outline of a Theory of Practice*, trans. by Richard Nice, Cambridge: Cambridge University Press (1977).

5 Nadine Reibling, Claus Wendt: ”Gatekeeping and Provider Choice in OECD Healthcare Systems”, in: *Current Sociology* 60/4 (2012), pp. 489–505; Barbara Starfield, Leiyu Shi, James Macinko: ”Contribution of Primary Care to Health Systems and Health”, in: *The Milbank Quarterly* 83/3 (2005), pp. 457–502.

6 Thomas Schmitt, Thomas Luiz, Stefan Poloczek, Tobias Huber, Marc Kumpch, Christian Madler: ”Sozialepidemiologie einer neuen Einsatzkategorie”, in: *Notfall & Rettungsmedizin* 5/2 (2002), pp. 102–109.

7 Dietmar Jobst, Stefanie Joos: ”Soziale Patientenanliegen: Eine Erhebung in Hausarztpraxen”, in: *ZFA Zeitschrift für Allgemeinmedizin* 90/12 (2014), pp. 496–501; Howard Waitzkin: *The Politics of Medical Encounters: How Patients and Doctors Deal with Social Problems.* New Haven: Yale University Press (1993); Thomas Zimmermann, Claudia Mews, Thomas Kloppe, Britta Tetzlaff, Moritz Hadwiger, Olaf von dem Knesebeck, Martin Scherer: ”Soziale Probleme in der hausärztlichen Versorgung: Häufigkeit, Reaktionen, Handlungsoptionen und erwünschter Unterstützungsbedarf aus der Sicht von Hausärztinnen und Hausärzten”, in: *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen* 131 (2018), pp. 81–89.

8 Institutionally, the rescue service is not included in the German Social Security Code IV (§ 27) which regulates healthcare.

9 Fabian Sieber, R. Kotulla, Bernd Urban, Se Groß, Stephan Prückner: ”Entwicklung der Frequenz und des Spektrums von Rettungsdiensteinsätzen in Deutschland”, in: *Notfall & Rettungsmedizin* 23/7 (2020), pp. 490–496.

10 Thomas Schmitt, Thomas Luiz, Stefan Poloczek, Tobias Huber, Marc Kumpch, Christian Madler: ”Sozialepidemiologie einer neuen Einsatzkategorie”, in: *Notfall & Rettungsmedizin* 5/2 (2002), pp. 102–109.

11 The German city of Oldenburg introduced a pilot project called ”Der Gemeindenotfallsanitäter” (”the emergency care paramedic”). Their task is to evaluate whether a client can be sorted into other institutional paths such as nursing care, GP care, or psychosocial services on-site. The goal of community paramedicine is to prevent unnecessary transports to the ER and facilitate clients' access to other services (see: Gemeindenotfallsanitäter/ Malteser Hilfsdienst gemeinnützige GmbH [2022]: *Der Gemeindenotfallsanitäter,* https://www.gemeindenotfallsanitaeter.de [8 January 2022]).

12 Berliner Feuerwehr: ”Struktur 2020: Die Berliner Feuerwehr organisiert sich neu”, www.berliner-feuerwehr.de/fileadmin/bfw/dokumente/Publikationen/FW_Struktur2020_Web-PDF.pdf (2020).

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17 Paula Braveman, Laura Gottlieb: ”The Social Determinants of Health: It's Time to Consider the Causes of the Causes”, in: *Public Health Reports* 129/2 (2014), pp. 19–31.

RIGHT TO THE CITY Foreword

How is the right to the city relevant for health for all and how does it already unfold in concrete practices of urban grassroots movements? How do the diverse structures of health inequalities unfold on the urban scale? How do urban movements address these inequalities through collective action and political struggles?
This polylogue presents insights from a roundtable discussion with critical urban scholars and health activists on health as right to the city. The discussion took place at the Radical Health Conference 2021 in Berlin. From the perspective of critical urban theory, Anke Strüver from the University of Graz explains the urban roots of health inequalities and their unequal embodiments. Vasilis Tsapas provides an activist account of how (health) inequalities are addressed in the everyday work of the Solidarity Clinic in Thessaloniki, a radical democratic and anti-hierarchical urban health collective. Andreas Exner as an activist scholar stresses the importance of radical democratic collaborations of right-to-the-city movements and grassroots health initiatives for health equality. Bettina Franke and Jonas Löwenberg from the community healthcare center *Poliklinik Leipzig* highlight the role of interdisciplinary work and the empowerment of local communities in approaching people's health from the bottom-up. Following this, the Critical Urban Research Group Münster emphasizes the role of urban space as an important scale for collective transformations of structural health inequalities in the sense of health as a right to the city. The session was moderated by Richard Bůžek and organized by Critical Urban Research Group (Iris Dzudzek, Richard Bůžek, Susanne Hübl, Lisa Kamphaus) from the University of Münster.

RIGHT TO THE CITY Collectivizing Health

Richard Bůžek: Anke Strüver, in your work you are investigating how health inequalities are unequally embodied in cities. Can you explain the roots of health inequalities on the urban scale in more detail? Where are the possibilities to transform health inequalities and how is this related to the right to the city?

Anke Strüver: As an urban geographer, I start with a very traditional introduction to answer this question. That is, what do we mean by "the right to the city"? Key thinkers here are David Harvey[1] and Henri Lefebvre. In the following, I refer to Henri Lefebvre. Henri Lefebvre defined the right to the city as it cannot be conceived of as a simple visiting right or as a return to traditional, pre-industrialized cities. Instead, the right to the city can only be formulated as a transformed and renewed right to urban life.[2]

> "The right to the city manifests itself as a superior form of rights: right to freedom, to individualization in socialization, to habitat and to inhabit. The right to the œuvre, to participation and appropriation (clearly distinct from the right to [capitalist] property), is implied in the right to the city."
>
> Henri Lefebvre: *Writings on Cities,* Oxford: Wiley-Blackwell (1996), pp. 173–174.

So, the emphasis for me is defining the right to the city as a right to 'just' urban life. Consequently, the question remains, what is 'just urban life'? I refer to 'just' in the sense of parity of participation,[3] i.e. justice relying on the connections between three dimensions of justice, namely distribution, recognition, and political representation. Urban life has always been characterized by social and spatial divides. Embodied health inequalities are but one example of these divides. They refer to the embodiment of both environmental exposure and social processes, and how these two elements come together. There are obvious connections between socioeconomic differences along class lines, which we can label as outcomes of capitalism. Also, there are connections between socioeconomic conditions and socio-cultural contexts including resulting racism and environmental degradation in or close to particular urban neighborhoods, which are often labeled as so-called 'poor neighborhoods'. Those labels go back either to their location, e.g. when they are close to waste incinerators, noisy infrastructures such as main stations or airports, or in the proximity of high-emission factories and alike. They also might be labeled as 'poor' neighborhoods, due to insufficient quality of housing or their population composition along economic and cultural lines or all of them. This is a scenario where all three stereotypes of poor neighborhoods come together and we can find them in every city. However, people in poor neighborhoods neither are generally nor automatically less healthy than in different neighborhoods nor are they deprived of a good life, due to their place of residence or individual misbehavior, especially not in Central Europe. Yet, health inequalities within cities are strikingly apparent.[4] Negative health outcomes, then, are rather an effect of socially mediated processes of the entire urban or even national society. These processes are rooted in the dominant social structures, and neither in people's individual behavior nor in the built urban environment as such.

Health is not only affected by individual behavior or built urban environments but mainly determined by dominant social structures such as gendered, classed or racialized inequalities.

The dominant social structures such as gendered, classed, and racialized distinctions result in spatial and social inequalities. For us as geographers, the relation between social and spatial inequalities is particularly important. What is very interesting for me in particular is the embodiment of these social and spatial inequalities, including the embodiment of environmental bads, but not in a clear cause-and-relation-logic. That means people's physical bodies are the place where social, spatial, and ecological or biological impacts materialize and result in better or worse health conditions. Thus, the environmental quality of places deeply affects bodies, but if we consider embodied health inequalities we need to look beyond individual bodies and individual people and rather concentrate on the structural relations within a given society. That is, we need to look beyond the individual and the social and environmental quality of places, and instead foreground the urban and societal structure that results in socio-spatial inequalities and qualities of places. The material self, the body, and the embodiment thus cannot be disentangled from processes that are simultaneously economic, cultural, and environmental. Therefore, a perspective on human health should be 'bio-social'. A bio-social perspective on human health includes an understanding of human and environmental exposure as well as human and environmental nature beyond biological determinism and also beyond both socio-cultural essentialism and (failed) individual behavior and responsibility for one's health. If we ask, how social differences become physically or biologically effective in terms of health inequality, we need to point to the fact, that the reasons for exposure to environmental stresses are socio-economic and/or socio-cultural injustice, especially racism, and yet always related to capitalism as institutionalized social order. But the consequences of injustice are still health-related and that is why health is very important. Returning to Lefebvre and the right to the city in the sense of the right to urban life and the quality of just urban life, he also made a plea for real and active participation in cities.[5] This includes participation in education and healthcare, in the collective appropriation of public and green spaces, and so on. These rights are considered collective rights, including the rights to be different and to have different spatial visions and demands.

Photograph by Severin Halder and Lisa Kamphaus (2022).

Participatory intervention to learn collectively about health in the city and how to shape it structurally on the urban scale.

Health as a right to the city and fundamental part of social justice needs collectivization and de-individualization.

Against this background, I argue that health as a right to the city needs to be approached as a collective social process, but includes perspectives on individual yet social forms of discrimination. Integrating health into the right to the city thus depends on de-individualizing health and focusing on health as a fundamental part of social justice.

RIGHT TO THE CITY Solidarity, Not Charity

Richard Bůžek: Vasilis Tsapas, the Social Clinic of Solidarity in Thessaloniki has established the provision of primary health care to all following an egalitarian approach through practices of radical democracy.[6] How do you address inequalities in your everyday work and how are practices of solidarity in the clinic related to other struggles and movements?

Vasilis Tsapas: The Solidarity Clinic in Thessaloniki was founded in 2011. This happened against the background of the beginning of a health crisis in Greece when people without health insurance were excluded from the public health system. That is, they had to effect out-of-pocket payments for visiting public doctors, the medicines they needed, and hospital treatments. The Solidarity Clinic is based on the principles of direct democracy and the absence of authority and hierarchy in itself. Everybody comes to the Solidarity Clinic as a person and everybody is volunteering there. All decisions are being taken in general assemblies where everybody can participate based on equality, all opinions count as equal to prevent any hierarchy. All decisions are usually taken with consensus or with very big and clear majorities. If we cannot meet these requirements, then decisions are postponed, re-discussed, etc. In the general assembly, we also discuss medical matters. Hence, the way how people are treated in the clinic is not a matter of the medical professionals only, but everybody participating in the Solidarity Clinic. We invite people, who have been treated in the clinic earlier, to participate in the assemblies and the decision-making procedures. We are autonomous from the state and its institutions, political parties, and the church, also financially. Instead, we are funded by people and social collectives only. We believe in the principle of rotation in all organizational roles in the clinic and the representation of the clinic to the outside. We regard ourselves as part of the anti-fascist and anti-racist movement of the community.

Social Clinic of Solidarity (KIA Thess), 2012.

"Against a system, which impoverishes life. We support you! We support solidarity." An invitation for a discussion about the dissolution of the Greek public healthcare system and the creation of the Social Clinic of Solidarity in Thessaloniki.

So how do we address inequalities in our everyday work? In our collective, we must address both the inequalities among the different people who come to the clinic seeking its services and the inequalities between the people working in the Solidarity Clinic and those who come to the clinic. First, preventing inequalities among people who come to the clinic requires never demanding anything in exchange from them. No proof of their situation, financial or insurance status, their origin, whether they are national citizens or have any sort of papers, etc. Everybody can come, if they feel that they cannot meet their needs in the national health system, we are doing our best to cover these needs. Everything that we give to the people is completely free, that is all medical and dental services, psychological support services, and all necessary medicines. If somebody needs any other sort of services that we cannot directly provide, for example, treatment from a medical sub-specialization, we have a wide network of medical doctors in the city who treat our patients for free. If we need laboratory tests, we work together with a network of laboratories in the city, so the people are being offered their services for free. If a bigger structure such as a hospital is necessary, we send these people there. We help them find their way through the state health system so that they receive the help and health services they require. As a result, everybody is being treated exactly the same way and procedure. Moreover, the clinic is a place where no discrimination regarding sex, race, origin, or sexual orientation is accepted. It is crucial to understand that from the moment in which someone enters the clinic. In very rare cases in the past when people in the clinic behaved in a discriminative manner, we very strongly stopped such behaviors. Second, we are trying to address the inequalities between the people who treat and the people who are treated. There is a very strong hierarchy between the medical doctors and the patients treated in the classical healthcare system. We try to address this inequality in our practice as we regard the people who are treated in the clinic as an active part of the medical treatment and decision-making. Instead of being passive receivers of medical treatments, we encourage them to participate in and define these treatments. Another important strategy is the formation of the so-called 'Different Medicine' group, which assembles all the people who treat patients from different medical and psychological specialties in the clinic. This Different Medicine group treats people in long sessions, combining multiple medical and paramedical professionals of physical and mental health. We are trying to see medicine from the perspective of the person who comes to get medical services. Therefore, we speak about solidarity, not charity. To avoid inequalities in our daily practices, we are organized in ways to ensure that the people receiving medical services are always on par with our medical staff in the clinic.

The Solidarity Clinic is an organic part of urban movements struggling for direct impacts in the community to address health inequalities.

Beyond that, we regard our collective of the Solidarity Clinic as part of the urban anti-fascist and anti-racist movement in Thessaloniki. We participate in urban struggles such as demonstrations and try to provide these struggles with medical coverage. For example, over the last few years, we have been supporting a big struggle around mining in a small village (Skouries, Megáli Panagía) on the outskirts of Thessaloniki. There we participated in demonstrations and other activities happening during the summer, with speeches, discussions, etc. Moreover, we created a medical facility – a workers' clinic– in a side venue of the squatted factory VIOME in Thessaloniki, which was recovered by the workers of the former factory. We have tried to establish a medical clinic inside the factory and to strengthen it against attacks from the state, in particular against brutal eviction by the police. Here, we also follow our approach to create a clinic in participation with the people who work there for the people who work there and other workers in the city. In this way, we attempt to be an organic part of this urban movement and to create relations with all the other movements in the city. At the same time, we believe that it could be valuable for grassroots movements to focus more on the primary health system because it has direct impacts on change in the neighborhood and the community.

RIGHT TO THE CITY Building Alliances

Richard Bůžek: Andreas Exner, as an activist researcher in Graz, you are dedicating your work to a feminist and socio-ecological transformation of society with a particular focus on solidarity-based economies. You have worked together with grassroots health activists in Austria. Which lessons can be learned from these struggles for a fruitful collaboration of right-to-the-city movements and grassroots health initiatives?

Andreas Exner: It is not easy to answer this question. Since about 2010, I was involved in a couple of initiatives, working with grassroots health activists in various ways of life. Mainly health professionals, but also people interested in health issues more generally. Moreover, I have a foot in fields of struggles that you could easily connect with right to the city and I am somehow affiliated with the right to the city network, which is mainly based in Vienna. The first observation is that in my opinion struggles concerning right to the city on the one hand and health on the other are poorly developed in Austria. You could say that probably for many countries, it always depends on your level of ambition or perspective, and how you assess things. I want to stress that these struggles have to increase. To connect different struggles related to health or right to the city issues in other realms of urban life, there has to be some activity going on.

Social justice necessitates more confrontational strategies to shift public policies significantly.

From the few instances where conflicts erupted in open struggles in Austria over the last years since the financial crisis of 2008, it is important to embody the perspective of the solidarity economy. In Styria, the province where I live and work, a forceful struggle as a response to austerity measures was pursued for a couple of months, with some activities even until quite recently. The austerity measures in Styria happened on a much lower level than those we know from Greece, but there were some similarities. In 2011, the former coalition between the conservative Austrian People's Party (ÖVP) and the Social Democratic Party (SPÖ) enforced budget cuts amounting to up to 25% in the social and cultural sector. This austerity policy was an outcome of the state-backed bank bailouts in the wake of the 2008 financial crisis. The budget cutbacks hit people at the bottom of the social ladder hardest, those who depend on various sorts of social assistance, and people with disabilities. Also, the cultural sector was affected. In the resistance that developed against these austerity measures, it became apparent that alliance building is fundamentally important for successful struggles against budget cuts, which in that case primarily affected the health system, but also for broader issues of the right to the city. For instance, if you think about people depending on personal assistance who cannot move any longer where they want to move when the state cuts back spending in the social sector that you would associate with the health system in the larger sense, then a very basic human right is not safeguarded, protected and enabled any longer. Therefore, it was crucial that many different actors came together. The first step was an alliance of cultural producers and activists affected by the austerity measures with the Communist Party (KPÖ), which is quite strong, especially in Graz, but also in the province of Styria at large. In a second step, health professionals and care workers jumped in and very quickly built an alliance including about 600 different organizations on the level of the province. They formed a coalition that they called *Plattform 25* and organized mass rallies. The first rally gathered around 10'000 people, which is also quite a huge number for Graz, the second allegedly gathered 15'000 people. As a result, they were quite successful in at least influencing the public discourse against these austerity measures.

Photograph by *Plattform 25* (2011).

Mass rally against cuts in provincial health and social care budgets, Styria 2011.

So, what can we learn from these struggles? There has been a debate on the strategic learnings from these processes, and several publications stress that alliance-building and cooperation across ideological fault lines are very important. This needs time. A broad variety of actors – for instance, health professionals, affected people, and their family members, political parties, parts of the trade union, and cultural activists – was one factor of the relative success in shaping at least the public discourse. However, there are also downsides.

Struggles against austerity measures in Styria hardly changed any material policies.

What we can learn from this failure is that you may be able to influence public discourse focusing on the quality of life and social justice issues, but you fail to shift public policies significantly. How can this happen? I think more confrontational strategies are necessary for these matters. Especially in Austria, it is a big problem that trade unions as very important actors in all these struggles are in my opinion geared towards cooperation at nearly all costs. Thus, the trade union probably would not have even engaged with these tremendous assaults on public health, if there had not been independent organizational processes going on that I briefly described above. When the unions jumped in, they hijacked the process as some said, they did not call for strikes but entered negotiations with the provincial government. So they told the *Plattform* to keep quiet until the outcomes of the negations between the trade union and the government would be presented. They warned that strikes or plans of occupying facilities would endanger the negotiations. In the end, the union conducted the negotiations, while the *Plattform* did not call for any strike, but the results were frustrating and discouraging for the movement. Hence, the lesson from this local struggle would be that while we can demonstrate with thousands of people in the streets when it comes to negotiations, we cannot achieve anything if political pressure wanes and negotiations are left to the unions. However, the *Plattform* engaged in ongoing activities over the following years up until 2014. For instance, the implementation of these changed policies involved struggles about how to interpret laws, etc., but in the end, it was a mixed result and this points to some further lessons.

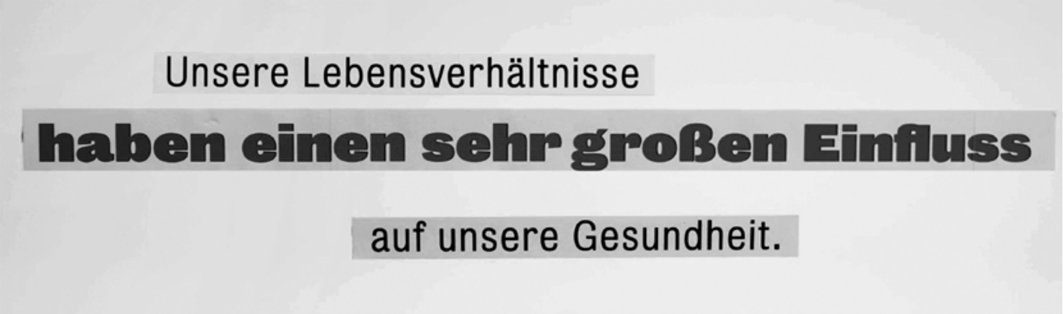
The right to the city requires a framework of radical democracy, which inhibits harmful measures on a population's health and well-being.

First, emphasizing again, alliance building across very different actors is highly important, which requires a certain openness towards others. Second, social movements have to think more about how to organize confrontational strategies in a very ambivalent relationship with trade unions. I think we need the trade unions on board, but at the same time, we also have to put pressure on the trade unions from the outside. Third, in general, we need to shift the framework within which public policies are discussed towards what Henri Lefebvre and others at his time in France called *autogestion*, which means self-government or deep democracy. You could also call this framework 'radical democracy', where it becomes increasingly unthinkable, that governments impose horrific measures on the population because the framework in itself would inhibit that thought from even occurring and social onslaughts to be planned and imposed. In this sense, the right to the city would mean that it becomes practically unthinkable that any kind of actor imposes harmful measures on a population's health and well-being. The examples of the Solidarity Clinic and the *Poliklinik* from this polylogue are particularly inspiring in this regard because they prefigure a change in economic relations towards economic democracy, an economy of *autogestion*, which is crucial to realize health as a right to the city in this deeper sense connected to self-government, often framed as commons or solidarity economies. I think it is particularly significant and interesting that within the health sector, in the narrow sense, examples of organizational democracy emerge. These approaches should be highlighted and multiplied.

RIGHT TO THE CITY Beyond Individual Health

Richard Bůžek: Bettina Franke and Jonas Löwenberg, both of you are professionals in psychotherapy and social work and engage in the Social Healthcare Center *Poliklinik Leipzig*, founded in 2020 as a collective of medical staff and social workers. Informed by the Social Determinants of Health approach, how exactly do you organize healthcare in a different way to address the structural cause of disease on the scale of urban neighborhoods? Where do you see intersections for collaboration with other active urban movements to change these structural causes of disease?

Bettina Franke and Jonas Löwenberg: We are a group of health professionals who were dissatisfied with the actual conditions in the healthcare system and our roles within that. We strive to create a new alternative for primary and social healthcare in Leipzig's district Schönefeld. On the one hand, we want to provide primary healthcare in interdisciplinary teams, thus we have medical doctors, psychologists, and social workers. We also work together with people from academia and with artists to expand our understanding of health. And we are also very inspired by the Greek Solidarity Clinics and their approach to overcoming the normalized hierarchies in the healthcare system, where doctors are on top and the care team or even the patients are at the bottom. We want to organize healthcare provision in a way in which the main caretaker for a person is chosen depending on the patient's needs, preferences, and main issues.



Unsere Lebensverhältnisse
haben einen sehr großen Einfluss
auf unsere Gesundheit.

Poliklinik Veddel, Gesundheit ist politisch! Was bedeutet Prävention in der Poliklinik Veddel?, Germany (2019).
VIDEO ▸ cache.ch/1706

"Our living conditions have a major impact on our health." Still from the film *Gesundheit ist politisch! Was bedeutet Prävention in der Poliklinik Veddel?* by Poliklinik Veddel. The film illustrates the importance of various social determinants of health in the context of disease prevention.

Moreover, with the *Poliklinik*, we want to create a social center, where people can come together to transform the social determinants of health, for example living conditions, discrimination, unemployment, availability of healthy diet, education, etc. Our health and well-being depend on social determinants far more than on individual behavior. For example, the risk of developing diabetes is higher for people with low incomes than for those with high incomes. In our healthcare center, we take a look at the living conditions together with the people who come to us. For instance, the high blood pressure of a person may be stress-related, so treatment with social or psychological counseling might be more appropriate than simply medication against the mere symptom.

With the *Poliklinik*, we want to create a social center, where people from the community are empowered to transform the issues that affect their health.

Our goal is to empower people in the community to work together on the issues that affect their health. Obviously, we see possibilities for collaboration everywhere. We work together with strikes, such as the nursing strikes that are happening right now in Germany, feminist strikes, or anti-racist rallies. Furthermore, we cooperate with the *Medinetz Leipzig*, an initiative that offers support and facilitates medical care to people without health insurance. We also cooperate closely with a renters' initiative, which connects people, who are affected by fraudulent service charges and other problems caused by the property management of powerful large-scale corporate landlords. These are the kind of initiatives, which we want to work together with and strengthen in our community. Leipzig has a great tradition of grass-roots initiatives. For a few years, people who experience psychiatry have self-organized their association to support each other. They employ their own social workers and form independent groups to help each other. We are also inspired by initiatives in Berlin that are making a community and healthcare center by and for trans-, and inter- and queer communities like *Casa Kuà*. We take up these inspirations and hope to support building them in our community in Leipzig-Schönefeld.

RIGHT TO THE CITY Spatializing Health

Richard Bůžek: Iris Dzudzek, Susanne Hübl and Lisa Kamphaus, you are from the Critical Urban Research Group Münster. What role does urban space play for collective transformations of structural health inequalities?

Iris Dzudzek, Susanne Hübl, and Lisa Kamphaus: Health is fundamentally political. Health inequalities are rooted in dominant social structures such as capitalism, racism, and patriarchy, which are mediated through (urban) space. Health inequalities stem from social processes. Consequently, social structures can potentially be changed through collective and transformative productions of space.[7]

Residents from the Hansaviertel community in Münster discuss (structural) causes of health and disease in a participatory mapping workshop.

Photograph by Lisa Kamphaus (2022).

Photograph by Lisa Kamphaus (2022).

Neighborhood walk with residents from the Hansaviertel, Münster, to experience health impacts in urban space.

Urban space is key here. Health and sickness are determined by social relations, which necessarily operate through space. These social relations and practices materializing in sites and human bodies can be proximate such as the workplace or mold infestation in an apartment or far away such as the causes of bad working conditions. In this sense, health and sickness are embodiments of global-local relations.[8] As Vasilis, Bettina and Jonas have shown from their concrete work in the Solidarity Clinic in Thessaloniki and the *Poliklinik Leipzig*, community healthcare centers are concrete sites, where people affected by such global, national, regional, or local relations, which articulate in the form of illness, seek medical treatments. And these anti-hierarchical and radical democratic healthcare centers are also sites, where the very roots of illness and related forms of structural violence[9] resulting in seemingly individual experienced suffering e.g. from discrimination, bad housing, or harmful working conditions can be identified, addressed, and transformed as collective problems that have to be changed to strengthen health for all.

On the urban scale, health is both experienced unequally through embodiments of social and environmental conditions and transformed through social coalitions.

The urban, then, is not only the site where the social and environmental conditions that make people sick are experienced and embodied unequally in people's everyday life but also where people can organize and build broad social coalitions within the community, the city, or the state, empowering them to reshape the social conditions affecting their health. In this vein, community healthcare centers provide crucial spaces to re-appropriate health and the multiple urban resources the city potentially provides, in the sense of health as a right to the city. Such collectivization strategies aim at re-politicizing health through building broad social coalitions across ideological fault lines which are challenged by unequal power relations within such coalitions or vis-à-vis the state. Collective struggles for social justice, then, are also struggles for health as a right to the city. To transform the social structures that determine health, urban health and right to the city movements need to act in concert.

Notes

1 David Harvey: *Rebel Cities: From the Right to the City to the Urban Revolution,* London: Verso (2012).
2 Henri Lefebvre: *The Urban Revolution,* Minneapolis, London: University of Minnesota Press (2003 [1970]).
3 Nancy Fraser: *Fortunes of Feminism: From State-Managed Capitalism to Neoliberal Crisis*, London: Verso (2013).
4 Iris Dzudzek, Anke Strüver: "Urbane Gesundheitsgerechtigkeit: Ökosozialepidemiologische Forschungsperspektiven für eine kritische Stadtgeographie verkörperter Ungleichheiten", in: *Geographische Zeitschrift* 108/4 (2020), pp. 249–271.
5 Henri Lefebvre: *Writings on Cities,* Oxford: Wiley-Blackwell (1996), pp. 173–174.

6 Iro Evlampidou, Manolis Kogevinas: "Solidarity Outpatient Clinics in Greece: A Survey of a Massive Social Movement", in: *Gaceta Sanitaria* 33/3 (2019), pp. 263–267; George Kokkinidis, Marco Checchi: "Power Matters: Posthuman Entanglements in a Social Solidarity Clinic", in: *Organization* (2021), pp. 1–19; "Establishment of the Social Clinic of Solidarity in Thessaloniki", in: *Social Clinic of Solidarity Thessaloniki*, www.kiathess.gr/en/about-us/declaration (2015).

7 Jaime Breilh: *Critical Epidemiology and the People's Health,* New York: Oxford University Press (2021), p. 114.

8 Richard Bůžek, Susanne Hübl, Lisa Kamphaus, Iris Dzudzek: "Wenn die Verhältnisse unter die Haut gehen: Urbane Gesundheit relational gedacht", in: *sub\urban: zeitschrift für kritische stadtforschung* 10/1 (2022), pp. 95–125, p. 118.

9 Paul Farmer: "An Anthropology of Structural Violence", in: *Current Anthropology* 45/3 (2004), pp. 305–325.

Further Readings

Göran Dahlgren, Margaret Whitehead: "Policies and Strategies to Promote Equity in Health: Background Document to WHO – Strategy Paper for Europe 2007/14" in: *Arbetsrapport/Institute for Futures Studies* 2007/14 (2007 [1991]).

Claudia Lang

KERALA Model

The small South Indian state of Kerala is often celebrated for its health achievements in spite of low economic growth and per-capita income. A central feature of what is often called the ″Kerala model″ of health is the state's prioritizing and investment in comprehensive primary health care. Kerala is an interesting case for thinking radical health, since here, concerns and actions that are often pursued by grassroot initiatives are implemented at a state level and translated into policies. Moreover, medical traditions such as Ayurveda and Homeopathy are structurally included in the health care system in a similar manner as biomedicine. Kerala has public and private Ayurveda and Homeopathy colleges; public and private primary, secondary and tertiary care level hospitals and clinics; professional organizations for Ayurveda and Homeopathy doctors, as well as a Department for AYUSH, which stands for the various non-allopathic systems of medicine recognized by the Indian state. In this essay, I trace radical health in Kerala by looking into primary health care (PHC) as it has been imagined, practiced and indeed radicalized since the 1970s.

How do policy makers in Kerala envision healthy futures by radically prioritizing primary health care in a context of limited financial resources? Which local ideas of radical health emerge in the contexts of these debates?

Kerala is well-known in development theory as a case of ″lopsided development″: a gross domestic product typical of low-income countries and social indicators similar to those of industrialized high-income countries. From the late 1950s onwards, the state's rate of growth has been well below the rest of India, and yet the state has made major progress in terms of health, education, population control, or land reform. What is often glossed as ″Kerala model″ of health has been characterized by strong civil society engagement and community participation in decision-making and care, both have also proved important in the local responses to COVID-19 and in Kerala's better fare in comparison to the impact of the pandemic in the majority of Indian states.

KERALA Alma Ata

Photograph by the Pan American Health Organization, Office of Public Information (1978). VIDEO ▶ cache.ch/1703

In 1978, the WHO/Unicef Alma-Ata conference launched the primary health care strategy as a tool to move towards ″health for all″.[1] The strategy was influenced by experiences with social medicine and community medicine predominantly but not only in the global South. It also resonated with ideas of decolonization, sustainable development, a critique of top-down vertical international health approaches, an emphasis on self-reliance, a critique of biomedicine and an interest in lay perspectives on health. In the intersectional PHC agenda, health was defined not only as access to clinical services but also to clean water, food, sanitation, housing, and safe living conditions.

Dr. Ekbal Bappukunju is a senior public health activist and one of the architects of Kerala's most recent health policy. Actively engaged in Kerala's People's Science Movement (KSSP) and in the international People's Health Movement that advocates for PHC in the spirit of the Alma-Ata Declaration,[2] he advocates for PHC and social medicine, drawing on the legacy of Alma-Ata and Rudolf Virchow, one of the founders of social medicine. Both, he suggests, have been largely influential to Kerala's postcolonial health policy. Health policy makers in Kerala take intersectionality in health serious. For example, the *New Kerala Mission* integrates health with other components, such as educational reforms, organic agriculture, waste management, and affordable housing for the poor.

"Earlier, it used to be separate missions. All missions have now been integrated. The name is continuing [and] the work is also continuing under the respective mission. But it has been integrated into a common platform now. It was also a common platform earlier but it was just a coordinating body, coordinating four missions [health, education, agriculture, housing]. Now there is one single mission, *Nava Kerala Mission*, now with four components: health, housing, ecology, and education. All the campaigns are discussed between the missions, by the coordinating agency of *Nava Kerala*. We have meetings between the missions. Now the *Haritha Keralam* [Green Kerala Mission] has started a campaign of better water in the rivers. It's called 'Let the rivers flow free', in Malayalam. That campaign is part of the *Healthy Life Campaign* itself. Though it is done by the *Haritha Keralam Mission*, it has an impact on health. We [the Health Mission] also take part in the discussions and it's a coordinated effort between the missions. When you have polluted rivers, there is no use of talking about healthy living. The work of the *Haritha Keralam Mission* is directly linked to *Aardram Mission* [Health Mission], there is a lot of coordination, more than in the first phase. In the first phase, there was a lot of independent activities, even though there was some coordination. Now it's all more cohesive and integrated. From the experience of the first phase, we learnt there should be more integration. That is why the whole set up was changed."

Interview with Dr. V. Jitesh, Trivandrum, Kerala (31 May 2022).

"Illness and death every day anger us. Not because there are people who get sick or because there are people who die. We are angry because many illnesses and deaths have their roots in the economic and social policies that are imposed on us."

Testimony of a participant in the 2nd People's Health Assembly, https://phmovement.org/ar/node/3311 (2005).

KERALA Participation

Crucially, health policy makers in Kerala also work to strengthen community participation in decision-making, governance and intervention in health. Community participation was key to the PHC strategy. The Declaration of Alma-Ata of 1978 advocated an intersectoral and multidimensional approach to health that included the socioeconomic determinants of health, emphasized affordability and the use of appropriate technology, pushed for self-reliance and self-determination and urged active community participation in health care and health education at every level.

Community participation stressed the idea that communities should be actively involved in the identification of their own health needs, as well as in the planning and implementation of the responses to those needs.

As a critique of top-down, vertical and technical approaches to health, the PHC strategy stressed bottom-up, horizontal and intersectional approaches rooted in site-specific, local processes. The radical PHC approach of Alma-Ata as an international strategy was replaced by the far less ambitious and more pragmatic and vertical selective PHC approach that focused on a few low-cost interventions that were easy to monitor and evaluate already one year later. However, its utopian force continues to be an inspiration for social movements working towards social medicine and health justice, especially in the Global South. And it continues to drive health policy-making in Kerala. In global health, community participation is often reduced to a buzzword and active community involvement in identifying local needs and planning and managing health activities is still rare. Kerala's PHC is a notable exception and thus an interesting case for the study of radical health.

"The concept of democratic decentralisation proposed here also requires a movement beyond representative democracy. Appropriate institutions and opportunities but also necessary capabilities have to be created at the lower levels in order for ordinary citizens to participate in the decision making, implementation, monitoring and sharing of the benefits and responsibilities of governmental activities."

T. M. Thomas Isaac: "Campaign for Democratic Decentralisation in Kerala", in: *Social Scientist* 9/10/29 (2001), p. 8.

In the initial years of primary health care in Kerala since the 1960s – well before the Alma-Ata conference - community participation had not been thought of in terms of the ability to make decisions regarding the organization of the primary health centres or the type of service provided. Community participation was understood as participation in costs and maintenance: an active involvement of the panchayats in the purchase of an adequate piece of land and the construction of the building, including proper housing for the medical officer in charge.

In the 1990s, the People's Campaign for Decentralized Planning led to a radicalization of participatory democracy in Kerala by devolving planning and financial power to the Gram Panchayats, the local self-governments.[3] Following the 1996 decentralization reform not only have primary health centres, as well as their ayurvedic and homeopathic equivalents, the dispensaries, been brought under local control. Panchayats have since then also played a key role in the prioritization of people's needs, the responses to these needs and in formulating development priorities. A Panchayat member explained to me:

"This is an initiative of the government to identify the needs of the society at the grass-root level and formulate projects locally to address the needs of the local community."

Interview with Panchayat member in Panavoor, Kerala (10 November 2016).

KERALA Community Health Workers

Photograph by Claudia Lang (2016).

Accredited Social Health Activists in Panavoor, Kerala.

The 2000s brought two important changes strengthening, or radicalizing, PHC. The first one was the introduction of a new cadre of volunteer field workers to further expand community participation: the Accredited Social Health Activists (ASHAs). This was a national scheme but it worked especially well in Kerala's context of local self-governments. ASHAs are trained female community health workers, acting as a link between the healthcare system and the community. They are the healthcare system's grassroot level. Visiting households on a daily basis, they take stock of health problems, facilitate access to health services, create awareness about healthy living, nutrition, basic sanitation and hygienic practices, immunisation and contraception, or in the context of the COVID-19 pandemic, accompanying patients to hospitals and providing first aid and palliative care. They also conduct screenings and mobilize people to come for medical consultations or attend health camps. ASHAs support the employed and salaried field staff of the primary health centres who also visit houses regularly.

"We are supposed to visit 250 houses or 1'000 population per month, each of us. [...] We get a honorarium of 1'500 Rupees [$18.20] per month. We get remuneration for specific tasks. For example, for TB [tuberculosis] and leprosy, we get remuneration. But these are very rare. For other diseases such as malaria or dengue, we don't get. We also get money if we bring a pregnant lady to the hospital. She should be registered within the first three months. And she should attend a government doctor and a government hospital. We are government staff, so we are promoting government care. For one pregnant lady being registered we get 300 Rupees [$3.60]. And for one child being brought to immunization we get twenty Rupees [$0.30]. We have to bring at least five children for immunization. [...] ASHA workers are usually from the community, those who have married into this place. They [employed community workers] are different, they are staff, they even come from other districts. They have frequent transfers. We belong to the community."

Interview with ASHA worker, Kalliyoor, Kerala (21 February 2019).

While the employed staff community workers are subjected to regular transfers, ASHAs are part of the community. They get a basic monthly honorarium and additional incentives for certain activities. Apart from financial remuneration, working as an ASHA provides symbolic and social capital; several ASHAs have become elected members of the local self government or are otherwise influential in their community. From a critical feminist perspective, ASHAs are the latest iteration of non-salaried workers at the bottommost layer of the healthcare system. Rather than as labor, their work counts as service or voluntary work, and different from employed health workers, ASHAs are not unionized. On the other hand, ASHAs hold important social capital and for many their work has been an entry into local politics.

KERALA Traditional Medicine

The second change that strengthened, or radicalized, Kerala's PHC was the wider integration of Ayurveda, and to a certain extent homeopathy, into PHC. Ayurveda is one of the medical systems promoted by the Indian Ministry of AYUSH, an acronym for Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy, and, since 2012, Sowa Rigpa. Kerala now boasts the largest number of private Ayurveda clinics in India; it also provides Ayurveda treatment in hospitals at every level of the healthcare system. ayurvedic dispensaries are the equivalent to the biomedical Primary Health Centres.

Photograph by Claudia Lang (2019).

Pharmacist at Ayurveda dispensary in Kalliyoor, Kerala.

Two main factors led to an increased investment into ayurvedic and homeopathic dispensaries on the village-level: First, with decentralized governance, decision-making and budgeting, communities were in a position to push through traditional or alternative medical care even on the PHC level. Second, national policies and programs for 'mainstreaming' AYUSH led to a further proliferation of ayurvedic facilities in rural areas. Kerala now hosts at least one Ayurveda and one Homeopathy dispensary in every Panchayat. Rather than an attempt to manage scarcity, as is the case in other parts of India, the integration of Ayurveda within PHC has been a way to offer choice for patients in Kerala. While patients largely frequent ayurvedic dispensaries for noncommunicable and chronic diseases, Ayurvedic dispensaries have also played a significant role in the prevention and treatment of COVID-19 and other infectious disease outbreaks. The integration of traditional medicine within primary health care is in line with WHO's PHC strategy. Yet, Kerala's specific way of integrating traditional medicine as parallel or juxtaposed PHC is unique in India and elsewhere and reveals a rare configuration of modernization of traditional medicine. A vast body of literature deals with other instantiations of Ayurveda's modernization such as the professionalization and standardization of education, standardization and reformulation of ayurvedic pharmaceuticals, translation of ayurvedic concepts of body and diseases in biomedical categories, the reinvention of ayurvedic disciplines such as psychiatry, or the reinvention of Ayurveda as spa. In other Indian states, ayurvedic doctors often stand in for absent biomedical physicians, by providing basic biomedical treatment in the newly designated health and wellness centres, the former primary health sub-centres. Rather than a failure of integration, the juxtaposition of ayurvedic centres on the primary health level provides the physicians in the ayurvedic dispensaries in Kerala with relative autonomy from the biomedical PHC providers. Paralleling the tasks of biomedical PHC physicians, ayurvedic doctors in ayurvedic dispensaries are engaged not only in clinical work but also in disease prevention and health promotion work that they call ″public health work″, ″social work″ or ″service to the community″, in collaboration with the ASHA workers.

″We are trying to teach ASHA workers what Ayurveda is, and by making use of them we are trying to propagate Ayurveda. For example, most people in Kerala think that Ayurveda is simply oil therapies for pain and for geriatric patients. We are trying to correct them. We have different projects of Ayurveda, here in the panchayat. We concentrate on children women and NCDs. We make people know about the strength of Ayurveda, and also the building of immunity through Ayurveda. We are correcting the lifestyle, daily and seasonal regimen, or the food habits of the people.″

Interview with Dr. Siddhi, Government Ayurveda Dispensary, Kalliyoor, Kerala (8 March 2019).

During the pandemic, Dr. Siddhi propagated health diet and lifestyle, dispensed Ayurvedic medicines to strengthen the immune system, and made sure ASHA workers distributed special powders for fumigation to control viral loads to all households.

KERALA Second PHC Revolution

As a response to the epidemiological transition and the massive rise in noncommunicable diseases and mental health issues, the increasing use of private and tertiary health care and exploding health expenditures, Kerala has launched the *Aardram Mission* in 2016 as of the overarching *New Kerala Mission*. Building explicitly on the WHO Alma-Ata Declaration's principle of community participation and decision-making, it aims at transforming the public health sector by strengthening primary health centres.

″We are making Kerala future-ready.″

Interview with Rajeev Rajeev Sadanandan, Kerala's former chief secretary of health, Frontline (29 September 2017).

″Before our Aardram mission, primary health care had mainly implemented national programs. While we have national programs for communicable diseases, noncommunicable diseases like diabetes, hypertension or mental health are not addressed by any national programs and so we didn't deal much with them in primary health care. But our health system couldn't keep up with the pace of the epidemiological transition. The health needs of the people were largely with chronic conditions, but the health system was going on with infectious diseases and family planning, which was not the priority of the population.″

Interview with Dr. Jameela, Aardram mission (21 March 2019).

Dr. Ekbal, member of the Kerala State Planning Board, imagined the scheme as a ″second primary health revolution″, intended to reshape Kerala's primary health care by recollecting key aspects of the Alma-Ata Declaration and adapting them to the needs of the early 21st century.

″I think that Aardram mission has a global relevance also, I would like to call it the second primary health care revolution.″

Interview with Dr. Ekbal Bappukunju, Trivandrum, Kerala (30 January 2018).

In interviews, architects of the *Aardram Mission* and medical officers in the family health centres walk me through the major shifts: What they call ″revamping″ of primary health care in Kerala through its *Aardram Mission* comprises, first, a major reconfiguration of the primary health centres, now renamed as family health centres, including ″patient-friendly services″ (longer working hours, more physicians, less waiting time), laboratories and digitization (electronic health records, telemedicine). It includes, second, a novel focus on the prevention and treatment of what is locally known as lifestyle diseases, namely diabetes and hypertension. A third component of Aadram is a dedicated depression program that integrates depression screening, pharmacological treatment and counseling into primary health care. It expands the skills of community health workers, and it remakes what it means to suffer, who suffers, and how to intervene. Fourth, the program continues to move towards a more radical bottom up planning process including not only medical officers but also community health workers at the grassroot level of the health care system, reflecting what Dr. Jitesh, executive director of Kerala's State Health Systems Resource Centre in 2021, called a ″paradigm shift″ in health planning. Finally, PHC in Kerala moves increasingly away from being modeled around disease towards what Dr. Jitesh called ″wellness″.

PHC in Kerala expands beyond curative services towards a more comprehensive approach to health as promotion, prevention and rehabilitation.

It is the former sub-centres, now renamed as family wellness centres, that cater to citizens' wellbeing in the form of medical check-ups, yoga activities or promoting healthy ways of living, eating and relating. Moreover, in line with an intersectional approach to health as embedded within larger social and ecological contexts, the *New Kerala Mission* of the Left Democratic government aims to intervene in public health not only through medical services but also through fostering social justice, education, and environmental health.

″So far everything has been about disease prevention, it's not about wellness. Now with Aardram, we're taking it a step further to the public to talk about wellness, being well and being healthy, instead of being free from disease.″

Interview with Dr. Jitesh, State Health System Resource Centre Trivandrum, Kerala (31 May 2021).

KERALA Radical Health

In pursuing political, economic and ecological responses along with medical and technological interventions, PHC in Kerala takes the intersectionality of health serious. The trajectory of PHC in Kerala is rooted in a sustained radical policy of investments in social development whose precondition has been the peculiar configuration of leftist politics that has characterized the state since its creation. Moreover, this prioritization in health has been based on democratically established and negotiated needs, rather than on the question of cost-effectiveness calculations or on performance indicators. This basic feature of health planning has resulted in a rare experience of democratization since the 1990s reforms that granted significant agency to the local Panchayats by decentralizing the definition of priority needs as well as the response to those needs.

The political radicality of PHC in Kerala is not only associated with the ability to grant access to health care as a classical understanding of social medicine would have it. Rather it is associated with rare choices and experiments regarding the targets and nature of health interventions.

Kerala's PHC as a particular form of radical health has kept vivid priorities, which were once part of the famous WHO primary health care strategy but have been marginalized since the 1990s. These are the building of horizontal infrastructures, the hiring and training of non-medical personnel, and the integration of traditional medicine. Moreover, in contrast to global health and its vertical programs that mainly target infectious diseases, Kerala's PHC has taken into account and targeted the mounting burden of noncommunicable diseases and mental health. Third, it has expanded narrow approaches to health by including the social and ecological determinants of health. Finally, it has provided forms of civil society engagement and community health that have also proved important in the local responses to COVID-19 and in Kerala's better fare in comparison with the impact of the pandemic in the majority of Indian states. The case of Kerala shows how the notion and experience of radical health is not only deeply rooted in the state's unique development experience on the one hand and larger movements of social medicine on the other. It is also continuously in flux and adapted to new challenges and needs such as the rising rates of chronic health conditions, environmental degradation and climate change.

Notes

1 Ted Brown, Marcus Cueto, Elisabeth Fee: "The World Health Organization and the Transition from 'International' to 'Global' Public Health", in: *American Journal of Public Health* 96 (2006), pp. 72–92.

2 "Kerala Sasthra Sahithya Parishad", https://kssp.in/about-us/; "People's Health Movement", https://phmovement.org/.

3 "Panchayat Raj" (nn.), in: *Participedia*, https://participedia.net/method/5402 (2019).

Vivian Laurens

BUILDING PEACE Buen Vivir

Since the late 1950s Colombia has endured an internal armed conflict involving several guerillas, paramilitary groups, and the Colombian military. The human toll of this war has been devastating; it is estimated that between 1958 and 2012, the armed conflict caused 220’000 deaths, 80% of which were civilians; eight million people were internally displaced, over 27’000 kidnappings were reported, and 25’000 people were forcibly disappeared.[1] In 2016, the Colombian government and the Revolutionary Armed Forces of Colombia, *Fuerzas Armadas Revolucionarias de Colombia* (FARC), signed a peace agreement to put an end to this armed conflict.

The Colombian peace accord stands as a revolutionary proposal that promises to transform Colombian society, and in particular the historically neglected rural areas.

The accord lays out a series of short- and long-term directives to comprehensively address violations of civil, political, social, economic and cultural rights. The first of these directives, the *Comprehensive Rural Reform* or *Reforma Rural Integral* (RRI), aims to transform the living conditions of rural communities by eradicating poverty and reactivating the agricultural sector. This includes a mandate to advance the right to health through the development of a national plan for rural health. The peace accord also stipulates that the design and implementation of all RRI provisions, including the national plan for rural health, should be developed with active participation of local communities to ensure that programs and policies developed conform to the localized conditions of each region.

Photograph by Vivian Laurens (2019).

Small rural community in the municipality of Meta in Colombia.

A unique feature of the Colombian peace accord, with transformative potential, is the inclusion of the indigenous epistemology of *Buen Vivir* as a guiding principle for the design and implementation of RRI provisions.[2]

"*Buen Vivir* is a way of life and epistemology of indigenous communities of the Andean regions of South America. *Buen Vivir* prioritizes interconnectedness and synergy between humans, non-humans, and the rest of the natural world. It aims to transform our anthropocentric way of life into a more harmonious biocentric existence, in which nature is recognized as a subject with rights, and fundamentally interconnected with human life."

Márquez Fernádez, Hidalgo Flor: *Contrahegemonía y Buen Vivir*, Edición: 2, Quito: Universidad Central del Ecuador (2012).

In Ecuador and Bolivia, indigenous communities mobilized in the past few decades to advocate for the transformation of life toward *Buen Vivir* through political, social, and economic reform. Notably, their efforts led to the inclusion of *Buen Vivir* in the new constitutions of Ecuador and Bolivia in 2008 and 2009 respectively. Since then, *Buen Vivir* has been used in other countries in Latin America to support similar advocacy efforts and in 2016 it made it into the Colombian peace accord. The text of the accord does not offer a lot of detail about how *Buen Vivir* can specifically be incorporated in the process of designing and implementing the various provisions. However, the inclusion of *Buen Vivir* in the accord has inspired innovative peace building proposals, specifically in the work of civil society groups. While it is unclear if the authors of the accord realized the transformative potential of *Buen Vivir*, the civil society groups that are utilizing *Buen Vivir* certainly have.

BUILDING PEACE Peace in Jeopardy

Almost six years have passed since the peace accord was ratified and unfortunately the implementation of the accord has been progressing a lot more slowly than stipulated. Based on peace processes around the world, the expectation is that between years four and six about 50% of the accord provisions should have been implemented. However, in Colombia as of 2020, only 28% of the accord provisions have been implemented.[3] Most worryingly, the comprehensive rural reform provisions are among the most affected by the sluggish implementation of the accord.

The rural reform provisions are meant to redress violations of human rights for the sectors of the Colombian population that were most affected by the armed conflict and who currently live in precarious socio-economic conditions.

Lack of political will is mostly to blame for the slow implementation of the peace accord. Iván Duque, former president of Colombia, who took office in 2018, run his campaign on opposition to the peace accord. His government actively blocked the progress of passing necessary laws and policies to implement the accord.[4]

Photograph by Byron Jimenez on Unsplash (2021).

National strike in Bogotá, Colombia (28 April 2021). The protestors sign says: "They are killing us and the media say we are dying."

In addition to the slow implementation of the peace accord, the period since its ratification has seen a concerning increase of violence, including the targeted assassination of community leaders and demobilized members of FARC. Between 2016 and 2021, 1'270 community leaders and 299 demobilized members of FARC have been assassinated. Between January 2020 and November 2021, 179 massacres were reported. Since 2016 more than 500 civil society organizations have received death threats affecting around 4'000 community leaders.[5] In light of stalling governmental action on moving the peace process forward, civil society has had to step in to build peace in their own communities at risk to their lives.

BUILDING PEACE Civil Society

Guided by *Buen Vivir*, civil society groups have been supporting the design and implementation of the peace accord's rural health care system provision, in a way that is truly developed by local communities.

The intersection of health, peace and *Buen Vivir* in the work of these communities reveals new possibilities for structuring transitional justice processes, for redefining health, and for long-term peacebuilding strategies.

Given the lackluster commitment to implement the peace accord during Iván Duque's administration (2018-2022), civil society has played a crucial role in efforts to keep the peace process alive. Here I share an example of the work of civil society to support the peace process in Colombia. Of particular interest is how these groups are operationalizing the link between peace, health, and *Buen Vivir* to transform their communities.

Plan comunitario de Salud
Rural
[Todos y todas podemos participar y construir lo]

Modelo especial de salud pública para zonas rurales dispersas, que permita brindar atención en los hogares o en los lugares de trabajo. Se pretende acercar la oferta de servicios de salud a las comunidades, la construcción y el mejoramiento de infraestructura de los puestos de salud, hacer seguimiento para garantizar la calidad en la atención y, se adoptará un modelo de salud con enfoque de género.

-Red Salud y paz -

Photograph by Vivian Laurens (2019).

Red SaludPaz community plan for rural health in the municipality of Meta, in Colombia, 2019. The plan says: "We can all participate and develop it. Special model of public healthcare for dispersed rural areas, that will allow to provide attention in the homes or the workplaces. The aim is to bring the offer of healthcare services to the communities, construct and improve the infrastructure of healthcare centers, follow up to guarantee quality care, and adopt a healthcare model with a gender focus."

I share here the work of the Health Peace Network, *Red SaludPaz* (RSP), which is a network of civil society organizations, and academic institutions committed to the construction of a peaceful society in Colombia.[6] RSP was founded on February 2017 by academics from the National University of Colombia in Bogotá to support the implementation of the peace accord, in particular the provision to transform rural health. RSP is composed of 39 civil society organizations and 21 academic institutions from all regions of Colombia. Since its inception, RSP has held bi-weekly meetings hosted in the campus of the National University with video-conference connectivity to allow members from around the country to join. Initially, the purpose of the meeting was to jointly develop the vision, mission and objectives of the network. Later the meetings have served as a space to share work being done around the country, to identify opportunities for collaboration and to develop joint initiatives that support their objectives. Importantly, RSP itself is not an organization. Rather, as its name denotes, it is a network that facilitates communication, coordination and collaboration of its members and their initiatives in order to strengthen their health and peace building efforts through unity.

The main goals of *Red SaludPaz* are to advance the right to health in Colombia and to support the transition to peace through the promotion of health.

For RSP, the right to health does not simply entail facilitating the delivery of health care; rather, it is a far-reaching project for the building of peace, and the healing the body, the mind, the community and the environment. From this expanded understanding of the right to health, RSP views health as a crucial component for building and maintaining peace, as such, RSP focuses on the right to health as a tool of peacebuilding. For RSP, the successful implementation of the rural health provision in the peace accord will represent redress for rights violations that originated and perpetuated the war: a crucial step towards achieving justice and establishing the social conditions for a peaceful society in the long term.

Red SaludPaz

¡ORGANIZACIONES CAMPESINAS, INDÍGENAS, AFROS, ACADEMIA, COMUNIDAD!

¡SOS!

Por la Salud Rural

Igresa a:

PRONUNCIAMIENTO DE LA RED SOBRE EL BORRADOR DE RESOLUCIÓN PARA EL PLAN NACIONAL DE SALUD RURAL EN COLOMBIA

Te invitamos a firmarlo

Flyer produced by *Red SaludPaz* (2020).

The flyer was widely distributed through several WhatsApp groups and addresses farmers, indigenous and afro people, academia and the community. It reads: "SOS! For rural healthcare. Enter a statement from the Network about the draft resolution for the national plan for rural healthcare in Colombia. We invite you to sign it."

BUILDING PEACE Phase 1

One of the first projects of RSP, which is still underway, takes place in the rural regions of Caquetá and Meta in the southwest of Colombia. Caquetá and Meta are historically and politically significant because they served as the epicenter of FARC-EP leadership from their inception in 1964, until they laid down arms in 2016.[7] As a result, Caquetá and Meta were disproportionately affected by the war. These rural regions are also extremely diverse; they are populated by farmers, several indigenous groups and FARC-EP ex-combatants, who themselves are an ethnically diverse group. The farmer groups in these regions have a long history of political and social organizing and many of their organizations have been active for over half a century. Four of these farmer organizations, *Corpoayari*, *Asopeproc*, *ASMUCACD* and *Ascal-G* are members of RSP. Along with academics from universities in Bogotá they have been working since 2017 on the design of a health care system for their communities in the context of the peace accord provision.

The goal of RSP in this project has been to create a truly collaborative process with the farmer organizations in which RSP is there to offer support as needed and not to lead. One of the main goals is to help strengthen the autonomy and capacity of the farmer communities to continue to advocate for themselves, without the need for intermediaries such as NGOs or humanitarian organizations. As such, the design of the community health care system has been largely driven by the communities with the guidance from the academics, who have a more robust understanding of the legal and political processes needed.

The projects in Caquetá and Meta have undergone two phases: the initial phase from 2017 until 2020 and a second transformative phase from 2021 to the present. The first phase of the project started with a quantitative and qualitative assessment of the health and health care conditions in these regions. This assessment was led by academics from Bogotá and conducted in collaboration with the farmer organizations.

This exploration revealed a precarious state of health among community members and extremely limited access to health care, which is a common experience in most of rural Colombia.

Based on this assessment over the course of two years, the farmer organizations and the Bogotá academics jointly developed a health plan for the communities of Caquetá and Meta, which they called the "Community Plan in Comprehensive Rural Health". Though the Bogotá academics collaborated closely with the farmer organizations in the development of this health plan, RSP members from Bogotá took a clear lead on the way health and health care was conceptualized. As such, the resulting plan reflects a very traditional health care design that did not fully reflect the ways in which these communities conceptualize health. Importantly, though *Buen Vivir* had already been incorporated in RSP's mission, it did not take any part in the development of this initial proposed plan.

The plan is composed of the following five lines of action: 1) Coverage and access to health care: this includes building physical infrastructure, employing health and administrative staff, and ensuring that the national government provides the necessary funding. 2) Comprehensive health care: comprehensive and intercultural health care that focuses not only on physical health, but also on the health and well-being of families, communities and the environment. 3) Recovery of ancestral knowledge and alternative therapies: Promote the recovery and maintenance of ancestral health practices and therapies and their meaningful integration into the health care system; encourage the development of projects for the production of medicinal plants. 4) Intersectoral health: promoting harmony with nature by protecting the environment and promoting safe and healthy working and educational environments. And finally, 5) Social and community participation: promoting the organisation and strengthening of community health groups, empowering communities to continue to demand the protection and promotion of the right to health, and to promote reconciliation between community members and reintegrated FARC ex-combatants. The design of this community health plan was completed by the end of 2019, but due to the pandemic in 2020, its implementation could not continue.

Photograph by Vivian Laurens (2019).

Meeting of organizations from Caquetá and Meta to discuss the implementation of the peace accord in their communities.

BUILDING PEACE Phase 2

In 2021, when the worst of the COVID-19 pandemic had passed, the community health project in Caquetá and Meta was revisited. Different members of RSP from the National University of Colombia in Bogotá joined this project. With this new team, the second phase of the project begun, one that led to a revision of the original proposed plan. This time, *Buen Vivir* was taken into account as a guiding principle for the design of the health plan.

The concept of health as set out in the Community Plan has been expanded to include the components that the communities of this region consider to be critical to the health and well-being of themselves and the natural environment in which they live.

As such, guided by *Buen Vivir*, the design of the community health plan was revised. The renewed project has been renamed: *Casas Comunitarias para la Salud y el Buen Vivir* and it includes the following four components: 1) Demand for the protection of the right to health, 2) Environment, agroecology, food autonomy, and territory, 3) Recovery of ancestral knowledge and health practices, 4) Fortification of identity and recovery of memory to strengthen the farmer organizations.

The first component focuses on demands for the protection and advancement of the right to health, which in Colombia is constitutionally protected and has been reaffirmed in the peace accord. This is in direct response to the current state of health care in Colombia, which relies on private insurance companies, and has largely failed to protect and uphold the right to health for most Colombians. Currently, the communities of Caquetá and Meta do not have permanent access to healthcare, and they must travel five to seven hours to the nearest healthcare facility when the need arises. Additionally, accessing care for these communities can be quite expensive, not just because of the cost of health care services but also due to the long-distance transportation costs and loss of labor for the days they take of work to travel. The development of this first component of the community health plan requires an educational component to teach these communities how to recognize specific violations of their right to health and to know to whom they should direct the demands. The role of RSP is to offer instruction on how the health care system works, but also to facilitate negotiations with the local and national governments to redress and resolve violations of the human right to health. The ultimate goal is to establish permanent and affordable access to quality health care in these communities.

The second component of the community plan responds in part to the environmental crisis in the region. Caquetá and Meta have continued to experience deforestation at an alarming rate, perpetrated by multinational companies to extract natural resources, by drug trafficking groups to plant coca fields, and by large scale farming operations. The goal of this second component is to protect the environment and to promote food sovereignty for the Caquetá and Meta communities. Some of it entails negotiations with the government to control the extraction of natural resources by multinational companies and to control the illegal deforestation by drug trafficking groups. Another piece is the recovery of seeds from the region, which pushes back against policies that protect seeds from multinational companies. Finally, this second component also involves the development of a local market for exchange of fresh produce in the region. These regions are large and cover several different climates, which allows for a wide diversity of crops to be planted. As such, a market exchange of produce among these regions would increase and fortify the diet of these communities and would ensure their food sovereignty.

The third component focuses on the recovery and support of ancestral medicine, including the use of medicinal plants, birthing practices, and other forms of doing health from the farmer populations as well as indigenous people in the region. Both groups are a part of these communities and have also been participating in this process.

Since the rural communities of Caquetá and Meta have never had permanent access to health care, they have conserved many of their medicinal knowledge and practices.

The goal is to support these practices and provide education to younger generations so that they can continue to be practiced for many years to come.

The fourth and final component concentrates on the recovery of the history of the organizations and of their territory to share with younger generations. Many of the younger generations are not aware of the long history of political and social organizing of the farmer organizations in the region. The objective is to preserve and share this history to instil a sense of pride and belonging in the rural regions, in particular for the younger community members. The four-part community health plan presents a unique understanding of what health and health care could entail. It starts with what is expected of a health plan, which is access to quality and affordable biomedical care. But then this health plan goes well beyond these boundaries. For Caquetà and Meta communities, health also means protecting the environment, diversifying crops, achieving food sovereignty, preserving their history, and strengthening their identity and pride as rural citizens.

Health is not just about the state of the human body but also about the state of the surrounding environment and of the communities living in it.

After a long history of governmental neglect of the rural regions, this type of health plan is requiring from the government that it invest in these regions, that it takes these regions into account. It is the neglect of rural areas that gave origin to the armed conflict more than half a century ago. Fulfilling this community plan for rural health in the context of the Colombian peace accord can be seen as a way for the government to directly address the origins of the war. It can also serve as reparation for the violations of human rights that gave origin to and perpetuated the armed conflict. But more importantly, given the text of the peace accord, fulfilling this plan would mean the government has implemented the health provision in the accord as promised.

Renewed Hope

In August 2022, Gustavo Petro and Francia Marquez were sworn in as the next president and vice-president of Colombia. This electoral outcome reflects a new era in historically conservative politics in Colombia. President Petro and vice-president Marquez are the first socialist leaders to be elected in the history of Colombia. For members of RSP around the country, the election of Petro and Marquez has represented a huge victory for their communities and for peace. Petro and Marquez campaigned on promises to revitalize the peace process and implement the peace accord to its full extent. The biweekly meeting of RSP following the elections took a different tone than all other meetings since its inception. In the past, RSP members where operating from a perspective of resistance against a government that was committed to sink the peace accord. But on that meeting after the elections, RSP members rejoiced and celebrated. During the two hour long meeting they shared their feelings of renewed hope, that finally a government that is committed to peace and justice has taken office.

Procedures to revive the implementation of the rural health provision in the peace accord have been revisited by the Petro administration. As part of this process, the national government is travelling around the country, gathering initiatives that are already underway in order to develop a blueprint for a rural health plan that responds directly to the needs of each region and its communities, as required by the peace accord. As a result, RSP has currently redirected its efforts to help communities around the country, including Caquetá and Meta, to present their community health projects to the government so that they can be included in the national plan for rural health. As such, a full implementation of community health in Caquetá and Meta is still in its early stages, hoping to receive the support from the national government that was promised in the agreement, but has never come. The national government is projected to finalize a design for the national plan for rural health by the end of 2022. While it is difficult to know how the national government will proceed after evaluating health-peace initiatives around the country, the push from civil society to reimagine health has been remarkable.

As these communities work to build peace through health care initiatives, they are engaging in a radical project to reconceptualize what health is and how peace could be built in their communities.

With *Buen Vivir* as a guiding principle, the consideration for humans and non-human nature as an interconnected and interdependent whole in the context of health calls for a radical transformation in the way both health and health care are understood. The experiences of radical transformation through *Buen Vivir* from Ecuador and Bolivia point to the difficult road ahead in implementing radical transformation. But importantly, those experiences also point to a hopeful view to the work of civil society in Colombia. Radical transformation is not easy, but perhaps not impossible.

Notes

1 Centro Nacional de Memoria Histórica: "¡Basta ya! Colombia: Memorias de Guerra y Dignidad", https://www.jep.gov.co/Sala-de-Prensa/Documents/basta-ya-memorias-guerra-dignidad-new-9-agosto.pdf (2013).

2 Jurisdicción Especial para la Paz: "Acuerdo Final para la Terminación del Conflicto y la Construcción de una Paz Estable y Duradera", https://www.jep.gov.co/Documents/Acuerdo%20Final/Acuerdo%20Final%20Firmado.pdf (2016).

3 Matriz de Acuerdos de Paz, Instituto Kroc de Estudios Internacionales: *Cinco Años de Implementación del Acuerdo Final en Colombia: Logros, Desafíos y Oportunidades para Aumentar los Niveles de Implementación, Diciembre 2016 – Octubre 2021*, Notre Dame: University of Notre Dame (2022).

4 Ariel Ávila: "Cinco Años del Acuerdo de Paz en Colombia", in: *El País*, https://elpais.com/opinion/2021-09-27/cinco-anos-del-acuerdo-de-paz-en-colombia.html (28 September 2021).

5 Indepaz: "5 años del Acuerdo de Paz – Balance en Cifras de la Violencia en los Territorios", https://indepaz.org.co/5-anos-del-acuerdo-de-paz-balance-en-cifras-de-la-violencia-en-los-territorios/ (2021).

6 "Red SaludPaz", http://www.redsaludpaz.org/sp/pags/index.cfm (2019).

7 Robert A. Karl: *Forgotten Peace: Reform, Violence, and the Making of Contemporary Colombia*, Oakland: University of California Press (2017).

INFRASTRUCTURES

AIR, BLOOD, BUILDINGS Air

A patient breathes rhythmically on an upper floor of the colonial main building. Through a mask, oxygen moves into their lungs, carbon dioxide moves out. A loved one, maybe a daughter or a husband by their bedside, probably tired and worried for their kin, is there to attend to the patient's needs day and night – feeding them, cleaning their body and clothes, administering medicines, and providing pastoral care, a kind word and reiterations of encouragement, as much for the patient's benefit as for their own.

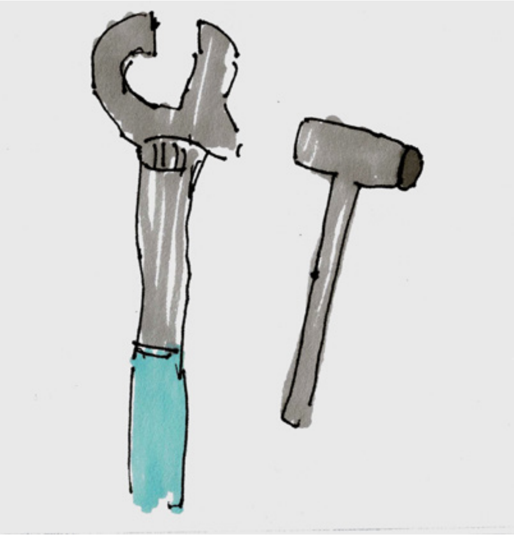
Nora is a social anthropologist and architectural designer. In 2019/20, with pens and sketchbooks, she studied the Yangon General Hospital in Myanmar, where she had been project architect for the rejuvenation and new campus masterplan since 2015. Her fieldwork methodology is drawing. Her sketches – including the ones in this contribution – are left as artifacts from the field throughout the text. They create a metanarrative to the written words; complimentary, or in their own right, they are an invitation to read 'between the lines'.

Via hundreds of meters of thin metal pipes, oxygen floods the patient's lungs. The pipes climb along white ward walls, around and over cornices, down red bricks that have been in place since the turn of the last century, into the ground-level basement where the manifold is located.

Here large oxygen bottles feed the system. They are delivered by young men on flatbed trucks. Every day, weekends and holidays included, the truck trudges through the Yangon traffic from the factory a few miles north. The lengths of the pipes vary with the patient's exact location – longer if they are on one of the two upper floors, shorter on the elevated ground floor. As the patient's breath moves in and out of their body unceasingly, the bottles feeding the manifold empty. The metal warms up and the cold dampness from the thermodynamic processes dissipates as the oxygen flows into the manifold feeding the patients' breaths on floors above.

As the tanks gradually empty, Hain Thura Kan, a worker from the oxygen department, or maybe one of his colleagues, sets off to check the manifolds in his care. The patients' breath is his day's metronome. Wrench in hand, Hein Thura Kan visits the different manifolds three times a day, at four-to-five-hour intervals in sync with the hospital's collective lung.

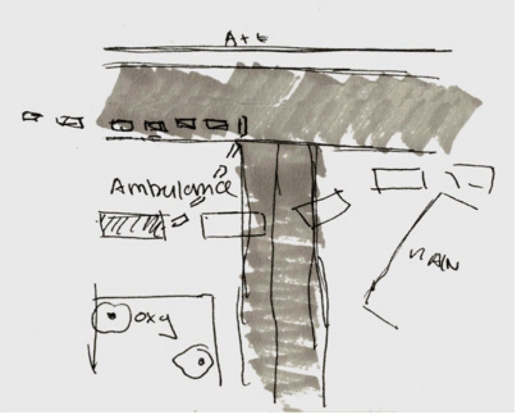
Clinking the wrench against the shoulder-high gas bottles, he checks their fullness. If they are empty, he loosens the bolt from the dry bottles and changes them for new cylinders, cold and damp from the condensed water on their surface. The thermodynamic process is his visceral cue. The clinging and banging, the touch of a hand sensing the temperature of the metal, a counting of empty and full cylinders, is a routinised intimacy, making sure everything is in order. Only the careful affective diligence with which Hein Thura Kan carries out his task betrays the awareness of its importance. Hein Thura Kan will never meet the patient, and the patient and their attendant would not pay an ounce of attention to the tall man with his wrench, hurrying from manifold to manifold in flip-flops, a T-shirt and high-tied *longyi*.[1]



Patients' breath is the metronome that organises maintenance rounds and delivery routines. Breath synchronises Hein Thura Kan's and the other oxygen department workers' journeys to the manifolds, and the navigation of flatbed trucks through the gruesome Yangon traffic, while patients are unlikely to ever cross paths with the keepers of their breaths. Infrastructure mediates relationships.

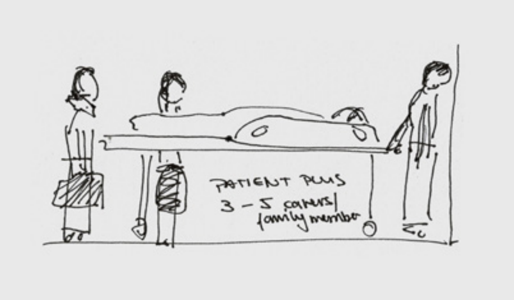
AIR, BLOOD, BUILDINGS Blood

An ambulance waits at the back of the Accident and Emergency Department (A&E), just outside the Oxygen Store, between the Main Building's West Wing and the Radiology and Laboratory Building in the thick of the main campus. A team of A&E workers, maybe a nurse as well, arrive with a patient on a gurney. Their flustered but calmly cooperating family members, with bags of necessities for a hospital stay, follow alongside. Maybe the patient is unconscious; sometimes a moan can be heard. A traffic accident victim, most likely.



Maybe they have multiple traumas and have already undergone surgery, maybe on their abdomen, at the operating theatre in the A&E. It is likely that they have been under anaesthesia and came up for this transfer in order to go under again upon arrival at the Neurosurgery Operation Theatre (OT). I have been told by neurosurgeons that other specialists are afraid of head injuries, so it is they who get in last and will keep the patient for recovery.

For some reason, which neither I nor one of the hospital’s anaesthetists have understood, the neurosurgery team refuses to operate in the A&E’s OTs. They insist on transferring patients, making them go in and out of anesthesia – in contrast, cardiac surgeons do operate in the A&E’s theatres if necessary; but they are also just next door as opposed to a ten minute walk and across a hazardous road, as is the case with the neurosurgery department. The question is really whether it is necessary to uphold antiquated understandings of specialities translated into hospital spaces.



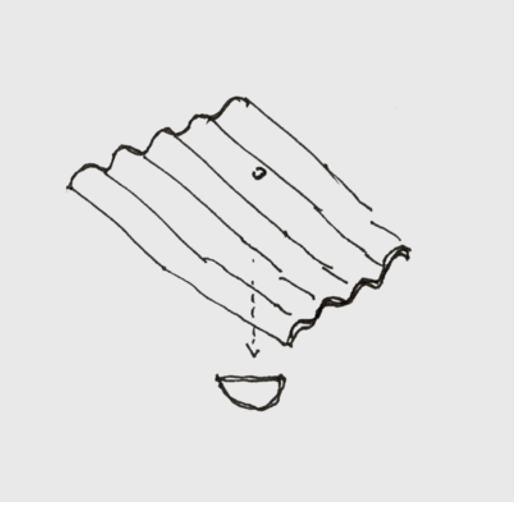
As I am musing about hospital space allocation, the ambulance with the patient makes its way across the busy and unforgiving hot or wet (depending on season) four-lane one-way road that divides the main campus from the extension site where neurosurgery is located with its two OTs and 150 bedded wards. If the ambulance were available when called by the A&E team, it now might get stuck in traffic while surmounting the fifty meters it must cover on one of the city’s busiest east-west arteries. On arrival, the patient is headed for operating theatre two, which is allocated for emergency cases – one level up, accessible with a lift at the other end of the building of the main entrance and the operating suite. The lift was installed in the last fifteen years only. The neurosurgery team has only two OTs – too little for their case load, I am told. This lack of space puts pressure on the speed at which surgeons operate. Paired with a high case load, the patient is operated on much faster than is typical in less pressured settings. Lack of space leads to shorter surgery times which means more bleeding – more bleeding requires more blood transfusions.

Transfusions come from the Blood Issue Room in the Main Building on the main campus across the hazardous road. The surgery team usually orders enough blood for any given surgery; however, in case of unforeseen circumstances, a worker is sent to fetch transfusions during surgery. This can take up to 45 minutes while the anaesthetised patient and the surgery team wait. Should the patient need a CT scan or other imaging services, they must track back to the main campus. The department's CT broke recently and has not been replaced. Once again, an ambulance is called to take the patient. This time, from the extension site to the main campus, the ambulance must circle the entire city block due to the one-way system around the hospital. Traffic jams are not uncommon. The pathway infrastructures and spatial configurations, stretched over two sites, have a direct effect on clinical services and patient care, as does the context of the hospital within the city. Embedded in an urban environment, roads, ambulances, and hands carrying blood relate and rupture at the same time.

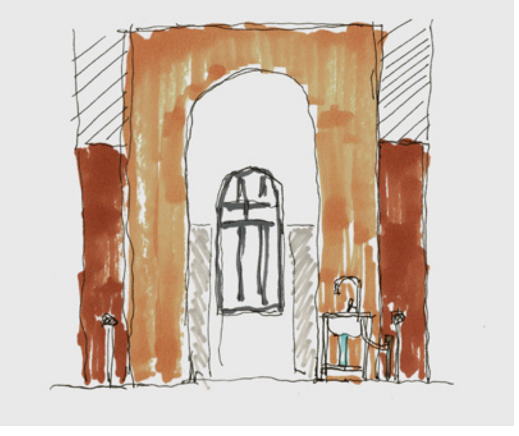
AIR, BLOOD, BUILDINGS Buildings

It is the younger members of U Than Thein Gyi's team that spend their time climbing the roofs once the seasonal rains stop. Throughout the rainy season, when U Than Thein Gyi, the head of the building maintenance department, arrives at his office at 9 a.m., he finds new reports filed by ward sisters with repair requests on his desk. Most tell of leaks in roofs. Behind the desk a large A0 vinyl print of my former team's masterplan is pinned on the wall – a symbol of planning and reminder of the 'bigger picture' so easily lost in the nitty gritty of tending to the leaking and creaking campus structures.

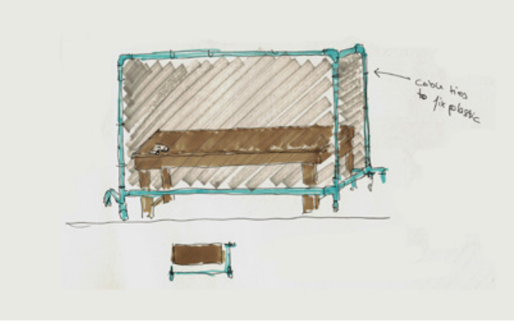
Daily, his team ventures out to mark the reported leaks so they can be fixed when it is safe to climb the roofs. Nurses know this process; buckets are put in OTs and wards to avoid flooding until the leak is attended to. Most of U Than Thein Gyi's team's time is spent fixing roofs as soon as the rains stop, checking for the causes of leaks – a seedling that took root in the gutter or slid its fingers in the crevices between bricks, cracking the building hull, roof sheets loosened by wind, general material decay.



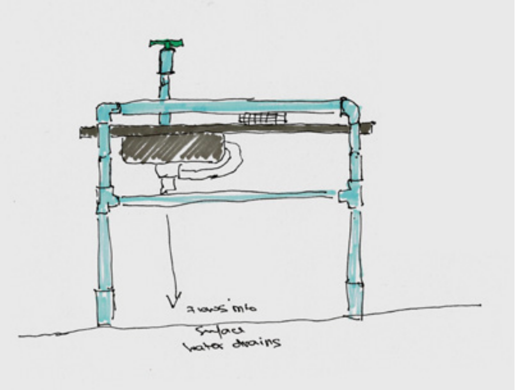
Another major part of this team's job is the maintenance of doors and windows: heavily used hinges decay through wear and tear. A door can only be opened so many times before it breaks but is an essential means of control – fire control, infection control, privacy.



Mold, which thrives in air conditioning units, needs to be removed and leaking pipes fixed. Mosses flourish in the humid environment around leaking pipes, sprouting in bright greens, climbing walls alongside the pipes, damaging the façade, making it prone to breach. One might ask, why all this leaking? The poorer the materials, the more repair and care is necessary. The poorer the construction, the more it leaks.



When COVID-19 hit, it was this team that sprang into action first. They put up light partitions, modifying the spaces for improved infection control. *Ad hoc* hand wash basins appeared. They were the vanguard on the battlefield of infectious disease, adapting the infrastructure to hold the virus at bay.



Materials decay, seasons cycle through the year, and nature slides its fingers into any crevice possible if not held at bay, dictating maintenance patterns and daily routines. The buildings are vessels for healthcare. They are part of patient care. But they can only extend their care if someone tends to them. The hospital is a place where built and natural environment are painstakingly orchestrated, where buildings and people are in careful synergy.

AIR, BLOOD, BUILDINGS Writing with Buildings

These three short ethnographic vignettes demonstrate the multiplicity of the hospital – or to borrow the terminology from Fanny Chabrol and Janina Kehr, *The Hospital Multiple.*[2] The hospital multiple is a place where humans and non-humans, services and spaces, built and natural environments, are in constant motion – walls breathe, blood and people shuttle back and forth while nature and time continuously encroach on the hospital's built environment, and the maintenance team is on the forefront of infection control. Patients', pipes', and pathways' daily existence overlap, entangle, and form visible and invisible synergies. The hospital buildings emplace all this. Here I am in Clifford Geertz's good company when I point out that place matters.[3] Infrastructure facilitates care; hence the three previous sections have been written with the hospital buildings. Writing with buildings helps us escape perspective. In her 2017 book *Five Ways to Make Architecture Political*, social anthropologist Albena Yaneva speaks about perspectivism when analyzing architectural projects.[4] While Yaneva focuses on architecture and the design of buildings, her argument is valuable for the continued existence of buildings and analysis of the life that unfolds within and between the structures. In the case of a hospital, analysis tends to be from the point of view of someone in particular: the patients, a disease, the nurses, the doctors, the cleaning staff, and everyone that looks after a building. However, analysing a building from the point of view of certain or even several individuals or groups only ever paints a partial picture. Yaneva proposes to witness what a building does with those who interact with it on a daily basis in a multiplicity of events in order to "escape perspective".[5] Writing with buildings is exactly that: an escape from perspectivism towards multiplicity analogous to the process of drawing, which places us into a landscape in which we participate. Buildings offer the ethnographer multiplicity in seeing, thinking, and writing. I am developing (in the sense that a photograph is developed) the hospital multiple conceptually from Annemarie Mol's *Body Multiple*.[6] Leaning onto Mol's scholarship, I am extending her proposition from practices done to bodies to practices and materiality with buildings. Through careful attention to events, activities, and practices (what we do with the hospital buildings), the hospital multiple appears – the hospital that in turn produces the body multiple, extended now from patients' bodies to everybody in the hospital. Multiple as in more than one, but still one hospital – understanding the hospital in this way it emerges as a place for healing, working, researching, teaching, living, dying and waiting at the same time.

AIR, BLOOD, BUILDINGS Practice

Writing with buildings, with the hospital's places and infrastructure, puts realities of daily life into sharp focus – not as an abstract category, the hospital in its generic form, but the hospital as a place, lived and complicated. Multiple scales emerge, from the specific detail to the hospital campus as a whole, a campus with many departments, spaces in between, and a long history in a bustling Southeast Asian metropolis. Emplaced and specific. As much as "no one lives in the world in general",[7] there is no hospital in general – however much ideas of best practice and standardized processes would lead us to believe in such a thing. Much of the daily tactics making a hospital work originate in the exactness of place. Being preoccupied with standardisation and best practice – mostly driven by capitalist interests – overlooks the realities of the hospital's daily life. At the same time, we (anthropologists at least) know that daily tactics and improvisation are the reality for many, if not all, hospitals.[8] Therefore, an ethnographic lens is pertinent, beyond academic acrobatics. Drawing on my ethnography and inspired by scholarship of people such as Anna Tsing, Ann Laura Stoler, and Yael Navaro-Yashin, I propose that, at the hospital, the distinction between human and non-human life collapses.[9] Infrastructures and the built environment mediate the functioning of the hospital. Here I understand mediation as relational, in the case of the breathing walls; as rupturing, where the road severs the flow of people and blood; or as indeed quite messy, where nature continuously encroaches onto the built environment. When thinking of the hospital, a space for healthcare, I propose to think, design, and plan with its multiplicity in mind; with its human and non-human entanglements; with functionality mediated and related by infrastructures. Ultimately, this implies thinking and making a hospital – the hospital multiple – through the category of practice. In this intervention, I have started radically rethinking infrastructure and the human at the hospital. One is dependent on the other. Walls breathe and blood flows between buildings – buildings that are taken care of by individuals. Buildings that mediate. Writing with buildings, writing the pipes into the ethnography, is part of this rethinking.

Notes

1 *Longyi* is a traditional leg dress for men and women in Myanmar (also called *htamain* for women). Usually worn at floor length, workers and manual labourers tend to tie them higher for convenience.

2 Fanny Chabrol, Janina Kehr: "The Hospital Multiple: Introduction", Somatosphere, http://somatosphere.net/2020/hospital-multiple-introduction.html (2020).

3 Clifford Geertz: "Afterword", in: Steven Feld, Keith H. Basso (eds.): *Senses of Place, School of American Research Advanced Seminar Series*, Santa Fe, New Mexico: School of American Research Press (1996).

4 Albena Yaneva: *Five Ways to Make Architecture Political*, New York: Bloomsbury (2017).

5 Albena Yaneva: *Five Ways to Make Architecture Political*, New York: Bloomsbury (2017), p. 7.

6 Annemarie Mol: *The Body Multiple: Ontology in Medical Practice*, Durham: Duke University Press (2002).

7 Clifford Geertz: "Afterword", in: Steven Feld, Keith H. Basso (eds.): *Senses of Place, School of American Research Advanced Seminar Series*, Santa Fe, New Mexico: School of American Research Press (1996), p. 262.

8 Ian Lichtenstein: *Everyday Adaptability in Ghanaian Hospitals,* MAT 6 (2019), pp. 142–151; Julie Livingston: *Improvising Medicine: an African Oncology Ward in an Emerging Cancer Epidemic*, Durham: Duke University Press (2012).

9 Anna Lowenhaupt Tsing: *The Mushroom at the End of the World: On the Possibility of Life in Capitalist Ruins*, New Jersey: Princeton University Press (2015); Ann L. Stoler (ed.): *Imperial Debris: On Ruins and Ruination*, Durham, London: Duke University Press (2013); Yael Navaro-Yashin: *Affective Spaces, Melancholic Objects: Ruination and the Production of Anthropological Knowledge*, Journal of the Royal Anthropological Institute (2009), pp. 1–18.

ACADEMIES OF SILENCE Introduction

Photography of a painting by Julia Nina Baumann (2022), acrylic on canvas, untitled.

Dealing with emotional distress in (post-)pandemic German academic institutions was often a challenge for the author herself during her research. Her emotions intertwined with those of her interlocutors in a unique way. In order to untangle the threads, the author was often helped by artistic reflections, like the one above, which also became part of her field notes.

German academic cultures have developed particular cultural norms, power structures, and conventions.[1] Regarding emotions, those conventions foster a value system that generally connotes feelings as 'unscientific' and 'irrational', which I have described as a "culture of no-feeling".[2] This has also led to the exclusion of difficult emotions from academic knowledge production and the construction of research methodologies to involve as little affect as possible.

"Researchers are typically torn between two opposing tendencies: experience from the field research squeezing to be expressed versus professional obligations and expectations restricting their expression [...]."

Dimitris Papageorgiou: "Field Research on the Run: One More (from) for the Road", in: Athena McLean, Annette Leibing (eds.): *The Shadow Side of Fieldwork: Exploring the Blurred Borders between Ethnography and Life*, Malden: Blackwell (2007), pp. 221–239, p. 232.

An exception to the latter is ethnographic methodology. Here the emic gaze, and thus empathy, are regarded as methodological tools, and emotional involvement is explicitly encouraged.[3] Ethnographers must thus perform an emotional balancing act between extremely affective fieldwork, which in addition often takes place in crisis regions, and seemingly unemotional everyday life in the academic community at home. The daily professional obligations of ethnographers usually include much more than the usual academic activities of teaching, fieldwork/research, data analysis and interpretation, reading, writing, publishing, and attending conferences. As many of my interview partners stated, a large part of their day was ″lost in bureaucracy″, applying for funding, visas, stays abroad and conference visits, in addition to meetings with colleagues, supervisors, and students in university committees, as well as answering emails. All these tasks are part of the everyday ethnographic life as well and are just as essential to the creation of knowledge as data collection or analysis itself. These tasks also shape the everyday emotional experience. To find out the exact role that feelings play in knowledge production and how they are perceived, it was therefore even more important for me to not only focus on fieldwork but to take a holistic view of ethnographic work.[4]

In this article, I will present some of my research findings on how (post-)pandemic German academia is dealing with emotions and mental distress.

I first reflect on my own role in the field and in writing this article. I then explain what led to the increased attention paid to emotional distress at German-speaking universities during the COVID–19 pandemic and to an increase in programmes and services offered by universities and study whether this can be seen as a radical change to the post-COVID-19 institutional handling of emotions. I then introduce my analysis of an academic ″culture of no-feeling″, in which individual researchers remain quiet about their feelings for fear of condemnation or negative consequences for their careers, as well as how institutions reinforce this culture. As I will show, universities often neglect mental distress, referring to self-improvement and productivity and thereby reproducing the ideal of the emotionally controlled researcher.

The author on her way to the university during the pandemic. In the otherwise typically crowded subway, she is all to herself.

Photograph by Julia Nina Baumann (2022).

ACADEMIES OF SILENCE Cultures of No-Feeling

Researching my 'own kin' has been a challenging but also rewarding privilege. As a social anthropologist myself, I was particularly close to my interlocutors and thus literally performed an ethnography at home. I consider it a great honour to have met inspiring colleagues who shared their feelings with me. However, my unusual proximity to the field also created challenges, as this excerpt from my field diary shows:

"I realized how much my interviews are part of a culture of constant performance pressure in which I feel trapped as well [...]. Even though I always keep asking about emotions, they still very rarely appear in what is spoken. Everything happens in the unsaid, between words, in facial expressions, in what is choked back, behind the defences and justifications [...]. How do I encapsulate the unsaid, the unspeakable, the inexpressible? How do I transform my research experiences into a text that will later be subject to the very evaluation criteria that I am analyzing without jeopardizing my own career?"

Entry from Julia Nina Baumann's field diary (2021). Excerpts from research data of all sorts used, such as all direct quotations from interview transcripts, have been translated into English by the author.

As a female PhD candidate and junior researcher, I was part of the very hierarchically structured academic culture, like my interlocutors. Even in interviews, I recognized the "culture of no-feeling", which made an open expression of sentiments difficult on both sides. Only the process of building mutual trust resolved this dilemma. Nevertheless, in some conversations, emotions were still not explicitly expressed but were instead evident between the lines in gestures and facial expressions. In addition to the many encouraging contacts, I was also often warned by senior colleagues not to become a "troublemaker", a *"Nestbeschmutzerin"* ("fouler of one's own nest/whistle-blower"), or to "navel-gaze" because that would jeopardize my career. Since this research is part of my PhD and academic qualification process, which will be evaluated and graded and will ultimately (re)shape my own chances for further academic achievements, it was sometimes difficult to manoeuvre between mere scientific interest and strategic considerations.

"I do not trust my superiors, and I have an emotion of anger toward them [...]. If I have to be honest, I do not really trust anyone in academia."

Interview with interlocutor, anonymized (2021).

Something similar concerned my interlocutors: no matter what status they possessed, they all saw themselves and their careers as dependent on a system that was characterized by cultures of precarity, mistrust, and silence.

They complained in particular about the employment conditions – a series of poorly paid, fixed-term contracts, with simultaneous overwork, poor work-life balance, and family incompatibility.

I was informed of a feeling of being at the mercy of a system that did not really appreciate them. Some also told me about exploitative relationships, discrimination, bullying, and harassment by superiors or colleagues.[5] All this led to a fundamental distrust and a feeling of competition. Thus, many feared consequences if they opened up to 'academic kin'. This already hints at an association of emotions with vulnerability and weakness within the academic working context leading to negative consequences or even failure. It was equally challenging to take an abstract view of academic realities and structures while being part of and dependent on them at the same time. To achieve a differentiated view, a high degree of self-observation was necessary, which I methodically pursued in the form of autoethnographic emotion diaries. In various supervision groups (a method adapted from psychotherapy), I also had the opportunity to talk about my material and my own experience and was thus able to gain another level of abstraction. At the same time, while strictly adhering to the principle of doing no harm, I was faced with the challenge of providing a holistic and critical analysis of the culture under observation without causing negative professional and psychological consequences for myself or my research participants. This balancing act has not only shaped my fieldwork but also influences how and in what ways I may frame my publications. This text hence purposefully sets itself outside of the artistic-experimental framework of this volume. The more academic style of writing is also a reflection of how academic cultures (re)shape emotions. It follows a structure as well as linguistic formalities and modes of presentation that are formed by the circumstances of its creation. In my case, this also means that certain things should remain unspoken. The radicality of the text thus does not consist in its form of presentation but instead in its content.

Choosing emotions as a subject is already a small act of rebellion in a culture where sentiments are often suppressed and where mental distress is heavily stigmatized.

Despite the academic format, through the raw presentation of my empirical material, underlying feelings will be transferred to the empathic reader who will thereby be able to share some of the emotions. This transfer to the reader is, in my view, a unique feature of ethnographic narration. The photographs inserted into the text as well as the soundscape underpin the more experimental storytelling of this volume.

ACADEMIES OF SILENCE Pandemic Distress

"A middle-aged woman sits on a comfortable armchair upholstered with brown velvet and a white lace blanket. Her hair is pinned up; flowers in delicate pastel shades intertwine on her blouse; plants stand to her right and left. She smiles at the camera. According to her, the online course will help me 'to release some of my exhaustion and frustration with the craziness of modern academia'. She calls the tapping method she presents a 'stress release first aid for academics, to release anger, frustration, exhaustion or other negative feelings'. She explains its 'scientifically proven positive effect', which shuts down stress receptors in the brain. She also describes herself as a 'Stress-Release Coach' and 'Emotional Freedom Therapist' and universities as one of the 'high-demand environments' where her work is desperately needed: 'The system we know is already challenging. It was already challenging before COVID. People are disillusioned with the frequent lack of response [...] and it has just really gone crazy. And you are not the only one even if sometimes it can feel like that', she tells me sitting on the other side of the screen. [...] With eyes closed and breathing calmly, she begins to draw attention to my own body, to tension and tightness. While tapping on different body points (head, eyebrow, chin, hand...), various statements are repeated about negative emotions (such as "I accept that I am exhausted by this system', 'There is never a good time to take a break', 'It is too much for one person'). Again and again, the own intensity of my feeling is requested after the tapping. The goal is to feel lighter and more relaxed. If the negative feelings 'that you often can't give a voice to' are named, a tapping round with positive associations is added. 'Please don't suffer in silence', she says 'I know you can't change the system and you can't restructure the whole university [...] but you can change your own stress level. And let's hope the changes in the system will happen soon'."

Entry from Julia Nina Baumann's field diary (2022).

This ethnographic vignette describes one of many courses on emotional distress offered to academics that I participated in during my research (online and in situ).

In recent years, there has been an increasing demand for advice on how to "survive and thrive in academia".[6] These academic "fear entrepreneurs" work with their clients' anxieties in a steadily growing market.[7] Recently, universities have increasingly become customers and providers of such services. In many cases, the courses are offered by the institutions and the instructors are paid by them, or by third parties, such as health insurance companies, for example as part of the university's health management. In most cases, however, the coaches at the workshops I attended were not employed by the university but were self-employed and were thus only remunerated for a number of hours. When talking to the course instructors, I was also interestingly told of poor working conditions as well as dependencies in many cases. They often regretted that the payment was usually not sufficient for longer-term offerings or that certain content was not promoted. Many felt that they were not free to design the course content but needed to follow certain guidelines set by the institutions.

In the pre-pandemic German-speaking academic world, such offers could have been found only sporadically. But the COVID-19 pandemic has significantly changed this situation and can – according to my research findings – be seen as a turning point in the consideration of emotional challenges in academic working life. German university websites now include, for example, online courses on "Dealing with negative emotions at work", offers from psychosocial counselling centres outside the university, such as the Covid Help Lines, and training on how to deal with those affected by crises. The reason for this is that the pandemic years brought everyday changes that affected all social groups in one way or another: for example, they led to persistent social isolation as a result of the stagnation of public life. Even if Germany, unlike other European countries, never experienced a complete lockdown with harsh curfews, so-called "social distancing", which soon became a buzzword for keeping safe distances, also had a significant negative impact on Germans' mental wellbeing, as recent studies imply.[8]

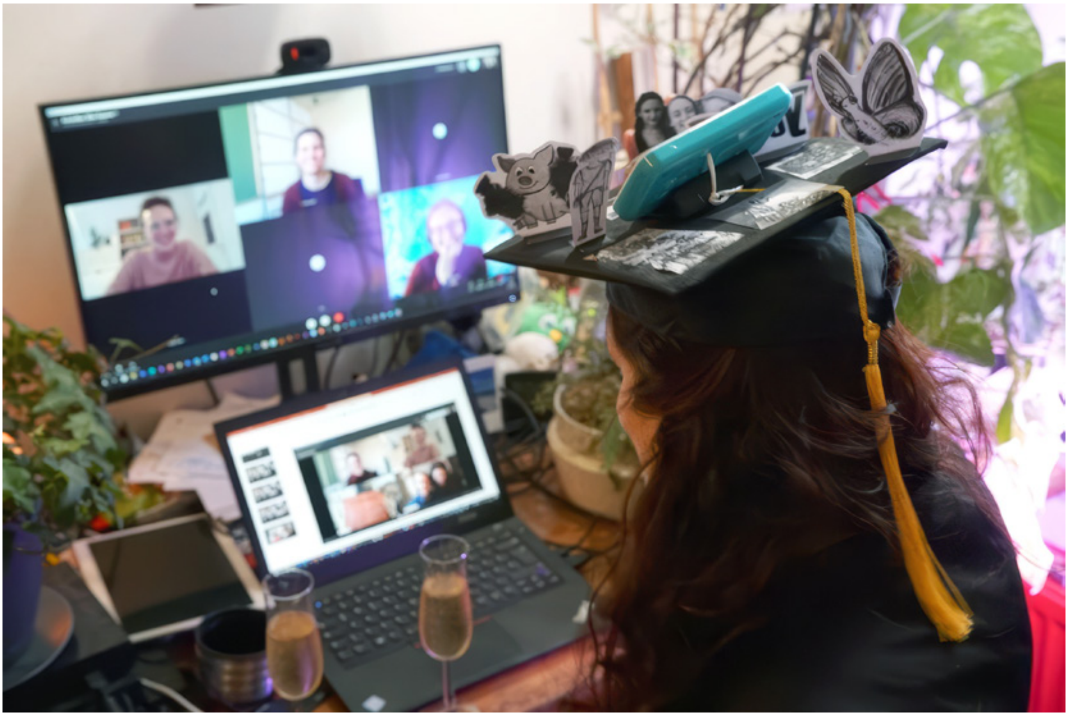
"During Covid and online teaching, the campus was completely dead, of course! […] Unfortunately, it hasn't recovered from that yet either, and probably won't again."

Interview with interlocutor, anonymized (2022).

"[During the pandemic] I didn't talk to people for weeks, you know […]. Also, the way the university works is very neoliberal, you know, they were paying us a hundred percent of our salary but were expecting 110%. We were working three times as much with online teaching and everything. There was absolutely no addressing of how that could be tough for anyone […], no addressing of the emotions, the feelings we all had and the sadness and some fear and […] I don't know, the loneliness and just […] the tiredness and economic concerns."

Interview with interlocutor, anonymized (2021).

Academic facilities were particularly affected by the pandemic. The previously crowded campuses were left empty; lectures, conferences and meetings were reduced to a minimum and held exclusively online. Even social events and ritualized celebrations had to be shifted to the virtual realm, as shown in the picture below of a virtual online thesis defence.



Photograph published with the permission of the creator, anonymized (2022).

Virtual Dis(connection): Defending a PhD thesis in the pandemic.

Universities mastered this transformation of everyday academic life into the online realm and virtual spaces only slowly. Subsequently, the pandemic initially began with widespread silence and stagnation, which is also reflected in the soundscape below, which acoustically accompanied the beginning days of my research.

Proximity in distance – an acoustic impression of a PhD student's day in the pandemic: The author has captured her work autoethnographically and acoustically. The focus was on the solitary silence that characterizes her everyday life as an academic, interrupted only by very rough, noisy pauses (footsteps on the asphalt, subway noise, announcements, alarm clocks, keystrokes on the keyboard, etc.). Interpersonal resonance (Rosa 2019) is hard to find in the recording. An exception is virtual conversations, which the author held during lookdown often either with friends and family or with her research interlocutors. But these are not recorded due to data protection but are only represented by empty tones at the beginning of the conversation. In this way, they show another dimension of silence, in this case a protective silence. The soundscape is thus by no means a value-free product but is intended quite deliberately to induce emotions in the listener and to make the insights gained from the research article 'experienceable' also on a physical level.

Soundscape: Proximity in distance – an acoustic impression of a PhD student's day in the pandemic (2022).
AUDIO ▸ cache.ch/1704

For academic staff, however, this still meant working from a home office and at a great distance from professional colleagues. In this environment, emotional impairment, sick leave, and mental health problems increased alarmingly among researchers. The mental health of students was particularly negatively affected.[9] While many surveys and publications have drawn attention to this fact, particularly at the undergraduate level, comparable attention to academic staff has been largely absent. Although there is occasional evidence that junior researchers in particular were extremely affected by the "hyper-uncertainty" brought on by the pandemic,[10] research at the post-doctoral and professorial levels is largely lacking. This reflects not only the previously described academic "culture of no-feeling", in which emotions are often seen as unprofessional but also the general stigmatization of people with emotional distress in Germany.[11] Often, this stigmatization also leads to taboo and thus to silence. Many affected persons do not talk about their condition for fear of condemnation, loss of status or job, or social exclusion.[12] The fear of consequences is particularly felt in professional contexts.[13] This was also reflected in my research.

Many researchers shared a feeling that it was almost forbidden to talk about mental health issues, problems with supervisors, or difficulties with fieldwork and research participants.

They feared being labelled by the academic community as not being a ′good researcher′ or not being seen as ′tough′ enough. Several early career researchers told me that their attempts to talk about emotional distress had been met with ″pull yourself together″ and ″buckle up″ advice by their supervisors or colleagues. However, many tenured professors also told me that they felt overwhelmed when people approached them with emotional problems. They missed having a contact person or advisor in the academic institution to whom they could turn for counselling.

ACADEMIES OF SILENCE University Structures

Although the pandemic has had a strong negative impact on the mental health of academics, it cannot be seen as a single trigger for certain emotional phenomena but rather acted as a burning glass and catalyst highlighting existing problems. As the worldwide biennial ″Nature PhD Survey″ from 2019 shows,[14] ″graduate students are more than six times as likely to experience depression and anxiety as compared to the general population″.[15] At the same time, very few of those who sought help found it at their university.[16] This was confirmed by several of my interviewees, who verified that it is very ″unusual″ or at least ″extremely difficult″ to apply for research supervision or mental support at funding agencies or universities. Many even spoke of refraining from requesting such support for fear of being seen as not high performing enough.[17] To avoid contacting their supervisors, loopholes are often sought.

″I knew that doing a doctorate is exhausting [...], it was completely clear to me that doing a PhD is pretty much certain to result in a mental health crisis.″

Interview with interlocutor, anonymized (2022).

″Getting any kind of supervision has always been difficult [...]. I would say that you must go privately to a psychotherapist, and he/she should diagnose you with something like borderline or schizophrenia. And then you apply privately for health insurance funding, and you will certainly get it with such a diagnosis and then you have your research supervision [...]. That is very common, and many people have done it that way [...].″

Interview with interlocutor, anonymized (2022).

Considering the strong stigmatization of mental illnesses, particularly schizophrenia, I was surprised to find out that academics preferred to face stigmatization from this invented diagnosis over psychological supervision at their workplace. To investigate why so many academics reported that they did not receive help at their workplaces, not even from the existing support services, I visited approximately 35 events, workshops, and programmes relating to emotion and mental distress at various German-speaking universities, online and in situ, before and after the pandemic. For example, I joined a further education programme that aimed to ″maintain and strengthen mental and physical health″. The course title implied that the workshop goal was ″building up resilience″ in academic work in particular. But in my experience, it mainly followed the tenor: the more efficiently you plan your time, the more work you can fit into less time, and thus the more opportunities for free time you can have and the better you will feel. Therefore, we learned various time management techniques, which should ″ultimately boost your productivity″. The course leader explained that stress is mostly caused by oneself, which is why in the second part of the workshop inner doctrines were to be identified and overcome, which would ultimately make us ″more efficient″ and therefore also more ″successful employees″: ″Doing your job right and getting things done in time will ultimately make you feel better″, he said. The script stated:

"The term work-life balance stands for a state in which work and private life are in harmony with each other, or in other words, it is a positive balance between life and work in which I not only feel good as a person, but I also feel particularly productive and meaningful."

Citation from the workshop script (2022).

This example shows clearly how strongly mental resilience is associated with productivity and performance in such courses. It was striking that already often in the title of these events, the words management and efficiency were linked to emotion and mental health. Even the organization of leisure time and relaxation was often placed in a competitive context and viewed through the lens of increasing efficiency. Time for personal sharing was limited to a few courses. Reflection on existing structures, which could also lead to the suffering of the participants, was mainly absent. Instead, psychological stress was stylized as the sole problem of the individual that should be "trained away", "overcome", or at least not become visible in everyday work performance by adopting the various "tips and tricks" taught in the courses.

Within this performance culture, the notion of emotionally or mentally distressed people within academic work cultures as not conducive to academia was particularly striking.

During a workshop on the role of university senior staff who were team leaders of employees with mental health problems, I first observed that the majority of the participants seemed to belong to the university's library and administrative staff. The course leader, a trained psychologist, confirmed that from her point of view researchers or lecturers would only very rarely take advantage of such offers. The realization that they also belonged to the executive staff had "not yet arrived" in most cases, she noted. At the same time, I was stunned at what definitions of mental illness were taught in the course: at first, the instructor presented various clinical pictures, strictly according to the *International Classification of Diseases 10th Revision* (ICD-10) and *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5). She regretted that she could "not take anyone like them with her" to "demonstrate" these conditions to the course participants.[18] "Someone told me this might be unethical", she said laughingly. Afterwards, the participants were called upon to describe their own experiences with mentally ill employees. From my point of view, this quickly developed into a round of complaints about employees who were 'not functioning well' and whom one would "actually like to get rid of, but who could not be dismissed so easily because of the regulations in the public sector", as one participant stated. I was the only one who openly stated that I had once experienced a mental crisis myself. I found it particularly frightening that the participants soon also shared quite dismissive stories of people with special needs, in this case a person who was hard of hearing, or older individuals or people from the lesbian, gay, bisexual, trans, intersex and queer (LGBTIQ+) community.

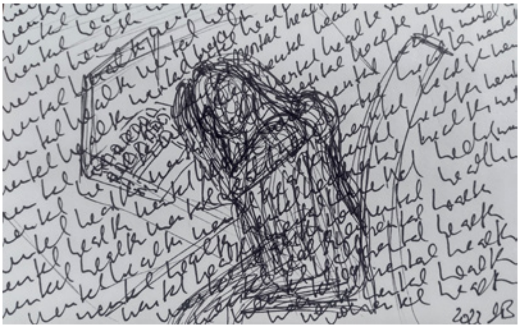
"We have a person in the team who no longer wants to be addressed as Mr. XY, but as Mrs. XY. I just can't remember that, and I think it's silly and now [s]he keeps saying [s]he feels mentally afflicted because we don't address her as Mrs. and [s]he keeps starting to cry and stuff [rolls her eyes]. I can't really take that seriously."

Entry from Julia Nina Baumann's field diary (2022).

Participant at a workshop on mental illness of university employees.

The course instructor did not interrupt these descriptions but used her expertise to give tips on how to deal with these individuals, which were not infrequently ways of ″bypassing the staff council and the labour law″. Courses like these, unfortunately, cannot be seen as exceptions at all in my field experience and show that the terms emotional distress or mental illness are likely to generally include people who seemingly do not fit into the system and/or seem to make work processes more challenging.

ACADEMIES OF SILENCE Radical Mental Health



Drawing by Julia Nina Baumann (2022), ball pen on paper.

The struggle for mental health in academia often became clear through what was left unsaid. In an attempt to document the unsaid, the author often used artistic methods to capture atmospheres as extensively and vividly as possible. The picture above shows such a drawing, jotted down quickly in her field diary shortly after an interview with an interlocutor. The main thing captured here is the interviewee's posture in quiet moments during the conversation, as well as the recurring mention of word pair ″mental health″.

German universities have become more attentive to mental distress because of the pandemic, which has certainly contributed to the fact that emotions are discussed at all within academic contexts and has created a greater awareness of emotional challenges in German academia (see #ichbinhanna). However, my findings show that these approaches aimed to integrate the individual back into a culture that has defined productivity and performance as its highest guiding value and understands any form of emotional experience as a constraint or 'personal transgression', even those that are considered beneficial.

″I was very surprised that we even had psychological supervision approved in our project application [...]. The money was there, but nevertheless, the supervision was the first thing cut by the project management due to the COVID restrictions.″

Interview with interlocutor, anonymized (2022).

The pandemic has reproduced a certain understanding of what it means to be a good academic more than ever: universities remain places of strict control over one's emotions, where feelings are connoted as unprofessional and must therefore be restrained.[19] But this extreme form of emotion work in highly competitive and insecure environments often does not remain without consequences. In my case, interviewees often told me that they perceived their emotional distress as a personal failure to "endure" the scientific system.[20] In my view, this is precisely why academics are particularly affected by mental health issues. At the same time, the universities' view of mental problems reinforces these predispositions. The idea of easing mental health issues by enhancing one's productivity is entirely in line with the spirit of universities, which are increasingly turning towards constant performance improvements in a business-like manner.[21] This change, often described under the keywords "neoliberalization" or "academic capitalism",[22] includes not only an ongoing shift away from state funding towards increased third-party funding but also a stronger market-based orientation of higher education. Universities established a service culture, education became a consumer good to a greater extent, and institutions now see themselves as success-oriented. Among other things, competition between researchers, universities, and states has been institutionalized and intensified.

Academic work is under growing pressure to perform, like the pressure to publish and to compete in precarious employment conditions.

Failure, formerly a crucial part of the trial-and-error principle of academia, is perceived as a competitive disadvantage. At the same time, university administration expanded constantly while external providers and agencies simultaneously played a growing role, such as in providing mental health courses. A stronger focus on mental distress is thus by no means indicative of a change in this culture. Many programmes are intended to serve only as bridging aid and are soon phased out again or have already been terminated, often accompanied by only short-term funding. This is also shown by the experience of my interlocutors who confirmed that psychological support, if it was provided at all, would be the first service to be cut. The declining number of participants from 2022, which many course providers have told me about, have led to the mistaken belief at universities that the mental load of employees and students has decreased again. But in recent months especially, when the effects of the pandemic gradually subsided, research participants reported to me an above-average number of absences from work due to mental health problems.

In academia, the idea seems to prevail that greater pressure due to the early expiration of contracts affects innovation potential and work effort. However, most scientific studies show that emotional stability is particularly important for good work performance.

Coupled with experiences of discrimination, poor prospects, precarious working conditions, family unfriendliness, and an almost unreachable work-life balance, academia is thus increasingly turning out to be an undesirable working environment.[23] Recent debates concerning precarity (#ichbinhanna) or work operations (#quietquitting) also reveal a shift in the academic community. The increasing number of diagnoses among young people could also be related to the fact that within this age group judgmental doctrines are on a steadily decreasing trend.[24] This might also indicate that they attach more importance to health-promoting working conditions and are more likely to seek psychotherapeutic help. Further research in this area remains immensely important. But certain departments, especially in the natural sciences, are already beginning to have problems properly filling their chairs. German academic institutions will have to respond to this trend, not least because rising illness rates will cause lasting damage to academic operations in the long term. Universities, as usually state-funded agencies, should play a model role here. This responsibility must be taken seriously, particularly because the health of new generations of researchers depends on it. We all, myself included, shape and stabilize an academic working culture that prioritizes work over health and wellbeing.

It is time to recognize that working cultures deeply affect research projects as well as researchers and have a lasting influence on the creation of knowledge.

A rethinking towards a radical health perspective to counteract this imbalance is therefore required. Attention must be drawn to mental burdens in academia and their systemic basis without fear of professional consequences. Research on one's own academic culture should be strongly encouraged. Emotions must be perceived as a fundamental part of academic work and not as an obstacle. This also includes developing a programme or training, preferably from external providers to avoid dependencies, for university staff, especially with supervising duties, on how to protect oneself and how to support others in dealing with emotional distress. Universities need to establish permanent positions and long-term funding that can offer long-term supervision and support in difficult situations. Power imbalances and dependencies should be reflected upon, in addition to individual agency. Together, academic culture must be redesigned by all of us to become an appreciative workplace that promotes cooperation and support. In ethnographic work and anthropological project assessment in particular, this also means not seeing fieldwork as the only risk for mental distress. Instead, projects must be understood holistically, and threats at home must also be taken seriously.

Notes

1 I would especially like to thank all those who shared their experiences of often difficult emotional situations in academia with me. Without this remarkably firm belief in my work and the trust placed in me here, this article would not have been written. It grew out of a paper I presented at the panel "Subordinate Feelings – Encountering Health Regimes in Psychiatry and Academia", which I co-chaired with Thomas Stodulka and Tynne Claudia Pollmann at the conference "Radical Health: Doing Medicine, Health Care, and Anthropology of the Good" at Freie Universität Berlin, June 24–27, 2021. I would therefore like to sincerely thank the conference organizers as well as my co-chairs and the editors of this volume for their commitment and constructive criticism. I would further like to thank the many friends and colleagues who have supported me on my own often rocky path to a PhD. Special mention should be made here of my partner, Arno Scholwin, in addition to Sakine Yildiz, Isabel Schönle, Veronika Pastorino, and Laura Thurmann, as well as the members of the SECTRA group, the Berlin 'Peer Support Group', and the Freiburg group of the ethnopsychoanalytic interpretation workshop led by Jochen Bonz. Special thanks go to my psychotherapist who accompanied me throughout the research phase and the Hans-Böckler-Stiftung for my doctoral scholarship. I also thank Thomas Stodulka, Anna Tuschling and Dominik Mattes for their effort in supervising my work. This article is part of my cumulative PhD, so small sections may overlap with other publications of mine.

2 Pierre Bourdieu: *Homo Academicus*, Frankfurt am Main: Suhrkamp (1988); in the following text, emotions, feelings, and sentiments are understood as synonyms. For a more precise specification, see Jack Barbalet: "Science and Emotions", in: *The Sociological Review* 50/2 (2002), pp. 132–150; Julia Nina Baumann: "The Ethnographers' Fear to Feel: Manoeuvring through an Affective Community of No-Feeling within the Academe", in*: Emotions and Society* 4/3 (2022), pp. 375–394; Charlotte Bloch: *Passion and Paranoia: Emotions and the Culture of Emotion in Academia*, New York, London: Routledge (2012), p. 140.

3 Vincent Crapanzano: "Afterword", in: Marc Manganaro (ed.): *Modernist Anthropology: From Fieldwork to Text*, Princeton: Princeton University Press (1990), pp. 300–308.

4 I carried out ethnographic research between September 2019 and September 2021 as well as in the spring of 2022 and conducted over forty semi-structured online interviews with a diverse range of ethnographers from different disciplines and backgrounds (in terms of class, gender, age, and ethnicity). My interviews have been accompanied by a series of informal talks with colleagues, academic staff, and academic activists in addition to participant observations at conferences, workshops, meetings, and coaching sessions within German-speaking academia. Gaining trust was therefore a crucial element in my research and is also the reason why in this article all direct quotes are provided without further context to protect the identity of my interlocutors in a rather small ethnographic community. Therefore, all places and persons mentioned in the text, in direct interview quotations and descriptions, are pseudonymized or even anonymized.

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16 Theresa M. Evans, Lindsay Bira, Jazmin B. Gastelum et al.: "Evidence for a Mental Health Crisis in Graduate Education", in: *Nature Biotechnology* 36 (2018), pp. 282–284.

17 Julia Nina Baumann: "The Ethnographers' Fear to Feel: Manoeuvring through an Affective Community of No-Feeling within the Academe", in: *Emotions and Society* 4/3 (2022), pp. 375–394.

18 The DSM-5 (by the American Psychological Association) and ICD-10 (by the World Health Organization) are two manuals that classify mental disorders. Psychiatric diagnoses, as well as treatment recommendations and payment by health care providers, are often based on these classifications.

19 Julia Nina Baumann: "The Ethnographers' Fear to Feel: Manoeuvring through an Affective Community of No-Feeling within the Academe", in: *Emotions and Society* 4/3 (2022), pp. 375–394; Arlie R. Hochschild: "Emotion Work, Feeling Rules, and Social Structure", in: *American Journal of Sociology* 85/3 (1979), pp. 551–575.

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TRAVELLING POLICIES Expanding HIV Treatment

Collage of fieldwork photographs by Thandeka Dlamini-Simelane, Hhohho Region, Swaziland (2022).

The clinic and working tools for expert patients.

> "It's been a long journey that started with PLHIV [People living with HIV/AIDS] considered frail people suffering from a debilitating and stigmatizing disease associated with promiscuity and a curse. We were walking tombs because HIV was the final verdict of someone infected with HIV back then. There was nothing valuable about an HIV-infected person. Things were slowly starting to change, and treatment was becoming available, but people were afraid to test and start treatment. People were needed who could give hope and be role models to encourage those who were frightened by the possibility of HIV infection. As more people became ill, including healthcare workers, healthcare facilities were overwhelmed and could not handle the influx of patients. Health facilities set out to find PLHIV who were willing to make their HIV status public and volunteer in clinics and hospitals. Initially, we [LHIV] were sought out, and we were a tight-knit group, new to such an environment, supporting each other. We were given a token of appreciation for our time, in the form of bus tickets, food, visibility materials, hotel nights to attend workshops, etc. The token became something tangible and semi-permanent. Some received a monthly stipend. As a result, the number of people willing to disclose their HIV status in order to enjoy the benefits associated with volunteering skyrocketed. The paradigm changed: PLHIV were no longer sought as volunteers, but strict recruitment procedures were introduced where we had to apply to be selected. Strict performance requirements and undesirable working conditions were imposed on those who were offered the jobs. The clinic space that was sought after by many to contribute to the HIV response, soon became a breeding ground for frictions among PLHIV, with nurses and other support staff. Being there was a matter of survival and obligation, rather than out of love to serve."

Interview with Ntazo, an expert patient, Swaziland (2013).

Ntazo is an expert patient. Expert patients refer to people that live with HIV (PLHIV) that work in health facilities, performing duties delegated by nurses. The drive by UNAIDS and WHO for patient-centered care meant patients' wishes should become the focus of care delivery. Their skills, knowledge, and information had to be considered in the management of chronic diseases, such as HIV. These principles are from the task-shifting strategy and greater involvement of people with AIDS (GIPA). In this article, I highlight how travelling global HIV policies and strategies (such as task shifting and GIPA) are reconfiguring established care practices and workplace dynamics in health facilities in resource-poor settings like Swaziland. Task shifting and GIPA are examples of travelling policies, used metaphorically to depict their origin from boardrooms in UN headquarters in Geneva and New York and their movement to high-disease burden countries of the South such as Swaziland to guide the HIV response. Furthermore, I explore how patients qualified through infection are used to closing a critical human resource gap and how this imbroglio plays out in everyday life. I also describe the translation process and the unintended consequences beyond the clinic that affect everyday life. I focus on the baggage of the travelling concepts and policies,[1] elucidating how such baggage potentially worsens the fragility of ailing public health systems and harms established structures used for coping with distress within a community.

TRAVELLING POLICIES Radical Treatment Expansion

The concept of the expert patient was first developed in the global North, particularly in the USA and the UK. It helps improve the quality of life of patients with long-term conditions by developing self-management skills, increasing patients' confidence and motivation to take control of their lives, and supporting other patients with chronic diseases.[2] The UN-WHO adopted the concept and described it as a task-shifting strategy to be implemented in resource-poor settings, primarily through the use of expert patients to avoid health worker shortages. In African settings, PLHIV were used to demonstrate the effectiveness of antiretroviral therapy (ART), promote patient adherence to HIV treatment, and demonstrate in a pragmatic way that ART offers a second chance at a long, healthy life.[3] In addition, adapting this concept facilitated greater involvement of people living with AIDS which became known as the GIPA principle, which UNAIDS was already pushing to strengthen HIV response. GIPA is a set of principles that pronounce rights and responsibilities of PLHIV and how they can enhance quality and effectiveness of the response to HIV. In Swaziland, PLHIV working in health facilities are referred to as expert patients, which is a local form of the GIPA. As PLHIV became expert patients in clinics, they became adepts in taking treatment, provided counselling of HIV treatment, and expanded experiential knowledge of living with HIV: how to resolve everyday challenges of living with the disease and with ART treatment.[4]

As PLHIV became increasingly involved in the delivery of care in Swaziland, new relationship dynamics and norms were reconfigured among health care workers and the new cadre of expert patients.

In this paper, I draw from a rich scholarship on voluntarism related to health care in Africa. Sometimes volunteerism is motivated by economic benefits,[5] while in other cases it provides an opportunity for personal development or recognition in society. In Ethiopia and Mozambique, socio-moral values drive people to volunteer.[6] Other studies focused on power dynamics and disputes between expert patients and nurses in clinical settings. I illustrate the different (therapeutic) practices and relationships that emerge when expert patients are the frontline workers in the delivery of HIV care in clinics in Swaziland. In Swaziland, the expert patient program was launched in 2006. When I conducted fieldwork in 2011, clinics had just begun to expand their service delivery to prepare for treatment scale-up. Clinics were transitioning from providing basic HIV services such as HIV testing to managing minilabs for point-of-care diagnostics, enrolling patients into HIV treatment, and tracking patients to monitor adherence. This created a demand to encourage people to get tested for HIV early to survive the disease. As a consequence, the demand for services increased exponentially and conventional health workers alone could not manage the influx of patients.

"I had been on HIV treatment for two years when the nurse in the clinic told me that they will be recruiting PLHIV who are taking ART the right way and have no obvious symptoms that they are sick. At that time, my adherence levels were so high that I was given meds for two months. Furthermore, the incumbent needed to be able to speak and write in English with good interpersonal skills. She said I fit the criteria and informed me that she recommended my name for the position. It wasn't long before I was offered the position. The Ministry of Health pleaded with the public to support the HIV response and was anchored by the King's call to the nation to contribute in some way towards the fight against HIV. I have been doing this job for six years now. I was told my main duty was to provide counselling to people that refuse to test and other menial tasks assigned by the nurses."

Interview with Ndumi, Swaziland (2013).

When the expert client program started, nurses' recommendations of adhering to ART patients were the predominant form of becoming an expert patient. During the study period, PLHIV had to apply and compete for expert patient positions. However, as treatment programs expanded and demand for expert patients soared, requirements changed and became stringent: requirements now included not only formal criteria such as a high school degree and a non-judgmental attitude towards HIV patients. They also included skills such as the ability to demonstrate a high level of care for others, impartiality for vulnerable individuals, and a commitment to working within the HIV field and a good reputation in the community.

Norms for expert patients were set by external funders who drove the HIV treatment expansion agenda in the country.

TRAVELLING POLICIES Everyday Work

"It's 7.30 a.m., and patients are streaming into the clinic to get ahead of the queue. You can quickly spot burgundy suits dotted in the crowds. They are expert patients who are also rushing into the clinic, but for completely different reasons. They need to be at their workstations before 8 a.m. to scrub floors, organise patient queues, and take out patient files scheduled for the day. This must be done before 8 a.m. or the day will be a disaster for the expert patients because picking the files out of the haystack when the patient is in front of you is time-consuming. The first exercise is patient care: Weighing, counting pills, counselling. Adherence counselling is tedious because you are dealing with people who are not cooperative. For those who don't default, counselling is equally arduous because they may be dealing with side effects or social problems that affect their willingness to take treatment. While an expert client is counselling, he or she may run out of medications, which they have to package according to the monthly rations that patients receive. This means leaving the workstation and abandon patients to fill the bottles, counting the pills one by one to make sure they have the right amount in them. Then you're done with the patient and move the remaining line along. The rest of the medicines in the clinic are packed by pharmacist assistants, who refuse to pack ARVs because everything related to HIV including medicines are perceived as tasks of expert patients."

Entry from Thandeka Dlamini-Simelane's field diary, Swaziland (2014).

It would be easy to assume that expert patients were full-time clinic staff, but they were volunteers who helped the nurses. They received only inconsistent, meagre compensation for their time. They worked five days a week and eight hours a day. Originally, they were to perform counselling duties, encourage people to test, keep them in treatment, and help those who stopped taking treatment to get on the right track. However, in their everyday practice, the expert patients did much more. Yet their attitude as volunteers did not change. During my fieldwork, expert patients began to take on the main tasks that required training to acquire skills.

Expert patients learnt these skills while working with nurses on a daily basis.

As a result, the scope of the work grew. Some of the tasks were quite technical for a layperson, such as taking vital signs and operating computers to electronically record medical data in the system. They also had to interpret lab results for patients, and educate patients about managing the side effects of treatment, by using their experiential knowledge of living with HIV. The usual procedures in the clinic had to be changed when it concerned expert patients. It is the duty of the orderlies to clean the entire clinic, but they refused to clean the workstations of the expert patients. Medications are packaged for all departments in the clinic, but the pharmacist did not pack ARVs. I even saw expert patients that brought their own coffee, tea, sugar and cutlery, even though all the staff was taken care of. The repertoire of professionals' engagement in the HIV response is not all bleak. Although the disease served to qualify them for work in health facilities, which was accompanied by a difficult work ethic, joy was also experienced in the midst of uncertainty. Through chats with expert patients and daily observations, I learned many intimate details about their lives, both inside and outside of work, as daily conversations and goodbyes were commonplace. I witnessed both frustrating and exhilarating moments of their work.

Expert patients complained about exploitation, irregular payment, or stigma. They also demonstrated great perseverance in performing their jobs and overcoming difficult work environments.

I saw how tenacity and despair, diligence and reverence of superiors sometimes led to their exploitation. Over the years, the struggles that expert patients endured, evolved drastically. For instance, there were more instances of shedding tears and sad moments because of stigma, and worrisome moments due to inconsistency of stipend payment. Now expert patients feel secure in their job and excited to execute their duties regardless of challenges because they have managed to cut their niche in the clinic spaces. For such reasons, gratitude is prevalent as their job gives new meaning to their lives. Becoming role models for other patients and being useful from being frail and dependent and ability to support their livelihoods.

In the midst of precarity and lack, using their sick bodies to secure a livelihood was the only available opportunity to survive.

"It's lunchtime, and everything comes to a halt in the clinic, as everyone has to take a break and grab a bite to eat before summing up the day's activities. It's a norm in the clinic for everyone to take a lunch box to work. Expert patients usually took their lunch on their desks because there was no place for them to sit or there was simply no way to mingle and eat with the rest of the staff. First, the lunchbox gave away the quality of the food they ate at home, as it was usually leftovers from dinner. Due to their low economic status, the quality of food eaten by expert patients was low. Therefore, it was not uncommon for expert patients to share their food; one person would bring starch, such as bread, and the other would bring vegetables or fruits such as avocadoes to share. Or one might bring sugar, the other tea. In the summer, they shared fresh produce such as corn and pumpkins. Sharing food strengthened the relationship between the expert patients and it was way to see which expert patients were friends and which ones were not."

Entry from Thandeka Dlamini-Simelane's field diary, Swaziland (2013).

There was a higher degree of closeness amongst expert patients than any other group of clinic staff. Expert patients used the affectionate term *bahlobobetfu* to refer to peers with whom they got along well. In SiSwati, it means a reliable person, especially in difficult times. The term has a pleasant connotation and represents a certain bond and a reciprocal relationship that is often the basis for their connection. For this reason, expert patients would not refer to nurses as *bahlobobetfu*, but rather as bosses.

"Once, the senior nurse called into her office and scolded me for treating a client badly. She was judgmental without even asking to hear my side. What hurt me most was that I wasn't even the one the client was complaining about, but the expert patient she was friends with. I was very hurt, but there was nothing I could do. I told Muhle [another expert patient]; she comforted me. She was really a great support to help me deal with it. In fact, as expert patients, we are our mutual support system. When we have problems, we share them with each other, cry it out, and comfort each other. Then we get back to work. We are like a family."

Focus Group Discussion with expert patients, Swaziland (2014).

In the absence of a structure for sharing grievances and complaints, expert patients found an effective way to cope with the stress of their jobs by supporting each other during challenging times, as Linda's story shows. Instead of turning to their superiors with their concerns, expert patients preferred to seek comfort from others. Consequently, expert patients were generally closer to each other than to the rest of the clinic staff. Those who worked in the same clinic seemed particularly close. All expert patients I spoke with agreed that the shared infection strengthened their bonds. They also supported one another when they had an emergency that required them to miss work or leave work early.

"The fact that we are known as HIV-positive employees in the clinic creates cohesion and solidarity between us. Our HIV unites us because we are the only people in the facility who got a job through the disease."

Focus Group Discussion with expert patients, Swaziland (2014).

"We simply ask *bahlobobetfu* to cover up or help with an extra task. [...] [When] I come with a problem from home, before we start work for the day, I call my peers and we talk about it."

Focus Group Discussion with expert patients, Swaziland (2014).

The trust and connection that was built were like a buddy system, not only for professional challenges but also for problems in their personal lives. The closeness shared by the expert patients and the support they gave each other was also used to mediate conflict between peers, reminding each other of their roles and the need for unity. This support network was not utilized by all; some expert patients resorted to other support systems to manage their work.

TRAVELLING POLICIES Conflictual Relations

In contrast to the affective ties amongst expert patients, I noted an ongoing subtle feud between expert patients and other support staff, especially the orderlies. Fundzi, who has been an expert patient for six years, recounted her experience:

"I cried all the time [because] the support staff [orderlies and janitors] forbade me to use the utensils and cups in the clinic. Also, I was not allowed to sit in the kitchen anymore because the nurse told me that we were not allowed to share the utensils with the nurses. I felt stigmatized."

Focus Group Discussion with expert patients, Swaziland (2014).

When Fundzi started working, she was destitute and could not even afford her own cutlery. The expert patients accused the orderly of mistreating her through stigmatization and exclusion. Nana, a woman who has been an expert patient for four years, also shared her experiences with a nurse:

"The nurse in our clinic refused to clean our workstations, saying she was hired to clean the offices for the staff. [...] She said she didn't understand why we couldn't do it ourselves because we were uneducated like her, that's what uneducated people do."

Interview with Nana, Swaziland (2014).

The treatment of the expert patients by the nurses seemed to be motivated by resentment, partly because they shared the same space in the clinic, but perhaps also because they had similar social status. Apparently, as full-time government employees, the orderlies felt superior to the expert patients who only had a temporary contract. These actions served to remind the expert patients that they were the lowest rank in the clinic's hierarchy. One could also interpret the friction between nurses and expert patients as a reflection of the fact that nurses were not targeted by HIV workplace programs that sensitize health workers on discrimination amongst themselves. As the patient's statements suggest, it is also possible that clinic staff viewed expert patients likely to infect them with HIV.

Expert patients also described conflicts with nurses. In clinics where nurses were reportedly hostile, expert patients also complained of harsh treatment by nurses, suggesting that other staff mimicked nurses' behaviour toward expert patients. In these clinics, where nurses provided less support and tolerated mistreatment, expert patients were less enthusiastic and complained more about the volume of work.

"In our clinic, we are like one big family. We often hear colleagues [expert patients from other clinics] complaining about mistreatment by nurses or other staff, but not in our clinic. We always hold meetings to discuss problems, and Umphatsi [our boss] makes sure that if there are complaints or problems from staff, not just expert patients, they are dealt with accordingly."

Focus Group Discussion with expert patients, Swaziland (2014).

The opposite was also true: where nursing staff were supportive, expert patients did not report mistreatment by other staff. Expert patients had healthier relations with all staff and were less likely to complain about their work, except for a frequent complaint about low pay, although the expansion of duties was characteristic of all clinics. In clinics with strong leadership, there was less friction between staff and expert patients. In clinics where support staff were hostile towards expert patients, nurses were quick to respond.

TRAVELLING POLICIES Threatened Solidarity

While many expert patients maintained strong bonds and supportive peer relationships, there were also exceptions as friction arose between them. Some separated from their closest associates and were seen as renegades for causing division. These included those who were allied with the nurses or full-time staff, but not with their colleagues. They were considered 'sell-outs' and were not part of the expert patient group. Although the expert patients did not actively discourage their peers from having relationships with other staff, they were implicitly expected to be loyal to each other. Those who were closer to other staff were considered untrustworthy and their loyalty dubious. In addition to being considered disloyal, they were also accused of being slothful in their duties and diligent towards the bosses' requests as their major priority was the nurses' private errands, and the nurses reciprocated by bailing them out when needed. Another source of friction among the expert patients was the difference in stipend levels.

”It would be better if all expert patients could receive the same amount of stipend.”

Interview with Vuma, Swaziland (2014).

”In fact, we do much more work compared to expert patients from other programmes. We take care of pregnant and TB patients.”

Interview with Phinda, Swaziland (2014).

”We have similar skills and training – so why the difference in the stipend amount?”

Interview with Sethu, Swaziland (2014).

Expert patients were paid different amounts directly by different donors. Such a scenario had harmful repercussions and caused disparities in the scope of their work and stipends received. Unequal pay contributed immensely towards creating divisions among expert patients. Moreover, expert patients competed and bragged about belonging to a donor considered rich. The 'rich donor' was the one who paid the expert patients a higher stipend, had flashy cars, and owned assets in the clinic. I call this feud among expert patients over assets, donarization.

”Sometimes we can even quarrel over stationery or furniture – imagine what happens if your donor is the poorer one.”

Interview with Ngeti, Swaziland (2013).

The expert patients positioned themselves as stewards of their donor's assets. For example, if one wanted to borrow a pen or chair, the expert client whose donor had donated the stationery might respond: 'Ask your donor to buy it for you'. Expert patients whose stipend was paid for by a wealthy donor seemed having more power over their fellow patients. Donorization implied that relationships were becoming unstable, cohesion within the group dissipating and a crack started. Needless to say, expert patients were concerned when these traits stuck out among them, challenging solidarity known to prevail among PLHIV.

TRAVELLING POLICIES Unintended Consequences

When the promoted travelling policies are implemented in the locale,[7] they leave far more complex traces beyond programmatic outcomes in health facilities. GIPA and task shifting not only resolved human resource shortages and contributed to HIV treatment expansion but also had unintended consequences beyond the clinic space. They leave a trail in the public health systems, consequently, the structures are weakened further, and structural violence becomes rife as the underprivileged become a bailout and suffer the most brunt. The article is an exposé of the feuding among PLHIV and the consequences of the inclusion of expert patients as an informal cadre into the healthcare system.

The article is an exposé of the feuding among PLHIV and the consequences of the inclusion of expert patients as an informal cadre into the healthcare system.

It explicates the complex resonances and dissonances that arise when PLHIV are involved in frontline health care service delivery, explores relational dynamics developed and illuminates the challenges faced by expert patients as they fulfil their roles. The repertoire of patients' engagement in the HIV response is not all bleak. Although the disease served to qualify them for work in health facilities, which was accompanied by a difficult work ethic, joy was also experienced in the midst of uncertainty. From debilitated people with a terminal illness who were stigmatized, they have become role models among PLHIV. They are grateful for the second chance at life that ART offers them and for the opportunity to raise their children and make a living.[8] Due to a lack of state funding, the expert client programme was externally funded, giving outside actors influence over the administration of the programme and weakening the state's role in directing the health discourse of its citizens.[9] Expert patients had different contracts which triggered territorialism and donorization that threatened existing solidarity and undermined the mutual support that expert patients enjoyed. Togetherness was replaced by the pursuit of individual gain and power over others. Limited resources in resource-poor settings force makeshift development arrangements to become the mainstay approach. Increased involvement of PLHIV in frontline service delivery in health facilities also weakened the solidarity that was prevalent among PLHIV. Earlier work portrayed PLHIV as a community of disease sufferers with strong collective efforts and enjoyed solidarity which led to the achievement of great milestones globally.[10] In Swaziland, the public health system is weak and so are the accountability structures. Precarity in clinics in the study facilitated prejudice to thrive. The kindness of superiors, great leadership skills, or sucking up to superiors become the only available options to protect the vulnerable from predatory practices. In instances where a nurse had good leadership and management skills, expert patients were generally motivated and there was less conflict and the reverse is true. Where nurses interacted poorly with patients, there was a high probability that expert patients also offered poor-quality services. In this quotient, one fact shines brightest: nurses and overall administration were the catalysts that determined whether the inclusion of expert patients in service delivery was both programmatically effective and rewarding for all health care facility staff.

As a result of the radical expansion efforts of treatment programs, staff welfare is at risk of being overlooked. Manipulation of underprivileged citizens thrive. This is the form of radicalism that ensues when resources are scarce.

When globally derived strategies are implemented in locales, the translation process plays out differently from the intended outcome. It is an intersection where the desperation to end AIDS by involving patients as a solution, conflates and conflicts with ethics, culture and politics. The seemingly insurmountable challenge of the acute shortage of health workers was instantaneously resolved by GIPA as a magic bullet. These were drastic and radical measures adopted to ensure treatment reaches all in the hardest hit, resource-limited settings of the world. The globalisation process, that is the local adaptation of global policies and strategies such as task shifting, need to be explored beyond the binary perspectives of its programmatic relevance and effectiveness. Equally important is to understand how global policies for treatment expansion may invade a society and how they can hamper, alter or configure new practices, shape norms and meanings and affect social processes. This is the baggage that travelling health policies from the North bring to the countries in the South.

Notes

1 Anita Hardon, Hansjörg Dilger: "Global AIDS Medicines in East African Health Institutions", in: *Medical Anthropology* 30/2 (2011), pp. 136–157.

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4 Margaret Kyakuwa, Anita Hardon, Zoe Goldstein: "The Adopted Children of ART: Expert Clients and Role Tensions in ART Provision in Uganda", in: *Medical Anthropology* 31/2 (2012), pp. 149–161.

5 Tomo Takasugi, Andrew C.K. Lee: "Why Do Community Health Workers Volunteer? A Qualitative Study in Kenya", in: *Public Health* 126/10 (2012), pp. 839–845.

6 Kenneth Maes, Ippolytos Kalofonos: "Becoming and Remaining Community Health Workers: Perspective from Ethiopia and Mozambique", *Social Science & Medicine* 87 (2013), pp. 52–59.

7 This chapter was written as part of a Welcome Trust funded project *Reimagining Reproduction: Making Babies, Making Kin and Citizens in Africa* (Project Number 22874/Z/21/Z), and I hereby acknowledge its support.

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9 Patricia Wilson: "A Policy Analysis of the Expert Clients in the United Kingdom: Self-Care as an Expression of Pastoral Power?", in: *Health & Social Care in the Community* 9/3 (2001), pp. 134–142.

10 Joao Biehl: "The Activist State: Global Pharmaceuticals, AIDS, and Citizenship in Brazil", in: *Social Text* 22/3 (2004), pp. 105–132; Steven Robins: "From 'Rights' to 'Ritual': AIDS Activism in South Africa", in: *American Anthropologist* 108 (2006), pp. 312–323.

Further Readings

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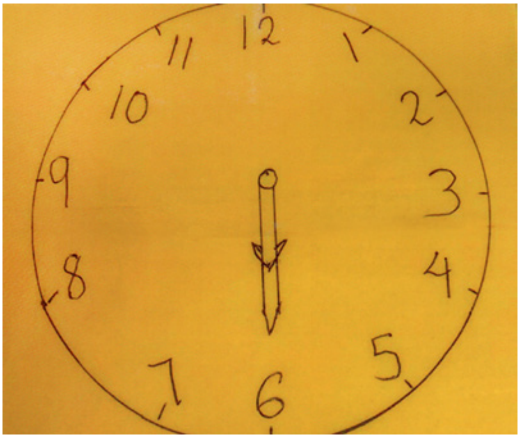
Jonathan M. Dapaah, Eileen Moyer: "Dilemmas of Patient Expertise: People Living with HIV as Peer Educators in a Ghanaian Hospital", in: *Ghana Studies* 15 (2013), pp. 195–221.

Lyson Tenthani, Fabian Cataldo, Adrienne K. Chan, Richard Bedell, Alexandra L. C. Martiniuk, Monique van Lettow: "Involving Expert Patients in Antiretroviral Treatment Provision in a Tertiary Referral Hospital HIV Clinic in Malawi", in: *BMC Health Services Research* 12/1 (2012), pp. 140–148.

Melina Rutishauser

HEALTH INSURANCE Entanglements



Postcard by Melina Rutishauser, Tanzania (2017).

At first glance, the time represented in this postcard is uniquely depicted. Nonetheless, it somehow irked me. I felt the need to take a second look at the picture. What is the time represented here? How should the picture be interpreted? How should the hour and minute hands be read? Indeed, moments of productive disruption to reconsider my own ideas, perceptions and narratives had become pivotal during my years of research.

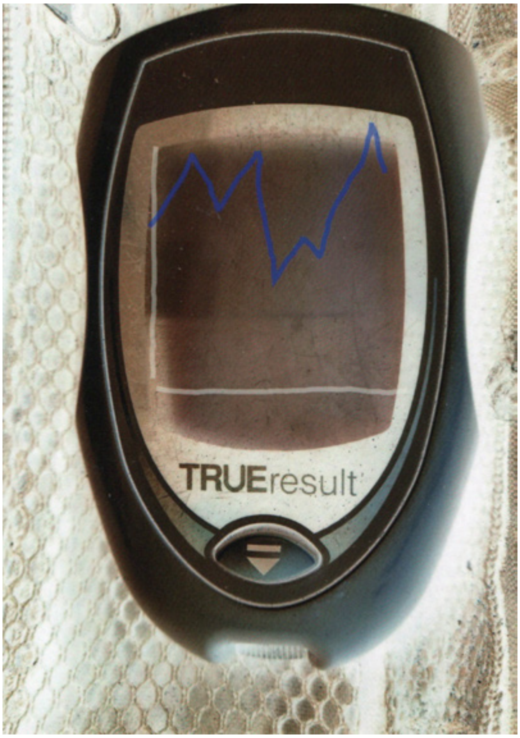
Do health insurance schemes as new health care infrastructure in the Kilombero Valley have the potential to change the way diseases are dealt with?[1] The National Health Insurance Fund (NHIF), one of the main health insurance schemes in Tanzania, with a broad and comprehensive benefit package for civil servants and formally employed individuals, seemed to foster 'good' biomedical health care for the ones diagnosed with Type 2 Diabetes Mellitus (T2DM). In the context of the Kilombero Valley, in the Morogoro Region, Tanzania, a broad and comprehensive health insurance package made a difference concerning the biomedical treatment of T2DM for those who were insured by the NHIF between 2016 and 2019, and could be perceived at least partially as 'radical health'.

The term radical in this context can be understood in two different ways: as a new form of health protection compared to what was possible in the past; and as essential for a sustainable long term biomedical treatment regime for T2DM.

But what are the challenges to achieve novel forms of healthcare and maintain and expand them to actually call them radical health for all? The contribution presented here interlinks postcards written by myself during the field research for my PhD with reflections on (in)visibilities created by and through digital technologies in T2DM health care infrastructures in Tanzania and their possible contribution to achieve healthier biomedical futures. The creation of the postcards – through the Swiss Post *PostCard Creator App* – became a method complementing the interviews, note taking, participation and observation and at the same time extending them, as it allowed my creativity to follow free associations and to express affects in another way.[2] The postcards were therefore important to depict thoughts and ideas in a visual and creative language and offering different forms of knowledge production. As formal field notes and the documentary photographs were not fitting the needed format to think through and deposit thoughts, I searched for another medium which would allow me an openness to think and look at things.[3]

Sending postcards allowed to let go of specific concerns and emotions for a moment and be mentally agile to create, figuratively speaking, new space for further considerations.

This distinguished it from the classical diary writings where I kept the notebooks with me all the time. However, as I had sent the postcards to my home in Switzerland, I knew the visual and written reflections were not lost as such and I could work again with them having a temporal and geographical distance. Additionally, as the postcard consists of a predefined space, the written and visual thoughts were a unit with a start and an end. These reflections could later on be arranged in different forms like constantly evolving mind maps. This stands in contrast to the rather linear form of the written diaries I produced in the field. Digital technologies were part of the creation of the postcards as well as present in the diagnosis of T2DM, but they were also relevant to health insurances. Through the utilization of certain health technologies, including for example test strips for the glucometer as well as other investigations and a range of pharmaceutical products, specific individuals gain access to biomedical treatments through health insurance schemes. The multi-layered aspects of technologies and the (in)visibility created at different levels by them caught my interest whilst talking to women and men with a T2DM diagnosis. The postcards presented here are engaging with this (in)visibility, as there are only objects depicted on the postcards even though T2DM is experienced by real people. But they allude also to questions and criticisms, for example by using different visualization techniques in the creation of each postcard, such as the X-ray filter on the image of the glucometer.



Postcard by Melina Rutishauser, Tanzania (2019).

A blood glucometer is a point-of-care device and as such a technological product which makes T2DM visible and shapes its biomedical management. Nevertheless, the depicted numbers on its screen do not represent the complex picture of the individuals' constraints and health capacities even though these aspects are influencing the displayed glucose value. How do insurance schemes influence Diabetes Mellitus (DM) (in)visibility through such technologies? For me personally, digital technologies always evoke a sense of disruption and disconcerting vigilance due to privacy concerns. Nevertheless, digital technologies are crucial in today's medical perceptions of DM and at the centre of the diagnosis of the disease.[4] However, digital technologies are also at the centre of a related health infrastructure – the health insurance schemes. Through the underlying datafication they establish new ways of monitoring and evaluating health expenses and health seeking behaviours.[5]

Like the glucometer, such data produces a specific visibility and creates a form of invisibility and inequality at the same time.

Many individuals were testing their glucose value not only at the visits on their monthly diabetes clinic days. Yet, in a place such as the Kilombero Valley, most individuals do not have the possibility and the financial means to buy their own glucometer, which was reported to cost around 65'000 TZS (approx. $28). Therefore, individuals often test at small private laboratories. To test at private laboratories instead of the diabetes clinic is more convenient due to the distance, the price, the time spent for testing and waiting and so forth. This data is missing and does thus not form part of a broader picture of the person's health by medical staff attending them in the clinic. In that regard it cannot enhance the correct adjustment of the T2DM medication. The blood glucose values measured remained in a note book in the laboratory. Additionally, the data also remains invisible to enable a broader picture on T2DM in a particular health care facility and thereby misses to inform health policies. Similar things could be observed concerning health insurance schemes. Individuals in the research area did know that this person or that neighbour got a service paid for by the NHIF. However, what a specific health insurance plan covers and why the policy of the benefit package changed at a particular point in time remained invisible to individuals diagnosed with T2DM with and without health insurances. There were mainly two insurance schemes present in the narratives of individuals in the Kilombero Valley: the National Health Insurance Fund (NHIF) and the improved Community Health Fund (iCHF - CHF Iliyoboreshwa). The NHIF is a mandatory health insurance scheme for civil servants and formally employed individuals, while the iCHF is a so-called pre-payment scheme for people without 'formal' employment in rural areas. The premium settings and the benefit packages of the two health insurance schemes differed substantially.

Insurance schemes do not operate in isolation.

Individuals that I met who were insured by the NHIF were either insured through their public employment status or due to their status as a dependent of an insured public employee. In that category, the NHIF had an employer/employee split where each party contributed three percent of the monthly salary which was deducted directly. It covered two parents and four dependents. The coverage however changes for the NHIF after the retirement of the previously employed main policy holder. After retirement only the former employee and her/his spouse are insured any longer, and only in case if such a change has been initiated by the main policy holder. If the main policy holder has contributed 120 months or more to the scheme, the retired individual and her/his spouse receive free health insurance services for the rest of their life.[6] The iCHF was paid by an annual lump sum of 30'000 TZS (approx. $13) in advance for a household of six individuals. During the years of the research the NHIF enabled individuals not only to access different types of public and private facilities on all levels up to Muhimbili National Hospital, including privately run pharmacies and accredited drug dispensing outlets (ADDOs), but also to get different technologically mediated investigations and pharmaceutical products as for example the test strips for the individual glucometer. In the same years, the iCHF did not pay for the test strips of the glucometer and only some pharmaceutical products for the treatment of T2DM were available at public health centres and public hospitals. There were no broader and well established agreements between the iCHF and privately run pharmacies or ADDOs during these years.[7] Insurance schemes as well as other technologies, such as different testing tools, form part of an interlocking system of power and inequalities.[8]

HEALTH INSURANCE Making (In)Visible

In a biomedical representation, DM is characterized by a high blood sugar level over a continuous period of time due to the impairment of the pancreas in producing insulin, or the inappropriate response to the produced insulin by the body cells due to an insulin resistance. DM thus belongs to a group of metabolic disorders, which are occurring in our body and are in its depiction typically not noticeable to the human eye. The medical technologies used – as for example a glucometer – assist by making the disease visible, representing digits of the glucose content in the blood. The technologies should therefore operate as a support to control the glucose content life-long and enhance access to biomedical treatment. Due to the characterization of DM, the outcome of a recommended daily test regime is not a positive or negative result as it would be for a malaria or HIV/AIDS test, but rather a sequence of numbers, which has to be interpreted and organised by human beings. Therefore, testing can offer different ways of understanding aspects of our health and thinking about health and disease. However, one should carefully look at what is being tested, how it is tested and how the data is interpreted and represented.

"[F]or many reasons that are both lay and professional, diabetes is a controversial and contested diagnosis."

Carolyn Smith-Morris: "The Chronicity of Life: The Acuteness of Diagnosis", in: *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, United States of America: Rutgers University Press (2010), p. 27.

During the research on T2DM, I was supported by two research associates: Dr. Judith Mheni and Dr. Eusebius J. Mikongoti, who are both medical doctors. During our encounters in 2019, the glucometer became increasingly present in the narratives of women and men diagnosed with T2DM from all socioeconomic statuses. Of the 34 individuals we were in regular contact with over these years, seven have purchased the device out of pocket. One person got it through a special promotion by the NHIF and a local pharmacy. However, the machine as such is not the most expensive part. What makes it expensive are the strips and the needles to get blood out of the fingertip. A set of fifty strips costed by then around 45'000 TZS (approx. $20), which is not even two strips a day. Each device requires different strips and needles. The micro-specifications of each glucometer are therefore very important, and spare parts are not always available for all types of devices on the local market. Out of the eight individuals who own a device, only two persons were not insured by the NHIF. One person paid for the test strips out of pocket and used it just in case of feeling unwell. The other has received the strips as a gift and was often not able to use the device at all. As DM is considered to be a chronic disease, the biomedical discourse represents it as a disease which requires continued monitoring – at least until the medications are adjusted in case that an individual is not using insulin. The insurance thereby bolstered the aspiration for 'modern individualized health care' through the emphasis on individual testing via a glucometer. Encouraging people to test their own blood glucose levels at home, and therefore to buy a glucometer, was mentioned by people from all backgrounds as a common piece of advice from doctors. According to medical professionals, this habit allows patients to better understand and assess their own health conditions.

Testing seemed to be gaining in importance in a local biomedical treatment regime.

In the narratives of individuals diagnosed with T2DM, the emphasis on testing in the monthly check-ups gave also way to the comprehensive instructions on dietary changes to control the glucose level in the blood. In present encounters at the clinic, the adherence and management of medicines and the measuring of the height, weight, the blood glucose content and the blood pressure level was emphasised as women and men recounted to us. Still, the emphasis on measuring had no influence on the long diagnostic journey to get a T2DM diagnosis yet, as narrated by other interlocutors.[9] A misidentification as malaria and/or HIV/AIDS due to the symptoms – such as pain all over the body, sweating, fever, extreme tiredness, thirst, headaches or losing weight – was mentioned by many individuals.[10] Nevertheless, diabetes was represented by medical professionals as becoming increasingly common. However, research and donor funded projects on DM were still rare. Or has DM just been marginalised by most donor-funded projects since decades as Amy Moran-Thomas' research indicates?[11] And how will health insurance schemes change or reinforce this discrepancy in the future in places like the Kilombero Valley? In the conversations with individuals diagnosed with T2DM, health insurance schemes were not represented to help shorten the diagnostic journeys. But being insured via the NHIF was said to be helpful to pay for the biomedical treatment costs afterwards, and to facilitate to receive a "favourable treatment" at private and public health care facilities on all levels of the hierarchically structured health care system. During the years of research, malaria treatment was covered by both insurance schemes the iCHF and the NHIF. Access to T2DM treatment was however limited through the iCHF by then. A sustainable and comprehensive access to biomedical T2DM treatment was only available for individuals insured via the NHIF.

The format of the postcard helped me to combine visual considerations and written thoughts.

In a multi-layered process – involving the selection of a topic, its visual conceptualization as well as the depiction by using different tools – I created visual reflections for the postcard front. On the reverse side of the postcard, I inserted a written comment, a reflection or questions and concerns which were linked to or contrasting the visual composition. The front and the back of the postcards were linked in one or the other way. Yet while looking at one side the other is invisible and allows in that moment to rethink of and explore additional associations. The postcard of the glucometer, for example, can enable us to critically reflect on so called true results, and how they can differ depending on the individuals and places involved in the process of measuring a disease. Not only does the time of the day influence the result, also the mental well-being such as fear, stress or heavy thoughts are changing it. Even the fact of having looked at food is activating the insulin production by our pancreas through messengers sent by the brain.

What then is a true result?

Applying the X-ray filter to the photography additionally triggers questions about different meanings of series of daily blood glucose readings. Who can afford several blood glucose readings a day in the Kilombero Valley? How much do we actually know about a person through these sequences of numbers? How do numbers affect the treatment? Which numbers – blood glucose value, insurance card number etc. – are influencing the actual biomedical treatment, and how so? Through the depiction of the device – without the lancets nor the testing strips which are essential to perform their actual function – questions concerning practical issues around its working arise. Where to get batteries, lancets, strips while living in the Kilombero Valley? How long are the strips available on the market? Is the type of glucometer on the list of the Medical Store Department of Tanzania, or was it just a donation by a program? The drawn graphs can remind an observer of the ups and downs – the chronicity with which T2DM is often associated, and the acuteness of the diagnosis and so forth. It can raise questions on when and how health insurances are needed and actually used.

HEALTH INSURANCE Hidden Costs

As I got to understand through conversations with individuals, DM often implied complex and expensive therapies which are regarded as life-long in a biomedical sense. The range of the costs for a biomedical treatment regime varied among our interlocutors and for the individuals over time, and was reported to be between 9’500 TZS and around 90’000 TZS (approx. $4-$44) per month without the myriad costs for the recommended diet, the testing tools and the transportation costs to the respective healthcare facility. In case of long-term implications, co-morbidities and synergetic interrelations, further investigations and additional medicines were recommended by medical professionals. The individuals could seldom manage these costs as well as the care scheme over many years alone. The cost did not only correlate with the progression of the disease and the long-term implications set in motion, including high blood pressure and/or an experienced stroke; but also, between individuals insured via the NHIF, the iCHF and out-of-pocket payments, due to the different service coverage policies of the insurance schemes. Where the NHIF covered different related investigations and a range of medicines for T2DM, the iCHF was represented by most individuals diagnosed with T2DM to alleviate the treatment costs only marginally and just if prescribed with some few specific pharmaceutical products available in public health centres and hospitals. None of the insurance packages covered the cost of the recommended diet, nor did they cover transportation costs to health facilities. These costs remained invisible for the health care system but not for the budget of the individuals diagnosed with T2DM.

Postcard by Melina Rutishauser, Tanzania (2017).

Access to technologically mediated infrastructures is fluctuating for individuals diagnosed with T2DM. The technological infrastructures are being transformed, adapted, shaped and redesigned, often influenced by international organisations. During the years of my research, there were several changes concerning the iCHF. Most importantly, its national roll-out to 26 regions of mainland Tanzania starting in 2019 and the increase of the annual fees to insure six individuals from 10'000 TZS to 30'000 TZS (approx. $4-$13) in the Kilombero Valley, which took place simultaneously. Access to health insurance was also fluctuating due to changes in the individuals' socioeconomic positions and changing relations to other individuals such as neighbours and kin. Therefore, health insurances manifest themselves concurrently, and over time as enabling and liberating, for example for elderly women formerly employed by the state as nurses or teachers, who after retirement were able to access private health care facilities and specialists all over the country without the need to ask relatives for financial support. At the same time, health insurances revealed themselves as inhibiting and excluding,[12] as for example they only cover biomedical treatment costs even though it is recommended and represented as essential to follow a balanced diet with vegetables and whole grains. Such a healthy diet is more expensive and less accessible than processed grains. Another example would be that individuals who are insured based on the employment status of a relative can lose their access to insurance coverage in case the employment status of the daughter/son, mother/father or their marital status has changed. In a biomedical treatment regime, DM cannot be covered by a minimum insurance package.

A comprehensive insurance system is a form of radical health, although its implementation seldom fulfils such a promise for all over a long period of time.

Health insurances are not radical in the sense of exceeding conventional ways of doing health for all. Nevertheless, to keep a curiosity in different and at times maybe even contradictory implications of such technologically mediated infrastructures as health insurance schemes, can help us to see some radical possibilities. In this regard, it is useful to (re)consider one's own standpoints and subdue oneself to a temporary sense of discomfort so as to perceive other aspects and "[...] challenge our own visions of the real".[13]

HEALTH INSURANCE Postcards

As versatile material objects, I had the possibility to assemble the postcards and reassemble them in different ways and create through that new ideas and focus on different insights. Assembling for example the depicted postcard of an individual glucometer (second postcard), a postcard of food and another with colourful pills drew attention to the different effects these products can have on the displayed blood glucose values. This allowed for reflections on how these aspects were presented in different occasions by different stakeholders. Complemented with the postcard on money (third postcard), questions on costs, availability and dependency of markets and policies and their global entanglements were arising. All these aspects were rather invisible while looking at one postcard alone. Additionally, because of the printed-out postcards, some of my thoughts became visible and palpable objects which I could take along with me and share with others. During the discussions with family, friends and colleagues from a qualitative data analysis group, additional layers of entanglements became visible. When a friend saw the postcard with the inscription "TRUEresult" on the glucometer, as well as the depiction of time on the first postcard in the present contribution, an interesting discussion emerged. We debated the entanglements of the true and therefore valuable results and their medical and individual links to time, for example concerning an individual's T2DM care during the harvesting season or a burial ceremony and the sleeping and eating rhythms shaping these moments, which may contradict biomedical recommendations elaborated in different guidelines. This discussion clearly triggered some interesting questions and thereby enhanced the analysis.

Notes

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2 Swiss Post: PostCard Creator App, https://www.post.ch/en/sending-letters/sending-letters/postcard-creator-app.

3 Mascha Gugganig, Sophie Schor: "Teaching (with) Postcards: Approaches in the Classroom, the Field, and the Community", in: *Teaching Anthropology* 9/2 (2020), p. 60.

4 Arlena Siobhan Liggins: *Making Diabetes: The Politics of Diabetes Diagnostics in Uganda*, Bielefeld: Transcript (2020), p. 30.

5 Jessica Mulligan: "Insurance Accounts: The Cultural Logics of Health Care Financing", in: *Medical Anthropology Quarterly* 30/1 (2016), pp. 37–61.

6 NHIF Retiree Benefit Plan, https://www.nhif.or.tz/pages/retiree#gsc.tab=0.

7 Angel Dillip, Albino Kalolo, Iddy Mayumana, Melina Rutishauser, Vendelin T. Simon, Brigit Obrist: "Linking the Community Health Fund with Accredited Drug Dispensing Outlets in Tanzania: Exploring Potentials, Pitfalls, and Modalities", in: *Journal of Pharmaceutical Policy and Practice* 15/1 (2022), pp. 1–12.

8 Brigit Obrist, Angel Dillip, Albino Kalolo, Iddy Mayumana, Melina Rutishauser, Vendelin Simon: "Toward Digital Participation? The Work of Aspiration in Improving the Community Health Fund in Tanzania", forthcoming.

9 Arlena Siobhan Liggins: *Making Diabetes: The Politics of Diabetes Diagnostics in Uganda*, Bielefeld: Transcript (2020), pp. 119–148.

10 Emmy Metta, Ajay Bailey, Flora Kessy, Eveline Geubbels, Inge Hutter, Hinke Haisma: "'In a Situation of Rescuing Life': Meanings Given to Diabetes Symptoms and Care-Seeking Practices among Adults in Southeastern Tanzania: A Qualitative Inquiry", in: *BMC Public Health* 15/1 (2015), p. 4.

11 Amy Moran-Thomas: *Traveling with Sugar: Chronicles of a Global Epidemic*, Oakland/California: University of California Press (2019).

12 Erik Bähre: *Ironies of Solidarity: Insurance and Financialization of Kinship in South Africa*, London: Zed Books Ltd (2020), p. 11, pp. 21–24.

13 Joel Robbins: "Beyond the Suffering Subject: Toward an Anthropology of the Good", in: *The Journal of the Royal Anthropological Institute* 19/3 (2013), p. 458.

PRACTICES

FIELDWORKING

″Instead of ′recognize the costs′, the ancient wisdom from the Temple of Apollo in Delphi ′recognize yourself′ – directed to each one of us – will help us shape the future of health and of humanity in the long run.″

Dietrich Grönemeyer – a renowned German doctor and best-selling author.[1]

Recognizing oneself effectively supports processes of self-healing. Self-help, in turn, can help overcome the immense shortcomings of today's highly technologized biomedical system, which often fails to integrate the basic human need for relatedness and meaning into therapies. This quote also recalls the ancient foundation of today's medical system, the Hippocratic Oath that every doctor and midwife takes nowadays. Evidence-based medicine has to pursue clinical studies that prove – for example – the efficacy of home remedies, but people living in highly urbanized societies urgently need help with civilizational chronic diseases too. This need is addressed by research approaches such as Salutogenesis, narrative or mind-body medicine, CAM (complementary and alternative medicine), or integrative medicine. They strive to meet the standards of scientific research while taking into account the holistic nature of health and illness, i.e., its interpersonal, emotional, social, or political aspects in the short or long term.

Through applied anthropological research and supporting efforts to prevent typical everyday ailments, the *Werkstatt Ethnologie Berlin* (WEB),[2] of which I am a member – in cooperation with Prof. Annette Kerckhoff – has been involved in the development of *Mamacura Workshops* since 2012. The concept grew out of a mutual interest in an anthropological perspective on the use of food for health and healing purposes. We are interested in all kinds of respective knowledge and skills, as well as how they are communicated and transformed along the way.

During the two-hour-long workshops, we first acquaint ourselves with the various participants by sharing each other's experiences and goals. Then we present relevant scientific information on nutrition and discuss different perspectives especially on the context of information transmission (for more information on the workshops, see: ″Kitchen Remedies from Around the World″).[3]

This procedure promotes reflection and develops awareness of some of the basic healing properties of self-help. The *Mamacura Workshops* provide knowledge through shared lived experience.

In this contribution, I draw on participant observation during my fieldwork on representations of ′healthy′ eating among the ″Neighborhood Mothers in Berlin-Neukölln″ (Ger. *Stadtteilmütter in Neukölln*) between 2012 and 2016 and the subsequent teamwork for the development of the *Mamacura Workshop*.[4] I am further inspired by an encounter with Dirck van Bekkum who works as an anthropologist employed as educator in a clinical setting and considers his work as ″fieldworking″.[5] This concept provides a framework for my own ″betwixt and between″ activity of using anthropological research tools for the purpose of preventive health. In the following, I offer an anthropological reflection on this experience and propose further possibilities in terms of practice and research. First, I introduce my (partly autoethnographic) fieldwork and lived research experience to illustrate how the workshop concept represents an effective, accessible, and inexpensive way of countering some of the aporias of the current dominant biomedical system. Then I present the anthropological tools used in the workshop and share my reflections on how anthropological research methods such as participant observation and (semi-directed) group interviews – adapted to this workshop setting – indeed promote healing through "radical empathy" and can be termed "fieldworking".[6] Further, I argue that the workshops offer a safe liminal space to share impressions and support self-healing processes. As such, they transcend a formal meeting and become empowering as a form of "help for self-help". Finally, I share the experience of four participants of the Mamacura Workshops that I have followed for several years. Their stories give some insights into how particular mindsets and peer dynamics guide processes of change. This exploratory practice is intended to be sustained through further research within the framework of citizen science and its integration in the (German) primary prevention and health promotion system.

FIELDWORKING Patchwork

For as long as I can recall, I have been interested in self-help strategies, i.e. in how food and specific activities can optimize our health, strength, and appearance. I was told that soup encourages growth and that red meat gives strength. Salad is a must with cheese because its fibers lock the fat and prevent high levels of cholesterol. A glass of wine a day prevents cardiovascular diseases. I was born at the end of the 1970s. Later, in the 1990s, the health advice pervaded TV ads: "eat five helpings of fresh fruits and vegetables a day," a rather simple but somehow challenging recommendation. Indeed, I did not care so much at that time because I was young and felt full of energy. I did not relate my stomach aches yet to my daily habits. Anyway, I was interested in good food as an *art de vivre* and gladly developed my cooking skills. An urge to care and understand more about health matters led me to become a nurse, and I started to experience the world as an autonomous young adult at the turn of the century.

My mother provided me with some important insights she gained during her own struggle with allopathic cancer treatment. Despite the disinterest and negative reactions of the medical team and some of her relatives regarding her need for holistic care, she insisted on continuing to complement her treatment with naturopathy and acupuncture. She often mentioned of how this helped her counter the side effects of chemo- and radiotherapy. She used to tell me that she felt heard and eased by the CAM practitioners. I thoroughly felt how important this holistic complementary approach was for her.

It made me realize how French society pressures people toward the hegemonic biomedical system despite its limited symptom-oriented approach and the tremendously destructive side effects and other collateral damage of – for instance – chemotherapy in cancer treatments.

Later, I moved to Germany and studied philosophy and social and cultural anthropology. In 2012, I started an internship at the association *Werkstatt Ethnologie Berlin*, which bridges academic research and everyday cultures in Berlin through workshops and other events. We organized an exhibition on transnational aspects of alternative medicine in Berlin. In May of that year, we had a three-week exhibition at the *Schiller Palais* in the district of Neukölln where healers, academics, and interested members of the public met for multiple events featuring Afro-Brazilian Candomblé, Traditional Chinese Medicine (TCM), Tibetan Medicine, Ayurveda, Shamanism, Korean Acupuncture, medicinal leeches, and Botanical Medicine. Furthermore, I worked as an assistant in three workshops conducted by Prof. Annette Kerckhoff – an expert in naturopathic self-help – on the topic of kitchen remedies.[7] In these workshops, a group of twenty women from all over the world exchanged their experience of healing colds and dealing with pain and swapped advice on beauty and wellness. The atmosphere was full of smiles and good humor, and a lot of fruitful ideas were shared. I documented the three sessions, transcribed the recipes, and shared the anthropological literature I had gathered on the topic. We published a book,[8] and I continued conducting fieldwork in the project *Stadtteilmütter in Neukölln* (engl. Neighborhood Mothers in Neukölln), where most of the initial workshop participants worked.

Photograph by Paulus Ponziak (2016).

Book cover *Hausmittel aus aller Welt* ("Home remedies from around the world"), Essen: KVC Verlag (2016).

All of these experiences and different perspectives formed a "patchwork" that largely informed the co-creation of a new workshop concept. I use the term "patchwork" to acknowledge its very composite form while preserving its legitimacy as a research object.[9] Realizing how inspiring the workshop was for people who rarely have the possibility to talk with a professional about their experience, we conducted further workshops with Annette. My simultaneous research on representations of health and healing helped me see that this setting was particularly favorable for the transmission of health-related information. As will be demonstrated in the following sections, the workshop atmosphere and the participants' mutual exchange and sensory experiences also shaped their memory and started processes of self-healing. We therefore decided to introduce a reflexive element on the transmission of information to promote awareness of that factor. And we also created some playful didactic materials reflecting these findings.

Illustration from a matching game made by the (web) designer Alexandra Tiede during the workshop "Picturing Encounters" by the Medienwerkstatt Encounters in Berlin (2019).

Sore throat and german onomatopeia for pain.

Illustration from a matching game made by the (web) designer Alexandra Tiede during the workshop "Picturing Encounters" by the Medienwerkstatt Encounters in Berlin (2019).

"Try lemon wrap".

Illustration from a matching game made by the (web) designer Alexandra Tiede during the workshop "Picturing Encounters" by the Medienwerkstatt Encounters in Berlin (2019).

Joint pain and Polish onomatopoeia for pain.

Illustration from a matching game made by the (web) designer Alexandra Tiede during the workshop "Picturing Encounters" by the Medienwerkstatt Encounters in Berlin (2019).

"Try cabbage wrap" (translated from Polish).

I consider the *Mamacura Workshops* as a space of experimentation and research that counterbalances some of the pernicious effects of neoliberal politics including the promotion of the industrialisation of healthcare and ecologically questionable healing practices.

As a process of "collaborative problem-solving involving empowered stakeholders in civil society", the *Mamacura Workshops* propose a space of "win-win" exchange for research and the public. They foster a "symbiotic transformation" that responds to the aporia concerning ailments in relation to chronic so-called 'civilisation diseases' such as diabetes or cardiovascular diseases.[10] Using scientifically approved home remedies is an efficient and cheap way of preventing disease and optimising the effects of concurrent biomedical therapies.

"More open-ended experiments are possible if anthropologists team up with innovative researchers in biomedicine to develop new conceptual models and to adopt novel observational techniques and 'smart' trials that incorporate ethnography to unravel complex interactions between local biologies, attributes of health systems, social infrastructures, and users' everyday lives."

Anita Hardon, Robert Pool: "Anthropologists in Global Health Experiments", in: *Medical Anthropology* 35/5 (2016), p. 447.

Hardon and Pool propose anthropological methods for "breaking the hegemony of randomized controlled trials in designing global health technologies" and unravel the "complex interactions" in global health.

FIELDWORKING "Fieldworking"

During my presentation at the Radical Health Conference,[11] Dirck von Bekkum expressed enthusiastic support for this experimental format of doing applied anthropological research. He is an anthropologist working as a group therapist, educator, and artisan in a clinical setting. In a recent publication, he suggested a conceptual framework ″to encompass both analytical and applicable knowledge and skills in clinical settings″, which he terms ″fieldworking″.[12] In this section, I illustrate how the *Mamacura Workshops* also require ″fieldworking″. In addition to the methods normally used for ethnographic research that led to the *Mamacura Workshop* concept, I use participant observation and notes during the workshops themselves to trace the relevant content and conduct an ″instant″ analysis of the data. The participants are aware from the start that the data will be used for research purposes. These notes and observations are systematically reflected in the second part of the workshop in order to emphasize the context of communication to convey healing information. In a ″learning by (consciously) doing″ process, the participants develop an awareness for and actually initiate a process of self-healing (see next section). This is jargon for research purposes, but during the workshop, I illustrate these principles by means of examples from the same or previous workshops.

The second part then unfolds as a documented group discussion in which participants reflect, remember, and resonate with each other in a variety of ways: orally, in writing, through drawings, active listening, or by even just being there. Bodily communication conveys insights as well. The participants' body language and facial expressions add nuance to their responses, and so does their silence. In some instances, these forms of expression may motivate but also discourage further discussion. Such a workshop dynamic requires what Koss-Chioino calls ″radical empathy″ – an essential element of any healing process.[13] Through the simultaneous exercise of communication and instant documentation, I aim to practically highlight a healing principle that can be conveyed together with kitchen remedies. The workshop promotes proximity and draws attention to the mutual dynamics of communication through which a process of (self-)healing can be put in motion.

This bridge-building workshop between health care and research – conceptualized as ″fieldworking″ – is therefore an interesting tool of analysis for further research and professional activity inspired by anthropological methods.

Drawing on his experience in clinical settings, van Bekkum argues that ″the moments of healing and transformation in divination rituals resemble (...) the practice of co-creating transitional spaces and communitas in therapeutic and educational contexts″.[14] In the next section, I illustrate how such a liminal space for healing is also co-created during the *Mamacura Workshops*.

FIELDWORKING Mamacura's Liminal Space

The *Mamacura Workshop* is a place of horizontal communication into multiple directions and a bottom-up as well as top-down visible, audible, but also invisible and inaudible, active or passive but always relevant exchange between professional experts and amateur researchers. The workshop is particularly interactive because it deals with experiences that are relevant for all involved persons. According to Beccy Blow's critical analysis, the essential criteria for empowerment structures, especially for adults with learning challenges are a meaningful dialogue, giving voice or decoupling power, and the need of control.[15] According to these criteria, the *Mamacura Workshop* can be considered empowering, especially for participants whose first language is not German.

Expert jargon needs to be adequately explained, illustrated, or simplified in order to be applied and used by non-professional participants. It also needs constant updating. This is an opportunity, especially for non-native speakers, to improve their language skills by learning fundamentally useful vocabulary and engaging in cultural exchange in a group setting. Therefore, the speaker or moderator should first assess whether the audience is puzzled by the vocabulary used and, consequently, either directly ask questions on the topic, spontaneously rephrase, or offer a translation into the appropriate language.

Awareness of the many possible customs and habits of the participants and empathetic adaptation to one's sensibilities and expectations transform a possible communication challenge into an opportunity for exchange.

"Ritualised" as such, the transmission of information takes place as much through form as through content. When this is done with respect and patience, as well as an interest in language, cultural exchange, and learning, one can observe that trust and a sense of security develop throughout the workshop. Such an atmosphere promotes positive peer dynamics and the co-creation of a safe and inspiring "liminal" learning space.

The specific worth of the *Mamacura Workshops* lies as much in their content as in the way they foster the encounter with intimately lived experiences. For it is precisely the sharing of these experiences that holds great potential for the transmission of health-related information and that is crucial for initiating a healing process. Throughout the workshops, I have received comments on the overwhelming health information in other realms and its possibly confusing effect on laypersons. Some try out what they read on their own and share their successes and failures with their peers, but the supportive group dynamic and direct access to a validating authority increase accountability and, therefore, levels of (self-)confidence. In that sense, peer dynamics increase the chances of successful "help for self-help". Moreover, the very moment of encounter itself in this ritualized liminal space can already have healing effects as well – healing effects that occur through "psychosocial mobilization of the patient's biochemical response system" or by virtue of the placebo effect because "meaning mends" and "metaphors heal".[16] In this sense, the workshops represent a space of "connection to a transcendent reality, which enables an open, loving and empathetic attitude" that is so relevant for healing dynamics.[17]

FIELDWORKING Vignettes Of Changes

I will now illustrate some transformative processes through vignettes of four participants I was able to follow over the years. Three of them had already participated in the initial workshops during the exhibition, and I met them again during my fieldwork one to three years later. To protect their privacy, their names have been changed. I first mention my own experience throughout these years.

Caroline

Starting with my own personal experience, I was diagnosed with the skin disease psoriasis around the age of ten. When the workshops started, I was gradually losing my mother, and my marriage was falling apart. So I developed flare-ups all over my body. I looked sick, and I knew I had to have heavy corticosteroids or anti-mitotic treatments if I wanted my skin to be healthy in the short term. But this would not cure the disease, and I would still have to rely on treatments and endure their side effects just to look normal. This was not an attractive trade-off for me. But thanks to this network, alongside my own fieldwork and freelance activities, I was able to develop my "help for self-help" and by juggling diet, sport, and meditation. I even managed – at times – to have almost completely clear skin for a while. So for me, this represents a very valuable life experience and an awareness that has probably helped me to avoid much more serious physical and psychological problems while coping with profound grief. Nevertheless, my skin health remains a challenge and requires constant care.

Ebru
Ebru was present at the exhibition, and I remember this otherwise quiet woman enthusiastically describing her back exercises during the initial workshop. I interviewed her a year later in the Neighborhood Mothers' shared office. I wanted to know more about her understanding of health and healing and how this was influenced by her work in the project. She was one of the most senior people in the project and employed with the special status of "integration pilot," which allowed her to work in the longer term. Ebru did not remember that we had met a year earlier at the exhibition, and she was more cautious and reserved than the other women I had interviewed. In any case, she explained to me her life trajectory from Turkey to her marriage in Germany, to her daughter, the stressful years of looking for a job, and the exhausting shifts working as a cleaning lady. She told me that she did not eat properly and developed diabetes, just like her mother. Working as a Neighborhood Mother meant a great improvement in her lifestyle, however, as this enabled her to have a calmer and more regular daily routine. Although she expressed satisfaction with her work, she could not consistently combine it with her sports, family duties, and health habits. In addition to taking prescribed medication, she mostly looked for remedies on the internet and tried them out before eventually sharing them with friends. We met a year and a half later in a park for a second interview, and this time the conversation was relaxed and more friendly. She expressed some difficulty in reconciling her dietary needs with the demanding mobility that home tutoring requires. She felt that she could not achieve a healthy work-life balance.[18]

Emeline
Emeline's interventions in the workshops were very lively, and Annette and I were fascinated by the way she shared with us the many health-promoting uses of shea butter. I realized through the project's fieldwork that our three workshops were part of the basic training that the Neighborhood Mothers were receiving for their qualification, which might be one reason for the first participants' enormous interest in them. A year after our first encounter, I interviewed Emeline. She told me about an experience she had had with her children which illustrates the importance of the project's contribution to the construction of symbolic systems – in Bourdieu's terms – through a complex process that is also related to the children's school. Emeline was 38 years old at the time of the interview and had arrived ten years earlier from Burkina Faso. For her, wellbeing plays a central role as a reference point for her food choices. She grew up in a family where money was scarce, but freshly prepared food was always available. Her mother ran a small food stall for a living. When Emeline emigrated to Germany with her sons, she was suddenly able to afford all the manufactured goods she had previously considered luxuries. At some point, however, her son developed tooth decay, whereas she had never had such problems. Therefore, she decided to avoid "sodas and sweets", as they recommended in the project and as she herself had grown up, but despite all her explanations, her son was reluctant to adapt his habits. This changed only when his teacher asked him about the food pyramid, and he was the only one who knew this concept. She told me:

> "And the teacher says: 'hey how come?!', 'yes my mother works as a Neighborhood Mother and at home we pay attention to that' [...] and then he was so proud [...] he says: 'Mummy look! Today at school I was the best!'" [laughter].

In fact, Emeline's son was so proud that it motivated him to uphold this self-image in class, and he even assisted his mother by convincing his younger brother to follow the same path. All in all, the workshop thus helped Emeline rediscover and implement healthy eating habits in her new environment that were also beneficial for her children's dental health.

Irina
Another participant, whom I met twice during this connection between the WEB and the Neighborhood Mothers, was Irina. I vividly remember her telling us about the virtues of the many special berries she used to pick with her father in Latvia or about the virtues of the Russian sauna. I met her again three years after the first workshops. At first, it was hard to recognize her. She looked very different. She used to wear a veil but now had a Mohawk haircut and wore tight clothes. She lived with a large female pitbull. The forty-year-old woman had come to Berlin twenty years ago after becoming pregnant. Her family was doing well, but at some point, her husband began to develop fundamentalist Muslim ideas. Their relationship became increasingly conflictual, and they separated. Without her consent, he decided to keep the four children with him. At this point, she started working as a Neighborhood Mother, but could not find families who spoke the same language as her and had to stop. Although she had only worked for the project for a few months, when we met two years later, she still had the full range of project brochures and leaflets on her shelf and used project-specific vocabulary such as the 'bricks' for the body parts and the 'food pyramid'. For her, the project was a way to help herself in a situation of lack of trust in German institutions, and she welcomed me as an "angel" who supported holistic and preventive approaches to health, as she was disappointed with medical help in Germany compared to Latvia.

These four vignettes show the *Mamacura Workshops*' influence on the participants' life course. My personal and professional interest in complementary, holistic approaches to health and the migration experience guided my research. Ebru was on the way to achieving a work-life balance. Emeline rediscovered her healthy eating habits, and Irina collected material for her support. This matched with our priorities: I continued to develop the concept of the workshop; Ebru felt that she lacked quality time for herself; Emeline's awareness triggered her son's change of perspective toward junk food; and Irina developed coping strategies in a particularly difficult phase. The awareness of our symptoms inspired us to act: In Emeline's and my case, the wellbeing of loved ones was of great importance, as was the possibility of remembering one's optimal state of health and the means to achieve it. The story of Emeline's son further showed how mindsets are directly or indirectly influenced by peer dynamics and how important congruent information from trusted sources is. Irina welcomed our interview as an invitation to revive her knowledge on Latvian practices of health prevention. But Ebru could not yet achieve the work-life balance that she felt was necessary for a healty diet. The four lived experiences highlight how networking through *Mamacura Workshops* can create, motivate, maintain, or develop awareness and give impetus to the possibilities of help for self-help through cheap, effective, and affordable kitchen remedies. Furthermore, autoethnographic methods enabled participants to reflect on and analyse their own use of kitchen remedies in their particular contexts. As this shows, these methods constitute a useful means for participatory research in the context of citizen science and for the co-creation of research objects together with medical professionals.

The insights gained through such methods productively contribute to the research. More than that, however, the research participants benefit from them inasmuch as they help them rediscover and develop particular health-related knowledge and skills throughout the process.

FIELDWORKING Perspectives

The participant observation conducted among the Neighborhood Mothers in Berlin-Neukölln over a period of three years and our ongoing exchange through the *Werkstatt Ethnologie Berlin* and the *Mamacura Workshops* have shown how the influence of the workshops fits in with the participants' life course according to their priorities and (bodily) awareness. It became clear that mindsets were directly or indirectly driven by peer dynamics and that the transmission of congruent information from different trusted sources is of utmost importance.
This research led to a "fieldworking" method for empowerment through supporting help for self-help strategies: an empowering secular ritual that disrupts the content-oriented circulation of information and offers a common lived experience focused on self-help through efficient, cheap, and accessible kitchen remedies as well as a space for translations and inspiration.
The *Mamacura Workshops* propose an encounter and a complementary approach for health promotion as well. Sherry Ortner cited Arjun Appadurai's call for anthropologists "to be mediators, facilitators, and promoters of the ethics of possibility". In a broader sense, the *Mamacura Workshops* also constitute a form of the "anthropology of the good" that promotes "the ethics of possibility, which can offer a more inclusive platform for improving the planetary quality of life".[19] Both approaches can be viewed as public anthropology that promotes exchange between researchers and the public.
Further research and workshops focused on ailments in the early stages of life or pregnancy would be interesting to explore. Equally, an exchange on the experience of aging could be beneficial to the general public. With these ideas in mind, I am currently exploring the possibilities of expanding the scope of this research, incorporating more co-creative methods offered by citizen science, and integrating the workshop context in the German preventive health system.

Notes

1 "Nicht ein 'Erkenne die Kosten', sondern die alte Weisheit vom Apollon-Tempel in Delphi 'Erkenne dich selbst' – an jeden von uns gerichtet – wird uns helfen, die Zukunft der Gesundheit und die Zukunft der Menschheit langfristig zu gestalten.", in: Dietrich Grönemeyer: *Medizin verändern*, München: Ludwig Verlag (2022), p. 10.

2 *Werkstatt Ethnologie Berlin*, https://werkstatt-ethnologie.de.

3 For more information on the workshops, please see: Caroline Contentin, Annette Kerckhoff: "Kitchen Remedies from Around the World", in: *Medienwerkstatt Encounters*, https://www.encounter-blog.com/en/household-remedies-from-around-the-world/.

4 The "Neighborhood Mothers" are mothers with an experience of migration who receive a specific training to work as mediators for families who have newly arrived in Berlin and speak the same native language. They give advice and support on child health, parenting, and administrative challenges relating to family life with children up to twelve years old; Senatsverwaltung für Bildung, Jugend und Familie: "Landesprogramm Stadtteilmütter", https://www.berlin.de/sen/jugend/familie-und-kinder/familienfoerderung/stadtteilmuetter/.

5 Dirck van Bekkum: "Being Moved Together during Co-Creating Transitional Spaces: A Navigated Quest in the Borderlands of Pluralistic Healing and Therapeutic Contexts", in: *Curare* 42/3+4 (2019), pp. 131–144.

6 Joan D. Koss-Chioino: "Spiritual Transformation, Relation and Radical Empathy: Core Components of the Ritual Healing Process", in: *Transcultural Psychiatry* 43/4 (2006), pp. 652–670.

7 Caroline Contentin el Masri, Elisabeth Hirsch: "Sibyllenwurz und Speisedampf: Bericht über die Ausstellung der Werkstatt Ethnologie Berlin vom 23.04.2012–01.05.2012", in *Curare* 36/3 (2013), pp. 180–186.

8 Annette Kerckhoff, Caroline Contentin el Masri: *Hausmittel aus aller Welt*, Essen: KVC Verlag (2016), https://kvc-verlag.de/buecher/naturheilkunde-fuer-zuhause/213/hausmittel-aus-aller-welt.

9 Günel Gökçe, Saiba Varma, Chika Watanabe: "A Manifesto for Patchwork Ethnography", in: culanth.org, Member Voices, Fieldsights, https://culanth.org/fieldsights/a-manifesto-for-patchwork-ethnography (9 June 2020).

10 Eric Olin Wright: *Envisioning Real Utopias*, London: Verso (2010), pp. 252–253.

11 https://nomadit.co.uk/radical-health/ (2021).

12 Dirck van Bekkum: "Being Moved Together during Co-Creating Transitional Spaces: A Navigated Quest in the Borderlands of Pluralistic Healing and Therapeutic Contexts", in: *Curare* 42/3+4 (2019), pp. 131–144.

13 Joan D. Koss-Chioino: "Spiritual Transformation, Relation and Radical Empathy: Core Components of the Ritual Healing Process", in: *Transcultural Psychiatry* 43/4 (2006), pp. 652–670.

14 Dirck van Bekkum: "Being Moved Together during Co-Creating Transitional Spaces: A Navigated Quest in the Borderlands of Pluralistic Healing and Therapeutic Contexts", in: *Curare* 42/3+4 (2019), p. 2.

15 Beccy Blow: "Empowering to Disempower: A Dilemma When Working with Adults with Learning Difficulties", in: *Anthropology Matters* 10/1 (2008), p. 19, https://www.anthropologymatters.com/index.php/anth_matters/article/view/43/80.

16 Daniel E. Moerman et al.: "Anthropology of Symbolic Healing", in: *Current Anthropology* 20/1 (1979), pp. 59–80, https://www.journals.uchicago.edu/doi/pdf/10.1086/202203; Sjaak van der Geest, Susan Reynolds Whyte, Anita Hardon: "The Anthropology of Pharmaceuticals: A Biographical Approach, in: *Annual Review of Anthropology* 25 (1996), p. 167.

17 Barbara Stöckigt, Florian Besch, Florian Jeserich, Christine Holmberg, Claudia M. Witt, Michael Teut: "Biographical Similarities between Spiritual Healers and their Clients in Germany: A Qualitative Study", in: *Anthropology & Medicine* 22/2 (2015), p. 177, https://www.anme-ngo.eu/images/cie/studien/Qualitative_study_Shamanism-spiritual_healers_2014.pdf.

18 Neighborhood Mothers are initially trained for five to six months on topics such as pre-school development, bilingual education and health care, and then pass on information and support to newly-arriving families speaking the same language. For this purpose, they organize ten meetings at the family's home, which means that they have to move around the neighborhood all day.

19 Sherry B. Ortner: "Dark Anthropology and Its Others: Theory since the Eighties", in: *Journal of Ethnographic Theory* 6/1 (2016), p. 65.

Tyyne Claudia Pollmann

INDISCIPLINARY MATTERS Elsewheres & Elsewhats

I would like to thank the *Radical Health* editorial team for offering this experimental format and for creating the opportunity to extend the transdisciplinary exchange that was initiated among some participants during the *Radical Health* conference at Freie Universität Berlin in 2021.[1] This contribution evolved from the conference panel *Suffering and Well-being in Regimes of Subordination*. Instead of uploading my conference contribution to *Made in academia*,[2] I decided to disclose background dichotomies prevailing in academia, introduce a concept of joint artistic knowledge productions, and create a hybrid discursive/non-discursive assemblage that makes the discussed topics tangible and multimodally accessible. I am excited about intercom's *cache* concept, which allows for the inclusion of previously neglected perspectives, matters, and perceptions that will emerge through "polyphonic perspectives" on phenomena that transgress disciplinarity. "Polyphony" indicates that not only one voice shall be articulated, while the "perspectives" imply multiple vantage points, announcing that a universal gaze shall not take place. The concept of joint artistic knowledge production is the outcome of a particular way of thinking and perceiving reality. It calls for new ways of writing.
I will use the footnotes as a space for new threads of transdisciplinary engagements on issues that cannot be elaborated on but are inextricably intertwined with the matters at hand. With an artistic (fine arts) and scientific (medicine) background, I have been performing artistic research projects since 2008 and have held a hybrid artistic-scientific professorship for anatomy and morphology at the weißensee kunsthochschule berlin (khb) since 2013. Working in the fields of artistic non-discursive knowledge production and drawing on my experience in clinical research, my thinking and writing may not always follow the rules of discursive writing and might appear unconventional to some recipients.[3]

Artistic Indisciplinarity. The rough ground of knowledge production is fragmented into territories with inscribed property claims. At their fraying edges, a plurality of transdisciplinary and bridging fields of study has recently emerged that at first glance seems to blur borders. Instead, these fields disclose neglected connections and entanglements that in turn reveal the complex structures of knowledge production. One of them is artistic research.

"If 'art' is but a mode of perception, 'artistic research' must also be the mode of a process. Therefore, there can be no categorical distinction between 'scientific' and 'artistic' research – because the attributes independently modulate a common carrier, namely, the aim for knowledge within research. Artistic research can therefore always also be scientific research. For this reason, many artistic research projects are genuinely interdisciplinary, or to be more exact, indisciplinary."

Julian Klein: "What is Artistic Research?", jar-online.net (23 April 2017).

George W. Ladd: "Artistic Research Tools for Scientific Minds", in: American Journal of Agricultural Economics 61/1 (1979), pp. 1–11; Ross Birell: "Jacques Rancière and the (Re)Distribution of the Sensible: Five Lessons in Artistic Research", in: Art & Research 2/1 (2008), pp. 1–11.

Artistic research is not a field of knowledge production that aspires to become included in the mainstream of scientific knowledge production that adheres to certain predefined rules and regulations and fabricated territories, claiming to produce objectifications and generalizations and thus allowing for only certain methods, languages and topics to be included. In contrast, art comprises a field of practices that, regardless of their medium, create local and temporal strategies that unfold their impact in the particular and probe into all areas of the real. Following Mersch, art is not ″about identity productions in the sense of repeatability or the finding of a causal nexus that explains the experiments performed″ but about a specific form of what he calls experimental reflexivity that takes place in the sensuous, not in the semantic field. ″Conjunction and intervention – to pick only two examples of experimental reflexivity – function as ′aesthetic arguments′ that are in no way inferior to discursive argumentation in their justification and validity″.[4]

Transdisciplinarity. Transdisciplinary setups only work if they do not strive to harmonize their different perspectives and working modes of knowledge production. The more clearly the heterogeneous approaches remain visible, the more distinctly their congruencies, synergies, contradictions, and blind spots can be detected.

″Art traverses the concepts, ′mixes them up′, debalances their structure, drives them into contradictions in order to exhibit precisely that which cannot be captured by them, as equally its subject is the unrepresentable, the excluded or the abandoned, which denies any canonization.″

Dieter Mersch: ″Kunst als epistemische Praxis″, in: Elke Bippus (ed.): *Kunst des Forschens: Praxis eines ästhetischen Denkens*, Zürich, Berlin (2009), p. 38.

″Transdisciplinarity has emerged over the last few decades as an attempt to address disciplinary fragmentation. It presents an alternative to the paradigm of simplification, reduction and disjunction, taking on the challenge of complexity and proposing to connect and contextualize knowledge. [...] It also tackles problems that have historically not been addressed because they are blind spots in disciplinary discourse, living in between disciplinary perspectives, or are simply considered too large to be addressed by hyperspecialized researchers.″

Alfonso Montuori, Gabrielle Donnelly: ″The Creativity of Culture and Culture of Creativity Research: The Promise of Integrative Transdisciplinarity″, in: Vlad Glăveanu (ed.): *The Palgrace Hand-book of Creativity and Culture Research*, London: Palgrace Macmillan (2016), pp. 743–756.

Artistic research has the potential to counter established procedures and their theories while allowing for the exploration of new and as of yet unestablished methods and informal investigations. In this way, it enables the production of alternative futures of knowledge production. According to Sauvangnargues, Deleuze perceives artistic activity not as a production of aesthetic forms but as capturing the forces that permeate our bodies and societies. The assembling, disclosing, and displaying of these forces allow intensifications, subverting stereotypes and clichés, thus unleashing political power through the artwork. This is the reason for the interest in artistic research from other research fields but also for the challenges of transdisciplinary projects.

″But the image is not a statement and, according to Deleuze′s distinction, requires semiotics and not semantics, that is, a theory of non-discursive signs that is not content to duplicate the rhetoric of signification or to imitate linguistic operations. Semiotics defines itself as a system of images and signs independent of language in general. Hence the difficulty of an analysis of the non-discursive arts, for it is necessary to learn in discourse what is not derived by it, and to extract thought from a signaletic, non-linguistic matter that is nevertheless not amorphous but semiotic.″

Anne Sauvagnargues: *Ethologie der Kunst: Deleuze, Guattari und Simondon*, Berlin: August (2019), p. 12. Authors′ translation.

Elsewheres. We learn, speak, think, analyze, feel, and develop ideas and methods in everyday settings and in a wide variety of situational environments. The basic production of human knowledge does not take place in any scientific field; life is a multimodal adventure.
This means that the content negotiated in discursive texts is not of a discursive origin. The selected data that is extracted from *Elsewheres* must be trimmed and translated, morphing into something else.[5] It still appears to be the pretension that discursive texts are plotted along a linear sequence of terms and proceed according to a stringent logic that needs to be followed for them to be classified as scientific.[6] Meanwhile, the so-called ″hard sciences″ research a wealth of non-discursive matters,[7] engaging all possible fields of sensory detection, acquisition, recording, transmission, formulation, and transformation. Multimodal settings not only illustrate or depict matter and their interconnections but detect new findings, generate new visions, install new solutions, and elicit new understandings of the investigated matters from *Elsewheres*. But, as Karen Barad points out:

″A performative understanding of scientific practices, for example, takes account of the fact that knowing does not come from standing at a distance and representing but rather from a direct material engagement with the world.″

Karen Barad: *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*, Durham, London: Duke University Press (2007), p. 49.

Moreover, philosophers – some with scientific backgrounds like Karen Barad (quantum physics) and Donna Haraway (biology) – generate new ways of ontoepistemological knowledge formations that transcend the outdated notion of science that underlies discursive textual production.

Elsewhats. The discursive/non-discursive dichotomy is usually based on the saying/seeing dichotomy.

″I want to encourage doubt about [the] presumption that representations (that is, their meaning or content) are more accessible to us than the things they supposedly represent. If there is no magic language through which we can unerringly reach out directly to its referents, why should we think there is nevertheless a language that magically enables us to reach out directly to its sense or representational content? The presumption that we can know what we mean, or what our verbal performances say, more readily than we can know the objects those sayings are about is a Cartesian legacy, a linguistic variation on Descartes' insistence that we have a direct and privileged access to the contents of our thoughts which we lack towards the 'external' world.″

Joseph Rouse: *Engaging Science: How to Understand Its Practices Philosophically,* Ithaca, New York: Cornell University Press (1996), p. 209.

Saying refers to language and seeing to visuality.[8] These channels feed semantic and semiotic enquiries, but we do not only say and see through a narrow slit of rationality. In addition, three other linguistic dichotomies introduced by Foucault create new distinctions:[9] The said/unsaid, the sayable/unsayable, and the to be said/not to be said. They assign new divisions to the "unsaid" between the possible/normal/permitted and the forbidden/concealed/abnormal.[10] The segregation of the senses – the visual, the auditory, the olfactory, the gustatory, the sensual/haptic – and their dumping into the vast, vague realm of the non-discursive, where further significant, indeterminate (and possibly indeterminable) conglomerates of intentions, desires, emotions and affects mingle, is opposed to the narrow discursive space, which appears as a clean transparent cube of cognitive deciphering of what has been pruned to fit the apparatus/dispositive/default. The realm of the non-discursive can apparently only be described as the negation of its counter-image, the discursive. Incorporating the input of our multimodal senses into studies to approximate the range of our perceptions that shape our creations might open new channels for this negated, unspecified residue of *Elsewheres* and *Elsewhats*.

Art and Science. A critical approach questioning the roots and prerequisites of science as well as art is necessary, as both fields of knowledge production have been (and still are) causing the exclusion of various forms of scientific and artistic activities. Cultural and scientific embodiments drag along their embeddings that go back centuries, containing suppressed, toxic, avoided, or omitted matters. This uncanny appendix of the tip of the iceberg turns out to be the gravity center of our own making, and it requires a reappraisal of its manifold ramifications. A joint, trans- or even indisciplinary approach, based on mutual acceptance of different perspectives and thus preserving the polyphony of different voices, will enable new insights to our complex worlds.

"The word I would use is 'perspectivism', different nomadic viewpoints from equally materially embedded and embodied locations, expressing the degree and quality of experience of different subjects. We need to acknowledge the multiple and internally contradictory aspects of our own knowledge practices by adopting a diversified materialist approach, which I would propose as the antidote to relativism."

Rosi Braidotti: "Posthuman, All Too Human: The Memoirs and Aspirations of a Posthumanist", in: *The Tanner Lectures on Human Values*, Yale University Press (2017), p. 43.

INDISCIPLINARY MATTERS visions4people

The artistic research project *visions4people – artistic research meets psychiatry*, a cooperation between the weißensee kunsthochschule berlin (khb) and the Department of Psychiatry and Neurosciences at the Charité Berlin Mitte, was carried out with students and people from psychiatric wards from 2016–2018.[11] The project was originally designed as an artistic educational endeavor, but it soon challenged basic assumptions and routines of thinking and acting. The course members were students from eight art and design disciplines, gathering empirical knowledge on site in direct exchange with the patients of the psychiatric clinic. The people – namely, the patients – were our most important communication partners. These interactions were the starting points for visions that were transformed into artistic or participatory designs, intending to positively contribute to the recovery process.

It would exceed the scope of this chapter to recount all events and steps of this two-year project. The publication *visions4people* contains original narrative excerpts, qualitative analysis, and nineteen artistic results as well as all 28 practices that emerged during the project.[12] Here, I will focus on experiences that generated a significant impact on my own interactions with students and on my work in academia. We learned from the patients that they had repeatedly been the subjects of studies, but no outcome had so far changed their situation. Therefore, they refused to fill in our questionnaires or to follow prefabricated tools and preferred instead to communicate freely. We agreed, started an open conversation, and thus left the investigator-investigated dichotomy with its hierarchical interrogator-respondent dialogue divide. Therefore, we did not collect data and did not write reports but rather started to write narratives from the first-person perspective, which were open to include all events and perceptions that appeared important during our meetings.
These "scape research narratives",[13] created by all course participants, generated multiple perspectives on one event, revealed our different sensitivities and assessments of situations. The polyphonic joint analysis of these events was of great value especially for coming to terms with conflictful situations. The lively, intense exchange with the patients extended into artistic collaborations and culminated in the idea of expanding the project and implementing a concept in which the patients would get the leading role for developing improvements in psychiatry. The extension for *visions4people* was unfortunately not granted.
visions4people taught us that an informal and direct exchange with the affected people might provide developments unforeseen at the time of the project proposal that will remain neglected if a design-modification cannot take place during the course of the study. It is an example of an open-ended procedure which can be adjusted to the realities in the field. Another outcome was the insight that research projects usually perform data extraction but leave the situation on the ground unchanged and that participation remains mere lip service if the participating party is not included in the decision-making processes. The effect of data collection appears questionable if concepts for remedying malpractices are not even considered. "From being affected to getting involved" summarizes a conclusion that applies not only to patients, nurses, therapists, researchers, and physicians in the field of psychiatry but to the vast field of academia. Being affected is the first impact of becoming aware of difficult situations, but cyclic research structures that include an exchange between the affected parties and the researching people on equal footing is needed to develop appropriate research results and possibilities for change.

From visions4people to Academia. The experiences and outcomes from visions4people proliferated into academia and provoked the following questions: If its institutions were made for students, why do they not share the power of decision-making processes? Who is making the decisions? Do the course contents and methods we teach include the constantly adapted awareness of actual developments, conflicts, desires? Do we teach how to learn? Why don't we learn how to learn – in a constant joint process? Learning structures are made: They can change.
These questions led to a new concept of joint learning and knowledge production and replaced the dichotomies of teaching/learning or teacher/student that fix the teacher in the role of a supervisor or instructor who charges the student's minds with narrow tasks[14] or even worse, with the teacher's own narrow viewpoints, reiterating a gaze on the topics that restricts new perspectives and new forms of exploration, stabilizing the status quo. Instead, the concept for joint knowledge production outlines a practice of joint learning: the course initiator generates a range of sources in which students and the initiator can roam, explore and discover various perspectives, create new ones, and decide on the contributions they want to develop.[15] All participants work along the lines of "sympoiesis," which might be translated as "making-with":

"*Sympoiesis* is a word proper to complex, dynamic, responsive, situated, historical systems. It is a word for worlding-with, in company."

Donna Haraway: *Staying with the Trouble: Making Kin in the Chthulucene*, Durham, NC/ London: Duke University Press (2016), p. 58.

By creating a common ground on equal footing, the teaching-learning activity can become a joint performance of knowledge production.[16]

Making and Perceiving Art: Immersion. For each course, I prepare a wealth of nondiscursive, discursive, and scientific input around a certain complex topic including different media. While exploring the scape together, the students and I form an interconnected responsive environment that attends to non-discursive, discursive, and scientific material. While the participants share their research, new important aspects surface. As making art is a non-discursive activity, a realm of diverse non-discursive outcomes are produced and discussed in the group. With the following examples, we leave the discursive realm and enter a space of multimodal presentations that activate a spectrum of additional channels of reception: signs, signals, constellations, narrations, and associations will oscillate between the work and recipient. Once included in a publication, forms, colors, sounds, moving images, and their plural entanglements and associations will unfold, bringing in their own logics of content, form, and perception and thus producing complex changes and impacts on the reception process. As a multimodal contribution is delivered simultaneously by multiple sensory organs, the mediation initiates physical, emotional, aesthetic, and cognitive input. The recipients are no longer readers or spectators or listeners but all of these in one. Modes of access that were excluded from discursive text conventions (which focus on cognitive perception and were created to reject other channels of perception) will reappear in a multimodal presentation. I decided to present videos as they emphasize this fundamental change of perception. And furthermore, the plurality of input caused by the perception of non-discursive material evokes another effect that is deliberately avoided in discursive engagement: immersion.[17]

"Meaning is not a property of individual words or groups of words but an ongoing performance of the world in its differential dance of intelligibility and unintelligibility."

Karen Barad: *Meeting the Universe Halfway. Quantum Physics and the Entanglement of Matter and Meaning,* Durham & London: Duke University Press (2007), p. 149.

Affective, emotional, cognitive, sensual, and physical activities are initiated, as the recipient experiences a fundamentally different form of perception. In my experience, the acceptance and introduction of immersive multimodal perceptions and the discussion of their effects evoke new aspects that now have emerged.

Artistic research practice. My courses are based on the approach of mutual learning and creating a shared, transdisciplinary, multidimensional, and polyphonic space in which students and I exchange perspectives while we are experimenting and producing together. The course topics develop successively from the experiences of the previous courses and are the outcomes of our joint activities that inspire new explorations for the following course, creating a continuous flow of artistic exploration and knowledge production.

INDISCIPLINARY MATTERS Senses of Detachment – Prospects for Change

This course took place during the first online Corona semester with students from the second semester of their studies, which fortunately meant that they had already met during the previous face-to-face semester. The course focused on the alarming global spread of COVID-19, which by then had spread to 187 countries and had led to a lockdown of more than half of the world's population.

In *Senses of detachment – Prospects for change*,[18] we looked at three crucial areas: a) medical knowledge and health procedures and their uncertainties, b) societal, social, political, economic, and ecological impacts and their disintegrations, and c) possible post-pandemic visions for social restructuring or structuring anew.

Our working methods were severely limited, and communication and collaboration were only possible via online platforms. Being confronted with this additional actant for the first time we sought to explore positive aspects of this inevitable condition.

The online mode enabled students who were stuck in their home countries or who were sick to still participate. Our activities consisted of group meetings, subgroup discussions, performances and surveys, and the students participated in online social dreaming sessions offered by Duke University. By sharing ideas and creating ways of cooperating online in an artistic manner, a lively exchange developed, and joint contributions were created.

Still from Johanna Hemming and Mathis Ekelmann, "Pandemic Dreaming" (2020). VIDEO ▸cache.ch/1712

Inspired by social dreaming, Johanna and Mathis created an online call for notes of dreams and used the input as starting points for their video Pandemic Dreaming. Here, video and animation sequences refer to the dreams while voices read out original anonymous text passages that were sent in. The auditory and visual input reveals a non-cognitively guided plausibility or logic that spreads from text to image and enables the recipient to immerse in a flow of Pandemic Dreaming.

INDISCIPLINARY MATTERS Human Subjects

The course title refers to the human matters (topics or subjects) that emerged during the year 2020 but also to human subjects as being both initiators and victims of their anthropocentric makings.[19] At the heart of the project were seven bilingual questions offering open text fields for students to anonymously comment on 'the year 2020', a deliberately vague term, to enable a wide spectrum of responses. I compiled all answers in alphabetical order and thus created a product called *an-alphabet*,[20] where the bilingual terms popped up in different places, although meaning the same, and thus subverted the order.

103 first semester students started the semester in a hybrid mode, but we soon had to switch to a hard, fully online lockdown. Berlin's incidence rates had skyrocketed, and vaccination was not in sight. An unusually high proportion of the 103 students reported being frightened and insecure in the face of the pandemic situation.

Artistic work is intensively concerned with space, material, and media, all of which were now missing: the students worked with anything they could find in their flats. Despite the multitude of political and socially explosive topics that were mentioned in the an-alphabeth, the artistic contributions mostly referred to the students' own states of mind during the lockdown. Below, you will find two videos as examples; both works were produced during the hard lockdown in the artists' own apartments.[21]

Still from Joe Kotteck, "You on me for yourself" (2020/21).
VIDEO ▶ cache.ch/1707

In this untitled black and white video, the protagonist's hands perform an improvised choreography which is accompanied by music in front of a black background, where the cautious and tender movements of the hands touch only themselves. The sensitivity of the scene in its harsh reduction, accompanied by spherical music, oozes an eerie, ominous, and unsettling atmosphere.

Still from Charlotte Brandhorst, "Ich bin Zuhause!" ("I am at Home!") (2020/21). VIDEO ▶ cache.ch/1708

The camera shows a narrow section of the artist's apartment: a table and the wall behind it. Sounds indicate that the protagonist has entered the room and has begun to prepare an espresso. The activity of this everyday event, performed wordlessly with sparse facial expressions, becomes increasingly bizarre. The film emits an intense and tense atmosphere that could be a mixture of frustration, fear, despair, or defiance. The absurdity of the scene reinforces and simultaneously alienates the recipient from this emotional turmoil.

INDISCIPLINARY MATTERS Zombody

The title *Zombody* is a fusion of rhizome and body.[22] The rhizome is an underground botanical sprout that enables a dispersion of plants that pop up in the next season without being detected by their enemies. Deleuze and Guattari used this phenomenon as a metaphor for an open, subversive, non-hierarchical growing network.[23] The course was our most experimental endeavor yet, and it practiced new forms of open and joint learning. *Zombody* started as a face-to-face course with eighteen students from the winter semester who could now finally get to know each other in person. This happened at a very slow pace at first: the masked students would sit quietly in the studio; you could hear the scratching of a pen. In addition, distancing rules dictated that only 50% of the students could work in the studio together at one time. Nevertheless, as the course progressed, an intensive exchange developed between the subgroups in the studio and during the excursions in outdoor spaces. For the open studio exhibition, a huge joint installation exhibition was planned, including all of the individual contributions, comprising sculptures, photos, paintings, performances, sounds, scents, as well as culinary and numerous interactive interventions. Unfortunately, the open studio exhibition was cancelled. Luckily, however, Franka Ilg's course contribution consisted of film sequences taken during the course: "Making-of Zombody". The audio part included a reading of the *an-alphabet*, created by Mano Leyrado.

Still from Franka Ilg, "Making-of Zombody" (2021).
VIDEO ▸ cache.ch/1709

The video is composed of film sequences that show the making of artistic contributions, while a collage of polyphonic voices read out passages from an-alphabet. The superimposed text passages are quotes from "Call us Zom". The recipients receive input from various sources, which produces an entangled stream of information that allows them to immerse themselves into the scenes from a range of different perspectives.[24]

INDISCIPLINARY MATTERS YOUtopia 41

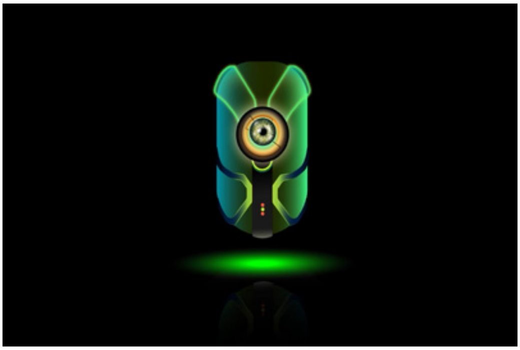
YOUtopia 41 was a project performed by 98 first semester students in the winter semester of 2021/22, offering them the opportunity to create their own individual utopia for the year 2041. The timing – only twenty years later – meant that the near future would be still palpable and could be experienced by the students.[25]

We started the journey to the future by first moving back to the past, watching and analyzing a film that summarizes the past two centuries of fossil resource extraction. Back in the present, we observed our closest environmental structures (such as body parts, clothing, food or furniture...) with microscopic gadgets, which enabled new perceptions of the commonly not accessible structures of common things, making tangible the interrelations between perception, discovery, cognition, and knowledge. The experimental outcomes formed what we called the "Collective Micro Matters Archive".

From here, the students set out to create their own individual *YOUtopia 41* by developing input on a particular topic that had piqued their interest, each choosing modes of transformation that would best suit their ideas. The topics included food scarcity and alternatives, architecture, energy solutions, what home means, nature and pollution, clothes, technical equipment, surveillance, psychotherapy, finances, species extinction, and more. The outcome of this project consisted of drawings, paintings, sculptures, prototypes, storyboards, comics, photographs and collages, videos, installations, performances, music, and combinations of these modes of expression. From the large number of productions, I will present three videos which take different approaches and offer multimodal experiences that elucidate the above-mentioned introduction.

Still from Hippolyte Moulun, ″2041-Capitalist Realism″ (2021/22).
VIDEO ▶ cache.ch/1738

The recipient is a citizen who in the year 2041 has won the lottery and therefore has received the permission to spend a night in the city center, which is otherwise reserved for the elite.



Still from Josua Josua, ″Hello (Downsizing Project)″ (2021/22).
VIDEO ▶cache.ch/1710

In the face of the global climate crisis with the issue of unmanageable energy and pollution, ″Hello″ is a two-minute trailer for a future company that offers a solution to pollution: the Downsizing Project. The subtle and detailed animation oscillates between humorous and sarcastic moments.

Still from Ananda L. Costa and Cora Jarchow, "Bugshake" (2021/22). VIDEO ▸cache.ch/1711

In late December and January 2022, the topics of deep learning, AI, and quantum computers emerged in the course. After the semester had finished, Ananda, Cora and I tested some AI software and created the experimental film *Bugshake*, a seven minute video produced with anonymous contributions from the "Collective Micro Matters Archive", while an AI software transformed the video sequences into audio files. Our team consisted of three human agents and one AI software actant, who now not only helped facilitate but furthermore co-created the production. This fact of co-creation implies a permeation of the borders between human and technological activities, allowing a yet unknown diffusive state of mingled transactions that are no longer separable: a diffused fusion.

The questioning of the human and the technological, the organic and the cybernetic were topics that emerged in YOUtopia 41 and shaped the new project Sci-Fi Anatomies which started in winter semester 2022/23 and was an example for the formerly mentioned continuous succession of artistic research topics. Although I develop topics for each semester, each course provides basic knowledge on specific developments in science and art and encourages students to question established attitudes and routines, experiment with new approaches, accept plural perspectives and voices, and collaboratively take first steps in creating contributions for multidimensional formations of artistic knowledge production.

INDISCIPLINARY MATTERS Unbelongings

In this contribution, I have introduced perspectives and voices from discursive vantage points that approximated the field of artistic research and joint knowledge production and investigated dichotomies that separate discursive from non-discursive activities, creating the terms *Elsewheres* and *Elsewhats*. The two-year cooperation *visions4people* led to the questioning of the investigator-investigated dichotomy with its hierarchical interrogator-respondent dialogue divide. It further proliferated into academia, where the teacher-student dichotomy led to a concept of joint knowledge production. While questioning the discursive/non-discursive dichotomy that underlies discursive conventions, I decided to include video examples that allow the recipients to immerse themselves in the sensual, affective, and intellectual qualities that they convey. Thus, the recipient mentally and tangibly transgresses the borders of the discursive text that morphs into a hybrid assemblage of discursive and non-discursive fractions and allows multilayered perceptions and new modes of knowledge perception and knowledge production.

"Indisciplinary Matters" tackles the science/art, interrogator/respondent, teacher/student and discursive/non-discursive dichotomies and offers a concept of joint artistic knowledge productions as a practice of learning that can be applied in diverse settings of transdisciplinary knowledge productions.

The hybrid discursive/non-discursive assemblage offers the experience of immersive perception. Thus, this contribution is also an experiment in probing whether so far neglected *Elsewheres* and *Elsewhats* may emerge. "It begins with the sensing of absence, getting aware of what has been constitutively foreclosed. And when you bring something back that was excluded, it bears a force of unbelonging that cannot be pacified".[26]

Notes

[1] https://nomadit.co.uk/radical-health/ (2021).

[2] https://www.researchgate.net/publication/363484670_Made_in_academia (2022).

[3] 'Unconventionality' is relative to the referees' conventions – while it seems a designated characteristic of art to be 'unconventional'.

[4] Dieter Mersch: "Kunst als epistemische Praxis", in: Elke Bippus (ed.): *Kunst des Forschens: Praxis eines ästhetischen Denkens*, Zürich, Berlin: diaphanes (2009), p. 39.

[5] "Elsewheres": Matters that surface during interrogation that might point to something out there. Term inspired by "embryonic elsewheres": Bayo Akomolafe, Alnoor Ladha: "Perverse Particles, Entangled Monsters and Psychedelic Pilgrimages: Emergence as an Ontoepistemology of Not-Knowing", in: *Ephemera: Theory and Politics in Organization* 17/4 (2017), p. 819.

[6] New thread on editing: The currently applied discursive text editorship still seems to be occupied with a hierarchical editor-author dichotomy, intending a correction while pruning the text in form and content. With an increasing number of authors with diverse cultural or professional backgrounds, this 'harmonizing' editing, bafflingly offered as "care work", will hopefully soon become a relic of the past. It is obvious that with a new understanding of discursivity we need a new editing process.

[7] New thread on the meaning of matters and the cultural specificity of scientific knowledge constructions.

[8] New thread: seeing is not restricted to cognitive activity and includes acts of liberating it from the intelligibility. "To see we must forget the name of the thing that we are looking at" (Claude Monet).

[9] Jozef Zelinka (ed.): *Regieren durch Vorbeugen*: *Eine kritische Analyse der Burnout-Prävention nach Michel Foucault*, Bielefeld: transcript (2022), p. 197.

[10] "The exercise of discipline presupposes a mechanism that coerces by means of observation; an apparatus in which the techniques that make it possible to see induce effects of power, and in which, conversely, the means of coercion make those on whom they are applied clearly visible" (Michel Foucault: *Discipline and Punish: The Birth of the Prison*, New York: Vintage Books [1995], p. 171).

[11] 24 students: 21 khb, 1 Freie Universität, 1 Humboldt Universität, 1 Technische Universität; app. fifty patients and personnel from psychiatry.

[12] Tyyne Claudia Pollmann: *visions4people – Artistic Research Meets Psychiatry*, Berlin: Jovis (2019).

[13] Original quotes from the narratives are found in the publication vi*sions4people*. The 56 narratives are available on request.

[14] Tasks whose solutions are predicted, and which are designed to produce gradable results.

[15] The projects are open-ended; a narrow objective would counterproductively curtail their results.

[16] The term performance is used with caution, as it can also include a deliberate staging that is contraindicated in a cooperative practice. It means rather the opposite: awareness of thoughts, ideas, emotions, and different perspectives that surface in an appreciative environment with a open-ended approach.

[17] New thread: immersion as a means of knowledge production.

[18] https://t-c-pollmann.de/wp-content/uploads/2022/08/5_Senses-of-detachment-Prospects-for-change_ori.pdf (2022).

[19] https://t-c-pollmann.de/wp-content/uploads/2022/08/4_Human-subjects_ori.pdf (2022).

[20] The *an-alphabet*, created by 103 students, was the source material, from which each student could choose a topic to generate an individual artistic outcome. Thus, the decision-making process now shifted to the students. The *an-alphabet* compiles the students' perspectives of the year 2020. It thus also has the characteristics of a documentary and can be downloaded as a pdf (https://t-c-pollmann.de/wp-content/uploads/2022/08/3_an-alphabet.pdf [2022]).

[21] Hard lockdown: only online teaching allowed.

[22] https://t-c-pollmann.de/wp-content/uploads/2022/08/2_Zombody_ori.pdf (2022).

[23] Gilles Deleuze, Felix Guattari: *Rhizom*, Berlin: Merve (1977).

[24] Call us Zom was an experimental text that captures the resonances from the students' artistic works in a non-discursive narrative. Tyyne Claudia Pollmann: "Call us Zom", https://t-c-pollmann.de/wp-content/uploads/2022/08/2b_Call-us-Zom_Zombody-ori_tcp.pdf (2022).

[25] https://t-c-pollmann.de/wp-content/uploads/2022/08/1_YOUtopia_ori.pdf (2022).

[26] Anselm Franke: "Speculative Narratives: Essay Exhibitions, Part of 'De-Centering Narratives'", Berlin: *Haus der Kulturen der Welt* (2019), https://www.hkw.de/en/app/mediathek/video/76723 (2019).

INTERSECTIONAL FEMINIST COMMUNITY CARE Intersectional Feminism, Health & Care

This project is situated in the context of intersectional feminism.[1] From this position, we see a lack of adequate, patient-centred healthcare for people living in Germany, with significant discrimination against people who don’t conform to binary gender identities and more discrimination against people who identify as female than those who identify as cis-male.[2]
The problem of inadequate health care, despite the fact that Germany is one of the few countries with a universal (multi-payer) health care system, has a number of overlapping causes, of which we will describe the ones we consider most pressing before moving on to discuss our approach to addressing this problem.

One fact that is immediately felt by patients who identify as female, trans, non-binary, or gender fluid is the patriarchal norms and standards that permeate conventional health care and health education.

In German medical education, medical research, and the provision of medical services, the latter most directly experienced by patients in doctors’ surgeries and hospitals, the able-bodied, white, heterosexual, cis-male body-mind is the standard measure of everything ranging from anatomy and neurology to diagnosis, disease progression, treatment and medication.[3] This gender bias has serious and dangerous consequences for the diagnosis and treatment of those who do not conform to the standard. In Germany, for example, it has been found that women and girls are less likely to be diagnosed with ADHD, and diagnosed much later, because the condition has different, less well-known symptoms in women than in men.[4]
Women also have different symptoms than men when they have a heart attack. As a result, they often don´t get the right treatment and are more likely to die from a heart attack than men.[5] According to a study on gender disparities in mental health from 2020, ″women receive a disproportionate diagnosis with mental health issues″ and ″receive more prescriptions for mood-altering drugs.″[6] Finally, a survey by the American Autoimmune Related Diseases Association found that ″62% of people with autoimmune disease had been labeled chronic complainers by doctors, or told they were too concerned with their health.″[7] Given that 75% of people with autoimmune diseases are women, it is clear that ″this dismissive attitude disproportionately affects women.″[8] As the above studies show, even when gender bias is taken into account, medical research is based on a binary gender model.

Studies of biased, disrespectful, or inadequate treatment of people who identify as trans, non-binary, or gender fluid remain scarce.

In addition, conditions that are specific to people who identify as female, trans* male, non-binary, or gender fluid, such as fertility issues, endometriosis, menopausal symptoms, hormone imbalances, and gender transition, have historically been under-researched and under-invested in due to patriarchal biases that bypass the biology of more than half of the population. This results in inadequate information and treatment options for affected patients. Some members of the medical profession are beginning to understand that their binary gender model and gender bias pose serious problems for affected patients. As a result, institutions such as the Charité’s Institute of Gender in Medicine, which studies gender differences in health and disease, are emerging in the medical landscape. The institute's research aims to develop gender- and diversity-sensitive strategies for the health care system as a whole, in preventive medicine, and in medical education and practice. Similarly, Prof. Dr. Gabriele Bolte and her team at the University of Bremen have developed a toolbox to operationalise gender diversity in health care and prevention research.[9]These research efforts have been anticipated and are complemented by alternative health services that aim to fill the gap in adequate gender-sensitive health care and have emerged from within the affected communities. Informal and self-organised groups and collectives such as the FFGZ Berlin (Feminist Women's Health Centre Berlin), the HeileHaus, and more recently, organisations such as the feminist midwifery collective Cocoon and the trans* and non-binary BIPOC health centre Casa Kuá have come together to care for the health of those who are excluded or overlooked by the medical profession in their specific needs, demands and desires.[10]

The patriarchal masculine norm and the resulting disadvantages for other gender identities can be observed and measured in areas beyond the immediate medical domain, where they continue to affect the health and well-being of people who are not heterosexual and cis male.

To take the workplace as an example, the design of office temperature and office furniture is based on a cis male model with chairs that are too large and therefore inappropriate for shorter bodies. Breastfeeding rooms or public breastfeeding facilities are still a rarity in corporate environments. Or, to take the example of transport, crash-test dummies are created based on cis male body proportions, putting people with different body types at greater risk in a car crash. These gender biases lead to the devaluation of women´s, trans, non-binary, and gender fluid health.[11]Another obstacle to gender-sensitive health care is the individualisation and capitalisation of health and illness. With increasing neo-liberalisation, health has become a commodity with a price tag and is thought of in terms of products and services. When the well-being of a society is addressed solely in an individual and profit-oriented framework, larger structural dynamics and societal needs are obscured and remain unaddressed. For example, many Germans are being treated individually for burnout due to work-related stress, suggesting that long working hours and today´s working conditions, combined with unpaid care work for family members, are a collective structural problem. However, the condition is still treated in an individualistic way. Health is seen as an individual matter and therefore requires and demands individual treatment. Such an individualisation of illness can lead to feelings of isolation or of being responsible for one's own state of health, even though the cause of one´s illness is caused by political decisions and economic strategies. Finally, a major problem that we have identified is the lack of gender-sensitive education and knowledge about individual and community health, both for health care providers such as health insurance companies, doctors and nurses, and for lay people. We feel that neither we, nor most of our friends, family or colleagues know enough about how their bodies and minds work and what they need and want. This is because the relevant information does not exist, is not shared or is not prioritised, for example in sex education in schools. There are few spaces and resources for body-conscious education, learning, and exploring one's anatomy, one's nervous system, one's menstrual cycle, or nutritional needs in a non-judgmental, playful environment. We have argued that this is due to the patriarchal norms that bias medical research and education towards the human body and mind, often privileging the mind over the body.

The lack of gender-sensitive education and knowledge makes it difficult for people to make informed and empowered choices and take responsibility for their own health and that of their loved ones.

It also creates a power imbalance between healthcare providers (doctors, hospitals and insurers) who have privileged but biased information about human health, and patients who lack the education to understand and contextualise their own health due to a lack of available resources. This lack is used against patients by treating them as uninformed or disregarding their knowledge of the issue as unprofessional. In addition, there is still a strong belief that doctors are somehow omniscient and that patients therefore willingly give up their own agency. However, the root of the problem lies in the incomplete knowledge that both doctors and patients have about gender-specific embodiment, illness and treatment. For example, if you report menstrual pain, the gynaecologist will usually offer you some form of contraceptive pill. To fill this gap, we propose seminars, workshops, kindergarten, school and university classes on gender-sensitive and inclusive body literacy: learning about the menstrual cycle, PMS and endometriosis; learning about ableism and anatomy; learning about gender transition, biomechanics and how our digestive systems work. These could draw on current research in the life sciences, on inclusive, gender-sensitive pedagogical protocols for teaching human biology, and on the rich knowledge traditions that have historically preceded, coexisted with, and challenged functional medicine, patriarchy, and modern capitalism. We are thinking here of traditions such as witchcraft and midwifery, of pre-colonial and highly regional and community-specific health protocols and practices, often transmitted orally. Such embodied and oral traditions have been systematically devalued and defunded in favour of allegedly value-neutral Western medicine. For the health of all and for a healthy community, it seems imperative to us to move away from a gender-biased perspective on human health and to centralise health perspectives and practices that enrich and challenge the existing patriarchal standard.[12] Programmes and initiatives are emerging at institutional, commercial and non-profit levels to address this lack of education. Examples include the above-mentioned programmes of the Charité Berlin and the University of Bremen; Queermed Deutschland, which offers a directory of queer sensitized doctors, therapists and practices, raises awareness among practitioners and empowers patients; the female-founded start-up Loom, which focuses on inclusive and gender-sensitive reproductive health and fertility; and the non-profit organisations The Pad Project and PERIOD. What we want to add to this burgeoning provision is our practice of creating playful, performative and community-building events and spaces where health and illness can be explored in a protective, caring and fun environment. For example, with our workshops on the future of intersectional feminist health and community care (two of which were held at the Radical Health conference in 2021), we provide space and time to imagine what healthy, safe, and enjoyable futures might feel and look like. Above all, our aim is primarily to provide concrete techniques, materials and tools to mentally and physically break away from the status quo and learn to imagine a different reality. In our experience, this has been the hardest part for many of our interlocutors: to be led into a zone where they are not held back by what is but can strategise and dream about what they need and want. We are here to provide that space and vision.

INTERSECTIONAL FEMINIST COMMUNITY CARE Careful Exercises

Here are two short exercises to help you feel grounded and to let go of stress.

SCORE

- We will do a short session shaking our body in order to get moving again and letting go of the stress accumulated during the day.
- This is to start acting from your body’s needs and desires.
- It will take about 10 minutes.
- Stand in a spot in your room where you have enough space to move and feel comfortable.
- Start with simply standing still.
- Feel your feet on the floor.
- Feel how the earth is holding you, how your body is held by the feet.
- You can feel your feet pushing into the earth and the earth pushing back.
- Do a first quick scan through your entire body. Where do you feel tension, what parts of your body are particularly stiff, just feel don´t judge.
- Now bend your knees a little so that your knees are not locked.
- Whenever you are ready start with lifting your heels off the ground, shifting the weight a little to your forefoot and then put the heels back down.
- This can be a really small movement.
- Giving small impulses initiated by your heels, traveling up through your legs, pelvis and spine.
- Starting very small.
- Without leaving your spot in the room, slowly begin to make the movement bigger and bigger until your whole body is shaking.
- Let your breath flow freely.
- Let the movement grow bigger and bigger.
- You can jump up and down.
- You can add your voice if you feel comfortable doing so, letting the voice out, sighing, moaning.
- Whatever comes up naturally.
- Let go of the day.
- Shake it out.
- Let all the tension fall away.
- Let your body move freely.
- Do nothing else but shaking
- Now slowly start to make the movement smaller again.
- Step by step.
- Putting your feet back on the ground, traveling down your body, shaking less and less until you stand still.
- Feel the movement inside your body without moving your body on the outside.
- Check in with yourself.
- How do you feel now?
- Is there something you still want to move? If so do so.
- You can shake specific body parts or give them a little massage, your hand or arm or leg whatever you need right now.
- You can brush your skin from head to toe with your hands.
- That´s it for today, thank you.

Esther Vorwerk, Somatic Exercise No 1:
”Shaking for release”, Berlin (2022).
AUDIO ▸ cache.ch/1715

Photograph by Anne-Sophie Reichert, "Shaking", Berlin (2022).

SCORE

- We will do a short body scan adding heavy objects onto our bodies.
- It will last for about 10 minutes.
- Start with preparing your space.
- Look for 2 heavy objects in your room you feel comfortable with putting on your body (books, a bike lock, a yoga block, a big salad bowl or a pot..).
- Roll out a yoga mat or make space on your bed or on your floor where you can lie down comfortably and be warm.
- You can add a blanket to cover your body if you want.
- Place the objects next to the mat.
- Make sure that you are undisturbed for the next couple of minutes, switching your phone into airplane mode.
- Lie down on your back. If that does not feel right, take some time to find another position that is comfortable for you.
- Close your eyes.
- If you prefer, you can also leave them open.
- Feel the spaces where your body is touching the floor.
- Feel how the floor is holding your body and let gravity do the work.
- Sinking your body into the ground.
- Start noticing your breath now.
- How it is entering your body.
- How it is moving through your body?
- Where can you feel it´s movement most vividly?
- Where do you feel most of the tension of the day?
- Place the heavy objects on the two body parts being the most tense.
- Breath into the spots.
- How does the pressure feel on your body? Is it changing how these parts feel?
- Now when you feel ready to, move your attention to your feet.
- How do they feel right now?
- How is your little toe feeling?
- Are they warm or cold or tingling?
- Maybe you feel nothing at all?
- That is okay too.
- What about your lower legs?
- Maybe you feel the skin around your bones.
- How are your knees feeling?
- Your upper legs, your hips and genitals?
- When you notice that your mind is wandering just notice it.
- And then come back to whatever part we are focusing on right now.
- How does your buttocks feel on the floor?
- Moving onto the lower back, is it tense or loose?
- Feel your sacrum on the floor.
- Moving up your spine vertebrae by

vertebrae.
- There are usually 24 vertebrae from your lower back all the way up until the atlas, the first cervical vertebrae that supports your skull.
- How do your shoulders feel?
- Moving around to your collar bones, your heart and lungs, the rib cage protecting your lungs.
- Moving on to your belly, how do your organs feel inside your body?
- Let go of your belly and start noticing your fingers, are they touching each other? Are they warm? Cold? Moist or dry?
- And your hands? How are they lying on the floor?
- Feeling into all your fingers.
- Give each finger some time and attention.
- Travel up again.
- The lower arm and the upper arm.
- Your shoulders and your neck and throat.
- How does swallowing feel?
- The back of your head.
- The top of your head.
- What about your forehead? Is it tense?
- Your eyebrows.
- Whatever comes up, just let it be what it is in this moment.
- Moving to the eyes, how do they feel in the eye sockets? Are they moving?
- Your cheeks and your nose.
- The breath entering your nose and coming back out of your nose.
- Your mouth, your lips touching or being open.
- Inside your mouth.
- The teeth and gums, your tongue maybe moving.
- Feeling your chin.
- Then letting go of your head and feeling into your whole body lying on the floor.
- Go with gravity and with each breath try to let go of some of the tension.
- When you feel ready to, remove the objects from your body.
- Lie still for a moment.
- How do you feel now?
- Maybe something lifted? Maybe nothing changed? Maybe your breath can flow more easily? Just notice don´t change anything.
- Now come back to the room, and start listening to the sounds surrounding you.
- Start wiggling your toes and fingers if you like to.
- And in your own time open your eyes again.
- Be mindful in the transition back into your ordinary life.
- And you can remind yourself throughout the day of the feeling that you had, lying down and feeling the weight on your body.

Esther Vorwerk, Somatic Exercise No 2: "Body Scan with Objects", Berlin (2022).
AUDIO ▶ cache.ch/1716

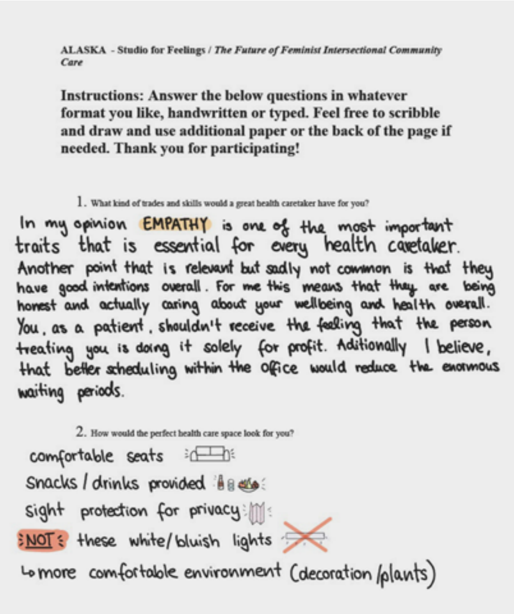
Photograph by Esther Vorwerk, "Body Scan with Chair", Berlin

INTERSECTIONAL FEMINIST COMMUNITY CARE A Small Archive

Here are three questions. Make yourself a cup of tea, find a cosy spot and take some time to answer these questions for yourself. You can do this after the exercises tour in the previous section if you like.

1. What kind of trades and skills would a great health care taker have for you?
2. How would the perfect health care space look for you?
3. What kind of community would you need to stay healthy?

If you have trouble getting started, find a small archive of answers for inspiration and perusal below.



ALASKA - Studio for Feelings / *The Future of Feminist Intersectional Community Care*

Instructions: Answer the below questions in whatever format you like, handwritten or typed. Feel free to scribble and draw and use additional paper or the back of the page if needed. Thank you for participating!

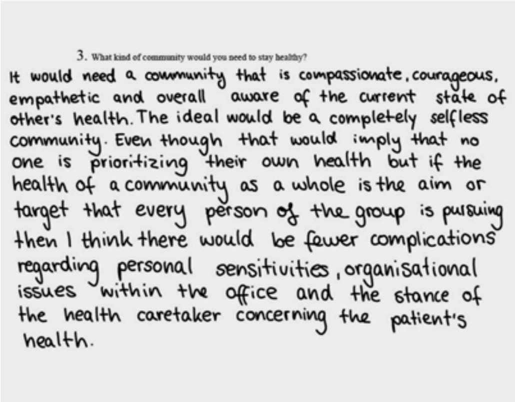
1. What kind of trades and skills would a great health caretaker have for you?

In my opinion EMPATHY is one of the most important traits that is essential for every health caretaker. Another point that is relevant but sadly not common is that they have good intentions overall. For me this means that they are being honest and actually caring about your wellbeing and health overall. You, as a patient, shouldn't receive the feeling that the person treating you is doing it solely for profit. Aditionally I believe, that better scheduling within the office would reduce the enormous waiting periods.

2. How would the perfect health care space look for you?

comfortable seats
Snacks / drinks provided
sight protection for privacy
NOT these white/bluish lights
↳ more comfortable environment (decoration /plants)

Mia Wieting, Oldenburg, Germany (2022).



3. What kind of community would you need to stay healthy?

It would need a community that is compassionate, courageous, empathetic and overall aware of the current state of other's health. The ideal would be a completely selfless community. Even though that would imply that no one is prioritizing their own health but if the health of a community as a whole is the aim or target that every person of the group is pursuing then I think there would be fewer complications regarding personal sensitivities, organisational issues within the office and the stance of the health caretaker concerning the patient's health.

Mia Wieting, Oldenburg, Germany (2022).

1. What kind of trades and skills would a great health caretaker have for you?

- An awareness of psychosomatic processes in relation to emotional stress, healing, repetitive strain injury patterns, trauma, and whatever other psychophysical issues (that appear to be ″just physical″ or ″just mental″) might also be informed by such an awareness.
- A sensitive, patient, outgoing personality. Someone who pays attention to detail and is interested in managing situations rather than passively following protocol by rote.
- Someone with strong translating skills, able to understand the expressed needs and concerns of patients and explain complicated medical ideas to their curious patients. I always resent it when a doctor or nurse explains things to me in a vague, shorthand way, even when I ask for more, in a way that betrays their shallow understanding of what´s going on. I love the health professional who can explain the underlying mechanisms, processes, and causes to me. I like my visit to the doctor to be a learning experience. I like to be trusted with my ability to understand.
- Diagnostic curiosity. Research curiosity. If I ever have a rare disease, I´d like to have an MD/PhD combo doctor leading my team, not a potentially checked-out multi-decade MD who´s on the phone.

2. How would the perfect health care space look like for you?

- I like it when all the providers are in the same building, so that if one doctor finds a particular problem, he can refer you ″straight upstairs″ for a particular test with a particular specialist. I'd like to see ″alternative″ modalities available in the same building. Acupuncture, Alexander Technique, Somatic Experiencing Therapy, TRE, Myofascial Release, should all be available in a medical setting. - Doctors working in TEAMS.
- Services paid for by my tax money. (I am so desperate to get out of the United States. I haven't been to the dentist in years, because I don't have dental insurance. I´m poor enough to qualify for ″state health care″ in NYC and I can report to you that it is an absolutely gutted system. It's been kept meagre and useless by the right and insurance industry lobbyists to serve as a forced example of the ″inherent inferiority″ of public services. It's under a stranglehold, and as a result it´s absolutely fucking useless. Almost no one accepts my insurance, and those who do are desperate doctors who have trouble keeping patients, as NY State and NYC City insurance pay providers a fraction of what private insurances pay them... I haven't seen a therapist in years, even though I need to, because nobody smart enough will take my insurance. - An American story: My housemate has a damaged tear duct from a dog bite. Her surgery hasn't healed properly, so she uses a lot of eye drops and wonders what to do next. The health of her eye is at risk, but she´s between insurances at the moment because she's just left her job and her new job doesn't start for a month. She is waiting to see a doctor, but, I repeat, the health of her EYE is at risk. There is a programme called COBRA that allows you to keep your insurance from your former employer for one year, but the monthly individual cost of her current plan, which was previously paid for by her employer, is $2'000. The perfect healthcare facility would be paid for by my tax dollars and would be ″free″ to me at the moment of need.

3. What kind of community would you need to stay healthy?

- A community that respects life, poetry, existence, friendship, love, time, leaves, turtles, trees. I live in a country that extorts my taxes to pay for bloated military contracts and robot dogs with guns on their backs, and which gives me almost nothing useful in return. College, health care; these essentials are out of reach.
- A community that respects and is ever curious about the perceptual potential of the subtle human being. A community where poetic intuition is combined with curiosity-driven and care-driven research.
- A community that understands the

dangers of excessive sedentarism is a community that protects the right of workers and students to move about. The right to move around, to get up and go for a walk and not be punished. I think that enforced sedentarism in schools works to direly desensitise us to important, subtle messages "between" body and mind. The urge to move is dulled and metabolic processes are compromised... Ubiquity blindness, industrial momentum, and conservatism keep practices and tools stagnant.
- A progressive approach to understanding the needs of the whole person is necessary for the health of the individual and community health. We're more subtle than we give ourselves the time and space to be.

E.J. Rosen, NYC, USA (2022).

1. What kind of trades and skills would a great health caretaker have for you?

transmorphosicorgasmicbeing
in sololuckysilence
barbaracherryblossom buds flowering
3 turning candles as always
dancing with my painted olympia traveller
now cantus in memoriam benjamin britten
healing danceperformancemusic
in exile in the fireplace room, with olive tree darling creature
& soulsister palmtree dancing
becoming nothing
cantus repeat:
dancing on four paws
silentium de arvo pärt falling and nestling
for alina 1 an embrace
into gently caressed pet
in tender silence
oh i love to paint to arvo pärt music!
the large spider is crossing the sheet
she has been around me for 1 week
following me from room to room
she's in the corner, I sleep
like every night with her
i miss her now

2. How would the perfect health care space look like for you?

in the moment with fire
writing poems
becoming empty
alone in speech silence
firesounddance

echo flame dance
always changing
sounds of water will be
behind the chimney wall
bath & beetroots
rosemary is blossoming at the kitchen window
13 cherry blossoms now
in my back there is a forest
a 350 year old oak la reina
winter oak at the pond
a meadow waist-high
vulvatic sex in a crop circle
falling stars
in you in me
swimming with a deer
in the pond
summer morning ritual for 1 week
water's edge to edge
alone in silence
with the erika typewriter vault inside

3. What kind of community would you need to stay healthy?

cero: peace
first: peace
second: supporting each other, helping each other with living & dying
third: in my queer ecology sense
the earthplanet as a living lifefull liquid organism
so many birds in the last years came to my backyard
from the countryside: there is more food here in the city
my last birthdayperformance in my white room changing to
pleasure public from age 14-85,
around 25 amazing kind creatures

friendcreatures – queer birds flying high through the flat
the white large room is closed, in silence until the performance starts
i am trust
i am joy
a white mulberrywood santur creature
on my body, sound emerges
with closed eyes:
seeing divination
listening silence
dancesoundtouch
in the now moment
being an orgasmic creature
you
being is a blessed present
with you

Marion Steinfellner, Vienna, Austria (2024).

Photograph by Herbert J. Wimmer and Marion Steinfellner, Berlin, Germany (2021).

Performance TranceMission.

Drawing by Amon Thein, Oldenburg, Germany (2022).

1. What kind of trades and skills would a great health caretaker have for you?

Empathy above all. Listening to my needs other than medication.

2. How would the perfect health care space look like for you?

Warm, open and with a big window so that I can be inspired and recharged by life outside. A big couch to sit on and meet with guests.

3. What kind of community do you need to stay healthy?

A community where people look out for each other and pay attention to what is going on around them. Everyone shares what they have and everyone is invited to do what they want. People who invite others into their spaces to hang out.

Amon Thein, Oldenburg, Germany (2022).

1. What kind of trades and skills would a great health caretaker have for you?

I think it is important that the person, the health worker, understands both the field of expertise, the profession, and continues to educate themselves, but also understands our humanity in a social network or social context. It is very important that they also do educate themselves in political issues. That they do understand that we are all differently situated in cultures or economies or our social positioning and that our social positioning also has an impact on our health. And rather than judging us or putting us down or paternalistically talking around us, talking above us, it´s important that they have the skills to talk to us. And if they need to, they should be able to ask for help, so if there´s a language problem, for example, there should be people who can translate, or if they don´t really understand the situation of a person from a different cultural or even socioeconomic background, that they should continue to educate themselves and get in touch with people from similar backgrounds. I think the most important thing is that it´s also a phrase that comes from the "Krüppelbewegung" in Germany and disability studies or also disability justice is "to talk with us and not about us".

2. How would the perfect health care space look like for you?

Lots of plants, bright, clean and accessible, easy to find in public and with small information leaflets on different topics.

3. What kind of community would you need to stay healthy?

I do have a community around me that supports me to stay healthy because I know that I can talk to people, I know that I can get practical help from people and I know that people can find solutions or be creative to support us when we need it. Support us, because now I'm talking about me and Nabbi, when we didn't have enough money for another IVF attempt. For example, while "unser Kinderwunsch" ("our desire to have children") friends around us started to raise money for us because they know that we do not need more words, we need practical help. So a good dose of people who have the ability to talk maybe just to offer you different perspectives or to educate themselves and yourself, but also people who know how to be practical and help and support.

Diana Thielen, Berlin, Germany (2022). Transcription of audio file by Esther Vorwerk.

INTERSECTIONAL FEMINIST COMMUNITY CARE Conclusion

The people who responded to our three questions above highlighted empathy and listening as key qualities in healthcare and communities. They talked about the need for healthcare spaces that are vibrant, comfortable and bright. Spaces that feel welcoming and safe. Respondents also mentioned the importance of politics. They talked about how important it is for health professionals to be able to recognise the different needs of different people, that people come with different experiences and resources. They stressed that everyone should get the care they need. They wanted a community that was open-hearted and thriving, and a system where body and mind were seen as one and treated with respect. This is where ALASKA comes in. As ALASKA we aim to create experiences that bring people into their bodies, remind them of movement practices they already know and introduce them to new ways of perceiving and feeling. We offer different experiences of care and strive for a more holistic, intersectional, feminist health system that is designed for and serves the different needs of different bodies. We envision a culture of care in which people have free and easy access to gender-inclusive education about their bodymind and learn to care for themselves and others in a gentle, compassionate way. Going forward, we will continue to gather and analyse insights from healthcare providers and patients from diverse backgrounds. We are also on a journey to learn how our approach can be truly intersectional, recognising and responding to intersecting levels of discrimination.

Our own radical health dream is to establish an intersectional feminist centre for compassionate health and care, with creative and somatic offerings that nurture personal and community health.

Notes

1 In this article, we initially focus on gender discrimination. However, by describing our perspective as intersectional, we acknowledge and draw attention to the fact that different dimensions of discrimination, such as class, race, ageism and ableism, intersect in the health sector.

2 Personally, both authors identify as cis female and acknowledge that this influences their stance on the issue.

3 Racism and ableism are rampant in the German healthcare system and have a strong impact on patient's experiences.

4 "ADHS: Warum die Diagnose bei Mädchen und Frauen so schwer ist", in: *ZDF Heute*, https://www.instagram.com/p/Cd2gpu6KBug/ (22 May 2022). The studies and reports on ADHD assumed binary gender.

5 Alana Biggers (ed.): "Gender Bias in Medical Diagnosis," in: *Medical News Today*, https://www.medicalnewstoday.com/articles/gender-bias-in-medical-diagnosis.

6 Amaia Bacigalupe, Unai Martín: "Gender Inequalities in Depression/Anxiety and the Consumption of Psychotropic Drugs: Are We Medicalising Women's Mental Health?", in: *Scandinavian Journal of Public Health* 49/3 (2020), pp. 317–24.

7 Alana Biggers (ed.): "Gender Bias in Medical Diagnosis", in: *Medical News Today*, https://www.medicalnewstoday.com/articles/gender-bias-in-medical-diagnosis.

8 Alana Biggers (ed.): "Gender Bias in Medical Diagnosis", in: *Medical News Today*, https://www.medicalnewstoday.com/articles/gender-bias-in-medical-diagnosis.

9 Gabriele Bolte, Sophie Horstmann: "DIVERGesTOOL: Toolbox zur Operationalisierung von Geschlechtlicher Vielfalt in der Forschung zu Gesundheitsversorgung, Gesundheitsförderung und Prävention" (2023), https://www.public-health.uni-bremen.de/mitglieder/gabriele-bolte/projekte/?proj=811&page=1.

10 For more information on the history of the (feminist) health movement, see Feministische Gesundheitsrecherchegruppe (ed.): *Practices of Radical Health Care: Materials of the Health Movement of the Seventies and Eighties*, Berlin (2019).

11 Caroline Perez Crialdo: *Invisible Women: Exposing Data Bias in a World Designed for Men*, London: Chatto & Windus (2019).

12 Silvia Federici: *Caliban and the Witch: Women, the Body and Primitive Accumulation*, Brooklyn: Autonomedia (2004); Projit B. Mukharji: *Doctoring Traditions: Ayurveda, Small Technologies and Braided Sciences*, Chicago: University of Chicago Press (2016); Caroline P. Crialdo: *Invisible Women: Exposing Data Bias in a World Designed for Men*, London: Chatto & Windus (2019).

MALARIA AND NEOCOLONIALISM
Introduction

Malaria is one of the oldest diseases known to humanity, and one of the deadliest. And probably the disease with the most dollars in its belly,[1] considering research and development funding, especially when military investments over the centuries are included.[2] So how is it possible that as late as 2023 malaria parasites still killed some 580'000 people, mostly children, in Africa?[3] Over the next decade, this number is likely to rise sharply as Artemisinin, the drug on which the World Health Organization (WHO), the Gates Foundation and the U.S.-Global Fund have relied on for the past twenty years, becomes less effective due to increasing resistance across the continent. Like all previous antimalarial drugs, Artemisinin has an expiry date of around thirty years, after which the malaria parasite has usually developed resistance to the active ingredient. After the mass deaths caused by chloroquine resistance in the 1990s, this disaster was as predictable as the previous ones.

This time, the drug in question was isolated from the antimalarial plant Artemisia annua: Artemisinin proved to be the most effective chemical agent against malaria, a discovery made in China already in the 1970s. But when malariologist Tu Youyou presented her findings at the first international Artemisinin conference in Beijing in 1981, the Western scientific community found it hard to believe that "backward" communist China had succeeded in extracting a potent antimalarial from a weed. A drug, moreover, based on an ancient recipe from Traditional Chinese Medicine (TCM), while US researchers, after testing 150'000 substances, could only come up with Mefloquine, a known neurotoxin that was responsible for U.S. soldiers running amok in Afghanistan, among other things.[4]

Before Novartis started selling antimalarial drugs in the form of Artemisinin Combination Therapies (ACTs), the WHO had argued for twenty years that this active ingredient did not meet safety standards or that Chinese production conditions – despite a brand new factory – were not good enough for export to African countries. At the time, the WHO was simply not interested in Artemisinin. According to malariologist Tu Youyou, one likely explanation for this lack of interest was the patent law in the West: a single compound could not be patented by the pharmaceutical industry (Interview with Katharina Weingartner, Beijing, February 2013). The situation changed, when Novartis, in collaboration with the Chinese Institute of Military Medicine, developed a combination preparation of Artemether, an Artemisinin derivative, and Lumefantrine. The resulting drug was finally approved in 2001 and initially sold as Riamet to travellers at a high price. When Novartis received a ten-year exclusive distribution contract from the WHO to sell it as Coartem throughout the African continent, it became the best-selling tablet for many years.[5]

In 2019, Tu Youyou, now a Nobel laureate for her discovery forty years earlier, and her team demonstrated that the way ACTs such as Coartem are administered was responsible for the development of parasite resistance, rather than the use of Artemisia annua as a herbal tea, as the WHO had previously promoted.[6] This occurred because the drug was administered for only three days, allowing the parasite to survive. Since the release of our film *The Fever*, two vaccines Mosquirix and R21/Matrix-M have been recommended by the WHO. The Gates Foundation had been developing Mosquirix since 2000, with GlaxoSmith Kline as a major shareholder. The vaccine was initially reported as around 70% effective, but this has since been significantly downgraded to rates as low as 30%. With four initial doses and booster shots every four years, the vaccine is difficult to administer in African countries and has shown serious side effects in trials, especially in girls.[7] More recently, Oxford University/Serum Institute of India/Novavax have released R21/Matrix-M with similar optimism, public health experts, however, caution against seeing this latest vaccine as another magic bullet.[8]

MALARIA AND NEOCOLONIALISM The Fever

In 2019, we released the documentary *The Fever*, which deals with the question why the many victims of malaria in sub-Saharan Africa must be understood as a product of (neo-)colonialism, racism, and profit interests.

Trailer of *The Fever*, https://vimeo.com/572592602 (2019).
VIDEO ▸ cache.ch/1733

We started our work in 2016, at a time when malaria deaths already seemed to be falling. We found co-producers and generous funding from Austrian, Swiss and German government film funds, and public television (ORF, ARD, SRF). With a budget of 1.2 million euros, we began our intensive research around the world, together with Abdallah Salisu, a political scientist and community activist from Ghana, Weina Zhao, a sinologist and filmmaker from Vienna and many others. Researching and filming for the documentary took six years. In the beginning we were more interested in the history of malaria, especially the links between tropical medicine and wars of conquest.

Would the colonisation of Africa have been possible at all without quinine? While European soldiers and missionaries died like flies, the local population above five years was largely immune.

Was the parasite ultimately an important defence against invaders? We conducted well over a hundred interviews with people all over the world, from Kampala to Beijing, Baltimore, Bangkok, and Basel, from Nairobi to Arusha and Daressalaam. We spent countless hours gathering valuable material; talking to mothers and children, nurses, doctors and herbalists, activists and organisers, historians, scientists, teachers, and coffin makers. In the end, in a small editing suite in Vienna, our dedicated team of filmmakers decided to tell the story of the looming malaria catastrophe from the perspective of those most affected by it. This simple, understandable decision was seen as radical and led to the co-producers walking away from the well-funded project; despite enthusiastic media response and screenings at international festivals, only one of the co-funding public television stations, ORF, has ever shown the film. "The film deals with a felt reality, not with facts, the scientists are missing", wrote one of the commissioning editors from the ARD to us in an e-mail. A bold statement, given that two of the protagonists are scientists teaching at major East African universities and one interviewee is a Nobel laureate.

The Fever finally had its sold-out premiere at the DOK Leipzig documentary film festival in November 2019. It follows four protagonists: Ugandan herbalist Rehema Namyalo, Kenyan entomologist Richard Mukabana, Ugandan pharmacologist Patrick Ogwang and Kenyan teacher and community health activist Paul Mwamu. But its central protagonist is Artemisia, a genus with species such as annua and afra, that was widely used in Traditional African Medicine (TAM),[9] before it was demonised and suppressed in the course of colonization.

MALARIA AND NEOCOLONIALISM
Dropped Interview Snippets

Only a small percentage of the footage made the cut, and the aforementioned decision to tell the story through protagonists from malaria-endemic regions disqualified many great interviews. We also decided to focus on a strong woman as the main character, an herbalist with decades of experience in successfully curing and preventing malaria in and around her rural community. The aim was to create a cinematic, emotionally engaging film that used the disease as a lens on colonialism and its continuing effects. The following interview clips include important voices that were lost in our selection process and have never been published before. Nevertheless, these voices shaped our film by imparting nuanced and complex knowledge within their respective fields of expertise which together informed what would become the essential message of *The Fever*:

Only a systemic, inclusive, decolonial approach will bring about sustainable change.

Interview with Dr. Flora Kessy, *The Fever* (2019).
VIDEO ▸ cache.ch/1726

Dr. Flora Kessy was a Tanzanian economist who sadly passed away in 2020. She was an Associate Professor of Social Policy and Development at Mzumbe University, and Executive Director of the Tanzanian Training Centre for International Health (TTCIH) in Ifakara. Her main research interest was poverty, particularly as it relates to health and access to health care. Kessy explains why malaria cannot be tackled with drugs alone, and that all aspects of people´s circumstances must be taken into account. This in itself is a strong argument for African scientists to be at the forefront of malaria control efforts, as they have the best understanding of the situation.

> ”If you want to eradicate or eliminate Malaria, you need to look at the peoples livelihood.”
>
> Interview with Dr. Flora Kessy, *The Fever* (2019).

Interview with Prof. Dr. Richard Mukabana, *The Fever* (2019).
VIDEO ▸ cache.ch/1727

Prof. Dr. Richard Mukabana of the University of Nairobi is a specialist in applied medical entomology and parasitology. He says he is tired of being employed as a 'field worker' for Western high-tech science institutes instead of focusing on implementing local solutions to vector control. He is also studying the role of community health work in reducing endemic infections around Lake Victoria. As a scientist, he thinks in complex terms. "There is always somebody ready to make a profit from this disease somewhere. It's usually not the ones with the disease". Mukabana describes how difficult it is for African scientists to get funding and to be heard in strategic decisions about disease control because of a strong perceived bias towards prestigious Western institutions. He explains how the exclusion of African scientists is particularly damaging when it comes to malaria.

"The wearer of the shoe knows where it pinches most."

Interview with Prof. Dr. Richard Mukabana, *The Fever* (2019).

Interview with Prof. Dr. Linsey McGoey, *The Fever* (2019).
VIDEO ▸ cache.ch/1729

Prof. Dr. Linsey McGoey is a Canadian sociologist who teaches at the University of Essex and specialises in social theory and economic sociology. She is known for her work on philanthrocapitalist ventures and their role in the global economy. Linsey McGoey further contextualises the struggle that Richard Mukabana has already touched on. Philanthrocapitalist foundations play a huge role when it comes to malaria and are probably the most powerful actors when it comes to making decisions in global efforts against malaria.

"Change must come from a change in global governance rules, global trade rules. It cannot come from simply increasing the amount of handouts that wealthy nations or their wealthiest people choose to give at their own prerogative."

Interview with Prof. Dr. Linsey McGoey, *The Fever* (2019).

Interview with Dr. Hans Herren, *The Fever* (2019).
VIDEO ▶ cache.ch/1728

Dr. Hans Herren is a Swiss entomologist, the CEO of the Millennium Institute in Washington, DC, and founder of Bio-Vision. Herren calculates the shockingly low amount of money it would take to prevent malaria deaths and shows that malaria control is not a question of possibility. Citing various examples, he explains the different scales by which life is protected in the global North and South. He also questions the way "development work" usually works: the Global North benefits while there is little room for self-determined strategies or local production.

"Our approach to development work also needs to change. We need to not always support our own companies in Europe, North America… but instead support for an alternative in Africa, in the developing countries, that works!"

Interview with Dr. Hans Herren, *The Fever* (2019).

Interview with Dr. Amit Sengupta, *The Fever* (2019).
VIDEO ▶ cache.ch/1730

Dr. Amit Sengupta was a medical doctor and founding member of the People´s Health Movement from India, who tragically died much too young. He talks about the power relations and issues such as drug patent laws that underlie the problems that Flora Kessy, Richard Mukabana, Linsey McGoey and Hans Herren discuss in their clips.

"That's about power. It is not about medicine. It is not about technology. It's about power."

Interview with Dr. Amit Sengupta, *The Fever* (2019).

Interview with Merlin Willcox, *The Fever* (2019).
VIDEO ▶ cache.ch/1731

Dr. Merlin Willcox is a clinical lecturer and medical researcher at the University of Southampton and a general practitioner, who has done extensive work on malaria and traditional herbal treatments. He addresses Western funding agencies´ lack of interest in knowledge that exists outside Western systems and talks about the displacement of Traditional African Medicine by Christian missionaries.

"That's where their strength lies. They have marvelous biodiversity, and not only biodiversity but traditional knowledge going with that biodiversity."

Interview with Merlin Willcox, *The Fever* (2019).

Interview with Prof. Dr. Salim Abdulla, *The Fever* (2019).
VIDEO ▸ cache.ch/1732

Prof. Dr. Salim Abdulla is a clinical epidemiologist in Tanzania and former director of the Ifakara Health Institute. Salim Abdulla calls for the strengthening of indigenous knowledge and the structuring of Traditional African Medicine – the oldest system of medical knowledge on the planet.

"If you compare the, as you say, the rich biodiversity that exist in Africa and the information that is been documented, related to the benefits of this biodiversity, is very very low. And this are the new areas, of what that also the government in Tananzia and North African countries need to improve."

Interview with Prof. Dr. Salim Abdulla, *The Fever* (2019).

Interview with Prof. Dr. Dr. Pedro Alonso, *The Fever* (2019).
VIDEO ▸ cache.ch/1734

Prof. Dr. Dr. Pedro Alonso is a Spanish physician and epidemiologist. He led the WHO's global malaria programme from 2014 to 2022 and admits that the WHO has made big mistakes in its malaria strategy in the past. He speaks of a lack of perspective and the importance of taking balanced and sustainable action against malaria in the future, never sporadic or spasmodic.

"We need to retain the lessons. (...) The cost of failure is massive. And therefore, this requires a very balanced, thoughtful, analytical, science based, evidence-based discussion."

Interview with Prof. Dr. Dr. Pedro Alonso, *The Fever* (2019).

However, the picture painted in these interviews shows that exactly these mistakes are currently being repeated. A balanced approach is not possible, as long as a large part of the population (and, moreover, the affected part of the population) is prevented from using their own knowledge and can't get funding for their own scientific projects. If the knowledge of some (mostly white persons, not affected by malaria) is treated as fact and the knowledge of others (affected by malaria in sub-Saharan Africa) is treated as "felt reality", there can be no balance. The continuing massive death toll from malaria shows that profit interests as well as racist and (neo)colonialist hegemonies are not only incompatible with the (long forgotten) WHO approach of "Health for All" but simply inhuman,[10] as Tu Youyou put it rather emotionally in The *Fever*, years before she received her Nobel Prize:

"If profit was the reason for the deaths of so many malaria patients, I find that not only immoral but truly inhuman."

Interview with Tu Youyou, *The Fever* (2019).

Notes

1 Randall M. Packard: *The Making of a Tropical Disease: A Short History of Malaria,* Baltimore: The Johns Hopkins University Press (2007).

2 Karen Masterson: *The Male Project,* London: Penguin (2014).

3 World Malaria Report, https://www.who.int/teams/global-malaria-programme/reports/world-malaria-report-2023 (2023).

4 Remington L. Nevin: "Idiosyncratic Quinoline Central Nervous System Toxicity: Historical Insights into the Chronic Neurological Sequelae of Mefloquine", in: *International Journal for Parasitology: Drugs and Drug Resistance* 4 (2014), pp. 118–125.

5 Thomas Schwarz: "Der Coartem-Deal – Einem geschenkten Gaul…", in: *Medicus Mundi Schweiz*, https://www.medicusmundi.ch/de/advocacy/publikationen/med-in-switzerland/einem-geschenkten-gaul (2001).

6 Jigang Wang, Chengchao Xu, Fu Long Liao, Tingliang Jiang, Sanjeev Krishna, Youyou Tu: "A Temporizing Solution to 'Artemisinin Resistance'", in: *The New England Journal of Medicine* (2019).

7 Jop de Vrieze: "First Malaria Vaccine Rolled Out in Africa — Despite Limited Efficacy and Nagging Safety Concerns: Mosquirix Faces Real-World Test in Malawi, Kenya, and Ghana", in: *Science.org*, https://www.science.org/content/article/first-malaria-vaccine-rolled-out-africa-despite-limited-efficacy-and-nagging-safety (2019).

8 Sarah Johnson: "Cheaper, More Effective Malaria Vaccine Wins WHO Approval: R21/Matrix-M Vaccine, Developed by the University of Oxford, Is the First Malaria Vaccine to Reach 75% Efficacy Target", in: *The Guardian*, https://www.theguardian.com/global-development/2023/oct/02/new-malaria-vaccine-approved-by-world-health-organization (2 October 2023).

9 "Traditional medicine (TM) is an important and often underestimated part of health services". It is "the sum total of the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health, as well as in the prevention, diagnosis, improvement or treatment of physical and mental illnesses", World Health Organization: *WHO Traditional Medicine Strategy 2014–2023,* Geneva: WHO Press, https://iris.who.int/bitstream/handle/10665/92455/9789241506090_eng.pdf?sequence=1 (2013), pp. 11, 15.

10 "Health for All" was a principle agreed upon in the Alma-Ata Declaration of 1978, signed by 134 national government members of the WHO. It was a written commitment to health as a human right, based on the principles of equity and community participation. It broadened the concept of health to include social justice, https://www.who.int/teams/social-determinants-of-health/declaration-of-alma-ata.

SUBJECTIVITIES

INCONGRUENT GESTURES Giving Birth

I went into labour on a Sunday evening, five days before my baby's due date. At 10pm on the Tuesday night, sleepless and terrified by the nauseating feeling of my own body contracting every ten minutes or so and with no relief in sight, I sought out medical assistance at the hospital where I was registered to give birth. I was hoping to get admitted onto the labour ward and be given something – anything at this point – to make the pain go away so I could rest before the big push. I was assessed as medically not ready enough (contractions not close enough, cervix not dilated enough) and sent home with paracetamol. I lay on the sofa for what turned into a third sleepless night, the cold, sticky, and slimy-to-the-touch pads of a mini-TENS machine on my back doing little to subdue the nauseating pain of the contractions. My waters broke at home at 5am on the Wednesday morning: a split second of relief and euphoria in what, at this point, was 58 hours of sensory overload. My second attempt to access maternity care was more successful. An exhausted, leaky, vomiting mess, I was permitted to join the labour ward for what my medical notes record as (only) four hours and 23 minutes of labour including:[1] a back that refused to be introduced to the needle of the epidural, likely on account of the curvature in my lower spine and despite the repeated attempts of two kindly and gentle anaesthetists; a doctor's fist shoved up my vagina without anaesthetic or informed consent to put a probe on the baby's head, an act I have since come to recognise as an instance of obstetric violence; a midwife who finally pushed the 'emergency stop' button, putting an end to the nonsense of 'normal birth' for the sake of it; an emergency C-section under general anaesthetic; the loss of 1.3 litres of blood to primary post-partum bleeding. The emergency C-section, classified on my medical record as a Category 1, ″immediate threat to the life of the woman or foetus″,[2] saved my baby's life, who was in cardiac distress and who had passed meconium in utero. It also most probably saved mine. I am not sure when a sense of those four hours and 23 minutes started to galvanise as a feeling of being suspended in some sort of spatiotemporal configuration somewhere between life and death.[3] I am grateful to the multitude of professionals who made sure that my baby and I landed on the side of life; but this was not the only feeling. I was also left discombobulated and misconfigured – six months after my son's birth I developed chronic lower back pain, sciatica, and the sort of depression that accompanies feeling debilitated, constrained in movement, and in constant pain. The pain persisted for two years and only subsided following laparoscopic surgery to remove two fibroids outside my womb. Since April 2013, I have lived in the uncomfortable knowledge and with the haunting feeling that had I been labouring back in time or in a remote elsewhere today, either one or both of us may not have made it through.

INCONGRUENT GESTURES Troubling Labour

This essay is about what it might mean to have conversations about such discombobulation, about being suspended somewhere between the living and the dead.[4] I stage these speculative conversations through the object of the fibroid, the reading of my medical record which I obtained from the hospital using a Freedom of Information request in 2019, ultrasound photography, old photographs of my paternal grandmother, and *The Simpsons*. Following my labour and in a second, independent medical opinion I sought out a few years later, I was told that, in all likelihood, the reason for my labour's 'failure' to progress was the presence of two fibroids outside my uterus.

The term ″failure to progress″ is the term that clinical staff used at the time to describe what had happened; it is also recorded as such in my medical record. In the US and the UK it is now described as an outdated term and terms such arrested labour, prolonged labour or slow progress in labour (NICE) are recommended instead.

″Evidence Based Birth″, https://evidencebasedbirth.com/friedmans-curve-and-failure-to-progress-a-leading-cause-of-unplanned-c-sections/ (2024).

Fibroids, or myomas, are described in the medical literature as ″benign tumours″ and develop in women of reproductive age. They can be found inside and/or outside the womb and its lining, and five different types of fibroids are identified, depending on their location. They can be single or multiple, and their sizes tend to vary from a few millimetres to 30cm or larger. Fibroids can cause increased menstrual bleeding, including clotting and painful periods. They can also cause pain during intercourse, as well as lower back pain, and are the leading reason for hysterectomies. Estimates of prevalence vary considerably, although latest estimates from countries of the globalised north, namely the UK and US, place prevalence between 70% of white and 80% of black women by age fifty.

NICE: ″Fibroids″, in: *NICE National Institute for Health and Care Excellence*, https://cks.nice.org.uk/topics/fibroids/ (July 2022) (only available in the UK).

The causes of fibroids are largely unknown.[5] It is these benign and enigmatic objects that form the starting point of this essay, which is part of a larger interdisciplinary project that explores and experiments with multimodality, reflexivity, childhood, motherhood, labour, and the body politic.[6] My project is inspired by reflective writing in medical anthropology in which authors use their own encounters with chronic illness, clinical abuse, and mis(se)diagnoses, to theorise illness, medicine, the body, and the social.[7] My project retains the value of turning the gaze on oneself as a way of generating new knowledge, challenging power relations, and finding ways to imagine these experiences and categories differently. My subject is the experience of living and labouring with an under-researched and medically dismissed gynaecological condition. Theoretically, however, my project departs from this work to join others who explore the entanglements of the medical and the social, the biographical and the historical, of science and technology, and of image and text in order to reveal a body multiple.[8] In line with this body of scholarship, I approach my theoretical task from a practice perspective.[9] As much as is possible, I look at the ways in which medicine attunes to, interacts with, and shapes its objects in its various and varied practices,[10] or at least how these practices are codified in medical and midwifery textbooks and systematic reviews, and recorded in medical records such as my own. My focus, however, is not on the medical practices themselves but on the ways in which these attunements, interactions, and shapings find their audiences: in this case, me, my fibroids, and my baby, the objects of medicine's varied practices. In this essay, I take up Donna Haraway's invitation to ″stay with the trouble″,[11] making a foray into this under-researched gynaecological condition of uterine fibroids under the conditions of pregnancy and labour.

″*Trouble* is an interesting word. It derives from a thirteenth-century French verb meaning 'to stir up', 'to make cloudy', 'to disturb'. We—all of us on Terra—live in disturbing times, mixed-up times, troubling and turbid times. The task is to become capable, with each other in all of our bumptious kinds, of response. Mixed-up times are overflowing with both pain and joy—with vastly unjust patterns of pain and joy, with unnecessary killing of ongoingness but also with necessary resurgence. The task is to make kin in lines of inventive connection as a practice of learning to live and die well with each other in a thick present.″

Donna Haraway: *Staying with the Trouble: Making Kin in the Chthulucene*, Durham, North Carolina: Duke University Press (2016), p. 1.

Haraway traces the noun ″trouble″ to its 13th century French root in the verb ″trubler″, meaning to ″stir up″, ″to make cloudy″, ″to disturb″ – all good descriptions for how I experienced living with fibroids.

I trouble labouring with fibroids by mixing modes and media, memories and stories, the then and the now as well as the not-yet. I experiment with images where words fall short in communicating the more affective, ephemeral, and sensory aspects of these attunements and interactions, without doing away with the words themselves. In this sense, the narrative I hope to have produced is a radicle that shatters a certain linear unity and knowledge derived from words alone.[12] This is not, then, an essay as such, but a bulb: a rhizome yet-to-come. In this rhizome yet-to-come, the bringing together of different sources of evidence and experience, including administrative records, memories, popular culture, and family albums, is not so much an analysis as it is a configuration of modes and media; it is a creation of "entanglements that matter" in order to reach a point "where it is no longer of any importance whether one says I".[13] The meaning of analysis here is one of "touching, not mastering", of "folding" mode and medium onto one another.[14] Analysis in this sense involves an engagement with the senses, a resonance between them, and an openness to one sense triggering another – it is "a mimetic form of analysis, of becoming (an)other".[15] This essay, as such, has been written through triggers: an anecdote triggers a thought that triggers an image that triggers an insight that triggers an essay. In the process and over the next period, the story changes from one of grief to one of joy: nomad thought,[16] wandering across your pages and screens.

Gilles Deleuze and Félix Guattari's opening paragraph in *A Thousand Plateaus* is a statement of authorship and of true collaboration: while each recognises the other's contribution to the final text, the process of thinking and writing together has made them other, no longer themselves. In this essay, I borrow the spirit of this statement of authorship in two ways. The first is in the collaboration that I stage between past-me and present-me in writing the story, a narrative that I have told many times, afresh. Like any good collaboration, we've had to work together to reach compromises in the interest of telling that story differently, more hopeful than first experienced, mining together for insights that may have initially got lost in the maelstrom of it all. The second sense in which I borrow Deleuze and Guattari's statement of authorship is in the ways in which text, image, and sound come together in the re-telling of this story to create meaning that neither text nor image nor sound alone can make, and where it is no longer of importance from which of these modes and media meaning emerges, because it is in their combining that meaning actually resides.

Gilles Deleuze, Félix Guattari: *A Thousand Plateaus*, Minneapolis: University of Minnesota Press (1987), p. 3.

To write about pregnancy, labour, and childrearing is also a challenge in dancing with grand narratives and scripts of midwives versus doctors, vaginal versus C-section births, breasts versus bottles, crying it out versus co-sleeping, as if these things were always natural or rational choices, or even choices at all. In this dance it is easy to misstep in search of certainties. This challenging dance is another sort of labour, itself in need of troubling. I hope to avoid the lure of certainty by mapping the ″messy actualities of practice″;[17] in this sense, this essay does not hold a resolution, for rhizomes never do. Instead, under fecund conditions, they multiply. To this end, and to keep me to the task of multiplicity, I have over the last ten years kept company with the likes of Ruth Behar, Andrew Irving and Michael Jackson in anthropology, and Jennie Ashworth, Hilary Mantel, Maggie O’Farrell, Marina Benjamin, and many, many other memoirists, essayists, and writers who, like the best sort of sociologists, turned their private troubles into public issues,[18] bearing different bodies of work to their publics.

″[...] wounded is a tricky thing for any woman to admit to being. Not least because any time a woman utters a sentence about her own experience, she becomes a kind of terrorist and there’s an army out there waiting to strike her down. Some days it feels like writing truthfully about her own life is the most subversive thing a woman can do [...].″

Jenn Ashworth: *Notes Made While Falling*, London: Goldsmiths Press (2018), p. 104.

″We do what we have to do to survive; as a species, we are inventive in the face of adversity. Robert Frost said, ’The best way out is always through’, and I believe this to be true but, at the same time, if you can’t go through, you can always go around.″

Maggie O’Farrell: *I am, I am, I am: Seventeen Brushes with Death*, London: Headline Publishing (2018), p. 233.

″[...] when biological destiny veers from the norm, there are parts of the psyche that take time to catch up. You understand what has happened, the medical disaster; you reason about it. But there are layers of realisation, and a feeling of loss takes time to sink through those layers. The body is not logical; it knows its own mad pathways.″

Hilary Mantel: *Giving up the Ghost: A Memoir*, London: Fourth Estate (2010), p. 230.

″No one objects to autobiography, as such, as a genre in its own right. What bothers critics is the insertion of personal stories into what we have been taught to think of as the analysis of impersonal social facts. Throughout most of the twentieth century, in scholarly fields ranging from literary criticism to anthropology to law, the reigning paradigms have traditionally called for distance, objectivity, and abstraction. The worst sin was to be ’too personal’. But if you’re an African-American legal scholar writing about the history of contract law and you discover, as Patricia Williams recounts in *The Alchemy of Race and Rights,* the deed of sale of your own great-great-grandmother to a white lawyer, that bitter knowledge certainly gives ’the facts’ another twist of urgency and poignancy. It undercuts the notion of contract as an abstract, impersonal legal document, challenging us to think about the universality of the law and the pursuit of justice for all.″

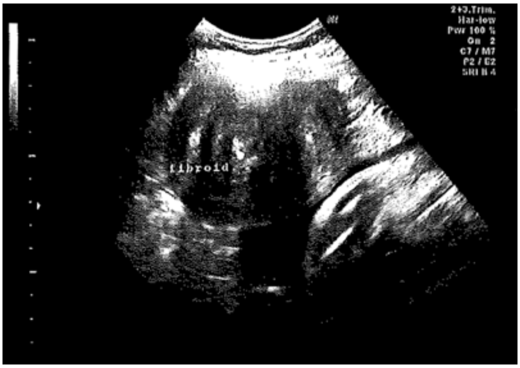
Ruth Behar: *The Vulnerable Observer*, Boston: Beacon Press (1996), pp. 12–13.

″When I was heavily pregnant I met an off-duty consultant obstetrician at a party: ’The thing about childbirth’, he slurred to me, in a confidential tone, gesturing with his wine glass towards my stomach, ’is that it’s either all fine or it completely fucks up. Theres nothing in between’. Not the most comforting pronouncement but perhaps one of the most honest.″

Maggie O’Farrell: *I am, I am, I am: Seventeen Brushes with Death*, London: Headline Publishing (2018), p. 79.

INCONGRUENT GESTURES Benign Objects

I was due to give birth in hospital because of the very-late-in-my-pregnancy discovery of these benign objects on my womb. A few weeks before the fibroids made themselves known, I had been to see the midwife for one of those regular check-ups. I had asked her about these perfectly formed, hard roundnesses that seemed to have made an unexpected appearance, almost overnight, on the left side of my body and just below my belly button. Could it be the baby’s head? I asked. My midwife felt around my bump with her hand as a perplexed look formed across her face. No, that can’t be, she said. The baby’s head is most definitely in your cervix, where it should be, she assured me. What about this other rounded hardness just below my belly button? A foot, perhaps? Neither of us can determine what this strange object is. I was soon to learn, in a rather blasé way, what those indeterminate objects were. I still remember the name of the consultant who carried out the ultrasound. It was the second ultrasound I'd had in two weeks, prompted by the sudden onset of a pain in my side. The previous one had been my scheduled 32-week scan that focused on the baby alone; despite the size of the fibroids, they remained, at this stage, undetected, as if woman, foetus, and fibroids did not reside in the same body. It was with some irony that I later realised that this separation was also reflected in the hospital's floorplan: ultrasounds for foetuses carried out on the lefthand side of the corridor, scans of mothers' troubling and troubled bodies carried out on the right, pregnancy an inconvenient entanglement of bodies and objects that technology and architecture would separate.



Photograph by Sevasti-Melissa Nolas (2013).

An ultrasound image of Sevasti-Melissa's fibroid. Reproduced from a copy of the author's medical record.

"Fibroids!", the consultant announced, after what felt like an inordinately long silence, punctuated only by the visuals of the ultrasound screen which I could see but not decipher, the baby no longer in focus. He dutifully measured them in centimetres: one was 8cm and the other 5cm which later,[19] post-pregnancy, would shrink to 6cm and 2.5cm respectively. He told me that I would need to make an appointment with my midwife because, looking at my clinical notes, a home birth would no longer be possible. Fibroids increase the risk of postpartum bleeding. I would need to give birth in hospital and under medical supervision. I went home to google "what are fibroids?".

INCONGRUENT GESTURES Primary Postpartum Bleeding

Primary postpartum bleeding is blood loss through the genital tract (uterus, cervix, vagina) following delivery. It can happen any time from the baby's birth and up to 24 hours following. Anything up to half to a litre of blood loss from a healthy woman living in a high-income country is considered minor/mild – as one midwifery textbook notes, half a litre of blood is the equivalent of a routine blood donation, usually inconsequential. Loss of over a litre of blood is considered major blood loss, and obstetric haemorrhage is the second leading cause of direct maternal death in the UK and Ireland.

Cecily Begley: "Physiology and Care during the Third Stage of Labour", in: Jayne Marshall, Maureen Raynor: *The Myles Textbook for Midwives* (Sixteenth Edition), Edinburgh, London: Elsevier (2014), p. 406; Eleni Mavrides, Shubha Allard, Edwin Chandraharan, Peter Collins, Laura Green, Beverly J. Hunt, Solon Riris, Andrew J. Thomson on behalf of the Royal College of Obstetricians and Gynaecologists: "Prevention and Management of Postpartum Haemorrhage", in: *BJOG 124* (2016), pp. e106–e149.

Giving birth in hospital was always how I had imagined it happening: I was born in a hospital, and I was going to give birth in a hospital. But in that first check-in appointment on a mild September day, I was seduced by the idea of a home birth, a 'normal birth'. "There's nothing quite as lovely as jumping into your own shower and climbing into your own bed after giving birth!", my midwife, with a healthy irreverence for children, informed me. And so, much against my own instincts, I started to lose myself in a cosy fantasy of home-birthing for the next six months, and began to write my birth plan accordingly.
The fibroid scan set in motion a series of meetings including a visit to the consultant obstetrician at the hospital, about which I emailed my midwife:

> "I saw the consultant obstetrician this afternoon. I'm attaching a picture of the notes that are in my file. [I did this because, in an unfortunate reinforcement of stereotypes, the notes were illegible, and I had half hoped that my midwife would be able to decipher them]. "He confirmed the fibroid. He did not appear to be too troubled by it, he said the baby's head is all the way in the pelvis now", ["troubled" my original phrasing; "the pelvis", not "my pelvis" – it occurs to me now that I was experiencing my body as somehow other, alien, objectified], "and he seemed to be of the view that the fibroid would not interfere with normal birth. Nevertheless, his initial recommendation was to have the baby on the labour ward, although he agreed that I could start my labour in the birthing centre providing it is possible to have a 'venflon'", [I write in the email like I know what I'm talking about, at the same time as the inverted commas indicate that this was not my language], "inserted in my hand in the BC (birthing centre), just in case. He also said that there was no medical reason not to use the birthing pool or TENS machine for pain relief during labour."
>
> Email (20 March 2013).

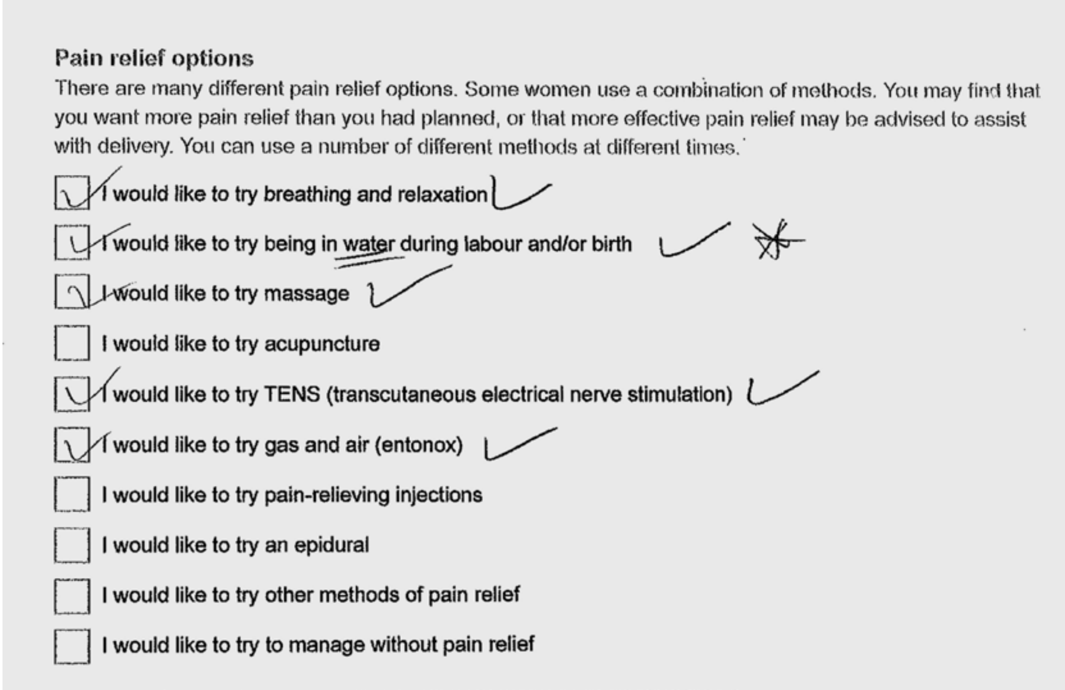
I remember the meeting with him well. Hanging on to the script of 'normal birth' that I had not myself been sure about months before, I had to push for him to agree to me starting labour in the Birthing Centre. The Royal College of Midwifery (RCM) describes the term 'normal birth' as "the most commonly used term to describe an uncomplicated, straightforward physiological labour and birth during the 1990s in the UK". THE RCM acknowledges that 'normal birth' is a term that people who give birth often find problematic and is currently running a research project to build consensus on better and more acceptable language.[20] For the RCM, the term 'normal birth' is "important to many midwives who see it as central to the role of the midwife, the bedrock of what we do and who we are". I am fighting the midwife's fight. I have lost sight of myself – if ever I had eyes on her to begin with. The only thing I seem to be able to hang on to is my birth plan, a last vestige of certainty. "This is clearly a change to my original birth plan", I write in my email to the midwife, the anger and confusion still palpable to me in the text all these years later. I recall it taking me ages to write that email, in the way it still does when I write a complaint or make a case. I want to be unequivocal. My email is business-like; it builds a case using well-structured paragraphs, each one containing a separate thought. Bullet points for the issues I want addressed. This surprises me when I go back over my files.

But the email is also a journey in search of meaning: in the midst of it all is a plea that echoes back at me across time. I want to be spoken to and recognised as a person. A human being. Not (yet) a body with(out) organs to be shuttled between ultrasound machines, labour wards, and birthing centres. I write:

"I would like to get a better idea of what the implications of 'increased risk of post-partum bleeding' means for me as a person and what I can reasonably expect to experience in terms of interventions/care straight after birth and the weeks that follow. I get the mechanics of uterus contracting (or not) and how this relates to bleeding", [I am not sure why I've written this because I haven't got a clue. I think what I mean is that it has been imparted to me that, from a physiological perspective, fibroids can make you bleed heavily], "but I still don't get a sense of what this means for me and the sort of intervention/care that comes with it."

Email (20 March 2013).

Of course, telling someone what they might reasonably expect to experience is in the same sort of genre as the so-called birth plan. "The problem of patient choice" is how Annemarie Mol puts it in her study of diabetes,[21] and the birth plan document provided to expectant mothers is written in the same genre of choice. The illusion that we have a choice is an illusion that blurs and obscures our practices of care. What will happen to me, and how will you care for me, is what I am really asking. Or maybe better still: please care for me, I am scared.



Pain relief options

There are many different pain relief options. Some women use a combination of methods. You may find that you want more pain relief than you had planned, or that more effective pain relief may be advised to assist with delivery. You can use a number of different methods at different times.

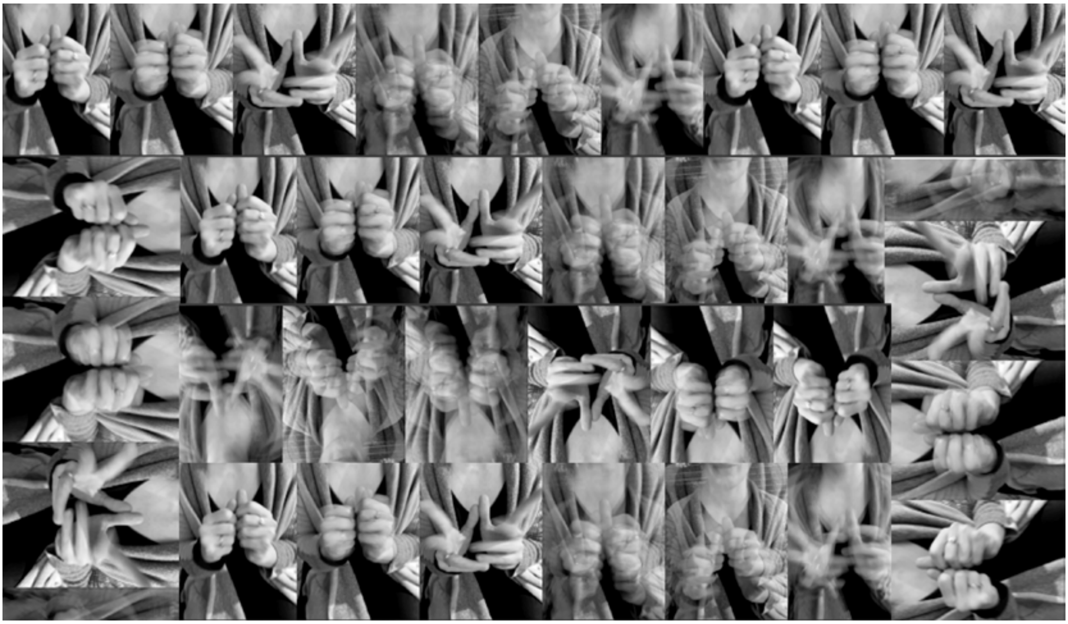
- ☑ I would like to try breathing and relaxation ✓
- ☑ I would like to try being in water during labour and/or birth ✓
- ☑ I would like to try massage ✓
- ☐ I would like to try acupuncture
- ☑ I would like to try TENS (transcutaneous electrical nerve stimulation) ✓
- ☑ I would like to try gas and air (entonox) ✓
- ☐ I would like to try pain-relieving injections
- ☐ I would like to try an epidural
- ☐ I would like to try other methods of pain relief
- ☐ I would like to try to manage without pain relief

Photograph by Sevasti-Melissa Nolas (2012).

A snapshot of my birth plan.

INCONGRUENT GESTURES Incongruent Gestures

Clear communication is prized in clinical textbooks and good practice guidelines. For example, midwifery training emphasises ″the need for midwives to be emotionally aware and develop good communication and interpersonal relationships with women, their partners and colleagues in the interdisciplinary team″ and student midwives are assessed on their interpersonal and communication skills.[22] In the context of primary postpartum bleeding, Guideline 52 of the Royal College of Obstetricians and Gynaecologists,[23] issued in December 2016, lists ″communication with the woman″ as the second most important aspect of the management of primary postpartum bleeding after identifying the severity of the haemorrhage: ″Communication with the patient and her birthing partner is important, and clear information of what is happening should be given from the outset″.[24] Before communication it is a case of minimising the risks.



Still from video by Sevasti-Melissa Nolas (2019).
VIDEO ▶ cache.ch/1737

Re-visiting that hand gesture that was used to illustrate postpartum bleeding to me; performed in my living room six years later, sitting where my midwife sat six years earlier, video recorded by my five-year old at the time of capture.

Yet despite the emphasis on clear communication in the clinical context, research on National Health Service (NHS) complaints suggests that many of those complaints are triggered by safety incidents and poor experiences,[25] including issues around listening and poor communication.[26] ″Bad health outcomes″, as medical anthropologist Charles Briggs puts it, ″provide seemingly indisputable evidence of failed health/communicative subjects″.[27] Arnold and Black make the case that care and communication are very much entangled: communication constitutes and shapes care giving and care receiving practice. The same authors also point out that language goes beyond the verbal and the logo-centric; they make a specific reference to gestures, and note that language as a form of care constitutes an intersubjective endeavour.[28] On the back of my email, my midwife makes an unscheduled home visit early one morning to try to explain what's going on. She feels she owes me that. This hasn't been handled well, she tells me. I am wearing a black wrap-around GAP maternity dress with black tights, the dress a hand-me-down from my best friend. I am due down in Brighton later to present at a conference, a last professional commitment before going on maternity leave. My midwife sits on one sofa. I sit on the other. She starts to explain. She talks about postpartum bleeding. That's what fibroids do. This is why I can't have a home birth. Her words are accompanied by what is supposed to be an illustrative hand gesture, but her words and gestures lie beyond the boundaries of my comprehension. The gesture makes it worse. I cannot even see comprehension as a silhouette on the horizon. The word incongruent derives from the Latin *incongruens*, which means not meeting together. The midwife and I were in the same room, sat opposite each other, bodies upright and still, eyes meeting in a picture-perfect representation of textbook 'good communication'. But we were not meeting together. We go around the fibroid houses several times, circling around and getting nowhere. My midwife's words, their meaning, feel hard and impenetrable, like the benign objects stuck to the outside of my womb. I feel angry, upset, and frustrated. My midwife is really trying to make meaning with her words and her hands, I can see that much. But I still don't understand. I feel like this risk she keeps referring to has no body. It is a ghost, difficult to grasp. I try. "What are you actually saying?" I venture. And then I take a risk, I reach out to touch the ghost. "Are you saying I might bleed to death? Is that what you mean?"

INCONGRUENT GESTURES Configuring Conversations

"The body is not an automaton operated by the person but the embodied person herself. We are our bodies; consciousness is not separated from the body."

Havi Carel: *Illness: The Cry of the Flesh*, London: Routledge (2019), p. 13.

Many a time, when words come tumbling out of my mouth seemingly without volition, I am still surprised by that I who has risen to the surface, who has ventured to risk. What embodiment, what consciousness, was she drawing on?

Complaints are "complex narratives",[29] and labour stories, like many other stories of life and death, get passed down the generations.[30] My mother's labour story was characteristic of the nonchalance and unflappability that I so admire about her: "waters broke in the morning, you arrived mid-afternoon, whole thing nine hours, had to call the friends with whom we were having lunch to ask for a rain check. As it happens, we never saw them again". But this is not the story that I grasp for on this occasion. Instead, my mind wanders down the years to another labour story that has been passed down to me by a son, my father, as a story of how he got his name. It is not the story of his birth but that of his brother, who was born in the north of Greece in the early 1940s. While the details have been lost to time, the labour, so the story goes, was so long, so painful, and so precarious that, at one point, it looked like the mother-and-baby-to-be, my not-yet-grandmother and not-yet-uncle, would be lost to family history. On that late October night, my grandmother did what she had always done when life threw her curveballs: she appealed to the nearest Saint, disrupting long-established name-giving traditions and practices of making family in the process. In Greece, tradition has it that the firstborn daughter/son is named after the paternal grandmother/grandfather, the second-born daughter/son is named after the maternal grandmother/grandfather and so on, crisscrossing the generations. Making good on her pledge, my grandmother gave her first-born son, my uncle, the name of the Saint she had appealed to, with her second son, my father, who arrived five years later, taking the name of his paternal grandfather.

"Spinning, weaving, binding, threading, braiding, and knotting are not only some of humanity's oldest techniques; they are amongst its oldest metaphors. In societies throughout the world, human relationships – including relationships with gods and sprits, with material possessions, and with abstract ideas such as history, society, fate, and destiny – are conceived of as bonds, ties, or strings, while wider fields of relationship are compared to networks, webs, and skeins, or the warp and woof of woven cloth."

Michael Jackson: *Life Within Limits: Well-being in a World of Want,* North Caroline: Duke University Press (2011), p. 158.

Photograph by V. Koutzavelis of Ioannina, Greece (ca. 1937).

My grandmother as a young woman in her engagement photograph. Photograph from the Sevasti-Melissa Nolas family photographic archive.

Post labour, my mind has raced back to this scene – one that I have only ever experienced vicariously through hand-me-down stories and my own imagination – to contemplate another woman's pain and terror and her response to this, a woman whose name I also bear. Yet, despite my grandmother's many concerted efforts, over the years, to instil religious belief in her grandchildren – and granddaughters especially – even as a child I chose to dwell in secularism and popular culture. So, as the midwife moves her hands in mysterious ways in my London living room, I appeal to my own church of popular culture: *The Simpsons.* All I can think about is Mr. Burns from *The Simpsons*. An incongruent and somewhat disturbing image, and I wish my lovely midwife would stop making that hand gesture.

Credit: Everett Collection Inc / Alamy Stock Photo.

Mr. Burns, a character from the Simpsons.

Coming of age in the 1990s, *The Simpsons* was a large part of my media landscape, even if I did not watch the show with the same fervour as the Japanese manga cartoon *Candy Candy*, or later *90210* and *Twin Peaks*. *The Simpsons* was always on, always there, providing a pitch-perfect parody of family life, schooling, nuclear energy, religion, femininities/masculinities, intergenerational relationships, and popular culture itself. As Jonathan Gray points out, parody ″has a great power and potential to write back to and even write over other texts and genres″,[31] a fertiliser for rhizomes and other living matter, we might say. The show's main parody character in particular – Bartman, Bart Simpson's superhero alter-ego – created what Mortiz Fink has called a ″remix culture″:[32] ″popular culture's practices of semiotic reworking and remixing″ by fans off-screen. Mr. Burns is Springfield's nemesis, a symbol of power and impending harm, a nuclear plant manager ″unconcerned for [his employees] safety and well-being″,[33] and clearly at least one woman's idiosyncratic figuration of the risks of postpartum bleeding. At the same time, Mr. Burns' hand gesture is an embodied memory for me, a gesture that my friends and I would bring out in those liminal spaces between classes, during breaks, and in our own time, as we hatched plots that no adult in authority could endorse. We did the Bartman on Mr Burns. And so, as a child of the MTV generation, in the face of a painful memory, I find myself once again doing the Bartman.

INCONGRUENT GESTURES Re-claiming the Benign

In this final section, I take up the opportunities offered by parody and the remix culture to reclaim and recast the benign. According to the Oxford English Dictionary, the term benign is derived from the Latin *benignus*, probably meaning well (*bene*) born (*genus*). Benign in medical terms, and in gynaecology specifically, is used to denote a non-cancerous growth. My own and other women's experiences of living with fibroids, as documented in scant qualitative research literature on the topic,[34] suggests that benign is far from the case.

"I remember having sort of heavy periods but they might have been more clotty periods early on and them being difficult to manage and not very nice but certainly this potential for flooding is scary. It's scary. And I've been caught out. I've been in a situation where I drove to the Trafford Centre shopping with my daughter and I had tampons and pads on and I stepped out of the car and there was this woosh and fortunately my daughter's a doctor so she's quite comfortable, she wouldn't have been embarrassed or anything by that. But I was terribly embarrassed. I couldn't move, I couldn't walk forward or backward and of course I had to send her into Marks & Spencer to get me some clothing, all of that. So it could be as bad as that standing up from sitting down somewhere at work and then realising your skirts or your trousers and got to deal with that kind of thing. Being kind of anxious about that possibility. Yeah, so yeah it can impinge on what you do. I tried not to let it impinge on things. I said I liked walking I try not to let it impinge on things like that but I'd be talking about stacks of supplies going round here there and everywhere with me that kind of thing. So, yeah, I think you perhaps know that other people struggle like that but you almost don't say anything, sort of feel I've got to manage it, I've got to cope with it. I can't say I'm going home now, I'm having a terrible day of it. You've got to just keep going."

Interview with Charlotte by Healthtalkonline (December 2008).

TalkHealth, an archive of patients' stories, hosts a single story of living with uterine fibroids. Charlotte, a 54-year-old African Caribbean woman, talks about her heavy periods and flooding.[35] She is diagnosed with fibroids and talks on camera about the different ways that she tries to manage her condition without initially going down the hysterectomy route. At the time of filming, however, she plans to go to her GP to ask for a hysterectomy.

I spend many months after the birth of my son living in chronic pain. I am unsuccessful in convincing my general practitioner (GP) to take my sciatica and chronic lower back pain seriously, in what has become an all too familiar story of what happens when women in pain encounter the medical profession. I am fobbed off with painkillers and the instruction to "do some stretches". My periods have also become ridiculous. In the end, it is a woman GP who makes the referral to a gynaecologist: a GP who happened to be available on the day and time I could make an appointment, who happened to be pregnant, and who also happened to be experiencing fibroids herself. It would take another GP referral, six months after the first one, to convince the sonographer and the duty gynaecologist (both women) at the same hospital I laboured in of the need for a laparoscopy to have the fibroids removed.

I review my own correspondence with friends and family in the period post-surgery and find that the fibroid's materiality has become an object of curiosity for both myself and for others. I am trying to imagine the embodiment of this invisible thing, to imagine what space it occupies in an already crowded body, how much it weighs. This materiality is important, carrying meaning and feeling. It is a materiality that, in medical jargon, is reduced to the benign through analogy to healthy and 'natural' objects, such as fruits and vegetables as well as the size of a foetus measured against weeks of gestation. Fruits and vegetables are used in clinical settings as descriptors of fibroid size: mine were approximated to me by the doctor who did the original scan pre-labour as the "size of an orange" and "the size of an egg". These are small to medium sized fibroids. Footballs, grapefruits, and watermelons are sometimes also conjured up in conversations. As Marina Benjamin writes in her memoir of hysterectomy and the menopause:

> "As it was, menopause arrived with no preamble, being handed to me by apologetic surgeons like the booby prize in the hospital raffle. The surgeons had excised my uterus, which with its *heavy load of fibroids weighed roughly the same as a bag of tangerines*, and my ovaries had gone with it in a two-for-one deal. Approaching 49, I found myself barren and in shock. Whatever dignity (if so might be termed the stuffing up of my fear) that I had momentarily mustered to sign the medical waiver lay in tatters around the hospital bed."
>
> Marina Benjamin: *The Middlepause: On Turning Fifty*, Melbourne: Scribe Publications (2016), p. 18. Emphasis added.

So, what might it mean to do the Bartman with these troublesome objects and to reclaim the benign?

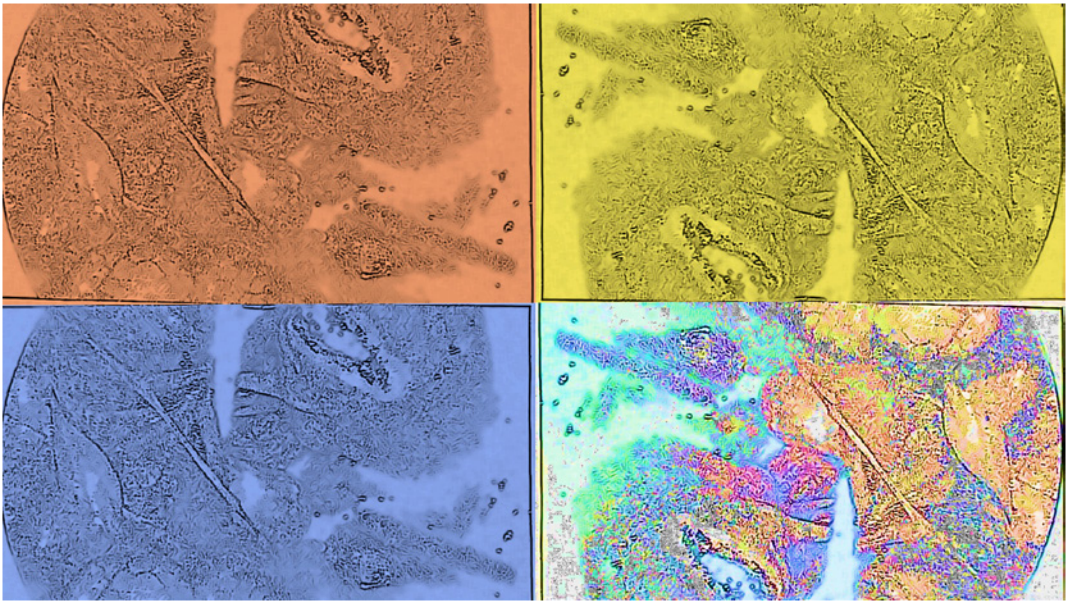
Life writing in the form of memoir is a well-established feminist practice which recognises the personal as political. "Memoir", Alison Light writes, "weaves its way between what is often called the private and the public"; it provides a "history from the inside".[36] The 'inside' I am concerned with is the private, in Light's terms, figured as that is in the affective and the everyday, but also more literally my 'insides' – that is, the areas of my body that, in this case, can only ordinarily be accessed through the imagination or with the help of medical imaging technologies; and I cannot do it with words alone.

Margate-based artist Hayley White makes large-scale charcoal drawings re-imagining the MRI scans of her twin fibroid: "The circle is the cell, the earth, moon, and sun. It's Gaia. The beginning and the end and everything we are and are not. Granular and galactic [...]" she writes about this drawing in the comment field under it on her Instagram.[37] Her fibroid series,[38] *Map: Finding Fibroids* (2020),[39] an artist's book made to be the same size as the largest fibroid in her womb, and *Glory Box* (2020) are creative expressions to understand, in her words, a medical condition. White's *Glory Box* and *Map* perform what Celia Lury and Nina Wakeford note of inventive methods, an "expansion of the present" and a "maximization of the agencies involved in social life".[40] The fibroid comes out of the body; it can be held and shaped, interrogated, and reconfigured. Even perhaps be made fun of. My own attempts are somewhat more prosaic; I find myself gravitating towards pop art as a way of loosening the hold this object has had on my body and mind, to inject some hedonism into those wholesome fruit and veg discourses. I also, as always, seek refuge in humour, and I return to laughter.[41]

Photograph by Hayley White, Charcoal on canvas 150cm x 150cm (2022); used with permission from the artist.

Photograph *Glory Box* by Hayley White (2020); used with permission from the artist.

Sculpture and artist's book *Glory Box* is 8cm square (the same size as the artist's largest fibroid) made with blood rag, string and images of MRI machine, hadron collider, photos of flint (stone) and fibroid scans. The box remains empty unless it houses one of the artist's smaller amulet sculptures.



Artwork "Remixing the benign: a Bartman homage to my fibroids" by Sevasti-Melissa Nolas.

Before going under the anaesthetic for my day surgery, I asked the surgeon to keep the removed fibroids. In a Michael Taussig *I Swear I Saw This*[42] moment, I wanted to see the pesky things when I came around. "Why?", the surgeon asks. "I'm curious", I respond. "What do you do as a profession?", he asks. "I'm a researcher", "What of?", "Health services", I say. This was a very-clunky-though-not-entirely-untrue shorthand at the time that I used to use to describe myself professionally when in a medical context.[43] He can't see the relevance of a health services researcher being curious about her insides. Nevertheless, he follows my wishes. When I come around, I am brought these benign objects to examine for myself. "Are you the lady who wanted to see her fibroids?", the recovery nurse asks me. "Yes!", I respond with as much enthusiasm as I can muster coming out of general anaesthetic. She puts what looks like a large yoghurt Tupperware under my nose, and I peer into the receptacle with child-like glee at the chopped up orange and scrambled egg.

INCONGRUENT GESTURES Coda

If care and communication are very much entangled,[44] then what this rhizome of an essay attempts to demonstrate are the many fibrous and sinewy threads that make up that entanglement. The attempt to perform configuration, to shape communication and care together, in medical encounters and in their re-telling necessitates a troubling labour across modes and media, time and space, the fictive and the real. Deleuze and Guattari's root-book, the classical book that imitates the world, the book beloved of experts, is useless in configuring life and death conversations.[45] Instead, and what I have attempted here, is an extraction of the principal root of binary logic - midwives versus doctors, vaginal versus C-section births, breasts versus bottles, crying it out versus co-sleeping - in order to graft a more radicle and radical form of showing and telling of care and communication through incongruent gestures, folded over, made anew, more hopeful than first experienced, drawing the reader into, I hope, the fecund mess of imagining things otherwise.[46]

Notes

1 Medical records will only record what is described as 'active' labour: the period of time following the rupture of the membranes and the dilation of the cervix more than 6cm.

2 NICE Guidance: "Caesarean Birth", in: *NICE National Institute for Health and Care Excellence*, https://www.nice.org.uk/guidance/ng192/chapter/Recommendations (March 2021).

3 Jenn Ashworth: *Notes Made While Falling*, London: Goldsmiths Press (2018); indeed, the original title of this essay was "Incongruent gestures: configuring conversations between life and death".

4 An earlier version of this essay was presented at the Critical Public Health workshop organised by Flora Cornish and Cathy Campbell at the London School of Economics in December 2019, as well as the Interrogating Speculative Futures workshop organised by Natassia Brenman and Natashe Lemos Dekker at Goldsmiths, University of London in July 2021. I am especially grateful to both Rochelle Burgess and Annelieke Driessen, respectively, for being such gentle and generous discussants. I thank Dominik Mattes and Janina Kehr for including the essay in their edited publication even though I was not able to present at the linked conference, and for all their enthusiasm and support of the project. Ellie Walton has, once again, been copy editor extraordinaire. I thank Julia Koroknai and Friederike Rosenbaum for all the hard work on formatting this essay. I am so grateful to dear friends, and my family, near and far who supported and encouraged me to write this essay, who read various drafts, who fed back, forwards and sideways, and who laughed and cried with me in all the right places.

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13 Sevasti-Melissa Nolas, Christos Varvantakis: "Entanglements that Matter", in: *Entanglements* 1/1 (2018), pp. 1–4; Gilles Deleuze, Félix Guattari: *A Thousand Plateaus*, Minneapolis: University of Minnesota Press (1987), p. 3.

14 Laura Marks: *Touch: Sensuous Theory and Multisensory Media,* Minneapolis: University of Minnesota Press (2002); Gilles Deleuze, Félix Guattari: *A Thousand Plateaus,* Minneapolis: University of Minnesota Press (1987).

15 Sevasti-Melissa Nolas, Christos Varvantakis: "Entanglements that Matter", in: *Entanglements* 1/1 (2018), pp. 1–4, p. 2.

16 Brian Massumi: "Translators Foreword: Pleasures of Philosophy", in: Gilles Deleuze, Félix Guattari: *A Thousand Plateaus*, Minneapolis: University of Minnesota Press (1987), pp. viiii–vx.

17 Sevasti-Melissa Nolas: "Towards a New Theory of Practice for Community Health Psychology", in: *Journal of Health Psychology* 19/1 (2014), pp. 126–136.

18 Ruth Behar: *The Vulnerable Observer*, Boston: Beacon Press (1996); Andrew Irving: *The Art of Life and Death: Radical Aesthetics and Ethnographic Practice*, Chicago: University of Chicago Press (2017); Michael Jackson: *The Accidental Anthropologist: A Memoir*, Dunedin: Longacre Press (2006); Jenn Ashworth: *Notes Made While Falling*, London: Goldsmiths Press (2018); Hilary Mantel: *Giving up the Ghost: A Memoir,* London: Fourth Estate (2010); Maggie O'Farrell: *I am, I am, I am: Seventeen Brushes with Death*, London: Headline Publishing (2018); Marina Benjamin: *The Middlepause: On Turning Fifty*, Melbourne: Scribe Publications (2016); Charles W. Mills: *The Sociological Imagination*, New York: Oxford University Press (1959).

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20 THE RCM acknowledges that 'normal birth' is a term that people who give birth often find problematic and is currently running a research project to build consensus on better and more acceptable language (https://pre.rcm.org.uk/rebirth-hub/what-is-the-rebirth-project/).

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43 Following my PhD in 2007, I did a six-month stint working as a researcher on a health services research project at a central London university, after which I spent a further two years working as a researcher and evaluator of child and adolescent mental health services.

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45 Gilles Deleuze, Félix Guattari: *A Thousand Plateaus*, Minneapolis: University of Minnesota Press (1987).

46 Gilles Deleuze, Félix Guattari: *A Thousand Plateaus*, Minneapolis: University of Minnesota Press (1987).

Stefan Reinsch

LIFE EXPECTANCIES Surviving Predictions

"My parents were told I wouldn't survive until the age of ten. When I got to the age of ten, I heard doctors say, 'You won't live until eighteen'. When I had beaten that age, and was twenty, then I was told that I wouldn't reach thirty. Now I am heading towards fourty [...]. That's how, somehow, I smuggled myself through life until now."

Interview with Ricky (2007).

Ricky grew up in a small town in southern Germany in the 1980s. He was born with cystic fibrosis (CF), a rare, progressive, and ultimately fatal genetic illness affecting many organs. At the time of Ricky's birth, life expectancy for someone with CF was around eighteen years in so-called developed countries.

Photograph by Johannes Rascher (2007).

Ricky during a hospital stay. He is holding a box of pills in his right hand. The shirt's logo states: "Der Sonne entgegen" ("Towards the sun"). On his left arm is the name of the island where he worked as surfing instructor. The images in this essay are part of a photo-ethnography project, in which Johannes, a photographer, and I followed people with CF through their lives. All people agreed to be part of the photo-series, as well as to online and print publication.

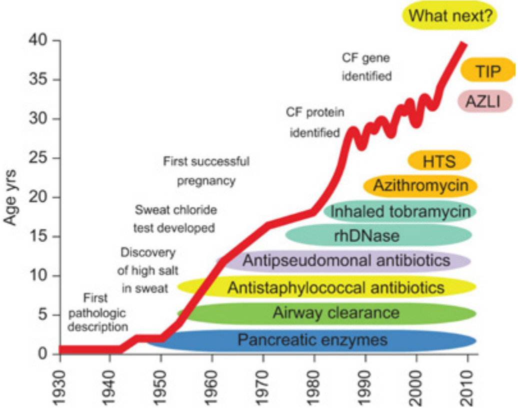
After his CF diagnosis as an infant, his parents abandoned him at an orphanage. His parents' radical rejection of him and his illness arose from an extreme position that several adults with CF, as well as some CF physicians, have related to me. At the time, health professionals sometimes advised caregivers against developing close attachment to a child with such a diagnosis. Speaking about growing up with CF, Ricky told me how he had repeatedly beaten the predicted life expectancy. I met Ricky for the first time in 2007 at a time when he was admitted for two weeks to the hospital ward where I was doing ethnographic research for my dissertation. He was then 36 years old, and the life expectancy for people with CF in Germany had doubled since the year of his birth. I found him to be an athletic and positively minded man. He was working part-time in a hardware store, leaving him the time necessary to do his therapy. At one episode in his early thirties, his health had deteriorated, and Ricky asked his employer for extended leave to work as a surfing instructor on one of the German islands in the North Sea – a place where people with CF go for climate cures. Ricky's creativity impressed me, as inhaling vapours from saline solution and physical exercise are two pillars of therapy for CF. After I graduated to become a physician, I started to work as a paediatrician in a university hospital in eastern Germany to be able to continue research with Ricky and the other young people who have CF.

I wanted to understand his endeavour to live a good life, while being confronted with his mortality, and the wearying threat of a worsening infection that could ultimately be fatal, thus defying repeatedly the odds of survival.

Indeed, Ricky was exceptional at this, and by telling his story, I now attempt to put words to this life with CF – a state that we physicians, and likewise patients living with CF, have found difficult to grasp. The changing demographics over the last decades have placed people with CF in a pioneering situation: few if any have previously enjoyed this position, so there have been scant role models among people with CF, leaving them to improvise their life in the course of living it.

LIFE EXPECTANCIES Cystic Fibrosis Care

CF is a hereditary disease affecting one in 2'500 people in Europe. A multi-organ disease of variable severity, its clinical hallmark is frequent respiratory infections that lead to progressive scarring of the lung tissue. Although currently there is no cure for CF, medical therapies can slow its progression.[1] Despite initiation of treatments in the first years of life, most people with CF will come to require a lung transplant at some point in their lives; those who do not receive a transplant often die from respiratory failure.[2] In Europe and North America, the life expectancy of someone with CF is now approximately fourty years, having continuously risen from about fifteen years in the 1960s. The development of a complex and demanding therapeutic regimen accounts for this substantial increase in life expectancy,[3] notably in including the introduction of basic-defect modulators. Current therapy involves approximately two hours of inhalation and chest physiotherapy every day, and up to seven different oral medications.[4] Despite optimism arising around the new and highly expensive therapies, life expectancy remains several decades less than among peers without CF. Adherence to the onerous therapeutic regimen is reported to be around 50% among CF patients.[5] This poor adherence to the complex, time-consuming therapy is the main cause of treatment failure and clinical exacerbation.[6] However, factors other than the regularity, number, and intensity of therapies can influence clinical progression of CF.[7] Independent factors in progression include gender of patients, their socio-economic status, and the place of treatment.[8]



J. Stuart Elborn: "Personalised Medicine for Cystic Fibrosis: Treating the Basic Defect", in: *Eur Respir Rev* 22 (2013), pp. 3–5. © European Respiratory Society, reproduced with permission.

Demographics with key dates and advances in CF care from the 1930s. Reproduced with permission under the Creative Commons Attribution-Non-commercial 4.0 licence. Original captions: Schematic illustration of how the introduction of novel cystic fibrosis (CF) therapies influenced patient survival over the decades. HTS: high throughput screening; AZLI: aztreonam for inhalation solution; TIP: tobramycin inhalation solution.[9]

LIFE EXPECTANCIES A Full Life

Phenomenologists have argued that the existential dynamic of people with CF is defined by continual biographical revisions in anticipation of their future illness trajectory and life course.[10] The experience of living with CF is like moving on uncertain terrain, pursuing a future that is threatened and continually redefined.[11]

"I want us to stop using the 'Life Expectancy' Statistic. Cystic fibrosis *life expectancy* gets tossed around like any number of statistics in the medical world. It's something that people love to talk about or use to show success and progress. [...] Now, I totally understand why the life expectancy stat is thrown around so loosely. It's used as a fundraising motivator, a sign of medical/scientific success and a notice for what a family can expect in life for a son or daughter who has just been diagnosed with CF. Certainly we use it [...] to show progress, but also why it is so important that we keep the fight going. The bottom line is that we still have a really long way to go, and at the end of the day, cystic fibrosis is still a killer, so it remains *terminal*. The only people that ever talk about it (other than right now) are people who don't have CF. I can tell you that I've never had a conversation with another CF patient and said, 'so what do you plan on doing with your 51 years of life?' [...] My goal in life is not to outlive the life expectancy of CF – I think that sets the bar too low – rather I want to live a full life [...]."

Gunnar Esiason: "I Want Us to Stop Using the 'Life Expectancy' Statistic", https://www.gunnaresiason.com/life-expectancy/ (15 November 2016).

Statement of a young man with CF.

People with CF are born with the condition, so they have never not had CF, and consequently do not know what it is like not to have it.[12] Otherness is part of the burden of living as a young person with a fatal chronic illness.[13] Like in many chronic conditions, belonging to the world of the healthy is something that young people with CF deeply desire.[14] Although mainly an invisible illness, CF can become apparent through frequent exacerbations of chronic respiratory infections, but also via the intrusive daily therapy that prevents exacerbations.[15] When disabling conditions like CF become visible, or what Goffman has called "discredited" or "stigmatized",[16] 'normal' people may react with staring; as a result, social interactions become uncertain and ambiguous, problematic, tense, or even awkward.[17] For people with CF, avoiding unwanted scrutiny or stigmatization, passing as 'normal', and achieving a sense of belonging to the world of the healthy, are therefore conditional on the absence of noticeable symptoms of their illness.

Photograph by Johannes Rascher (2007).

A couple during an admission at the CF ward. One of the partners has CF.

LIFE EXPECTANCIES Shared Doctoring

Often people with CF like Ricky do not at first glance appear to be sick. To outsiders, their illness may become invisible through their therapy, but if they conceal their therapy from others, the therapeutic work that made their illness invisible also becomes absent from the perspective of outsiders. The young people with CF, whom I met in the course of my ethnographic research, fervently aspired towards the attainment of seeming normality. Invisibility of illness is achievable with the help of the very complex and demanding therapeutic regimen.

"The thing about patients with CF is that they're good scientists. They always experiment. So, they stop doing their treatments. And what happens? They don't get sick. Therefore, they conclude, Dr. Warwick [one of the most eminent CF physicians in the US] is nuts. [...] We must help them interpret what they experience as they experiment."

Atul Gawande: "The Bell Curve: What Happens When Patients Find Out How Good Their Doctors Really Are?", in: *The New Yorker* (6 December 2004).

This therapy allows people living with CF to acquire a new, albeit temporary, 'healthy' self. The absence of symptoms visible to others is, however, not stable, but a liminal state that is revocable at any moment. One reason for this is the complex daily therapeutic regimen which consists of taking pills by the handful, exercising vigorously, and undergoing chest physiotherapy and inhalation therapy. Much of this burdensome and time-consuming therapy occurs at home, thus limiting the time available for 'normal' activities. Besides, patients consider their treatment as a marker of illness and stigmatisation.[18] Acknowledging the 'burden of therapy' they face and claiming the kinds of social support to which they are entitled as 'disabled' people may come with the loss of a sense of belonging in the land of the able bodied.[19] Many young people with CF deeply desire a temporary citizenship of that figurative country. Especially adolescents and young adults with CF contend with a continuous challenge to integrate the therapeutic regimen into their daily life, along with school, work, and engagement with family, friends, and leisure activities.[20]

Aiming to merge seamlessly with the life of their healthier peers, young people with CF employ an arsenal of tactics to hide the strenuous efforts behind their appearance of normalcy.

Considering these ambivalent effects of therapy, and given that nobody can be one hundred percent compliant with long-term treatments, some authors have suggested that educated non-adherence to a treatment may be an adaptive way of coping.[21] Other clinicians have gone a step further, suggesting that a reasonable strategy for clinicians would be to aim towards "educated non-adherence", implying that the patient is capable of deciding, together with the CF team, what is important for him or her and what might be skipped for a certain time. In this pragmatic view, adjusting medication and therapy-related decision-making are joint efforts, whereby a patient with CF and the health care providers arrive at a compromise or optimization about what minimal therapy suffices for the patient at a certain moment to live a good life.[22] The next sections present some collaborative experiments in everyday life with the aim to achieve such a good life. In these experiments, professional knowledge and therapeutic decision-making are linked with patients' tactics and expertise, thus presenting examples of what Mol, Moser and Pols have called "shared doctoring" and "therapeutic tinkering".[23]

Photograph by Johannes Rascher (2007).

A handful of pills along with each meal that become 'absent present' therapy, once swallowed.

LIFE EXPECTANCIES Still Be Ill in a Week

"When I was still at primary school, some teachers sent me home when I was coughing, saying 'come back when you are healthy'. But I would still be ill in a week! So, I realised that I didn't have to cough as much if I didn't inhale in the morning. Smart, aren't I?"

Interview with Adriane (2007).

One frequently employed tactic in dealing with chronic illness is to disclose it only to certain people or in certain circumstances.[24] However, the visibility and frequency of CF therapy makes difficult this tactic of passing and covering.[25] As a result, people with CF sometimes abandon their therapy altogether, in hopes of appearing normal in the public sphere. Adriane, a 22-year-old patient with CF and a medical student, reflected upon this decision as a double bind: To appear normal during a period of relatively stable health, she had to neglect her therapy. Although this young patient did her inhalation at home, she still appeared ill to her peers and teachers when she coughed in school. Insofar as coughing made her illness apparent, the therapy was not effective. Even if it led to better health in the long term, inhalation therapy had the adverse effect of making her illness conspicuous.

Photograph by Johannes Rascher (2007).

Physiotherapy session to mobilise mucus.

When more treatment leads to symptoms that are more visible, like increased coughing due to respiratory treatment, while less treatment leads to greater chances to spend time in activities with peers, skipping therapy can seem a rational choice.

This conundrum is not limited to schoolchildren. To compensate for the visibility of treatment, adult CF patients may overemphasize their ability to fulfil social roles and their capacity for autonomous functioning, while at the same time reducing visibility and the burden of therapy.[26] The dilemma of disclosure for people with potentially 'invisible' chronic illness, and the incumbent threats to emotional and physical wellbeing is an issue for many conditions.[27] With CF, visibility is something that is not firmly in the patient's hands, but rather in a precarious state; a time with absence of visible illness is something revocable at any moment by unexpected exacerbations. The medical literature generally attests to how therapy has the potential to make an illness invisible. In CF, however, therapy can have the opposite effect, as with the necessity to cough after inhalation therapy.

LIFE EXPECTANCIES Tinkering with Therapy

"My colleagues told me 'Maja, you really look bad'. Then I called the CF ward and asked to be admitted.
This was a semi-social admission; my physician and I were totally clear about it. It was just too much with work and private life at that moment […] I consider doing my therapy, in the way that it now fits into my life, as a disadvantage, because you don't belong to any group. You are not part of the ill ones […] but neither are you part of the healthy ones. That makes it difficult, because you must justify yourself whenever you try to integrate yourself [into either group]. You are not part of any group, and you must excuse yourself for what you don't have – illness or health."

Interview with Maja (2007).

Tinkering with their therapy over extended periods, people living with CF become experts in an emerging "medical form of life"[28] that feeds back into their relations with clinicians and researchers, their body, and with fellow patients. Their garnered experience allows them to recognize hints that their basic therapy is failing, which calls for taking different measures. One tactic is to seek admission to the CF ward, which extracts them from the public space and into the protected space of the hospital. Another tactic is fitting even more therapy into their life. A discussion about the respective merits of both tactics evolved on the CF ward when, during an interview with Maja, a 32-year-old physician who herself has CF, a younger patient with CF, Adriane, entered the room. Maja had just related how she had continued working, ignoring her worsening health state resulting in worsening of her chronic respiratory infection, called acute exacerbation. When her colleagues gently prevailed upon Maja to take a sick leave, she organised with her physician a two-week admission to the CF ward for a course of intravenous (IV) antibiotics.

Photograph by Johannes Rascher (2007).

Frequent courses of aggressive antibiotics lead to scarring of accessible veins. This makes placing an IV access a procedure that requires skill and time. Some patients would know where to find a good vein that was not visible, and a physician who was not skilled in the eyes of the patient would not be allowed to 'try' puncturing this vein. The physician shown in the image was called upon in such a situation. Before the image was taken, he had asked the patient to warm his arms under running water for five minutes to dilate the veins and make them more visible. In addition, he was using a yellow needle that is comparatively small and flexible, making it easier to access small veins, but more difficult to puncture the scarred veins in CF patients.

Adriane was in a similar situation of a worsening infection. While her physician thought Adriane should enter hospital for a course of IV antibiotics, Adriane herself was reluctant to suspend her daily life for several weeks. She wanted to continue attending her classes at medical school and go on an excursion. Her physician and she settled on a home IV course that would allow her to participate in daily life, with the only restriction of carrying an IV line under her shirtsleeve, which she had to connect to a self-compressing container carried in her trouser pocket. This technical fix became problematic as the aggressive antibiotics used in CF led to clogging of Adriane's veins, a frequently occurring difficulty. During the interview with Maja, Adriane entered the room and asked if Maja, whom she knew to be a physician highly skilled in the procedure, would be able to place a new IV access. Adriane explained she was having trouble finding an on-duty physician at that time. She needed to start her next cycle of IV therapy while in between two classes, which made it difficult to wait until a physician on the ward became available. Adriane did not have time for this now. She had already assembled all the necessary materials, so Maja had only to place the needle. This ordinarily simple procedure required more skill than on a regular patient though, as many superficial and easy-to-puncture veins will have scars from the repeated antibiotics courses. As a result, it often takes several minutes to locate and puncture a suitable vein, even in young patients.

Recruiting a fellow patient to help her out seemed somewhat on the fringes, but this expedience shows how the situational and embodied knowledge of the two patients interacted.

This helped formulate a tactic to replace the blocked IV line without attracting undue attention. The aspiration was that none of Adriane's fellow students should notice she was on an IV course or ask questions concerning her prolonged absence, so that she could continue fitting therapy into her life. The situation that young people like Maja and Adriane faced seemed like a double bind: The more therapy they did, the better they looked to others, but the better they looked, and the more their illness and need for assistance became inconspicuous, the higher were people's expectations regarding their level of functioning. Years of experiencing this double bind led Maja to see fitting therapy into her life as a disadvantage.

LIFE EXPECTANCIES Immigrants to Health

"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick."

Susan Sontag: *Illness as Metaphor*, New York: Farrar, Straus and Giroux (1978), p. 1.

Invisibility of illness leads to heightened expectations from others regarding the patient's social functioning, and not belonging to what might be called the "kingdom of the ill", as famously described by Susan Sontag in her book, *Illness as Metaphor.*[29] The double status of someone with CF – at once inherently ill and sometimes appearing healthy – results in unintelligibility of the patient as a person with a chronic illness, as most outsiders will try to sort them into one group or the other.

Photograph by Johannes Rascher (2007).

While on the ward for a course of IV antibiotics, two young people with CF went out shopping. In this image, you can see the plastic tube of the IV access protruding under sleeve of the woman's right arm. While not officially sanctioned, health care providers sometimes tolerate such excursions, as they enhance participation in life. I am fond of this image, as it reminds me of the flexible approach of the CF ward, as well as of the precarious aspect of visible normality in people with CF from the perspective of outsiders.

The ambivalence of visibility obliges patients to negotiate conflicting priorities that can only be reconciled temporarily and in part. Reflecting upon these negotiations longitudinally, with consideration of how they evolve over the course of life, shows that a patient's tactics have undergone evolution over time and in response to evolving therapeutic regimen, whereby they shape identification. Identification as a person with CF changes when CF remains invisible, and therapy has become unproblematic. In this regard, one particularly interesting narrative to emerge from this study was that of Magdalena, a 32-year-old woman with CF. She spoke openly and energetically as we talked about living with a chronic illness, and how life with CF had evolved since her childhood. Asked to describe the experience of growing up with CF to people unfamiliar with the condition, she introduced the theme of migration as a metaphor.

"When I was an adolescent, I said, 'Hi my name is Magda, and I have cystic fibrosis'. I was rather harsh and quick, but this was a process of identification. [...] Today, I consider my cystic fibrosis to be like my migrant background. It made me who I am, but it doesn't define me. Now, for half a year I've been taking a new medication[a recently introduced basic defect modifier that is specific for certain mutations] and currently you may not notice my CF. A while ago I met a young man, and we had a couple of dates. I only told him on the fourth or fifth date that I had CF, and he said he hadn't noticed. [...] A couple of dates later when we were eating together, I took pills, digestive enzymes. And he said, 'I completely forgot that you have this CF'. That would not have been possible half a year ago, because now I don't have to cough anymore. Despite a lot of therapy, and especially towards the evening, [I would have to cough] if a lot of sputum had built up. [With this new medication] identification with the illness will be different in the future, just as the question what my environment notices of my illness."

Interview with Magdalena (2021).

For Magdalena, as with many young people I encountered in the course of my research, CF was not only a medical condition that she had, but also an 'identification'. While this identification did not mean she was living according to the dictates of some convention, her illness was not something that she concealed, but rather spoke about openly. She learned that "it is no use hiding; people will find out anyhow". The degree of visibility declined, however, with the advent of new therapies, and this in turn changed the awareness of others about her illness, and thus changed the identification.

Over the years, I came to understand living with CF like a temporary migration into the land of the healthy.

The daily process of migration through therapy is hard work. Belonging to the world of the healthy is revocable at any moment. Belonging is liminal, being neither strictly to the group of the healthy, nor to the group of the ill. By this, I mean that therapeutic work helps people with CF to become immigrants to the land of health. The term derives from the self-understanding of some people with CF, i.e., it is an emic concept, arising from the native point of view. This neatly inverts Sontag's metaphor of illness as migration to the kingdom of the sick. Unlike in Sontag's cultural analysis of tuberculosis and cancer, the metaphorical process of migration in CF is not from health to illness, as people with CF have always had CF. The metaphor of entering the land of health differs from the concept of "biosociality" as developed by Rabinow.[30] While entry temporarily effaces membership in or identification with the group of the ill, despite the shared biomedical features, therapeutic migration is the counterpart of biosociality. According to the progression of the illness and developments in therapy, the migration needs constant re-adjustment. The process of migration from the land of the ill to that of the healthy never comes to an end, but is always temporary and subject to revocation. For people like Ricky, Maja and Magdalena, we might think of it like a non-permanent visa. This metaphor differs importantly from the concepts of "biological citizenship",[31] "pharmaceutical citizenship",[32] and "therapeutic citizenship".[33] Therapeutic immigration does not lead to citizenship, be it biological, therapeutic or pharmacologic, as might be said of people taking a medication. Moreover, those concepts postulate a status coming with a set of rights and responsibilities that derive from taking a medication, or from adherence to therapy. The identity as an immigrant to the land of health remains liminal, since one occupies an intermediate and shifting position poised between illness and health. For people like Adriane, who chose not to use the 'visa', hiding therapy comes with the additional cost that no particular rights available to chronically ill or disabled people derive from this liminal status. For them, I propose that their immigration remains an asylum, a position of security that is revocable at a moment's notice.

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Rachel Kingsley

UNCERTAIN LEGALITY Friendship

"Friendship is not built on promises,
but actions."

Unknown.

Stephen and I met in 2006 and we were instant friends. We were both coming into adulthood, finding ourselves and figuring out who exactly we were. Throughout my life, I had a tumultuous relationship with my mother, one that often turned physical and emotionally abusive. I thought the freedom of attending university, even while still living with her, would help the situation, but the relationship continued to deteriorate. I dropped out of university during my first semester and moved out on my own. I started to find a peace and a freedom that I had not yet experienced under the weight of the explosive relationship at home. Stephen and I both worked dead-end jobs that barely paid the rent and we both struggled financially and socially. Our friendship grew, nonetheless. We'd stay up late at a coffee shop and talk for hours and hours, most nights of the week. He learned about the abusive relationship I had with my mother, and I learned about his childhood in New York. Between conversations about our day and stories that made us laugh until we cried, Stephen told me about the death of his father, and he learned about my father's suicide. After a few years of drifting through adulthood, I started to make plans for my future, but Stephen seemed stalled. He never spoke about his future and brushed off questions about college or traveling; he simply said he was taking a gap year so that the conversations surrounding his future were diverted to other topics and the questions ended. But his gap year became gap years and his progress became static.

Finally, after years of inquiries and stalled plans, Stephen disclosed that he was "undocumented".

Admittedly, I didn't understand what that meant, and I certainly didn't understand the social, political, racial, and cultural circumstances that surrounded the experience and meaning of being undocumented in the United States. I did, however, understand that our futures were both laid out for us, except, I was the only one that could escape the fate that I was leaving behind. Stephen knew that most people didn't know what it meant to be undocumented, especially during a pre-9/11 America.

"Remember, this was 15 years ago... nobody really knew what undocumented was and there wasn't DACA [Deferred Action for Childhood Arrivals] or Dreamers [Development, Relief, and Education for Alien Minors]. People didn't know. Unless you were involved in that situation, you probably didn't know. The people that knew—you were my friends; you understood and didn't judge me for it."

Conversation with Stephen (2020).

Learning of Stephen's undocumented status helped me understand why he could or couldn't do or explain certain things. At that time, I was not aware of how Stephen's undocumented status would impact and shape both his life and mine.

UNCERTAIN LEGALITY Undocumented

Image by Shepard Fairey: *Dream Act Now*, National Museum of American History (2016).

Changes in United States federal immigration policies of the 1980s and 1990s produced a large, settled undocumented population.[1] As a result of increased undocumented family settlement, an unprecedented number of children grow up without legal residency status in the U.S. Policy makers in the United States have been reluctant to respond to undocumented youths' long-term presence. The Development, Relief, and Education for Alien Minors (DREAM) Act was first introduced in Congress in 2001 to provide a pathway to citizenship for eligible undocumented immigrants who migrated to the United States as children. However, legalization efforts for the DREAM Act came to a halt in Congress.

In 2012, then President Obama initiated the Deferred Action for Childhood Arrivals (DACA) program. The program allows temporary deportation relief from youth and young adults for two years, temporary Social Security numbers, and renewable work permits. Eligibility requirements for DACA are extensive, as the applicant must have entered the country before the age of sixteen and be under the age of 31 on June 15, 2012; have continuously resided in the United States since June 15, 2007; be at least fifteen years old and be in school; have graduated high school in the United States; received a General Education Diploma or have been honorably discharged from military service. Additionally, applicants cannot have been convicted of a felony, a significant misdemeanor offense, or multiple misdemeanor offenses.

Photograph by Rachel Kingsley (2021).

Travels with Stephen, Clearwater Beach, Florida.

Stephen, like many Dreamers, lives in a mixed-status family. His sister was born in the United States, thus becoming a United States citizen, and his mother obtaining legal residency status, and subsequently became a United States citizen when she married a United States citizen. However, Stephen was not the only one in his family experiencing an undocumented status; his brother, three years his elder, also became undocumented when their residency authorization expired. Leaving the United States would have meant leaving his mother and sister, while staying in the United States meant living under the weight of illegality.

"My [undocumented] status started when I was sixteen... my family had a G1 status for residency in the [United] States, but my dad got cancer and passed away in 2004 and at that point, we lost that status."

Conversation with Stephen (2020).

"I didn't even know there were that many [Dreamers] other than myself. It was isolating at the time."

Conversation with Stephen (2020).

Stephen's story is not unlike other Dreamers, with his undocumented status profoundly shaping his teenage years and into his adulthood.

Stephen admitted to feelings of isolation and depression during that time. When the DACA program was announced, Stephen and I spoke about the possibilities for a future — the possibility of Stephen having a future that gave him more freedom; freedom to change his future and to live outside of the shadows. But there was hesitancy — as part of the DACA application, the United States government required applicants to provide information for each of their family members, including any other undocumented individuals, if they were not eligible or did not apply to the program. If Stephen applied for the program, he would be forced to provide the government with the location and personal information of his undocumented brother, who chose not to apply to the DACA program.

"I was very hesitant to apply. The program came out in 2012. I waited two years before I actually applied to it. I'm not very trusting of the government because they tend to change with every administration. Since DACA was an executive action, I felt more apprehensive about the application and program, you know? At the end of the day there was freedom [...] being able to possibly have a future. My brother, at the time, could have applied, but he did not. He didn't trust the program because you're handing immigration and customs enforcement all your information, so he didn't apply [and remained undocumented]."

Conversation with Stephen (2020).

UNCERTAIN LEGALITY Relationships

Photograph by Rachel Kingsley (2018).

Travels with Stephen, St. Augustine Beach, Florida.

I spent weekends with Stephen and his family, cooking out and watching movies together. I had a strained and distant relationship with my own family, but his family accepted me wholeheartedly. Stephen and his stepdad would cook out on the grill and we three would spend hours by the grill. I spent Thanksgivings, Memorial Days, and Christmas dinners with Stephen and his extended family. Stephen wasn't only a friend; he was my family now. He was someone with whom I felt connected, not judged, and unconditionally supported. In 2014, Stephen's stepfather, for whom he was very close and who encouraged and supported him throughout the DACA application process, passed away unexpectedly from a brain hemorrhage. Six days later, my stepbrother passed away from a fatal car accident. In all honestly, the loss of Stephen's stepfather impacted me more than that of my stepbrother. My stepbrother's relationship with my mother and stepfather was very strained and we had not spoken to him in many years. My stepbrother was someone that had come in and out of my life sporadically, depending on the interactions he had with my mother, and was someone who I didn't really know. Stephen's stepdad, on the other hand, was someone I saw as family. More than the sadness and grief I felt for Stephen's stepdad, my heart hurt more for Stephen. The loss of a parent, even one without blood relation, leaves part of your being missing. Holidays and family dinners would never be the same. Stephen's stepdad would never be around to see him married or have children. It was something I had experienced with the suicide of my own father, and I knew Stephen's life, and Stephen himself, would never be the same. Even through the grief and loss of his stepfather, Stephen sat next to me at my stepbrother's funeral and held my hand throughout the service. Stephen is self-less, often putting his own hurt aside to make sure those around him are safe.

"How can I make plans or a future with someone when my future is so uncertain?"

Conversation with Stephen (2020).

"It was always a barrier [in a relationship] where I couldn't explain certain things without explaining my [undocumented] status. If I want to have any sort of serious relationship, I need to explain my status and have my partner understand. And that's the thing... the level of intimacy that a romantic relationship requires and the forethought and planning."

Conversation with Stephen (2020).

After the loss of his stepfather, romantic relationships did not seem important to Stephen. Dating was, and is, particularly challenging. Stephen is forced to disclose his immigration status early on in his potential relationships, usually after only a handful of dates.

His undocumented status not only impacted his immediate family, but also the relationships around him.

Instead of focusing on a new and exciting relationship, Stephen must worry about how to disclose his status to potential partners and how they may respond. Even with DACA status, Stephen has an uncertain future which shapes the opportunities and limitations for relationships. Disclosing his immigration status to a potentially new romantic partner not only made Stephen apprehensive, but it could be potentially dangerous.

UNCERTAIN LEGALITY Membership

"Unauthorized immigrants may form conjectural or fragmented membership identities in response to shifts in various local-, state-, and national-level social and political contexts."

Kara Cebulko, Alexis Silver: "Navigating DACA in Hospitable and Hostile States", in: *American Behavioral Scientist* 60/13 (2016), pp. 1553–1574.

Living in the Southern United States, immigration, and especially 'illegality', can be dangerous. As a predominantly conservative area of the United States, immigration is highly contentious, with certain immigrants being seen as a 'threat' to their economy, community, and even culture. Disclosing immigration status, especially an undocumented status, could lead to violence against both the immigrant and their family. Who or what kind of immigrant that is accepted is shaped both culturally and politically. National borders are made into more than physical boundaries, they are made into ideological boundaries. Thus, ideological boundaries are tied to the right to be in the nation-state. Citizens of nation-states focus on the spatial violations of immigrants and believe it has nothing to do with racial differences, rather, it is about who is 'allowed' and who is not. Although undocumented youth are incorporated as elementary and secondary school students throughout the United States, their sense of membership varies depending on their community, state, and stage in life. Because Stephen had grown up in the United States and has no foreign accent, people rarely assumed or questioned his immigration status.

In the United States, conversations surrounding 'illegal' or undocumented immigrants are highly racialized.

The Latino body becomes the site of suspicion. Since Stephen is Southeast Asian, it was not assumed that he was undocumented, although Stephen did often experience racism and bigotry throughout his life in the United States. Stephen felt connected to his community and connected to us, but never fully felt accepted by the United States, he felt as though he was a secondary member of American society, by his race and by his immigration status, and the intersection of the two.

Photograph by Kate Moum (2018).

Discussions of membership within the nation-state often invoke the idea of nationhood as an imagined community, people united by a shared culture. President Obama relied on this notion when he introduced the DACA program in 2012, stating: "They are Americans in their heart, their minds, in every single way but one: on paper".[2] President Obama argued that undocumented youth should have a pathway to citizenship because they were already "culturally and socially American". A central argument of the DACA program was that extending membership to undocumented youth who were raised in the United States would not be disruptive to the established authorized population. By evoking the idea of a shared culture, President Obama's announcement of the DACA program placed unauthorized youth into partial societal and political membership positions that would not challenge the nation-state's control over its borders and access to membership within those borders.

Stephen, like other Dreamers, was placed to a category of 'good' immigrants, those who would not disrupt the status-quo and that would fit neatly into a narrative of 'hard-working' and 'upstanding' immigrants. Advocacy groups and politicians were quick to highlight the stories of Dreamers that emphasized the 'good' and 'deserving' immigrant whose parents were responsible for forcing them into a life of illegality.

Dreamers are politically and socially seen as aligned with the values and morals of 'true' Americans, even when their partial membership statuses create and maintain barriers to achieve long-term life goals, including attending university.

Stephen asked me to write him a letter of support to the United States immigration for his residency application. I used the 'good' immigrant narrative to form my letter of support. I hated writing it. I was writing what they wanted to hear on the surface, but there was so much more to Stephen and the life he has in the United States. I found myself regurgitating the 'deserving' immigrant narrative that would not be a drain on resources or disrupt the larger community. In the United States, conversations surrounding immigrants exist within a binary of 'good' and 'bad' and I found myself perpetuating the binary in my letter of support.

"Other [Dreamers] have accomplished so much, and I haven't. I look at what they have done, and I struggle to think about all of the things I haven't done. I think, I should have done more, but I couldn't at the time, but I should have found a way to have done more, like them."

Conversation with Stephen (2020).

Stephen never felt a part of the 'high-achieving' group of Dreamers. In many states, including the one Stephen lives, DACA recipients are not eligible for federal student loans and must pay internationally student tuition and fees to attend university. Stephen and his family were not able to afford the immense tuition required for Stephen to attend college. Stephen's dreams of getting an education and the career that he wanted seemed to slip further away, even with his DACA status.

UNCERTAIN LEGALITY Limits to Health

During my mid-twenties I had finally found a home in academia. Working full-time, I put myself through my undergrad degree, but during my junior year at university, I became addicted to opioids. I had always struggled with my mental health, I knew I was different, but I couldn't figure out what exactly made me different. As an adult, I could not escape the trauma of my childhood. Doctors put me on anti-depressants, but those didn't seem to work, and in some cases, made my mental health worse. During my junior year of university, I experienced a leg injury that caused me to be bedridden for almost three months. Stephen would come over almost every day to cook me dinner, make sure I was taken care of, and offer human connection. He would help lift me up to go to the bathroom and make sure I wasn't in pain. I would take my pain medication as often as I could, and refills were easy to get. I spent my days high and asleep, and suddenly I found that my brain was quiet. I liked who I was more on opioids than I was sober. I kept my addiction a secret from those around me, but Stephen started to notice. When I had not had my pain medication, I began to shake and sweat. He knew there was something wrong and told me that I had to get help and I had no other options. Years later, I admitted that he had saved my life. Stephen also struggled with his physical, mental, and emotional health, but did not have the resources that were available for me. He struggled with thoughts of suicide and feelings of hopelessness. Mental health was anything but accessible for Stephen.

DACA recipients are excluded from almost all affordable healthcare options, even though they are considered lawfully present, eligible for a work permit, receive a Social Security number, and pay taxes.

The Affordable Care Act (ACA; also termed Obamacare) was introduced to provide affordable insurance for more Americans. The law provides eligible Americans with subsidies that lower costs for individuals and households with incomes between 100—400% of the United States poverty level. The ACA also expanded the Medicaid program, which covers health expenses for adults with incomes below 138% of the federal poverty line, however, states had the power to accept the expanded Medicaid program, so not all states accepted the expansion. Although DACA recipients have temporary work authorization, pay taxes, and have a Social Security number, recipients are not considered lawfully present, and thus, are not eligible for the ACA. These policy exclusions further create an unnecessary distinction between individuals granted DACA status and individuals granted immigration through other methods, such as asylum or refugee statuses. Stephen could not access psychiatry or therapy, and instead, was forced to live with his depression and suicidal ideation. Stephen's mental and physical health have been greatly impacted by the limited health coverage options he has had.

"I haven't been to a doctor or had a physical in… it's been years… over a decade. I wasn't making enough money to do that, and my status caused me to lack access to affordable insurance. The only doctors I see are my eye doctor, and recently, I've been seeing a dentist. It had been so long since I was able to go to a dentist that I have so many teeth I have to replace that it's a financial nightmare. I basically have to spend about $34-35'000. It's a nightmare. I haven't had the ability to afford going to the doctor. My status has a lot to do with [my health] because I haven't been able to afford healthcare because I don't qualify for affordable healthcare [under the Affordable Care Act] and I can't afford health insurance because I don't qualify for the discounted rates through the ACA because of my [immigration] status."

Conversation with Stephen (2020).

I was diagnosed as a diabetic in my early twenties. Although I have received relatively consistent diabetes healthcare, there have been times where I have experienced barriers to diabetic care, including cost and lack of insurance. In the United States' privatized healthcare system, if an individual does not have health insurance, either paid for through their employer or individually, it is highly unlikely that they are able to afford continuous care, and often rely on emergency-only medical treatment. Stephen believes that he has diabetes, or at least is pre-diabetic, based on symptoms and reactions that his body has. Unfortunately, he is unable to get the diagnosis and treatment that he requires.

UNCERTAIN LEGALITY Body Politics

Photograph by Rachel Kingsley (2018).

Travels with Stephen, Cannon Beach, Oregon.

Unable to leave the country to experience travel, Stephen and I have traveled across the United States together, twice. Together, we've seen the Mojave Desert, eaten beignets in the French Quarter of New Orleans, explored the Caprock Canyons of Texas, and have driven the Pacific Northwest Coast.

For over seven years, Stephen has been on a waiting list to receive a United States Green Card, a short term for legal permanent residency in the country. The process is long and expensive, with extensive wait times and legal fees that can amount to the tens of thousands of dollars. Although Stephen has authorized residency in the United States, his DACA status makes him ineligible to leave the United States, except for an authorized trip for emergency situations, such as the death of an immediate family member. Stephen is a prisoner in the United States, as his movements are limited to inside the borders. If he leaves, Stephen faces the possibility of being deported. Unable to leave the country to experience travel, Stephen and I have traveled across the United States together, twice. Together, we've seen the Mojave Desert, eaten beignets in the French Quarter of New Orleans, explored the Caprock Canyons of Texas, and have driven the Pacific Northwest Coast. If Stephen receives permanent residency status, he will be able to leave the confines of the United States border and finally be able to experience his dream of traveling the world.

For now, his body is monitored and tracked to stay within the confines of the US border.

Over the years, Stephen and I saw a shift in the political climate of the United States. Intense radicalization and racialization of immigration, and immigrants themselves, created an uneasy feeling across the country. The rise and popularity of Donald Trump was disturbing. During his election campaign, President Trump promised to "immediately terminate"[3] DACA, which was included in his ten-point immigration plan. The plan highlighted the termination of DACA as well as another program directed at parents of U.S. born children and lawful permanent residents.

"We will immediately terminate President Obama's two illegal executive amnesties in which he defied federal law and the Constitution to give amnesty to approximately five million illegal immigrants."

"Transcript of Donald Trump's Immigration Speech", in: *New York Times*, https://www.nytimes.com/2016/09/02/us/politics/transcript-trump-immigration-speech.html (2016).

Presidential candidate Donald Trump in August 2016.

On September 5, 2017, Attorney General Jeff Sessions stated the Trump administration would in fact rescind the DACA program, potentially effecting 800'000 DACA recipients. In 2017, then-Attorney General Jeff Sessions simply declared DACA illegal and unconstitutional. Sessions argued that the program should be rescinded because he said it was unlawful from the start. Stephen and I waited with bated breath: Could the DACA program really be rescinded? Would the federal government forcefully deport him? What about his brother? Where would they go? Who would they stay with? How would they communicate? Anxiety began to rise, and again, Stephen was facing an uncertain future for his life in the United States. At first, we talked about the what-ifs all the time, trying to make plans and plans for our plans. But over time, we stopped talking about the what-ifs. There were no other plans we could make, no other what-if options. The wait was crushing.

Cathedral of Learning, University of Pittsburgh, Pittsburgh, Pennsylvania.

Photograph by Maria Oswalt (2019).

The DACA argument finally made it to the Supreme Court. In a major rebuke to President Trump, the U.S. Supreme Court has blocked the administration’s plan to dismantle an Obama-era program that has protected 800’000 DREAMers from deportation. The vote was five-four, with Chief Justice John Roberts’ opinion. Roberts’ opinion for the court was a narrow but powerful rejection of the way the Trump administration went about trying to abolish the program known as Deferred Action for Childhood Arrivals, or DACA. Roberts wrote: ″We do not decide whether DACA or its rescission are sound policies, the wisdom of those decisions is none of our concern. Here we address only whether the Administration complied with the procedural requirements in the law that insist on ’a reasoned explanation for its action’.″ But, as Roberts observed, the attorney general offered no detailed justifications for canceling DACA. Nor did the acting secretary of homeland security at the time, Elaine Duke, who put out a memo announcing the rescission of DACA that relied entirely on Sessions’ opinion that the program was unlawful. As Roberts noted, Duke’s memo didn’t address the fact that thousands of young people had come to rely on the program and who also have 200’000 children of their own who are U.S. citizens, not to mention that DACA recipients pay $60 billion in taxes each year.

″Dreamers are Americans. Many have spent most of their lives in the United States. They live, study, work, and worship in our communities. They have served on the frontlines during the COVID-19 pandemic […] only Congress can provide a permanent legislative fix to provide lasting stability for these young people and their families. My immigration bill, the U.S. Citizenship Act, creates a pathway to citizenship for undocumented individuals in our country, including Dreamers. In March, the House took a critical first step and passed the American Dream and Promise Act. Congress must find a way to pass these legislative solutions and I will continue to work towards passage of legislation protecting Dreamers and creating a path to citizenship for undocumented immigrants. These young people represent the best of America, and we can’t let them down.″

The White House: ″Statement by President Joseph R. Biden, Jr. on DACA Day″, https://www.whitehouse.gov/briefing-room/statements-releases/2021/06/15/statement-by-president-joseph-r-biden-jr-on-daca-day/ (2021).

President Joseph R. Biden, Jr. on DACA Day in June 2021.

U.S. President-elect Joe Biden has promised a quick and dramatic reversal of the restrictive immigration policies put in place by his predecessor President Donald Trump. While Biden pledged to undo many of Trump’s policies starting the first day he takes office on 20 January, 2021, the layers of reforms will take much longer to implement. Biden has said he would create permanent protection for DACA recipients. Vice president-elect Kamala Harris said in an interview with Univision on 12 January, 2021, that the administration planned to shorten citizenship wait times and allow DACA holders, as well as recipients of Temporary Protected Status (TPS), to ″automatically get green cards″, but did not state when or how these changes would happen. However, with the government’s focus on the COVID-19 pandemic, the

Black Lives Matter movement, the war in Ukraine, and the current economic inflation issue, Dreamers have once again been put on hold, with their futures uncertain, again.

UNCERTAIN LEGALITY Transformation

Health isn't limited to the presence or absence of disease or infirmity; rather, it encompasses all wellbeing, physical, mental, and social. Health disparities do not emerge in a vacuum; rather, inequities are produced and maintained through exclusionary social structures that systematically exclude certain groups to favor other groups. For DACA recipients living in a quasi-legal state, their wellbeing is determined by structures that limit their ability to maintain positive mental, physical, and emotional wellbeing. By limiting Dreamers' access to healthcare and health insurance, health inequities and inequalities become imbedded as a way of life. The radical health framework requires us to not simply examine the structures that create and perpetuate health inequalities; it also requires us to transform those very structures to redress systemic inequalities that lead to systematic disparities. Radical health demands that we, as anthropologists and scholars alike, move beyond simply advocating for change, but rather, propose structural solutions that create health equity for all.

Notes

1 Roberto G. Gonzales, Veronica Terriquez, Stephen P. Ruszczyk: "Becoming DACAmented", in: *American Behavioral Scientist* 58/14 (2014), pp. 1852–1872.

2 The White House: "Remarks by the President on Immigration", https://obamawhitehouse.archives.gov/the-press-office/2012/06/15/remarks-president-immigration (2012).

3 "Transcript of Donald Trump's Immigration Speech", in: *New York Times*, https://www.nytimes.com/2016/09/02/us/politics/transcript-trump-immigration-speech.html (2016).

Further Readings

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Devin Dwyer: "Supreme Court Blocks Trump from Ending DACA", in: *ABC News*, https://abcnews.go.com/Politics/supreme-court-makes-major-decision-daca/story?id=71254750 (2020).

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Author's collective

Beatriz Aragón Martín works at the intersections of medicine and anthropology. Trained as a general practitioner, she has been working in primary healthcare with minoritized populations in Madrid, Spain since 2007. Fostered by her clinical experience she studied anthropology, receiving her PhD in Anthropology from the University College London in 2017. Her research focuses on health inequalities in minoritized groups, racism and racialization in healthcare.

Julia Nina Baumann is a psychological anthropologist, currently finishing her PhD at Freie Universität Berlin, Germany. She has studied in Munich, Augsburg and Berlin and has ethnographically researched, taught, and published on various topics regarding STS, emotion/affect, mental health, migration/refugees, and power/hierarchy in Germany and abroad. In her doctoral research she focused on the emotional experience of ethnographers in their everyday academic lives. In her analyses based on her empirical data, she describes academic worlds as a "cultures of no-feeling" in which researchers' emotions, such as fear, anger or courage and love, nevertheless have to be constantly renegotiated. Julia sees herself in this and in her previous works as a critically engaged anthropologist and hence also takes a stand against precarious academic working conditions of all kind and power abuse at universities. She instead advocates ways in which academic projects are seen in a holistic way through which emotions can be given a place in research.

Richard Bůžek is a researcher in Critical Urban Geography at the University of Münster, Germany. In his PhD project at the intersection of economic and urban geography, he scrutinizes the financialization of ambulatory healthcare provision through private equity investment and progressive bottom-up alternatives for health for all.

Adrián Carrasco Munera is from Vallekas (Madrid) and works in Usera (Madrid) as a Family and Community physician. He loves getting involved in multiple projects and collectives: PACAP (a Programme of Community based Activities in Primary Care), La Cabecera, LGTBIQ+ Health working group. He is an artist and, holding a black belt in karate, he "twerks" down to the floor. When he has some free time, he studies Cultural and Social Anthropology.

Caroline Contentin is a scientific fellow at the Werkstatt Ethnology Berlin, an association specialized in the social and cultural anthropology of daily life in Berlin. She also works as a nurse for Occupational Health and as a lecturer at the Deutsche Hochschule für Gesundheit und Sport. The focus of her anthropological research is the influence of the narrative on the therapeutic use of food and the dynamics of its transmission. Her aim is to contribute to the integration of self-help-based preventive practice into the health care system.

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Iris Dzudzek is a professor in Critical Urban Geography at the University of Münster, Germany. In her research she engages with questions of power and knowledge, urban and planetary health and environmental justice. As a spokesperson for StadtLaborMünster, she explores the role of urban interventions and experiments as platforms of transformative geographies. For her work on the governmentalities and power effects of the globally circulating creative policy script she was awarded the prize for the best PhD thesis in German Human Geography.

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Lisa Kamphaus works as a project coordinator and researcher in the cooperative project Gesundheit in der nachhaltigen Stadt at the Institute of Geography and the City of Münster, where she develops a participatory approach for health justice in Münster through collaborative community research and reflects upon that in her PhD.

Janina Kehr is a Professor of Medical Anthropology and Global Health at the Institute for Social and Cultural Anthropology at the University of Vienna. She has done extensive ethnographic fieldwork in hospitals and public health institutions in France, Germany and Spain. Her research interests revolve around the politics, colonial hauntings, moral economies and environmental side-effects of biomedicine and public health, particularly regarding global infectious diseases, pharmaceuticals and hospitals. She is invested in interdisciplinary collaborations and in fostering academic spaces of solidarity and understanding.

Rachel Kingsley is a PhD candidate at the Department of Anthropology at the University of South Florida. Rachel holds a master's degree in Applied Anthropology from Oregon State University and a B.A. in Anthropology from Georgia State University. Rachel is an applied medical anthropologist and works in both clinical and community health settings. Rachel's dissertation focuses on barriers to engagement of continuous human immunodeficiency virus (HIV) care for individuals living with a comorbid diagnosis of HIV and major depression or anxiety disorder diagnoses. Rachel is also a Graduate Research Assistant in the College of Nursing and the Department of Mental Health Law and Policy at the University of South Florida.

Daniela Krüger studied social sciences at Humboldt-Universität zu Berlin, University of Bologna and City University of New York. She received her PhD in Sociology from Humboldt-Universität zu Berlin, where she focused on the current challenges in emergency care from a sociological perspective. She is currently working as a postdoctoral researcher in Health Service Research in Emergency and Acute Medicine at the Charité-Universitätsmedizin Berlin.

Julia Koroknai is an MA student in Social and Cultural Anthropology at the University of Vienna, where she focuses on topics related to medical anthropology and public health. She contributed to the publication under the guidance of Univ.-Prof. Mag. Dr. Janina Kehr, initially as a student assistant and subsequently as an editor. In this capacity, she was responsible for managing content within the system and maintaining communication with both authors and the editorial team.

Helmar Kurz is a lecturer and researcher in Medical Anthropology and Transcultural Psychiatry with a nursery background. He focuses on religious/spiritual and sensory/aesthetic aspects of care, healing, and well-being. Affiliated with the Department of Social and Cultural Anthropology at the University of Münster, Germany, he engaged in the research program "Diversification of Mental Health: Therapeutic Spaces of Brazilian Spiritism" funded by the German Research Foundation (DFG) from 2015–2018, resulting in his PhD thesis on the Voice of Good Sense: Diversification of Mental Health and the Aesthetics of Healing in Brazilian Spiritism (2022). He critically dedicates himself to "Epistemologies of Care" as a negotiation of medical practice, academic discourse, and public experiences. He is a co-editor of Curare: Journal of Medical Anthropology which is affiliated with AGEM (Arbeitsgemeinschaft Ethnologie und Medizin).

Claudia Lang is a medical anthropologist and a Heisenberg senior researcher at the University of Leipzig and the Max-Planck Institute for Social Anthropology, Halle. Currently, she is a visiting scholar at Tufts University, Boston. Earlier she was an ERC-funded postdoctoral fellow with GLOBHEALTH at the Cermes3/INSERM in Paris and held academic positions at the University of Munich, Münster and Leipzig. Her research focuses on the reconfiguration of mental health care through digitization. Other research areas include depression, Ayurveda, global/planetary health and environmental grief. Her regional focus is India. She is the author of Depression in Kerala, co-author of Global Health for All, and co-author of The Movement for Global Mental Health.

Vivian Laurens is a PhD candidate in Medical Anthropology at the University of Connecticut. Her research focuses on the relationship between the right to health and peacebuilding in post-conflict societies. Currently, she is investigating this topic in the context of Colombia's peace process, which stands out for incorporating transitional justice measures designed to support peace building through the development of a national plan for rural health. In this research project she is particularly interested in examining the role that the right to health and the indigenous epistemology of Buen Vivir are playing in the peacebuilding efforts of civil society in Colombia.

Jonas Löwenberg is a social worker at the Social Health Care Center Poliklinik Leipzig in Germany. In the community healthcare center founded in 2020, the collective of medical staff and social workers offers general medical health and psychosocial advice. The Poliklinik's approach is informed by the Social Determinants of Health. That is, the Poliklinik aims to actively decrease and eliminate social inequality in health and wellbeing through community care and interdisciplinary work in the neighborhood.

Lucia Mair is a PhD candidate at the Department of Social and Cultural Anthropology at University of Vienna, in the research group Health Matters. Trained as a physician and medical anthropologist, her work focuses broadly on issues of social and health inequality, and the ways in which the two are intertwined and acted on by different actors within and outside health care. In her PhD project, 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 organization, everyday experience and welfare state infrastructure. Previously, she studied Medicine, European Ethnology and Medical Anthropology and Sociology in Munich, Bonn, Liverpool, Nairobi and Amsterdam.

Dominik Mattes is Guest Professor of Social and Cultural Anthropology at Freie Universität Berlin with a long-standing interest in critical medical anthropology and global health, religious diversity, migration and belonging, and the anthropology of affect and emotion. His PhD research revolved around the social, political, and economic implications of providing and living a life with antiretroviral HIV therapy in Northeastern Tanzania. In his current research project, he explores affective registers of political mobilization in the context of radical secular and religious climate activism in Berlin.

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Sevasti-Melissa Nolas (she/her) is an independent researcher, writer and visual artist. She is known for her research on childhood publics, children's visual cultures, children's archives, multimodal ethnography, and publics creating methodologies. Her work has been published in anthropology, sociology, gender studies and childhood studies journals. She co-founded and directs the children's photography archive and the linked research program childhood publics. She also co-founded and co-edited the journal entanglements: experiments in multimodal ethnography (2018–2022). This is her first publication on the topic of reproductive health; the essay is part of a new project that experiments in writing otherwise.

Marta Pérez is a professor of Anthropology at the Complutense University of Madrid, where she teaches students in anthropology and psychology. She has taught courses on health, mobility, and healthcare systems at Duke University, in Madrid and at the National School of Healthcare in Spain. She has engaged in research on healthcare exclusion, institutional violence and patriarchal and racist state practices. She participates in the movement towards universal healthcare in Spain and is part of the militant research collective on common practices of health and care, deinstitutionalization, and institutional invention called Entrar Afuera.

Tyyne Claudia Pollmann is an artist and professor of Anatomy and Morphology at the Kunsthochschule Berlin-Weißenseein Berlin since 2013. She studied Medicine, Philosophy and Fine Arts in Düsseldorf, London, and

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Friederike Rosenbaum holds an M.A. in Social and Cultural Anthropology from Freie Universität Berlin, with a specialization in political anthropology, postcolonial studies, and cultural sociology. Her research has explored how protest, flight, and exile shaped belonging and resistance struggles within the Nicaraguan diaspora in Hamburg, Germany, as examined in her master´s thesis. She contributed to the publication as part of her work as a student assistant for Prof. Dr. Dominik Mattes and later became an editor.

Melina Rutishauser is a PhD candidate at the Institute of Social Anthropology at the University of Basel and was part of the SNSF Project "Participation in Social Health Protection: An Anthropological Case Study in Tanzania" (2017–2021) supervised by Prof. em. Dr. Brigit Obrist van Eeuwijk. Her interest in photography started during her BA in Media Studies at the University of Basel and was continuously developed further. Between 2014–2015, Melina engaged in a Photography degree program at the University Candido Mendes in Rio de Janeiro, Brazil, which she concluded with a work on women's relation to their haircuts and hairstyles. During the stay in Rio de Janeiro, Melina co-organized two collective photography exhibitions.

Estrella Sánchez-Gamborino works as a general practitioner in Vallecas, Madrid. She studied Medicine at Universidad Complutense de Madrid and started her medical residence in that same neighborhood in 2017, realizing at that time the importance of social determinants of health. Moved by that idea and assuming human health is more than just biology, she is currently studying Social and Cultural Anthropology at Universidad Nacional a Distancia.

Angela Schuster is an epidemiologist, Global Health specialist and MD. She holds a PhD on morbidity and quality of life of cutaneous Larva Migrans in Manaus, Brasil. Since 2018 she has been working as a postdoc researcher and lecturer at the Institute of General Practice at Charité-Universitätsmedizin Berlin. With a right based approach her research uses qualitative and quantitative methods to study sexual and reproductive health, AMR and Planetary Health, with special focus on access to health of deprived groups in the Global South and North. As a scientific advisor of the Berlin Health Collective, she engages in the promotion of integrated primary care centers through practical engagement and research.

Anke Strüver is professor for Urban Geography at the University of Graz. In her work, she investigates the socio-spatial interdependencies in urban everyday life. Anke's research is informed by perspectives from feminist and posthuman geographies, as well as political ecology and political economy focusing on embodied urban (health) inequalities.

Vasilis Tsapas works as an intensive care physician in a public hospital and is part of the collective of the Social Solidarity Clinic in Thessaloniki. The clinic was founded in 2011 as a response to the disastrous consequences of austerity for people's health in Greece and offers free universal access to primary healthcare for everyone. The clinic is organized according to principles of autonomy, self-government as well as collective democratic decision-making.

Esther Vorwerk writes creative and scenic texts. She creates interactive installations, performances and workshops. In her work she critically engages with issues of gender, trauma, intersectional discrimination, and body memory. A major concern of hers is to shape conditions for a new, more respectful, open communication in the context of discrimination and illness. Her works have been shown in Germany, Israel, the USA and Austria, among other places. Furthermore, she is a co-founder of ALASKA-Studio for Feelings. ALASKA investigates emotions as bodily, sensuous phenomena. Their work takes the shape of environments, workshops, performances and interactive installations. She is currently pursuing a Master's degree in creative writing at the Hochschule der Künste Bern.

Ehler Voss is an anthropologist working at the intersections of medical anthropology, media anthropology, political anthropology and the anthropology of religion. He researches the transatlantic entanglements of orthodox and heterodox knowledge cultures from the nineteenth century to the present, including the interferences of occultism and media history and their relations to medical, scientific and technological innovations. He is managing director of the collaborative research platform Worlds of Contradiction (WOC) and Privatdozent at the Department of Anthropology and Cultural Research at the University of Bremen; chair of the Association for Anthropology and Medicine (AGEM); editor-in-chief of the medical anthropological journal Curare; and co-founder and co-editor of boasblogs.

Hannah Weingartner is a member of the Fight the Fever organization, which was created as an impact campaign for the documentary film The Fever. The association with chapters in Kenya and Vienna supports local strategies against malaria. Hannah Weingartner holds a B.A. in Political Science and is currently studying Philosophy and Psychotherapy in Vienna.

Katharina Weingartner is a member of the Fight the Fever organization, which was created as an impact campaign for the documentary film The Fever. The association with chapters in Kenya and Vienna supports local strategies against malaria. After many years in New York as a radio journalist and filmmaker, Katharina Weingartner now lives in Vienna as a political activist and a director and producer of political documentary films and radio programs.

Nora Wuttke is a social anthropologist, artist, and architectural designer. As an anthropologist of infrastructure and the (built) environment, she maintains a multidisciplinary practice that combines ethnography, architecture, and arts-based sensory/visual methodologies. Nora received her architecture degree from the Technical University of Munich in 2009 and completed an MA in Social Anthropology of Development at SOAS University of London in 2010. She spent a decade in China and Myanmar as an architectural designer and ethnographic researcher. From 2015, she worked on the Rejuvenation Project of Yangon General Hospital, developing a campus masterplan, and from 2018 engaging with it as her ethnographic field site. In 2018, Nora pursued a PhD in Anthropology and Sociology at SOAS, where she was the department's first artist in residence from 2020–22. In 2022/23, she held an artist in residence position at UCL's Thomas Coram Research Unit while finalizing her PhD at SOAS. Since 2023, she is a post-doctoral researcher at Durham University, focusing on energy infrastructures.

Ana Zamora is currently a medical resident in Family Medicine in Madrid, Spain. Already a specialist in Public Health and Preventive Medicine (Instituto de Salud Carlos III, 2014–2018), she finished her medical degree at the Universidad Autónoma de Madrid in 2012. During the pandemic she was a field epidemiologist within the Public Health Department in the Autonomous Community of Madrid and then a technical officer for Health Promotion within the city of Madrid. As part of her research activity, she has focused her work on the social determinants of health in different contexts and countries, as well as on health systems organization, especially regarding access to healthcare.

Contributions

Beatriz Aragón Martín – COLLECTIVE CARE, RUPTURE & REPARATION

Julia Nina Baumann – ACADEMIES OF SILENCE

Richard Bůžek – RIGHT TO THE CITY

Adrián Carrasco – RUPTURE & REPARATION

Thandeka Dlamini-Simelane – TRAVELLING POLICIES

Iris Dzudzek – RIGHT TO THE CITY

Andreas Exner – RIGHT TO THE CITY

Bettina Franke – RIGHT TO THE CITY

Susanne Hübl – RIGHT TO THE CITY

Lisa Kamphaus – RIGHT TO THE CITY

Janina Kehr – COLLECTIVE CARE

Rachel Kingsley – UNCERTAIN LEGALITY

Daniela Krüger – COLLECTIVE CARE, COORDINATING CARE

Claudia Lang – KERALA

Vivien Laurens – BUILDING PEACE

Jonas Löwenberg – RIGHT TO THE CITY

Lucia Mair – COLLECTIVE CARE

Sevasti-Melissa Nolas – INCONGRUENT GESTURES

Marta Pérez – COLLECTIVE CARE, RUPTURE & REPARATION

Tyyne Claudia Pollmann – INDISCIPLINARY MATTERS

Anne-Sophie Reichert – INTERSECTIONAL FEMINIST COMMUNITY CARE

Stefan Reinsch – LIFE EXPECTANCIES

Melina Rutishauser – HEALTH INSURANCE

Estrella Sánchez-Gamborino – RUPTURE & REPARATION

Angela Schuster – COLLECTIVE CARE, COORDINATING CARE

Anke Strüver – RIGHT TO THE CITY

Vasilis Tsapas – RIGHT TO THE CITY

Esther Vorwerk – INTERSECTIONAL FEMINIST COMMUNITY CARE

Hannah Weingartner – MALARIA AND NEOCOLONIALISM

Katharina Weingartner – MALARIA AND NEOCOLONIALISM

Nora Wuttke – AIR, BLOOD, BUILDINGS

Ana Zamora – RUPTURE & REPARATION

cache 04

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Health and healthcare provision are an utterly complicated affair. Critical medical anthropologists have shown how even the most intimate aspects of illness and health are to be understood in the light of larger political-economic forces that shape human existence and experience. In current times of proliferating socio-economic inequalities, anthropogenic climate change, and violent political conflict, the authors of this volume attend to the multiple ways in which health is envisioned, theorized, and actually 'done' despite much adversity. Assembling a diverse mix of scholars, healthcare practitioners, activists, and artists, the volume is concerned with the relations between health, power, and inequality, but also looks at diverse aspirations for collective care, solidarity, friendship, and more just futures.

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