Feeling Out of the Box

Ambivalences of Unexpected Amelioration among Sickened Health Professionals through Displacing Cooperations in Brazil

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Abstract How do people with diagnosed autoimmune diseases feel, and what they do and think when they unexpectedly encounter an unregistered drug that may help them to heal, instead of palliatively controlling symptoms of autoimmune reactions through conventional immunosuppressants? What then if they are health professionals who became patients? How does such an encounter affect their lives, their perceptions and attitudes towards their respective medico-legal environments? In this article, I analyse letters exchanged between a physician in Brazil and eight of his patients, who are also health professionals, mainly between 1997 and 2000, concerning their experiencing of using an unregistered medicine, the "anti-brucellic vaccine" (VAB), to treat different immunopathologies such as rheumatoid arthritis. Considering VAB users as capable of systematically evaluating and communicating their experiences of illness and recovery, I seek to understand and discuss the tensions surrounding the repositionings and attitudes of affected health professionals within the co-production of medical evidence in the context of disruptive biotechnological innovation in Brazil. Apparently, their own experience with VAB seemed to have enabled them to re-ground their medical knowledge, experience, and skills in relation to their own and someone else's health in anticipation of the mediation regularly played out by conventional medical knowledge, technologies and procedures. Furthermore, when VAB-using physicians self-analyse and dialogue with others, writing and exchanging evaluative reports about their own and others' health and therapeutic experiences of using VAB, they seemed to implicitly co-produce medical evidence that can be taken into consideration by potential users.

Keywords immunotherapies – displacing cooperation – therapeutic narratives – evidence making – Brazil

"In me what feels is always thinking."
Fernando Pessoa (1969 [1914]: 144)

Introduction

In September 1997, physician Genésio P. da Veiga received a letter from Luís asking him about the possibility of gaining treatment for his 55-year-old wife Fernanda, who was constantly suffering from joint pain in her knees, mostly in colder weather. Luís wrote that "according to medical orientation" (letter from 1997), Fernanda presented with symptoms of rheumatoid arthritis, a typical autoimmune disease characterized by joint inflammation that established rheumatology considers to be incurable and, therefore, chronic. Since her diagnosis, she had carried out conventional treatment with palliative drugs based on immunosuppression to relieve the symptoms. However, Luís was not sure "whether the medication is correct [...] or whether she has not been conducting the prescribed treatment adequately". He only knew that in the course of Fernanda's treatment, "the results [of using conventional drugs], in fact, have not been favourable until this moment". After being encouraged by one of his close friends, a physician living in a neighbouring city, whose respective wife considered herself "cured from arthritis" through Veiga's treatment, Luís decided to contact Veiga directly, stating: "I would like to obtain your orientation to know how to proceed".

The therapy Luís was looking for was called "anti-brucellic vaccine" (VAB), a drug produced in Bra-

zil by Veiga and also used by other physicians and patients against several immunopathologies for many years. Nevertheless, following the rationale of vaccinotherapy as one of the biotherapies, which medico-scientists developed in the first half of the 20th century (Löwy 2005; 2008; also Cope 1966: 39–61), and based on a colloidal understanding of immunopathologies as complex multifactorial metabolic disturbs sometimes referred to as *collagenosis* (e.g. Schor 1974), VAB has rather unspecific immunostimulating effects and is used for curative purposes. This approach is the opposite of that of immunosuppressants. The latter increasingly became the standard therapeutic approach to palliatively treat symptoms of immunopathologies worldwide concomitantly with the rise and acceptance of "autoimmunity" as a new biomedical paradigm (Kuhn 2012[1962]), after which stimulation of one's immune system in the context of "autoimmune diseases" would worsen one's symptoms (Anderson & Mackay 2014). Keeping up with this trend, even the newest and most technologically sophisticated pharmaceuticals offered in rheumatologic offices, such as the biologicals (e.g., monoclonal antibody drugs like adalimumab, etanercept, and rituximab), were designed to function in accordance with this same rationale. In 2005, the *Brazilian Health Regulatory Agency* (ANVISA) officially prohibited the production, commercialisation and distribution of VAB. Officially, for it was unregistered. After a period of approximately ten years circulating irregularly, VAB became available again through another medicinal product (Vilar 2024), just a few years before Veiga's death at the age of 102 in early 2018.

A series of questions arise from this briefly resumed figuration, which entwines lay people, scientists and health professionals; chronicity and the witnessing of unexpected healing, globally established pharmaceuticals and a competing locally unregistered version of a Brucella-based immunostimulant drug to treat immunopathologies. For instance, how do physicians, caregivers and patients with diagnosed autoimmune diseases feel, think and act when they unanticipatedly encounter a therapy that helps them to heal, instead of palliatively controlling symptoms through conventional treatments? Which role do trust, medical knowledge, the senses and antigenic power play in the evaluation of people in adopting or refusing a novel therapy? What kinds of evidence, and means to produce evidence, meet the criteria to evaluate a new drug in the context of autoimmunity in Brazil and for whom?

In this article, I seek to understand some tensions surrounding the positioning of VAB users within the co-production of medical evidence in the face of disruptive biotechnological innovation and co-regulation in Brazil *before* VAB prohibition. My intention is to know how some of the conditions of possibility for physicians, patients and caregivers enabled these players to cooperate or not with each other in liminal contexts in Brazil. I particularly pay attention to different sorts of displacements that are implied when some among them cooperate to promote an off-label biotechnology that they see as innovative and promising. With this in mind, I here focus on one question that condenses the abovementioned interlinked problematizations. Given that several physicians tended to ignore and/or be understandably sceptical towards VAB, for it was absent in their treatment protocols, what could explain the uptake by some of these allopathic health professionals of VAB, as users and promoters, cooperating with Veiga and, in some cases, regularly prescribing and/or recommending VAB?

To address this question, I analyse health reports in form of letters written by health professionals educated at medical schools who themselves became chronic patients or caregivers and who, after having personally witnessed VAB healing effects through unconventional means, began to cooperate with Veiga, and occasionally engaged in VAB's promotion as a promissory biotechnological innovation. My argument is that, by seriously addressing how VAB users systematically evaluate and communicate their therapeutic experiences, it becomes possible to observe ambivalences that emerge when, as one finds on Luís' letter, a physician recommends an unregistered drug, and therefore endorses a therapeutic possibility that is largely unknown within established biomedicine.

According to Ciara Kierans & Kirsten Bell, ambivalences can be seen "as something produced by (and productive of) our orientation to the social world" (2017: 26–27); and here I would include dis- and reorientation as well. Like technologies in general, and as an unauthorized biotechnology in particular, VAB might be "intrinsi-

cally ambivalent in its effects" (ibid.; referring to de Laet & Mol 2000). Simultaneously, VAB's effects upon the world depend on the attitudes of those who encounter it, who (re)position VAB and themselves amidst flows and forces "within which [VAB is] made to work or fail" (Kierans & Bell: 27). Thus, delineating VAB-related ambivalences might contribute, on the one hand, to reveal whom and what are involved in the networks of power through which VAB is circulated and informally co-regulated; be it as an object of dispute and/or a way to improve health, evidence making, market competition, ethical and moral questioning etc. On the other, it can reveal how VAB users deal with the dynamics of such networks, which often unfold through biomedical interstices, before the judicialization of VAB.

Apart from introduction and conclusion, this article is divided into two main sections. In the first, I briefly contextualise VAB's development and evidence-making issues, and recall general aspects of becoming a health professional and of related expectations. I also highlight some implications of working with letters as a way to learn about the therapeutic experiences and attitudes of VAB-related health professionals who deviated from standard treatments. In the second section, I approach central moments in the letters' authors' therapeutic trajectories, and consider the ways through which these sick health professionals became involved in the co-production of medical evidence as they moved from being immunosuppressant users to being VAB users. Mainly, I explore how they directly experience immunopathologies, conventional treatments and VAB, and how they re-assess their trained senses and ontoepistemological commitments before amelioration as standing between divergent biomedical therapeutic models, and respective orientations and expectations.

Contextualisation and analytical framing

Brucella, Brucellosis and VAB

"The vaccine", as many users referred to VAB, was indeed a lysate of dead Brucella, a bacterium that might cause an anthropozoonosis called brucellosis and has a multifaceted trajectory.

Since its identification by microbiologist David Bruce in Malta in 1886/1887 as responsible for the *Malta fever* (later called *undulant fever*), variations of the gram-negative bacteria genus Brucella have been extensively researched, mainly through the examination of host animals such as *brucella abortus* in cattle, *suis* in pigs, *melitensis* in goats and sheep, etc. (Akpinar 2016). As several other microorganisms, Brucella – named after Bruce – has an intriguing relationship with symptoms of immunopathologies in humans. However, the signs of its presence and agency in human bodies are hardly recognisable as its history of involvements with multiple scientific endeavours suggests, including the set of multidisciplinary apparatuses, practices and mindsets through which scientists could learn to perceive, conceptualize and work with it. For instance, Brucella has also been used as a material in the development of different biotechnologies ranging from vaccines (de Mello 1979) to bioweapons (Pappas *et al.* 2006). More recently, it also has become the object of proteomic and genomic analyses with paleontological and archaeological goals, which also investigate how brucella and animals have mutually adapted to each other in the long durée (Greco *et al.* 2018; Suárez-Esquivel *et al.* 2020; Rothschild & Haeusler 2021).

In 1956, microbiologist Genésio Pacheco, then president of the World Health Organization's "International Commission on Brucellosis", and primatologist Milton Thiago de Mello, later president of the Brazilian Academy of Veterinarian Medicine, both based at the Institute Oswaldo Cruz in Brazil, published a treatise on brucellosis in Portuguese (Pacheco & de Mello 1956). Pacheco also worked with Veiga, who was his homonymous nephew and a recently graduated physician working as a laboratory technician at the National Plague Service. Yet, opposition from other physicians was common at that time, who contended that brucellosis was irrelevant in Brazil.

For decades, Pacheco and his team argued that the increasing number of cases of brucellosis among animals reflects its correspondent increase among humans. Its incidence "[…] in Brazil is huge [and] knowledge about its existence is too small, therefore its diffusion takes place freely" (Pacheco *et al.* 1969: 747). As Veiga told me, this controversy arose partly on account of the

symptomatology of brucellosis taught at the medical schools in the country, which had been based on its most common European variant, the *melitensis*. The problem being that in Brazil brucellosis was and still is predominantly provoked by the types *abortus* and *suis*, which present different symptoms. In addition, brucellosis is highly contagious. Known as a "disease of a thousand symptoms" (Pacheco *et al*. 1969: 752), it is difficult to diagnose, which has contributed to making brucellosis almost invisible as a health problem. Experts have therefore mostly ignored it, whilst local non-professionals have managed to identify the symptoms by comparing similar cases.

It was only in 2001 that the *Brazilian Federal Government* initiated the *National Program of Control and Eradication of Animal Brucellosis and Tuberculosis*, officially recognising brucellosis as a national epidemic. Although most medical professionals remain unacquainted with its spread among humans and continue to see it mainly as a zoonosis, recent studies corroborate the claims made by Pacheco and Veiga that human brucellosis in Brazil is endemic, and its effects are multiple, and still largely misunderstood, and underestimated (e.g. Maurelio *et al*. 2022; Nogueira & de Castro 2022; Bourdette & Sano 2023).

In 1979, de Mello called attention to a forty-year-long associated controversy around the best treatment for brucellosis. Several attempts had been made to develop vaccines that could substitute for the standard antibiotic-therapy. Among those vying for vaccine development, a further discussion arose as to whether to use living, attenuated or dead brucella (de Mello 1979: 676). Pacheco and his team had their own breakthrough in the 1960s with a "curative vaccine" named Bruvac (Pacheco *et al*. 1969), which they designed mainly to cure already contaminated patients. Whilst Pacheco used Bruvac, Veiga used another similar registered drug called Brulise, which he had developed earlier. Both drugs were approved and registered by the then *Brazilian National Medicine and Pharmacy Inspection Service*. Nevertheless, the debate around best treatment rages on in Brazil and elsewhere (Wareth *et al*. 2020).

In the 1980s, after his retirement, Veiga compared his own observations of VAB on arthritis-affected patients with brucellosis, with the results of a 1950s experiment (Meiselas *et al*. 1961; Veiga 1969). After finding evidence that VAB had the potential to treat arthritis, he adapted it to treat people with this and other immunopathologies off-label. Despite having been successfully applied in several cases, as the results of a small-scale study with 377 patients suggest, the treatment was not recognized in the established field of rheumatology and it did not figure in public health policies. With it, Veiga's continued use of VAB entered a grey area.

Health professionals, medical competence and institutional reproduction

Some of Veiga's patients were themselves also health professionals. To understand the impact of their VAB therapeutic experiences on their perceptions and attitudes regarding their personal, professional and institutional environments, and their approaches to drug evaluation, it is useful to first consider what it means to become and live as a health professional.

In general, the medical profession track includes a long education process that implies multiple changes related to, among others, personal knowledge, worldview, ethical posture, lifestyle, self-presentation, public and corporate commitments, social status, as well as perceptual, emotional and sensorial (pre)dispositions. As ethnographies of medical schools and physicians' education show (e.g. Becker *et al*. 1992 [1961], Atkinson 1976), this learning process tends to deeply affect their perception of their environments and how they pursue the goal of identifying and treating diseases in distinct ways.

On the one hand, medical students have to learn through a series of predefined exercises how to identify symptoms and relate them to a growing catalogue of described ailments. For that, neophytes should develop a receptiveness for what patients narrate about what they feel, and do not feel, in their bodies. Likewise, they should develop the skill, knowledge and practical capacity to "categorize and rank" (Carr 2010: 18) both whom utters and the uttered (Foucault 1989 [1963]). That includes becoming able to (de)codify symptoms that sometimes remain invisible for the untutored eye. To remain functional when confronted with potentially stressful and overwhelming situ-

ations, they also learn to constrain their empathy through protective mechanisms such as by treating patients during surgical operations or emergencies (Goffman 1961).

On the other hand, they are instructed about existing authorised technologies that aim to produce accurate, numeric views about the patients' vital signs, which their own human senses may not precisely ascertain, such as imaging occurrences under the skin, listening to air currents through the lungs, or gauging accurate body temperature readings. An important task for medicine and nursery students, thus, is to familiarise themselves with and learn to use such monitoring-intervening devices, from the most cutting-edge to the simplest ones (Faulkner 2009).

Part of the training therefore consists of internalising the idea that medical technologies are more reliable than human feelings and perceptions, even though medical technologies function mostly as inorganic extensions of the physicians' bodies by helping them to sense, perceive and do things they could not do otherwise. Concomitantly, their users not only delegate much of their sensory capacities and judgments to these instruments but also are affected by them in several ways. Put differently, in tandem with the development of their professional skills, neophytes learn to commit to and co-operate with technologies, and the premises upon which they were designed, which sometimes may even take over their tasks, and reframe their techno-scientific, sensorial and intuitive calculations.

Likewise, prospective health professionals must learn which drug one should prescribe from those authorised by legal-scientific institutions responsible for separating what works from what does not, what belongs to Medicine and what does not. As part of scientific and health institutions, physicians and bioscientists have to know what they come to know through reliable sources of information and truth (e.g. Beisel, Calkins & Rottenburg 2018). These comprise institutionalized means to which they commit and which they reproduce in order to reproduce themselves as recognisable legitimate health professionals and, despite internal differences and contradictions, to take part in medical and life sciences as if these were a single unified body. I.e. at least as a façade that stands before and is continually re-introduced as such to uninitiated audiences.

That is why the use of devices and substances designed or converted for medical purpose is regulated by legitimate institutions that establish the standards of what counts as evidence, proof, and truth through conventions. These same conventions produce official documents in which the elements that constitute and reproduce biomedicine are framed, filtered, stabilised, and actualised, such as curricula, legislation, treatment protocols, techno-regulatory and ethics guidelines, and research agendas (Cambrosio 2010). Thus, entering the biomedical world as a health professional who co-constitutes it, and who is also co-produced by it, also unfolds as a displacement from an ordinary life. This displacement simultaneously generates a distinctive consciousness which is co-formative of a particular epistemic culture, and therefore of a way of being in the world (Knorr-Cetina 2007: 363).

This does not mean that health professionals live in a parallel reality. Far to the contrary, the efforts of differentiation that make up biomedicine take place amidst contingent alliances and conflicts between sociocultural, politico-economic, scientific-religious and other-than-human forces that affect and are affected by them (Fleck 2019 [1935]). Biomedical realities express, co-constitute and are co-constituted by the geopolitical and historical circumstances under which they emerge. In other words, the distinct consciousness, recurrent practices and affective predispositions normally associated with the formation of health professionals are *installed* within the broader society in which they act as institutional actors who "play critical roles in stabilizing and maintaining institutional arrangements, as well as power structures within them" (Churcher *et al.* 2023: 11). In this sense, for instance, health professionals (re) produce distinctive marks that help them preserve their recognisability as authoritative and legitimate professional medical practitioners.

Yet, what happens to this distinct consciousness and the behaviour associated to it when health professionals become chronically ill, go through conventional treatments without positive results, and then try an unconventional therapy, to which they attribute a substantial amelioration of their condition?

Letters as research material and as sensorial mediums

To sketch a picture of the therapeutic journeys of health professionals who used VAB to treat rheumatoid arthritis, I explore eight letters sent to Veiga. These were mostly written between 1997 and 2000 by a cardiologist, a veterinarian, a nurse, a psychologist, a general surgeon, a dentist, a clinician, and a health insurance agent. I selected them from hundreds of letters that are part of the vast personal archive of Veiga, which grew over the decades since the 1980s, and to which I obtained access, for these are the ones which reveal a singular perspectival conjunction. I.e., their authors were (or still are) health professionals, chronic patients, users of conventional and then unconventional treatment, and finally patients in recovery process, or healed ones. I did not find negative self-reports written by these or other health professionals within any of my research materials that I could use here to counterbalance the positive ones.

On two occasions after Veiga's passing, a close relative and guardian of his letters, as well as a central interlocutor in my research since 2018, granted me access to the originals and allowed me to copy those of almost 300 authors, in 2019 and 2021. As I explain elsewhere (Vilar 2024), my access to them and further research empirical materials was facilitated, among other reasons, by my status as a former VAB user. Some of these letters were with a collaborating physician who was initially unsure about bringing the letters to one of our meetings, but changed his mind after having talked to their guardian. In principle, these were all letters that Veiga's relative-guardian and their collaborators keep with them. The rest remain scattered.

As parts of an archive that can no longer be found in a single place, many letters were lost through residence changes in the last years. Besides, Veiga discretely had forwarded some to medical scientists and health professionals to draw their attention to VAB's efficacy and to potentially initiate medico-scientific cooperation. For instance, in a private letter written in 1988 to Veiga, a scientific collaborator and professor of biomedicine at a public university reported the results of tests that he conducted with VAB in animals:

> I did an experiment where I induced arthritis in rats using collagen II and, during the induction time, I vaccinated two groups of rats with the [Brucella] endotoxin in the dilutions of 1/100 and 1/500 against another group that received physiological saline. In 15 days, all animals that received saline presented symptoms of arthritis in the joints of the hind legs and those that received the vaccine, in both groups, had nothing.
>
> In another experiment, three groups of animals received, with an interval of three days, for 30 days, the vaccine in dilutions of 1/50, 1/100 and 1/500 each group. After this period, all animals and a control group that had received saline were treated with collagen II to induce arthritis. After 28 days, we obtained the following result: All animals in the control group [...] had arthritic symptoms. Those who received vaccine diluted 1/100 and 1/500 did not show symptoms. This experiment is being repeated.

Apart from this cooperation at laboratory level, the great majority of the letters consists of partial health reports written by lay VAB users, at different moments of their therapy, in response to Veiga's request for evaluation of his treatment. The identities of the letters' authors are diverse and include not only diagnosed people but also caregivers, patients' relatives, and accompanying physicians. Many wrote messages on the back of the self-evaluation form that was sent to them by Veiga, and some attached the results of their laboratory exams. Some letters point to how health professionals worked in cooperation with patients to decide frequency and dosages at the clinical and ambulatory contexts.

These correspondences generally unfolded at the same time as phone conversations between Veiga and his patients which aimed to monitor and eventually modify the dosages in the course of the therapy. In their narratives, VAB users frequently describe early attempts to get better by using conventional treatments, and sometimes explain their emotional states and living conditions before, after and during their shift from immunosuppressants to VAB. Extrapolating Veiga's request for therapeutic feedback, the letters not only communicate the change of symptoms and substantial improvement or cure, but also gratitude, good wishes, indignation, hope, fear, anger, relief, encouragement, frustration, thoughts about conventional pharmaceuticals, medical in-

stitutions and the value of living. I therefore use this rich content to analyse these letters as textual narratives.

As Anne Byrne states, "the importance of narrative for framing, understanding, and interpreting experience and organizing knowledge of the world is now widely recognized by scholars and researchers […]" (2017: 44; see also Cortazzi 2001; Stanley 2004). While acknowledging the limitations of letters (for example, that they represent only one side of a conversation, which is only partially available, and that there is little biographical knowledge of their authors), one can understand and explore them as dialogical and reciprocal textual narratives that are part of ongoing correspondences in at least two ways.

Firstly, as a "discourse with a clear sequential order that connects events in a meaningful way for a definite audience and thus offers insights about the world and/or people's experiences of it" (Byrne 2017: 44; referring to Hinchman & Hinchman 1997: xvi). These insights, presented from the perspective of letters' authors as insiders, include matters of "private, personal, or familial interests [and] a situation or professional occupation, proffering a public profile to fit the human qualities of personal or professional practices" (Byrne 2017: 45). Secondly, the letters can be attended to as "a story with a plot involving a change in the situations of fortunes of a main character" (ibid.: 44). Letters are registers of key moments of the authors' ongoing and contingent interpretative processes, providing researchers with the opportunity to focus "on the roles of narrative participants in constructing accounts and in negotiating perspectives and meanings" (ibid.), as well as to know "the techniques and strategies that writers use to tell their story" (ibid.).

Given the heterogeneity of the papers, such as the ink used, markers of the passage of time, diverse calligraphies, attached documents, disclosed personal information of their authors, quantity and diversity of accompanying stamped letter envelopes etc., I had no doubt of the authenticity of the letters that I analyse here; a conviction reinforced by other aspects. In principle, as letters addressed privately to a health professional, most of their authors did not have the pretension to turn them into public documents. Even though many writers were clearly willing to contribute to Veiga's efforts to demonstrate VAB's efficacy and legitimacy to the biomedical establishment, and seemed aware that someone else could read their messages later (Simmel 1992[1908]: 429–432), the letters, as sensorial mediums, are primarily situated within the domain of physician-patients relationships, and therefore subjected, in principle, to concealment and discretion.

Furthermore, in contrast to the private exchange of letters and phone calls of Veiga's era, nowadays most cooperation work between scientists and non-scientists to underpin biotechnological innovations, in general, take place via the internet (e.g. Sleeboom-Faulkner 2014; Song 2017; Petersen *et al* 2019). Social networks became popular in Brazil from the 2000s and the internet became an ideal public platform through which strangers can share therapeutic stories, and get together. Instead, the private letters to Veiga were generally not aimed at influencing public opinion or at pressuring medico-regulatory institutions. Not least, the letters that I use here, with one exception, were written and exchanged before ANVISA prohibited VAB.

Self-reports as medical evidence

To my knowledge, Veiga never publicly revealed the letters that he received from his patients and collaborators. When he was formally prosecuted, he included 34 letters in his legal defence, but only the judge and the involved parties could access these. However, it is clear that he aimed to use them to enrich a broader corpus of medical evidence that could help improve VAB's status. Hence, he privately shared and discussed some of them as medical cases with medical partners and potential scientific collaborators.

Yet, a major ambivalence arose during such cooperations given that a progressive dismissal of patients' narratives and testimonies in the standard process of evaluating the therapeutic effects of substances was concomitantly taking place. While personal therapeutic experiences and respective narratives are vital in producing diagnoses, they do not always play a role in the evaluation of the effects of substances that are proposed as potential pharmaceuticals. Reverberating an axiom of modern medical science after which a "*cure proves nothing*" (Stengers 2003: 14), one of

the main arguments used to justify this dismissal is the view that human senses, perceptions and feelings, being apprehended as subjectivity, would contaminate neutral and/or objective assessments of antigenic power (e.g. Greenhalgh 2001: 301; Balaj 2022).

In the context of efforts to overcome related limitations, practices such as randomised clinical trials (RCTs) have increased and gained legitimacy worldwide. This particular set of standard scientific criteria for the discovery of universal truths has since the 1990s had a decisive impact on the approval or refusal of any drug by regulatory institutions, including VAB. To illustrate this, I now make a short comparative digression by setting out the way in which a central legal institution in Brazil argued against the liberalisation of another contested drug, which had been presented as an unspecific immunostimulant.

In contrast to VAB, which remained a silent controversy, the case involving the synthetic phosphoethanolamine (or "Fosfo") as a promissory cure for cancer gained worldwide resonance (Castro 2017; Ferrante 2019; Vilar 2020). By stating that the law 13.269, of 13 April 2016, which facilitated access to Fosfo in exceptional circumstances and without being registered at ANVISA, was not based on "rational justification", the then Prosecutor General of the Republic of Brazil (PGR) echoed further similar explanations argued by medico-scientific regulatory institutions (PGR 2018, 22 October: 8). Emphasizing that evidence-based medicine (EBM), as a "systematic process of discovering, evaluating and using findings as a base for clinic decisions", is the established model for the production of scientific evidence in Brazil, the PGR argued that the use of published "scientific articles of partial research results" and of "unsystematic patients reports" are inadequate evidence of a substance's capacity to heal (ibid.: 7–9).

In disqualifying involved scientists and stakeholders, it seems that here too, as Isabelle Stengers observes elsewhere, "*irrationality*" (2003: 15, emphasis in original) is mobilized "to condemn not only charlatans who use cures as proof of some kind of snakes oil's effectiveness, but also the public that lets itself be taken in by this proof" (ibid.: 16). Nevertheless, in principle, in imagining and seeking to practice rational measurements of health realities exclusively through vehicles that circumnavigate human affects, established biomedicine and regulatory science run the risk of producing knowledge that is detached from lived experience (Ingold 2010). Not for nothing, EBM and its component RCTs have been regularly criticised by members of medical communities, social scientists and humanities scholars (e.g. Epstein 1995; McKevitt 2013; Adams 2016; Ahuja 2019; Ratnani *et al.* 2023). Some of EBM's limitations might reproduce and deepen the discrepancy between biomedicine as part of a modern science's longing to apprehend reality from outside it and this same reality as though scientists would not inhabit it and participate in it (Merleau-Ponty 2007 [1961]; Tambiah 1990).

In VAB's case, sick health professionals searching for further therapeutic possibilities are among several actors who "navigate contemporary medical, humanitarian, and governmental regimes in search of rights and resources" (Adams & Biehl 2016: 124), including healing ones, and expose themselves to the unknown.

> Experiences, often unpredictable, of the social, political, and medical effects of interventions also give rise to new claims of efficacy, new regimes of truth and falsity, and new political and epistemological engagements with outcomes that matter to people. These cumulative experiences form alternative, practice-based forms of evidence that can challenge orthodoxies and perceptual deficits of all kinds and are, in our view, the very fabric of alternative theorizing in global health and beyond. (ibid.)

Indeed, Veiga and his collaborators did nothing to oppose an EBM approach. To the contrary, they were willing to combine EBM with further modes of knowledge production that included patients' narratives about their own therapeutic experiences, laboratory tests and bibliographic research. They also used methods of comparison with conventional drugs, by integrating data from the accumulated therapeutic experiences. Veiga also sought to co-organise a clinical trial in the early 1990s with rheumatologists in the city of São Paulo that were recommended to him by the *Health Municipal Secretary*. He contacted them for this purpose. However, as he argued in his defence, they simply did not answer.

Mutual affects between sick health professionals, conventional drugs and VAB

Feeling and communicating pain and following standard treatment

In his letter from 1998, veterinarian Juarez, from Paraguay, stated that his problem "started with severe pain in my left arm one night in April 1990". Although the pain apparently vanished after he took "some anti-inflammatory drugs, muscle relaxants, etc. [...] as the days went by, there were pains in the joints of the fingers, wrists, wristbands, which forced me to consult with a rheumatologist". Similarly, surgeon Xavier explained that in "1990, I was affected by an inflammatory process in all joints of my body, having all the evidences of positive rheumatic activities". As in Juarez's case, Xavier also sought a rheumatologist who conducted laboratory tests, which confirmed his prediction. Not all health professionals treated by Veiga had arthritis. Navy doctor Kalil, for instance, explained that in his case it is "another immunological disorder – *pemphigus vulgaris* – confirmed by histopathological examination".

Usually, as soon as a physician, as an institutional actor, produces a diagnosis attesting an immunopathology, palliative therapy begins. "We immediately started conventional treatment based on ASA [acetylsalicylic acid] (6 g. x day), indomethacin (50 g. x day) and chloroquine diphosphate", wrote Xavier. In Juarez's case, the rheumatologist gave him "a series of possibilities to start the treatment, which in the end were based on diclofenac, methotrexate, chloroquine, plus 5 mg of cortisone". Routine laboratory tests continued as part of medical monitoring. Despite that, Juarez stated: "My general condition remained the same if no improvement, with mild to severe pain, and the perception I had about the disease was that it increasingly compromised more joints, hands, elbows, soles etc." Like others who undergo palliative treatment, Juarez sought further physicians and medical possibilities, switching "from doctor to doctor", as another VAB user wrote. Indeed, Xavier's experience of recurrent inflammations is emblematic of what many chronic patients go through:

> After a long period of use of drugs with changes in anti-inflammatory drugs to piroxicam, sodium diclofenac, always used with analgesics such as dipyrone and protectors of the gastric mucosa such as cimetidine, there was no improvement in the condition. I could even say that there was a worsening. (Letter from 1997)

Juarez's experience with conventional treatment echoes that of Xavier with the difference that the first more explicitly expressed his fear that the excessive and regular use of palliative drugs was causing his malaise.

> A year later and with three years or so since the beginning of the disease [...], I started to have a new pain crisis more intense than usual. I then went to another rheumatologist who advised me on applications with gold salts, diclofenac, cortisone 5 mg, after a while chloroquine was added, the gold salts applied every 15 days. I can tell you that with this treatment or with this scheme, I stayed for almost five years, having the disease relatively controlled, but always in pain. At a certain time of the year with more pain than at others, but always taking medication, which has always worried me about the time I spend taking these medications. Until, on one occasion, in one of the many routine checks that I did every three months with the doctor, I realized that the disease was progressing and bothering me more each day. (Letter from 1998)

Further health professionals shared the concern that conventional treatment negatively affects the health of chronic patients. General practitioner Arthur, for instance, who reported on the health state and therapeutic experience of his wife, Catarina, who was diagnosed with polyarthralgia, verified long-term sequels occasioned by additional drugs that should relieve the side effects of primary drugs. According to him, for five years, Catarina "suffered from widespread pain, which periodically removed her from work, creating serious professional problems. She underwent all conventional treatments given by rheumatologists, such as anti-inflammatory drugs that ended up altering her gastric mucosa with pains that persist today" (letter from 2000). In the case of Luísa, an experienced nurse, it did not help to look for further treatment possibilities in Europe. As she wrote, "I went through several specialists and each one saturated me more with so many medications, which

only caused me more pain, because I was already impregnated with so many drugs for pain and this only complicated me, [so much so that] even my human dignity was shaken" (letter from 2013).

As I could observe in public talks, rheumatologists ascertain that contemporary immunosuppressants have less side effects as the medication used in the 1990s (Vilar 2024). The fulfilment of the biomedical promise of a stabilised relief for autoimmune symptoms, i.e., of achieving "remission" (instead of searching for a "cure"), remains understood as being conditional on patients remaining on their palliative path. And yet, despite several technological changes, the standard treatment remains guided by the same immunosuppression-centred thought style and, consequently, palliative. Not surprisingly, as Charles E. Rosenberg wrote not long ago, "For the clinician, [...] [autoimmune diseases] are a group of well-established, if frustratingly intractable, ailments to be diagnosed and treated. For sufferers and their families they are misfortunes to be experienced and endured" (Rosenberg 2014: xi). This seems also valid for health professionals as patients.

Involuntary symmetrisation

According to some studies, when physicians become chronic patients, they may change their perception and actions towards their patients and colleagues as part of their pursuit of learning how to live as a permanently ill person (e.g. Klitzman 2008; Kay *et al*. 2008; Oprisan *et al*. 2016). As doctors in patients' clothes and vice versa, sick physicians and other health professionals keep both roles while interacting ambiguously with the health care system, from receiving pharmaceutical treatment after diagnosis to regular check-ups. These interventions not only occasionally relativize their medical authorities by turning them into patients of other health professionals, but also co-shape their horizons of expectation, and their intimate and personal lives.

In contrast to people with curable diseases, people with chronic ones in general, and immunopathologies in particular, are regarded as (virtually) perpetually ill and likely to become increasingly unwell. By becoming artificially immunocompromised through immunosuppressants, which in addition to their often short-term effects and high costs normally provoke several side effects leading them to take additional drugs for their life time (Dumit 2012), such chronically ill patients begin relationships with new actors and within new networks that characterise the world of disability which they join from the moment of diagnosis onwards. In this world, they actively recreate themselves as immunocompromised persons while seeking to achieve remission, retard the inevitable, control the unpredictable, and protect themselves from quackery.

Yet, their unintended initiation into the realm of chronic living seems to lead to at least two mutually implicated situations in their lives. Firstly, they become displaced from the position of figures symbolically immune against and/or above ailments, and now they occupy places of vulnerability. Secondly, by seeking to come to terms with their conditions, they are granted the possibility of diminishing the distance between themselves and their patients. In other words, having a first-hand understanding of how their patients feel in multiple situations in their daily lives, being affected by comparable *intensities* (Favret-Saada 2012: 441–442), including unsignifiable ones and knowing unmeasurable pain that are hard to see, sick health professionals might recalibrate the usual differentiations between themselves and their patients, and the diseases which they seek to treat. They now unintentionally face a mutually understandable destiny.

Moreover, in reporting symptoms through their letters, sick health professionals did not only verbalize visible potential signs on the surface of their bodies to Veiga but also those intensities that they could feel under their skin. As they shifted their sensorial attention between their bodily interior and exterior as interconnected environments, they articulated their feelings and perceptions with their vocabulary and knowledge in ways that render them intelligible. This includes regarding symptoms as discontinuities of an otherwise healthy state. While assessing changes in their health by paying attention to their exteroceptive and interoceptive senses, they interacted with a multitude of others. In so doing, they seemed to co-manipulate and describe their health state while discerning between different intensities at play in and through their bodies, particularly the impact of different medications.

Switching treatments

The feeling of not getting better after years of treatment, and the recognition that illness may only worsen, seem to be a key moment during the therapeutic journey of a chronic patient. A growing scepticism concerning the effects of existing conventional pharmaceuticals may provoke a fissure in the trust that keep their expectation attached to the palliative path, opening up patients' receptivity towards unknown therapies. Besides the possibility of skipping standard treatment altogether (e.g. DUMIT 2012: 174–179), the revelation that the biomedical expectation of a future cure will not be fulfilled within one's life span tend to reinforce the chronic patient's disposition to look for something outside the palliative path. This potential search is also partially encouraged by rheumatologists themselves, who often orient their clients to try to find out what might be good to control inflammation processes on a more individual level (such as physiotherapy, diet and psychological support). However, for them this should only be pursued *as long as it does not jeopardize the conventional treatment*, what is clearly not the case for many people who come across VAB.

"Already disillusioned and sad for not getting better with conventional treatment and physiotherapy, I heard about the vaccine", wrote XAVIER (letter from 1997). Given the emerging lack of prospects and the constant search for relief, dental surgeon Ana expressed her decision *to bet* on VAB:

> I use VAB as an alternative for the treatment of RSI [repetitive strain injury] since January 1996 on my own initiative. I received a referral from a friend and I myself sought treatment because I had already undergone many previous therapies without any results. I was not induced to use it, nor to believe it would be efficient. Due to the lack of alternative treatments, I read Dr Veiga's explanatory leaflets and decided to use VAB. (Letter from 1997)

Prospective VAB users had to evaluate the many potential risks of taking an unregistered substance that is little known amongst rheumatologists. They also had to evaluate the requirement to quit conventional treatments to allow VAB to work properly. As I stated in the introduction, while VAB works through a stimulation of one's immunity as a way to rehabilitate it, palliative treatments are engaged in suppressing the immune system's activities to prevent an increase of autoimmune symptoms. In principle, these therapeutic models are mutually exclusive. To adopt one means to have to give up the other.

The experiences of people abandoning conventional treatment as a condition for using VAB vary. Being a health professional makes the decision more difficult. An eventual adoption of VAB automatically re-positions those health professionals who opted to try it, as their decision puts them *en route* to collision with not only authorized pharmaceuticals, but also with the authorisers (i.e., the medico-legal institutions themselves to which they are committed as licensed medical experts), including their own colleagues.

Arthur described his dilemma when he heard about VAB for the first time and resisted his wife Catarina's decision to use it:

> In 1997, a friend of the family, a non-rheumatologist, ordered VAB and presented it to my wife based on results she had already seen. I confess that, at that time, I did not believe in this vaccine unknown in the medical field and I even advised my wife not to use it for fear of the side effects that could arise. (Letter from 2000)

However, Catarina chose *to bet* on a close friend's favourable testimony of VAB as a guarantee in the face of the potential risks of adopting an off-label drug, rather than on her physician-husband's suspicion who did not know about VAB. As Arthur explains, "Despite my advice and driven by the hope of being without the pain, my wife took the vaccine religiously for a year, with another year of maintenance dose, having finished the treatment in July 1999" (letter from 2000). In this case, it may appear at first that trust based on institutionalised expertise (i.e., vertical, hierarchic) was subsumed to trust based on friendship (i.e., horizontal, non-hierarchic). Yet, the positive experience of Catarina's close friend regarding VAB rather occupied a gap within her husband's medical education. After all, ARTHUR's suspicion concerning VAB was not based on homologated biomedical knowledge about VAB's effects but rather on its absence. Therefore, there was no institutionalised expertise to consult. In other words, Catarina was not standing between two truths but rather be-

tween her friend's shared hope based on personal experience with a specific thing and her husband's shared fear of the unknown based on an impersonal general caution.

Similarly, health professionals can discuss their decision on whether to adopt VAB with friends who sometimes belong to the medical field. In Juarez's case, a physician friend, knowing about his health state, informed him about VAB, as this friend had "a daughter who had the same problem" (letter from 1998).

Beyond the mobilisation of trust present in the dynamics of mutual identification and interpersonal relationships, several potential users travelled long distances to meet Veiga, to have their health state directly evaluated by him and learn more about VAB. Veiga administered VAB case by case, according to the individual medical history of each patient. Sometimes, people were advised to completely stop conventional treatments before starting VAB, whereas others would gradually decrease conventional drugs. According to Arthur's observations about Catarina's treatment, "already in the middle of the treatment, she started to feel pain relief and abandoned the use of anti-inflammatory drugs" (letter from 2000). Xavier stated, "I abandoned the use of conventional treatment and today I use only the vaccine and, when there is some worsening of the disease, I use some anti-inflammatory" (letter from 1997). Luísa explained that "three months after undergoing VAB treatment, […] I no longer take the drugs I used to take. I only take the vaccines. […] As I am a nurse, after starting the vaccine, I gradually weaned off the medications" (letter from 2013). Juarez also described coming off elements of his medication regime:

> I started treatment on July 11, 1998. At that time, I was taking 200 mg of chloroquine daily, plus fortnightly applications of gold salts (sodium aurothiosulfate 0.05 mg), plus 100 mg of daily backup, plus 5 mg of cortisone also daily. Today, almost 90 days after starting the first dose of the vaccine, I am taking 100 mg of voltaren and 5 mg of cortisone daily. The other drugs (gold salts, chloroquine) have been suspended since the vaccine started. (Letter from 1998)

Based on their specialities, I assume that most of the letters' authors worked more as technicians than as scientists searching for biotechnological innovations. They followed pre-established protocols and tended to use and reproduce therapeutic techniques, drugs and devices designed by someone else, without necessarily having to critically reflect on their own practices (as institutionalised ones), despite the tinkering that their professional praxis requires (Löwy 2008: 172). Yet, when confronted with the option of adopting VAB they have to take a decision and think about it without having other previously elaborated biomedical thinking route to rely on.

Switching treatments would inevitably provoke attritions within their biomedical worlds by turning professional expectations upside-down, as some related acts of biomedical disobedience that I addressed elsewhere show (e.g. Vilar 2020; 2024). Nevertheless, not only their health, career and reputation might be put in risk. If, unexpectedly, the adopted unconventional drug positively works by doing exactly the opposite of what the conventional treatment does, then switching treatments might result in a mutual estrangement and potential decoupling between those health professionals who try it and the hegemonic immunosuppression paradigm.

Feeling and communicating amelioration and using VAB

Of the eight health professionals I foreground here who became patients and VAB users, Flávia was the only patient who stated that she could not cease conventional treatments. As she put it, "I would love to be able to reduce this medication, but I don't see how to get rid of the corticoid", yet she "felt a marked improvement, […] and the crises are not so intense anymore" (letter from 1997). The other health professionals, on the contrary, reported relief when departing from conventional treatment. As Iara wrote, "What has bothered me a lot is the feet. [The right foot] hurts more than the left, but just being able to run out of cortisone and anti-inflammatory drugs is already great" (letter from 1997). She continued:

> I started the second glass [i.e. phial] on 14 July 1997, and I have a 90% improvement in my general condition, I have not felt any more reactions, neither allergic nor pain (reaction). I still feel pain,

> except that my knees have improved a lot. [...] Foot pain is constant, but you can take it. [...] I have slept better and I am 70% more active (agile) in everything, the morning stiffness has decreased 70%, I am already exercising my activities in the clinic where I work almost normally. I can already lift weights above five kg (before I couldn't even do 500 g). (Letter from 1997)

Iara's "reactions" correspond to those that may eventually occur when one increases VAB dosage during the desensitization phase of Veiga's therapy, which in total took two to three years on average. VAB users feel and perceive such reactions through a worsening, instead of a weakening, of the autoimmune symptoms few hours after a dosage change. In this case, Veiga instructed the patient to repeat the previous dosage a couple of times before increasing it again some weeks later. In her letter, Iara's past reactions are overshadowed by her description of health improvements.

Also emphatically, Xavier wrote that his amelioration was not only physical but emotional as well.

> I started using [VAB] according to [Veiga's] orientation and, after the first bottles [i.e. phials], it started to get better oedema, pain, morning stiffness, walking improved and also the joy of life, because the irritability and depression caused by the disease disappeared. [...] More than three years after using the vaccine, without interruption, if I am still not cured, I had an improvement of 70% of the previous condition and, I must add that during all this period that I used the vaccine, I never had a side effect. [...] Therefore, it is worth mentioning that the vaccine was important in my recovery and, perhaps without it today, I would be in a wheelchair or inactive in a bed. (Letter from 1997)

There are VAB users who go as far as to speak about *cure*, as Kalil did:

> I interrupted [i.e. concluded] my treatment after 198 injections according to the instructions given to me by [Veiga's] brochures and by [him] on some phone calls. [...] After the first stage, I started to show improvements [...]. I have never used corticosteroids, except in local applications. I also never had any reaction to the vaccine and since I stopped treatment, on 8 February 1997, I consider myself practically cured; which I attribute to the use of VAB. (Letter from 1998)

In their reports, VAB users firmly connected their corporeal and emotional well-being with improvements in other domains of life, such as the rehabilitation that allowed them to gradually return to work, and to take care of their ordinary affairs. Cristina wrote:

> I have been on treatment with the vaccines for 9 months. When I started the process with Veiga's medicines, I was walking with a crutch, practically dragging myself. Today I am without support, walking without limping. I still cannot walk much, but the improvement was great. (Letter from 2000)

As Ana also enthusiastically wrote, following a recovery of her capacity to move, she throw herself back into the flow of collective daily life.

> The great relief is that I find myself active in the exercise of the profession that caused me such an injury, when in other times there was a need to interrupt with great difficulty, my professional activity, this had profoundly negative consequences from a financial, family and emotional point of view. (Letter from 1997)

Likewise, in her letter from 2013, Luísa replies to Veiga as the following:

> For the past two years, I was already depressed with so much pain. And with my impending disability, as I hadn't been able to drive a car for more than two years. And these days, I even managed to drive a little: I feel that little by little my life is returning to normal. [...] I no longer need a wheelchair, and I manage to do my activities at home and I am gradually returning my quality of life. I am already able to move around alone, only with the help of a crutch when I have to leave the house and do some walking.

The feeling of musculoskeletal and emotional improvements, along with the possibility of rehabilitating to the point of resuming activities which had to be left aside, causing multiple losses, seem to mutually reinforce each other synergistically (e.g. Barak 2006). Apparently, stop feeling pain refers not only to a growing absence of suffering but also to the re-achievement of homeostasis as VAB users may experience it through feelings of improvement and wellbeing.

It is noteworthy that VAB users, as health professionals, are quite aware of EBM as the standard evaluation criteria to attest the efficacy of any substance with pharmaceutical pretensions. Nevertheless, most of them tend to reposition the evidence-based aspect of RCTs as secondary in comparison to the primacy of their lived amelioration experience that they attribute to effects co-generated through VAB. Ana's statement illustrates this point straightforward:

> I have no means to prove the results scientifically, but I was able to observe that, in the six years in which I present the disease, those of 96 and 97 [during which Ana used VAB] were the best for me, without however having a total cure. (Letter from 1997)

Likewise, based on his direct observation of Catarina's therapeutic trajectory, her physician-husband Arthur provided a clinical verification with potential validity: "As a doctor I can attest to the vaccine's efficacy, since she has been pain-free for more than two years without the medication she used to take and six months without VAB."

In this sense, the authors of the letters that I exam here could help solve a core problem of biomedicine as a branch of modern science. As I mentioned in section 2.4, despite the crucial importance of an objective approach, the efficacy of EBM methods is sometimes criticised for its seemingly excessive analytical distancing from reality that, as part of contemporary biomedical attempts to pasteurize medical assessments, often exclude patients' reports that could be considered as co-constitutive of medical evidence. This distancing resembles Maurice Merleau-Ponty's critical characterization of the methodological rationale of modern science as "surveying thought, thought of the object in general" (2007 [1961]: 352). For him, modern scientists paradoxically aim at producing knowledge empirically through experimental manipulation of indices and variables within closed abstract models that, in parallel, simulate the reality it tries to *grasp* (e.g. Ingold 2010: 74–75) without touching or getting it. For this reason, according to him, modern scientific thinking should instead "be placed back in the 'there is' which precedes it, back in the site, back upon the soil of the sensible world and the soil of the worked-upon world such as they are in our lives and for our bodies" (ibid.; also Ingold 2010, 2022). This seems to be the case at least for Iara, Flávia, Xavier, Kalil, Cristina, Ana, Luísa and Catarina, for whom the process of evaluating the efficacy of different medications cannot be separated from their own and others' lives' destinies.

By skipping conventional treatment, and exposing themselves to an opposite therapeutic model, while cooperating with peers and non-peers, the actions of these physicians show how they opportunely carry out this ontoepistemological re-grounding work, which implies a re-hierarchisation of sources that they can use to co-produce potential medical evidence. In so doing, they reinforce an understanding of evidence making as "[…] not only the domain of global experts, but an ethical and political proposition that knowledge can come in many forms and be distinctively mobilized" (Adams & Biehl 2016: 124).

Dissemination and boundarization

Following their witnessing of VAB's therapeutic effects, some health professionals shared their positive experiences in ways that could engage potential users. As Arthur, for instance, wrote:

> I have already recommended the vaccine for a cousin who suffers from RSI and was even retired by a medical board due to professional incapacity. Despite being at the beginning of the treatment, she started driving and leaving the house again, which she had not done for some time. (Letter from 2000)

Such recommendations, as a part of the displacing cooperations that I explore in this article, held the potential to surreptitiously disseminate the effects of VAB and, with it, to prepare the conditions of possibility for its future medical acceptance, not only among potential patients but also among members of immunological and rheumatological communities and networks.

Nevertheless, an unregistered drug is assumed to be dangerous (and many surely are) while authorised therapies are supposed to work, and medicine is supposed to pursue ways of achieving a cure, or to at least attempt to heal patients. Broadly speaking, dissemination of a potentially dangerous drug is not only ethically unacceptable and subject to criminal codes. It is also

unethical to stimulate hope among people in situations of vulnerability in order to make profit by selling false products. Yet, when the opposite of this seems to occur, i.e. when an unregistered drug seems to work, destabilizing the expectation of established biomedicine, then the authority of regulatory institutions, and their representatives and apparatuses, might become relativizable and be thrown into question. That seems to be the case especially from the perspective of those who quit the medication conventionally prescribed and embrace unconventional therapy in order to feel better and achieve amelioration.

In this sense, as part of the cascade of discontinuities propelled by their use of VAB as a biotechnology personally experienced as capable of challenging chronicity, some VAB-related health professionals also expressed a particular lament due to, as Arthur put it,

> the fact that the vaccine is not publicised in the medico-hospital milieu. I really think that we [as health professionals] are depriving a large number of patients of getting rid of joint pathologies and their painful consequences, not to mention the low cost that this [i.e. VAB] represents for public health… (Letter from 2000)

On the one hand, that is probably why several of Veiga's correspondents, in tune with this lament, responsively expressed a correspondent wish, as Iara wrote, that Veiga, whose name became to some extend inseparable from VAB, could "bring to others relief, joy, life and cure" (Letter from 1997). On the other, as Arthur ends his letter to Veiga with "Congratulations" accompanied by the imperative "and keep up this beautiful and extremely important work, which only true doctors can do" (Letter from 2000), he anticipatedly rehabilitate Veiga, few years before VAB's ban, by evoking the core and self-defining biomedical differentiation between true and false physicians, doctors and charlatans.

Such displacements seem to provide a clue about how the encounters of letters' authors with VAB co-generated further ambivalences that affected their health, perception and attitudes towards themselves and their respective private and professional environments.

Concluding remarks

Most scholarship on chronic pain and disability seems to focus on the suffering subject and on how people manage to live as chronic patients (e.g. Miles 2013; Gonzalez-Polledo & Tarr 2018). There appears to be a limited scholarship on people's experiences of improvement from chronic illness, particularly on how biomedical actors themselves improve through unconventional means and related implications. Contributing to fill this gap, I have analysed eight self-reports of sick health professionals who, after unsuccessful experiences with conventional immunosuppressive therapy, successfully tried VAB as an unknown off-label drug based on the opposite principle of unspecific immunostimulation. My primary aim has been to try to understand how health professionals cooperate with each other in unpredictable and risky circumstances in order to practice their profession, and to improve from immunopathologies that most of their peers regard as chronic. For it, I presented and discussed aspects of how sick physicians, conventional treatments and VAB as a disruptive biotechnological innovation mutually affect each other. In so doing, I have considered their reported experiences in terms of repositionings that took place through displacing cooperations as parts of the co-production of medical evidence in Brazil.

Overall, the letters show aspects of how their authors mobilised different resources, as part of their evidence-making efforts, to evaluate the efficacy of conventional and unconventional drugs, such as clinical information, trustworthy relationships and testimonies, and their own sensorial and experiential knowledge (e.g. Lambert 2009; McKevitt 2013; Song 2017; Balaj 2020). The descriptions of the letters' authors of how palliative treatment, following short-term relief, mostly worsened their health in the middle and long-term reinforce the liminal and ambiguous character of immunosuppressants as authorized drugs, which are only used because there would be nothing else available to treat immunopathologies that are regarded as chronic. Paradoxically, the expressed therapeutic frustration with immunosuppressants, which could be linked to a neoliberal politics of resignation (Benson & Stuart 2010), seems to have played an important role in

the elaboration of a political economy of hope (Novas 2006) towards VAB as a promising biotechnological innovation, despite its risks as an unregistered drug.

As health professionals trained and educated to believe in the efficacy of registered drugs, the personal therapeutic experiences of the authors challenge not only the chronicity of their immunopathologies, but also immunosuppression as the guiding paradigm of contemporary rheumatology. Emerging ambivalences found expression in frictions, tensions and uncertainties, but also in realignments between them and constituents of their multiple environments. VAB users recount their potential resolutions as having unfolded alongside two basic life-changing displacements that they underwent. The first displacement took place when they shifted from the state of living as healthy persons to the state of living as chronic patients following the conventional immunosuppressing palliative path. The second took place when they shifted from the state of living as immunocompromised chronic patients without expectations of health improvement (or, as one says in Brazil, as *desenganados*; i.e. after having been "undeceived" by their colleagues) to a state of unexpected amelioration informally achieved through a then unknown immunostimulating curative path. Throughout their passages from one state to another, health professionals intercalated experiences of exposing themselves and of being vulnerable with those of making use of what was on their ways, including biotechnologies, medico-scientific explanations, their own expertise, others' witnesses, emotional support, personal bonds, contacts etc. (Ingold 2022: 58).

Backed by displacing medical mindsets and practices, and informed by the health changes in daily life that they experience through biotechnologies based on opposite principles, health professionals transfiguratively re-evaluated the pharmaceutical landscape they are taught to reproduce. Their participation both in established biomedicine and in cooperative networks that circumvent the later contributed to this. In particular, their own experience with VAB seems to have enabled them to re-ground their medical knowledge, experience and skills in relation to their own and someone else's health in anticipation to the mediation regularly played out by conventional medical knowledge, technologies and procedures. Furthermore, when VAB-using physicians self-analyse and dialogue with others, writing and exchanging evaluative reports about their own and others' health and therapeutic experiences of using VAB, they seemed to implicitly co-produce medical evidence that might be taken into consideration by potential users.

Acknowledgements

I would like to thank all colleagues who shared their thoughts, critics and suggestions concerning parts of this article that I presented, in 2020, at the EASST/4S meeting and at the Colloquium of the Research Group 'Biotechnologies, Nature and Society' at the Goethe University Frankfurt, especially Thomas Lemke. I also thank Harriet Gardner and Lesley Branagan who respectively proofread and copy-edited different drafts of this manuscript, and for their remarks. I am especially in debt with Ehler Voss and Cornelius Schubert for their invitation to submit this article to *Curare*'s special issue "Ambivalences of Healing Cooperations in Biomedical Settings", and to the anonymous reviewers. The research work, from which this article is an output, was funded by the Deutsche Forschungsgemeinschaft (DFG, German Research Foundation); project number 419940268. I do not have any conflict of interests to declare.

Notes

All translations of source material reproduced in this article originally written in Portuguese and Spanish were translated by myself into English. I anonymized all letters' authors but not the names of historical persons and/or the dead. Finally, I herewith state that I am not a health professional and I am not authorized to confirm the efficacy or inefficacy of any drug.

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This article has been subjected to a double blind peer review process prior to publication.

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